2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical reports

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents of technical reports

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Section 2: Cultural safety

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Contents

Introduction

In Australia, stillbirth disproportionately affects women who are Aboriginal and/or Torres Strait Islander and those of migrant and refugee background, particularly those from South Asian, Oceanic and African countries.[1] In New Zealand, women of Pacific and Indian ethnicities also experience high rates of late stillbirth.[2] Stillbirth is more common in communities where social disadvantage, early motherhood and geographical isolation exist.[1,3,4]

The clinical and social support needs of bereaved mothers are individual and diverse.[5] Cultural and religious beliefs influence maternal grief and loss rituals following a perinatal loss.[6] Providing care to parents and families around stillbirth and neonatal death requires healthcare professionals to acknowledge and respect a wide range of beliefs and cultural practices. The diversity of cultures within Australian and New Zealand populations requires healthcare professionals to not impose societal or personal cultural perspectives of grief and bereavement on parents.[7] Healthcare professionals must strive to provide environments where families feel safe to express their cultural needs, traditions and rituals without fear or shame.

Events such as pregnancy and childbirth are embedded deeply in sociocultural tradition.[8] For many cultures, birth is the first ceremony in life and death is considered a final ceremony. Death-related rituals are highly culturally diverse.[9] It is thus important to understand tradition, society, and culture, and to examine the sociocultural contexts of pregnancy and childbirth, as well as death and mourning. Social, cultural, and religious beliefs and values can help parents as they grieve for their baby—this often includes the need for rituals and customs to be performed while in hospital.[7,10]

Aboriginal and Torres Strait Islander families may need the space to perform ceremonies such as smoking of the mother and baby, use of ochre following a baby's passing. However, the diversity across Aboriginal and Torres Strait Islander families from different regions (countries) within Australia highlights the need for healthcare professionals to understand the significance of birthing and passing on country.

There is considerable diversity within cultural groups. For example, some Hmong women living in Australia believe that disharmony in personal health as well as in the supernatural world causes miscarriage, stillbirth and neonatal death; some studies in African, Asian and migrant Australian communities describe instances of stigma relating to perinatal death.[11] It is important for healthcare professionals not to make assumptions, but to ask all parents about their needs and to seek further guidance from them where appropriate.[5]

The key task for healthcare professionals is to sensitively establish what families want. This involves asking parents whether there are rituals or practices that are important to their culture or belief system and that they wish to see happen.[5,7]

Methodology

The Guideline Development Committee identified key research questions (Table 1) about considerations to ensure culturally safe care of bereaved families.

Table 1. Research questions

1	What can healthcare professionals do to create a culturally safe care environment for parents following stillbirth or neonatal death?
2	What resources can staff use to ensure an increased understanding of culturally safe care?
3	What resources are available to staff to support their understanding of individualised cultural perspectives?
4	How do you support staff to routinely arrange an interpreter if the staff do not understand the language of the mother/parents?
5	How do staff better understand the needs of diverse and/or vulnerable groups?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 1. PICO criteria

PICO	Inclusion criteria

Population	Defined in Australia and Aotearoa New Zealand as:
	• Stillbirth
	  ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[2,12]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[2,12]
	• Inclusion of perinatal deaths following termination of pregnancy
	  ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).

Intervention	Resources to support delivery of culturally safe care: • resources (written, electronic, audio, audio-visual, services, tools) • accessibility of facilities

	• translation (translation, languages, interpreters, adaption).
Comparator	• Not applicable – no comparator within research question
Outcomes	Outcomes, processes, and experiences of culturally safe care for aspects of care associated with • doulas • death, burial, handling of the baby • dialogues • bereavement • grief • traditions, rituals, customs. Outcomes, processes, and experiences specific to the following populations were searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families.

Literature search

Search strategies were conducted on 31 May 2022 and incorporated all PICO criteria and restricted to publications in English (Table 4). A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and were restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus.

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- wrong *language*: The study was not published in English.
- wrong *publication dates*: The study was published prior to 2017.
- wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[13] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- **Methodological limitations:** Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[14]
- **Coherence:** How clear and cogent the fit is between the data from the evidence and synthesis findings?[15]
- **Adequacy:** The richness and quantity of data supporting the findings[16]
- **Relevance:** The extent to which the evidence from studies is applicable to the context specific in the guideline.[17]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence supporting the synthesis findings was formulated following this review, and details of any concerns were identified and listed.[18] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: What can healthcare professionals do to create a culturally safe care environment for parents following stillbirth or neonatal death?

Mistrust and conceptions about 'modern' medicine and treatment facilities may be perceived by some bereaved parents that health services are unable to provide culturally safe care.[19] Given stillbirth's profound impact on parents' identity and psychosocial health, hospital services need to be more sensitive and proactive to parents' cultural, spiritual and religious needs when they care for the family/whānau, including the stillborn baby and handling the baby's body.[20,21] Cultural influences and social norms related to faith traditions, healthcare distrust, perceived discrimination, or even regional differences, may shape the perceptions and preferences of the parents and families. Too often, differences in practice patterns have been attributed to race and ethnicity without more critical exploration of the social construction of these categories.[22]

Culturally safe care can be achieved by:

- avoiding cultural stereotypes and culture-based assumptions alongside recognising that diversity exists within cultural groups and between individuals
- asking all parents whether they have any religious, cultural, or spiritual needs and empowering families by assisting with requests where possible
- offering to contact appropriate cultural support services to assist with needs if the parents wish including elders, cultural leaders, or family/whānau members.
- determining with the parents whether an interpreter is needed and, if so, engage an accredited interpreter (some women may not wish to have a male interpreter, or an interpreter of a particular religion)
- being aware that vulnerable groups may have a history of trauma and loss.[23,24]

Cultural safety is often impeded by restrictions in size of gatherings in hospitals, limiting involvement of extended family/whānau, cultural elders and religious or spiritual advisors. Opportunities for cultural or religious practices may have also been reduced by policy and hospital guidelines.[23] It is critical for healthcare professionals to support parents' religious and cultural needs during and after perinatal death, to have an understanding of the parents grieving experience[5,25-29], as well as the mourning rituals and burial ceremonies across diverse cultures.[28] Spirituality may help healing, finding inner peace, solace, and meaning which may or may not be related to religion. Rituals and ceremonies surrounding symbolic and spiritual connections may help with acceptance of grief.[5,30] A recent Australian study highlights the importance of rituals and ceremonies for men from culturally and linguistically diverse backgrounds, where it may be seen as the man's responsibility to facilitate burials and other rituals and practices.[29]

Communication

Understanding that in some cultures, healthcare professionals do not disclose to women that their baby has died, emphasises the sensitivity needed around discussions about a baby's death in the Australian healthcare setting. Healthcare professionals have a crucial role in creating a respectful care environment and offering information to parents about their baby's death, as well as adequate counselling and bereavement care, but this must be done in a culturally sensitive manner.[31]

In sub-Saharan Africa, women value being given full attention (for example, maintaining eye contact where appropriate, sitting down) of the attending healthcare professional when discussions

concerning the baby's death, birth and family/whānau needs take place. They also highlight the need to be told the truth. Some expressed their relief when healthcare workers offered to disclose the news to their relatives, helping women to ease potential blame, or questions from family members.[32]

Communication during the disclosure of death, the birth and care should always be respectful, honest, and free from distractions. Guidelines on perinatal bereavement care suggest using a sensitive language, selecting appropriate and simple messages, and ensure enough time is given for their absorption.[32]

Creation of a culturally safe environment incorporates the need for understanding that communication is a crucial component of the environment. In a sensitive time such as the death of a baby, honest communication and use of simple terminology to avoid misunderstanding and frustration is critica.[32] Healthcare professionals need to fully explore parents' choices so that care is coordinated and the wishes of the family/whānau are carried out where possible.[28]

When disclosure of the baby's death occurred in open spaces such as the labour ward, obstetric theatre, or postnatal ward, where privacy could not always be guaranteed, women may feel frustration, shame and trauma when placed next to mothers of living babies.[5,32]

Recognition of parenthood

The meaning of rituals for a baby that has died are highly culturally diverse. For example, in some Asian cultures, participating in death-related rituals permits a mother to do something for her deceased child, helps relieve parental guilt by doing their best for their deceased baby, allows parents to cope with the death, and have hope for a successful subsequent pregnancy.[9] Motherhood of a stillborn baby may not be recognised in some settings.[28] Examples of this include hiding grief, not verbalising doubts, not asking questions about the absence of fetal activity, not questioning healthcare workers, and not asking to see and hold the baby.[32] Within some cultural groups, stillbirths are believed to stem from bad omens, witchcraft or immorality and women who experience repeated losses are frequently reported to be shunned and even abandoned by their partners and families. [33,34] Mothers, fathers and, sometimes, the wider family/whānau experienced public stigma as a result of stillbirth and particularly after multiple baby deaths.[35]

Investigations

It is important for health professionals to understand the factors which influence a parent's decision for autopsy after perinatal loss. During a qualitative study, Aboriginal and/or Torres Strait Islander women (n = 5) who consented to autopsy following a stillbirth identified the following reasons for giving their consent: wanting to find out why their baby died; to confirm prior diagnosis; to reduce doubts about possibility of maternal causes; to understanding future risk; and to help others.[36] Women who declined autopsy stated the following reasons for declining autopsy: not being approached or asked about autopsy in a sensitive manner; not having enough time to think following the stillbirth; distress about the autopsy procedure and the need to protect their baby from further harm (ref). It is important that both parents are involved in the decision-making, and that parents are given enough time after the stillbirth to make the decision for/against autopsy.[36]

Women in more disadvantaged positions in society, particularly in the UK, are reportedly less likely to be offered, or consent to, a postmortem, and less likely to receive the results in a meeting with a consultant.[37] These differences may relate partly to communication problems between health professionals and women from ethnic minority groups, and those with fewer educational

opportunities. There may also be assumptions about religious and cultural observances that may preclude postmortem being offered. In an online survey designed to explore the views of healthcare professionals and parents around the autopsy consent process in the UK, 65% of midwives and 56% of obstetricians, but only 3% of parents, considered religion and culture to be significant barriers to consent for autopsy. In this study 11% of women gave 'against their beliefs' as a reason for declining a postmortem.[37,38] In a qualitative study of the acceptability of stillbirth investigations in sub-Saharan Africa, healthcare professionals felt that cultural considerations impacted on their confidence in holding open conversations with parents about investigations.[39] However, religious and cultural concerns are not reasons to avoid discussions about investigations.[37] Offers of postmortem investigations and discussions of possible benefits should be carried out sensitively by a consultant, a midwife known to the woman, or a specialist bereavement midwife.[40]

Between and within cultural groups, views differ regarding investigations following the death of a baby and healthcare professionals should not assume that viewpoints are ubiquitous within groups. Less invasive approach to postmortem investigation is more acceptable to the Muslim and Jewish communities in the UK and has the potential to increase uptake in these religious groups, particularly if turnaround times can be minimised and awareness raised among community members.[41] Parents from Arabic backgrounds expressed gratitude for being in a country like Sweden, where they were offered obstetric ultrasound examinations to screen for fetal anomalies and were able to decide for themselves whether to continue or terminate the pregnancy.[42] Some families expressed that they might have made a different decision concerning whether to continue or terminate the pregnancy, if they had comprehended the information offered by health professionals with more clarity.[42]

Although it has been reported that consanguineous couples have lower engagement in antenatal testing, rates of consent to postmortem investigations were similar to non-consanguineous couples.[43]

Environment

The hospital environment, for some women, is associated with an environment of trauma and quite often silence can be employed as a defensive strategy to protect the woman from blame and shame. Racial microaggression is a subtle form of institutional racism that can occur in health settings and lead to (further) exclusion.[44,45] Racial microaggression can be "everyday verbal [or] nonverbal…slights, snubs, or insults, whether intentional or unintentional, that communicate hostile, derogatory, or negative messages."[46] To enable good obstetric care, healthcare professionals need to acknowledge issues associated with gender and racial discrimination,[47] and empower women and families to voice their cultural needs, including environment and surroundings.[48]

As well as access to cultural support services, every hospital should have multiple copies of holy books, such as the Qur'an available for bereaved Muslim families, to use while hospitalised.[49]

Questions 2 and 3: What resources can staff use to ensure an increased understanding of culturally safe care? What resources are available to staff to support their understanding of individualised cultural perspectives?

If in doubt, one of the most helpful things a healthcare professional can do is to give parents choices and ask 'what can I do to better meet your needs?'[49] When parents are given choices, they will choose the options that they find most helpful and supportive.[49] As a multicultural society, health care

within Australia needs to accommodate and be open-minded in assisting families of all cultures to feel safe; especially in expressing their needs around cultural rituals and ceremonies of birth and death.

Within hospitals, cultural support is usually accessible in person or through hospital recommended resources. In a Danish study of bereaved parents' religious beliefs and practices, most parents had religious/spiritual beliefs, and for some parents, these beliefs strengthened after loss.[50]As most maternity healthcare chaplains in the UK and Ireland are involved in the care and support of bereaved parents, they are well placed to provide supportive care should parents wish to discuss postmortem options with them.[51]

Perinatal services should be aware of, and have access to, high-quality resources to support their communities during the perinatal period.[47,52] A project called *The Healing the Past by Nurturing the Future* is co-designing resources tailored to support Aboriginal and Torres Strait Islander parents during the perinatal period.[53] The project has identified four essential elements, Culture (cultural traditions, practices and strengths), Relationality (family, individual, community and services), Safety (framework, choice and control) and Timing (the right time socio-emotionally and stage of parenting), to facilitate support strategies for Aboriginal and Torres Strait Islander parents.[53]

Resources are being specifically developed for bi-cultural workers to share information about stillbirth for migrant and refugee women in community settings in Victoria.[1] In NSW, pregnancy education classes are being adapted to improve stillbirth literacy among migrant women. A study called *Talking About Stillbirth* is exploring perspectives of recent parents of migrant and refugee background, regarding beliefs and understandings of stillbirth, as well as experiences of grief and loss. The study will also document families' experiences of interactions with health professionals when experiencing a major pregnancy complication, as well as the perspectives of healthcare professionals caring for these families. The study has a strong translational focus, through early and ongoing engagement of health administrators and policy makers, to inform timely development of maternity service enhancement strategies surrounding stillbirth care [1]. Considerations for CALD men's specific needs should be addressed during the development of policy and strategies for stillbirth and neonatal death care.[54]

Recently, and from practical necessity, virtual ceremonies and support resources are web-based, and in some countries, virtual, eternal and practical cemeteries have been created in China, and elsewhere.[55] Web-based resources and support groups can help to meet cultural needs in resource limited settings in Australia. Videos on YouTube dedicated to stillbirth children can be considered as a new form of modern manifestation of mourning, such as support groups, special rites, and tattoos, and may be useful in support for parents.[55]

The Arab Muslim Perceptions of Perinatal Loss Care (AMPPLC) instrument has been designed to collect data about perinatal loss care as experienced by immigrant Arab Muslims in the US. The instrument is available in Arabic and English. A pilot of the AMPPLC instrument found some discrepancies between responses from immigrant Arab Muslims and previously published literature about Muslim preferences after perinatal loss.[49] This finding reinforces that healthcare professionals should not make assumptions about the care that Arab Muslim families wish to receive and what options they should be offered.

Healthcare professionals, women and their families should have access to culturally safe guidance on stillbirth prevention to support culturally responsive care.[56] Stillbirth disproportionately affects women who are Aboriginal and/or Torres Strait Islander and those of migrant and refugee

background. Obesity, diabetes, hypertension, smoking, fertility issues and lack of antenatal care have been identified as important contributors to higher stillbirth risk in Aboriginal and/or Torres Strait Islander women in North Queensland.[56] Migrant women in the UK have individual preferences for how stillbirth reduction messages would be best communicated including written information, use of the internet, social media and learning in group contexts. However, women believed that the healthcare professional, in particular the midwife, is key in communicating these messages which other media can reinforce. Use of short videos, viewed through the phone were thought to be effective in backing up the key messages around stillbirth prevention communicated by the midwife:

> **"films with graphics and things, that you can see not only hear, it might be a good way to spread that information, just because if you don't understand what's been saying you can have the photos or pictures and you can understand it" [38]**

A recent study on bereaved parents' beliefs and perceived causes of stillbirth in Afghanistan, highlights the importance of delivering stillbirth prevention messages that dispel misinformation of the causes of stillbirth at the community level.[57]

Question 4: How do you support staff to routinely arrange an interpreter if the staff does not understand the language of the mother/parents?

Low literacy is a primary factor contributing to health disparities. Strategies that aim to improve the health literacy include use of health care interpreters, patient navigators, and other means of communication such as pictograms, images, photographs, audio, and videos. These have the potential to improve antenatal counselling for migrant families and could also be applied to situations involving care around stillbirth.[42]

Different strategies for dealing with language barriers in health care [include] offering supplemental written information in different languages, using translating applications and communication with the aid of medical interpreters. Combining face-to-face counselling with supplemental written information has been shown to enhance knowledge about antenatal screening and could be used in situations relating to stillbirth. Translating apps are potentially useful services that are available around-the-clock. However, they require sufficient ability to read sufficiently and may not translate meaning.[42]

Medical interpreters are guided by a set of medical interpreting standards designed to ensure an accurate and clear line of communication. To achieve high quality in medical interpreting, the following nine standards need to be sufficiently met: accuracy, advocacy, confidentiality, cultural awareness, impartiality, professional development, professionalism, respect, and role boundaries. However, problems with the accuracy of interpretation have been reported, illustrating the need for interpreters trained in advanced medical terminology. Adequate information via an interpreter and improved training of health professionals are important aspects of care for women.[42]

> **"Honestly, I didn't understand how seriously malformed the child was because I didn't master the language well enough. The information from the staff was not easy to understand either. If I had understood [correctly], I would have taken a different decision. The staff used many words and phrases that were difficult to understand at a time when I was feeling grief for my child.".[42]**

Restrictions during the COVID-19 pandemic limited interpreter services to telephone access only, which may not be accessible as face-to-face interactions.[23]

Question 5: How do staff better understand the needs of diverse and/or vulnerable groups?

Doctors [in Israel may] approach women assuming that religious aspects will be decisive in making the decision to continue or terminate the pregnancy. Addressing emotional aspects in their communication with families or arranging for a social worker to accompany them in their meetings with families, offers emotional support to families who face a difficult decision.[58]

Asking parents alone to take full responsibility for decisions involving the life and death of their unborn or newly born baby is typically not culturally or socially acceptable in the Muslim community. Information should be provided to both parents as decisions are usually discussed by both parents, but the father is often the overt decision-maker in some settings.[49]

Muslim parents and family members should be offered the opportunity to see and hold the deceased baby. Large numbers of extended family members and friends may visit the bereaved family while they are hospitalised to provide support because to fail to do so is considered shameful. Desecration or disfigurement of a dead body is forbidden since bodies should be buried intact. Therefore, taking locks of hair is generally not permissible but organ donation and forensic autopsy are exceptions and are permitted. Nurses should ask permission before taking footprints or photographs of the deceased baby. The baby should be washed, anointed, shrouded, with prayer and then burial, preferably within 24 hours of the death. Babies over 4 months of gestation are also named.[49]

Across sub-Saharan countries, bereaved women are likely to be receptive to healthcare professionals' body language and gestures. They felt the pain was shared and they valued being given the full attention (for instance, maintaining eye contact, sitting down) of the attending healthcare professional when informed about the death of their baby and also highlighted the need to be told the truth [32]. On the other hand, women felt neglected and afraid when privacy was breached and when they were placed next to mothers of living babies in the postnatal ward.[32]

It may be helpful for hospitals who serve an urban population to offer a perinatal bereavement support group for young women and their family members. Participants also found comfort in their faith in God. Thus, it may be helpful for nurses to assess the spiritual needs and preferences of young black women in the US experiencing perinatal loss and to encourage them to reach out to their immediate families and to their community of faith for support.[59]

Social disadvantage considerations

Stillbirth is strongly associated with adverse socioeconomic determinants of health. In the UK, women in areas of greatest social deprivation in high-income countries have higher rates of stillbirth compared with women residing in areas of greatest[60,61] affluence . This may be related to nutrition, health behaviour such as smoking, access to health care, social support and other factors including difficulty accessing and understanding information and having little control and power over their own care.[60] Women living in the most deprived areas often report poorer experiences of care compared to women in more advantaged areas .

> **"The midwives at the hospital were very slow in dealing with me when I got there, took their time finding machinery, other midwifes/doctors. I constantly asked for pain relief, and to know what was going on, it took roughly an hour for them to actually tell me."**
>
> **"After they took him they never said nothing to me until 10-15 mins later. I felt alone and left out with what was happening."**
>
> **"Midwife stayed 10 minutes, had never met us before and was clearly uncomfortable."[60]**

Country-specific considerations

Health and welfare are compromised by conflict in countries such as Iraq and Jordan with water and food supply and sanitation affected, roads and communication channels destroyed, all of which may

directly or indirectly translate to poorer dietary intake and hygiene practices and increased perinatal mortality. Level and quality of services may fall short of minimum standards due to limited funding, lack of trained personnel, staff shortages and turnover, as well as lack of medical supplies (including not seeking care from postnatal services in the first few hours/days when risk of neonatal death is highest).[62]

Grief is long-lasting and often not socially validated, leading to isolation. Stillbirth is highly stigmatised in many LMIC communities. The high rate of neonatal death and expected likelihood of survival in LMICs also means grief may be viewed differently in society compared to a death of an older child.[63] In a qualitative study conducted in Kenya and Uganda, Mills and colleagues (2023) found that health workers were deeply sensitive to the impacts of stillbirth for women and families and acknowledged that bereaved care and support is often inadequate.[64]

A powerful message was how culturally heterogenous the healthcare provision was among the different LMICs, even within the same country. Despite these cultural differences and societal contexts, a key theme throughout the different studies evaluated by Mc Neil et al.[65] was the negative experience of women who experience stillbirth, and the blame, stigma, and lack of support from family, their community, and healthcare workers. Several studies identified the cultural stigma about perinatal death and repressed opportunities to grieve [65].

In sub-Saharan Africa, the widespread perception that stillborn babies are 'not human', can mean that women are denied the possibility of mourning openly. The woman is discouraged to share her experience by her community due to the societal fear of 'bad luck' associated with stillbirth. This inability to mourn openly reduces the capacity to seek and access support, and increases the potential for psychological harm and intense grief.[32]

In Ghana, gender equality and lack of decision-making power are significant issues for women, with blame for bad maternal and neonatal outcomes often directed at mothers who carry the weight of innumerable societal and systemic problems beyond their control.[66] Some mothers in Ghana reported that religion plays a strong role in coping with infant loss. All 'strongly agreed' that it was God's will for their baby to die. A few mothers reported self-blame for the loss and all but one, who felt hard physical labour during pregnancy affected the baby, said they were not responsible for the death. However, three women reported that someone else blamed them. One mother referenced accusations of witchcraft.[67] Asram (an illness with supernatural causes) is believed to be a leading cause of newborn death in Ghana.[68] Although healthcare professionals did not believe in Asram themselves, they were universally aware of these traditional beliefs as a primary cause of newborn illness and linked practices related to Asram and its traditional medicine treatments to known neonatal conditions. Healthcare professionals varied in the amount of latitude they gave patients regarding Asram, with some rationalising why these beliefs have persisted in Ghanaian society and others frustrated with the persistence of potentially harmful traditional health practices to prevent or treat Asram. Finally, open discussion and dialogue with patients about Asram was important to prevent delays in care and enable healthcare professionals to manage critical newborn illness. The one global theme that has emerged is that Asram represents a barrier for healthcare professionals, creating perceived challenges in prompt care-seeking, treatment compliance and patient—healthcare professionals communication.[69]

Across a number of countries in Eastern Africa, practices and beliefs surrounding stillbirth have been a source of stress, fear, stigma, and anxiety especially to the women. Conforming to cultural practices

meant that parents were prevented from: holding and seeing their baby, openly discussing the death, memory-making and attending the burial. The conflict between addressing their own needs and complying with community norms hindered parents' grief and adjustment [32,35]. There is an urgent need to develop culturally sensitive community programs geared towards demystifying stillbirths and providing an avenue for parents to grieve in their own way.[35]

During a qualitative study conducted across three NICUs in Iran, healthcare professionals expressed difficulties supporting parents, particularly fathers, presence in the NUCU due to cultural-religious barriers religious and a lack of facilities.[70,71] (Nurses often prevented the father visiting their infant in the NICU, as breast-feeding and skin-to-skin contact between mothers and their infants in the presence of other men isn't culturally acceptable.[70] A shift in care providers' attitudes and policy procedure to better support fathers in this population is needed.[71] (

In Ethiopia, health care seeking and economic reasoning, socioeconomic and structural barriers are internalised as part of everyday life. What was at stake in these decisions was not only the individual baby, but the survival of the household.[72]

In Africa, one study found that for Muslim Somali women, the experience of losing a baby at birth yields the meaning "Balancing feelings of anxiety, fear and worries for one's own health and life by accepting Allah's will, putting trust in him." This meant women temporarily withdrew from others to make themselves emotionally and physically ready to give birth to their stillborn baby. Following the birth of their baby, the emotional pain was turned into precious memories of their baby which was comforting to mothers.[73]

In Bangladesh, most people in the community, including the mothers-in-law, fathers-in-law and traditional birth attendants still practised traditional neonatal care, preferring to seek help from traditional birth attendants and village doctors, and lastly from health facilities.[74]

In Pakistan, bereaved women may have difficulty in expressing how they feel after experiencing stillbirth and are unlikely to mourn publicly because stillbirth is not deemed to be a human death.[33]

In Thailand, where perinatal death can be considered the result of the past karma of a woman who did bad deeds in a past life, death is frequently perceived as punishment for women who previously violated social rules during pregnancy until the postpartum period. Such social perceptions impact women in a way that makes them feel judged and evaluated negatively, with interpretations of perinatal death as women's sinfulness attached to the spirit of motherhood. This causes women to suffer from feelings of self-blame and stigmatisation. Belief in reincarnation made it easier for grieving women to accept perinatal death as it followed the natural cycle of life.[75]

Muslim families with perinatal loss in the US have a strong preference for female physicians and nurses to care for them.[49]

For Black, Asian and minority ethnic women, and in particular migrant women in the UK, most women had never heard the word 'stillbirth' in English and for some the word did not exist, or they had not come across it, in their first language.[38]

In LMICs, women may also experience chronic physical ill-health related to traumatic birth including obstetric fistula, in addition to the death of their baby.[35]

Many healthcare workers in South Africa are themselves women of colour who have histories of being silenced and excluded being able to speak for, and advocate on behalf of, their patients depend on their empowerment and having a voice. These are difficult and complex issues, and there are layers of silencing and exclusion. Ultimately, questions of good obstetric care cannot be separated from broader questions about social and gender justice.[48]

Despite differences in language, nationality, cultural background and religion, the actions of neonatal nurses providing end-of-life care in Saudi Arabia were indicative of openness and respect towards other religious beliefs and cultural practices in their support and care for families.[76]

Grey literature and other sources

In addition to the published academic literature, both international and national government agency and parent support organisation (e.g., Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to care around decision-making at the time of perinatal death or termination of pregnancy for fetal anomaly. A targeted Google search was also conducted using a combination of the following keywords: shared decision-making following stillbirth; shared decision-making following neonatal death; shared decision-making following perinatal death; shared decision-making for termination of pregnancy for fetal anomaly. The findings of the grey literature are supported by both the current and previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*.

The Stillbirth Centre for Research Excellence's Safer Baby Bundle is a national initiative with five evidence-based elements to address key areas where improved practice can reduce the number of stillborn babies. The Cultural Adaptation of the Safer Baby Bundle project is now being implemented to culturally adapt the Safety Baby Bundle for migrant and refugee women and Aboriginal and Torres Strait Islander women.

Migrant and refugee women were consulted through focus groups, interviews and interactive online sessions and provided stories, perceptions, and experiences of stillbirth in their communities. This information will be used by researchers to codesign culturally appropriate resources on stillbirth prevention, maternity care, and professional development for healthcare professionals.[77]

Sorry Business Babies resources were developed by culturally adapting the Safer Baby Bundle elements to the Aboriginal and Torres Strait Islander community context.[78] In 2022, the Indigenous Research Management Team of the Stillbirth Centre for Research Excellence (Stillbirth CRE) tested the Sorry Business Babies resources in focus testing workshops based on yarning and in conferences/forums. Participants were Aboriginal and Torres Strait Islander women, families, and community members who, in some instances, were also maternity health care professionals working with Aboriginal and Torres Strait Islander communities. Feedback about the resources was highly favourable (average score of 8.65/10) and acknowledged for their strengths-based and culturally appropriate wording, colourful design and artwork, and suitability. The final resources are now being revised based on the feedback received and will be piloted on a wider scale in 2023.[78]

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This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also include methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies	GRADE-CERQual Overall confidence Rating of evidence	Guideline recommendations
		Consensus-based recommendation 2.1: A multidisciplinary team should oversee care across the continuum from diagnosis through birth and death planning to transition from hospital to community. The team should: • provide continuity of care and carer • hold regular meetings with parents and family/whānau • ensure medical records include a care plan (e.g a perinatal palliative care plan) that has been developed with the parents and the plan is accessible to all team members, parents and family/whānau • consider supports that may be required to meet the cultural, religious, and/or spiritual needs of parents and family/whānau • engage other relevant healthcare workers and interpreters, where needed. **This recommendation is cross-cutting across several technical reports. For additional evidence synthesis and GRADE-CERQual rating, see Appendix 3H: Communication between healthcare professionals.*
	This recommendation is cross-cutting across several technical reports. For additional evidence synthesis and GRADE-CERQual rating,* ***see Section 3: Technical report for effective*	**Evidence-based recommendation 2.4:** Use respectful and sensitive language and terminology that is honest, realistic, and understandable. • Take the lead from parents regarding preferred language for their baby.

		communication for GRADE CERQual rating of this recommendation.	• Use the word 'baby' or 'bub' if acceptable to parents. • Ask parents if they have named their baby and, if so, seek permission to use the name.
		This recommendation is cross-cutting across several technical reports. For additional evidence synthesis and GRADE-CERQual rating, **see Section 3: Technical report for effective communication for GRADE CERQual rating of this recommendation.*	**Evidence-based recommendation 2.5:** Be aware that stress and grief can greatly affect how people absorb, retain, and respond to information. Tailor information by: • using open-ended questions • repeating information and checking with parents that they understand • offering parents culturally and linguistically appropriate parent-facing information and resources about perinatal grief and what to expect • allowing parents time and space to read information and resources when they are ready.
Aboungo 2020 Actis Danna 2023 Asim 2022 Christou 2019 Henderson 2017 Lassi 2019	Meyer 2018 Mone 2021 Pollock 2020 Redshaw 2018 Thieleman 2020 Pearson 2023 Zhuang 2023	*Moderate confidence* Minor concerns of evidence coherence, evidence relevance, adequacy of data, methodological limitation	**Evidence-based recommendation 2.13:** Care must be appropriate to parents' cultural, religious and/or spiritual needs. Healthcare professionals should: • recognise that parents and family/whānau come from a wide range of backgrounds and acknowledge diversity within and between cultural groups • avoid cultural stereotypes and culture-based assumptions • be aware of and responsive to individual, cultural, religious and/or spiritual approaches to death and expressions of grief and loss

			• be aware of and respond appropriately to families with a history of trauma and loss and previous negative experiences with health services particularly: - intergenerational trauma among Aboriginal and Torres Strait Islander families - complex trauma among women of refugee background • acknowledge the importance of each cultural group's vital support systems such as kinship and community care for Aboriginal and Torres Strait Islander families and Māori families/whānau. • seek advice and support from experienced health workers and engage cultural support services where required.
Actis Danna 2023 Alaradi 2021 Al Mutair 2019 Ayebare 2021 Boyle 2022	McNeil 2020 Osman 2017 Smidova 2019 Sun 2018 Sun 2021 Sun 2022 Tseng 2018	*Low confidence* No or minor concerns of evidence coherence, minor concerns of evidence relevance. Moderate concerns of adequacy of data, and methodological limitations.	Consensus-based recommendation 3.12: Ask parents and family/whānau throughout care about cultural needs regarding perinatal loss practices and handling of their baby's body. • Always ask parents and family/whānau permission before handling their baby.
Alaradi 2021 Al Mutair 2019 Alvarenga 2021 Das 2021 (a) Feroz 2019 Garcia 2020 Kilcullen 2020	Lewis 2019 Munguambe 2021 Nuzum 2021 Spierson 2019 Tikmani 2021 Tsai 2017 Zhuang 2023	*Moderate confidence* No or minor concerns of relevance, and coherence. Minor concerns of data adequacy and moderate concerns of methodological limitations.	Evidence-based recommendation 6.6: Healthcare professionals must respectfully ask parents and family/whānau throughout their care if they have cultural, religious, or spiritual care needs including preferences for discussing and making decisions about investigations to understand why their baby died. • Healthcare professionals should avoid making assumptions and must work in partnership with families/whānau to ensure care is

Kwesiga 2021	individualised and that their needs are met, seeking further guidance where needed. **This recommendation is cross-cutting across several technical reports. For additional evidence synthesis and GRADE-CERQual rating, see Section 6: Technical report for communication and decision making around investigations for perinatal death.*

Table 4. Search strategy

Database		
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/
	2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.
	5	1 or 2 or 3 or 4
	6	exp transcultural care/ or exp vulnerable population/ or exp indigenous health care/ or exp health disparity/ or indigenous people/
	7	(parent* or mother* or father* or "patient*" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or M#ori or wh#nau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya* or arab* or community of cultural* or "limited English" or "language barrier*" or "other language*" or spirituality).ti,ab.
	8	(((written or electronic or audio or audio-visual or visual or virtual or translat* or language or accessib* or socio-cultural or interpret*) adj4 (information or service or facilit* or resource* or tool* or material* or service or care)) or ((tradition* or intercultur* or sensitive or folk or religio* or cultural or "culture specific" or mindful or compassion*) adj9 (bereavement or grief or griev* or care* or information or service or facilit* or resource* or tool* or material* or service or doula or doctor or healer or elder or midwife or care or attendant or dialogue or practice* or custom* or burial or death or dies))).ti,ab.
	9	((cultural* or tradition* or literacy or disability) adj3 (safe* or appropriat* or need* or resource* or adapt* or perspective* or view*)).ti,ab.
	10	8 or 9
	11	6 or 7
	12	5 and 10 and 11

CINAHL	#	Query
	S21	S5 AND S16 AND S19
	S20	S5 AND S16 AND S19
	S19	(S17 OR S18)
	S18	AB ((cultural* or tradition* or literacy or disability) N3 (safe* or appropriat* or need* or resource* or adapt* or perspective* or view*))

S17	AB (((written or electronic or audio or audio-visual or visual or virtual or translat* or language or accessib* or socio-cultural or interpret*) N4 (information or service or facilit* or resource* or tool* or material* or service or care)) or ((tradition* or intercultur* or sensitive or folk or religio* or cultural or "culture specific" or mindful or compassion*) N9 (bereavement or grief or griev* or care* or information or service or facilit* or resource* or tool* or material* or service or doula or doctor or healer or elder or midwife or care or attendant or dialogue or practice* or custom* or burial or death or dies)))
S16	(S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15)
S15	(MH "Health Care Costs")
S14	(MH "Lay Midwifery") OR (MH "Family Traditions Scale") OR (MH "Medicine, Persian") OR (MH "Medicine, East Asian Traditional") OR (MH "Medicine, Latin American Traditional") OR (MH "Medicine, Chinese Traditional") OR (MH "Medicine, African Traditional") OR (MH "Medicine, Traditional") OR (MH "Medicine, Native American Traditional")
S13	(MM "Healthcare Disparities")
S12	(MM "Islam")
S11	(MM "Jews")
S10	(MM "Cultural Diversity")
S9	(MM "Transcultural Care")
S8	(MM "Indigenous Peoples")
S7	(MM "Rural Health Personnel")
S6	AB (parent* or mother* or father* or "patient*" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or M#ori or wh#nau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya* or arab* or community of cultural* or "limited English" or "language barrier*" or "other language*" or spirituality)
S5	S1 OR S2 OR S3 OR S4
S4	AB ((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort)) or "prenatal diagnosis")
S3	AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) N1 loss*) OR stillb*)
S2	AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*)
S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")

Scopus	((*fetal* OR *foetal* OR *fetus** OR *perinatal* OR *prenatal* OR *antenatal* OR *"peri natal"* OR *intrapartum* OR *intrauterine* OR *"intra uterine"* OR *utero* OR *newborn** OR *neonatal*) W/2 (*death** OR *wast** OR *demise** OR *mortalit**))) OR ((*pregnancy* OR *foetal* OR *fetal* OR *fetus* OR *perinatal* OR *"peri natal"*) W/1 (*loss**)) OR (*stillb**) OR ((*"fetal malformation"* OR *"congenital abnormality"* OR *"fetal anomaly"* OR *"congenital anomaly"* OR *"fetal anomalies"* OR *"congenital anomalies"*) W/3 (*terminat** OR *abortion* OR *abort*)) AND (parent* or mother* or father* or "patient*" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or M?ori or wh?nau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya* or arab* or community of cultural* or "limited English" or "language barrier*" or "other language*" or spirituality) AND (((written or electronic or audio or audio-visual or visual or virtual or translat* or language or accessib* or socio-cultural or interpret*) W/4 (information or service or facilit* or resource* or tool* or material* or service or care)) or ((tradition* or intercultur* or sensitive or folk or religio* or cultural or "culture specific" or mindful or compassion*) W/9 (bereavement or grief or griev* or care* or information or service or facilit* or resource* or tool* or material* or service or doula or doctor or healer or elder or midwife or care or attendant or dialogue or practice* or custom* or burial or death or dies))) OR ((cultural* or tradition* or literacy or disability) W/3 (safe* or appropriat* or need* or resource* or adapt* or perspective* or view*))

Pubmed

#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR "Abortion, Induced"[Mesh]	Mesh
#2	**"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*"** OR “Neonatal loss*” OR “Neonatal mortalit*”OR “Neonatal death*” OR “Neonatal Demise*” OR “Newborn death*” OR “Newborn mortalit*”	**Title/abstract**
#3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])	**Title/abstract**
#4	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or “prenatal diagnosis”) AND (terminat* or abortion or abort))	**Title/abstract**
#5	#1 OR #2 OR #3 OR #4	

#6	("Vulnerable Populations"[Mesh]) OR "Cultural Diversity"[Mesh]) OR ("Cultural Competency"[Mesh] OR "Transcultural Nursing"[Mesh])) OR ("Health Services, Indigenous"[Mesh] OR "Indigenous Peoples"[Mesh])) OR "Health Care Costs"[Mesh]	Mesh
#7	(parent*[Title/Abstract] OR mother*[Title/Abstract] OR father*[Title/Abstract] OR "patient*"[Title/Abstract] OR "women understand*"[Title/Abstract] OR "women* view*"[Title/Abstract] OR "women* experience*"[Title/Abstract] OR "woman* understand*"[Title/Abstract] OR "woman experience*"[Title/Abstract] OR migrant[Title/Abstract] OR immigrant[Title/Abstract] OR family[Title/Abstract] OR families[Title/Abstract] OR refugee*[Title/Abstract] OR "indigenous"[Title/Abstract] OR "torres strait islander*"[Title/Abstract] OR ATSI[Title/Abstract] OR "aborigin*"[Title/Abstract] OR "islander*"[Title/Abstract] OR remote*[Title/Abstract] OR "linguistically diverse"[Title/Abstract] OR "literacy"[Title/Abstract] OR "low income"[Title/Abstract] OR "cultural care"[Title/Abstract] OR elders[Title/Abstract] OR maori[Title/Abstract] OR whanau[Title/Abstract] OR Maori[Title/Abstract] OR Jew*[Title/Abstract] OR Muslim*[Title/Abstract] OR Hindu*[Title/Abstract] OR buddhist*[Title/Abstract] OR religio*[Title/Abstract] OR Christian*[Title/Abstract] OR orthodox[Title/Abstract] OR Uighur*[Title/Abstract] OR Rohingya*[Title/Abstract] OR arab*[Title/Abstract] OR community of cultural*[Title/Abstract] OR "limited English"[Title/Abstract] OR "language barrier*"[Title/Abstract] OR "other language*"[Title/Abstract] OR spirituality[Title/Abstract])	Title/ abstract
#8	#6 OR #7	
#9	("culturally safe*"[Title/Abstract] OR "culturally appropriate"[Title/Abstract] OR "cultural need*"[Title/Abstract] OR "cultural resource*"[Title/Abstract] OR "cultural adapt*"[Title/Abstract] OR "cultural perspective*"[Title/Abstract] OR "cultural view*"[Title/Abstract] OR "traditional safe*"[Title/Abstract] OR "traditionally appropriate*"[Title/Abstract] OR "traditional need*"[Title/Abstract] OR "traditional resource*"[Title/Abstract] OR "traditional adapt*"[Title/Abstract] OR "traditional perspective*"[Title/Abstract] OR "traditional view*"[Title/Abstract] OR "disability appropriate*"[Title/Abstract] OR "disability need*"[Title/Abstract] OR "disability resource*"[Title/Abstract] OR "literacy appropriate*"[Title/Abstract] OR "literacy need*"[Title/Abstract] OR "literacy resource*"[Title/Abstract] OR "literacy adapt*"[Title/Abstract])	Title/ abstract
#10	"Written resource*"[Title/Abstract] OR "Electronic resource*"[Title/Abstract] OR "audio-visual resource*"[Title/Abstract] OR "visual resource*"[Title/Abstract] OR "virtual resource*"[Title/Abstract] OR "language resource*"[Title/Abstract] OR "accessible resource*"[Title/Abstract] OR "socio-cultural resource*"[Title/Abstract] OR "Electronic service*"[Title/Abstract] OR "audio-visual service*"[Title/Abstract] OR "visual service*"[Title/Abstract] OR "virtual service*"[Title/Abstract] OR "translator service*"[Title/Abstract] OR "language service*"[Title/Abstract] OR "accessible service*"[Title/Abstract] OR "Written material*"[Title/Abstract] OR "Electronic material*"[Title/Abstract] OR "Audio material*"[Title/Abstract] OR "audio-visual material*"[Title/Abstract] OR "visual material*"[Title/Abstract] OR "virtual material*"[Title/Abstract] OR "language material*"[Title/Abstract] OR "accessible material*"[Title/Abstract] OR "socio-cultural material*"[Title/Abstract] OR "Written tool*"[Title/Abstract] OR "Electronic tool*"[Title/Abstract] OR "Audio tool*"[Title/Abstract] OR "audio-visual tool*"[Title/Abstract] OR "visual tool*"[Title/Abstract] OR "virtual tool*"[Title/Abstract] OR "translator tool*"[Title/Abstract] OR "language tool*"[Title/Abstract] OR "accessible tool*"[Title/Abstract]	Title/ abstract
#11	(tradition*[Title/Abstract] OR intercultur*[Title/Abstract] OR sensitive[Title/Abstract] OR folk[Title/Abstract] OR religio*[Title/Abstract] OR cultural[Title/Abstract] OR "culture specific"[Title/Abstract] OR mindful[Title/Abstract] OR compassion*[Title/Abstract]) AND (bereavement[Title/Abstract] OR grief[Title/Abstract] OR griev*[Title/Abstract] OR care*[Title/Abstract] OR information[Title/Abstract] OR	Title/ abstract

		service[Title/Abstract] OR facilit*[Title/Abstract] OR resource*[Title/Abstract] OR tool*[Title/Abstract] OR material*[Title/Abstract] OR doula[Title/Abstract] OR doctor[Title/Abstract] OR healer[Title/Abstract] OR elder[Title/Abstract] OR midwife[Title/Abstract] OR care[Title/Abstract] OR attendant[Title/Abstract] OR dialogue[Title/Abstract] OR practice*[Title/Abstract] OR custom*[Title/Abstract] OR burial[Title/Abstract] OR death[Title/Abstract] OR dies[Title/Abstract])
	#12	#9 OR #10 OR #11
	#13	#5 AND #8 AND #12
Australian Indigenous HealthInfoNet		(culture or cultural or tradition) AND (stillb* or “infant death” or “neonatal death” or “baby death”)
Informit Indigenous Collection		[All Fields: bereavement OR All Fields: grief OR All Fields: griev* OR All Fields: tradition* OR All Fields: ritual* OR All Fields: support OR All Fields: cultural*] AND [All Fields: death OR All Fields: dies OR All Fields: dead OR All Fields: 'sorry business'] AND [All Fields: baby OR All Fields: stillb* OR All Fields: neonat* OR All Fields: child] AND Publication Date: (01/01/2017 TO 12/31/2018)
Cochrane		#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Death] explode all trees #3 MeSH descriptor: [Perinatal Mortality] this term only #4 MeSH descriptor: [Abortion, Induced] this term only #5 (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mORtalit*) #6 ((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) ADJ1 loss*) OR stillb*)):ab (Word variations have been searched) #7 ((((“fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") ADJ3 (terminat* or abortion or abort)) or "prenatal diagnosis")):ti,ab,kw #8 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 #9 MeSH descriptor: [Vulnerable Populations] explode all trees #10 MeSH descriptor: [Cultural Diversity] explode all trees #11 MeSH descriptor: [Transcultural Nursing] explode all trees #12 MeSH descriptor: [Health Care Costs] explode all trees #13 MeSH descriptor: [Health Services, Indigenous] explode all trees #14 MeSH descriptor: [Hospice Care] explode all trees #15 MeSH descriptor: [Midwifery] explode all trees #16 ((parent* or mother* or father* or "patient*" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or Maori or whanau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya* or arab* or community of cultural* or "limited English" or "language barrier*" or "other language*" or spirituality)):ab

#17	#9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16
#18	(((written or electronic or audio or audio-visual or visual or virtual or translat* or language or accessib* or socio-cultural or interpret*) ADJ4 (information or service or facilit* or resource* or tool* or material* or service or care)) or ((tradition* or intercultur* or sensitive or folk or religio* or cultural or "culture specific" or mindful or compassion*) ADJ9 (bereavement or grief or griev* or care* or information or service or facilit* or resource* or tool* or material* or service or doula or doctor or healer or elder or midwife or care or attendant or dialogue or practice* or custom* or burial or death or dies)))
#19	((cultural* or tradition* or literacy or disability) ADJ3 (safe* or appropriat* or need* or resource* or adapt* or perspective* or view*))
#20	#18 OR #19
#21	#8 AND #17 AND #20
#22	LIMIT #21 2017-2022

Figure 1. PRISMA flow diagram of screening evidence

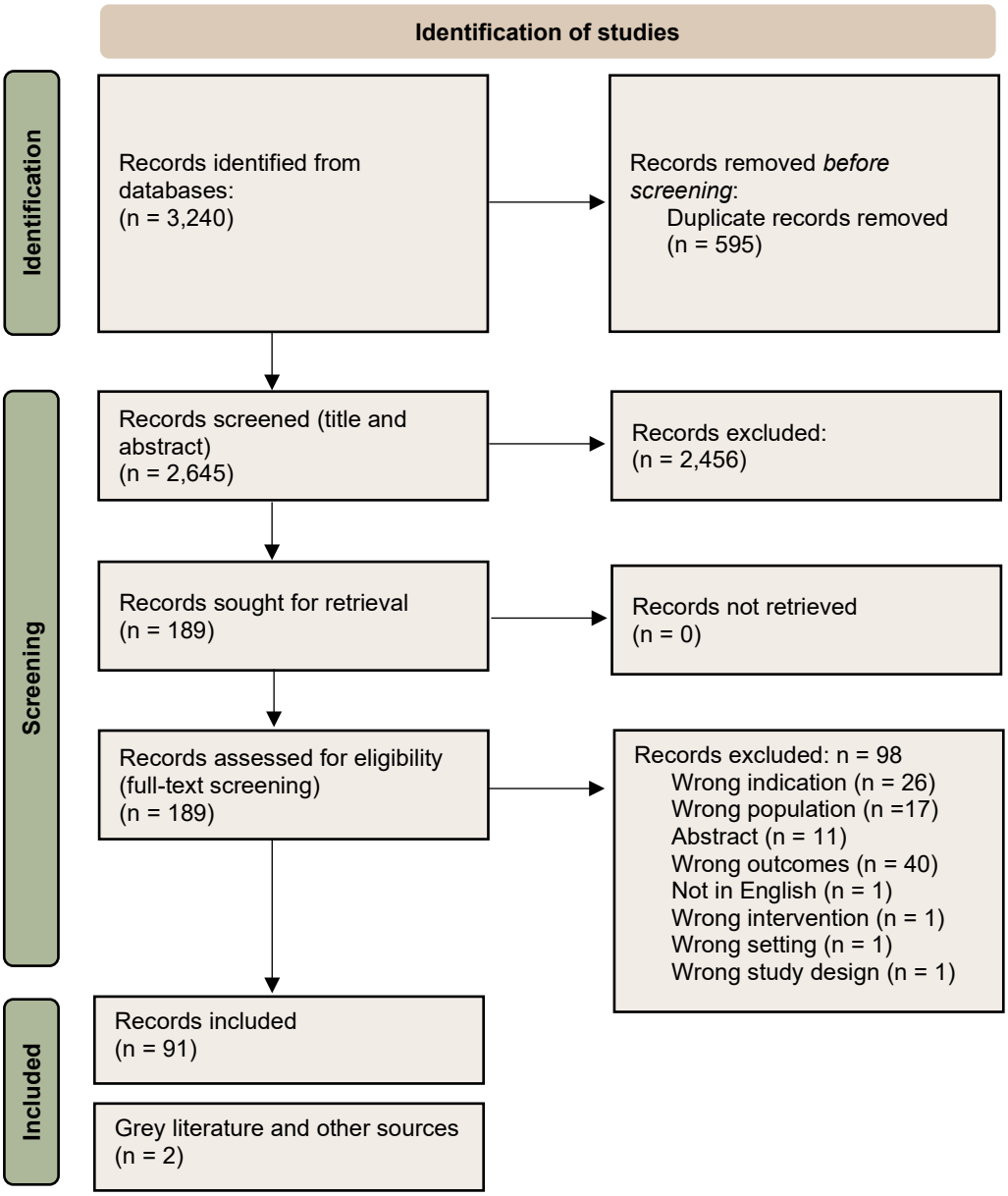

Table 5. Study characteristics

Study	Country/ period	Locality (state/national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
ACOG Committee 2019	USA (2019)	NA	Committee opinion	HIC	Qualitative	Descriptive review	NA	NA	TOPFA	Perinatal palliative comfort care	None mentioned	Patients appropriate for perinatal palliative comfort care, essential components of care, challenges and benefits for patients, healthcare professionals and health care entities, and ethical considerations	Checklist for text and opinion papers
Berry 2019	Multiple (Nov 2017-May 2018)	NA	Literature	NA	Qualitative	Systematic review	NA	NA	TOPFA	Impact of communication in discussing an intrauterine diagnosis of a fetal congenital anomaly on perinatal grief	Non-English articles, articles published prior to 2008, grey literature and those that did not focus on communication of an anomaly	Peer-reviewed articles on communication styles, techniques, and stances by healthcare professionals when communicating a fetal anomaly diagnosis detected in	Checklist for systematic reviews and research syntheses

												utero, published in English in last 10 years	
Boyle 2020	Australia	National	Guideline, literature	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth, NND	Perinatal bereavement care guidelines	None mentioned	Components of best practice perinatal bereavement care	Checklist for text and opinion papers
Abdel Razeq 2021	Jordan (NR)	2 NICUs	Semi-structured interviews	LMIC	qualitative	Thematic analysis	NA	12 mothers	NND	experience of mothers whose babies died in NICU	not stated	mothers of neonates born alive and then died in NICU	Checklist for qualitative research
Aboungo 2020	Ghana (NR)	One district in the Northern region of Ghana, 4 communities	Interviews, focus groups	LMIC	qualitative	Thematic analysis	NA	126	NND	attribution of blame for death	not stated	Women's groups; traditional birth attendants; traditional chiefs and elders; community health nurse; midwife; nurse; traditional healers	Checklist for qualitative research

Actis Danna 2023	Malawi, Tanzanie, and Zambia	Women who had given birth at tertiary referral hospitals in Tanzania, Malawi and Zambia	Semi-structured interviews	Low income	Qualitative	Grounded Theory (Symbolic Interactionism)	NA	33 women	Stillbirth (within the preceding 12 months)	The purpose of this study was to understand how and when women became aware of the death of their babies.	Women <18 years of age	Women who had experienced a stillbirth in the preceding 12 months and had the capacity to consent.	Checklist for qualitative research
Ahmed 2020	Pakistan 2018	One district in Sindh province	Interviews, focus groups	LMIC	qualitative	Thematic analysis	NA	36 for interviews (25 mothers with a recent perinatal loss, 3 family members, 8 healthcare officials), 17 for focus groups	Stillbirth, NND	access to, and quality of care during pregnancy and birth	not stated	4 groups - women who had a perinatal death in the last 12 months; family members of these women; female medical officers and district health management officials; and lady health workers	Checklist for qualitative research
Ahmed 2020 (2)	Pakistan 2018	One rural district in southern Sindh province	Interviews	LMIC	qualitative	Thematic analysis	NA	25 women	Stillbirth, NND	use of home remedies; support for bereaved women; acknowledgement of women's grief	not stated	women who had experienced a perinatal death in the previous year	Checklist for qualitative research

Alaradi 2021	USA (June 2017-Aug 2019)	Two large mosques in Louisville, KY	Questionnaire	HIC	Quantitative	NA	Cross-sectional study	79	Miscarriage (n=12), Stillbirth(n=4), NND (n=5)	Arab Muslims' perception of perinatal loss care in the USA	None mentioned	Arab Muslims over 18years of age. Not a requirement to have had experienced perinatal loss.	Checklist for analytical cross-sectional studies
Alvarenga 2021	Multiple (Dec 2017)	NA - synthesis	5 databases	LMIC & HIC	Qualitative	Meta-synthesis	NA	21 studies (570 parents from 13 countries)	stillbirth	to understand the experience of spirituality for parents following stillbirth	not addressed	parents experiencing stillbirth 20 weeks plus	Checklist for systematic reviews and research syntheses
Asare 2020	Ghana (dates not reported)	one public hospital & 2 private hospitals	Interviews	LMIC	Qualitative	Thematic analysis	NA	20 parents	stillbirth, NND, child death	emotional, social, psychological and economic experiences of child loss	NA	parents experiencing child loss in past 8 years	Checklist for qualitative research
Asim 2022	Pakistan (June 2018-May 2019)	rural villages of district Thatta Sindh	Interviews	LMIC	Qualitative	Thematic analysis	NA	8 women	stillbirth	Lived experience of multiple stillbirths	NA	women experiencing multiple stillbirths, with last stillbirth occurring within the period of last 12 months from the date of interview	Checklist for qualitative research

Ayebare 2021	Uganda; Kenya 2017-19	5 health facilities in urban, peri-urban and semirural communities	Interviews	LMIC	Qualitative	Thematic analysis	NA	134 parents; 61 health workers	stillbirth	support from family and friends after stillbirth; cultural constraints; spiritual, supernatural and social beliefs about causes of stillbirth	NA	Women and male partners who had experienced a stillbirth, in five urban, peri-urban and semirural facilities and surrounding communities in Kenya and Uganda within the previous 12 months; health workers including midwives, nurses and doctors who regularly provided care for bereaved women in the same facilities	Checklist for qualitative research
Bakari 2021	Ghana (dates not reported)	3 districts in Ashanti regions (rural and urban)	interviews; FGDs	LMIC	Qualitative	Thematic analysis	NA	100 women: 80 Fatal Gestational Diagnosis; 20 interviews	Miscarriage, stillbirth, NND	knowledge, attitudes and beliefs regarding neonatal mortality	NA	all women had lost a baby (stillbirth, miscarriage or baby born alive) in the study area	Checklist for qualitative research

Boyle 2022	Australia (April 2020)	National	Online survey	HIC	Qualitative	Content analysis	NA	35	Stillbirth, NND, TOPFA	healthcare professionals views of the impact of COVID on provision of respectful care to parents and resulting practice changes	None specified	healthcare professionals who provided perinatal bereavement care in clinical settings or through support organisations in Australia	Checklist for qualitative research
Carlsson 2019	Sweden (2015)	National	Web-based open-ended questionnaire	HIC	Qualitative	Thematic analysis	NA	6	Prenatal diagnosis of fetal anomaly	Experiences of immigrants with Arabic or Sorani interpreter needs when presented with a antenatal diagnosis of foetal anomaly	None mentioned	participants needed to require interpreter services to understand information from health professionals at the time of diagnosis, and be able to read and write in either Arabic or Sorani	Checklist for qualitative research
Christou 2019	Afghanistan (Oct-Nov 2017)	one urban and two rural districts of Kabul province, Afghanistan	Interviews	LIC	Qualitative	Thematic analysis	NA	55 (mothers (21) and fathers (9)) who had experienced a recent	Stillbirth	how community and healthcare providers' perceptions and practices around stillbirth	None mentioned	women and men that recently experienced a stillbirth, female elders, community health workers, healthcare	Checklist for qualitative research

								stillbirth, female community elders (3), local CHWs (5), various healthcare professionals at tertiary-level facilities (11), and government health officials (2)		influence stillbirth data quality in Afghanistan		professionals, and government officials in Kabul province, Afghanistan	
Das 2021	India 2018-2019	At and around a tertiary care hospital in Delhi	Observations, interviews and focus groups	LMIC	Qualitative	Thematic content analysis	NA	104	Stillbirth (n=44 parents of 22 stillbirths), NND (n=24 parents of 12 NND)	Perceptions of parents, community and religious leaders on acceptability of minimally invasive tissue sampling (MITS)	Parents from outside Delhi were excluded	Parents of deceased children, neonates or stillbirths, community members and religious leaders	Checklist for qualitative research
Ekland 2022	Denmark (Jan 2016-Dec 2019)	National	Web-based Questionnaire survey	HIC	Quantitative	NA	Cross-sectional study	713	Stillbirth, NND, TOPFA	Religious/spiritual beliefs, practices, changes, and needs among parents bereaved by	None mentioned	parents who lost a child during pregnancy (from gestational week 14),	Checklist for analytical cross-sectional studies

										pregnancy or neonatal loss in a Danish context; and to assess gender differences in religiosity/spirituality in this population of bereaved parents.		during birth, or in the neonatal period (4 weeks postpartum).	
Fenstermacher 2019	USA (dates not reported)	3 inner city hospitals in Pennsylvania	Interviews at 3 time points	HIC	Qualitative	Constant comparative analysis	NA	8	Stillbirth, NND	Bereavement support needs of black urban women in late adolescence after perinatal loss	None mentioned	non-Hispanic, unmarried, English speaking black urban women ranging in age from 18 to 21 years (late adolescence) with a recent perinatal loss, with no prolonged hospital stay after their loss	Checklist for qualitative research
Fernandez-Basanta 2020	2013-18	NA	Literature	NA	Qualitative	Qualitative systematic review	NA	14 studies	Stillbirth, NND, TOPFA	Coping experiences of parents following perinatal loss.	Grey literature, discussion or review papers and papers not in English, Portuguese, or Spanish were excluded	Original qualitative articles or mixed articles from which the qualitative results could be extracted published between 2013	Checklist for systematic reviews and research syntheses

												and July 2018. Inclusion was restricted to studies whose sample comprised mothers, fathers or parents and whose type of loss was miscarriage, TFA, foetal death, or neonatal loss.	
Feroz 2019	Pakistan 2018	National Institute of Child Health (NICH), Karachi, Pakistan	Focus groups and interviews	LMIC	Qualitative	Thematic analysis	NA	40 (32 for focus groups and 8 key informant interviews)	Stillbirth, NND	Health professionals' attitudes and perceptions related to MITS	None specified	healthcare professionals including residents, consultants, staff nurses and trainees working at the NICH hospital were included in focus groups. Interviews were conducted with public health experts, clinicians, and bioethics experts.	Checklist for qualitative research

Gamlin 2018	Mexico (date not stated)	Towns and villages in Northwest Mexico	Interviews, observations of family and community dynamics	Upper middle income	Mixed	Ethnography	Descriptive	62	Stillbirth, NND	Wixárika women's family and community dynamics, experiences of antenatal and postnatal care in clinics and hospitals, and pregnancy outcomes	None stated	All women in towns and villages that make up the indigenous governship of Yuáwime (name of governship changed to protect identify) who were known to be pregnant, could be contacted and consented.	Checklist for qualitative research
Garcia 2020	England (Dec 2014-March 2016)	Unclear	Interviews	HIC	Qualitative	Framework analysis	NA	6	Stillbirth, NND	Experiences of bereavement after stillbirth of Pakistani, Bangladeshi and White British mothers	Women who had delivered infants but earlier than the preceding six-month bereavement period, retrospective records showing bereaved infants over 24months (to eliminate retrospective bias and inaccurate memory recall), women aged under 16 years of age at the	Delivered their infant in the previous 6 to 24months, stillborn or NND within 7 days of birth, 16 years or older at conception, maternal ethnicity of Pakistani, Bangladeshi or White British documented in their records, residing within fixed postcode of the town. Consent obtained.	Checklist for qualitative research

											time of conception, maternal ethnicities other than Pakistani, Bangladeshi and White British, not living in the predefined post codes.		
Gesser-Edelsburg 2017	Israel (2014-2015)	North Israel	Interviews	HIC	Qualitative	Constructionism	NA	29	TOPFA	The experiences of Muslim women at high risk for congenital anomalies and how their doctors communicate the risk	None mentioned	Obstetricians and gynaecologists in high-risk pregnancy wards in northern Israel. Women were in-patients in high-risk pregnancy wards in two hospitals and had genetic diagnosis of congenital anomalies	Checklist for qualitative research
Gopichandran 2018	India (dates not mentioned)	Tamil Nadu, primary health care setting (no specific hospital described)	In-depth interviews	LMIC	Qualitative	Thematic analysis	NA	10 (mothers [n=8], community health worker [n=1], hospital duty	Stillbirth	The experience of stillbirth, feelings, and emotions related to the experience, support received,	None mentioned	Mothers who experienced stillbirth in the past 1 year (n=8)	Checklist for qualitative research

								nurse [n=1])		coping strategies, social impact, impact on family and meaning attributed to the experience			
Henderson 2017	UK (2013)	National	Postal survey	HIC	Mixed-methods	Thematic analysis	Cross-sectional descriptive study	477	Stillbirth	Experience of parents in relation to postmortem following stillbirth	None specified	Women who experienced a stillbirth in 2013	Checklist for qualitative research and checklist for studies reporting prevalence data
Huberty 2017	Multiple (2016)	International literature	Literature	NA	Qualitative	Narrative review	NA	2 articles	Stillbirth	Systematic review of experimental interventions for women after stillbirth	Stillbirth not defined or if paper was a meta-analysis or review	Articles were eligible if they were: (1) published in English, (2) published in a peer-reviewed journal, (3) published in 1980 or later, (4) an intervention that evaluated (qualitative or quantitative methods) mental and/or physical health, and (5) included	Checklist for systematic reviews and research syntheses

											women who had experienced a stillbirth (in utero fetal death at more than 20 weeks of gestation).	
Kalu 2019	Nigeria (2017)	1 maternity unit in Eastern Nigeria	Semi-structured interviews	LMIC	Qualitative	Thematic analysis	NA	10	Miscarriage (up to 24 weeks gestation)	experiences of women's use of religious and spiritual beliefs as coping resources after miscarriage	None mentioned	women 18 years of age or older and those who had miscarriage 18–24 months prior to the study.	Checklist for qualitative research
Karki 2019	Nepal (2018)	1 remote district in Nepal (10 villages)	Interviews, hospital records, records from village health committees and village leaders	LMIC	Mixed methods	Narrative	Cross sectional	20 for interviews	NND	Neonatal mortality in Nepal and cultural perceptions of neonatal death and morbidity	None mentioned	local health staff, the village health committee and the village leaders; interviews with members of the women's committee of the villages	Checklist for analytical cross-sectional studies and checklist for qualitative research
Kilcullen 2020	Australia (2005-2015	Townsville Hospital	Semi-structured interviews with women	HIC	Qualitative	Thematic analysis	NA	5	Stillbirth	Aboriginal and Torres Strait Islander women's decisions to consent for autopsy after stillbirth	Women with active mental health difficulties	Aboriginal and Torres Strait Islander women who experienced stillbirth between 2005-2015	Checklist for qualitative research

Kwesiga 2021	Multiple (Guinea-Bissau, Ethiopia, Uganda, Bangladesh and Ghana); 2018	5 Health and Demographic Surveillance System sites in 5 countries in sub-Saharan Africa and South Asia	Focus groups	LIC and LMICs	Qualitative	Thematic analysis	NA	82 survey interviewers and supervisors, 172 women (28 focus group discussions)	Miscarriage, stillbirth, NND	Barriers and enablers to reporting adverse pregnancy outcomes	None mentioned	women (survey respondents of the EN-InDEPTH study) and survey interviewers (and supervisors)	Checklist for qualitative research
Lappeman 2020	South Africa, 2018	one hospital located in an impoverished and violent area of the West Cape Province	Interviews	LMIC	Qualitative	Thematic analysis	NA	7 nurses	stillbirth	how the nurses feel and talk about their work in the labour ward, specifically as it relates to stillbirths	NA	nurses who had worked in the labour ward for at least four months and cared for at least one stillborn	Checklist for qualitative research
Lappeman 2022	South Africa (2018-2019)	one hospital located in an impoverished area	Interviews	LMIC	Qualitative	Thematic analysis	NA	10	stillbirth	women's experience of hospital care following stillbirth	women < 18; who drank medication or self-harmed to terminate the pregnancy; abused substances; had families working in the labour ward of the hospital	mothers experiencing stillbirth at the hospital between January and August 2018	Checklist for qualitative research

Lassi 2019	Multiple (2016-2017)	International	Literature (5 databases)	LMICs	Qualitative	Narrative synthesis	NA	159 studies	NND	Healthcare seeking for maternal and newborn illnesses in LMICs	studies on health care seeking for specific maternal and newborn illnesses such as jaundice etc. or for preterm babies	observational or qualitative studies from LMICs that assessed the factors associated with health care seeking for maternal and newborn illnesses	Checklist for systematic reviews and research syntheses
Le Grice 2017	New Zealand (dates not reported)	National	Interviews	HIC	qualitative	Thematic analysis	NA	43 participants (26 women, 17 men)	abortion; stillbirth	Māori perspectives on abortion	NA	Self-identified Māori men and women	Checklist for qualitative research
Markin 2018	USA/Haifa: period ns	NA	Opinion, literature	HIC	Qualitative	narrative	NA	NA	Stillbirth, NND, TOPFA	Cultural taboo against perinatal grief	NA	NA	Checklist for text and opinion papers
Martins 2020	Brazil (Jan-Nov 2016)	Ribeirao Preto Medical School of University of Sao Paulo	Interviews including standardised survey questionnaires	UMIC	quantitative	NA	Cross-sectional	28 pregnant women	Fetal anomaly	Influence of religiosity on coping ability of women with malformed fetuses	NA	Pregnant women attending the High-Risk Pregnant Division of the hospital, for a diagnosis of fetal	Checklist for analytical cross-section studies

											abnormalities with a pre- or postnatal prognosis ranging from some degree of impairment to risk of death	
McNeil 2020	Multiple (Dec 2019)	International	Literature	LMICs	Qualitative	Narrative review	NA	11 papers	Stillbirth, NND	Grief and bereavement support for parents after the death of a child	None mentioned	Articles were included if they specifically evaluated the bereavement experience of parents after the death of a child in a LMIC	Checklist for systematic reviews and research syntheses
McNojia 2020	Pakistan (June 2017-Sept 2017)	Thatta district in Sindh Province of Pakistan	Interviews and focus groups	LMIC	Qualitative	Thematic analysis	NA	4 women for interviews, 43 for focus groups (29 women, 14 traditional birth attendants)	Stillbirth	Perceptions and experiences of women and traditional birth attendants regarding stillbirths	None mentioned	The eligibility criteria for in-depth interviews was to include women who experienced stillbirth within last 3 months of the date of delivery interview regardless of place of delivery; for focus group discussions with rural women included	Checklist for qualitative research

												women who experienced pregnancy during past 2 years of date of the interview irrespective of pregnancy outcome; TBAs who had more than 5 years of experience of conducting deliveries in Thatta and in practice; study participants to be permanent residents of Thatta.	
Meyer 2018	Ghana (2012)	One hospital in Kumasi, Ghana	Semi-structured Interviews	LMIC	Qualitative	Thematic analysis	NA	8	NND	Experience of infant loss for bereaved mothers in Ghana	mothers from the larger study for whom contact information or phone access was not available, lived more than 2 hours away from the hospital, were unreachable by phone (number disconnected, wrong number,	mothers who were 18 or older, spoke English or Twi, lost a baby since participating in the larger study a year ago, lived within 2 hours of the hospital and could be reached by phone agreed to be interviewed	Checklist for qualitative research

											no answer), and those who denied having received care at the hospital		
Mills 2021	Kenya and Uganda (July 2017-May 2019)	5 facilities in Nairobi and Western Kenya, Kampala and Central Uganda	Interviews	LIC, LMIC	Qualitative	Thematic analysis	NA	75 women, 59 men	Stillbirth	Parents' experience of care and support after stillbirth	NA	women and men over 18 years of age who had experienced the stillbirth of their baby (≤1 year previously) and received care in the included facilities.	Checklist for qualitative research
Mills 2022	Kenya, Uganda (dates not reported)	5 facilities in Kenya and Uganda	Interviews	LIC and LMIC	Qualitative	Thematic analysis	NA	N=61 (nurse midwives (n=37), midwives (n=12) and doctors (n=10), 1 hospital social worker, 1 reproductive health counsellor)	Stillbirth	Lived experiences of healthcare professional (midwives, doctors, and others), caring for women after stillbirth in Kenya and Uganda	NA	Healthcare professionals regularly providing care for women and families after the death of a baby in included study facilities	Checklist for qualitative research

Milton 2021	Nigeria (Jan 2019)	One tertiary hospital (Murtala Muhammad Specialist Hospital) in Kano, Northern Nigeria	Focus group discussions	Lower-middle income	Qualitative	Inductive thematic analysis	NA	31	stillbirth	Stillbirth perceptions and experiences of Nigerian mothers	Women who had experienced stillbirth in their most recent pregnancy were excluded based on sensitivity.	Mothers with and without previous experience of stillbirth, who had given birth to a liveborn baby at Murtala Muhammad Specialist Hospital in 6 months prior to the study were included.	Checklist for qualitative research
Mone 2021	UK (2008-2019)	1 tertiary prenatal centre	Clinical notes, genetic laboratory notes	HIC	Quantitative	NA	Cohort study	n = 280 (62 consanguineous pregnancies; 218 non-consanguineous pregnancies)	Congenital anomaly	Background characteristics, uptake of prenatal and postnatal investigation and, diagnostic outcomes of UK consanguineous couples and non-consanguineous couples presenting with a fetal structural anomaly.	None mentioned	Couples referred to the West Midlands Regional Genetics Service with a history or current fetal structural anomaly	Checklist for cohort studies

Moyer 2017	Multiple (2005 - 2016)	NA	Literature	LMICs	Qualitative	Systematic review	NA	16 articles	NND	The extent to which social autopsy methods are used in LMICs	Review articles	Original peer-reviewed research articles focused on maternal/neonatal/infant/child health and explicitly mentioning social autopsy instrument, tool, survey, interview guide or questionnaire.	Checklist for systematic reviews and research syntheses
Munguambe 2021	Mozambique (Sept 2013-Apr 2015, Dec 2016-Dec 2017)	Manhica district	Interviews, observations, clinical records	LIC	Qualitative	Content analysis	NA	15 for acceptability study, 114 for experienced acceptability study: 35 for observations, 11 informal conversations, 68 clinical records; 10 interviews	Anticipated acceptability: Stillbirth (n=4), NND (n=4); Experienced acceptability: Stillbirth(n=32), NND (n=45)	Consent to MITS procedures in children	None mentioned	Family members of children under 5 including stillbirths in the study period	Checklist for qualitative research

Nedruetai 2022	Thailand (2020-2021)	4 community hospitals in Northeast Thailand	Interviews	UMIC	Qualitative	Thematic analysis	NA	25	Stillbirth, NND	Grief journey in Thai women experiencing a perinatal death	Women with mental health disorders excluded	Thai women who had experienced the loss of children from perinatal death in the labour room, neonatal or paediatric intensive care units, or emergency room at public community hospitals were purposefully selected according to the following inclusion criteria: (1) age >18 years; (2) duration between six months and two years after experiencing perinatal death, and (3) ability to understand and communicate in Thai.	Checklist for qualitative research

Nuzum 2021	UK and Ireland	National	Online survey	HIC	Quantitative	NA	Cross-sectional descriptive study	46	Stillbirth	Role of maternity healthcare chaplains in decision making, information provision and support around perinatal postmortem with bereaved parents	None specified	Maternity healthcare chaplains	Checklist for studies reporting prevalence data
Olivier 2021	USA (dates not reported)	NA	Opinion, literature	HIC	Qualitative	Narrative	NA	NA	Miscarriage, stillbirth, NND	Relational cultural theory as a therapeutic approach to perinatal loss	NA	NA	Checklist for text and opinion papers
Onarheim 2017	Ethiopia (Oct-Nov 2015)	In and around the town of Butajira	Observations, interviews and focus groups	LIC	Qualitative	Thematic analysis	NA	41 participants for interviews, 7 focus groups	NND	Families' decision making and health-care-seeking for ill newborns in Ethiopia	None mentioned	Four groups of participants were purposively selected and included (i) mothers or primary caretakers with sick newborns, (ii) mothers or primary caretakers who had experienced a	Checklist for qualitative research

												newborn loss, (iii) health workers, and (iv) community members.	
Osman 2017	Somalia 2015	Eight villages in a district in Somaliland	Interviews	LIC	Qualitative	Phenomenological	NA	10	Stillbirth (10)	Maternal experience of stillbirth	pregnant or unmarried women	Women who had given birth in a health facility to a baby with no signs of life at or after 28 weeks GA within 6 months prior to interview.	Checklist for qualitative research
Paudel 2018	Nepal (Feb-June 2015)	Two mountain villages in Nepal	Interviews	LMIC	Qualitative	Thematic analysis	NA	62 (42 women, 15 healthcare professionals, 5 stakeholders)	Stillbirth, NND	Beliefs and experiences of women and their families in remote mountain villages of Nepal about perinatal sickness and death	NA	women and their families who had experienced a neonatal death or stillbirth in the previous 4 years; healthcare professionals including skilled birth attendants; female community health volunteers; support staff and auxiliary health worker; Other	Checklist for qualitative research

												stakeholders including local journalists and staff of NGOs working in maternal and child health	
Pollock 2020	Multiple (2018)	International literature	Literature (5 databases)	NA	Qualitative	Scoping review	NA	23 articles	Stillbirth	Current knowledge surrounding stillbirth stigma, specifically the extent, type and experiences of bereaved parents	Non-English articles. Articles not published at the time of this scoping review being submitted for publication (October 2018) were not included	The inclusion criteria for articles were; (1) written in English; (2) focused on stillbirth (3) the abstract or title included the words stigma OR silence.	Checklist for systematic reviews and research syntheses
Qian 2020	China (Jan-Apr 2019)	One tertiary hospital	Expressive writing at 4 different time points from diagnosis through to 1 month after discharge	UMIC	Qualitative	Thematic analysis	NA	20	TOPFA	Psychological trajectories of women undergoing pregnancy termination for foetal abnormality	women who had postpartum complications (e.g. postpartum massive haemorrhage) or serious mental disorders (e.g. schizophrenia)	women who (a) were pregnant for more than 14 weeks, (b) decided to terminate their pregnancies due to foetal abnormality or stillbirth, (c) were able to write Chinese and willing to express their emotions through writing and (d) had access to	Checklist for qualitative research

												WeChat (a chatting software) and were able to complete the follow-up research	
Rahman 2017	Qatar (no dates)	National	Opinion piece	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND	Population dynamics of Qatar and trends in maternal and neonatal mortality	NA	NA	Checklist for text and opinion papers
Redshaw 2018	UK (2013)	National	Structured questionnaire including open text responses	HIC	Mixed methods	Thematic analysis	Retrospective cohort	472 for quantitative component (366 women in less deprived quintiles, 106 women in most deprived quintiles); 78 for qualitative component	Stillbirth	Disadvantaged women's' experience of care after stillbirth	NA	Women aged 16 years and over who registered a stillbirth or neonatal death between January and March 2012 or between June and August 2012 in England	Checklist for cohort studies and checklist for qualitative research

Rent 2021	Ghana (2018)	2 hospitals in Kumasi, Ghana	Interviews	LMIC	Qualitative	Thematic analysis	NA	20	Stillbirth, NND	Perspectives of medical providers about Asram and implications of traditional newborn care practices on newborn health and outcomes	None mentioned	able to converse in English and experience of at least 1 month working with newborn infants	Checklist for qualitative research
Roberts 2021	India: 2012; 2020	Mungeli district in Chhattisgarh; Mumbai	Interviews	LMIC	Cross sectional and qualitative	Thematic analysis	Cross-sectional	217 rural & 149 urban women	stillbirth	perinatal grief	NA	women between 18 and 49 years	Checklist for analytical cross-sectional studies and checklist for qualitative research
Smidova 2019	Czech Republic	NA	Narrative review	HIC	Narrative review	Qualitative	NA	NA	NA	"death at birth"	NA	NA	Checklist for text and opinion papers
Sani 2021	France: 2014	online	videos on YouTube	NA	qualitative	qualitative	NA	50 videos; 2,429,576 views; 2,563 comments	stillbirth	responses to videos on stillbirths	NA	videos accessed by stillbirth as a keyword	Checklist for qualitative research

Sterpu 2020	Sweden: 2017	Stockholm	Medical records	HIC	retrospective cohort	quantitative	retrospective cohort	79 stillbirths; 78 women	stillbirth >= 22 weeks	preventable factors; delays	NA	women with a stillbirth >= 22 weeks in Stockholm in 2017	Checklist for cohort studies
Suejong 2017	South Korea	Korean NICUs	NICU nurses	HIC	qualitative	qualitative	qualitative	20 neonatal nurses	neonatal nurses' perceptions of end of life care and quality of care	facilitators and barriers in achieving quality of end of life care	NA	participating nurses had to (a) be currently working in a Korean NICU, (b) have at least 1 year of experience working in a NICU, (c) have experienced at least one patient death in the NICU, and (d) be able to speak and understand Korean.	Checklist for qualitative research
Rumbold 2020	Australia (dates not reported)	NA	Opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth	Addressing disparities in stillbirth risk and care for Indigenous and migrant and refugee communities in Australia	NA	NA	Checklist for text and opinion papers

Spierson 2019	UK (May 2011-June 2012)	National (through British Association of Perinatal Medicine)	Online survey	HIC	Quantitative	NA	Cross-sectional study	98	NND	Healthcare professionals' practices and views on neonatal postmortem	Those who did not work with neonates and/or did not complete the majority of the survey	Neonatal healthcare professionals in UK	Checklist for analytical cross-sectional studies
Stacey 2021	UK (2019-2020)	4 NHS trust districts	Interviews	HIC	Qualitative	verbatim and thematic analysis	NA	30 women	Stillbirth (30)	Women's views on how to develop culturally appropriate interventions to deliver key messages around stillbirth prevention	None listed	Women classified as Black, Asian and Minority ethnic women who had migrated to the UK in their lifetime.	Checklist for qualitative research
Sun 2018	Taiwan (Aug 2012 - July 2014)	Tertiary hospital	Interviews	HIC	Qualitative	Phenomenological	NA	20	TOPFA	How fathers experience TOPFA while their spouses are hospitalised in Taiwan	None mentioned	Partners of women who were hospitalised for TOPFA at a maternity unit in a teaching hospital in Taoyuan and: aged ≥ 20 years, married, able to communicate in Mandarin or Taiwanese, and agreed to audio recording of personal interviews.	Checklist for qualitative research

Sun 2021	Taiwan (Aug 2016- Jul 2018)	Medical centre in Taoyuan County	Interviews	HIC	Qualitative	Phenomenological	NA	20 couples (40 individuals)	Stillbirth	The meaning that parents attach to the care of the remains of their stillborn babies in Taiwan	Couples that did not provide consent	1) pregnant women age 20 years old or more; (2) married and whose spouse is also invited; (3) their child were diagnosed with foetal death and the couple accepted induction of labour for stillbirth; (4) participants must be able to communicate in Mandarin or Taiwanese.	Checklist for qualitative research
Thieleman 2020	Romania (June-Nov 2013)	National through an organisation for bereaved parents	Online survey including open-text responses	HIC	Mixed methods	Thematic analysis	Cross-sectional	237	Stillbirth, NND, Infant death, child death	Anxiety, depression, and trauma responses among grieving Romanian parents and to explore their lived experiences of bereavement	None mentioned	Over 18 years of age, and those who experienced the death of a child from any cause, including miscarriages.	Checklist for qualitative research and checklist for analytical cross-sectional studies

Al Mutair 2019	Saudi Arabia, July-November 2018	1 private hospital in Riyadh	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	13	NND	Staff experience of providing care to dying infants/children and their families	Not specified	NICU/PICU staff who cared for at least one child who had died	Checklist for qualitative research
Tikmani 2021	India and Pakistan (NR)	3 hospitals in South India, 2 public hospitals in Pakistan	Observations using a structured questionnaire	LMIC	Quantitative	NA	Cross-sectional study	1283	Stillbirth (n=219 India; n=470 Pakistan), NND (n=260 India; n=334 Pakistan)	Parental acceptance of MITS to understand the cause of death	None mentioned	Women who delivered a stillborn baby or had a preterm liveborn baby who later died	Checklist for cross-sectional studies
Tsai 2017	USA (dates not reported)	National (through 16 organisations)	Telephone interviews using vignettes	HIC	Qualitative	Thematic analysis	NA	23	TOPFA	Attitudes towards prenatal genetics among Southeast and East Asian women living in the United States for varying amounts of time and to explore sociocultural factors influencing those attitudes	None mentioned	English-speaking women of Southeast and East Asian descent who were 18 years or older and members of Asian cultural organisations based in the United States	Checklist for qualitative research

Tseng 2018	Taiwan (dates not reported)	2 teaching hospitals in Taiwan	Interviews	HIC	Qualitative	Thematic analysis	NA	16	Stillbirth	Meaning of rituals after stillbirth	unmarried mothers or pregnant adolescent	women who experienced stillbirth during weeks 20 to 40 of pregnancy; had participated in rituals after diagnosed with a stillbirth; and consented to participate in the study	Checklist for qualitative research
Tucker Edmonds 2021	USA (dates not reported)	2 academic medical centres in Midwest	Interviews	HIC	Qualitative	Content analysis	NA	30	Women at risk for periviable delivery	Racial differences in perceptions of pain/suffering, disability, and coping among pregnant women facing the threat of a periviable delivery	Women who were incarcerated, medically unstable, or actively in labour	English and Spanish-speaking pregnant women ages 18+ who presented at two labour and delivery units for a pregnancy complication that posed a threat for periviable delivery (defined for the study as 22 0/7–24 6/ 7 weeks' gestation)	Checklist for qualitative research

Vail 2018	India (2017)	1 state (Bihar)	Semi-structured interviews	LMIC	Qualitative	Thematic analysis	NA	18	NND	Logistical, structural and cultural barriers to evidence-based practices in immediate neonatal care and neonatal resuscitation	NA	Nurses who participated as mentors in the AMANAT maternal and child health quality improvement project and had participated in two phases of the AMANAT intervention	Checklist for qualitative research
Wong 2021	Hong Kong / May-December 2019	Pamela Youde Nethersole Eastern Hospital, Hong Kong	Structured open-ended questions through self-administered questionnaire (n=26) or phone interview (n=25)	HIC	Qualitative	Thematic analysis	NA	51	Stillbirth, TOPFA, NND	Aimed to explore the views of Hong Kong Chinese women who experienced perinatal loss on seeing and holding the baby and on commemorating the baby	NA	Chinese women who experienced the loss of a baby or fetus (caused by miscarriage, TOPFA, stillbirth, or NND) perinatally (from second trimester [12 gestational weeks] to 28 days of life after birth) within 5 years and had been under the care of the Bereavement Team at the hospital	Checklist for qualitative research

Zareba 2020	Poland / June 2014-May 2016	First Department of Obstetrics and Gynaecology, Centre of Postgraduate Medical Education, Warsaw	Questionnaire completed during hospital stay	HIC	Quantitative	NA	Prospective cross-sectional study	150	TOPFA	To determine the influence of religious and moral beliefs on contraceptive use, assisted reproduction and pregnancy termination in Polish women requesting a termination of pregnancy for medical reasons	Women were excluded who were not compliant with Act and/or who did not consent to participate in the study	Compliance with the criteria of the 7 January 1993 Family Planning, Protection of the Human Fetus and Conditions for Pregnancy Termination Act; diagnosed fetal anomaly without maternal indications for termination; consent to participate in the study	Check list for analytical cross-sectional studies

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data.

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall appraisal	Relevance
Abdel Razeq 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Aboungo 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Include	U
Actis Danna 2023	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	P
Ahmed 2020	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Ahmed 2020 (2)	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Al Mutair 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R

Asare 2020	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Yes	Yes	Include	P
Asim 2022	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	I
Ayebare 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Bakari 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	I
Boyle 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Carlsson 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Christou 2019	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Das 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Fenstermacher 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Feroz 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Gamlin 2018	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Exclude	I
Garcia 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Gesser-Edelsburg 2017	Yes	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Yes		R
Gopichandran 2018	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	R
Henderson 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R

Kalu 2019	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	P
Karki 2019	Unclear	Yes	Yes	Unclear	Unclear	Yes	No	Yes	Yes	Yes	Include	P
Kilcullen 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Kwesiga 2021	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	R
Lappeman 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Lappeman 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	P
Le Grice 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Mcnojia 2020	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	P
Meyer 2018	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Mills 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Mills 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Milton 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Munguambe 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Nedruetai 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Onarheim 2017	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	I

Osman 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Paudel 2018	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Qian 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Redshaw 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Rent 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Sani 2021	Unclear	Yes	Unclear	Unclear	Unclear	No	No	Unclear	Not Applicable	Unclear	Include	R
Stacey 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Suejong 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Sun 2018	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	Include	R
Sun 2021	Yes	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	Include	P
Thieleman 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Tsai 2017	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Tseng 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Tucker Edmonds 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Vail 2018	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Include	R

Wong 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Alaradi 2021	Yes	Yes	Unclear	No	No	No	Yes	Yes	Include	R
Ekland 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Karki 2019	Yes	Yes	No	No	No	No	No	Yes	Include	R
Martins 2020	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	P
Roberts 2021	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Include	I
Spierson 2019	Yes	Yes	Unclear	Yes	No	No	Yes	No	Include	U
Thieleman 2020	Yes	Yes	Unclear	No	No	No	Yes	Yes	Include	P
Tikmani 2021	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Include	R
Zareba_2020	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	U
Moudi 2017	Yes	Yes	Unclear	Unclear	No	NA	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic reviews

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimise errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Alvarenga 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	unclear	Yes	Include	R
Fernandez-Basanta 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Yes	Include	R
Huberty 2017	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	NA	No	Yes	Yes	Include	U
Lassi 2019	No	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	NA	Include	R
McNeil 2020	Unclear	Yes	Yes	No	Unclear	Unclear	Unclear	Yes	No	Unclear	Yes	Include	R
Moyer 2017	Yes	Yes	No	Yes	Yes	Yes	Yes	NA	NA	Not applicable	Yes	Include	U
Pollock 2020	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Unclear	Not applicable	Yes	Include	I
Berry 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Henderson 2017	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	R
Nuzum 2021	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes	No	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/sources logically defended?	Overall appraisal	Relevance
Markin 2018	Yes	Yes	Yes	No	Yes	Yes	Include	R
Olivier 2021	Yes	Unclear	Yes	No	Yes	NA	Include	P
Rahman 2017	Yes	Unclear	Yes	Unclear	Yes	NA	Include	P
Rumbold 2020	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
Smidova 2019	Yes	Unclear	Yes	Unclear	Yes	NA	Include	R
ACOG Committee 2019	Yes	Yes	Yes	Unclear	Yes	NA	Include	R

Boyle 2020	Yes	Yes	Yes	Yes	Yes	NA	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Mone 2021	No	Yes	No	No	No	Yes	Yes	NA	NA	NA	Yes	Include	R
Redshaw 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Sterpu 2020	NA	Yes	Yes	No	No	Yes	Unclear	NA	NA	NA	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. Detailed GRADE-CERQual assessment

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE_CERQual appraisal
2.1	A multidisciplinary team should oversee care across the continuum from diagnosis through birth and death planning to transition from hospital to community. The team should: • provide continuity of care and carer • hold regular meetings with parents and family/whānau • ensure medical records include a care plan (e.g a perinatal palliative care plan) that has been developed with the parents and the plan is accessible to all team members, parents and family/whānau • consider supports that may be required to meet the cultural, religious, and/or spiritual needs of parents and family/whānau • engage other relevant healthcare workers and interpreters, where needed.	NA	NA	NA	NA	NA	**This recommendation is cross-cutting across several technical reports. For additional evidence synthesis and GRADE-CERQual rating,* ***see Section 3: Technical report for effective communication*** *for GRADE CERQual rating of this recommendation.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE_CERQual appraisal
2.4	Use respectful and sensitive language and terminology that is honest, realistic, and understandable. • Take the lead from parents regarding preferred language for their baby. • Use the word 'baby' or 'bub' if acceptable to parents. • Ask parents if they have named their baby and, if so, seek permission to use the name.	NA	NA	NA	NA	NA	**This recommendation is cross-cutting across several technical reports. For additional evidence synthesis and GRADE-CERQual rating,* ***see Section 3: Technical report for effective communication*** *for GRADE CERQual rating of this recommendation.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE_CERQual appraisal
2.5	Be aware that stress and grief can greatly affect how people absorb, retain, and respond to information. Tailor information by: • using open-ended questions • repeating information and checking with parents that they understand • offering parents culturally and linguistically appropriate parent-facing information and resources about perinatal grief and what to expect • allowing parents time and space to read information and resources when they are ready.	NA	NA	NA	NA	NA	**This recommendation is cross-cutting across several technical reports. For additional evidence synthesis and GRADE-CERQual rating,* ***see Section 3: Technical report for effective communication*** *for GRADE CERQual rating of this recommendation.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE_CERQual appraisal
2.13	Care must be appropriate to parents' cultural, religious and/or spiritual needs. Healthcare professionals should: • recognise that parents and family/whānau come from a wide range of backgrounds and acknowledge diversity within and between cultural groups • avoid cultural stereotypes and culture-based assumptions • be aware of and responsive to individual, cultural, religious and/or spiritual approaches to death and expressions of grief and loss • be aware of and respond appropriately to families with a history of trauma and loss and previous negative experiences with health services particularly: - intergenerational trauma among Aboriginal and Torres Strait Islander families - complex trauma among women of refugee background • acknowledge the importance of each cultural group's vital support systems such as kinship and community care for Aboriginal and Torres Strait	11 studies included, five qualitative studies, three mixed methods studies, two systematic reviews, and one cohort study.	Minor concerns for all methodological limitations of the included studies were recorded. No or minor concerns of methodological limitation were noted for two of the included studies; one qualitative and one mixed-methods study. Five of the included studies were deemed to have minor concerns of methodological limitations. One scoping review, and four qualitative studies. Moderate concerns of methodological limitations were noted for four of the included studies; two qualitative that failed to report the cultural background of the researcher(s), and to discuss the impact of the researcher(s) culture on the analysis and findings. Unclear methodology was also noted. One cohort study as exposures weren't measured using valid methods. The same study also demonstrated cohort selection bias also. One systematic review was assessed to have concerns regarding critical appraisal,	Minor concerns of combined study relevance. Five studies were deemed relevant to the cultural aspects of care around stillbirth and neonatal death. Three studies were deemed to be partially relevant to care around stillbirth hand neonatal death. Two qualitative studies and one mixed-methods study. One scoping review and one qualitative study were deemed indirectly relevant to the cultural aspects of care around stillbirth and neonatal death. One qualitative study was deemed to have unclear relevance to the cultural aspects of care around stillbirth and neonatal death.	Minor concerns of coherence across the included studies.	Minor concerns of evidence adequacy are noted through examination of the included studies. The included evidence is sourced from low-, middle- and high-income country populations. Outcomes included stillbirths (n=1103), neonatal deaths (n=134), TOPFA (n=280) and composite perinatal death outcomes (n=237). Viewpoints of exclusively mothers are included in three studies, and parent's viewpoints are analysed through a majority of the included studies (n=1057). The viewpoint of healthcare professionals is included through two qualitative study's analysis and traditional birth attendants, healers and elders are included through one analysis. The evidence included spans across the outcomes of interest, but some concerns due to the lack of included viewpoints of healthcare	**Moderate Confidence** Minor concerns of evidence coherence, evidence relevance, adequacy of data, methodological limitations

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE_CERQual appraisal
	Islander families and Māori families/whānau. • seek advice and support from experienced health workers and engage cultural support services where required.		methods to minimise errors and bias.			professionals, traditional birth attendants, and omission of community viewpoints.	
3.12	Ask parents and family/whānau throughout care about cultural needs regarding perinatal loss practices and handling of their baby's body. • Always ask parents and family/whānau permission before handling their baby.	11 studies included. All 11 use qualitative data, one cross-sectional one systematic review, and one text/opinion piece.	Moderate concerns of methodological limitation were noted across the included studies. Two of the included studies were assessed to have minor concerns of methodological limitation. The remaining nine studies were noted to have moderate concerns of methodological limitation. Across all qualitative studies with moderate concerns, omission of the researcher(s) cultural position	Minor concerns of included evidence relevance. Nine of the included studies are deemed relevant to cultural aspects of care around stillbirth and neonatal death. Two of the included qualitative studies are deemed partially relevant.	No or minor concerns regarding coherence of evidence included from studies.	Moderate concerns regarding the adequacy of data included from the evidence. The evidence is sourced from populations spanning across high-, middle- and low-income countries. Outcomes included through the evidence include stillbirth (n=197), neonatal deaths (n=18), termination of pregnancy for fetal anomaly (n=20 and composite perinatal mortality (n=35).	**Low confidence** No or minor concerns of evidence coherence, minor concerns of evidence relevance. Moderate concerns of adequacy of data, and methodological limitations.

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE_CERQual appraisal
			and the resultant impact of research findings and analysis was noted. Furthermore, five lacked congruence between the stated and actual methodology. For one qualitative study, concerns were noted that participant voices were not adequately representing in findings. Concerns regarding confounder identification and integration through analysis are noted for the included cross-sectional study. The outcome measures were also noted to lack standard criteria for assignment. The systematic review included lacked a clear research questions and concerns regarding bias, errors and critical appraisal were also noted.			Viewpoints included through the evidence include mothers, parents, and healthcare professionals. Additionally, one study included community viewpoints, and one examined exclusively non-birthing partner's view. Moderate concerns were noted for the adequacy of data due to the small cohort sizes included across the studies, and a disproportionate number of stillbirths included.	
6.6	Healthcare professionals must respectfully ask parents and family/whānau throughout their care if they have cultural, religious, or spiritual care needs including preferences for discussing and making decisions about investigations to understand why their baby died. • Healthcare professionals should avoid making assumptions and must work in partnership with	13 included studies, all qualitative. Of the qualitative, one is a systematic review, two cross-sectional studies, and one prevalence study. The remaining are primary research studies.	Moderate concerns for methodological limitation were noted for the included studies. No or minor concerns of methodological limitation were noted in three of the included studies; one systematic review and two qualitative studies. Minor concerns were noted in methodology of three included studies: two qualitative and one cross sectional study.	No or minor concerns of the included studies relevance were noted. Eleven of the include3d studies were deemed relevant to the cultural aspects of care around stillbirth and neonatal death. One qualitative study is deemed partially relevant and one cross sectional	No or minor concerns regarding coherence of evidence included from studies.	Minor concerns of data adequacy were noted through review of the included studies. Seven of the included studies sourced their populations form high income countries. The remainder sourced study cohorts from low- or middle-income countries. Outcomes across the evidence include stillbirth (n= 1363), neonatal death (n=767),	**Moderate confidence** No or minor concerns of relevance, and coherence. Minor concerns of data adequacy and moderate concerns of methodological limitations.

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE_CERQual appraisal
	families/whānau to ensure care is individualised and that their needs are met, seeking further guidance where needed.		Moderate concerns were noted to affect methodological limitations for seven included studies: three qualitative cohort studies, three cross sectional studies, and one prevalence study. Concerns of qualitative methodology identified a lack of clear statement of the researcher(s) cultural position, and analysis of how this may impact findings. Methodological congruity between the stated methodology and methods reported were also noted. Cross sectional studies identified as having moderate concerns were due to a lack of confounder identification and adjustment, as well as omission of the researcher(s) cultural position and influence on research findings.	study is deemed to be of unclear relevance.		termination of pregnancy for fetal anomaly (n=23) and composite perinatal mortality outcomes (n=300). Viewpoints encompassed through analysis across the included studies include parents, mothers, healthcare professionals (individual and focus group), community members and healthcare chaplains.	

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 3: Perinatal loss care: breaking bad news

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Respectful and supportive perinatal bereavement care needs to begin when a baby is diagnosed with a life-limiting condition or when death is confirmed. Involvement of various healthcare professionals present will vary depending on the setting of care.[1] Being told of a baby's death or life-limiting condition is a life-changing moment for parents. How news is communicated to parents has both immediate and lasting impacts. Years after their baby's death, parents often recall in detail the circumstances in which they were informed of the death, the words used and the actions and attitudes of those involved.[1] Delays in receiving information about a life-limiting diagnosis is worrying and distressing for parents.

Signs of a problem may first be discovered by sonographers or other healthcare professionals who may not be empowered or authorised to communicate their observations to parents.[1] Balancing immediate and detailed information for parents at the point of diagnosis may present challenges to healthcare professionals.

Good communication, both verbal and non-verbal, is a core component of respectful and supportive perinatal bereavement care. This is often raised in studies of parents' experiences of care. Good communication involves healthcare professionals finding the right words, the right approach, and attention to both what is said and how it is said.

Methodology

The Guideline Development Committee developed key research questions around breaking bad news and perinatal loss care (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	What are the care and support considerations for communicating bad or unexpected news to parents and families during the antenatal or neonatal period?
2	What are the considerations for communicating with parents and family around time delays, and are there strategies healthcare professionals can use to limit delays?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 2. PICO criteria

PICO	Inclusion criteria
Population	Defined in Australia and Aotearoa New Zealand as: • Stillbirth o birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term

	'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[2,3]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[2,3]
	• Inclusion of perinatal deaths following termination of pregnancy
	  ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).

Intervention	Studies exploring perinatal loss care following stillbirth or neonatal death in maternal or newborn services.
Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes and experiences of parents, family members, healthcare professionals around perinatal loss care including care that specifically addresses communicating (breaking) of bad news and diagnosis of stillbirth or life-limiting condition. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Search strategies were conducted on 23 April 2022 and incorporated all PICO criteria and restricted to publications in English (Table 4). A top-up search was conducted on 12 September 2023. Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- Wrong *population*: The study did not focus on termination of pregnancy, stillbirth or neonatal death as defined in Table 2.
- Wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- Wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- Wrong *language*: The study was not published in English.
- Wrong *publication dates*: The study was published prior to 2017.
- Wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[4] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- **Methodological limitations:** Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[5]
- **Coherence:** How clear and cogent the fit is between the data from the evidence and synthesis findings?[6]
- **Adequacy:** The richness and quantity of data supporting the findings.[7]
- **Relevance:** The extent to which the evidence from studies is applicable to the context specific in the guideline.[8]

Each domain was assessed individually, and concerns were assessed as:

- No concerns or very minor concerns regarding domain
- Minor concerns regarding domain
- Moderate concerns regarding domain
- Serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated, and details of any concerns were identified and listed.[9] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1. What are the care and support considerations for communicating bad or unexpected news to parents and families during the antenatal or neonatal period?

How news is communicated to parents has both immediate and lasting impacts. Parents often recall in detail many years later the circumstances in which they were told of their baby's death, the words used, and the actions and attitudes of those involved.[10,11] The ways in which healthcare professionals communicate and provide care can shape parents' entire grieving process.

A coordinated multidisciplinary approach is the most effective means of communicating bad news, reducing the risk of receiving differing or even contradictory information.[12,13] When bad news needs to be given, the attitudes of the healthcare professionals involved, the clarity of the message, the time spent in providing this information and the physical surroundings in which it is reported are all important considerations.[14-16]

> **"There are many ways of breaking bad news; no way is good, but some are better."[17]**

Ideally, bad news should be delivered to the parents by a senior healthcare professional who is familiar and trusted by the parents.[12,18,19] The appropriate healthcare professional for breaking bad news of perinatal death or diagnosis varies, and there may be some confusion as to where the responsibility lies. General agreement suggests that this should be the obstetrician, without excluding the support that other team members may provide.[12] In most settings, it may be a junior healthcare professional/clinician who makes an initial diagnosis. This may cause distress to parents who are waiting for a second opinion,[11] as well as the early diagnosis, which is often based on incomplete information. Following this, expectant parents may be informed about the nature and long-term consequences of the diagnosis before it is confirmed, which may cause additional stress.[17]

The whole maternity team,(obstetricians, sonographers, nurses, midwives, anaesthetists, hospital attendants, ward staff, cleaners, clerks, administrative staff etc.) should be trained in breaking bad news empathetically and honestly.[20] Communication with parents should be non-judgmental, parent-led, and should take a shared decision-making approach to care planning.[21-23] It is important to break bad news with direct and concise explanations, including parents in decision-making, treatment, and prognosis, encouraging expression of feelings and questions, and adjusting the message to the parents' culture, religion, and language.[18]

Bad news should ideally be communicated to both parents together, and if not possible, the mother/birthing partner first before others.[12,24] Mothers report that conveying the information of diagnosis to their partners is traumatic,[14] therefore time should be allowed for their partners to attend appointments, if needed.

Support considerations

Parents face many difficult and emotionally charged decisions when their unborn child has died or is diagnosed with a life-limiting condition. The healthcare team should also embrace flexibility when the care plan is changing and communicate this openly to parents.[25] Access to immediate, targeted support and information is aligned with improved coping and adaptation, while delays in accessing specialist and psychological support clearly impact negatively upon parents' experiences [26-29]. It is important to

allow time to process new information, especially uncertain findings [26-29]. Effective information-sharing and supplementary written information also helps enhance understanding.[17] Written information allows parents to revisit and reconsider the information in their own time.[30]

For antenatal diagnosis of a fatal/life-limiting condition, healthcare professionals have an opportunity to positively impact parental outcomes.[14] Expressions of empathy and acknowledgement of the parents' feelings are valued.[13] Parents reported improved satisfaction with their experiences of receiving a prenatal diagnosis when they perceived their healthcare professionals were empathetic, sensitive, and could connect with them.[14] Parents feel supported to make informed decisions after the diagnosis of a fetal anomaly when their healthcare professional can deliver clear, reliable, comprehensible, and adequate information with empathy.[30-33]

When breaking bad news about prenatal diagnosis, it is important to provide emotional support and to prepare women for possible negative outcomes. Bad news should never be given over the telephone, and an appointment should be made with parents to discuss results.[14,17]

Healthcare professional training and education

Communicating adverse pregnancy outcomes, such as fetal death, requires empathy and self-reflective behavioural skills. Parents expressed appreciation when healthcare professionals communicated clearly, with compassion, and used words that validate the personhood of their loss.[13,34] It is essential that the person who does communicate a death has adequate background and training.[35,36] Training in breaking bad news using simulation exercises has been proven efficient in multiple fields but is poorly studied in the context of reporting fetal anomalies.[31,37] For training in sensitive subjects such as breaking bad news, many programs use simulated patients who can give constructive feedback, helping learners to gain confidence to deal with real-life challenges.[38]

During antenatal ultrasound scans, fetal death is evident on imaging, and confusion as to who should convey the diagnosis to parents may be apparent. Some sonographers expect the radiologist/sonologist to impart the results if there was bad news, while others believed it was "their call" and "judgement" and part of a sonographer's role.[39] Important policy queries arising in the sonographic situation include:

- Are there protocols in place for communicating "bad news" to pregnant parents?
- What impact does communicating adverse outcomes have on sonographers?

Formal training with structured guidelines and policies is likely to reduce the anxiety sonographers feel when openly communicating with the woman/parents.[35,36,39] Parents' expectations of the sonographer have increased over recent years with the increase in knowledge mainly due to parents accessing information through the internet. A recent study exploring the views, experiences, and practices of Australian sonographers in communicating adverse outcomes to pregnant women revealed that parents undergoing antenatal ultrasounds expect to know the result instantaneously, which may put pressure on sonographers while conducting ultrasounds.[39]

Considerations for healthcare professional wellbeing

Communication with bereaved parents, from sharing the news of the baby's death to providing ongoing information and explanations is a particular challenge, even for the most experienced healthcare professional.[40] For the healthcare professional communicating fetal death to the family, conversations have been shown to evoke moderate to high degrees of stress among obstetricians. Internally and externally mediated strategies are required to handle situations appropriately to gain professional

resilience.[41,42] In an Australian online survey, obstetricians with wider clinical experience reported less negative situational affect, stress or challenge when communicating bad or unexpected news, with higher perceived situational control and stronger self-concept. Physicians with stronger empathy reported higher situational affect, more perceived stress and challenge, yet remained constant in their perception of self-concept and control over the situation.[41]

Question 2. What are the considerations for communicating with parents and families around time delays, and are there strategies healthcare professionals can use to limit delays?

Delays in receiving information are worrying and distressing for parents.[14,21] Signs of a problem may first be discovered by sonographers or other healthcare professionals who may not be empowered or authorised to communicate their observations to parents.[11,39] Parents may be extremely sensitive to verbal and non-verbal messages, such as sudden silence or concerned tone.[30] Advising parents that there may be periods of silence during scanning and other procedures is recommended.[43]

Healthcare professionals must deal with the difficult task of defining the right amount of information to be given to expectant parents when certain information is not known.[17] However, not all healthcare professionals will be prepared for these discussions and other healthcare professionals may have more comfort and skill with these conversations.[10,44] In an interview study conducted with mothers in Brazil,[44] women were quick to realise when something was wrong with their babies after birth. It is important to view the communication of bad news concerning life limiting diagnosis or stillbirth as a process that requires time and effort and not a "*single or isolated act*".[12]

> **"Gradually. I think that we should tell them everything, that the information must be complete, and not concealed or ignored, no matter how painful it may be. On the other hand, it mustn't be blurted out too abruptly. All extremes are bad; being told little by little might be agonising, but all at once can be devastating." Healthcare professional[12]**

Acknowledging delays and keeping parent(s) informed

Breaking bad news must balance the parent's desire to know results immediately with the need to ensure correct diagnosis, the ability of the healthcare professional to provide more information about next steps and adequate presence of family or friends.[10] The way in which bad news is shared has a significant effect on parent's coping and adjustment, where healthcare professionals can either help families feel supported and cared for or lead to parents feeling abandoned or blamed. Another challenge that healthcare professionals might face in providing immediate and detailed information to expecting mothers are situations when a support person is not present. In these cases, it is suggested that when an anomaly is detected, the healthcare professional delivering the news to the mother directly asks her if she would like to have other support persons available before hearing the results. Giving mothers a choice will give them some control over the situation, while also fostering a sense of support and understanding from the healthcare professional.[14]

One of the key reasons for delay in communicating bad news to parents includes the unavailability of senior staff to make or confirm the diagnosis. For example, during the night in the hospital.[11] In a qualitative study undertaken with parents in the UK, parents identified various diversionary techniques used by staff when they became aware of a diagnosis but were unable or unauthorised to communicate

the information to parents.[11] This created a sense of mistrust and parents felt that healthcare professionals were withholding information:

> **"The (Consultant) kind of said 'listen, this is the situation' and I felt like saying 'you've known this for a couple of weeks and haven't told us".[11]**

In an integrative review of healthcare professionals' communication with parents during a prenatal diagnosis,[14] parents expressed confidence in their healthcare professional when they communicated expeditiously with parents (preferably within 24 hours). Even in cases where a definitive diagnosis was not yet possible (e.g. in cases of a positive screening indicating an increased risk of disorder), parents appreciated it when this was explained in detail at the time, rather than waiting for confirmation of the diagnosis. When information was communicated in a timely manner, it helped parents to cope with the diagnosis and anticipate the future. On the other hand, mothers reported feeling neglected when there was a delay in receiving information about the diagnosis, resulting in shock, defeat, hurt, anger, and distrust for the healthcare professional.

Further, verbal information about the diagnosis supplemented with written information, including a list of reliable and valid resources (e.g. support groups, internet sites) could be immensely beneficial in ameliorating additional distress for parents during the waiting period.[14,21] Parents value being kept informed about the diagnostic process and having short constant intervals or appropriate information delivery to help them minimise their anxiety, distress, confusion, and frustration.[12,17] Expectant parents also highly value privacy and individualised care. They appreciate when the diagnosis is delivered with clarity, respect, and sensitivity, with further information being made available promptly, and referral to the medical specialist, or to a multidisciplinary team to confirm/invalidate the diagnosis as appropriate.[45]

When a baby dies, parents report facing many difficult and time-critical decisions at a time of intense loss and grief, sometimes becoming aware of options, or of consequences of their decisions, when it was too late. Parents require immediate, reliable, and detailed information when an anomaly is detected or suspected.[14,30] Limiting delay of conveying any diagnosis or suspected diagnosis allows parents to initiate decision-making sooner.[14,30] Parents value honest, timely provision of information and guidance, given with compassion and without judgment.[46,47] When definitive diagnosis cannot yet be confirmed, parents appreciated being assured that everything possible was being done to confirm diagnosis.[14]

Appropriate space and surroundings

Ensuring parents/family are cared for in an appropriate space around the time of breaking bad news is essential. All maternal and newborn services should have a private room with at least one experienced healthcare professional available to confirm a diagnosis of perinatal death or of a life limiting condition, including nights and weekends.[11,21,47] Further, standard protocols, ongoing training in ultrasonography and communication skills, and support packages should be in place for all healthcare professionals likely to be involved in the diagnosis of stillbirth or a life limiting condition.[21,47]

Grey literature and other sources

Note. Grey literature is not included in the GRADE assessment of the evidence-based recommendations.

The websites of international and national government agencies and parent support organisations (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) were searched for relevant information relating to breaking bad news to parents during the antenatal or neonatal period. A targeted Google search was also conducted using a combination of the following keywords: stillbirth; neonatal death; perinatal death; breaking bad news; breaking bad news to parents; breaking bad news to families; protocol for breaking bad news; sharing bad news; breaking bad news at the time of stillbirth or neonatal death. The findings of the grey literature are supported by both the current and previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*.

When it comes to breaking bad news, honest and timely communication is key.[48,49] Parents should be informed as soon as something is suspected of being wrong, even if healthcare professionals are unsure of the diagnosis.[49] Parents appreciate straightforward information, and uncertainty around diagnosis should not delay important conversations that could ultimately increase distress.[48,50] In Australia and the UK, healthcare professionals are encouraged to prepare carefully before breaking bad news and ensure that sufficient time is given without any interruptions (at least 30 minutes). Moreover, the news should be given by a consultant where possible and both parents should be seen together in a quiet and private room.[49-52] When there is only one parent, another family member or friend should be present to help provide support.[50] It is also recommended that a member of the specialist nursing team is present to provide support during subsequent home visits, as well as at the initial appointment.[53] Other considerations when breaking bad news include:

- Using empathetic language
- Allowing time for questions and offering sympathy
- Enquiring about any cultural or religious needs or preferences
- Establishing whether an interpreter is required.

In addition to the National Health Service guidelines in the UK,[53] healthcare professionals can access resources, such as posters and fact sheets that guide them through the process from start to finish (e.g., preparation before an ultrasound examination, during the ultrasound examination once they are certain of the findings, and after the ultrasound examination).[54] Any parent-facing resources or written information should be provided to parents following discussions.[55,56] Parents should be given enough time to absorb the information they have been given with ongoing opportunities to express any concerns or ask questions. Additionally, healthcare professionals should ensure that parents have been given the opportunity to check their understanding of the information.[49]

Another UK guideline is the Royal College of Obstetricians & Gynaecologists's *Care of Late Intrauterine Fetal Death and Stillbirth* [56]. Healthcare professionals have access to this guideline for strategies on how to break bad news to parents. These include empathic techniques such as seeking to identify the individual needs and emotions of parents to determine their thoughts and wishes without trying to shape them.

The UK's National Bereavement Care Pathway, led by Sands, acknowledges the challenges associated with breaking bad news at the time of perinatal death. The pathway highlights the importance of good communication and training of staff so they can develop the skills to sensitively let parents know when something is wrong. Healthcare professionals should be aware of the many emotions that parents will experience during this difficult time. Staff should at least be knowledgeable on what to say to parents

if they need to request support from a more senior member of the team (including being honest if they cannot provide sufficient information to the parents). Clear and honest communication is key, with time allowed for parents to absorb information. Parents may want the baby's name to be spoken in conversation if they have been given a name [49].

Both the published literature and grey literature note that breaking bad news is often difficult for healthcare professionals and needs to be delivered with respectful and compassionate language[49,57]. To assist healthcare professionals in breaking bad news and providing respectful and compassionate care, protocols such as SPIKES (Setting, Perception, Invitation, Knowledge, Empathy, Summarise/Strategise) have been developed.[48,52,57] While these guidelines and resources have been developed to help guide healthcare professionals in their conversations with parents, healthcare professionals are still encouraged to seek training to improve their communication skills.[49,53] All staff involved in maternity and newborn care are also encouraged to look after their wellbeing following a traumatic event (e.g., informing parents of fetal death) and debrief with colleagues if appropriate.[48]

In Australia, guidelines and resources have also been developed to help healthcare professionals deliver bad news.[58] Organisations such as Red Nose offer online training options to help meet workplace needs and requirements. Topics include self-care to minimise the risk of burnout, supporting distressed patients over the phone, and breaking bad news.[59]

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies	GRADE-CERQual Overall Confidence Rating of evidence	Guideline recommendations
		Consensus-based recommendation 3.1: The option of ultrasound should always be available and used to diagnose death or other conditions in an unborn baby. A second opinion should be considered where appropriate. • Ensure sonographers are considered as part of the multidisciplinary team and are aware of the clinical context and receive relevant information when caring for parents in the context of perinatal loss. • Advise parents that there may be periods of silence during procedures such as scanning. • Adverse findings should be communicated by an experienced and empathetic healthcare professional.
		Consensus-based recommendation 3.2: Prior to breaking bad news, ensure that you are well-placed to answer parents' questions by gathering relevant information and consulting with colleagues, where needed. If you are uncertain of an answer or information is unavailable, assure parents that you will seek the information they need.
Aggarwal & Moatti 2022 Atienza-Carrasco et al. 2018 Atienza-Carrasco et al. 2020 Bakhbakhi et al. 2017 Gesser-Edelsburg & Gold et al. 2017 Gopichandran 2018 Hodgson & McClaren 2018	Moderate confidence *No or minor concerns of coherence, minor concerns of relevance and adequacy of data, moderate concerns of methodological limitation.*	**Evidence-based recommendation 3.3:** When breaking bad news: • communicate the news in a safe and private space to both parents together; if this is not possible, communicate to the woman first, before others. • use thoughtful and clear communication and sensitive terminology when referring to the baby (e.g. ask parents if they have a name for the baby and ask permission to call the baby by name). • acknowledge parents' distress, feelings, and concerns. • assure parents that everything possible is being done to ascertain the baby's condition and offer to stay for support or to answer questions • inform parents of expected time delays between investigations and results and keep parents updated.

Kratovil & Julion 2017 Littlemore et al. 2020 Lou et al. 2017 Luz et al. 2017 Muin et al. 2022 Nuzum et al. 2017 Setubal et al. 2017 Setubal et al. 2018 Shahbari 2017 Smith et al. 2020 Teefey et al. 2020 Thomas et al. 2017 Zodan & Orelli 2018		
Aggarwal & Moatti 2022 Dekkers et al. 2019 Denney-Koelsch et al. 2018 Fernández-Basanta et al. 2021 Lou et al. 2017 Shakes & Cashin 2021	Low confidence *No or minor concerns of methodological limitation, minor concerns of relevance, and moderate concerns of coherence and adequacy of data.*	**Consensus-based recommendation 3.4:** Do not leave parents on their own without information. If a woman has attended alone, offer to contact her partner or other support person, and ensure that she is supported by a healthcare professional and not left alone until that person arrives.
		Consensus-based recommendation 3.5: Advise parents of the possibility of passive movement of the unborn baby following diagnosis of death. If parents report movements after the scan, offer support and a repeat scan.

Table 4. Search strategy

Database	Search strategy		
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR "Abortion, Induced"[Mesh]	Mesh
	#2	"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR “Neonatal loss*” OR “Neonatal mortalit*”OR “Neonatal death*” OR “Neonatal Demise*” OR “Newborn death*” OR “Newborn mortalit*”	Title/abstract
	#3	((“fetal anomal*” OR “congenital anomal*” OR “congenital malformation”) AND (“termination of pregnancy” OR abortion OR “pregnancy termination”))	Title/abstract
	#4	#1 OR #2 OR #3	
	#5	"Physician-Patient Relations"[Mesh] OR "Nurse-Patient Relations"[Mesh]	Mesh
	#6	("bad news"[Title/Abstract] OR "truth telling"[Title/Abstract] OR "difficult news"[Title/Abstract]) AND (english[Filter])	Title/ abstract
	#7	(("truth"[Title/Abstract] OR "disclo*"[Title/Abstract] OR "reveal"[Title/Abstract] OR "break*"[Title/Abstract] OR "give"[Title/Abstract] OR "communicat*"[Title/Abstract] OR "news"[Title/Abstract]) AND (("prenatal diagnosis"[Title/Abstract] OR "unexpected news"[Title/Abstract] OR "death"[Title/Abstract] OR "loss"[Title/Abstract] OR "negative"[Title/Abstract] OR "prognosis"[Title/Abstract] OR "fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "fetal malformation"[Title/Abstract]) AND "fetal malformation"[All Fields])) AND (english[Filter])	Title/ abstract
	#8	("unexpected news"[Title/Abstract] OR "psychological consequence*"[Title/Abstract] OR "psychological sequelae"[Title/Abstract] OR "psychosocial"[Title/Abstract]) AND (english[Filter])	Title/ abstract
	#9	("difficult conversation*"[Title/Abstract] OR "challenging conversation*"[Title/Abstract] OR "hard conversation*"[Title/Abstract]) AND (english[Filter])	Title/ abstract
	#10	#5 OR #6 OR #7 OR #8 OR #9	
	#11	#4 AND #10	

Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/
	2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab..
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.
	5	(prenatal adj2 (diagnosis or prognosis)).ti,ab.
	6	*prenatal diagnosis/
	7	1 or 2 or 3 or 4 or 5 or 6
	8	("bad news" or "unexpected news" or "psychological consequence*" or "psychological sequelae" or psychosocial).ti,ab.
	9	("bad news" or "truth telling" or "difficult news").ti,ab.
	10	((truth or disclo* or reveal or break* or give or communicat*) adj4 ("prenatal diagnosis" or "unexpected news" or death or loss or negative or prognosis)).ti,ab.
	11	("difficult conversation*" or "challenging conversation*" or "hard conversation*").ti,ab.
	12	*psychosocial care/ or *doctor patient relation/ or *nurse patient relationship/
	13	8 or 9 or 10 or 11 or 12
	14	7 AND 13
CINAHL	S11	S9 AND S10
	S10	S4 OR S5 OR S6 OR S7 OR S8
	S9	S1 OR S2 OR S3
	S8	AB (("unexpected news" OR "psychological consequence*" OR "psychological sequelae" OR psychosocial))
	S7	AB (("difficult conversation*" OR "challenging conversation*" OR "hard conversation*"))
	S6	AB ((truth or disclo* or reveal or break* or give or communicat* or news) N4 ("prenatal diagnosis" or "unexpected news" or death or loss or negative or prognosis or "fetal anomal*" or "congenital anomal*" or "fetal malformation"))
	S5	AB ("bad news" or "truth telling" or "difficult news")
	S4	(MM "Psychosocial Care (Saba CCC)") OR (MM "Nurse-Patient Relations") OR (MM "Physician-Patient Relations")
	S3	AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) N1 loss*) OR stillb*)
	S2	AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*)
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
SCOPUS	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*) (pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal") W/1 (loss*)) (stillb*)	

	AND (((*"bad news"* OR *"unexpected news"* OR *"psychological consequence*"* OR *"psychological sequelae"* OR *psychosocial*)) OR ((*"truth telling"* OR *"difficult news"*)) OR ((*truth* OR *disclo** OR *reveal* OR *break** OR *give* OR *communicat** OR *news*) W/6 (*"prenatal diagnosis"* OR *"unexpected news"* OR *death* OR *loss* OR *negative* OR *prognosis* OR *"fetal anomal*"* OR *"congenital anomal*"* OR *"fetal malformation"*)) OR ((*"difficult conversation*"* OR *"challenging conversation*"* OR *"hard conversation*"*)))	
Australian Indigenous HealthInfoNet	(sorry AND business) AND (stillborn OR baby OR newborn OR infant) OR (“breaking bad news”)	
Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees
	#2	MeSH descriptor: [Perinatal Death] explode all trees
	#3	MeSH descriptor: [Perinatal Mortality] this term only
	#4	MeSH descriptor: [Abortion, Induced] this term only
	#5	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mORtalit*
	#6	((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) ADJ1 loss*) OR stillb*)):ab (Word variations have been searched)
	#7	MeSH descriptor: [Physician-Patient Relations] this term only
	#8	MeSH descriptor: [Nurse-Patient Relations] this term only
	#9	((("unexpected news" OR "psychological consequence*" OR "psychological sequelae" OR psychosocial))):ti,ab,kw
	#10	((("difficult conversation*" OR "challenging conversation*" OR "hard conversation*"))):ab
	#11	(((truth or disclo* or reveal or break* or give or communicat* or news) ADJ6 ("prenatal diagnosis" or "unexpected news" or death or loss or negative or prognosis or "fetal anomal*" or "congenital anomal*" or "fetal malformation"))):ti,ab,kw
	#12	(("bad news" or "truth telling" or "difficult news")):ti,ab,kw
	#13	#7 OR #8 OR #9 OR #10 OR #11 OR #12
	#14	#1 OR #2 OR #3 OR #4 OR #5 OR #6
	#15	#13 AND #14
Informit Indigenous Collection	"pregnancy terminat*" OR "Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR "Neonatal loss*" OR "Neonatal mortalit*" OR "Neonatal death*" OR "Neonatal Demise*" OR "Newborn death*" OR "Newborn mortalit*"	

Figure 1. PRISMA flow diagram of screening evidence

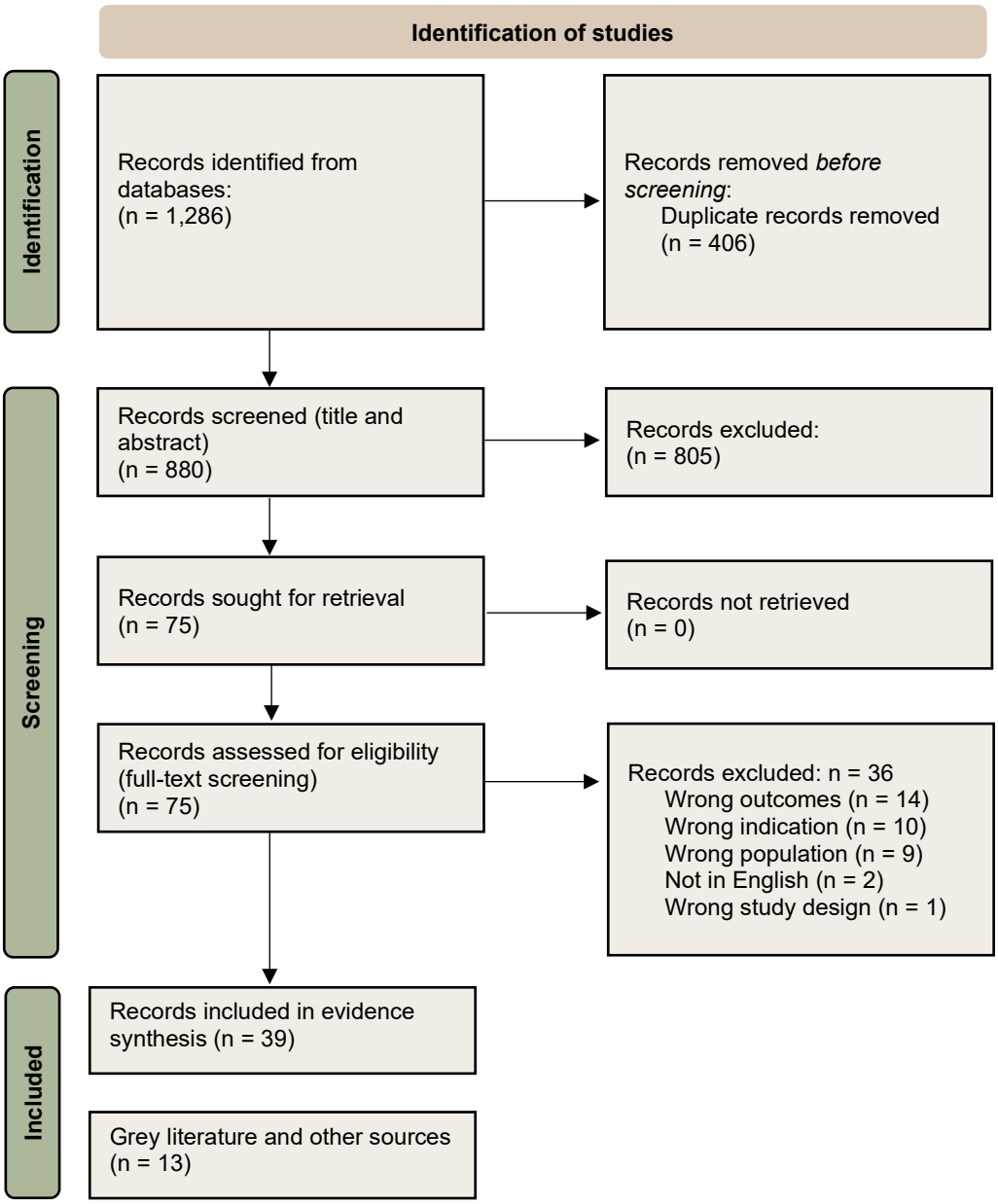

Table 5. Study characteristics

Study ID	Country (Period)	Locality (state/national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Aggarwal & Moatti 2022	India (2022)	NA	Literature	LMIC	Qualitative	Narrative review	NA	NA	NA	Bereavement care	NA	NA	Checklist for text and opinion papers [a]
Atienza-Carrasco et al. 2018	Spain (Jun–Sept 2015)	Costa del Sol Health Agency (Marbella, Spain)	Interviews, observations	HIC	Qualitative	Phenomenological	NA	37 interviews	TOPFA	Giving bad news	NA	Healthcare professionals (22 obstetricians, 4 midwives, 3 nurses, 8 nursing assistants) with at least 1 year experience	Checklist for qualitative research [b]
Atienza-Carrasco et al. 2020	Spain (2015–2017)	Costa del Sol Health Agency (Marbella, Spain)	Interviews, observations	HIC	Qualitative	Phenomenological	NA	27 interviews	TOPFA	Receiving bad news	NA	Qualitative: pregnant women of at least 18 years, with no mental disability and who are able to understand Spanish and express themselves correctly in Spanish.	Checklist for qualitative research

Bakhbakhi et al. 2017	Multiple (dates not reported)44	NA	Published research, guidelines, and best practice points	HIC	Qualitative	Descriptive review	NA	NA	Stillbirth	Best practice points in bereavement care research in high income countries	NA	Published research, guidelines, and best practice points in care following stillbirth in high income countries	Checklist for text and opinion papers
Dekkers et al. 2019	Netherlands (2012–2015)	Rotterdam	Online questionnaire	HIC	Quantitative	NA	Cross-sectional	76 women; 36 partners	TOPFA	Optimal time for psychosocial care	Women who were; treated from 2016 onwards, not fluent in Dutch, with intellectual disabilities, undergoing another TOP at the time of research invitation, or who underwent a TOP for maternal health issues.	Cross-sectional: 76 women; 36 partners All women and partners, who underwent a TOP-by medical treatment-for fetal anomaly.	Checklist for analytical cross-sectional studies [c]
Denney-Koelsch et al. 2018	USA (dates not reported)	Rochester	Interviews	HIC	Qualitative	Phenomenological	NA	16 women; 14 partners	Health-care interactions during termination of pregnancy for fetal anomaly	Feeling cared for; experiencing added burden	NA	Adult women over 18 years who chose to continue their pregnancy following lethal fetal diagnosis	Checklist for qualitative research

Dombrecht et al. 2020[18]	Belgium (Dec 2017–Jul 2018)	Four tertiary hospital neonatal intensive care units	Interviews & questionnaires	HIC	Qualitative	Thematic analysis	NA	30	NND	Barriers to and facilitators of end-of-life decision making by neonatologists and neonatal nurses in neonates	NA	Neonatologists at one of four Flemish Hospitals between December 2017 and July 2018 who had been the attending/treating to at least one child who had died in the past year, and nurses who had been the most involved.	Checklist for qualitative research
Dubenetzky 2017	NA (dates not reported)	NA	Literature	NA	Qualitative	Narrative review	NA	NA	Stillbirth	Psychological impact on parents	NA	Studies focusing on women >18 years who had experienced a stillbirth. Men were also examined in the study.	Checklist for text and opinion papers
Fernández-Basanta et al. 2021	Spain (2020)	NA (review)	Five databases	Global	Qualitative	Mata-synthesis	NA	11 studies	Stillbirth	Emotional experiences of midwives and nurses when caring for parents who have suffered an involuntary pregnancy loss	NA	Original qualitative or mixed articles considered adequate for the research objective.	Checklist for systematic reviews and research syntheses [d]

Geerlings 2019	Ghana (dates not reported)	Four districts across the upper west, upper east and northern regions of Ghana	Interviews	MIC	Qualitative	Narrative interviews; Thematic network analysis	NA	155	NND, near-miss	Mothers' perceptions of the cause of newborn illness and/or death in Northern Ghana	NNDs and near-misses where the primary carer was a close family member rather than the mother (fathers, aunts, grandparents)	Mothers who experienced a neonatal death or near miss that occurred who were able to answer detailed questions about the events leading up to the death or near-miss event.	Checklist for qualitative research
Gesser-Edelsburg & Shahbari 2017	Israel (2014–2015)	North Israel	Interviews	HIC	Qualitative	Constructionism	NA	29	TOPFA	The experiences of Muslim women at high risk for congenital anomalies and how their doctors communicate the risk	NA	Obstetricians and gynaecologists in high-risk pregnancy wards in northern Israel. Women were in-patients in high-risk pregnancy wards in two hospitals and had genetic diagnosis of congenital anomalies	Checklist for qualitative research
Gold et al. 2017	USA (dates not reported)	Michigan state (state-wide analysis)	Postal questionnaire - participants identified by Michigan Department	HIC	Quantitative	NA	Cross-sectional (population-based study)	609 (n=377 bereaved mothers and 232 with	Stillbirth, NND	Who communicates the loss to parents and who is present to support at the	Women who had an infant die beyond the first month as these may have been sudden or unexpected	Women who experienced a stillbirth after 20 weeks of gestational age, those with a live birth but early	Checklist for analytical cross-sectional studies

			of Community Health					surviving infants)		delivery or death	home deaths and parental experiences after these losses are different	infant death in the first 28 days of life and a control group of women who had a live birth and surviving child in the same time.	
Gopichandran 2018	India (dates not reported)	Tamil Nadu, primary healthcare setting (no specific hospital described)	In-depth interviews	LMIC	Qualitative	Thematic analysis	NA	10 (mothers [n=8], community health worker [n=1], hospital duty nurse [n=1])	Stillbirth	The experience of stillbirth, feelings, and emotions related to the experience, support received, coping strategies, social impact, impact on family and meaning attributed to the experience	NA	Mothers who experienced stillbirth in the past 1 year (n=8)	Checklist for qualitative research
Gueneuc et al. 2021	France (dates not reported)	Hospitals	Questionnaire	HIC	Quantitative	NA	Cross-sectional	193	Difficulties in communicating bad news relating to fetal anomaly	Capacity of simulation to improve communication of bad news	NA	Physicians, midwives, and training physicians in antenatal services	Checklist for analytical cross-sectional studies

Hodgson & McClaren 2018	Multiple (dates not reported)	International	Literature	NA	Qualitative	Narrative review	NA	NA	TOPFA	Parents' experiences following prenatal diagnosis of fetal abnormality and decision making about continuing or terminating the pregnancy	NA	Parents' experiences of prenatal diagnosis of fetal abnormality and decision making; and how practitioners can support through this time	Checklist for text and opinion papers
Köktürk Dalcalı et al. 2022	Turkey (dates not reported)	NICU of one city hospital in Turkey	Semi structured interviews	UMIC	Qualitative	Thematic analysis	NA	7	NND	Emotional responses of NICU nurses to work in neonatal unit and to neonatal deaths	NA	Nurses working in the NICU in one city hospital	Checklist for qualitative research
Kratovil & Julion 2017	Multiple (dates not reported)	International literature	Literature	NA	Qualitative	Integrative review	NA	33 articles	Parents experience of receiving a prenatal diagnosis	To explore healthcare professionals' impact on parents' experiences of receiving a prenatal diagnosis.	Articles focused only on parents' experiences with termination of the affected pregnancy.	Only articles that included original data were included where the mother remained the primary informant.	Checklist for systematic reviews and research syntheses
Lafarge et al. 2017	England (May–Jul 2013)	3 hospitals	Interviews	HIC	Qualitative	Inductive and deductive thematic analysis	NA	15 healthcare professionals	TOPFA	Health professionals' perceptions of women's coping with TOPFA and to what extent	Consent withheld.	Health professionals involved in the pregnancy management of women in three hospitals in	Checklist for qualitative research

										these perceptions are congruent with women's accounts.		England. Women - Aged over 18 years old, had experienced a TOPFA, recruited through a support organisation for parents who face/undergo TOPFA.	
Littlemore et al. 2020	UK (dates not reported)	NHS hospitals	Hospital documentation, interviews, and focus groups	HIC	Qualitative	Content analysis and linguistic analysis	NA	83 (27 bereavement care providers, 16 workers at support agencies, 30 interviews with women, 10 women and partners for focus groups)	Pregnancy loss (miscarriage, stillbirth, TOPFA)	Choices about disposal of baby's remains; how choices are communicated by healthcare professionals to parents	NA	Bereavement care providers, paid and volunteer workers at support agencies, women experiencing pregnancy loss and partners	Checklist for qualitative research

Lou et al. 2017	Multiple (Mar–Apr 2016)	Anglophone and European countries	PubMed, EMBASE, CINAHL, PsycINFO	NA	Qualitative	Systematic review	NA	28 studies (591 women, 182 men, 595 affected pregnancies of which 232 were terminated)	TOPFA	Parental response to severe or lethal antenatal diagnosis	Exclusion criteria were as follows: (1) parental response to screening results prior to actual diagnosis, (2) expected behaviour in case of future diagnosis, (3) parental response to postnatal diagnosis, and (4) clinicians experiences of parents' response	Qualitative studies reporting on parental responses to severe prenatal diagnosis in any trimester	Checklist for systematic reviews and research syntheses
Luz et al. 2017	Multiple (dates not reported)	International literature	PubMed, PsycINFO PsycArticles	NA	Qualitative	Systematic review	NA	32 studies	TOPFA	Expectant parents' and/or health professionals' subjective experience of the breaking of bad news in relation to antenatal diagnosis of a fetal anomaly	Studies were excluded if they involved investigating psychological reaction to prenatal screening tests (and not to a prenatal diagnosis of a fetal anomaly), maternal (and not fetal) diagnosis, emotional impact of	(a) original studies 1997-2016, (b) studies of psychological experiences(c) pregnant women, partners, or perinatal health professionals, and (d) study variables were clearly defined.	Checklist for systematic reviews and research syntheses

										medical termination of pregnancy exclusively		
Moore et al. 2020	USA (2018–2019)	University of South Alabama Children's and Women's Hospital	NA (program description)	HIC	Qualitative	Narrative review	NA	NA	Fetal anomaly	Description of program to assist families with fetal anomalies and/or a terminal diagnosis	NA	NA	Checklist for text and opinion papers
Muin et al. 2022	Austria (Sep–Oct 2020)	National	Online survey	HIC	Quantitative	NA	Cross-sectional survey	341 obstetricians	Stillbirth	Personality traits and stress coping among obstetricians diagnosing and communicating fetal death	NA	Obstetricians and gynaecologists registered with the Austrian Society of Obstetrics and Gynaecology	Checklist for analytical cross-sectional studies
Muin et al. 2021	Austria (2020)	National	Online survey with one open ended question	HIC	Mixed methods	Content analysis	Cross-sectional study	369 for quantitative component, 74 responded to open-ended question	Stillbirth	Facilitators and strategies used by obstetricians when communicating intrauterine fetal death to parents	NA	Austrian obstetricians and gynaecologists registered with the Austrian Society of Obstetrics and Gynaecology	Checklist for analytical cross-sectional studies Checklist for qualitative research

Silva et al. 2017	Brazil (Jan–Jun 2016)	One NICU	Semi-structured interviews	UMIC	Qualitative	Thematic analysis	NA	8	NND	Nursing care practices in relation to providing end of life care to newborns and their families in NICU	NA	The inclusion criteria were: 1) be a nurse or nursing technician, with at least one year of experience in an NICU; 2) have undergone an end-of-life care experience.	Checklist for qualitative research
Nuzum et al. 2017	Ireland (2008–2013)	1 tertiary maternity hospital	Interviews	HIC	Qualitative	IPA	NA	17 parents (12 mothers, 5 fathers)	Stillbirth	Communication of bad news to parents following a diagnosis of stillbirth	NA	Parents of babies who had received a diagnosis of stillbirth were purposively sampled from three years - 2008, 2010, and 2013	Checklist for qualitative research
Pereira et al. 2018	Brazil (Jul 2012–Jul 2014)	One city in Northeast Brazil	Semi-structured interviews	UMIC	Qualitative	Thematic analysis	NA	15	NND	Communication of a child's death and grief support provided to women who lost a newborn	Women with mental impairment	Mothers living in the city of São Luís who lost a child at gestational age equal to or higher than 32 weeks, and weight at birth equal to or higher than 2500 g.	Checklist for qualitative research

Setubal et al. 2017	Brazil (June 2014–Feb 2015)	One medical school in Sao Paulo, Brazil	Surveys	UMIC	Qualitative	Framework analysis	NA	20	Stillbirth, NND	To analyse the perception of residents regarding a training program in communicating bad news in perinatology	NA	Volunteer residents from the 1st to the 4th year from the obstetrics and paediatrics programs at a medical school in São Paulo, Brazil	Checklist for qualitative research
Setubal et al. 2018	Brazil (2014–2015)	Medical school in Campinas, Brazil	Patients and residence feedback surveys	LMIC	Quantitative	NA	Randomised controlled intervention study	58	Stillbirth, NND	Whether a structured training session would enhance perinatology residents' skills in breaking bad news	Residents who were not available to participate in one or both simulations and/or in the SPIKES (setting, perception, invitation, knowledge, emotion, and summary) training were excluded from the final analysis	Gynaecology & obstetrics and paediatrics residents enrolled in the 2014 school year at a medical school in Campinas, Brazil	Checklist for randomised controlled trials [e]
Shakes & Cashin 2020	Australia (dates not reported)	Lismore, NSW	Narrative	HIC	Qualitative	Narrative analysis	NA	1	TOPFA	Review of medical records and photos to recall moments of the experience and prompt reflection	NA	NA	Checklist for text and opinion papers

Smith et al. 2020	UK (Sep 2016–Aug 2017)	Two parent support organisations, 4 clinical sites	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	38 (10 couples, 18 mothers)	Miscarriage, stillbirth, NND, TOPFA	Parents' healthcare experiences before, during, and after their baby's death between 20 and 23+6 weeks of gestation	NA	Parents whose baby died before, during, or shortly after birth at 20+0 to 23+6 weeks of gestation.	Checklist for qualitative research
Teefey et al. 2020	NA (review)	International literature	Literature review	NA	Qualitative	Literature review	NA	NA	Stillbirth, NND, TOPFA	Psychological implications in expectant parents after a prenatal diagnosis	NA	NA	Checklist for text and opinion papers
Thomas et al. 2017	Australia (dates not reported)	Metropolitan Sydney, NSW (n=9). 1 rural based.	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	10 (9 Sydney metropolitan, 1 rural)	Stillbirth, TOPFA	Views, experiences, and practices of Australian sonographers in communicating an adverse outcome to pregnant patients in different departmental settings in public and private sector practice	NA	Participants who performed ultrasounds on obstetric patients were accepted from public and private practice settings	Checklist for qualitative research

Zodan & Orelli 2018	Switzerland (Aug 2015–Feb 2016)	Triemli Municipal Hospital (TMH) in Zurich	Patient/residents questionnaire	HIC	Quantitative	NA	Controlled before after study	276 (265 patients, 11 residents)	Communication in an emergency gynaecological setting.	1) Impact of clinician communication can change patients' satisfaction; 2) to encourage residents to observe how communication influences patients and physicians.	In-patients from other departments of TMH sent for an additional gynaecological examination, patients with repeated consultations, patients who were seen by both the attending resident and the consultant, and German speaking patients	Patients presenting during full working time (24 hours a day) in the emergency walk-in clinic	Checklist for cohort studies [f]

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data

Table 6. Study quality assessment

Qualitative studies

	Is there congruity between the stated philosophical perspective and the research methodology ?	Is there congruity between the research methodology and the research question or objectives?	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice-versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Do the conclusions drawn in the research report flow from the analysis, or interpretation of the data?	Overall appraisal	Relevance
Atienza-Carrasco et al. 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Atienza-Carrasco et al. 2020	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	R
Denney-Koelsch et al. 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	R
Dombrecht et al. 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	I
Geerlings 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Gesser-Edelsburg &	Yes	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Yes	Include	I

Shahbari 2017											
Köktürk Dalcalı et al. 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Littlemore et al. 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Silva et al. 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Nuzum et al. 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Pereira et al. 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Setubal et al. 2017	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U
Gopichandran 2018	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	R
Lafarge et al. 2017	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Yes	Unclear	Include	U
Muin et al. 2021	Unclear	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Yes	Include	P
Smith et al. 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Thomas et al. 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	Were the criteria for inclusion in the sample clearly defined?	Were the study subjects and the setting described in detail?	Was the exposure measured in a valid and reliable way?	Were objective, standard criteria used for measurement of the condition?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the outcomes measured in a valid and reliable way?	Was appropriate statistical analysis used?	Overall appraisal	Relevance
Dekkers et al. 2019	Yes	Yes	Yes	Yes	NA	NA	Yes	Yes	Include	P
Gold et al. 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Gueneuc et al. 2021	Yes	Yes	No	No	Yes	No	Yes	Yes	Include	R
Muin et al. 2022	Yes	Yes	No	No	Yes	No	Yes	Yes	Include	R
Muin et al. 2021	Yes	Yes	Unclear	No	No	NA	Yes	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic reviews

	Is the review question clearly and explicitly stated?	Were the inclusion criteria appropriate for the review question?	Was the search strategy appropriate?	Were the sources and resources used to search for studies adequate?	Were the criteria for appraising studies appropriate?	Was critical appraisal conducted by two or more reviewers independently?	Were there methods to minimize errors in data extraction?	Were the methods used to combine studies appropriate?	Was the likelihood of publication bias assessed?	Were recommendations for policy and/or practice supported by the reported data?	Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Fernández-Basanta et al. 2021	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	U
Kratovil & Julion 2017	Yes	Yes	Yes	Yes	NA	Yes	Yes	Yes	No	Yes	Yes	Include	R
Lou et al. 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Luz et al. 2017	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	No	Yes	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	Is the source of the opinion clearly identified?	Does the source of opinion have standing in the field of expertise?	Are the interests of the relevant population the central focus of the opinion?	Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	Is there reference to the extant literature?	Is any incongruence with the literature/ sources logically defended?	Overall appraisal	Relevance
Aggarwal & Moatti 2022	Yes	Yes	Yes	Yes	Yes	No	Include	R
Bakhbakhi et al. 2017	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
Dubenetzky 2017	Yes	Yes	Yes	No	Yes	Yes	Include	P
Hodgson & McClaren 2018	Yes	Yes	Yes	Yes	Yes	NA	Include	R
Moore et al. 2020	Yes	Yes	No	No	Yes	Unclear	Include	U
Shakes & Cashin 2020	Yes	Yes	Yes	Yes	Yes	NA	Include	I
Teefey et al. 2020	Yes	Yes	Yes	Yes	Yes	NA	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	Were the two groups similar and recruited from the same population?	Were the exposures measured similarly to assign people to both exposed and unexposed groups?	Was the exposure measured in a valid and reliable way?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	Were the outcomes measured in a valid and reliable way?	Was the follow up time reported and sufficient to be long enough for outcomes to occur?	Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	Were strategies to address incomplete follow up utilised?	Was appropriate statistical analysis used?	Overall appraisal	Relevance
Zodan & Orelli 2018	Yes	NA	Yes	No	No	NA	Yes	NA	No	NA	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Randomised controlled trials

	Was true randomisation used for assignment of participants to treatment groups?	Was allocation to treatment groups concealed?	Were treatment groups similar at the baseline?	Were participants blind to treatment assignment?	Were those delivering treatment blind to treatment assignment?	Were outcomes assessors blind to treatment assignment?	Were treatment groups treated identically other than the intervention of interest?	Was follow up complete?	Were participants analysed in the groups to which they were randomised?	Were outcomes measured in the same way for treatment groups?	Were outcomes measured in a reliable way?	Was appropriate statistical analysis used?	13. Was the trial design appropriate, and any deviations from the standard RCT design accounted for in the conduct and analysis of the trial?	Overall appraisal	Relevance
Setubal et al. 2018	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
3.1	The option of ultrasound should always be available and used to diagnose death or other conditions in an unborn baby. A second opinion should be considered where appropriate. • Ensure sonographers are considered as part of the multidisciplinary team and are aware of the clinical context and receive relevant information when caring for parents in the context of perinatal loss. • Advise parents that there may be periods of silence during procedures such as scanning. • Adverse findings should be communicated by an experienced and empathetic healthcare professional.	NA	NA	NA	NA	NA	Consensus-based recommendation
3.2	Prior to breaking bad news, ensure that you are well-placed to answer parents' questions by gathering relevant information and consulting with colleagues, where needed. If you are uncertain of an answer or information is unavailable, assure parents that you will seek the information they need.	NA	NA	NA	NA	NA	Consensus-based recommendation

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
3.3	When breaking bad news: • communicate the news in a safe and private space to both parents together. If this is not possible; communicate to the woman first, before others • use thoughtful and clear communication and sensitive terminology when referring to the baby (e.g., ask parents if they have a name for the baby and ask permission to call the baby by name) • acknowledge parents' distress, feelings, and concerns • assure parents that everything possible is being done to ascertain the baby's condition and offer to stay for support or to answer questions • inform parents of expected time delays between investigations and results and keep parents updated.	21 studies are included. Nine of the included studies are qualitative primary research, four are narrative reviews, and three systematic reviews. The remaining studies include three cross-sectional studies, one cohort study and one randomised controlled trial.	Moderate concerns of methodological limitation are noted of the included studies. Ten of the included studies demonstrate no or minor concerns of methodological limitation. The remaining eleven studies are deemed to have moderate concerns of methodological limitation, including eight qualitative studies, two cross-sectional studies, and one cohort study. Qualitative studies are consistently noted to lack a statement of each researcher's cultural position, and to account for the impact on analysis and findings. Three furthermore lacked congruity between the stated philosophical perspective and research methodology. Two cross-sectional studies both omitted reliable measurements of exposures and failed to employ strategies to account for confounders. The included cohort study neither identified, or accounted for confounders through analysis.	Minor concerns of study relevance were noted of the included studies. 11 of the included studies are deemed directly relevant to breaking bad news during care around stillbirth and neonatal death. Three of the included studies were deemed to be of partial relevance to breaking bad news during care around stillbirth and neonatal death, and five have indirect relevance. Two studies, one qualitative and one randomised controlled trial, were deemed to have unclear relevance to breaking bad news during care around stillbirth and neonatal death.	No or minor concerns of coherence were noted.	Minor concerns of the adequacy of data included from evidence sources is noted. Data included from the evidence provided by the studies is sourced from predominantly high-income country populations, and four studies sourced cohorts from middle income countries. Outcomes of interest within the evidence include stillbirths (n=633), neonatal deaths (n=377), terminations of pregnancy for fetal anomaly (n=1059) and composite perinatal mortality outcomes (n=116). Viewpoints provided by the evidence include predominantly mothers and healthcare professionals. A minority of studies included non-birthing partners' viewpoints. The view of sonographers is included in one included study.	**Moderate confidence** *No or minor concerns of coherence, minor concerns of relevance and adequacy of data, moderate concerns of methodological limitation.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
3.4	Do not leave parents on their own without information. If a woman has attended alone, offer to contact her partner or other support person, and ensure that she is supported by a healthcare professional and not left alone until that person arrives.	Six studies are included, two systematic reviews and two narrative reviews. One qualitative study and one cross-sectional study.	No or minor concerns of methodological limitation. No or minor concerns are noted for five of the included studies. Moderate concerns were noted for the included qualitative study, concerns related to the lack of a statement of each researcher's cultural position and any impact this may have on analysis and findings.	Minor concerns of relevance of the included studies are noted. Two studies are deemed to be relevant to breaking bad news during care around stillbirth and neonatal death, the included cross-sectional study is deemed to be of partial relevance. One narrative review and one systematic review are deemed to be of indirect relevance, and one systematic review of unclear relevance to breaking bad news during care around stillbirth and neonatal death.	Moderate concerns of coherence are noted as the evidence regarding leaving parents alone and supporting them with psychological support and allied healthcare professionals is mixed.	Moderate concerns of adequacy of data are noted. The population sources included in the evidence span across high-, and middle-income countries. Outcomes of interest within the evidence include stillbirths, and terminations of pregnancy for fetal anomaly (n=916). Viewpoints contained within the evidence include mothers and partners. Moderate concern of the adequacy of data are noted due to the lack of neonatal deaths included in the outcomes of the evidence sources, and the lack of viewpoint from healthcare professionals.	**Low confidence** *No or minor concerns of methodological limitation, minor concerns of relevance, and moderate concerns of coherence and adequacy of data.*
3.5	Advise parents of the possibility of passive movement of the unborn baby following diagnosis of death. If parents report movements after the scan, offer support and a repeat scan.	NA	NA	NA	NA	NA	**Consensus-based recommendation**

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 3: Perinatal loss care: shared decision making

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Parents who experience perinatal death face many difficult, time-pressured, and emotionally charged decisions. This occurs at a time when feelings of shock, disbelief, confusion, and guilt can be overwhelming.[1] Some of the decisions that may need to be made include those relating to the mode and timing of the baby's birth, spending time with the baby, seeing and holding the baby, collecting mementoes, taking the baby home, autopsy and other investigations to understand why a baby died, and funeral arrangements. Many parents may also struggle with making the 'right' decisions for their baby and their family.[1] Social stigma and complex medical, ethical, and legal dimensions may add to parents' distress around decisions.[2-5] While the decisions faced vary according to the baby's diagnosis, all parents require information and non-judgemental support.[5]

Supporting parents in decision making requires more than a one-off conversation.

Giving parents options, time to consider those options, and opportunities to discuss and revisit their decisions is essential.

According to the Australian Commission on Safety and Quality in Health Care,[6] "Shared decision making involves discussion and collaboration between a consumer and their healthcare provider. It is about bringing together the consumer's values, goals, and preferences with the best available evidence about benefits, risks, and uncertainties of treatment, to reach the most appropriate healthcare decisions for that person."

As a core goal of care, parent-centred decision making includes:

- recognising the many difficult and complex decisions faced by parents
- respecting different approaches to making decisions
- understanding that parents' concerns, preferences, goals, and wishes may change
- ensuring adequate time, information, and support is available from healthcare professionals.

Interactions with healthcare professionals in maternal and newborn services can have a memorable impact on parents, and careful considered communication is essential throughout.[7] Parents' decision making may be influenced by a number of factors, such as personal values, extended family, societal norms, religious beliefs, and legal issues.[8,9] While it is important that healthcare professionals are cognisant of these individual differences, providing all the available options to parents is critical as they are often not in a position to recognise what is possible and what ultimately might be important to them. Decisions that parent's make after loss not only impacts them on an immediate, short-term basis, but also have long-term impacts on their coping and adjustment. In general, less involvement in decision making is one of the predictors of regret about healthcare decisions.[10] To support parents in a time-sensitive manner, it is important that healthcare professionals establish trusting relationships with the parents and are empathetic to their individual situation.[11]

Methodology

The Guideline Development Committee developed key research questions around shared decision making for perinatal loss care (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	How can healthcare professionals provide care within a shared decision making framework engaging parents to the extent they wish and providing adequate information? Does this lead to improved outcomes for parents and families?
2	How do healthcare professionals ensure the 'right' decision makers are in the mix?
3	What are the shared decision making considerations and specific information and support needs of parents following termination of pregnancy?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 2. PICO criteria

PICO	Inclusion criteria
Population	Defined in Australia and Aotearoa New Zealand as: ○ Stillbirth ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[12,13] ○ Neonatal death ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[12,13] ○ Inclusion of perinatal deaths following termination of pregnancy ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).
Intervention	Studies exploring perinatal loss care following stillbirth or neonatal death in maternal or newborn services.

Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes and experiences of parents, family members, healthcare professionals around perinatal loss care including care that specifically addresses shared decision making and care planning (e.g. labour and birth, maternal and neonatal care, bereavement care, postmortem investigations). Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Search strategies were conducted on 9 March 2022 and incorporated all PICO criteria and restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- wrong *population*: The study did not focus on termination of pregnancy, stillbirth or neonatal death as defined in Table 2.
- wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- wrong *language*: The study was not published in English.
- wrong *publication dates*: The study was published prior to 2017.
- wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using the applicable Joanna Briggs Institute developed critical appraisal tools. The QUADAS-2 tool was to be used if diagnostic evaluation studies were to be assessed. Table 6 contains detailed quality assessment of individual studies. All studies were included regardless of quality assessment, and all components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Development Committee based on the evidence synthesis in this report and recommendations from the previous iteration of the CASaND guideline. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the

Guideline Development Committee between September 2022 and June 2023 for feedback and consensus on recommendations included in this report.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[14] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[15]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[16]
- Adequacy: The richness and quantity of data supporting the findings[17]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[18]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated, and details of any concerns were identified and listed.[19] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: How can healthcare professionals provide care within a shared decision making framework engaging parents to the extent they wish and providing adequate information? Does this lead to improved outcomes for parents and families?

Supporting parents in decision making can help improve their long-term health and wellbeing; however, it requires more than a one-off conversation.[20] Giving parents options, time to consider those options, and opportunities to discuss and revisit their decisions is essential.

Health care providers are encouraged to model effective, compassionate communication that respects patient cultural beliefs and values and to promote shared decision making with patients.[21]

Asking parents what they want to know and how they want to make decisions, tailors care and information to suit individual needs.[22,23] Parents who were satisfied with their care are more likely to have received help with decision making from healthcare professionals.[24] Parents commonly report variability in care practices for their baby and themselves including lack of continuity of care and support from a coordinated healthcare team. In a study conducted in Spain, a range of healthcare professionals were interviewed to identify and examine their experiences and practices caring for

parents who experienced perinatal loss. Parent-centred decision making was identified as an aspect of care that was lacking.[25]

Lack of communication with parents was reflected in exclusion of mothers from decisions regarding the preparation of their baby's burial, autopsy, and funeral arrangements, perceived as *protectiveness* by most healthcare professionals.[25] When parents are not involved in the decision making process (i.e. if parents are not offered the opportunity to hold the baby, or keep some objects as mementos), it may lead to feelings of regret in the future, as reflected in this quote by a healthcare professional.[25]

Understanding parents' individual needs will facilitate joint decision making.[26] The desire and ability to make informed choices may vary between women, with the preparedness of the patient and the clinical context.[1] Assumptions influenced by culture, ethnicity, and personal values, misconceptions, and lack of staff training result in insensitive interactions and lack of joint decision making, particularly relating to mode of birth or deciding to have a postmortem examination of the baby.[26] Staff should be trained to reach joint decisions, by appropriately preparing parents for birth and afterwards, and supporting their desires to retain or regain some sense of control.[26]

Mode (and timing) of birth is one area where joint decision making is important. It is crucial for healthcare professionals to understand the reasons why parents may request a particular mode of birth (e.g. some women may prefer caesarean birth over vaginal birth), so that they can counsel women effectively about the risks and benefits and can help them make informed decisions regarding the birth of their baby.[7] Joint decision making and support from healthcare professionals is vital for parents who may feel emotionally unprepared for the birth.

Parents should be assured that decisions are not required immediately, and discussions should take place on multiple occasions to enable parents to consider the information they have received and to follow-up on matters of concern to them.[27] Cues from parents should be used to guide the timing and amount of detail presented and it may be helpful to provide information in an incremental manner.[8] Information provided verbally should be supported by parent-centred information in written or electronic formats.[27]

Providing information in a step-by-step manner enables patients to exert some control in a situation over which they have very little control.[28] However, it is often acknowledged that while decision making tools are available, they may prove less useful in time pressured contexts.[1]

Nurses and doctors feel under-prepared to have conversations with families regarding end-of-life and bereavement issues. All healthcare professionals in this setting need to receive training to ensure they can provide appropriate care following a perinatal death. Staff who have experienced such losses need to be supported via the debriefing process and offered psychological support if needed.

One of the most helpful things healthcare professionals can do is to give parents choices and ask 'what can I do to better meet your needs?' Hutti & Baker (2020) in [29]

"...choice and empowerment is key. Making sure that families are still given time and choice in those initial days. I always say – they will leave, and discover what you did not offer them, so make sure you offer." [30]

Inadequate or limited information, poor communication, or less involvement in decision making processes are predictors of regret about medical decisions. Ensuring parents feel fully informed and adequately involved in the decision making process may minimise regret, regardless of the decision made.[31] Parents may regret certain decisions they made, particularly around choice of stillbirth investigations such as autopsy, and funeral arrangements.[7,32] Opportunities to make memories with their baby is often reported by parents as a source of regret.

> **"I wished to see her once. When we had got her out of the hospital, I hugged her. As my mind had not worked on the spot, I could not see her face. Later, I was more regretful, as after we reached home, the baby had already been buried. For a few days it was coming to my mind that, I should have seen her face at least once'." Father, Afghanistan [33]**

> **"Ask them if they want to take some memento because many times you find that afterward they regret not having taken anything. I know there are hospitals that make a box of memories that is taken and handed over, and that's good because it helps with mourning." Spain [25]**

Question 2: How do healthcare professionals ensure the 'right' decision makers are in the mix?

Decision making after perinatal loss takes place in the context of relationships beyond healthcare professionals and the views of other family members or significant others are often involved.[34] Healthcare professionals should support women and their families in a parent-centred decision making process that respects individual autonomy as well as relational and emotional influences in their lives.[21] The birth plan should be tailored to address specific patient wishes such as who will attend the birth and their roles in the delivery room.[21]

It is important to recognise there may also be differences between partners and their decisions may change over time.[8] Some parents may wish to involve their extended family or community Elders in their decisions. Every attempt should be made to accommodate parents' request to include their significant others in their decision-making process, if this is desired by parents. In Australia, COVID-19 pandemic restrictions made the use of telehealth more prevalent in clinical settings that provided increased opportunities to enable the involvement of extended family and other significant people;[34] however, further training may be required for healthcare professionals to develop skills in this area.

Healthcare professionals must acknowledge that families may have diverse cultural and religious beliefs and needs concerning who is involved in decision making. The key to providing culturally sensitive care is to avoid applying knowledge of culture like a 'cookbook' and assuming that all families will want certain types of care because of their racial or ethnic background. Instead, healthcare professionals should use their knowledge of culture to inform and expand care options that are offered to bereaved parents. When parents are given choices, they will choose the options they find most helpful and supportive.[29]

Healthcare professionals should not limit options offered to bereaved parents based on perceived notions of what is acceptable to members of a particular cultural group. In a study conducted in the United States to explore the perceptions and attitudes of immigrant Arab Muslims regarding bereavement care practices, preferences of bereaved Arab Muslim mothers were more like Western

bereaved mothers than different. Bereaved mothers want kind, supportive, and individualised care after perinatal loss.[29]

Question 3: What are the shared decision making considerations and specific information and support needs of parents following termination of pregnancy?

Decisions regarding pregnancy management after an anomaly is identified are considered extremely personal and many factors may be taken into consideration. Regardless of the decision reached, information on prognosis and expected quality of life have been described as extremely important to women across many cultures. Doubt while making pregnancy management decisions is a predictor of negative long-term outcomes.[35]

Parents report increased satisfaction when treated with compassion and given resources to help them cope with the emotionally devastating experiences associated with a life-limiting fetal diagnosis.[24] Some strategies that healthcare professionals may adopt to enhance parent satisfaction, include sharing information in a timely and sensitive manner, providing consistent messaging, giving emotional support, and partnering with parents to create a plan of care.[24] Genetic counsellors play an important role in supporting families undergoing termination of pregnancy and are trained to educate parents about the identified anomaly, facilitate understanding and informed decision making, advocate for the patient, identify support resources, and recognise and address psychosocial concerns. In a study conducted with women who had undergone a termination of pregnancy within the last 10 years in USA, women perceived genetic counsellors had a positive impact and felt confident in their personal decision making when they provided objective care and emotional support, gave information on aetiology and recurrence risks, identified support resources, and made a plan with women for follow-up care.[36] On the other hand, a qualitative study conducted with parents experiencing a termination of pregnancy in Switzerland indicated that decentralised care and lacking continuity between caregivers led to negative experiences for parents.[37]

Parental beliefs, culture, and values influence decisions made and inform appropriate discussions that should take place and factors that should be considered. Healthcare professionals may hold preconceived assumptions influenced by culture, ethnicity, and personal values. It is vital for healthcare professionals to recognise personal bias to avoid inadvertently negatively impacting parental experience during care surrounding perinatal loss. Common assumptions made by healthcare professionals, as reported by parents, include assumptions about how parents will react, assumptions that parents will wish to terminate the pregnancy, and assumptions that standardised care rather than individualised care is appropriate. Assumptions based on personal beliefs and bias—often unrecognised—risk healthcare professionals providing inappropriate care. Emotional and spiritual well-being is also often overlooked, as care is focused on the physical aspects of the pregnancy and fetal anomaly.[38,39]

Family conference has been described as beneficial for facilitating discussion and decision making after antenatal diagnosis. Family conference models/birth plans can elucidate understanding and perceptions of the condition of the unborn baby and the prognosis, taking physical, psychological, social, familial, and spiritual issues into consideration. The first step (acknowledgement) is to support the family to acknowledge the fetal condition through discussion, then assist them to form a birth plan. The second step (contextualise) involves the identification of the family's values and needs, minimising suffering when possible, and encouraging family and fetal bonding. The third step (establishing goals) establishes the care objectives and necessary actions. Only when the setting has

been fully understood does the preparation for birth occur in the fourth step (organise birth). Finally, (follow-up) the team ensures follow-up after birth, in the neonatal period, and beyond.[40].

Literature shows that termination of pregnancy is also an intensely challenging experience for men. Men/fathers experience feelings of shock, fear, anger, and sadness, yet are often overlooked by healthcare professionals, further exacerbating their grief.[41,42] Throughout the subsequent decision making and termination process, men frequently set aside or hide their emotions to adopt supportive roles to remain strong to 'protect' their female partners while simultaneously acting as a parent, bystander, information-gatherer, and joint decision maker.[41] It is therefore imperative to promote genuine inclusion of fathers at all stages of pregnancy and childbirth. For example, strategies could incorporate the adoption of inclusive language that is family-centred rather than exclusively mother-infant centred; reviewing training materials and informational resources to ensure they are inclusive of father's experiences and needs; routinely assessing fathers' mental health and well-being before discharge from hospital and during targeted follow-up (particularly following loss and when men have a history of mental health concerns); and establishing connections with a wide range of male-friendly community (and termination of pregnancy) support services to facilitate referral from hospital to community. Regarding termination of pregnancy specifically, healthcare professionals should consider the timing of offering support to men given presentations of grief may be delayed. Assessments of men's needs should also be sensitive to experiences of guilt, shame, or blame, which can complicate grief.[41]

Grey literature and other sources

Note. Grey literature is not included in the GRADE assessment of the evidence-based recommendations.

In addition to the published academic literature, both international and national government agency and perinatal loss support organisation (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to care around decision making at the time of perinatal death or termination of pregnancy. A targeted Google search was also conducted using a combination of the following keywords: shared decision making following stillbirth; shared decision making following neonatal death, and shared decision making following perinatal death. The findings of the grey literature are supported by both the current and previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline.*

In the UK, healthcare professionals can refer to the Sands National Bereavement Care Pathway,[43] or the Royal College of Obstetricians & Gynaecologists (RCOG) *Care of Late Intrauterine Fetal Death and Stillbirth* (Green-top Guideline No. 55)[44] for assistance when developing a care plan and supporting parent-centred decision making. According to these resources, decision making will vary depending on the parents' individual needs. Furthermore, fathers and partners may have different needs that are separate from the mother.[44] Healthcare professionals should acknowledge that all decisions are personal, and that the parents may need some time to think about their options. Only the parents can decide what is right for them and their baby[43] and should be given as much time as they need to consider their options, ask questions and make decisions.[43,45,46] Healthcare professionals should be prepared to have multiple discussions with parents or repeat information if necessary while decisions are being made.[45]

Parents appreciate being asked about their wishes and preferences during discussions with healthcare professionals in relation to decision making.[46] All parents should be provided with the opportunity to participate in decisions relating to their baby and the relevant information needed to make the decision. To assist with decision making about autopsy and other investigations, parents should be provided with written, verbal, and electronic information.[45] In most cases of perinatal death, parents will need to be informed and supported in making decisions about seeing and holding their baby, as well as memory making.[43] If parents decide not to see or hold their baby, this decision should be respected.[45]

Healthcare professionals should be well-prepared to lead discussions around any immediate decisions that parents need to make. Ideally, this will be a designated member of staff who has an established rapport with the family, and who is someone the parents are familiar with and trust.[43] Healthcare professionals should approach discussions with empathy and sensitivity, particularly in relation to autopsy and investigations.[45]

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies		GRADE-CERQual Overall confidence rating of evidence	Guideline recommendations
Berry 2019 Boyle 2022 Boyle 2020a Boyle 2020b Cassidy 2018 Davis-tuck 2021 Dickens 2020 Feroz 2020 Horey 2021	Kerns 2018 LaFarge 2017 Mendes 2017 Obst 2021 Redshaw 2018 Schirmann 2018 Shakespeare 2020 Stock 2019 Wool 2017	Low confidence *Minor concerns of coherence and methodological limitation. Moderate concerns of relevance and data adequacy.*	**Consensus-based recommendation 3.6:** Arrange a formal consultation with parents to discuss their understanding of the diagnosis and options available. Ensure that parents have clear information and time to consider all available options where they need to make decisions. Provide culturally and linguistically appropriate information in a range of formats. • Refer to Appendix 1B: *Guiding Conversations booklet* and Appendix 1C: *Jiba Pepeny: Star Baby* booklet for Aboriginal and Torres Strait Islander families.
ACOG 2019 Bernardes 2020 Berry 2019 Brierley-Jones 2018 Das 2021b Emaway altaye 2018 Kerns 2018	Li 2017 Maistrellis 2019 Obst 2021 OCC6 2017 Okuga 2017 Pueyo 2021 Phaophan 2021 Smith C 2020	Low confidence *Minor concerns of coherence and methodological limitation. Moderate concerns of relevance and data adequacy.*	**Consensus-based recommendation 3.7:** Develop a detailed care plan across the phases of care including: • pregnancy care plan, including individualised preparation and support for labour and birth • maternal birth care plan including timing and mode of birth • newborn care plan • perinatal loss care plan • discharge plan and ongoing support. Discussions around care planning should: • identify who parents want involved in decision making (e.g. family/ whānau members, other support persons, community Elders or spiritual leaders or other specialists)

			• acknowledge parents' (or their chosen support person's) role as primary decision maker and carer of their baby • incorporate parents' values, preferences, wishes and needs.
Bakhbakhi 2017 Berry 2019 Camacho Avila 2020 Christou 2021 Cronin 2018	Nurse-Clarke 2019 Middlemiss 2021 Maistrellis 2019 Siasakos 2018 Smith L 2020	Low confidence *Minor concerns of coherence and methodological limitation. Moderate concerns of relevance and data adequacy.*	Consensus-based recommendation 3.8: Provide multiple opportunities for parents to ask questions and explore their concerns with the same informed, experienced, and trusted healthcare professional. • Provide opportunities for parents to revisit their decisions but inform them of time critical issues (e.g. mode of birth, how baby's condition may change, time to autopsy).

Table 4. Search strategy

Database	Search strategy	
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR ("Abortion, Eugenic"[Mesh]) OR "Abortion, Legal"[Mesh]
	#2	"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR “Neonatal loss*” OR “Neonatal mortalit*”OR “Neonatal death*” OR “Neonatal Demise*” OR “Newborn death*” OR “Newborn mortalit*” OR “pregnancy termination” or “termination of pregnancy” or (“fetal malformation” or “congenital abnormality” or “fetal anomaly” or “congenital anomaly” OR “fetal anomalies” or “congenital anomalies” AND (terminat* or abortion or abort))
	#3	#1 OR #2
	#4	"Indigenous Peoples"[Mesh] OR "Transients and Migrants"[Mesh] OR "Refugees"[Mesh] OR "Health Disparity, Minority and Vulnerable Populations"[Mesh] OR "Vulnerable Populations"[Mesh] OR "Culturally Competent Care"[Mesh]
	#5	parents or mother* or father* or “patient understan*” or “patient need*” or “patient resource*” or “patient experience*” or “patient view*” or "patient decision-making" or "patient decision making" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or “cultural care” or elders or maori or whanau
	#6	#4 AND #5
	#7	"Health Care Economics and Organizations"[Mesh]
	#8	(cost* OR econom*)
	#9	#7 OR #8
	#10	#9 OR #6
	#11	"Palliative Care"[Mesh] or "Decision Making, Shared"[Mesh] or "Disenfranchised Grief"[Mesh]
	#12	Regret or sedation or “pain relief” or “mode of birth” or “mode of delivery” or “timing” or “place of birth” or “place of delivery” or “birth plan” or “birth planning” or “birth option*” or “vaginal birth” or “vaginal delivery” or “caesarean” or “time to delivery” or “time to deliver” or “time to birth” or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or counselling or counselling or “funeral arrangements” or decisions or “values” or “palliative care” or “prenatal palliative care” or “grieving parent*” or “grieving families”
	#13	#11 OR #12
	#14	#3 AND #10 AND #13
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/

	2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.
	5	1 OR 2 OR 3 OR 4
	6	exp transcultural care/ or exp vulnerable population/ or exp indigenous health care/ or exp health disparity/ or indigenous people/
	7	(parents or mother* or father* or "patient understan*" or "patient need*" or "patient resource*" or "patient experience*" or "patient view*" or "patient decision-making" or "patient decision making" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or M#ori or wh#nau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya*).ti,ab.
	8	6 OR 7
	9	*health care cost/
	10	(cost* or econom*).ti,ab.
	11	9 OR 10
	12	(Regret or sedation or "pain relief" or (("mode of" or "place of" or "timing") adj1 (birth or delivery)) or ((birth or deliver*) adj2 (plan or planning or option* or "time to")) or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or "funeral arrangements" or decisions or "palliative care" or "prenatal palliative care" or "grieving parent*" or "grieving" or grief or ((bereavement or "post-natal" or postnatal) adj4 (counselling or counselling)).ti,ab.
	13	*palliative therapy/ or *shared decision making/
	14	12 OR 13
	15	11 OR 14
	16	5 AND 8 AND 14
CINAHL	S20	S5 AND S10 AND S19
	S19	(S17 OR S18)
	S18	S13 AND S17
	S17	S14 OR S15 OR S16
	S16	(MM "Palliative Care")

S15	(MM "Decision Making, Shared")
S14	AB (Regret or sedation or "pain relief" or (("mode of" or "place of" or "timing") N1 (birth or delivery)) or ((birth or deliver*) N2 (plan or planning or option* or "time to")) or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or "funeral arrangements" or decisions or "palliative care" or "prenatal palliative care" or "grieving parent*" or "grieving" or grief or ((bereavement or "post-natal" or postnatal) N4 (counselling or counselling))
S13	S11 OR S12
S12	AB (cost* or econom*)
S11	(MM "Health Care Costs")
S10	S6 OR S7 OR S8 OR S9
S9	AB (parents or mother* or father* or "patient understan*" or "patient need*" or "patient resource*" or "patient experience*" or "patient view*" or "patient decision-making" or "patient decision making" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or M#ori or wh#nau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya*)
S8	(MM "Healthcare Disparities")
S7	(MM "Indigenous Peoples")
S6	(MM "Transcultural Care")
S5	(S1 OR S2 OR S3 OR S4)
S4	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
S3	AB (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort))
S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
S1	(MM "Perinatal Death") OR (MM "Abortion, Induced")

SCOPUS	(TITLE-ABS-KEY((Regret or sedation or "pain relief" or (("mode of" or "place of" or "timing") W/1 (birth or delivery)) or ((birth or deliver*) W/2 (plan or planning or option* or "time to")) or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or "funeral arrangements" or "palliative care" or "prenatal palliative care" or "grieving parent*" or "grieving" or grief or ((bereavement or "post-natal" or postnatal) W/4 (counselling or counselling))))) AND (TITLE-ABS-KEY((parents or mother* or father* or "patient understan*" or "patient need*" or "patient resource*" or "patient view*" "women understand*" or "women view*" or "women experience*" or "woman understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya*))) AND ((TITLE-ABS-KEY((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*))) OR (TITLE-ABS-KEY((stillb*))) OR (TITLE-ABS-KEY(((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal") W/1 (loss))))) AND (LIMIT-TO (LANGUAGE,"English"))
Australian Indigenous HealthInfoNet	(sorry AND business) AND (stillborn OR baby OR newborn OR infant)
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Death] explode all trees #3 MeSH descriptor: [Perinatal Mortality] explode all trees #4 MeSH descriptor: [Abortion, Induced] explode all trees #5 ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mORtalit*)):ti,ab,kw #6 #1 OR #2 OR #3 OR #4 OR #5 #7 MeSH descriptor: [Minority Health] explode all trees #8 MeSH descriptor: [Vulnerable Populations] explode all trees #9 MeSH descriptor: [Parenting] explode all trees #10 MeSH descriptor: [Health Care Costs] explode all trees #11 ((parents or mother* or father* or "patient understan*" or "patient need*" or "patient resource*" or "patient experience*" or "patient view*" or "patient decision-making" or "patient decision making" or "women understand*" or (women NEXT view*) or (women NEXT experience*) or "woman understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or M#ori or wh#nau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya*)):ti,ab,kw #12 MeSH descriptor: [Decision Making, Shared] explode all trees

	#13 MeSH descriptor: [Palliative Care] explode all trees #14 ((Regret or sedation or "pain relief" or (("mode of" or "place of" or "timing") ADJ1 (birth or delivery)) or ((birth or deliver*) ADJ2 (plan or planning or option* or "time to")) or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or "funeral arrangements" or decisions or "palliative care" or "prenatal palliative care" or "grieving parent*" or "grieving" or grief or ((bereavement or "post-natal" or postnatal) ADJ4 (counselling or counselling)))):ti,ab,kw #15 #12 OR #13 OR #14 #16 #7 OR #8 OR #9 OR #10 OR #11 #17 #6 AND #15 AND #16
Informit Indigenous Collection	"pregnancy terminat*" OR "Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mORtalit*" OR "Fetal demise*" OR "Foetal mORtalit*" OR "perinatal wast*" OR "perinatal mORtalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mORtalit*" OR "prenatal demise*" OR "Antenatal mORtalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mORtalit*" OR "Intrapartum Death*" OR "Neonatal loss*" OR "Neonatal mORtalit*" OR "Neonatal death*" OR "Neonatal Demise*" OR "NewbORn death*" OR "NewbORn mORtalit*"

Figure 1. PRISMA flow diagram of screening process

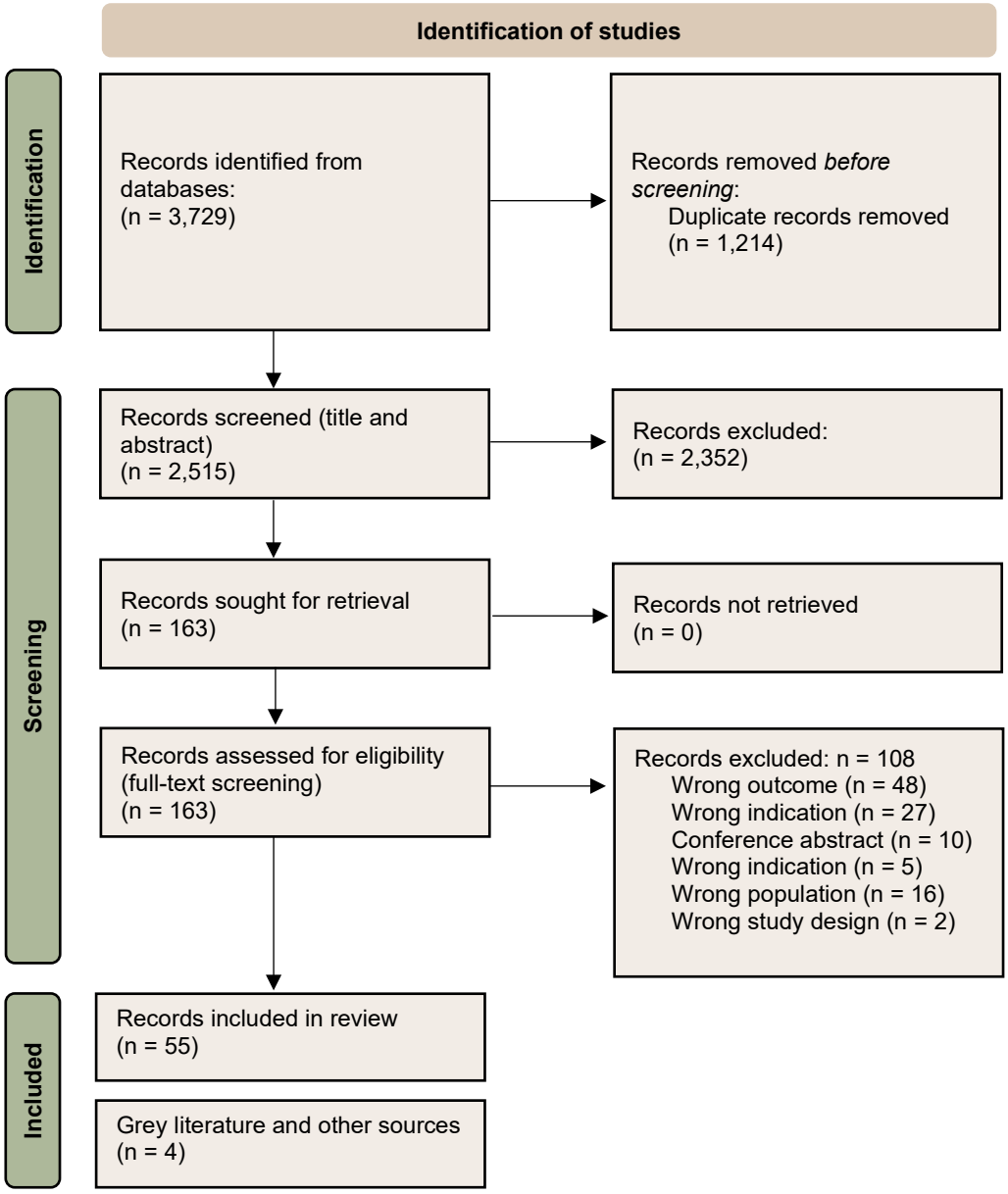

Table 5. Study characteristics

Study ID	Country (period)	Locality	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest	Factors assessed	Exclusions	Inclusions	Quality assessment tool
ACOG Committee 2019	USA (2019)	NA	Committee opinion	HIC	Qualitative	Descriptive review	NA	NA	TOPFA	Perinatal palliative comfort care	None mentioned	Patients appropriate for perinatal palliative comfort care, essential components of care, challenges and benefits for patients, healthcare professionals and healthcare entities, and ethical considerations	Checklist for text and opinion papers
Adiyaman 2021	Turkey (Jan 2016-Dec 2019)	One tertiary hospital in Izmir	Patient case records	UMIC	Quantitative	NA	Retrospective cohort study	146	TOPFA	Rates of TOP and decision making process following the diagnosis of Trisomy 21	None mentioned	Women with prenatal diagnosis of Down Syndrome	Checklist for cohort studies
Alaradi 2021	USA (June 2017-Aug 2019)	Two large mosques in Louisville, KY	Questionnaire	HIC	Quantitative	NA	Cross-sectional study	79	Miscarriage (n=12), Stillbirth (n=4) NND (n=5)	Arab Muslims' perception of perinatal loss care in the USA	None mentioned	Arab Muslims over 18years of age. Not a requirement to have had experienced perinatal loss.	Checklist for analytical cross-sectional studies

Bakhbakhi 2017	Multiple (not dated)	NA	Published research, guidelines and best practice points	HIC	Qualitative	Descriptive review	NA	NA	Stillbirth	Best practice points in bereavement care research in high income countries	None mentioned	Published research, guidelines and best practice points in care following stillbirth in high income countries	Checklist for text and opinion papers
Bedwell 2021	Africa (2018)	**Quantitative:** 2 tertiary facilities in Lake Zone, Tanzania and Mansa region, Zambia **Qualitative**: Antenatal and postnatal clinics, primary and secondary facilities, community in Tanzania and Zambia.		LMIC	Mixed methods	Grounded Theory	Retrospective cohort study	1885	Stillbirth (≥28 weeks) (n=261)	Contributors and beliefs towards unexplained stillbirth	Twins and neonatal deaths	**Quantitative:** Women who delivered at two tertiary institutes. **Qualitative:** Women (n=48), partners of women (n=19)	Checklist for cohort studies Checklist for qualitative research
Bernardes 2020	Brazil (May 2015-Sept 2016)	One tertiary fetal medical centre	Retrospective medical records of family conferences	UMIC	Qualitative	Content analysis	NA	50	TOPFA	Family conferences in prenatal palliative care follow-up after the diagnosis of life-limiting fetal condition	None mentioned	Participation in at least one family conference with the perinatal palliative group at the hospital and delivery at the hospital or another centre followed by	Checklist for qualitative research

												participation in postnatal family conference	
Berry 2019	Multiple (Nov 2017-May 2018)	NA	Literature	NA	Qualitative	Systematic review	NA	NA	TOPFA	Impact of communication in discussing an intrauterine diagnosis of a fetal congenital anomaly on perinatal grief	Non-English articles, articles published prior to 2008, grey literature and those that did not focus on communication of an anomaly	Peer-reviewed articles on communication styles, techniques, and stances by healthcare professionals when communicating a fetal anomaly diagnosis detected in utero, published in English in last 10 years	Checklist for systematic reviews and research syntheses
Boyle 2020	Australia	National	Guideline, literature	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth, NND	Perinatal bereavement care guidelines	None mentioned	Components of best practice perinatal bereavement care	Checklist for text and opinion papers
Boyle 2020 (2)	Australia (2020)	NA	Author views and literature	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth	National approach to research to improve shared decision making in stillbirth care and other initiatives in this area	None mentioned	Shared decision making literature and stillbirth CRE initiatives	Checklist for text and opinion papers

Boyle 2022	Australia (April 2020)	National	Online survey	HIC	Qualitative	Content analysis	NA	35	Stillbirth, NND, TOPFA	Healthcare professional views of the impact of COVID on provision of respectful care to parents and resulting practice changes	None specified	Healthcare professionals who provided perinatal bereavement care in clinical settings or through support organisations in Australia	Checklist for qualitative research
Brierley-Jones 2018	England (2014-2015)	Three hospitals in North East England	Focus groups, semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	60	Stillbirth	Views of health professionals and health care staff across three hospitals in the management of stillbirth	None mentioned	Consultant obstetricians, trainees, midwives, midwife sonographers and chaplains	Checklist for qualitative research
Buskmiller 2021	Multiple (2001-2020)	NA	Literature	NA	Qualitative	Narrative review	NA	NA	Fetal anomaly	Scoping review of perinatal palliative care	None mentioned	Background, quality, and benefits of offering PPC and ethical principles that support it being offered	Checklist for text and opinion papers
Camacho Avila 2020	Spain (Apr 2017-May 2018)	2 hospitals in Southeast Spain	Interviews	HIC	Qualitative	Hermeneutical phenomenology	NA	21 (13 mothers, 8 fathers)	Stillbirth (n=17), NND (n=4)	Parents' experiences in relation to professional and social support after perinatal loss	spoke a language other than English or Spanish, or experienced a miscarriage, pregnancy	A mother or father 18 years and older at the time of perinatal loss, to have experienced a	Checklist for qualitative research

											termination due to genetic birth defect or multifetal pregnancy reduction.	stillbirth or a neonatal death, and the loss had been suffered at least 2 years before the interview.	
Cassidy 2018	Spain 2013-2016	National	Online self-completion questionnaire	HIC	Qualitative	Phenomenological	NA	796	Pregnancy loss stratified by GA (n=668 stillbirths >=20 wks GA)	Bereaved parents experience of care quality following intrauterine death	Respondents born outside of the Spanish national territory. Parents reporting neonatal deaths	Women who reported that their baby died within 60 months prior to survey completion.	Checklist for qualitative research
Christou 2021	Afghanistan (Oct-Nov 2017)	3 high-volume referral maternity hospitals in Kabul and 2 lower-level health facilities and surrounding communities in 2 rural districts ~25–30 km west and north of Kabul city	Interviews	LIC	Qualitative	Deductive thematic analysis	NA	55 (21 mothers, 9 fathers, 3 female community elders, 20 HCPs, 2 govt officials)	Stillbirth	Parents' and healthcare professionals' experiences of care after stillbirth	None mentioned	Women and men experiencing stillbirth, community female elders, healthcare providers and key informants including govt officials, hospital directors, chiefs of wards	Checklist for qualitative research
Cronin 2018	New Zealand (2012-2015)	20 New Zealand District Health Boards	Face to face interviews, and maternity and postmortem records	HIC	Quantitative	NA	Case Series	169	Stillbirth (n=169)	Exploration of factors influencing decision making about postmortem examination.	Pregnancies with a known congenital abnormality at recruitment.	Women with singleton pregnancies that ended in late stillbirth (>=28 weeks GA) without	Checklist for case series studies

											known congenital abnormality.	
Das 2021	India (2018–2019)	At and around a tertiary care hospital in Delhi	Observations, interviews and focus groups	LMIC	Qualitative	Thematic content analysis	NA	104	Stillbirth (n=44 parents of 22 stillbirths), NND (n=24 parents of 12 NND)	Perceptions of parents, community and religious leaders on acceptability of minimally invasive tissue sampling (MITS)	Parents from outside Delhi were excluded	Parents of deceased children, neonates or stillbirths, community members and religious leaders	Checklist for qualitative research
Davies-Tuck 2021	Australia (2018)	Monash Health, Victoria	Cross-sectional survey of maternity care staff	HIC	Quantitative and qualitative	Thematic analysis and narrative review	Cross-sectional survey closed response questions	120	Stillbirth	Staff experience with new guidelines for post-term surveillance of South Asian women	None	Clinical staff providing maternity care at Monash Health sites	Checklist for qualitative research Checklist for analytical cross-sectional studies
Dickens 2020	NA	NA	Literature	NA	Qualitative	Literature review	NA	NA	Stillbirth, NND	Management, support and experiences of lactation after perinatal death	NA	NA	Checklist for text and opinion papers
Emaway Altaye 2018	Ethiopia (Dec 2014-2015)	115 districts from four agrarian regions of Ethiopia	Surveys, interviews, health population records	Low income	Quantitative	NA	Cross-sectional study	4684	Maternal and newborn health care practices (childbirth at a health facility,	The effects of self-reported exposure to the Family Conversation strategy during	Women in communities where some of the contextual variables were not available.	Women with children aged 0 – 11 months living in the 115 districts where the Family Conversations	Checklist for analytical cross-sectional studies

									visited by a health worker within 48h of birth, clean cord care, newborn dried, wrapped and delayed bathing, immediate breastfeeding)	antenatal period on maternal and newborn health care practices during childbirth and postpartum period		strategy were implemented.	
Fernandez -Alcantara 2020	Spain (Feb–Sep 2016)	3 public hospitals in province of Granada	Interviews	HIC	Qualitative	Thematic analysis	NA	16	Stillbirth, NND, TOPFA	Experiences and practices of experienced professionals attending to perinatal loss in the hospital context in Spain	Consent withheld	Inclusion criteria for participation were (i) being a professional in a discipline (health care or other) regularly involved in intervening in cases of perinatal loss and (ii) having at least 5 years of professional experience in attending to perinatal losses. Consent obtained.	Checklist for qualitative research

Feroz 2020	Multiple (Pakistan, India, Bangladesh, Kenya, Ethiopia)	Nationally across 5 countries	Key informant interviews with researchers from all 5 MITS Alliance member projects	LMIC	Qualitative	Critical review	NA	Not specified	Stillbirth, NND	Comparison of counselling and consent methods used in MITS in five countries	Not specified	Researchers from five MITS Alliance member projects working with stillbirth and neonatal populations	Checklist for qualitative research
Horey 2021	40 countries (Dec 2014-Feb 2015)	NA	Survey	HIC and MIC	Quantitative	NA	Descriptive	3041	Stillbirth	Bereavement care practices after stillbirth in high and middle-income countries	Stillbirth > 5yrs prior to completing the survey	Self-reported stillbirth ≤ 5 years prior to completing survey	Checklist for studies reporting prevalence data
Kerns 2018	USA (2009-2013)	2 academic centres - University of California, University of Michigan	Interviews	HIC	Qualitative	Modified grounded theory	NA	36	TOPFA	Women's experiences of being counselled about the diagnosis and options for termination in the setting of fetal anomalies and pregnancy complications, factors associated with making their decision, how they experienced their decision process	None mentioned	Women undergoing termination of pregnancy at the University of California and the University of Michigan were eligible for the study if they were between 14- and 24-weeks' gestational age, over 18 years of age, and English speaking.	Checklist for qualitative research

Kerns 2020	US (2010-2011)	National	Survey	HIC	Quantitative	NA	Descriptive	794	TOPFA	Maternal-fetal medicine and family planning physicians' attitudes and practice patterns around second-trimester abortion for abnormal pregnancies	Members without a known email address	Members of the Society for Maternal-Fetal Medicine and Family Planning subspecialists associated with the Family Planning Fellowship with a known email address.	Checklist for studies reporting prevalence data
Lafarge 2017	England (May–July 2013)	3 Hospitals	Interviews	HIC	Qualitative	Inductive and deductive thematic analysis	NA	15 healthcare professionals	TOPFA	Healthcare professionals' perceptions of women's coping with TOPFA and to what extent these perceptions are congruent with women's accounts.	Consent withheld.	Healthcare professionals involved in the pregnancy management of women in three hospitals in England. Women aged >18 years, had experienced a TOPFA, recruited through a support organisation for parents who face/undergo TOPFA. Data from 27 interviews with women	Checklist for qualitative research

												reported elsewhere.	
Lewis 2019	UK (2016-2017)	National	Cross-sectional survey, interviews, focus groups	HIC	Qualitative	Thematic analysis	NA	439 free-text responses, 20 parent interviews, 25 HCPs	Miscarriage, Stillbirth, NND, TOPFA, Infant death	Parental decision making about post-mortem	None specified	Bereaved parents- including pregnancy loss, neonatal or infant death, HCPs from a range of clinical backgrounds involved in discussing or conducting post-mortem examinations with parents	Checklist for qualitative research
Li 2017	US and China (2012-2013)	NA	Online pregnancy forums	high income and upper-middle income	Qualitative	Content analysis	NA	852	TOPFA	Cultural and social factors affecting decision making about prenatal testing and TOPFA	None mentioned	Online posts using terms related to non-invasive prenatal testing as well as company and brand names on the website BabyCentre (US baby forum) and Babytree (Chinese baby forum).	Checklist for qualitative research

Maistrellis 2019	USA (dates not stated)	One public tertiary academic hospital and one private D&E clinic	Medical charts	HIC	Quantitative	NA	Cross-sectional cohort study	514	TOPFA	Patient and clinical related factors associated with selecting pregnancy termination method for fetal anomaly, IUFD or PPROM.	Patients in spontaneous labour who may have been steered toward continued labour and may not have been offered D&E as a delivery method.	Patients with a hospital medical record and have received counselling about the options of D&E and IOL at 17 - 24 weeks gestation for fetal anomaly, IUFD, or PPROM as the medical diagnosis.	Checklist for analytical cross-sectional studies
Mendes 2017	Multiple (Jan–June 2015)	International	Web data from perinatalhospice.org (comments from parent advocates, clinicians and researchers)	NA	Qualitative	Content analysis	NA	Unclear	Perinatal palliative care	Ethical considerations in perinatal palliative care	None mentioned	Comments around ethical considerations in PPC by members of the private lists of the international website perinatalhospice.org	Checklist for qualitative research
Middlemiss 2021	UK (2018-2019)	South west England	Ethnographic interviews, observations, analysis of guideline documents and material culture	HIC	Qualitative	Ethnography	NA	31	Stillbirth (n=12), TOPFA (n=10)	Factors affecting care trajectories in women experiencing pre-viable second trimester pregnancy loss	None mentioned	Women experiencing pregnancy loss between 13 weeks and 24 weeks	Checklist for qualitative research

Moudi 2017	Iran (Feb 2012–Oct 2013)	One prenatal diagnosis centre in Zahedan, Iran	Interviews, routinely collected hospital data	LMIC	Mixed methods	Thematic analysis	Descriptive cross-sectional study	102 for quantitative analysis, 39 for interviews	TOPFA	To determine foetal outcomes affected by thalassemia and to explore reasons women had for deciding against TOPFA	None mentioned	Quantitative: all pregnancies diagnosed with thalassemia during the study period; Interviews: women who had agreed to undergo CVS sampling, had received positive CVS results, and had decided against pregnancy termination, despite positive β-TM diagnosis.	Checklist for qualitative research Checklist for analytical cross-sectional studies
Noge 2020	South Africa (2012-2013)	One district in the Free State, SA	Interviews, Perinatal Problem identification Program records, focus groups	UMIC	Qualitative	Content analysis	NA	36 mothers and significant others; 19 midwives	Stillbirth	Sociocultural norms contributing to high stillbirth rates	None mentioned	Mothers experiencing stillbirth at a hospital in the district three to four years before interviews, and who resided in the region; midwives	Checklist for qualitative research
Nurse-Clarke 2019	USA (not mentioned)	One urban medical centre	Qualitative in-depth interview data	HIC	Qualitative	Content analysis	NA	20	Stillbirth	Application of tenets of Swanson's theory of caring in practice by labour and	None mentioned	Secondary analysis of interviews conducted with labour and delivery nurses with experience	Checklist for qualitative research

										delivery nurses when caring for women with stillbirth		caring for mothers who had a stillbirth	
Obst 2021	Australia (Oct 2019-March 2020)	National	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	10	TOPFA	To explore men's experiences and needs for support following TOPFA	None mentioned	Heterosexual men over 18 years of age who experienced TOPFA with a female partner between 6 months and 11 years ago	Checklist for qualitative research
OCG6 2017	Multiple (dates not mentioned)	International literature	Literature	NA	Qualitative	Narrative review	NA	NA	Peri viable birth	Newborn outcomes after peri viable birth, current evidence, and recommendations regarding interventions in this setting, and provides an outline for family counselling	None mentioned	Peri viable period and outcomes for infants born in this period, clinical considerations and management, recommendations for peri viable birth	Checklist for text and opinion papers
Okuga 2017	Uganda (April-July 2015)	Two districts in Eastern Uganda	Interviews, focus group discussions	LIC	Qualitative	Content analysis	NA	8 women and their caregivers 8 community leaders/ members	NND	To describe and explore illness recognition, decision making and appropriate care seeking	None mentioned	Women whose newborn became ill and died within 28 days of life while they were at home when the illness was	Checklist for qualitative research

								of women's groups (6 FGDs)		for mothers and newborn illnesses and complications		recognised and their caregivers: community leaders and women's saving groups	
Paize 2020	UK (Jan 2010-Dec 2015)	Liverpool Women's Hospital	Postal survey	HIC	Mixed methods	Content analysis	Descriptive statistics (%s)	26	NND	Parents' experience of end of life and bereavement care in NICU	None mentioned	Parents whose baby died in the neonatal unit of the Liverpool Women's Hospital between Jan 2010-Dec 2015	Checklist for qualitative research
Phaophan 2021	Thailand (May 2018-June 2019)	One university clinic in Bangkok	Semi-structured interviews	UMIC	Qualitative	Thematic content analysis	NA	142	TOPFA	To assess factors influencing decisions concerning prenatal diagnosis (PND) and termination of pregnancy for β-thalassemia in Thai pregnant women	None mentioned	Thai Buddhist pregnant women with a singleton pregnancy awaiting prenatal diagnosis of thalassemia	Checklist for qualitative research
Power 2020	Ireland (dates not specified)	National	Survey	HIC	Quantitative	NA	Modified Delphi, descriptive study	n = 12 round 1 Delphi; n = 7 round 2 Delphi	TOPFA, Stillbirth, NND	Education needs of voluntary organisations supporting parents experiencing perinatal loss	None mentioned	Support organisations who provide care to parents and families who experience pregnancy loss or perinatal death	Checklist for analytical cross-sectional studies

Pueyo 2021	Multiple (Dec 2018-March 2019)	International	Literature	NA	Qualitative	Scoping review	NA	NA	NND	Nursing interventions for perinatal bereavement care in neonatal intensive care units	Studies with a focus on treating perinatal grief with pharmacological interventions, studies with a focus on stillbirth, miscarriages or TOP for non-medical reasons	Studies focusing on NND in the context of NICU after admission for a critical or EOL condition, published between 2000-2019. English and Spanish language papers	Checklist for systematic reviews and research syntheses
Ravaldi 2018	Italy (2009-2015)	National (11 hospitals)	Hardcopy survey questionnaire	HIC	Quantitative	NA	Cross-sectional study	674	Stillbirth	Current practices of healthcare professionals caring for women experiencing a stillbirth and to explore their training needs	None mentioned	Practising midwives, obstetricians, nurses, and psychologists of the ob/gyn wards in 11 Italian hospitals	Checklist for analytical cross-sectional studies
Redshaw 2018	England (2012-2013)	National	Questionnaire	HIC	Quantitative	NA	Descriptive	249	NND	Experience of women whose baby died in the neonatal period of their care in the perinatal period, on delivery suite, and in the neonatal unit, and how this	None mentioned.	Women aged 16 years and over in England who registered a neonatal death between Jan-March 2012 or June - Aug 2012	Checklist for analytical cross-sectional studies

										relates to the gestational age at which their baby was born			
Schirmann 2018	Australia and New Zealand (Dec 2015-Feb 2016)	National	Online survey	HIC	Qualitative	Framework analysis	NA	454	Stillbirth (n=454)	Mothers' decision making needs for autopsy consent following stillbirth	Male respondents and mothers experiencing a loss earlier than 20 weeks	Mothers residing in Australia or New Zealand who reported a stillbirth after 20 weeks' gestation were included	Checklist for qualitative research
Shakespeare 2020	Global (September 2017 - October 2018)	26 countries	Systematic reviews, meetings & online surveys	NA	Mixed methods (policy-Delphi methodology)	Thematic analysis	Descriptive (Likert scale)	Round 1 n=23 Round 2 n=19 Round 3 n=236 Round 4 n=30 Round 5 n=143	Bereavement care after stillbirth	Global consensus on a set of feasible and evidence-based core principles for best practice bereavement care after stillbirth	None mentioned	International clinical and academic experts and healthcare workers with experience in providing bereavement care	Checklist for qualitative research Checklist for analytical cross-sectional studies
Siassakos 2018	UK 2013	Three maternity hospitals	Interviews, focus groups, service provision data	HIC	Qualitative	Thematic analysis	NA	Parents of 16 stillborn babies, 22 maternity staff	Stillbirth	Views of bereaved parents and maternity staff to improve bereavement care for families	Twin pregnancy and loss, intrapartum stillbirth	Parents with a stillborn baby (gestational age more than 23 weeks, 6 days)-singleton stillbirths with the fetal death diagnosed before the onset of labour, maternity staff	Checklist for qualitative research

Smith L 2020	UK (dates not stated)	3 hospital settings in South West of England	Interviews	HIC	Qualitative	cross-sectional qualitative study; Thematic analysis	NA	33	Stillbirth, NND	Experiences and perceptions of HCPs of using a cold cot following the loss of a paper	None mentioned	NICU and CDS staff who have had experience of caring for bereaved parents. A maximum variation sampling in terms of participants disciplines (i.e., medical, nursing, midwifery, chaplaincy) was also attempted to represent differing perspectives in bereavement care provision.	Checklist for qualitative research
Smith C 2020 (2)	UK (Sept 2016–Aug 2017)	Two parent support organisations, 4 clinical sites	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	38 (10 couples, 18 mothers)	Miscarriage, stillbirth, NND, TOPFA	Parents' healthcare experiences before, during and after their baby's death between 20 and 23+6 weeks of gestation	None mentioned	Parents whose baby died before, during or shortly after birth at 20+0 to 23+6 weeks of gestation.	Checklist for qualitative research

Stock 2019	UK (Oct 2016-Jan 2017)	National	Online survey	HIC	Mixed	Content analysis	Descriptive	217	congenital anomaly	Parental views of antenatal testing and termination following a diagnosis of cleft lip	None mentioned.	Parents of children born with CL/P who received an antenatal diagnosis and were given the option of TOP, recruited via UK-based charity, the Cleft Lip and Palate Association website, newsletter, and social media.	Checklist for qualitative research Checklist for case series studies
Wool 2017	Multiple (Feb 2015)	Online survey	Online survey, distributed via email and posted on websites in February 2015 by webmasters that support families who have experienced a fetal life-limiting diagnosis	HIC	Quantitative	NA	Cross-sectional	405	Stillbirth, NND	To identify which quality indicators predict patient satisfaction with care in a prenatal setting when a fetus has been diagnosed with a life-limiting condition	None mentioned	Mothers or fathers >18 years who experienced a life-limiting fetal diagnosis and opted to continue the pregnancy living anywhere in the world. Participants needed to be able to communicate in English and access and use a computer. Participants were welcome to contribute to	Checklist for analytical cross-sectional studies

									the study regardless of the interval between the birth and survey.

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall appraisal	Relevance
Bedwell 2021	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U
Noge 2020	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Berneres 2020	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Boyle 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Brierley-Jones 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Camacho Avila 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	P
Cassidy 2018	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Christou 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	I
Das 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	I
Davies-Tuck 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P

Fernandez-Alcantara 2020	Yes	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Feroz 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	Unclear	Include	U
Kerns 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Lewis 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Lafarge 2017	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Yes	Unclear	Include	R
Li 2017	Yes	Yes	Yes	Unclear	Yes	No	No	Yes	Not applicable	Yes	Include	U
Mendes 2017	Unclear	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	Include	U
Middlemiss 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Noge 2020	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Nurse-Clarke 2019	Unclear	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	Include	P
Obst 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	R
Okuga 2017	Unclear	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	Include	
Paize 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	I
Phaophan 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Schirmann 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Shakespeare 2020	Yes	Yes	Yes	Yes	Yes	No	Not applicable	No	Yes	Yes	Include	P
Siassakos 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	R
Smith C 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Smith L 2020 (2)	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Stock 2019	Yes	Unclear	Unclear	Yes	Yes	No	No	Yes	Unclear	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Wool 2017	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	I
Alaradi 2021	Yes	Yes	Unclear	No	No	No	Yes	Yes	Include	R
Ravaldi 2018	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	P
Maistrellis 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Redshaw 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Power 2020	Yes	Yes	Not applicable	Yes	Not applicable	Not applicable	Yes	Not applicable	Include	P
Emaway Altaye 2018	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate ?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate ?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimize errors in data extraction?	8. Were the methods used to combine studies appropriate ?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate ?	Overall appraisal	Relevance
Berry 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	R
Pueyo 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	No	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case-report studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Kerns 2020	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Horey 2021	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	NA	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/sources logically defended?	Overall appraisal	Relevance
Bakhbakhi	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
Boyle 2020 (2)	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Buskmiller 2021	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	I
ACOG Committee 2019	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	R
Dickens 2020	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	P
OCG6 2017	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population ?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Bedwell 2021	Yes	Not applicable	Unclear	Yes	No	Yes	Unclear	Yes	Yes	Not applicable	No	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case-series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Relevance
Cronin 2018	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	No	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

REF	RECOMMENDATION	STUDIES CONTRIBUTING	METHODOLOGICAL LIMITATIONS	RELEVANCE	COHERENCE	ADEQUACY OF DATA	GRADE-CERQUAL APPRAISAL
3.6	Arrange a formal consultation with parents to discuss their understanding of the diagnosis and options available. Ensure that parents have clear information and time to consider all available options where they need to make decisions. Provide culturally and linguistically appropriate information in a range of formats. • Refer to Appendix 1B: *Guiding Conversations booklet* and Appendix 1C: *Jiba Pepeny: Star Baby* booklet for Aboriginal and Torres Strait Islander families.	16 studies were included. Of these, seven are primary qualitative studies, three are mixed-methods studies that analysed both quantitative and qualitative data, two cross sectional studies, two prevalence studies, one systematic review and three narrative reviews.	Moderate concerns of methodological limitation. Six of the included studies are deemed to have no or minor concerns of methodological limitations. Eleven of the included studies are deemed to have moderate concerns of methodological limitation through critical appraisal. Six primary qualitative studies and two mixed-methods studies, one narrative review, and one prevalence study are all noted to have concerns of the qualitative work including: lack of a statement of researcher cultural position, and influence of the researcher on the findings and analysis. Most of the studies also are noted to have unclear congruity between the philosophical perspective and stated methods. One included mixed methods study is noted to have major concerns of methodological limitation of all aspects of the study methodology.	Overall assessment demonstrated moderate concerns of relevance. Seven of the included studies were directly relevant. Three studies were deemed partially relevant to parent-centred decision making, and five studies demonstrated indirect relevance to parent-centred decision making. It was noted that the studies demonstrating indirect relevance focused on topics surrounding parent-centred decision making but parent-centred-decision making was not a focused outcome. Three studies demonstrated unclear relevance to parent-centred decision making, one prevalence study of autopsy consent, one study sourcing evidence from lower-income countries,	Overall assessment demonstrated minor concerns of coherence.	Overall assessment demonstrated minor concerns as multiple viewpoints were included, a large number of stillbirths and composite perinatal deaths. Neonatal deaths and termination of pregnancies for fetal anomalies were fewer in number collectively from the studies, and the fathers/support persons viewpoint was inadequately represented by the included studies. The data included in evidence synthesis were sourced predominantly from high-income countries except for two study populations from a low- or middle- income populations. The combined populations included 4,862 stillbirths, 249 neonatal deaths, 263 termination of pregnancies for fetal anomalies, and 440 composite perinatal deaths (un-stratified neonatal deaths and stillbirths). Five of the included studies did not report the population size.	Low confidence *Minor concerns of data adequacy, and coherence. Moderate concerns of methodological limitation and relevance.*

				and one that focused on how to initiate discussions that would lead to parent-centred decision making, but not the decision making process.		The viewpoint of solely mothers was represented in two of the included studies, and one study contained the support person/father's viewpoint only. Five studies included both parents' viewpoints, and seven studies included the viewpoint of healthcare professionals. One narrative review was noted to be solely the opinion of the author.	
3.7	Develop a detailed care plan across the phases of care including: • pregnancy care plan, including individualised preparation and support for labour and birth • maternal birth care plan • newborn care plan • perinatal loss care plan • discharge plan and ongoing support. Discussions around care planning should: • identify who parents want involved in decision making (e.g. family/whānau members, other support persons, community Elders or spiritual leaders, or other specialists) • acknowledge parents' (or their chosen support person's) role as primary decision maker and carer of their baby • incorporate parents' values, preferences, wishes and needs.	15 studies were included. Of these, nine are primary qualitative studies, two are systematic reviews, two are narrative reviews and two cross-sectional studies were included.	Moderate concerns of methodological limitation are noted. Nine of the included studies are noted to have no or minor concerns of methodological limitation. Six of the included studies are noted to have moderate concerns of methodological limitation. All six are qualitative primary research studies, and all fail to provide a statement of the researcher's cultural position, and the influence on analysis and findings. Three are also noted to lack congruity between the stated methods and methods performed, and one is additionally noted to have unclear research methodology congruence with philosophical perspective.	Minor concerns of evidence relevance were noted. Seven of the included studies were directly relevant to support during the decision making process, and a further three studies were noted to be partially relevant. Indirect relevance to support during parent-centred decision making was noted concerning two of the included studies, both studies assessed parent-centred decision making in lower- or middle-income countries and the processes are noted to be of indirect relevance to the Australian setting.	Minor concerns of coherence are noted.	Overall assessment of adequacy of the included data presented moderate concerns. The viewpoints of multiple stakeholders in the parent-centred decision making process were included. Despite this, the population lacked adequacy for stillbirth and neonatal deaths. Most of the population included composite perinatal death outcomes, therefore adequate stillbirth and neonatal death samples were unable to be clearly delineated. The data included in evidence synthesis were sourced from a variety of income countries including high, middle and low. The combined populations included 82 stillbirths, 32 neonatal deaths, 1604 termination of pregnancies, and 4,722 perinatal deaths	**Low confidence** *Minor concerns of relevance and coherence. Moderate concerns of methodological limitation and data adequacy.*

				Three studies were deemed of unclear relevance, two using populations of lower- or middle-income countries including one with focus on bereavement care, and the remaining study demonstrated a focus on prenatal testing.		(composite outcomes; neonatal deaths and stillbirths). Mother's and father's viewpoints were included through three separate studies. Two studies included parents alongside healthcare professional viewpoints. Four included studies presented solely healthcare professional viewpoints. In addition to the above, two studies contained community voices (local and online) and one study presented care consensus for previable birth.	
3.8	Provide multiple opportunities for parents to ask questions and explore their concerns with the same informed, experienced, and trusted healthcare professional. • Provide opportunities for parents to revisit their decisions but inform them of time critical issues (e.g. mode of birth, how baby's condition may change, time to autopsy).	Ten studies included. Six primary qualitative studies, one case series, one cross-sectional and two reviews (one systematic and a narrative review).	Minor concerns of methodological limitation are noted. Eight of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. Two included qualitative primary research studies are assessed to have moderate concerns of methodological limitation due to lack of a statement of researcher cultural position, and failure to account for this impact of the research findings and analysis. One also lacks congruity between	Moderate concern was noted for relevance of the evidence included concerning parent-centred decision making. Three of the included studies were deemed directly relevant. Four of the studies were noted to be partially relevant, and three studies were deemed to be indirectly relevant to parent-centred decision making.	Minor concerns were noted concerning coherence of the included studies. This was attributable to the lack of studies directly relevant to provision of information during the parent-centred decision making process.	Overall assessment of adequacy of the included data presented moderate concerns as although the viewpoints of mothers, parents and healthcare professionals were included, the sample sizes were not specified for these groups, and data lacked adequacy for outcomes reported. The data included in evidence synthesis were sourced predominantly from high-income countries except for one study that included a low-income country population. The combined populations included 289 stillbirths, 4 neonatal	Low confidence *Minor concerns of coherence and methodological limitation. Moderate concerns of relevance and data adequacy.*

		the methodology and philosophical perspective states.	Indirect relevance was noted for three of the studies as the focus of the study was not parent-centred decision making, but rather cold cot use or autopsy consent. The remaining study, deemed of indirect relevance, was conducted using a low-income country population that was of limited relevance to the Australian setting.	deaths, 524 termination of pregnancies, and 33 perinatal deaths (composite outcomes; neonatal deaths and stillbirths). Two of the included studies focused solely on the mother's viewpoints, one solely on parents' viewpoints, and four on healthcare professionals' viewpoints. Two studies included both parents and healthcare professionals' viewpoints.

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 3: Perinatal loss care: effective communication

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Good communication between healthcare professionals and bereaved parents and family involves finding the *right words* and the *right approach* with attention to *what* is said and *how*. Studies of parents' experiences of perinatal bereavement care repeatedly highlight three critical elements of good communication: sensitivity and compassion; clear understandable information; and respect for individual needs and preferences.[1] Where appropriate, it is important that both parents are involved in communication, information provision, and decision-making to ensure the loss of partners is recognised. The death of a baby affects families, and the needs of siblings, grandparents, and other family members should be considered.

Methodology

The Guideline Development Committee developed key research questions around effective communication and the provision of perinatal loss care (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	How should healthcare professionals interact and engage with parents and families along the continuum of perinatal loss care, starting when the death of a baby occurs or is anticipated?
2	How do healthcare professionals ensure the appropriate people are included in the communication and decision-making process?
3	How can information and resources be provided in a sensitive and timely manner at each touchpoint of care? What is the best method or form of information?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 1. PICO criteria

PICO	Inclusion criteria

Population	Defined in Australia and Aotearoa New Zealand as:
	• Stillbirth
	  ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion[2,3]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth[2,3]

	• Inclusion of perinatal deaths following termination of pregnancy ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).
Intervention	Studies exploring perinatal loss care following stillbirth or neonatal death in maternal or newborn services.
Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes, and experiences of parents, family members, and healthcare professionals around communication and provision of perinatal loss care across the continuum of care from the time of breaking bad news and diagnosis of stillbirth or life-limiting condition, through to bereavement care and follow-up. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Search strategies were conducted on 26 April 2022 incorporated all PICO criteria and were restricted to publications in English (Table 4). A top-up search was conducted on 12 September 2023. Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus.

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group

with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- Wrong *population*: The study did not focus on termination of pregnancy, stillbirth, or neonatal death as defined in Table 2.
- Wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- Wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- Wrong *language*: The study was not published in English.
- Wrong *publication dates*: The study was published prior to 2017.
- Wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using the applicable Joanna Briggs Institute developed critical appraisal tools. The QUADAS-2 tool was to be used if diagnostic evaluation studies were to be assessed. Table 6 contains a detailed quality assessment of individual studies. All studies were included regardless of quality assessment, and all components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence of the recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the Care Around Stillbirth and Neonatal Death Clinical Practice Guideline. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and June 2023 for feedback and consensus on recommendations included in this report.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[4] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[5]

- **Coherence:** How clear and cogent the fit is between the data from the evidence and synthesis findings?[6]
- **Adequacy:** The richness and quantity of data supporting the findings[7]
- **Relevance:** The extent to which the evidence from studies is applicable to the context specific in the guideline.[8]

Each domain was assessed individually, and concerns were assessed as:

- No concerns or very minor concerns regarding the domain
- Minor concerns regarding domain
- Moderate concerns regarding domain
- Serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated, and details of any concerns were identified and listed.[9] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: How should healthcare professionals interact and engage with parents/family along the continuum of perinatal loss care, starting when the death of a baby occurs or is anticipated?

In maternal and newborn services, a range of healthcare professionals from many disciplines are involved with bereaved parents during and immediately following the death of a baby. The actions of healthcare professionals and their timing are critical to high quality care at every stage of the continuum of care.[10-12] Healthcare professionals have a major role in supporting parents to make decisions that minimise regret and avoid missed opportunities.[13,14] The behaviours and attitudes of healthcare professionals significantly influence parents' decision-making and coping ability after stillbirth.[15]

Healthcare professionals involved in bereavement care have "one chance to get it right".[16]

Poorly managed interactions can lead to a negative and lasting impact on bereaved parents for years and sometimes decades.[16] Bereavement care is not always reliably patient-centred or respectful. Open disclosure is the process whereby healthcare staff discuss events with patients and families openly following an unexpected negative outcome that occurred in the hospital. Lack of openness or honesty from staff and management after unexpected adverse events adversely affects trust in healthcare professionals and/or the hospital system. Bereaved parents value the opportunity to give and receive feedback regarding clinical care provided around the time of their pregnancy loss, and a single point of contact to direct their questions.[17]

Healthcare professionals, by implementing the recommended best practices, are aware of what is required but might not have had the emotional resources to engage with the women. In a qualitative metasynthesis of parents' experiences of perinatal loss, participants described that their interactions with healthcare professionals greatly affected their pregnancy experience. However, communication with healthcare professionals was often painful, disconnected, and uncomfortable. Parents sensed the discomfort of the healthcare professionals, especially when they discussed a poor prognosis. Furthermore, communication by healthcare professionals was often ambiguous and unclear. Several participants reported that they were sent home without knowing when they would need to return for follow-up care. Communication and supportive patient-centred care were especially important to parents.[18] These findings were congruent with that of another scoping review of parents' perspectives of unmet needs where there was considerable mention of understaffed, poorly resourced, and poorly coordinated services [19]. Similarly, an Australian study showed that only 13% of babies with an antenatal diagnosis had a documented neonatal resuscitation plan, representing a significant missed opportunity for communication with families about the benefits and burdens of available interventions, as well as to provide supportive care. It also highlights the complexity and sensitive nature of antenatal discussions with parents.[20]

The silence, or the few explanations, as well as the absence of empathic expressions, causes parents to feel alone, terrified, and insecure in the face of the diagnosis of stillbirth or neonatal death.[21] In contrast, compassionate care has long-lasting impacts on parents:

> **"I was impressed by the delivery room midwife, … the warmth with which she treated my wife. She let me stay with her, she held her hand and spoke to her gently … at such a hard time, that sort of personal treatment was comforting, and even today we still remember it as the most positive thing about that sad experience" [22]**

Bereaved parents may be young and inexperienced concerning death and bereavement and may rely on healthcare professionals for adequate and sensitive support and guidance[23]. Parents find it helpful when healthcare professionals talk about practical, as well as emotional issues or support parents by being together in their silence or tears.[23] Parents who had experienced kindness and compassion remarked on how supported they felt by this and how this approach had helped them get through a difficult time.[24] Parents find it valuable when they are supported by hospitals to see the deceased baby, are assisted with funeral options and autopsies, and are supported in completing the necessary legal documents.[25] Women who had lost pregnancies between 20 and 37 weeks in Australia were generally positive about the quality of information and emotional support provided by individual healthcare professionals, but some directed blame at inappropriate hospital policies and systems.[26]

During the COVID-19 pandemic, personal protective equipment, including surgical masks, impeded face-to-face communication, non-verbal communication, and expressions of empathy by healthcare professionals. However, telehealth was generally viewed as acceptable, useful, and in some instances preferred by some parents with the advantage of more people being able to be involved where needed.[27]

Respectful and compassionate communication

Respectful care is defined by the World Health Organization as care provided 'in a manner that maintains their dignity, privacy and confidentiality, ensures freedom from harm and mistreatment, and enables informed choice and continuous support during labour and childbirth'. Identifying objective measures of dignity and respect is challenging; respectful care requires adaptation to cultural norms and individual preferences and is based on expectations and awareness of rights.[28,29] Healthcare professional training must be developed and implemented with a focus on communication. Communication that balances reassurance with taking concerns seriously, and ensures adequate support and information is provided to parents should be utilised.[28,30] Parents appreciate it when clear explanations are provided using sensitive lay language rather than medical terminology.

Healthcare professionals can make a significant difference through direct interactions with bereaved couples by conveying empathy, information, and guidance regarding what to expect physically, emotionally, and socially.[31] Healthcare professionals need to approach difficult conversations with veracity, compassion, and sensitivity.[32] Sensitivity, kindness, and an empathetic attitude have been reported as a positive experience by parents. It is important that parents feel their identity as parents are recognised and their baby is treated with respect and kindness just like any other newborn baby.[33] Care needs to be highly individualised to be perceived as supportive by parents.[34-36]

Bereaved parents need humanistic, caring, and sensitive approaches by healthcare professionals.[19] In a scoping review of parents' unmet palliative care needs, experiences of closed communication and unmet needs surrounding professional knowledge on their child's disease or condition were evident. Unmet care needs included inaccurate information being given, healthcare professionals inadequate preparation for appointments (including parents having to retell their story), parents not feeling valued or respected by healthcare professionals, medical jargon, and patronising language.[19] Similar findings were observed in an Australian study exploring the experiences of parents of critically ill newborns. Many parents reported that they had been failed by inadequate medical evaluations and decisions.

Parents felt powerless in the face of medical superiority and guilty for not challenging medical decisions during pregnancy as they felt that this may have altered the outcome for their baby.[37] Healthcare professionals need to be mindful of the uniqueness of each perinatal loss and bereaved family, and respect and accept the family's wishes.

Training considerations for effective communication skills

Appropriate training in perinatal bereavement care including good communication, appropriate attitudes, and provision of meaningful information to grieving women is needed.[30] Training should incorporate sensitive communication, psychological support and counselling, and support in decision-making before, during, and after birth.[10] Respectful care maintains parents' dignity and control and enables them to engage with healthcare facilities.[38] Education, training, resources, and support are identified as critical enablers for best practice care following perinatal death. These include both formal educational initiatives and informal debriefing and sharing of experiences with colleagues. Organisational responses are important to support healthcare professionals and to prevent burnout among those working in highly emotionally demanding roles, including those who deal regularly with perinatal loss.[39,40]

Researchers recommend that every unit should always have available at least one healthcare professional experienced in confirming with certainty the diagnosis of stillbirth and trained in straightforward, empathic, but not overly emotional ('touchy-feely') communication.[41] Healthcare professionals in maternal and newborn settings may encounter death infrequently[31,42] and, as a result, may feel inadequately prepared to take care of families when death occurs. Further, perinatal death has a profound impact on the psychological and physical wellbeing of healthcare professionals.[43]

In an Australian study, authors highlighted parents' experiences of interactions with healthcare professionals who demonstrated integrity, honesty, empathy, good listening skills, respect, and professionalism. In comparison, parents reported interactions with some healthcare professionals who were 'obviously uncomfortable' with the situation and responded by taking control and making 'inappropriate' comments. Bereaved mothers reported that these types of interactions led to them feeling disempowered, belittled, and misunderstood.[44] In 2017, a scoping review examined the impact of perinatal death on the perspectives of healthcare professionals in maternity care settings and found two major themes: (1) experiences; and (2) needs of healthcare professionals. Shorey and colleagues[39] identified several personal factors that led to negative experiences including a lack of experience in dealing with stillbirth and neonatal death, junior-raking and younger healthcare professionals, insufficient communication skills, lack of knowledge and training, lack of support, and feelings of inadequacy. Similarly, a qualitative study with midwifery students showed that student midwives avoided having in-depth discussions of stillbirth care with bereaved parents and experienced extreme anxiety when coping with the situation alone.[45] Thus, adequate education, emotional, and institutional support acknowledging the stress and needs of healthcare professionals is needed, which would further enhance the supportive care that parents and families need at this time.

In a UK study, more disadvantaged women were significantly less likely to see their stillborn baby or to be offered information about support groups or written information or advice about managing their breastmilk and other issues of importance. Similarly, after hospital discharge, women were significantly less likely to have confidence and trust in their midwives, less able to ask the questions that they wanted, and their baby was significantly less likely to have an autopsy.[46]

> **"I feel what happened was completely avoidable. I feel I was put in a bracket with everyone else, but everybody is different. If they had just**

listened to me and treated me on an individual basis, things could have been different."[46]

Overall, women residents in the most deprived areas were significantly less satisfied with their care, indicating a need for the provision of sensitive, compassionate, and individualised care to be made available to all women.[46]

On the other hand, in a study undertaken in the USA, parents were grateful for the expression of kindness, sympathy, and empathy they received from the hospital staff. Many parents reported that staff would consistently offer help and ask if anything was needed. However, some mothers worried that staff forgot or did not care for fathers in the way that they did for mothers.[47]

Parents also appreciated it when staff treated their stillborn like a live baby. Examples include when staff would point out and make comments about the baby's features, take measurements, and hold the baby like a live baby.[47] Many parents have a desire to have their babies acknowledged as irreplaceable individuals and appreciate when healthcare professionals use their baby's name, which serves as an acknowledgment of their baby and their unique relationship with them.[18,48,49]

However, it is important that healthcare professionals caring for bereaved parents guard against making assumptions, listen carefully, and remain sensitive to the language preferred by the parents about the loss they have experienced.[50] Training staff in exchanging appropriate information with parents and maintaining a respectful attitude will help parents reach decisions that they will be less likely to regret in the long-term such as mode of birth or autopsy examination of the baby.[41]

Question 2: How do healthcare professionals ensure the appropriate people are included in the communication and decision-making process?

Key healthcare professionals in maternal and newborn services should be identified as part of a multidisciplinary approach to care and should ideally include a bereavement midwife, lead clinician, general practitioner, chaplain, or bereavement counsellor.[51] Parents value continuity of care. Ideally, parents should be under the care of a dedicated and consistent team of healthcare professionals.[16] Lack of a single point of contact means families do not know who to contact or approach and it can be difficult for families to direct their questions to the appropriate personnel. Since parents may meet different staff members at different times across the continuum of care, it is important that all healthcare professionals have evidence-based training in perinatal loss care and communication.[38]

Family members and other key support person(s)

While most studies in perinatal bereavement are focused on parents' experiences of bereavement support and care (mothers more so than fathers), research is now emerging on the support needs of grandparents and how they can be supported to support the parents.[52-54] While the needs of each family are different, with cultural and individual variations[55], family and community play a significant role in helping parents' cope after perinatal loss.[56,57] There are many decisions that need to be made after the death of a baby. Parents will be faced with so many options from healthcare professionals at the height of their bereavement and having other support people around will help with guidance and decision-making.[58]

In a scoping review exploring fathers' experiences of grief and loss following stillbirth and neonatal death, several studies reported that fathers felt diminished and disregarded by family and the

healthcare system when concerns about loss were directed only to their partners.[59] Being recognised and validated as a grieving father and not merely as a supportive partner was an important component of men's experience of perinatal death. Similarly, Australian research with grandparents showed that while some grandmothers found hospital staff to be kind, others experienced unhelpful encounters with hospital staff before their child's pregnancy loss and a lack of support. In most cases, no support was offered, and no information or education was provided. While all grandmothers indicated that they preferred the focus of support to be on their children when a loss occurs, they expressed frustration at the lack of information made available to them at the time of the loss, resulting in more difficulty supporting both their child and themselves: "…*help me help my child*." Grandfathers also noted that finding support was challenging, with limited options available.[53]

Termination of pregnancy considerations

In a study conducted with parents who experienced a termination of pregnancy, parents expressed a preference for receiving support from a maternal-fetal medicine specialist to help them understand the severity and consequences of the anomalies found and to counsel them in their decision regarding termination. Parents showed a preference for support from mental healthcare professionals to help with their emotional responses.[60] Similarly, another study with parents who experienced a lethal fetal diagnosis during pregnancy showed that parents valued healthcare professional opinions and recommendations. This helped parents make difficult medical decisions.[61]

Question 3: How can information and resources be provided in a sensitive and timely manner at each touchpoint of care? What is the best method or form of information?

The way in which healthcare professionals communicate and convey information to the woman and her family, at the time of stillbirth, shapes the overall experience of care. Information provision is a process that should happen gradually [62]. It is important for those responsible for delivering information to consider the way that they pace the information. Healthcare professionals should provide as much information as they can and ensure there are no gaps, so parents do not feel the need to "stitch bits of information" together. The information may need to be provided in manageable chunks so that it is not overwhelming. However, these chunks must be internally coherent and the links between them made clear. Women should be given opportunities to make informed choices regarding how to proceed, based on complete information.[63]

Healthcare professionals need to be aware of the importance of keeping parents informed about what is happening and sowing seeds slowly, along with well written information and normal expressions of empathy.[41] When a diagnosis of stillbirth is made, either antenatally or in labour, parents appreciate being notified jointly of the death without delay in a clear and honest way. They also appreciate when healthcare professionals use compassionate language, express sympathy, and provide the woman and her partner with an opportunity for some private time to share emotions.[10,64] Poor, delayed, and inconsistent messaging and the use of medical jargon should be avoided.[10] It is important to listen to parents to determine their individual needs regarding information.[41] Parents should be provided ample time to process the information, ask questions, and farewell their baby,[65] and should be supported with decision making about various procedures, family involvement, memory making, and saying goodbye.[64,66]

In a survey study conducted in the UK, between 8% and 15% of respondents did not feel that language used at the diagnosis of fetal death was sensitive, clear, and unambiguous. Further, parents did not always receive written information about their care or postmortem investigation.[24]

Healthcare professionals need to ensure that they do not advise parents based on their own personal values or ideology when providing information to parents, but remain objective and allow the parents to come to their own decisions independently, ensuring that patient autonomy is maintained.[24]

In an interview study with women who had a prenatal diagnosis of severe abnormality, women valued healthcare professionals' empathy, particularly during the communication of the diagnosis, and their ability to read women's emotions accurately.[67] In contrast, a lack of empathy could result in failure to adequately respond to women's needs, particularly with regard to information.[67] In another qualitative study exploring parents' responses to and needs from healthcare professionals during pregnancy with a lethal fetal diagnosis, parents reported seeking information and expert guidance from healthcare professionals who maintained hope, communicated in a caring, nonjudgmental, straightforward manner, and showed sensitivity to their developmental journey.[61]

Cassidy[68] outlined a five-step process for healthcare professionals to assist grieving parents:

1. Communicating complete sensitivity and empathy.
2. Having a working knowledge of common grief reactions, stages of bereavement, and signs or symptoms of complicated grief.
3. Being familiar with their clinic's protocols regarding bereavement.
4. Being aware of the family's needs and making appropriate referrals.
5. Following up with the family to ensure that their needs are being met.

Adequate time and appropriate space for processing information

Parents should feel supported by healthcare professionals to process information and make decisions in their own time.[69] It is important for healthcare professionals to acknowledge and make parents aware of the impact of grief on their ability to process information and make decisions.[64] Having uninterrupted time to discuss sensitive and/or complex clinical situations in a quiet and private environment is viewed as helpful by parents and families to understand and process the received information and ask all relevant questions. In an international survey of bereaved parents' experiences of respectful care, parents reported their care to be kind and respectful in most geographical regions, however, parents wanted more time with healthcare professionals and adequate information.[28] System-level changes are required to ensure that healthcare professionals can spend sufficient time with parents.

Appropriate resources to meet parents and family support needs

A scoping review of parents' unmet palliative care needs showed that parents valued team-specific booklets, including information about the team members and how to contact the service they are accessing. Parents also highlighted the need for frequent reminders of the services available to families, including support groups.[19] Information and resources for ongoing community-based support should be provided to parents and family before they leave the hospital. It is important that names and contact information for local grief counsellors and community and peer support groups and organisations are provided to all parents.[64,70]

In an Australian study of fathers' experiences of support following neonatal death, fathers were provided with written information on support options however, only a few of these supports were specific to them. Most fathers reflected that existing supports were limited in variety and availability and highlighted the importance of diverse support options. Most fathers emphasised that they still

required individualised bereavement support, separate and different from the support provided to the mother of the baby. All fathers in this study reported positive experiences of support within the hospital setting, including being provided with privacy, clear explanations of medical complications, and sensitive delivery of information.[71]

Similarly, mothers report a need for long-term follow up and support, as reflected below:

> **"I don't think there was a lot of support...there was a support kind of understanding what was going to happen and going through the loss, but once the loss happened, I left like 'ok, here you go - you can go home'. [I needed more] than just the pamphlet and here you go".[72]**

Grey literature and other sources

Note. Grey literature is not included in the GRADE assessment of the evidence-based recommendations.

In addition to the published academic literature, both international and national government agency and perinatal loss support organisation (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to effective communication at the time of perinatal death or termination of pregnancy. A targeted Google search was also conducted using a combination of the following keywords: effective communication at the time of stillbirth; effective communication at the time of neonatal death; effective communication at the time of perinatal death; and healthcare professional communication around stillbirth and neonatal death. The findings of the grey literature are supported by both the current and previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*.

The American College of Obstetricians and Gynecologists (ACOG) recommends that the results of the autopsy, placental examination, laboratory tests, and cytogenetic studies should be communicated to the involved clinicians and the family of the deceased infant in a timely manner.[73] Involving relevant family members and clinicians in the communication and decision-making process could be highly valuable for many families.

The UK National Bereavement Care Pathway advises healthcare professionals to actively listen and take the lead from the parents regarding preferred language and to acknowledge the unique needs of parents in this regard. If the parents use the term "baby" or "my baby," then the healthcare professional should use those terms as well—but not before the parents do.[64]

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies	GRADE-CERQual Overall Confidence Rating of evidence	Guideline recommendations
Actis Danna et al. 2023 Aggarwal & Moatti 2022 Al Mutair 2019 Atkins et al. 2022 Bond et al. 2018 Boyle et al. 2022 Camacho Ávila et al. 2020 Carlsson 2019 Cassaday 2018 Catlin 2018 Constantinou et al. 2019 de Andrade Alvarenga 2021 Due et al. 2018 Fenstermacher 2019 Fernández-Basanta 2021b Furtado-Eraso et al. 2021 González-Ramos 2021 Gopichandran 2018 Hvidtjørn et al. 2021 Littlemore & Turner 2019 Martínez-Serrano et al. 2018 Martínez-Serrano et al. 2019 Mendes et al. 2017 Nuzum 2017a	Moderate confidence *Minor concerns of relevance, coherence and data adequacy. Moderate concerns of methodological limitation.*	**Evidence-based recommendation 2.4**: Use respectful and sensitive language and terminology that is honest, realistic, and understandable. • Take the lead from parents regarding preferred language for their baby. • Use the word 'baby' or 'bub' if acceptable to parents. • Ask parents if they have named their baby and, if so, seek permission to use the name. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*

Nuzum et al. 2018 O'Connell 2019 Obst 2021 Paize 2020 Randolph 2021 Ravaldi 2018 Redshaw 2021 Rich 2018 Smith & Dickens 2020 Stacey 2021		
Actis Danna et al. 2023 Aiyelaagbe et al. 2017 Alaradi et al. 2022 Atkins et al. 2022 Ayebare 2021 Azeez et al. 2021 Berry et al. 2021 Camacho Ávila et al. 2020 Carlsson 2019 Cassidy 2018 Catlin 2018 Constantinou et al. 2019 de Andrade Alvarenga 2021 Denney-Koelsch et al. 2018 Due et al. 2018 Fenstermacher 2019 Fernández -Basanta 2019 Gopichandran 2018 Helps et al. 2020	Moderate confidence *Minor concerns of relevance, coherence and data adequacy are noted. Moderate concerns of methodological limitation.*	Evidence-based recommendation 2.5: Be aware that stress and grief can greatly affect how people absorb, retain, and respond to information. Tailor information by: • using open-ended questions • repeating information and checking with parents that they understand • offering parents culturally and linguistically appropriate parent-facing information and resources about perinatal grief and what to expect • allowing parents time and space to read information and resources when they are ready. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*

Kalanlar 2020
King et al. 2021
Lafarge et al. 2022
Lewis 2019
Littlemore & Turner 2019
Martin-Ancel 2022
Martínez-Serrano et al. 2018
Mendes et al. 2017
Noble-Carr 2021
Nuzum 2017a
Nuzum et al. 2018
Obst 2020
Randolph 2021
Ravaldi 2018
Redshaw 2018
Siassakos et al. 2018
Smith & Dickens 2020
Stacey 2021
Tucker-Edmonds 2021
Wong 2021

Table 4. Search strategy

Database	Search strategy		
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR "Abortion, Induced"[Mesh]	Mesh
	#2	**"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*"** OR “Neonatal loss*” OR “Neonatal mortalit*”OR “Neonatal death*” OR “Neonatal Demise*” OR “Newborn death*” OR “Newborn mortalit*”	**Title/abstract**
	#3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])	**Title/abstract**
	#4	((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or “prenatal diagnosis”) AND (terminat* or abortion or abort))	**Title/abstract**
	#5	#1 OR #2 OR #3 OR #4	
	#6	**"Hospice Care"[Mesh]**	Mesh
	#7	bereave* or grief or griev* or "decision-making" or "decision making" or compassion* or "parent centred" or "parent centred" or "patient-centred" or "patient centred" or psychosocial or phsycholog* or psychotherapy* or psychopath* or emotion* or guilt or regret* or cope* or coping or stress* or stigma or taboo or sensitive or memento* or photograph* or ritual or commemorat* or “depression support” or “grief support” or “griev* support” or “emotional support” or “parent support” or “mother support” or “father support”	**Title/ abstract**
	#8	(triage[Title/Abstract] OR touchpoint*[Title/Abstract] OR presenting[Title/Abstract])	**Title/ abstract**
	#9	("naming"[Title/Abstract] OR "name"[Title/Abstract] OR "referring to"[Title/Abstract] OR "call*"[Title/Abstract]) AND ("baby"[Title/Abstract] OR "body"[Title/Abstract] OR "deceased"[Title/Abstract] OR "babies"[Title/Abstract] OR "neonate"[Title/Abstract] OR "newborn*"[Title/Abstract])	**Title/ abstract**
	#10	#6 OR #7 OR #8 OR #9	
	#11	"health services, indigenous"[MeSH Terms] OR "Transcultural Nursing"[MeSH Terms] OR "Obstetrics"[MeSH Terms] OR "Health Personnel"[MeSH Terms] OR "Rural Health Services"[MeSH Terms] OR "Indigenous Peoples"[MeSH Terms] OR "Neonatology"[MeSH Terms] OR "Physician-Patient Relations"[MeSH Terms] OR "Health Care Costs"[MeSH Terms]	Mesh
	#12	(professional* or nurs* or doctor* or physician* or midwi* or therapist* or "health care professional*" or "health care person*" or obstetric* or gynecolog* or neonatology* or paediatric* or "healthcare	**Title/ abstract**

	professional*" or "healthcare worker*" or "health-care provider*" or "health care provider*" or "healthcare provider*" or sonographer* or radiographer* or radiologist*)	
#13	(cost* or econom*)	Title/ abstract
#14	(refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or cultural or elders or maori or whanau)	Title/ abstract
#15	("women understand*" or "women view*" or "women experience*" or "woman understand*" or "woman experience*" or migrant or immigrant or family or families)	Title/ abstract
#16	#11 OR #12 OR #13 OR #14 OR #15	
#17	#5 AND #10 AND #16	

Embase

1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/
2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
3	((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)) or "prenatal diagnosis").ti,ab.
4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.
5	1 or 2 or 3 or 4
6	(bereave* or grief or griev* or "decision-making" or "decision making" or compassion* or "parent centred" or "parent centred" or "patient-centred" or "patient centred" or psychosocial or psycholog* or psychotherapy* or psychopath* or emotion* or guilt or regret* or cope* or coping or stress* or stigma or taboo or sensitive or "resource appropriate care" or memento* or photograph* or ritual or commemorat* or ((depressi* or bereavement or grief or griev* or emotion* or parent* or mother* or father* or parent*) adj3 support*) or (recognition adj3 (parenthood or motherhood or fatherhood))).ti,ab.
7	((naming or name or "referring to" or "call*") adj6 (baby or stillb* or body or decease* or babies or neonate or newborn*)).ti,ab.
8	(triage or touchpoint* or presenting).ti,ab.
9	*bereavement/ or exp bereavement counseling/ or exp bereavement support/
10	*psychosocial care/
11	6 OR 7 OR 8 OR 9 OR 10
12	exp transcultural care/ or exp health care personnel/ or exp obstetrics/ or gyneacology/ or exp neonatology/ or newborn intensive care/ OR exp vulnerable population/ OR exp rural health care/ or exp indigenous health care/ or exp health disparity/ or indigenous people/ or *health care cost/
13	(parents or mother* or father* or (patient* adj2 (understan* or need* or resource* or experience* or view* or "decision-making" or "decision making" or "shared decision"))).ti,ab.

	14	(professional* or nurs* or doctor* or physician* or midwi* or therapist* or "health care professional*" or "health care person*" or obstetric* or gynecolog* or neonatology* or paediatric* or "healthcare professional*" or "healthcare person" or "healthcare worker*" or "health-care provider*" or "health care provider*" or "healthcare provider*" or sonographer* or radiographer* or radiologist*).ti,ab.
	15	(cost* or econom*).ti,ab.
	16	(refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or cultural or elders or maori or whanau or M#ori or wh#nau).ti,ab.
	17	("women understand*" or "women need*" or "women view*" or "women experience*" or "woman understand*" or "woman experience*" or migrant or immigrant or family or families).ti,ab.
	18	12 or 13 or 14 or 15 or 16 or 17
	19	5 and 11 and 18
	20	limit 19 to yr="2017 -Current"

CINAHL

#	Query
S25	S5 AND S11 AND S24
S24	S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23
S23	(MM "Rural Health Personnel")
S22	(MM "Obstetrics")
S21	(MM "Health Care Costs")
S20	(MM "Intensive Care, Neonatal")
S19	(MM "Indigenous Peoples")
S18	(MM "Health Personnel") OR (MM "Healthcare Disparities")
S17	(MM "Transcultural Care")
S16	AB ("women understand*" or "women need*" or "women view*" or "women experience*" or "woman understand*" or "woman experience*" or migrant or immigrant or family or families)
S15	AB (refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or cultural or elders or maori or whanau or M#ori or wh#nau)
S14	AB (cost* or econom*)
S13	AB (professional* or nurs* or doctor* or physician* or midwi* or therapist* or "health care professional*" or "health care person*" or obstetric* or gynecolog* or neonatology* or paediatric* or "healthcare professional*" or "healthcare person" or "healthcare worker*" or "health-care provider*" or "health care provider*" or "healthcare provider*" or sonographer* or radiographer* or radiologist*)
S12	AB (parents or mother* or father* or (patient* N2 (understan* or need* or resource* or experience* or view* or "decision-making" or "decision making" or "shared decision")))
S11	S6 OR S7 OR S8 OR S9 OR S10

	S10	(MM "Psychosocial Care (Saba CCC)") OR (MM "Support, Psychosocial")
	S9	(MM "Bereavement Support (Saba CCC)") OR (MM "Bereavement")
	S8	AB (triage or touchpoint* or presenting)
	S7	AB ((naming or name or "referring to" or "call*") N6 (baby or stillb* or body or decease* or babies or neonate or newborn*))
	S6	AB (bereave* or grief or griev* or "decision-making" or "decision making" or compassion* or "parent centred" or "parent centred" or "patient-centred" or "patient centred" or psychosocial or phsycholog* or psychotherapy* or psychopath* or emotion* or guilt or regret* or cope* or coping or stress* or stigma or taboo or sensitive or "resource appropriate care" or memento* or photograph* or ritual or commemorat* or ((depressi* or bereavement or grief or griev* or emotion* or parent* or mother* or father* or parent*) N3 support*) or (recognition N3 (parenthood or motherhood or fatherhood)))
	S5	S1 OR S2 OR S3 OR S4
	S4	AB ((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort)) or "prenatal diagnosis")
	S3	AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) N1 loss*) OR stillb*)
	S2	AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*)
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")

SCOPUS

((TITLE-ABS-KEY ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*))) OR (TITLE-ABS-KEY (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal") W/1 (loss*)))) OR (TITLE-ABS-KEY ((stillb*))) OR (TITLE-ABS-KEY (((("fetal malformation" OR "congenital abnormality" OR "fetal anomaly" OR "congenital anomaly" OR "fetal anomalies" OR "congenital anomalies") W/3 (terminat* OR abortion OR abort))))))

AND ((TITLE-ABS-KEY ((bereave* OR grief OR griev* OR "decision-making" OR "decision making" OR compassion* OR " parent centred" OR "parent centred" OR "patient-centred" OR "patient centred" OR psychosocial OR phsycholog* OR psychotherapy* OR psychopath* OR emotion* OR guilt OR regret* OR cope* OR coping OR stigma OR taboo OR "resource appropriate care" OR memento* OR photograph* OR ritual OR commemorat* OR ((depressi* OR bereavement OR grief OR griev* OR emotion* OR parent* OR mother* OR father* OR parent*) W/3 support*) OR (recognition W/3 (parenthood OR motherhood OR fatherhood))))) OR (TITLE-ABS-KEY (((naming OR name OR "referring to" OR "call*") W/6 (baby OR stillb* OR body OR decease* OR babies OR neonate OR newborn*)))) OR (TITLE-ABS-KEY ((triage OR touchpoint* OR presenting)))) AND ((TITLE-ABS-KEY ((parents OR mother* OR father* OR (patient* W/2 (understan* OR need* OR

	resource* OR experience* OR view* OR "decision-making" OR "decision making" OR "shared decision"))))) OR (TITLE-ABS-KEY ((professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR "health care professional*" OR "health care person*" OR obstetric* OR gynecolog* OR neonatology* OR paediatric* OR "healthcare professional*" OR "healthcare person" OR "healthcare worker*" OR "health-care provider*" OR "health care provider*" OR "healthcare provider*" OR sonographer* OR radiographer* OR radiologist*))) OR (TITLE-ABS-KEY ((cost* OR econom*))) OR (TITLE-ABS-KEY ((refugee* OR "indigenous" OR "torres strait islander*" OR atsi OR "aborigin*" OR "islander*" OR remote* OR "linguistically diverse" OR cultural OR elders OR maori OR whanau OR m?ori OR wh?nau))) OR (TITLE-ABS-KEY (("women understand*" OR "women
Australian Indigenous HealthInfoNet	Baby AND (Bereavement AND Care)
Cochrane	

ID	Search Hits
#1	MeSH descriptor: [Fetal Death] explode all trees
#2	MeSH descriptor: [Perinatal Death] explode all trees
#3	MeSH descriptor: [Perinatal Mortality] this term only
#4	MeSH descriptor: [Abortion, Induced] this term only
#5	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mORtalit*)
#6	((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) ADJ1 loss*) OR stillb*)):ab (Word variations have been searched)
#7	((((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") ADJ3 (terminat* or abortion or abort)) or "prenatal diagnosis")):ti,ab,kw
#8	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7
#9	((bereave* or grief or griev* or "decision-making" or "decision making" or compassion* or "parent centred" or "parent centred" or "patient-centred" or "patient centred" or psychosocial or phsycholog* or psychotherapy* or psychopath* or emotion* or guilt or regret* or cope* or coping or stress* or stigma or taboo or sensitive or "resource appropriate care" or memento* or photograph* or ritual or commemorat* or ((depressi* or bereavement or grief or griev* or emotion* or parent* or mother* or father* or parent*) ADJ3 support*) or (recognition ADJ3 (parenthood or motherhood or fatherhood)))):ti,ab,kw
#10	(((naming or name or "referring to" or "call*") ADJ6 (baby or stillb* or body or decease* or babies or neonate or newborn*))):ti,ab,kw
#11	((triage or touchpoint* or presenting)):ti,ab,kw
#12	MeSH descriptor: [Hospice Care] this term only
#13	#9 OR #10 OR #11 OR #12

	#14	MeSH descriptor: [Health Services, Indigenous] this term only
	#15	MeSH descriptor: [Transcultural Nursing] explode all trees
	#16	MeSH descriptor: [Neonatologists] explode all trees
	#17	MeSH descriptor: [Health Personnel] explode all trees
	#18	MeSH descriptor: [Health Care Costs] this term only
	#19	MeSH descriptor: [Vulnerable Populations] this term only
	#20	((parents or mother* or father* or (patient* ADJ2 (understan* or need* or resource* or experience* or view* or "decision-making" or "decision making" or "shared decision")))):ti,ab,kw
	#21	((professional* or nurs* or doctor* or physician* or midwi* or therapist* or "health care professional*" or "health care person*" or obstetric* or gynecolog* or neonatology* or paediatric* or "healthcare professional*" or "healthcare person" or "healthcare worker*" or "health-care provider*" or "health care provider*" or "healthcare provider*" or sonographer* or radiographer* or radiologist*)):ti,ab,kw
	#22	((cost* or econom*)):ti,ab,kw
	#23	((refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or cultural or elders or maori or whanau)):ti,ab,kw
	#24	(("women understand*" or "women need*" or "women view*" or "women experience*" or "woman understand*" or "woman experience*" or migrant or immigrant or family or families)):ti,ab,kw
	#25	#14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24
	#26	#8 AND #13 AND #25
Informit Indigenous collection	"pregnancy terminat*" OR "Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR "Neonatal loss*" OR "Neonatal mortalit*" OR "Neonatal death*" OR "Neonatal Demise*" OR "Newborn death*" OR "Newborn mortalit*"	

Table 5. Study characteristics

Study ID	Country (Period)	Locality (state/national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool

ACOG 2020	USA (2020)	National	Care consensus	HIC	Qualitative	Narrative	NA	NA	Stillbirth	Recommendations for care after stillbirth and management of subsequent pregnancy	NA	NA	Checklist for text and opinion papers [a]
Abdel Razeq 2021	Jordan (dates not reported)	2 NICUs	Semi-structured interviews	LMIC	Qualitative	Thematic analysis	NA	12 mothers	NND	Experience of mothers whose babies died in the NICU	NA	Mothers of neonates whose babies died in the NICU	Checklist for qualitative research [b]
Actis Danna et al. 2023	Malawi, Tanzania, and Zambia (dates not reported)	Women who had given birth at tertiary referral hospitals in Tanzania, Malawi, and Zambia	Semi-structured interviews	LIC	Qualitative	Grounded theory (symbolic interactionism)	NA	33 women	Stillbirth (within the preceding 12 months)	The purpose of this study was to understand how and when women became aware of the death of their babies.	Women <18 years of age	Women who had experienced a stillbirth in the preceding 12 months and had the capacity to consent.	Checklist for qualitative research
Afonso 2021	Multiple (dates not reported)	Multiple-international literature	Literature	NA	Qualitative	Narrative review	NA	NA	Palliative care	Palliative care in perinatal and neonatal congenital heart disease	NA	NA	Checklist for text and opinion papers
Aggarwal & Moatti 2022	India (2022)	NA	Literature	Lower Middle Income	Qualitative	Narrative review	NA	NA	NA	Bereavement care	NA	NA	Checklist for text and opinion papers

Agwu Kalu 2018	Ireland (Aug 2013-July 2014)	Three large public maternity teaching hospitals in urban Ireland	Self-administered questionnaire, focus groups	HIC	Mixed methods	Content analysis	Cross-sectional study	277 for survey, 11 for focus groups	Stillbirth, NND	Psychosocial factors that impact on midwives' confidence to provide bereavement support to parents who have experienced a perinatal loss	Student midwives and agency midwives	Midwives and nurses who were registered with the Nursing and Midwifery Board of Ireland and were employed by the hospitals to work in the maternity services, and who provided care to bereaved parents.	Checklist for qualitative research Checklist for analytical cross-sectional studies [c]
Aiyelaagbe et al. 2017	UK (2014-2015)	St Mary's Hospital, Manchester UK	Interviews	HIC	Qualitative	Pilot Thematic analysis	NA	58	Stillbirths (antepartum and intrapartum), early neonatal deaths (n=NR)	Parents' experience of bereavement care	NA	Parents of stillborn babies, or babies that died in the delivery unit.	Checklist for qualitative research
Alaradi et al. 2022	USA (June 2017-Aug 2019)	Two large mosques in Louisville, KY	Questionnaire	HIC	Quantitative	NA	Cross-sectional study	79	Miscarriage (n=12), Stillbirth (n=4), NND (n=5)	Arab Muslims' perception of perinatal loss care in the USA	NA	Arab Muslims >18 years. Not a requirement to have experienced perinatal loss.	Checklist for analytical cross-sectional studies

Al Mutair 2019	Saudi Arabia, July-November 2018	1 private hospital in Riyadh	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	13	NND	Staff experience of providing care to dying infants/children and their families	Not specified	NICU/PICU staff who cared for at least one child who had died	JBI Qualitative Appraisal CL
Atkins et al. 2022	International (dates not reported)	44 high and middle income countries	Online survey	High and middle income countries	Quantitative	NA	Cross-sectional	3769	Stillbirth	Parents reported experience of care during pregnancy and around the time of stillbirth, and the factors associated with reporting respectful care. Parental access to bereavement care practices.	Participants were excluded if the reported gestational age at stillbirth was below 20 weeks	Self-identified bereaved parents of stillborn babies	Checklist for analytical cross-sectional studies
Aydin 2019	Turkey (April-July 2017)	1 tertiary hospital	Interviews, hospital records	Upper-middle income setting	Qualitative	Thematic analysis	NA	10	Termination of pregnancy for medical indication	Experiences of women who have a termination of pregnancy for medical indication	NA	Women hospitalised between April- July 2017 at the Akdeniz University Clinics of Obstetrics and Gynaecology	Checklist for qualitative research

												who were: >18 and <45 years, free of chronic and psychiatric diseases, hospitalised because of pregnancy termination and without medical complications during hospitalisation, able to communicate in Turkish, and consented to participate	
Ayebare 2021	Uganda; Kenya 2017-19	5 health facilities in urban, peri-urban and semirural communities	Interviews	LMIC	Qualitative	Thematic analysis	NA	134 parents; 61 health workers	stillbirth	support from family and friends after stillbirth; cultural constraints; spiritual, supernatural and social beliefs about causes of stillbirth	NA	Women and male partners who had experienced a stillbirth, in five urban, peri-urban and semirural facilities and surrounding communities in Kenya and Uganda within the previous 12	JBI qualitative

											months; health workers including midwives, nurses and doctors who regularly provided care for bereaved women in the same facilities	
Azeez et al. 2021	Australia (2020)	National	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	10 fathers	NND	Fathers' experience of support following neonatal death	NA	Men experiencing a neonatal death at least 6 months before the interviews	Checklist for qualitative research
Bakhbakhi et al. 2017	Multiple (dates not reported)	NA	Published research, guidelines and best practice points	HIC	Qualitative	Descriptive review	NA	NA	Stillbirth	Best practice points in bereavement care research in HICs	NA	Published research, guidelines, and best practice points in care following stillbirth in HICs	Checklist for text and opinion papers
Bakhbakhi et al. 2018	UK (May-June 2017)	Two geographically different maternity hospital sites in Bristol and Manchester	Focus groups	HIC	Qualitative	Thematic analysis	NA	22	Stillbirth, NND	Views of healthcare professionals and other key stakeholders on parental	NA	Clinical staff including midwives, obstetricians, neonatologists, nursing staff, and	Checklist for qualitative research

										engagement in the perinatal mortality review		chaplaincy services	
Barry 2017	Ireland (Jan - March 2015)	Tertiary Hospital	Interviews	HIC	Qualitative	Thematic analysis	NA	6	Infant death	The influence of the Amulet artwork (reduced by artist Marie Brett, who worked with women exploring the hidden world of infant loss) and exhibition on midwifery students' perspectives of caring for bereaved parents	NA	Postgraduate midwifery students (registered nurses) who attended the Amulet exhibition; consent obtained	Checklist for qualitative research
Beck 2019	UK (2017-2018)	1 maternity hospital and national online questionnaire	Questionnaires	HIC	Mixed	Content analysis	Descriptive (cross-sectional and before-and-after design)	33 members of the public; 46 clinicians	Stillbirth, NND	The experiences of parents, relatives, and professionals who accessed the Stillbirth Stories archive to evaluate whether accessing	NA	Members of the public (including bereaved parents, relatives, or people who had no experience of perinatal death) accessing the archive	Checklist for qualitative research Checklist for analytical cross-sectional studies

										this archive of clinicians' and parents' experiences of perinatal death was beneficial		between 5 Oct 2017 - 15 Dec 2017. Maternity professionals working in a large tertiary maternity unit in the UK.	
Bedwell 2021	Africa (2018)	**Quantitative:** 2 tertiary facilities in Lake Zone, Tanzania and Mansa region, Zambia **Qualitative**: Antenatal and postnatal clinics, primary and secondary facilities, community in Tanzania and Zambia.	Case records and interviews	LMICs	Mixed methods	Grounded theory	Retrospective cohort study	1885	Stillbirth (≥28 weeks) (n=261)	Contributors and beliefs towards unexplained stillbirth	Twins and neonatal deaths	**Quantitative:** Women who delivered at two tertiary institutes. **Qualitative:** Women (n=48), partners of women (n=19)	Checklist for qualitative research Checklist for cohort studies [d]
Berry et al. 2021	Multiple (2019-2020)	Western cultural countries (US, UK, Australia)	Literature	HIC	Qualitative	Systematic review	NA	5	Stillbirth, NND, TOPFA	Parents' experiences of perinatal loss in a Western cultural context	Articles were excluded if they were reports of studies conducted in non-Western cultures, of twin	Peer-reviewed articles published in English within the last 10 years, about	Checklist for systematic reviews and research syntheses [e]

											pregnancies, or of the perinatal loss experiences of others (e.g., healthcare professionals, siblings, surrogate parents, grandparents, etc.). We also excluded quantitative studies, scale validation studies, and grey literature.	qualitative research conducted in Western countries (e.g., the United States, the United Kingdom, and Australia) that were focused on parents' experiences of perinatal loss (resulting from miscarriage, stillbirth, neonatal death, or termination of pregnancy related to fetal anomalies).	
Bond et al. 2018	Australia (2006-2011)	Sydney hospitals	Postal surveys	HIC	Mixed methods: qualitative and quantitative	Thematic analysis	Cross-sectional retrospective study	36	Stillbirth	Experience of care during and after stillbirth	Pregnancy loss prior to 32 weeks gestational age. Non-English speaking parents.	Women who experienced stillbirth after 23 weeks and delivered at one of the seven tertiary	Checklist for qualitative research Checklist for analytical cross-

												maternity centres in Sydney, New South Wales.	sectional studies
Boyle et al. 2022	Australia (April 2020)	National	Online survey	HIC	Qualitative	Content analysis	NA	35	Stillbirth, NND, TOPFA	Healthcare professional's views of the impact of the COVID-19 pandemic on the provision of respectful care to parents and resulting practice changes	NA	Healthcare professionals who provided perinatal bereavement care in clinical settings or through support organisations in Australia	Checklist for qualitative research
Boyle 2020	Australia (dates not reported)	National	Guideline, literature	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth, NND	Perinatal bereavement care guidelines	NA	Components of best practice perinatal bereavement care	Checklist for text and opinion papers
Brierley-Jones et al. 2018	England (2014-2015)	Three hospitals in North East England	Focus groups, semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	60	Stillbirth	Views of healthcare professionals and healthcare staff across three hospitals in the management of stillbirth	NA	Consultant obstetricians, trainees, midwives, midwife sonographers and chaplains	Checklist for qualitative research

Camacho Ávila et al. 2020	Spain (Apr 2017-May 2018)	2 hospitals in Southeast Spain	Interviews	HIC	Qualitative	Hermeneutical phenomenology	NA	21 (13 mothers, 8 fathers)	Stillbirth (n=17), NND (n=4)	Parents' experiences in relation to professional and social support after perinatal loss	Spoke in a language other than English or Spanish, or experienced a miscarriage, pregnancy termination due to genetic birth defect or multifetal pregnancy reduction.	A mother or father 18 years and older at the time of perinatal loss, had experienced a stillbirth or a neonatal death, and the loss had been suffered at least 2 years before the interview.	Checklist for qualitative research
Camacho Ávila et al. 2019	Spain (Apr 2016-May 2017)	2 hospitals in the South of Spain	Interviews	HIC	Qualitative	Thematic analysis	NA	21 (13 mothers, 8 fathers)	Stillbirth, NND	Experiences and perceptions of parents who have suffered a perinatal death	NA	(1) Being a mother or father who has suffered a loss through the perinatal death of their child, from the 22nd week of gestation to the first week of life. (2) The death occurring between 3 months and 5 years prior to the study (3) The	Checklist for qualitative research

												mother or father had to speak Spanish or English. (4) Signing the informed consent form.	
Carlsson 2019	Sweden (2015)	National	Web-based open-ended questionnaire	HIC	Qualitative	Thematic analysis	NA	6	Prenatal diagnosis of fetal anomaly	Experiences of immigrants with Arabic or Sorani interpreter needs when presented with a antenatal diagnosis of foetal anomaly	None mentioned	participants needed to require interpreter services to understand information from health professionals at the time of diagnosis, and be able to read and write in either Arabic or Sorani	Qualitative appraisal CL
Cassaday 2018	Multiple (dates not reported)	NA	Literature	NA	Qualitative	Narrative review	NA	NA	Miscarriage, stillbirth, NND	Impact of pregnancy loss on psychological functioning and grief outcomes	NA	Risk factors of complicated grief, gender differences in the grieving process and impact on relationships and the role of healthcare professional	Checklist for text and opinion papers

												in screening and treatment of perinatal loss	
Cassidy 2018	Spain (2013-2016)	National	Online self-completion questionnaire	HIC	Qualitative	Phenomenological	NA	796	Pregnancy loss stratified by GA (n=668 stillbirths ≥20 wks. GA)	Bereaved parents' experience of care quality following intrauterine death	Respondents were born outside of the Spanish national territory. Parents reporting neonatal deaths	Women who reported that their baby died within 60 months prior to survey completion.	Checklist for qualitative research
Cassidy 2021	Spain (2013-2016)	National	Online survey, interviews, and observations of an online support forum	HIC	Mixed methods	Thematic analysis	Descriptive	Qualitative: 10 for interviews; 22 online forum observations; 52 open-ended responses Quantitative surveys: 796	Miscarriage, Stillbirth, TOPFA, NND	Disenfranchisement of perinatal grief and how it impacts parents	NA	Interviews included all pregnancy losses (stillbirths or pregnancy terminations) and neonatal deaths; the survey included only intrauterine and intrapartum deaths from 16 weeks onwards, including TOPFA.	Checklist for qualitative research Checklist for studies reporting prevalence data [f]
Catlin 2018	USA (2016)	Texas	Interdisciplinary summit / Delphi study	HIC	Qualitative	Narrative	NA	32	Stillbirth	The needs of women who present with actual or potential	NA	NA	Checklist for text and opinion papers

										pregnancy loss to the emergency department			
Christou et al. 2021	Afghanistan (Oct-Nov 2017)	3 high-volume referral maternity hospitals in Kabul and 2 lower-level health facilities and surrounding communities in 2 rural districts ~25–30 km west and north of Kabul city	Interviews	LIC	Qualitative	Deductive thematic analysis	NA	55 (21 mothers, 9 fathers, 3 female community elders, 20 healthcare professionals, 2 government officials)	Stillbirth	Parents' and healthcare professionals' experiences of care after stillbirth	NA	Women and men experiencing stillbirth, community female elders, healthcare providers, and key informants including government officials, hospital directors, chiefs of wards	Checklist for qualitative research
Cole et al. 2017	USA (dates not reported)	Tertiary Hospital	Case study	HIC	Qualitative	Case study	NA	1	NND and Stillbirth	Description of a perinatal palliative care program	NA	Different components of a perinatal palliative care program at one hospital	Checklist for case report studies [g]
Constantinou et al. 2019	Multiple (2019)	International literature	Literature (4 databases)	NA	Qualitative	Scoping review	NA	55 papers	Children with life-limiting conditions	Unmet needs of children with life-limiting conditions and their families, from the	Papers not written in English, not reporting primary research, and discussing children who died from	Papers from the perspective of parents of children aged 0–19 years, who have a life-limiting condition	Checklist for systematic reviews and research syntheses

										perspective of parents	stillbirth, accidental or unexpected circumstance	and are receiving palliative care.	
Davidson 2018	NA	NA	Opinion	NA	Qualitative	Narrative piece	NA	NA	Stillbirth, NND	Honouring the loss of a baby to aid the grieving process for bereaved parents	NA	NA	Checklist for text and opinion papers
de Andrade Alvarenga 2021	Canada (2015-2017)	7 regions of Quebec province in Canada	Secondary data analysis of interviews conducted with mothers experiencing perinatal death	HIC	Qualitative	Thematic analysis	NA	33	Stillbirth, NND, TOPFA	Bereaved mothers' experience of hope following perinatal death	NA	Women who experienced a perinatal death in the ten months preceding the interview, received services from one of the participating establishments (hospitals, birthing centres, community organisations), and were able to understand and speak French.	Checklist for qualitative research
Dekkers et al. 2019	Netherlands (2012-2015)	Rotterdam	Online questionnaire	High income	Quantitative	NA	Cross-sectional	76 women; 36 partners	Psychosocial care for TOPFA	Optimal time for psychosocial care	Women who were; treated from 2016	Cross-sectional: 76 women; 36 partners All	Checklist for analytical cross-

											onwards, not fluent in Dutch, with intellectual disabilities, undergoing another TOP at the time of research invitation, or who underwent a TOP for maternal health issues.	women and partners, who underwent a TOP-by medical treatment for fetal anomaly.	sectional studies
Denney-Koelsch et al. 2018	USA (dates not reported)	Rochester	Interviews	High income	Qualitative	Phenomenological	NA	16 women; 14 partners	Healthcare interactions during termination of pregnancy for fetal anomaly	Feeling cared for, experiencing added burden	NA	Adult women over 18 years who chose to continue their pregnancy following lethal fetal diagnosis	Checklist for qualitative research
Domogalla et al. 2022	USA (dates not reported)	Rural area, State	Face-to-face interviews	HIC	Qualitative	Descriptive phenomenological	NA	10	Stillbirth, NND	Experience of care the participants had in the hospital following the death/pregnancy loss	NA	Mothers who had experienced a pregnancy loss, SIDS death, stillbirth, infant loss (<1 year), or child loss (<5 years) where the child was diagnosed with a	Checklist for qualitative research

												terminal health concern at birth	
Due et al. 2018	Australia (2013)	South Australia	Interviews	HIC	Qualitative	Thematic analysis	NA	15	Stillbirth	Women's experiences with the healthcare system following pregnancy loss in South Australia	NA	Women aged >18 years, fluent in English, resident of South Australia at the time of their loss and have experienced at least one pregnancy loss at any stage between conception and birth. Women who had experienced multiple losses were eligible for inclusion.	Checklist for qualitative research
Farrales et al. 2020	USA (dates not reported)	Unclear	Focus groups	HIC	Qualitative	Thematic analysis	NA	27	Stillbirth	Experiences of grieving parents during their interaction with healthcare professionals during/after	NA	Participants were recruited from a cohort of bereaved parents who participated in a two-day	Checklist for qualitative research

										the stillbirth of a baby		workshop on the topic of grief after stillbirth. 19 years of age or older. Consent obtained.	
Fenstermacher 2019	USA (dates not reported)	3 inner city hospitals in Pennsylvania	Interviews at 3 time points	HIC	Qualitative	Constant comparative analysis	NA	8	Stillbirth, NND	Bereavement support needs of black urban women in late adolescence after perinatal loss	NA	Non-Hispanic, unmarried, English speaking black urban women ranging from 18 to 21 years (late adolescence) with a recent perinatal loss, with no prolonged hospital stay after their loss	Checklist for qualitative research
Fernández-Alcantara 2020	Spain (Feb – Sep 2016)	3 public hospitals in province of Granada	Interviews	HIC	Qualitative	Thematic analysis	NA	16	Stillbirth, NND, TOPFA	Experiences and practices of experienced professionals attending to perinatal loss in the hospital context in Spain	Consent withheld	Inclusion criteria for participation were (i) being a professional in a discipline (healthcare or other) regularly involved in	Checklist for qualitative research

												intervening in cases of perinatal loss and (ii) having at least 5 years of professional experience in attending to perinatal losses. Consent obtained.	
Fernández-Basanta 2021 (2)	Spain (Feb – April 2019)	10 primary healthcare centres in northern Spain	Interviews	HIC	Qualitative	Phenomenological hermeneutic approach	NA	11	Stillbirth	The experiences of primary healthcare midwives who care for parents who have suffered an involuntary pregnancy loss	NA	Primary healthcare midwife and having experience in providing care to parents who have suffered an involuntary pregnancy loss.	Checklist for qualitative research
Fernández-Basanta 2022	Spain (2020)	NA (review)	PubMed and 4 other databases	global	Qualitative	Mata-synthesis	NA	11 studies	Stillbirth	Emotional experiences of midwives and nurses when caring for parents who have suffered an involuntary pregnancy loss	NA	Original qualitative or mixed articles considered adequate for the research objective, whose the sample comprised	Checklist for systematic reviews and research syntheses

												nurses and midwives whose type of loss were miscarriages and stillbirths, were included.	
Fernandez-Medina 2022	Spain (March-May 2021)	National	Interviews	HIC	Qualitative	Hermeneutical phenomenological approach	NA	13	Stillbirth, NND	How bereaved women perceive the expression and donation of their breastmilk	TOPFA and multiple pregnancies	≥18 years at the time of perinatal loss, have experienced a stillbirth or a neonatal death in the last 5 years, and have donated their breast milk to a non-profit milk bank in Spain. Consent obtained.	Checklist for qualitative research
Ferreira Paris et al. 2021	Brazil, Canada (dates not reported)	Maringa in Southern Brazil; Gatineau in Canada	Semi-structured interviews	UMIC; HIC	Qualitative	Thematic analysis	NA	44 (26 Brazilian women, 18 Canadians)	Stillbirth	Professional care for maternal grief following stillbirth	NA	Mothers whose address was in Maringa after authorisation by the municipal health department of deaths	Checklist for qualitative research

												investigated by the mortality committee, and mothers who participated in the grief support group at Center d'Études et de Recherche en Intervention Familiale (CERIF) in Gatineau	
Fuller & Kuberska 2022	UK (2016-18)	National	Secondary data from interviews conducted as part of another study	HIC	Qualitative	Narrative analysis	NA	20 (Stillbirth=9; TOPFA= 11)	Stillbirth, TOPFA	Aspects of memorialisation present in narratives of pregnancy loss	NA	Cis-gendered women who either experienced stillbirth or who had terminated their pregnancy following a diagnosis of fetal anomaly	Checklist for qualitative research
Furtado-Eraso et al. 2021	Multiple (2020)	International literature	Literature (4 databases)	NA	Qualitative	Narrative synthesis	NA	22 studies	Stillbirth, NND	Emotional care following perinatal loss	Theoretical reports, case studies, clinical cases, and grey literature	Original research published articles between January 2015	Checklist for systematic reviews and

												and January 2020, including quantitative and qualitative studies written in either English or Spanish with the full text available	research syntheses
Garcia 2020	England (Dec 2014- March 2016)	Unclear	Interviews	HIC	Qualitative	Framework analysis	NA	6	Stillbirth, NND	Experiences of bereavement after the stillbirth of Pakistani, Bangladeshi, and White British mothers	Women who had delivered infants but earlier than the preceding six-month bereavement period, retrospective records showing bereaved infants over 24 months (to eliminate retrospective bias and inaccurate memory recall), women aged <16 years at the time of conception,	Delivered their infant in the previous 6 to 24 months, stillborn or NND within 7 days of birth, 16 years or older at conception, maternal ethnicity of Pakistani, Bangladeshi, or White British documented in their records, residing within the fixed postcode of the town.	Checklist for qualitative research

											maternal ethnicities other than Pakistani, Bangladeshi and White British, not living in the predefined postcodes.	Consent obtained.	
Gilmour et al. 2017	Australia (01/01/2012-30/06/2014)	Royal Brisbane and Women's Hospital, Brisbane, Queensland	Medical charts and death certificates	HIC	Quantitative	NA	Retrospective cohort study	46	NND	End-of-life care provided in an Australian tertiary neonatal centre, where paediatric palliative care was accessible via a consultative service	Stillborn, pre-viable infants (<400g/<23 weeks GA), aged>1 year, no opportunity for palliative care intervention	Liveborn infants, born 01/01/2012-30/06/2014, neonatal admission at the Royal Brisbane and Women's Hospital died aged ≤1 year	Checklist for studies reporting prevalence data
Gold 2017	USA (dates not reported)	Michigan State (state-wide analysis)	Postal questionnaire – participants identified by the Michigan Department of Community Health	HIC	Quantitative	NA	Cross-sectional (population-based study)	609 (n=377 bereaved mothers and n=232 with surviving infants)	Stillbirth, NND	Who communicates the loss to parents and who is present to support at the delivery or death	Women who had an infant die beyond the first month as these may have been sudden or unexpected home deaths and parental experiences	Women who experienced a stillbirth after 20 weeks of gestational age, those with a live birth but early infant death in the first 28 days	Checklist for analytical cross-sectional studies

											after these losses are different	of life and a control group of women who had a live birth and surviving child at the same time.	
González-Ramos 2021	Multiple (Nov 2019-May 2020)	International literature	Literature (4 databases)	NA	Qualitative	Scoping review	NA	34 studies	TOPFA	Emotional responses of women undergoing TOPFA	Opinion pieces and articles with teenage sample	Qualitative and quantitative studies published in English or Spanish between 2014-2020 which included first-person accounts of women's emotional responses when they had a termination.	Checklist for systematic reviews and research syntheses
Gopichandran 2018	India (dates not reported)	Tamil Nadu, primary healthcare setting (no specific hospital described)	In-depth interviews	LMIC	Qualitative	Thematic analysis	NA	10 (mothers [n=8], community health worker [n=1], hospital duty nurse [n=1])	Stillbirth	The experience of stillbirth, feelings, and emotions related to the experience, support received,	NA	Mothers who experienced stillbirth in the past 1 year (n=8)	Checklist for qualitative research

										coping strategies, social impact, impact on family and meaning attributed to the experience			
Guimarães 2019	Portugal (dates not reported)	1 level 3 NICU in Portugal	Case studies	HIC	Qualitative	Narrative	NA	2	Prenatal palliative care for severe fetal anomaly	Overview of a perinatal palliative care program following prenatal diagnosis of severe fetal anomaly at a NICU in Portugal	NA	Prenatal diagnosis of fetal anomaly	Checklist for case report studies
Hanschmidt 2018 (2)	Germany (Oct 2015-Feb 2016)	1 university hospital in Leipzig	Self-report questionnaires	HIC	Quantitative	NA	Cross-sectional	148	TOPFA	Women's help-seeking for emotional problems following an abortion after diagnosis of fetal anomaly	NA	Women who had undergone termination of pregnancy following the diagnosis of a fetal anomaly at the University Hospital Leipzig (Department of Obstetrics). Women had	Checklist for analytical cross-sectional studies

												to be at least 18 years at the time of assessment and had to have experienced their abortion after diagnosis of fetal anomaly 1–7 years earlier	
Harden 2018	USA (dates not reported)	NA	Opinion, literature	HIC	Qualitative	Narrative	NA	NA	Miscarriage, stillbirth, NND	Factors impacting grief after perinatal loss	NA	NA	Checklist for text and opinion papers
Helps et al. 2020	Ireland (2005-2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	Stillbirth, NND	Bereavement care provided to families following perinatal death/pregnancy loss as described in national inquiry reports	NA	National inquiries into perinatal deaths/pregnancy loss services between 2005-2018.	Checklist for qualitative research
Hendriks 2022	Switzerland (dates not reported)	Tertiary perinatal centre of a Swiss University Hospital	Participatory observations in the perinatal centre; interviews	HIC	Qualitative	Content analysis	NA	10	TOPFA	Communication with healthcare professionals, end-of-life decisions, and parents'	NA	Parents: Parents who had a TOPFA ≥20 weeks gestation at a tertiary perinatal	Checklist for qualitative research

										wishes and preferences during late termination of pregnancy		centre of a Swiss University Hospital one or more years before the onset of the study. healthcare professionals : Perinatal healthcare professionals working in a discipline relevant to perinatal end-of-life decision-making (i.e. midwife, nurse, obstetrician, neonatologist, clinical director) at the tertiary perinatal centre of a Swiss University Hospital	
Horey 2021	40 countries (Dec 2014-Feb 2015)	NA	Survey	HIC and MIC	Quantitative	NA	Descriptive	3041	Stillbirth	Bereavement care practices after stillbirth in high and	Stillbirth > 5y prior to completing the survey	Self-reported stillbirth ≤ 5 years prior to completing the survey	Checklist for studies reporting prevalence data

										middle-income countries			
Hutti & Limbo 2019	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND, TOPFA	Application of Hutti Perinatal Grief Intensity theoretical framework and guided participation in nursing care for bereaved families	NA	NA	Checklist for text and opinion papers
Hvidtjørn et al. 2021	Denmark (2012-2018)	A midwifery-led specialised unit for bereaved parents at Aarhus University Hospital in Denmark	Hospital electronic health records	HIC	Quantitative	NA	Descriptive cross-sectional	579	Miscarriage (>14 weeks), missed abortion (>14 weeks), termination of pregnancy (>14 weeks), stillbirth, NND	Clinical characteristics of women admitted to a specialised unit for bereaved parents and characteristics of women who stayed more than 2 days	NA	All women at Aarhus University Hospital who experienced spontaneous pregnancy loss after 14 weeks gestation, TOPFA, intrauterine death, or intrapartum death between 1 January 2012, and 31 December 2018. Women who experienced	Checklist for studies reporting prevalence data

												the death of a newborn in the NICU within the first 48 hours after birth and desired a stay in the unit were also included.	
Ireland et al. 2019	Australia (dates not reported)	Townsville Hospital NICU	Interviews	HIC	Qualitative	Grounded theory	NA	17 families representing 21 extremely preterm babies and one baby with congenital malformatio ns	NND	Experiences of parents of critically ill newborns who were cared for in a regional tertiary neonatal unit	NA	Extreme prematurity or complex antenatal surgical diagnosis, family's resident in the North Queensland area at the time of admission, fluent in English, and delivered between 2010 and 2015	Checklist for qualitative research
Jones 2017 (2)	Multiple (dates not reported)	International literature	Literature	NA	Qualitative	Meta-synthesis	NA	10 studies (581 women)	TOPFA	Women's experiences of labour and birth when having a TOPFA in the second	Previously published literature reviews and systematic reviews	English language qualitative articles that were original research studies and published	Checklist for systematic reviews and research syntheses

										trimester of pregnancy		between 1996-2016, that were peer-reviewed and had full text available to view.	
Jones et al. 2019	Western countries (2000-2019)	Mixed	Data from previous studies of men's grief	HIC	Qualitative	Scoping review	NA	27 studies	Stillbirth and NND	Impact of perinatal death for men, the meaning of loss and father's identity, the extent to which men were able to express grief, and how grief was mediated by the support of health professionals	Studies before 2000; studies from countries with likely substantial cultural, religious, and healthcare differences; studies which exclusively looked at miscarriage, fetal loss before 24 weeks, lethal fetal abnormalities, and SIDS.	Studies from 2000 exploring parental experiences of perinatal death and healthcare support following	Checklist for systematic reviews and research syntheses
Kalanlar 2020	Turkey (dates not reported)	49 hospitals across Ankara, Istanbul, and Izmir	Postal questionnaires	UMIC	Quantitative	NA	Cross-sectional study	29	Perinatal death including stillbirth and neonatal death.	Managers, head physicians, head nurses, midwives, and specialist physicians caring for families	Dialysis, in vitro fertilisation, medical, physical therapy, and rehabilitation centres. Hospitals	Purposive sampling to select provinces with the highest number of hospitals.	Checklist for analytical cross-sectional studies

										following perinatal death	which were shut down did not agree to take part, and did not have a maternity service were filtered out		
Kamranpour 2019	Iran (2017-2018)	State, Rasht, Iran health centres	In-depth semi-structured interviews	UMIC	Qualitative	Content analysis	NA	42	TOPFA	Parents' feelings around TOPFA and what needs they had after	No diagnosed psychological disorders	At least 1 year after termination	Checklist for qualitative research
Kamranpour 2021	Iran (Oct 2017-Apr 2018)	Health centres of Rasht city, Iran	Interviews, field notes	LMIC	Qualitative	Content analysis	NA	40 (25 women, 2 spouses and 13 healthcare professionals)	TOPFA	Informational and educational needs of women who have experienced TOPFA	NA	Women who had experienced pregnancy termination because of fetal anomalies, having the ability to understand the questions and transfer experiences and views, having passed at least 1 year from the pregnancy termination	Checklist for qualitative research

												incident and not having any known psychological diseases; their spouses and healthcare professionals including forensic medicine specialists, gynaecologists, perinatologist, psychologist, reproductive health specialists, midwives, and nurse	
Kennedy 2017	UK (dates not reported)	Global	Published literature, blogs, charity websites, online news articles, and milk bank websites	HIC	Qualitative	Narrative review	NA	NA	Stillbirth, NND	Experience of bereaved mothers regarding milk donation following perinatal loss	NA	NA	Checklist for text and opinion papers

Kerns 2018	USA (2009-2013)	2 academic centres – TheUniversity of California, The University of Michigan	Interviews	HIC	Qualitative	Modified grounded theory	NA	36	TOPFA	Women's experiences of being counselled about the diagnosis and options for termination the setting of fetal anomalies and pregnancy complications, factors associated with making their decision, how they experienced their decision process	NA	Women undergoing termination of pregnancy at the University of California and the University of Michigan were eligible for the study if they were between 14- and 24-weeks' gestational age, over 18 years of age, and English speaking.	Checklist for qualitative research
Kilcullen 2020	Australia (2005-2015)	Townsville Hospital	Semi-structured interviews with women	HIC	Qualitative	Thematic analysis	NA	5	Stillbirth	Aboriginal and Torres Strait Islander women's decisions to consent for autopsy after stillbirth	Women with active mental health difficulties	Aboriginal and Torres Strait Islander women who experienced stillbirth between 2005-2015	Checklist for qualitative research
King et al. 2021	USA (dates not reported)	National	Interviews	HIC	Qualitative	IPA	NA	8 couples (16 individuals)	Stillbirth	Experience of stillbirth and their hospital encounter for couples	NA	Intact couples, 18 years or older at the time of stillbirth,	Checklist for qualitative research

												married for at least 6 months at the time of stillbirth, biological parents of the stillborn, English-speaking, within 10 years of the stillbirth, and able to take part in the interview together	
Knighting 2019	UK (2012-2015)	1 children's hospital in the UK	Pre-post questionnaires, interviews	UK	Mixed methods	Thematic analysis	Pre- and post-intervention	70 for quantitative component; 4 for interviews	NND	Evaluation of a palliative care education workshop	NA	Staff from neonatal units in the 9 hospitals of the Neonatal Clinical Network and other appropriate professionals working across the area including those from thechildren's hospices who attended the workshop	Checklist for qualitative research Checklist for quasi-experimental studies [h]

Lafarge 2017	England (May-July 2013)	3 Hospitals	Interviews	HIC	Qualitative	Inductive and deductive thematic analysis	NA	15 Healthcare professionals	TOPFA	Healthcare professionals' perceptions of women's coping with TOPFA and to what extent these perceptions are congruent with women's accounts.	Consent withheld.	Healthcare professionals involved in the pregnancy management of women in three hospitals in England. Women >18 years old who had had a TOPFA, were recruited through a support organisation for parents who face/undergo TOPFA. Data from 27 interviews with women reported elsewhere.	Checklist for qualitative research
Lafarge et al. 2022	France (May 2015-May 2017)	Unclear	Interviews	HIC	Qualitative	IPA	NA	8	Prenatal diagnosis of fetal anomaly, NND	Women's experiences of their interactions with practitioners when severe abnormalities are	NA	Women born with a baby with a severe abnormality discovered at birth or with an abnormality more severe	Checklist for qualitative research

										discovered at birth		than anticipated	
Lappeman 2022	South Africa (2018-2019)	One hospital located in an impoverished area	Interviews	LMIC	Qualitative	Thematic analysis	NA	10	Stillbirth	Women's experience of hospital care following stillbirth	Women <18; who drank medication or self-harmed to terminate the pregnancy; abused substances; had families working in the labour ward of the hospital	Mothers experiencing stillbirth at the hospital between January and August 2018	Checklist for qualitative research
LeDuff III 2017	Multiple (dates not reported)	Global	Literature (4 databases)	NA	Qualitative	Literature review	NA	NA	Miscarriage, Stillbirth, NND	Role of transitional objects to facilitate grieving following perinatal loss	NA	Full-text English language articles published between 2011-2016	Checklist for text and opinion papers
Leitao 2021	Ireland (2019-2020)	National for the pilot workshop; 3 maternity units for the second workshop	Paper feedback questionnaires completed after the two program workshops	HIC	Quantitative	NA	Descriptive	36 for the first workshop; 47 for the second workshop	Stillbirth, NND, TOPFA	Evaluation of a perinatal bereavement care training program for healthcare professionals	NA	Healthcare professionals participating in the training workshops	Checklist for studies reporting prevalence data
Lewis 2019	UK (2016-2017)	National	Cross-sectional survey, interviews, focus groups	HIC	Qualitative	Thematic analysis	NA	439 free-text responses, 20 parent interviews, 25	Miscarriage, Stillbirth, NND, TOPFA, Infant death	Parental decision making about postmortem	NA	Bereaved parents-including pregnancy loss, neonatal or	Checklist for qualitative research

								healthcare professionals				infant death, HCPs from a range of clinical backgrounds involved in discussing or conducting postmortem examinations with parents	
Lin 2021 (2)	Taiwan (dates not reported)	One regional teaching hospital in northern Taiwan	Reflective group sessions	HIC	Qualitative	Thematic analysis	NA	10 nurses participating in 8 group sessions	Stillbirth	Nurses' experiences of labour of a stillborn baby	NA	Nurses with direct stillbirth nursing care experience in one hospital in Taiwan	Checklist for qualitative research
Littlemore 2020	UK (dates not reported)	NHS Hospitals	Hospital documentation, interviews, and focus groups	HIC	Qualitative	Content analysis and linguistic analysis	NA	83 (27 bereavement care providers, 16 workers at support agencies, 30 interviews with women, 10 women and partners for focus groups)	Pregnancy loss (miscarriage, stillbirth, TOPFA)	Choices about disposal of baby's remains; how choices are communicated by healthcare professionals to parents	NA	Bereavement care providers, paid and volunteer workers at support agencies, women experiencing pregnancy loss and partners	Checklist for qualitative research
Littlemore & Turner 2019	UK (2016-18)	National	Interviews	HIC	Qualitative	Metaphor analysis and content analysis	NA	35 bereaved individuals (31 women, 3 partners, 1 friend); 18 healthcare professionals	Miscarriage, Stillbirth, TOPFA	Metaphors used by people when talking about their past experiences	NA	Women who had experienced miscarriage, TOPFA, or stillbirth in England a	Checklist for qualitative research

										of pregnancy loss		minimum of 6 months before the interview, their partners, and friends; bereavement healthcare professionals who worked with bereaved parents	
Lockton 2021	Australia (dates not reported)	National	Interviews	HIC	Qualitative	Thematic analysis	NA	10	Stillbirth, NND, TOPFA	Grandfathers' experiences of grief and support following the loss of a grandchild in pregnancy or the neonatal period	NA	Australian grandfathers, fluent in English, whose child/ren had experienced a pregnancy loss or neonatal death between 6 months and 5 years previously	Checklist for qualitative research
Lockton 2021 (2)	Australia (dates not reported)	National	Interviews	HIC	Qualitative	Thematic analysis	NA	14	Stillbirth, TOPFA, Miscarriage	Grandmothers' experiences of grief and support following a child's pregnancy loss	NA	Australian grandmothers whose son or daughter had experienced a pregnancy loss between six months	Checklist for qualitative research

												and five years prior	
Lou 2021	Denmark (Feb 2016-July 2017)	University and regional hospitals in the Central Denmark region	Explorative semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	21 couples (of 24 recruited)	TOPFA	Ways that women/couples articulated their relation to the fetus/child following a termination of pregnancy due to antenatal diagnosis of Down syndrome	NA	Women/couples who had recently terminated a wanted pregnancy	Checklist for qualitative research
Martel 2018	Canada (dates not reported)	Level 3/4 NICU	One focus group and one semi-structured interview	HIC	Qualitative	IPA	NA	6 nurses (focus group); 1 semi-structured interview	NND	Neonatal nurses' experiences with end-of-life photography	NA	Neonatal nurses- Inclusion in the study required participants to have worked in the NICU for at least two years and to have taken end-of-life photos at least twice preceding the interview.	Checklist for qualitative research
Martin-Ancel 2022	Spain (dates not reported)	National	Literature	HIC	Qualitative	Narrative review	NA	NA	Stillbirth, NND, TOPFA	Guidelines for perinatal	NA	Characteristics of palliative	Checklist for

										palliative care		care for perinatal life limiting and life-threatening diseases	qualitative research
Martínez-Serrano et al. 2018	Spain (Feb 2012-March 2014)	10 public hospitals; 1 primary health centre	Three focus groups	HIC	Qualitative	Hermeneutic phenomenological analysis	NA	18 midwives	Stillbirth	Experiences of midwives regarding attention given during labour in late fetal death	Any midwives who had undergone a similar event either personally, or within their immediate family, were excluded	Midwives having experience in attending cases of late fetal death	Checklist for qualitative research
Martínez-Serrano et al. 2019	Spain (2012-2017)	1 hospital and local pregnancy loss support organisation	Interviews	HIC	Qualitative	Thematic analysis	NA	11 parents (7 mothers, 4 fathers)	Stillbirth	Mothers' and fathers' experience of care received during delivery in cases of stillbirth	Those with psychological functional impairment and not fluent in Spanish?	Women and men over 18 years of age, who during a monitored low obstetric and neonatal risk pregnancy were attended for labour after stillbirth, through a vaginal birth.	Checklist for qualitative research
McNeil 2020	Multiple (Dec 2019)	International	Literature	LMICs	Qualitative	Narrative review	NA	11 papers	Stillbirth, NND	Grief and bereavement support for parents after	NA	Articles were included if they specifically evaluated	Checklist for systematic reviews and

										the death of a child		the bereavement experience of parents after the death of a child in a LMIC	research syntheses
Mendes et al. 2017	Multiple (Jan-June 2015)	International	Web data from perinatalhospice.org (comments from parent advocates, clinicians, and researchers)	NA	Qualitative	Content analysis	NA	Unclear	Perinatal palliative care	Ethical considerations in perinatal palliative care	NA	Comments around ethical considerations in perinatal palliative care by members of the private listserv of the international website perinatalhospice.org	Checklist for qualitative research
Metz 2020	Multiple (dates not reported)	International literature	Review of the literature	NA	Qualitative	Narrative review	NA	NA	Stillbirth	Management, evaluation, and strategies for prevention of stillbirth	NA	Risk factors, potential causes, and clinical considerations in the management of stillbirth	Checklist for text and opinion papers
Meunier 2021	Multiple (2018)	International	Literature (eight databases)	NA	Qualitative	Scoping review	NA	15 papers	Stillbirth, NND	Experience of workers coping with perinatal loss	NA	1) studies using a qualitative or quantitative design; 2) written in English or	Checklist for systematic reviews and research syntheses

												French; 3) addressing both perinatal loss and the experience at work of fathers and/or mothers.	
Meyer 2018	Ghana (2012)	One hospital in Kumasi, Ghana	Semi-structured Interviews	LMIC	Qualitative	Thematic analysis	NA	8	NND	Experience of infant loss for bereaved mothers in Ghana	Mothers from the larger study for whom contact information or phone access was not available, lived more than 2 hours away from the hospital, were unreachable by phone (number disconnected, wrong number, no answer), and those who denied having received care at the hospital	Mothers who were 18 or older, spoke English or Twi, lost a baby since participating in the larger study a year ago, lived within 2 hours of the hospital, and could be reached by phone agreed to be interviewed	Checklist for qualitative research

Mills 2021	Kenya and Uganda (July 2017-May 2019)	5 facilities in Nairobi and Western Kenya, Kampala, and Central Uganda	Interviews	LIC, LMIC	Qualitative	Thematic analysis	NA	75 women, 59 men	Stillbirth	Parents' experience of care and support after stillbirth	NA	Women and men over 18 years of age who had experienced the stillbirth of their baby (≤1 year previously) and received care in the included facilities.	Checklist for qualitative research
Milton 2021	Nigeria (Jan 2019)	One tertiary hospital (Murtala Muhammad Specialist Hospital) in Kano, Northern Nigeria	Focus group discussions	Lower-middle income	Qualitative	Inductive thematic analysis	NA	31	Stillbirth	Stillbirth perceptions and experiences of Nigerian mothers	Women who had experienced stillbirth in their most recent pregnancy were excluded based on sensitivity.	Mothers with and without previous experience of stillbirth, who had given birth to a liveborn baby at Murtala Muhammad Specialist Hospital in 6 months prior to the study were included.	Checklist for qualitative research
Mondanaro 2021	USA (dates not reported)	New York; Mount Sinai Beth Israel Hospital	Opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, TOPFA	Choice and effect of popular music within a clinical music therapy approach to	NA	NA	Checklist for text and opinion papers

										the curation of a perinatal bereavement event within a large hospital system in a metropolitan area			
Moreira Schmalfuss 2019	Brazil (dates not reported)	NA	Opinion; literature	UMIC	Qualitative	Narrative	NA	NA	Stillbirth	Limitations of nursing care for women with fetal death	NA	NA	Checklist for text and opinion papers
Musodza 2021	Australia (dates not reported)	UK, Australia, Sweden, USA)	Scoping review (OVID, EBSCO host, Google Scholar, Research Direct Western Sydney University, Research Gate and Google)	HIC	Qualitative (scoping review)	Scoping review, thematic analysis	NA	10	Stillbirth	The experiences of female maternity healthcare professionals when they return to work following a personal pregnancy loss or neonatal death	Papers which set out to address the experiences of healthcare professionals not working in maternity units (e.g., sonographers), or healthcare professionals still in training (e.g., student midwives). Other exclusions were blog entries, articles in non-professional	Papers written in English were directly related to the research question: "What are the experiences of maternity healthcare professionals who work in a maternity setting when they return to work following a personal pregnancy loss or perinatal loss". Grey	Checklist for systematic reviews and research syntheses

											journals, magazines or websites, and papers not written in English.	literature was also included, such as personal stories, videos, and book chapters	
Nguyen 2019	Australia (published during or after 2000)	Australia, Switzerland, USA. Sweden, South Africa, Israel, Ireland,	Scoping review (Medline (Ovid), PsychINFO (Ovid), CINAHL (EBSCO), and Families and Societies (EBSCO)	HIC	Qualitative (scoping review)	Thematic analysis	NA	100	Stillbirth and NND	Lived experiences of men whose partner has experienced a stillbirth or miscarriage	Men whose partner has experienced a neonatal death, undergone a voluntary abortion, Studies where qualitative data do not distinguish between type of pregnancy loss, articles in languages other than English with no sufficient translation, secondary analysis of primary data, review of the literature, Book chapters,	Men of any age or country whose partner has experienced a miscarriage or stillbirth, Focus on miscarriage, stillbirth and neonatal death but analysed data separately, focus on the experiences of men in relation to miscarriages or stillbirth. This can be told by men themselves, their partners, family members or	Checklist for systematic reviews and research syntheses

						theses/dissertations, Quantitative studies or mixed design studies, Studies conducted before 2000	health professionals, The sample included experiences of men and women but analysed data separately, Articles in English or with sufficient translation, collected primary data on the experiences of men or personal recollections from the author, Journal articles, industry reports, grey literature conducted after 2000

Noble-Carr 2022	Australia (November 2019-April 2020)	Three tertiary hospitals in three eastern Australian states and territories	Semi-structured in-depth interviews (hour-long semi-structured interview, or a written survey of approximately 15 open-ended questions).	HIC	Qualitative	Thematic analysis	NA	7	Stillbirth and NND	Whether the support role that fathers often assume in relation to infant bereavement and infant feeding remains consistent in the context of bereavement and bereaved lactation care and will highlight if the specific needs of non-birthing parents are being considered	NA	Potential non-birthing parent participants were identified via interviews with bereaved mothers, who at the end of their interview, agreed to provide their partner with an invitation pack, including participant information and consent forms.	Checklist for qualitative research
Noble-Carr 2021	Australia (2019)	3 large tertiary hospitals located in 3 Eastern states and territories	Interviews and focus groups	HIC	Qualitative	Thematic and interactional analysis	NA	113	Stillbirth, NND	Factors that shape the delivery of hospital-based lactation care for bereaved mothers	NA	Professionals most likely to interface with bereaved families after stillbirth and infant death, and who may be called upon to offer lactation care. These	Checklist for qualitative research

												included obstetricians, neonatologists, midwives, neonatal nurses, lactation consultants, social workers or pastoral care workers, HMB staff, and specialist perinatal bereavement nurses.	
Nurse-Clarke 2019	USA (dates not reported)	One urban medical centre	Qualitative in-depth interview data	HIC	Qualitative	Content analysis	NA	20	Stillbirth	Application of tenets of Swanson's theory of caring in practice by labour and delivery nurses when caring for women with stillbirth	NA	Secondary analysis of interviews conducted with labour and delivery nurses with experience caring for mothers who had a stillbirth	Checklist for qualitative research
Nuzum et al. 2018	Ireland (2008-2013)	One tertiary university maternity hospital	Semi-structured interviews with mothers and fathers who experienced stillbirth	HIC	Qualitative	Interpretative Phenomenological Analysis	NA	17	Stillbirth	Comparison of lived experiences of bereaved parents with an expected or unexpected stillbirth,	NA	Parents who received a diagnosis in utero that their baby had a life-limiting condition and was	Checklist for qualitative research

										under the themes of maintaining hope, the importance of personhood, protective care, and relationships		unlikely to survive OR parents who experienced anunexpected stillbirth	
Nuzum 2017	Ireland (2008-2013)	1 tertiary maternity hospital	Interviews	HIC	Qualitative	IPA	NA	17 parents (12 mothers, 5 fathers)	Stillbirth	Communication of bad news to parents following a diagnosis of stillbirth	NA	Parents of babies who had received a diagnosis of stillbirth were purposively sampled from three years -2008, 2010, and 2013	Checklist for qualitative research
Obst 2021 (3)	Australia (2017)	National/Australia	Semi-structured interviews	HIC	Qualitative	Thematic Analysis	NA	n=7	Stillbirth	Healthcare professionals' experiences supporting men following stillbirth and their views on current support and options for future support	NA	Over 18, fluent in English, healthcare professionals with experience providing formal care or grief support to men who have experienced a pregnancy	Checklist for qualitative research

												loss, in the last 5 years	
Obst 2019	Australia (2017)	State (South Australia)	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	n=8	Stillbirth	Men's experience with grief, and their perceptions of supports available	NA	Men whose female partners had recently experienced a pregnancy loss	Checklist for qualitative research
Obst 2021	Australia (Oct 2019-March 2020)	National	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	10	TOPFA	To explore men's experiences and needs for support following TOPFA	NA	Heterosexual men over 18 years of age who experienced TOPFA with a female partner between 6 months and 11 years ago	Checklist for qualitative research
Obst 2020	Multiple (1998-2018)	International	4 databases; Qualitative, quantitative or mixed methods studies with data on men's grief or predictors of grief following a pregnancy or neonatal loss	NA	Qualitative	Narrative synthesis	NA	46 studies	Stillbirth/neonatal death	Primary data on men's grief and/or predictors of grief after a pregnancy loss or neonatal death;	Articles not published in English, abstracts, editorials, opinion pieces, discussion, or review articles or those with no primary data; studies using a comparator	Qualitative, quantitative, or mixed methods studies published from 1998 to October 2018 with primary results of men's grief following pregnancy or neonatal loss	Checklist for systematic reviews and research syntheses

											that didn't present men's data separately; studies investigating grief after termination for viable fetal anomaly or elective abortion.		
Obst 2021 (2)	Australia (2000–2021)	National	Web-based survey	HIC	Quantitative	NA	Cross-sectional	n=228	Stillbirth, NND, TOPFA	Development of a model to quantify men's grief and find factors associated with grief intensity; participant characteristics, Paternal Antenatal Attachment Scale, Perinatal Grief Scale-33, Grief Patterns Inventory-Revised, Crisis Support Scale, Conformity	NA	18 or older with an experience of pregnancy loss or neonatal death in Australia within the last 20 years,	Checklist for analytical cross-sectional studies

										to Masculine Norms Inventory, and Male Role Norms Inventory-Short Form.			
O'Connell 2019	Ireland (2017)	1 maternity teaching hospital	Semi-structured interviews	HIC	Qualitative	IPA	NA	4	Prenatal diagnosis of anomaly	Lived experience of mothers who continued with their pregnancies after prenatal diagnosis of anencephaly	NA	Mothers, whose babies were diagnosed with anencephaly antenatally and chose to continue with the pregnancy; mothers were more than one year post bereavement and were not pregnant at the time of the interviews	Checklist for qualitative research
Ogunbanjo 2020	England (Feb-Apr 2019)	Hospital (NHS foundation trust)	Focus groups, interviews	HIC	Qualitative	Thematic analysis	NA	Focus group 1 n=6, focus group 2 n=4; Interviews n=2	Stillbirth, NND, SIDS	How health visitors perceive their support role to parents after a stillbirth or neonatal death	NA	Health visitors within the trust	Checklist for qualitative research

Paize 2020	UK (Jan 2010-Dec 2015)	Liverpool Women's Hospital	Postal survey	HIC	Mixed methods	Content analysis	Descriptive statistics (%s)	26	NND	Parents' experience of end of life and bereavement care in the NICU	NA	Parents whose baby died in the neonatal unit of the Liverpool Women's Hospital between Jan 2010-Dec 2015	Checklist for qualitative research
Paraíso Pueyo 2021	Multiple (2018-2019)	International literature	Literature (4 databases)	HIC	Qualitative	Scoping review	NA	9 papers	NND	Nursing interventions to help parents of neonates admitted to neonatal intensive care units cope with perinatal loss	Studies relating to stillbirth, TOP for non-medical reasons, miscarriage	Studies published between 2000-2019 that included mothers and/or fathers and/or the immediate family who have experienced the death of an infant in the perinatal period in a NICU. Papers written in Spanish whose title and abstract had also been written in English.	Checklist for systematic reviews and research syntheses

Pereira 2018	Brazil (Jul 2012-Jul 2014)	One city in Northeast Brazil	Semi-structured interviews	UMIC	Qualitative	Thematic analysis	NA	15	NND	Communication of a child's death and grief support provided to women who lost a newborn	Women with mental impairment	Mother living in the city of São Luís who lost a child at gestational age equal to or higher than 32 weeks, and weight at birth equal to or higher than 2500 g.	Checklist for qualitative research
Popoola 2022 (2)	Nigeria (2017)	Saki	Semi-structured interviews	LMIC	Qualitative	Thematic analysis	NA	20	Stillbirth	Nigerian women's experiences of grief after stillbirth	Women who were pregnant at the time of recruitment	To be eligible for study participation, the participant must be a Yoruba living in Saki, and at least 6 months must have passed since stillbirth to minimise causing distress	Checklist for qualitative research
Popoola 2021	Nigeria (2017)	Saki	Interviews, social network diagrams	LMIC	Qualitative	Thematic analysis	NA	20	Stillbirth	Social networks of women who have experienced a stillbirth in Nigeria and the factors influencing	None mentioned	Women who experienced a stillbirth was more than six months but less than three years ago	Checklist for qualitative research

										their social networks			
Punches 2019	USA (June 2016-Jan 2017)	2 Midwestern US hospitals	Interviews	HIC	Qualitative	Thematic analysis	NA	8	Stillbirth	Women's experiences of pregnancy loss in the ED	Limited English or Spanish proficiency, cognitive impairment as identified by the ED physician, induced abortion, history of invasive fertility treatments, history of more than two pregnancy losses, and risk for depression	Women between 18 and 45 years, diagnosed in the ED with a confirmed pregnancy loss, and discharged home to self-care from the ED.	Checklist for qualitative research
Randolph 2021	United States (dates not reported)	Upper Midwest region community	Women who had experienced pregnancy loss	HIC	Qualitative	Face-to-face semi-structured interviews	NA	10 women	Stillbirth	Women's experiences with pregnancy loss and grief	No current diagnosis of major depressive disorder, or persistent grief disorder	Women at least 12 months after a pregnancy loss	Checklist for qualitative research
Ratislavova 2020	Czech Republic (2015-2017)	National (within hospitals)	Pre- and post-course surveys	UMIC	Quantitative	NA	Pre-post study	200	Stillbirth/NND	Improvement in medical professionals scores after completion of the course,	NA	Medical professionals or others who completed the PLC course and	Checklist for studies reporting prevalence data

										learning objectives included understanding the process after perinatal loss, communication, plans for care and education of parents, and grief		agreed to complete pre and post course evaluations	
Ravaldi 2018	Italy (2009-2015)	National (11 hospitals)	Hardcopy survey questionnaire	HIC	Quantitative	NA	Cross-sectional study	674	Stillbirth	Current practices of healthcare professionals caring for women experiencing a stillbirth and to explore their training needs	NA	Practising midwives, obstetricians, nurses, and psychologists of the Obstetrics and Gynaecology wards in 11 Italian hospitals	Checklist for analytical cross-sectional studies
Razeq 2018	Jordan (April-Oct 2015)	NICUs of two major hospitals in Amman, Jordan	Semi-structured interviews	UMIC	Qualitative	Thematic analysis	NA	12	NND	Mothers' experience of losing a newborn infant at a NICU	Mothers living outside Amman	Mothers whose neonates died after being admitted to the NICUs for at least 24 hours	Checklist for qualitative research
Redshaw & Henderson 2018	UK (2013)	National	Structured questionnaire including	HIC	Mixed methods	Thematic analysis	Retrospective cohort	472 for quantitative component	Stillbirth	Disadvantaged women's experience	NA	Women aged 16 years and over who	Checklist for

			open text responses					(366 women in less deprived quintiles, 106 women in most deprived quintiles); 78 for qualitative component		of care after stillbirth		registered a stillbirth or neonatal death between January and March 2012 or between June and August 2012 in England	qualitative research Checklist for cohort studies
Redshaw 2018	England (2012-2013)	National	Questionnaire	HIC	Quantitative	NA	Descriptive	249	NND	Experience of women whose baby died in the neonatal period of their care in the perinatal period, on delivery suite, and in the neonatal unit, and how this relates to the gestational age at which their baby was born	NA	Women aged ≥16 years in England who registered a neonatal death between Jan-March 2012 or June – Aug 2012	Checklist for analytical cross-sectional studies
Redshaw 2021	England (dates not reported)	National	Questionnaires	HIC	Qualitative	Thematic analysis	NA	249	NND	Experience of women whose baby died in the neonatal period of their care in the perinatal	NA	Women aged ≥16 years in England who registered a stillbirth or neonatal death in two	Checklist for qualitative research

										period, on delivery suite, in the neonatal unit and afterwards.		3-month periods	
Rich 2018	US (dates not reported)	NA	Literature; Opinion	NA	Qualitative	Narrative review	NA	NA	Stillbirth/NND	Integration of findings from prominent theory to build an evidence-based framework for patient care after perinatal loss	NA	NA	Checklist for text and opinion papers
Rocio Guzman 2018	US (dates not reported)	Hospital	Interviews with staff, observation of parents bereavement support group, review of existing protocols	HIC	Qualitative	Program evaluation	NA	NA	Stillbirth, NND	Staff and parents' experiences of neonatal bereavement , staff experience of an education lesson on bereavement care	NA	NICU nurses caring for bereaved mothers and Mothers whose infants passed away	Checklist for qualitative research
Sénéchal 2022	Canada (2018)	Tertiary hospital specialising in maternal and fetal health	Medical records	HIC	Quantitative	NA	Retrospective case series	151	TOPFA	Evaluation of the counselling and TOPFA process and bereavement of women following	NA	Women who underwent TOPFA at the study centre (a tertiary Canadian hospital specialising	Checklist for case series studies [i]

										TOPFA at a tertiary Canadian hospital specialising in maternal and fetal health		in maternal and fetal health) in 2018	
Shakespeare 2020	Global (September 2017 – October 2018)	26 countries	Systematic reviews, meetings & online surveys	NA	Mixed methods (policy-Delphi methodology)	Thematic analysis	Descriptive (Likert scale)	Round 1 n = 23 Round 2 n = 19 Round 3 n = 236 Round 4 n = 30 Round 5 n = 143	Bereavement care after stillbirth	Global consensus on a set of feasible and evidence-based core principles for best practice bereavement care after stillbirth	NA	International clinical and academic experts and healthcare workers with experience in providing bereavement care	Checklist for qualitative research Checklist for analytical cross-sectional studies
Shakespeare 2019	Multiple (2017)	International	Literature (6 databases)	LMIC	Mixed methods	Narrative synthesis	Meta-analysis	34 studies across 17 countries	Stillbirth	Parents' and healthcare professionals' experiences of care after stillbirth in LMIC	Studies explicitly addressing miscarriage, fetal anomaly, and neonatal death alone were excluded. Review articles, opinion pieces, and books were excluded.	Qualitative, quantitative, and mixed method studies that addressed parents' or healthcare professionals' experience of care after stillbirth in LMIC	Checklist for systematic reviews and research syntheses

Sharma 2022	India (2020)	National	Online survey	LMIC	Quantitative	NA	Descriptive cross-sectional	281	Stillbirth	Experience, views, and practices of healthcare professionals while managing women with stillbirths	NA	Healthcare professionals including medical officers, physicians, nursing officers, and obstetricians & gynaecologists	Checklist for studies reporting prevalence data
Sheehy 2022	UTS, Sydney, Australia (June 2021)	NSW	In-depth interviews	HIC	Qualitative	Thematic analysis	NA	15 midwives	Perinatal loss	Early career midwives' experiences of clinical encounters of perinatal grief, loss, and trauma	NA	Midwives who had undertaken their pre-registration education and had commenced working as a registered midwife in Australia and were within their first five years of practice, were eligible to participate.	Checklist for qualitative research
Shen et al. 2022	China (Oct 2020-March 2021)	One medical university in Guangzhou, China	Semi-structured interviews	UMIC	Qualitative	Thematic content analysis	NA	12	Stillbirth, NND, TOPFA	Experiences of undergraduate midwifery students	Students with no experience in caring for	Full-time midwifery undergraduate students who were	Checklist for qualitative research

										facing perinatal death during their internship	women with perinatal loss	interning in delivery wards	
Shorey et al. 2017	Multiple (2016)	International	Literature (12 databases)	NA	Qualitative	Scoping review	NA	30 papers	Stillbirth, NND	Impact of perinatal death on the perspectives of healthcare professionals working in maternity units	Neonatal death beyond one month of the baby's age and studies examining the experiences of neonatal intensive care units' staff (doctors, nurses, and midwives) without specifying the age of neonate death, which could include up to a year after baby is born, were excluded from this review.	The Inclusion criteria for the articles were: 1) exploring the experiences and needs of healthcare professionals (either nurses, doctors, and midwives separately or all in one study); 2) perinatal death including fetal death from week 20 onwards or neonatal death within a month after the birth of the baby; and 3) maternity units, including obstetrics and	Checklist for systematic reviews and research syntheses

												gynaecological settings.	
Siassakos et al. 2018	UK (2013)	Three maternity hospitals	Interviews, focus groups, service provision data	HIC	Qualitative	Thematic analysis	NA	Parents of 16 stillborn babies, 22 maternity staff	Stillbirth	Views of bereaved parents and maternity staff to improve bereavement care for families	Twin pregnancy and loss, intrapartum stillbirth	Parents with a stillborn baby (gestational age more than 23 weeks, 6 days)- singleton stillbirths with the fetal death diagnosed before the onset of labour, maternity staff	Checklist for qualitative research
Silverio 2021	UK (Nov-Dec 2020)	National	Interviews	HIC	Qualitative	Template analysis	NA	24	Late miscarriage–- 14 to 23+6 week'' gestation (n=5), Stillbirth (n=16), NND (n=3)	Bereaved parent'' experience of care during the COVID-19 pandemic	NA	Parents who experienced a late miscarriage, stillbirth or NND during the COVID-19 pandemic	Checklist for qualitative research

Smith 2021	USA (Aug 2018–-Jan 2019)	3 private online support groups	Online survey	HIC	Quantitative	NA	Cross-sectional study	124	TOPFA	Factors that lead to women to accept or decline genetic counselling prior to TOPFA; The impact of genetic counselling on wome''s coping mechanisms and grief following TOPFA, assessed with the brief COPE survey and short version of the PGS.	Participants who were unsure as to whether they saw a genetic counsellor prior to TFA, and/or did not complete the COPE and/or PGS surveys.	English-speaking women who had undergone a TFA within the last 10 years in the United States and were at least 18 years of age at that time, recruited through three private online support groups.	Checklist for analytical cross-sectional studies
Smith & Dickens et al. 2020	UK (Sept 2016-Aug 2017)	Two parent support organisations, 4 clinical sites	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	38 (10 couples, 18 mothers)	Miscarriage, stillbirth, NND, TOPFA	Parents' healthcare experiences before, during, and after their baby's death between 20 and 23+6 weeks of gestation	NA	Parents whose baby died before, during, or shortly after birth at 20+0 to 23+6 weeks of gestation.	Checklist for qualitative research

Smith 2020	UK (dates not reported)	3 hospital settings in South West of England	Interviews	HIC	Qualitative	Cross-sectional qualitative study; Thematic analysis	NA	33	Stillbirth, NND	Experiences and perceptions of healthcare professionals of using a cold cot following the loss of a paper	NA	NICU and CDS staff who have had the experience of caring for bereaved parents. A maximum variation sampling in terms of participants' disciplines (i.e., medical, nursing, midwifery, chaplaincy) was also attempted to represent differing perspectives in bereavement care provision.	Checklist for qualitative research
Sorce 2019	US (dates not reported)	One hospital	Pre-post questionnaires	HIC	Quantitative	NA	Pre-test, post-test evaluation	54	Stillbirth, NND	Evaluation of an education session for perinatal nurses using standardised patients and role play during perinatal bereavement	NA	Nurses in the study institution	Checklist for quasi-experimental studies

Sriarporn 2017	Thailand (July 2012-December 2012)	Chiang Mai, Thailand	Interview questionnaire (demographic and obstetric & GQWPT	UMIC	Quantitative	NA	Pre-test, post-test	30	TOPFA	Effects of an informational and emotional support program for Thai women suffering from grief after TOP.	NA	(i) being at least 18 years of age; (ii) agreeing to participate in the study; (iii) having intended to have a baby; (iv) having had no prior abortions; and (v) lacking any active psychiatric problems that could confound expressions of grief.	Checklist for analytical cross-sectional studies
Stacey 2021	UK (2019-2020	4 NHS trust districts	Interviews	HIC	Qualitative	verbatim and thematic analysis	NA	30 women	Stillbirth (30)	Women's views on how to develop culturally appropriate interventions to deliver key messages around stillbirth prevention	None listed	Women classified as Black, Asian and Minority ethnic women who had migrated to the UK in their lifetime.	JBI qualitative checklist
Steen 2019	USA (dates not reported)	One hospital in Minneapolis, Minnesota	Feedback from staff and parent evaluations	HIC	Qualitative	Thematic analysis and narrative review	NA	NA	Stillbirth, NND	Description of a perinatal bereavement program	NA	Different components of a perinatal bereavement	Checklist for qualitative research

												program at one hospital	
Sun 2018	Taiwan (Aug 2012–- July 2014)	Tertiary hospital	Interviews	HIC	Qualitative	Phenomenological	NA	20	TOPFA	How fathers experience TOPFA while their spouses are hospitalised in Taiwan	NA	Partners of women who were hospitalised for TOPFA at a maternity unit in a teaching hospital in Taoyuan and: aged ≥20 years, married, able to communicate in Mandarin or Taiwanese, and agreed to audio recording of personal interviews.	Checklist for qualitative research
Sun 2021	Taiwan (Aug 2016- Jul 2018)	Medical centre in Taoyuan County	Interviews	HIC	Qualitative	Phenomenological	NA	20 couples (40 individuals)	Stillbirth	The meaning that parents attach to the care of the remains of their stillborn babies in Taiwan	Couples that did not provide consent	1) pregnant women aged ≥20 years; (2) married and whose spouse is also invited; (3) their child was diagnosed with fetal	Checklist for qualitative research

												death and the couple accepted induction of labour for stillbirth; (4) able to communicate in Mandarin or Taiwanese.	
Thieleman 2020	Romania (June-Nov 2013)	National through an organisation for bereaved parents	Online survey including open-text responses	HIC	Mixed methods	Thematic analysis	Cross-sectional	237	Stillbirth, NND, Infant death, child death	Anxiety, depression, and trauma responses among grieving Romanian parents and to explore their lived experiences of bereavement	NA	>18 years of age and had experienced the death of a child from any cause, including miscarriages.	Checklist for qualitative research Checklist for analytical cross-sectional studies
Thornton 2021	Australia (dates not reported)	National	Interviews	HIC	Qualitative	Grounded theory	NA	18 (13 mothers, 5 fathers)	NND	Parent perceptions of memory making interventions in the NICU	NA	Parents who experienced the loss of their baby in the NICU	Checklist for qualitative research
Tucker-Edmonds 2021	USA (dates not reported)		Interviews	HIC	Qualitative	Content analysis	NA	30	Women at risk for periviable delivery	Racial differences in perceptions of pain/suffering, disability, and coping	Women who were incarcerated, medically unstable, or actively in labor	English and Spanish-speaking pregnant women ages 18+ who presented at two labor	Qualitative appraisal CL

										among pregnant women facing the threat of a periviable delivery		and delivery units for a pregnancy complication that posed a threat for periviable delivery (defined for the study as 22 0/7–24 6/ 7 weeks' gestation)	
Wallace 2018	Canada, USA (2013)	National (2 online support groups)	Online survey with open-ended questions	HIC	Mixed methods	Narrative synthesis	Cross-sectional	114	Prenatal diagnosis of anomaly	Parent perspectives of support received from physicians and/or genetic counsellors following a decision to continue a pregnancy with a prenatal diagnosis of trisomy 13/18	Participants who did not indicate informed consent; were not >18 years; where the diagnosis of Trisomy 13/18 was made after delivery	Parents aged 18 years and over with a child with a prenatal diagnosis of trisomy	Checklist for qualitative research Checklist for analytical cross-sectional studies
Warland 2019	Multiple (dates not reported)	NA	Literature, Opinion	NA	Qualitative	Narrative/ bok chapter	NA	NA	Stillbirth	Challenges for midwives in relation to stillbirth education and providing	NA	NA	Checklist for text and opinion papers

										sensitive evidence-based care after stillbirth			
Wong 2021	Hong Kong / May-December 2019	Pamela Youde Nethersole Eastern Hospital, Hong Kong	Structured open-ended questions through self-administered questionnaire (n=26) or phone interview (n=25)	HIC	Qualitative	Thematic analysis	NA	51	Stillbirth, termination of pregnancy, NND	Aimed to explore the views of HongKong Chinese women who experienced perinatal loss on seeing and holding the baby and on commemorating the baby	NA	Chinese women who experienced the loss of a baby or fetus (caused by miscarriage, TOPFA,stillbirth, or NND) perinatally (from second trimester [12gestational weeks] to 28 days of life after birth) within 5 years and had been under the care of the Bereavement Team at the hospital	JBI Qualitative appraisal CL
Wool 2019	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND, miscarriage	Integrated system of care for perinatal bereavement	NA	NA	Checklist for text and opinion papers

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical

Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data

Figure 1. PRISMA flow diagram of screening evidence

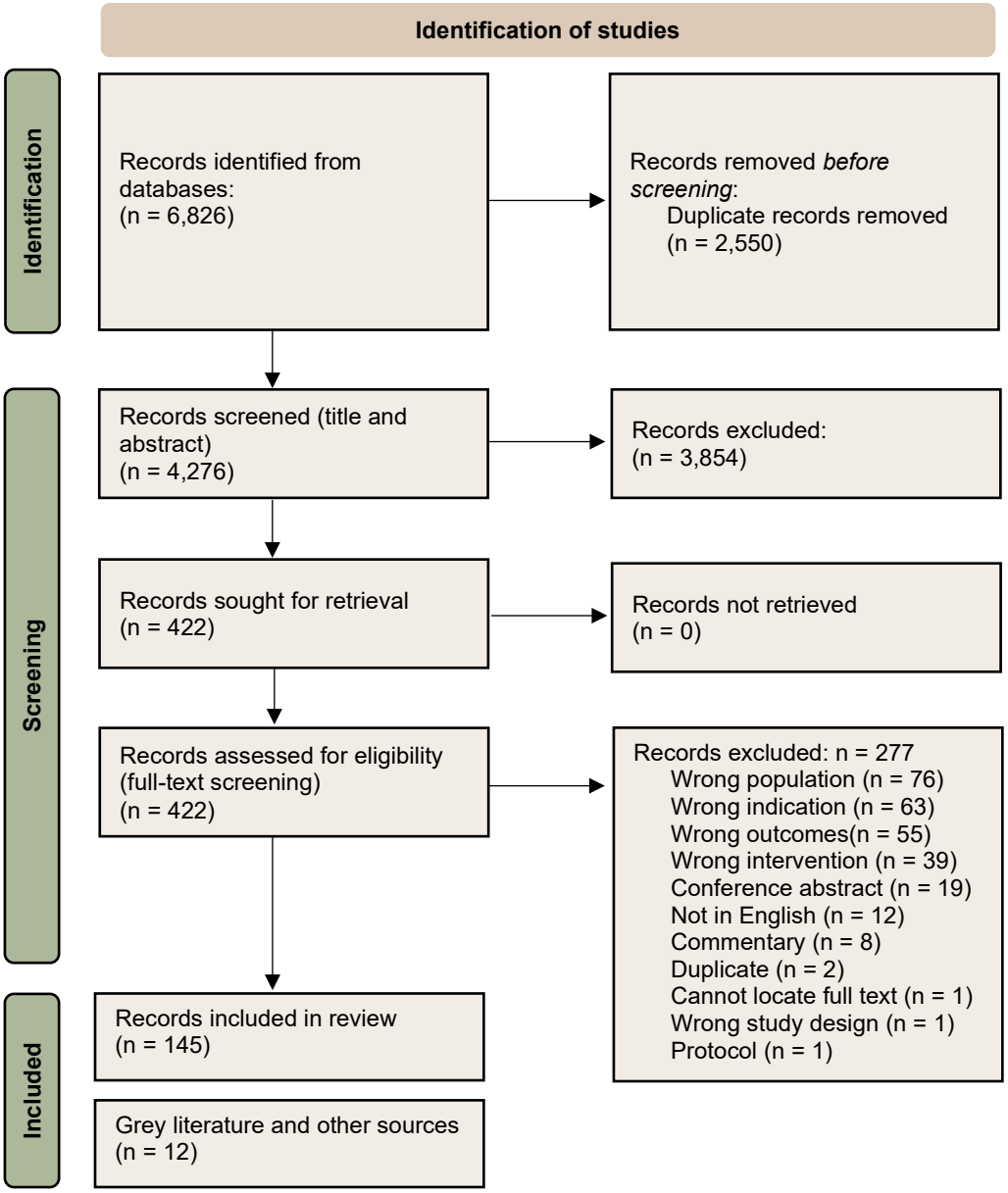

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology ?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by **an appropriate body**?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation , of the data?	Overall appraisal	Relevance
Abdel Razeq 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Actis Danna et al. 2023	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	I
Agwu Kalu 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Aiyelaagbe et al. 2017	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Al Mutair 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Aydin 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I

Ayebare 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Azeez et al. 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Bakhbakhi et al. 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Barry 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Beck 2019	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	
Bedwell 2021	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Bond et al. 2018	Yes	Unclear	Yes	Yes	Unclear	No	No	Unclear	Yes	Yes	Include	R
Boyle et al. 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Brierley-Jones et al. 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Camacho Ávila et al. 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	I
Camacho Ávila et al. 2019	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	I
Carlsson 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Cassidy 2018	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Cassidy 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	R

Christou et al. 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U
de Andrade Alvarenga 2021	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Include	R
Denney-Koelsch et al. 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	I
Domogalla et al. 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Due et al. 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Exclude	R
Farrales et al. 2020	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	U
Fenstermacher 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Fernández-Alcantara 2020	Yes	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Fernández-Basanta 2021 (2)	Yes	Yes	Yes	No	Yes	Yes	No	Unclear	Yes	Unclear	Include	R
Fernandez-Medina 2022	Yes	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	Include	I
Ferreira Paris et al. 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Fuller & Kuberska 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	U
Garcia 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U

Gopichandran 2018	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	I
Helps et al. 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	I
Hendriks 2022	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Ireland et al. 2019	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Kamranpour 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Kamranpour 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Include	R
Kerns 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Kilcullen 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
King et al. 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Unclear	Yes	Include	R
Knighting 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Lafarge 2017	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Yes	Unclear	Include	R
Lafarge et al. 2022	Yes	Yes	Yes	Yes	Yes	No	No	Unclear	Unclear	Yes	Include	R
Lappeman 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	U
Lewis 2019	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I

Lin 2021 (2)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Include	U
Littlemore 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Littlemore 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Lockton 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Lockton 2021 (2)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U
Lou 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Martel 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Martin-Ancel 2022	Unclear	Yes	Yes	Yes	Yes	Unclear	No	NA	NA	Yes	Include	R
Martínez-Serrano et al. 2018	Yes	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Unclear	Include	R
Martínez-Serrano et al. 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Mendes et al. 2017	Unclear	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	Include	I
Meyer 2018	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U
Mills 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Milton 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U

Noble-Carr 2022	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Noble-Carr 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Nurse-Clarke 2019	Unclear	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	Include	I
Nuzum et al. 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Nuzum 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Obst 2021 (3)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Obst 2019	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Obst 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	I
O'Connell 2019	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	I
Ogunbanjo 2020	Yes	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	Include	U
Paize 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	R
Pereira 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Popoola 2022 (2)	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	U
Popoola 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U

Punches 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Randolph 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Razeq 2018	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U
Redshaw & Henderson 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Redshaw 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Rocio Guzman 2018	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Unclear	Yes	Include	U
Shakespeare 2020	Yes	Yes	Yes	Yes	Yes	No	NA	No	Yes	Yes	Include	I
Sheehy 2022	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	I
Shen et al. 2022	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U
Siassakos et al. 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	I
Silverio 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Smith & Dickens et al. 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Smith 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R

Stacey 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Steen 2019	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	No	Yes	Include	U
Sun 2018	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	Include	U
Sun 2021	Yes	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	Include	I
Thieleman 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Thornton 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Tucker-Edmonds 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Wallace 2018	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	Include	U
Wong 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Agwu Kalu 2018	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Include	U

Alaradi et al. 2022	Yes	Yes	Unclear	No	No	No	Yes	Yes	Include	R
Atkins et al. 2022	Yes	Yes	Yes	Yes	No	NA	Unclear	Yes	Include	R
Beck 2019	Yes	Yes	Unclear	No	No	NA	Unclear	Yes	Include	U
Bond et al. 2018	Yes	Unclear	Yes	Yes	No	No	Yes	Yes	Include	R
Dekkers et al.2019	Yes	Yes	Yes	Yes	NA	NA	Yes	Yes	Include	U
Gold 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Hanschmidt 2018 (2)	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	Include	U
Kalanlar 2020	No	No	No	No	No	No	No	Unclear	Include	R
Obst 2021 (2)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Ravaldi 2018	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	Include	I
Redshaw 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Shakespeare 2020	Yes	No	Unclear	No	NA	NA	Yes	Yes	Include	I
Smith 2021	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	Include	U
Sriarporn 2017	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	U

Thieleman 2020	Yes	Yes	Unclear	No	No	No	Yes	Yes	Include	U
Wallace 2018	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate ?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate ?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimise errors in data extraction?	8. Were the methods used to combine studies appropriate ?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate ?	Overall appraisal	Relevance
Berry et al. 2021	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	NA	Yes	Yes	Include	U
Constantinou et al. 2019	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	Include	U
Fernández-Basanta 2021	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	R
Furtado-Eraso et al. 2021	Unclear	Yes	Yes	Unclear	NA	NA	Unclear	Yes	Unclear	Yes	Yes	Include	U
González-Ramos 2021	Yes	Yes	Yes	Yes	NA	NA	Unclear	Yes	Unclear	Yes	Yes	Include	I
Jones 2017 (2)	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	Include	I
Jones et al. 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	NA	Yes	Include	I
McNeil 2020	Unclear	Yes	Yes	No	Unclear	Unclear	Unclear	Yes	No	Unclear	Yes	Include	U
Meunier 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	No	NA	Yes	Include	U
Musodza 2021	Yes	Yes	Yes	Yes	NA	NA	Unclear	NA	NA	Yes	Yes	Include	U

Nguyen 2019	Yes	Yes	Yes	Yes	NA	Yes	Yes	NA	NA	NA	Yes	Include	U
Obst 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Yes	Include	R
Paraíso pueyo 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Include	U
Shakespeare 2019	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Include	I
Shorey et al. 2017	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Unclear	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Cassidy 2021	Yes	Yes	Unclear	Yes	Unclear	Unclear	No	Yes	Unclear	Include	R
Gilmour et al. 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Include	U
Horey 2021	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	NA	Include	U
Hvidtjørn et al. 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Leitao 2021	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Include	U

Ratislavova 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Sharma 2022	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/sources logically defended?	Overall appraisal	Relevance
ACOG 2020	Yes	Yes	Yes	Yes	Yes	NA	Include	U
Afonso 2021	Yes	Unclear	Yes	Unclear	Yes	NA	Include	U
Aggarwal & Moatti 2022	Yes	Yes	Yes	Yes	Yes	No	Include	R
Bakhbakhi et al. 2017	Yes	Yes	Yes	Unclear	Yes	NA	Include	U
Boyle 2020	Yes	Yes	Yes	Yes	Yes	NA	Include	I
Cassaday 2018	Yes	Yes	Yes	Yes	Yes	NA	Include	R
Catlin 2018	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Davidson 2018	Yes	Yes	Yes	No	Yes	Unclear	Include	U

Harden 2018	Yes	Unclear	Yes	Unclear	Yes	NA	Include	R
Hutti & Limbo 2019	Yes	Yes	Yes	Unclear	Yes	NA	Include	U
Kennedy 2017	Yes	Unclear	Yes	Yes	Yes	NA	Include	U
LeDuff III 2017	Yes	Yes	Yes	Unclear	Yes	Unclear	Include	U
Metz 2020	Yes	Yes	Yes	Unclear	Yes	NA	Include	U
Mondanaro 2021	Yes	Unclear	Unclear	Unclear	Yes	NA	Include	I
Moreira Schmalfuss 2019	Yes	Unclear	Unclear	Unclear	Yes	NA	Include	U
Rich 2018	Yes	Unclear	Yes	Unclear	Yes	NA	Include	R
Warland 2019	Yes	Yes	Yes	Unclear	Yes	NA	Include	U
Wool 2019	Yes	Unclear	Yes	Unclear	Yes	NA	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Quasi-experimental studies

	1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Knighting 2019	Yes	Yes	Yes	No	Yes	Yes	NA	Yes	Yes	Include	U
Sorce 2019	Yes	NA	NA	NA	Yes	No	NA	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Bedwell 2021	Yes	NA	Unclear	Yes	No	Yes	Unclear	Yes	Yes	NA	No	Include	R
Redshaw & Henderson 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case report studies

	1. Were patient's demographic characteristics clearly described?	2. Was the patient's history clearly described and presented as a timeline?	3. Was the current clinical condition of the patient on presentation clearly described?	4. Were diagnostic tests or assessment methods and the results clearly described?	5. Was the intervention(s) or treatment procedure(s) clearly described?	6. Was the post-intervention clinical condition clearly described?	7. Were adverse events (harms) or unanticipated events identified and described?	8. Does the case report provide takeaway lessons?	Overall appraisal	Comments (including reason for exclusion)
Cole et al. 2017	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Include	U
Guimarães 2019	Unclear	No	Yes	Yes	Yes	Yes	No	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Comments (including reason for exclusion)
Sénéchal 2022	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	No	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

Ref	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
2.4	Use respectful and sensitive language and terminology that is honest, realistic, and understandable. • Take the lead from parents regarding preferred language for their baby. • Use the word 'baby' or 'bub' if acceptable to parents. • Ask parents if they have named their baby and, if so, seek permission to use the name. This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*	34 studies are included. 25 studies are primary qualitative studies. Six narrative reviews, and four systematic reviews are included. Three mixed methods studies are included incorporating both quantitative and qualitative analysis, two prevalence studies are included, and one cross-sectional study.	Moderate concerns of methodological limitation are noted. 27 of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. 14 studies are noted to have moderate concerns of methodological limitation. Critical appraisal noted concerns with methodology of 12 primary qualitative studies and two mixed methods studies. Consistent concerns noted for qualitative studies include a lack of statement concerning each researcher's cultural position, along with the resultant impact on analysis and findings. Unclear congruity between methods and intent was also noted. Two mixed-methods studies are noted to have moderate concerns of methodological limitation due to the appraisal of their qualitative components. Critical appraisal noted consistent lack of a statement of each researcher's	Minor concerns of study relevance are noted. 17 studies are deemed directly relevant to bereavement care, and 22 of the included studies are deemed indirectly relevant to bereavement care. The remaining two studies are deemed of unclear relevance to respectful and supportive bereavement care.	No concerns of coherence are noted.	No concerns of data adequacy are noted. Of the studies included, 30 source their study cohorts from high income country populations. One from upper-middle income countries, and four from lower- and middle-income countries. Outcomes of interest included across the data include stillbirths (n=1,158), neonatal deaths (n=275), and termination of pregnancy for fetal anomaly (n=591). Viewpoints included across the primary data include that of mothers (n=1768), parents (n=1519), and healthcare professionals (n=1057). No concerns of data adequacy are noted.	**Moderate Confidence** *Moderate concerns of methodological limitation. Minor concerns of study relevance, and no concerns of data adequacy and coherence.*

Ref	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			cultural position , or of the impact on the findings and analysis. Lack of congruity between the methodology, intent, and resultant analysis of results was also noted.				
2.5	Be aware that stress and grief can greatly affect how people absorb, retain, and respond to information. Tailor information by: • using open-ended questions • repeating information and checking with parents that they understand • offering parents culturally and linguistically appropriate parent-facing information and resources about perinatal grief and what to expect • allowing parents time and space to read information and resources when they are ready. This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*	39 studies are included. Of the included studies, 27 are primary qualitative research, six are cross-sectional studies, four are systematic reviews, and two are narrative reviews.	Moderate concerns of methodological limitation are noted. 22 of the included studies are deemed to have no or minor concerns of methodological limitation through critical appraisal. 16 studies are deemed to have moderate concerns of methodological limitation through critical appraisal. 14 of the studies noted to have moderate concerns are primary qualitative research, and all were noted to lack a statement of researcher cultural position, and also a majority lacked a statement of impact that this would have on findings and analysis. Seven were noted to lack congruity between the intent and methodology, and two were noted to have unclear adequacy of participants voices through the included results. One cross-sectional study is noted to have moderate concerns of	Moderate concerns of relevance are noted. 18 studies are noted to be directly relevant to respectful and supportive bereavement care. 18 studies are noted to be indirectly relevant to respectful and supportive bereavement care. The remaining two studies are deemed to be of unclear relevance to respectful and supportive bereavement care.	No concerns of coherence are noted between the studies included.	Minor concerns of data adequacy are noted. 31 of the included studies source their cohorts from high income countries. Four studies source their cohorts from lower and upper middle-income countries, and one included study sources its cohort from low-income countries. Outcomes included across the data include stillbirth (n=4664), neonatal deaths (n=259), termination of pregnancy for fetal anomaly (n=40), and composite perinatal mortality outcomes (n=1563). Viewpoints expressed through the data are mothers' views included through 7 studies, parents' views included across 12 studies, and the view of healthcare professionals included across 12 studies. Minor concerns of data adequacy are noted due to only	**Moderate confidence** *No concerns of coherence, minor concerns of data adequacy, and moderate concerns of methodological limitation and relevance.*

Ref	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			methodological limitation due to confounders not being identified and accounted for. One systematic review is noted to have moderate concerns of methodological limitation due to unclear search strategy, unclear sources, and a lack of independent quality appraisal.			one study specifically focusing on fathers' views of respectful and supportive bereavement care.	

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 3: Perinatal loss care: birth care planning

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Parents face many difficult and emotionally charged decisions when their unborn baby has died or is diagnosed with a life-limiting condition. Some of those decisions are those made by many pregnant women, such as the mode and timing of the baby's birth and options for pain relief.[1] Antenatal diagnosis of a baby's death or likely death means that expectations are shattered and plans that might have been made are drastically altered. Birth and death planning need to occur side by side at a time of shock, grief, and intense emotions. Healthcare professionals have a vital role in supporting parents to make the best possible decisions for their family by exploring options for birth and for meeting and interacting with their baby.

Supporting parents and families to make shared, informed, and supported decisions about birth options has been identified as one of eight core principles in a study designed to reach a global consensus on bereavement care after stillbirth.[2] Specific information and counselling needs may centre on supporting decisions about mode of birth, induction of labour, options for pain relief, length of stay, meeting and interacting with the baby, and memory-making.

Methodology

The Guideline Development Committee developed key research questions around labour and birth care planning (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	What are the information, counselling, and support needs of parents when making decisions about labour and birth care planning following the diagnosis of intrauterine fetal death or diagnosis of a life-limiting condition? What are parents' needs during labour and birth?
2	What are optimal modes of birth following an antepartum fetal death or when a baby is expected to die at or soon after birth?
3	Does having a birth plan improve physical and psychosocial outcomes for parents and what elements of a revised birth plan are most important?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 1. PICO criteria

PICO	Inclusion criteria
Population	Defined in Australia and Aotearoa New Zealand as: • Stillbirth ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR

	where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[3,4]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[3,4]
	• Inclusion of perinatal deaths following termination of pregnancy
	  ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).

Intervention	Studies exploring perinatal loss care following stillbirth or neonatal death in maternal or newborn services.
Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes, and experiences of parents, family members, and healthcare professionals around perinatal loss care specific to labour and birth care planning including mode and timing of birth, pain relief, maternal, and newborn care. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Search strategies were conducted on 21 July 2022 incorporated all PICO criteria and were restricted to publications in English (Table 4). A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and were restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus.

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full-text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- Wrong *population*: The study did not focus on termination of pregnancy, stillbirth, or neonatal death as defined in Table 2.
- Wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- Wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- Wrong *language*: The study was not published in English.
- Wrong *publication dates*: The study was published prior to 2017.
- Wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains a detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical

report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August/September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[5] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[6]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[7]
- Adequacy: The richness and quantity of data supporting the findings.[8]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[9]

Each domain was assessed individually, and concerns were assessed as:

- No concerns or very minor concerns regarding the domain
- Minor concerns regarding domain
- Moderate concerns regarding domain
- Serious concerns regarding the domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated, and details of any concerns were identified and listed.[10] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: What are the information, counselling, and support needs of parents when making decisions about labour and birth care planning following the diagnosis of intrauterine fetal death or diagnosis of a life-limiting condition? What are parents' needs during labour and birth?

Parents will often look to healthcare professionals for guidance and direction as they prepare for the birth of a baby who has died or is likely to die. Often parents report feeling unprepared for the labour and birth experience.[11,12] Parents need clear information about every step of the process to prepare for the birth and to support their decision-making.[13-15] This includes information about the procedures that may be part of the birthing process, what to expect regarding the appearance of the baby, and giving parents' permission to choose what is most comfortable for them regarding interactions with their baby.[15] Parents appreciate it when midwives and other healthcare professionals help them understand what labour and birth might be like, how their baby might look and feel, and validated the birth experience.[11,15] Wool and Catlin[16] underline the importance of dignity and support for the birthing process in all forms of perinatal loss, regardless of when in the pregnancy the loss occurs, or the reasons for the pregnancy ending.

Siassakos and colleagues[13] highlight that, even when a baby has died, the parents' priority is still with their baby. Treating parents like any other parent giving birth is an important part of preparing women for labour and birth and this has added importance for women with earlier losses who may not have had the opportunity to attend antenatal classes.[11] For women whose baby was born between 20- and 24-weeks' gestation, being cared for "like a pregnant woman with a baby" helped preparation for the birth experience.[11]

Care during the labour of a stillborn baby has received little attention. It is important for healthcare professionals to understand that parents are likely to be experiencing "clouded thinking" and information needs to be provided with this in mind.[15]

Preparation for what happens when the baby is born is critical. For antepartum stillbirths, this includes the silence when a baby is not born alive. For babies with a fetal heartbeat, the parents should be prepared for the possibility of their baby being born alive, even if for a very short time, and any care that would be provided in these circumstances.[17] Preparation for birth according to familial values is one of the main objectives of prenatal palliative care for a life-limiting fetal condition. In a study of medical records of family conferences from a perinatal palliative care group, women and family members described feelings such as anxiety and fear related to the nearness of the moment of childbirth, due to not knowing the baby's response, fear of childbirth, and unfamiliarity with childbirth. There were also discussions around the kind of contact, mementoes, and rituals that the family might want. For some families, it was very important to see the child's malformation, whereas others did not want to see the apparent aspects of the malformation.[18] Thus, careful consideration and identification of family needs and values are important to provide parent-centred care to families.

With the appropriate support, and during an intense time of physical and emotional pain, parents can still have a positive birth experience. Some will even feel a sense of pride and excitement when meeting their baby. Sensitive language from healthcare professionals is key to a positive birth experience for women giving birth.[11]

Methods for induction of labour

Misoprostol is widely used and shown to be effective for induction of labour.[19] Additionally, in the UK, Tomlinson et al.[20] implemented across 13 maternity units an integrated care pathway that included measures to address diverse methods for induction of labour. Their guideline-directed approach recommends appropriate doses of misoprostol and diamorphine for analgesia. The nature of the evidence base and the (in)ability of mothers (and their partners) to make the 'right' decisions when faced with an emotive, stressful, and time pressured life event such as stillbirth make decisions difficult; for example, caesarean section versus normal (vaginal) birth in stillbirth and going home or remaining in hospital for 48 h before birth.

For termination of pregnancy, the dosage of misoprostol is usually dependent on the gestational age of the baby.[14] In the cases of intrauterine fetal death, misoprostol may cause increased sensitively and extra caution is recommended regarding dosage.[14]

Pain relief options

Parents' preferences for pain relief will vary. Some women "want to feel everything" to have as full as possible an experience with their baby. Others will want to be shielded from physical pain.[21] A mixed methods study in Spain found that sedative use was pervasive in perinatal loss, often without adequate

discussion with parents about their use or side effects. Later regret may follow for parents due to reduced parent agency and involvement in decisions about care and the consequences of sedative use for opportunities for time and memory making with their baby.[22]

Mode of birth considerations

While determining a mode of birth, healthcare professionals need to consider the gestational age of the baby, the mother's medical and obstetric history, and the preferences and wishes of the parents.[23-25] These will vary from case to case. The risks and benefits will also vary from case to case[23]. In a UK study exploring the challenges in care after stillbirth,[13] parents mentioned that after it was confirmed that the baby had died, staff priorities shifted from the baby to the mother's physical needs whereas parents' priorities were still with their baby. Although families often asked for a caesarean birth, this was considered unacceptable by staff largely because of a lack of understanding of the several different reasons why parents might ask for a caesarean birth. This might include reasons related to the mother, such as to restore their sense of control by having a choice in the timing and mode of birth, not being prepared sufficiently for a vaginal birth process, to shorten the process from diagnosis to birth, or to avoid labour pains. Other potential reasons could be related to their thoughts about the impacts on their baby such as believing that resuscitation after a quick caesarean might save the baby. Some parents may perceive caesarean birth to be less traumatic for the baby. Thus, it is recommended that staff should always explore the reasons why families ask for a caesarean so they can make a joint decision regarding the mode and timing of birth. Also, parents should be thoroughly prepared for every step of the process when discussing the mode of birth following a stillbirth diagnosis.[13]

Length of stay

Parents' preferences regarding the length of their stay after birth vary. In a Danish specialised unit for perinatally bereaved parents, parents decided the length of their stay after birth. Some families went home on the day of birth, whereas others stayed for up to one week. This extended stay enabled parents to spend time with their deceased baby and create memories.[26] Therefore, there is a need for individualised care for families in this regard.

Meeting and interacting with the baby

Many studies have highlighted the importance of memory creation, seeing, holding, and taking photos of the baby, in helping parents' grief after perinatal loss. The UK National Bereavement Care Pathway recommends that parents should be reassured that deciding whether to see and hold their baby is an individual choice with no right or wrong decisions. Many parents appreciate guidance to help make these decisions.[11] Photographs also play an important role, not only in creating memories but also in preparing parents for how their baby looked before seeing them face-to-face.[11] Unfortunately, several studies have shown that parents are sometimes not appropriately supported to meet and interact with their baby.[27-29] This absence of parent-centred decision-making on seeing and holding the baby and memory-making, manifested as profound regret for parents.[27] Healthcare professionals should therefore be supported with appropriate training in this regard so they can support parents and families make the right decisions for them.

Information, counselling, and support considerations around termination of pregnancy

Following termination of pregnancy, some babies may have vital signs after birth. This brief opportunity for parents/family to meet the baby and say goodbye while alive may be a welcomed opportunity for some families.[26] Communication with women undergoing termination of pregnancy needs to include explanations of all possible outcomes and their consequences (e.g. carrying the fetus to term followed

by palliative care of the infant, maximum medical treatment of anomalies diagnosed antenatally, or termination of the pregnancy).[30]

A retrospective cohort study in Germany examined antenatal obstetric approaches around the termination of pregnancy. For induction of labour, Dathan-Stumpf and colleagues[30] highlighted that internationally, the drugs and methods used to induce labour vary greatly and most studies on late termination focus on methods to induce labour. In this study, the drug usually used at the Leipzig University Hospital was misoprostol. However, the administration of misoprostol was contraindicated in women who had had a previous caesarean section because of the higher risk of rupture. Mechanical methods such as double-balloon catheter which can be filled either in the uterus or the vagina with up to 80 ml of saline solution are also used and left up to 24 hours in situ. Mechanical methods alone are often insufficient to induce labour and need to be complemented by the addition of other methods during the procedure.[30] This study also found that later terminations were associated with low rates of maternal complications and that misoprostol was not superior to other drugs in relation to the time between induction of labour and delivery.

Question 2: What are the optimal modes of birth following an antepartum fetal death or when a baby is expected to die at or soon after birth?

The optimal mode of birth following an antepartum fetal death or expected death of a baby is one that combines medical considerations and parent preferences and wishes.[23,24] A qualitative study involving 60 healthcare professionals in three UK hospitals highlighted the challenge of achieving an approach that balances parent-centred decision making and profession-directed care in the highly stressful and time-pressured circumstances around stillbirth.[31] Tensions were particularly apparent in relation to choices about mode of birth and the time between diagnosis and birth of a stillborn baby. High quality research evidence about the psychological and emotional consequences of these choices is not available.

Decisions about the mode and timing of birth may become increasingly complex when a baby is diagnosed with severe fetal anomalies. Parents may have to consider options that include a late termination or continuing the pregnancy as well as options for palliative care when a baby is born alive.[30]

In Australia, USA, and UK guidelines for the management of antepartum stillbirths generally recommend vaginal birth, with caesarean section reserved for special circumstances such as an increased risk of uterine rupture.[32-34] In the USA, women who experience stillbirth usually give birth vaginally regardless of whether labour was spontaneous or induced or whether they had a prior caesarean delivery. However, 15% underwent caesarean delivery, often without a documented obstetric indication.[35] Additionally, caesarean delivery in the USA is recommended only in exceptional circumstances as there is an increased risk of maternal morbidity, especially when there has been a prior hysterotomy.[36] A descriptive cohort study of 579 Danish women who birthed at a specialised perinatal loss unit reported that most gave birth vaginally.[26]

A retrospective review of 634 antepartum stillbirths that occurred between 2010 and 2015 adds to limited information about the mode of birth and use of analgesia in an Australian setting.[1] Most women with an antepartum stillbirth had their labour induced (72.1%). The overall caesarean rate was relatively low (8.5%) but higher for term births. Other factors associated with increased likelihood of caesarean

were medical indications such as placenta praevia or placental abruption, history of previous caesarean section, birth at a metropolitan hospital, maternal chronic condition, and large-for-gestational age birthweight. Clinician preferences, and what clinicians feel may be best for parents, may also influence decisions.[1] Parents' expectations about how their baby will be born may not always match the clinical recommendation for vaginal birth. Parents may expect a caesarean birth and may not be emotionally prepared for a vaginal birth. A UK study explored the views of bereaved parents and healthcare professionals in interviews and focus groups and showed that parents asked for a caesarean birth following antepartum fetal death for different reasons that ranged from wanting to restore a sense of control, to a perception that caesarean birth may be less traumatic for the baby.[13] Exploring with parents their reasons for seeking a caesarean and their underlying concerns and the provision of information that addresses those concerns is essential for supporting parent-centred decision making. Discussions about the mode of birth should include the thorough preparation of parents for every step of the process and conclude with the development of a revised parent-centred birth plan.

One qualitative study conducted in Afghanistan involving 55 parents and healthcare professionals[27] showed that in some settings parents may not be consulted about options for the management of birth and may not be told that their baby has died until sometime after the birth. Again, this may be driven by a desire to protect bereaved parents from distress and is based on healthcare professionals' perceptions of what is best for parents rather than understanding parents' needs or preferences.

Question 3: Does having a birth plan improve physical and psychosocial outcomes for parents and what elements of a revised birth plan are most important?

Birth plans are widely used in pregnancy to document and communicate parents' preferences and wishes. In the same way, birth plans are increasingly recognised as an important component of care when a baby is expected to die.[37] Perinatal palliative care planning includes a birth care plan, palliative care plan, and bereavement care plan to support the baby, parents, and family based on their, values, preferences, wishes, cultural, religious, and spiritual needs (see *Chapter 4: Perinatal palliative care*). Parallel planning is an important process of developing multiple plans for ongoing care and takes into consideration the often-unpredictable course of conditions and potential outcomes and can help prepare parents and families for what may happen during pregnancy, childbirth, and after birth.

Many parents will already have a birth plan and news of their baby's diagnosis may see that plan drastically change as they face navigating the birth and death of their baby. Reviewing and updating an existing birth plan may serve as a supportive function by helping parents to explore their fears, values, hopes, and wishes while also communicating these to their healthcare professionals. In addition to being an important communication tool, the process of birth planning can also be therapeutic for families. The birth plan in a palliative care context goes beyond the traditional birth plan to include prenatal, perinatal, and neonatal care, giving parents and families a sense of control in this challenging time, while also providing an opportunity to honour the life of their baby.[37] It is important that staff balance supportive listening with exploration of the parents' and family's values by facilitating a discussion of their goals and translation of these goals to birth plans.[37]

Based on parent interviews, staff focus groups, and review of service provision, Siassakos et al.[13] recommend that discussions with parents about mode of birth for a stillborn baby and their preparation

for every step of the process should conclude with the development of a revised parent-centred birth plan. Birth plans should be documented and included in the medical record so that all healthcare professionals can access and respect them.[16]

It is important to keep in mind that goals of care may evolve and change as pregnancy progresses and after delivery, as the family's views and needs may change.[37] Therefore, a birth plan must be flexible to account for potential variance in outcomes and should include the physical and comfort needs of the baby, as well as the existential need to be loved.[16]

In their review on the importance of birth planning when a life-limiting fetal diagnosis is made, Cortezzo et al.[37] recommend that key components of a palliative care birth plan should include:

- Important information for the healthcare team including parents' and baby's name (if known), a diagnosis of the baby, and names and numbers for important members of the healthcare team and important support persons for the family.
- Parent's wishes for labour and delivery. This includes mother's desires for fetal monitoring, preference for mode of birth and pain relief, who they would want to be present during the time of labour, and any other special requests, for example some women request music, aromatherapy, dim lights, or time alone with their partner during labour.
- Parents' wishes for medical care of their baby including any interventions they would or would not want.
- Wishes for memory making and support should be noted, such as who they want to be involved in memory making activities and the creation of mementoes and photographs.
- Parents' wishes for end-of-life care including location of death, organ donation, autopsy, and funeral arrangements.

Grey literature and other sources

Note. Grey literature is not included in the GRADE assessment of the evidence-based recommendations.

In addition to the published academic literature, both international and national government agencies and parent support organisation (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to birth planning following the death of an

unborn baby or a diagnosis of a life-limiting condition. A targeted Google search was also conducted using a combination of the following keywords: mode of birth following fetal death diagnosis; and mode of birth following life-limiting diagnosis. The findings of the grey literature are supported by both the current and previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline.*

The UK's Royal College of Obstetricians and Gynaecologists (RCOG) guideline for *Care of Late Intrauterine Fetal Death and Stillbirth*[32] recommends that a detailed birth plan be put in place once a diagnosis of a fetal death or life-limiting condition has been made. This birth plan should be discussed with parents and informed and guided by parent-centred decision making. Involving parents in the development of the plan may give them a sense of control.[38] The plan should include mode of birth, options for pain relief, timing, and memory making opportunities.[32] Additionally, parents may plan for who they would like to be present at the time of the birth, and any rituals that are important to them (e.g. naming ceremony or baptism).[39] Healthcare professionals should engage an interpreter when developing a birth plan, if required. The birth plan should be read by the entire healthcare team.[32,40] Healthcare professionals should also respect and honour the parents' choices and follow the birth plan without repeatedly asking the parents for guidance or direction.[38]

In addition to parents' choices, the birth plan should consider the woman's medical condition and previous intrapartum history. Conditions that should influence immediate steps towards delivery include sepsis, pre-eclampsia, placental abruption, or membrane rupture.[32] In the UK, RCOG recommends vaginal birth as the mode of birth for most women; however, a caesarean will need to be discussed and considered with some parents.[32]

During the timing of birth discussions, The Australian Commission on Safety and Quality in Health Care's *Stillbirth Clinical Care Standard* advises healthcare professionals to ensure that they are providing women with consistent information based on current evidence. Healthcare professionals should also discuss with parents what they would like to happen when the baby is born.[40] All outcomes of discussions relating to timing of birth should be documented in the woman's healthcare record.[41]

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This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies	GRADE-CERQual overall confidence rating of evidence	Guideline recommendations
Brierley-Jones et al. 2018 Christou et al. 2021 Hidalgo-Lopezosa et al. 2023 Horey et al. 2021 Hvidtjørn et al. 2021 Monari et al. 2022 Siassakos et al. 2018 Smith et al. 2020 Warland 2023 Wool & Catlin 2019	Moderate confidence *Minor concerns of relevance, coherence and adequacy of data. Moderate concerns of methodological limitation.*	**Evidence-based recommendation 3.9:** Engage with parents to develop a detailed care plan that considers their values, preferences, wishes, and concerns. • Discuss advantages and disadvantages of options with parents and accompanying family/whānau or support person. • Provide appropriate information so that parents know what to expect and can make informed decisions about their care. • Ensure care plans are filed in medical records to ensure good communication between all healthcare professionals and members of multidisciplinary team.
Bailey et al. 2022 Boyle et al. 2017 Brierley-Jones et al. 2018 Ramseyer et al. 2021 Rossi 2019 Siassakos et al. 2018	Moderate confidence *Minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*	**Evidence-based recommendation 3.10:** For labour and birth, parents should be given as much time as they need to make decisions about options offered. • Advise parents that labour and vaginal birth may provide physical and emotional benefit, compared to a caesarean birth without obstetric indication. However, parents' values, preferences, and wishes need to be respected. • Ensure parents understand what usually happens when labouring with a baby who has died and what their baby may look and feel like following birth (for example physical appearance, size, tone, and temperature). • Advise parents that the full range of pharmacological and non-pharmacological pain relief options are available for them.

	• Offer strong pain relief/sedation with caution as this may interfere with opportunities for spending time with the baby.

Table 4. Search strategy

Database	Search strategy	
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/
	2	((fetal or foetal or fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal") adj1 loss*) or stillb*).ti,ab.
	5	1 or 2 or 3 or 4
	6	((appearance or maccerat* or see* or hold* or contact or "spend time" or "have time" or "give time") adj3 (baby or stillb* or neonate* or infant* or fetus* or foetus* or babies or twin* or bub*)).ti,ab.
	7	(("pain relief" or sedat* or anesthe* or anaesthe* or analgesi*) AND ((labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* adj4 contraction*))) or ((while or undergo* or during) adj2 (stillbirth or deliver* or terminat* or induction or abort*))).ti,ab.
	8	(((plan* or mode* or time or timing or type* or expect* or engage* involve* or pool or bath or submersion) adj2 (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* adj4 contraction*))) or ((while or undergo* or during) adj2 (stillbirth or deliver* or terminat*or induction or abort*))).ti,ab.
	9	*analgesia/
	10	*conscious sedation/ or *sedation/
	11	*vaginal delivery/ or *delivery/
	12	*water birth/ or *birth/ or *traditional birth attendant/
	13	*childbirth/ or *patient participation/ or *labor/
	14	6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
	15	(parents or mother* or father* or patient or woman* or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or cost or economic*).ti,ab.
	16	("health care" or healthcare* or practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or gynecolog* or carer or "care management" or "counsel*").ti,ab.
	17	15 or 16
	18	5 and 14 and 17
CINAHL	S20	S5 AND S16 AND S19
	S19	(S17 OR S18)

S18	AB ("health care" or healthcare* or practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or gynecolog* or carer or "care management" or "counsel*")
S17	AB (parents or mother* or father* or patient or woman* or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or cost or economic*)
S16	S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15
S15	(MM "Childbirth")
S14	(MM "Birth Setting")
S13	(MM "Doulas")
S12	(MM "Water Birth")
S11	(MM "Vaginal Birth") OR (MM "Delivery, Obstetric")
S10	(MM "Sedation") OR (MM "Conscious Sedation") OR (MM "Hypnotics and Sedatives")
S9	(MM "Analgesia") OR (MM "Analgesia, Obstetrical") OR (MM "Analgesia, Epidural")
S8	AB (((plan* or mode* or time or timing or type* or expect* or engage* involve* or pool or bath or submersion) N2 (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* N4 contraction*))) or ((while or undergo* or during) N2 (stillbirth or deliver* or terminat*or induction or abort*)))
S7	AB (("pain relief" or sedat* or anesthe* or anaesthe* or analgesi*) AND ((labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* N4 contraction*))) or ((while or undergo* or during) N2 (stillbirth or deliver* or terminat*or induction or abort*)))
S6	AB ((appearance or maccerat* or see* or hold* or contact or "spend time" or "have time" or "give time") N3 (baby or stillb* or neonate* or infant* or fetus* or foetus* or babies or twin* or bub*))
S5	(S1 OR S2 OR S3 OR S4)

	S4	AB (((pregnancy OR foetal OR fetal OR feta((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort)) or "prenatal diagnosis") us OR perinatal OR “peri natal” OR neonatal) N1 loss*) OR stillb*)
	S3	AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) N1 loss*) OR stillb*)
	S2	AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*)
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
Scopus	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/1 (death* or wast* or demise* or mortalit*)) OR (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/1 (terminat* or abortion or abort)) OR (((pregnancy or foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*) AND ((appearance or maccerat* or see* or hold* or contact or "spend time" or "have time" or "give time") W/2 (baby or stillb* or neonate* or infant* or fetus* or foetus* or babies or twin* or bub*)) OR (("pain relief" or sedat* or anesthe* or anaesthe* or analgesi*) W/2 ((labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* W/2 contraction*))) or ((while or undergo* or during) W/2 (stillbirth or deliver* or terminat* or induction or abort*))) OR ((plan or plans or mode* or time or timing or type* or expect* or engage* or involve* or pool or bath or submersion) W/2 (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* W/2 contraction*))) or ((while or undergo* or during) W/2 (stillbirth or deliver* or terminat* or induction or abort*)) AND ("health care" or healthcare* or practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or gynecolog* or "care management" or "counsel*") OR	

	(parents or mother* or father* or patient or woman* or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or cost or economic*)
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Death] explode all trees #3 MeSH descriptor: [Perinatal Mortality] explode all trees #4 MeSH descriptor: [Abortion, Induced] explode all trees #5 ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) NEAR/2 (death* OR wast* OR demise* OR mortalit*)):ti,ab,kw #6 (((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal" OR neonatal) NEAR/1 loss*) OR stillb*))):ti,ab,kw #7 (((((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") NEAR/3 (terminat* or abortion or abort)) or "prenatal diagnosis"))):ti,ab,kw #8 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 #9 (((appearance OR maccerat* OR see* OR hold* OR contact OR "spend time" OR "have time" OR "give time") NEAR/3 (baby OR stillb* OR neonate* OR infant* OR fetus* OR foetus* OR babies OR twin* OR bub*))):ti,ab,kw #10 ((("pain relief" OR sedat* OR anesthe* OR anaesthe* OR analgesi*) AND ((labor OR labour OR delivery OR parturition OR birth* OR childbirth OR intrapartum OR "intra partum" OR peripartum OR "peri partum" OR caesarean OR (uter* NEAR/4 contraction*))) OR ((while OR undergo* OR during) NEAR/2 (stillbirth OR deliver* OR terminat* OR induction OR abort*)))):ti,ab,kw #11 (((plan* OR mode* OR time OR timing OR type* OR expect* OR engage* OR involve* OR pool OR bath OR submersion) NEAR/2 (labor OR labour OR delivery OR parturition OR birth* OR childbirth OR intrapartum OR "intra partum" OR peripartum OR "peri partum" OR caesarean OR (uter* NEAR/4 contraction*)))):ti,ab,kw #12 (((while OR undergo* OR during) NEAR/2 (stillbirth OR deliver* OR terminat* OR induction OR abort*))):ti,ab,kw #13 MeSH descriptor: [Delivery, Obstetric] explode all trees #14 MeSH descriptor: [Parturition] explode all trees #15 MeSH descriptor: [Doulas] explode all trees #16 MeSH descriptor: [Hypnotics and Sedatives] explode all trees #17 MeSH descriptor: [Analgesia] explode all trees #18 ((((plan* or mode* or time or timing or type* or expect* or engage* involve* or pool or bath or submersion) NEAR/2 (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* NEAR/4 contraction*))) or ((while or undergo* or during) NEAR/2 (stillbirth or deliver* or terminat*or induction or abort*)))):ti,ab,kw #19 ((("pain relief" or sedat* or anesthe* or anaesthe* or analgesi*) AND ((labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* NEAR/4 contraction*))) or ((while or undergo* or during) NEAR/2 (stillbirth or deliver* or terminat*or induction or abort*)))):ti,ab,kw #20 (((appearance or maccerat* or see* or hold* or contact or "spend time" or "have time" or "give time") NEAR/3 (baby or stillb* or neonate* or infant* or fetus* or foetus* or babies or twin* or bub*))):ti,ab,kw #21 #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20

	#22	(("health care" or healthcare* or practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or gynecolog* or carer or "care management" or "counsel*")):ti,ab,kw
	#23	((parents or mother* or father* or patient or woman* or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or cost or economic*)):ti,ab,kw
	#24	#22 OR #23
	#25	#8 AND #21 AND #24
PubMed	1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR "Abortion, Induced"[Mesh]
	2	"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR “Neonatal loss*” OR “Neonatal mortalit*”OR “Neonatal death*” OR “Neonatal Demise*” OR “Newborn death*” OR “Newborn mortalit*”
	3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])
	4	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or “prenatal diagnosis”) AND (terminat* or abortion or abort))
	5	#1 OR #2 OR #3 OR #4
	6	((appearance[Title/Abstract] OR maccerat*[Title/Abstract] OR see[Title/Abstract] OR hold*[Title/Abstract] OR contact[Title/Abstract]) AND (baby[Title/Abstract] OR stillb*[Title/Abstract] OR neonate*[Title/Abstract] OR infant*[Title/Abstract] OR fetus*[Title/Abstract] OR foetus*[Title/Abstract] OR babies[Title/Abstract] OR twin*[Title/Abstract] OR bub[Title/Abstract]))
	7	(("pain relief"[Title/Abstract] OR sedat*[Title/Abstract] OR anesthe*[Title/Abstract] OR anaesthe*[Title/Abstract] OR analgesi*[Title/Abstract]) AND ((labor[Title/Abstract] OR labour[Title/Abstract] OR delivery[Title/Abstract] OR parturition[Title/Abstract] OR birth*[Title/Abstract] OR childbirth[Title/Abstract] OR intrapartum[Title/Abstract] OR "intra partum"[Title/Abstract] OR peripartum[Title/Abstract] OR "peri partum"[Title/Abstract] OR caesarean[Title/Abstract] OR (uter*[Title/Abstract] AND contraction*[Title/Abstract]))) OR ((while[Title/Abstract] OR undergo*[Title/Abstract] OR during[Title/Abstract]) AND (stillbirth[Title/Abstract] OR deliver*[Title/Abstract] OR terminat*[Title/Abstract] OR induction[Title/Abstract] OR abort*[Title/Abstract])))
	8	(((plan*[Title/Abstract] OR mode*[Title/Abstract] OR time[Title/Abstract] OR timing[Title/Abstract] OR type*[Title/Abstract] OR expect*[Title/Abstract] OR engage* involve*[Title/Abstract] OR pool[Title/Abstract] OR bath[Title/Abstract] OR submersion) AND (labor[Title/Abstract] OR labour[Title/Abstract] OR delivery[Title/Abstract] OR parturition[Title/Abstract] OR birth*[Title/Abstract] OR childbirth[Title/Abstract] OR intrapartum[Title/Abstract] OR "intra partum"[Title/Abstract] OR peripartum[Title/Abstract] OR "peri partum"[Title/Abstract] OR caesarean[Title/Abstract] OR (uter*[Title/Abstract] AND contraction*[Title/Abstract]))) OR

		((while[Title/Abstract] OR undergo*[Title/Abstract] OR during[Title/Abstract]) AND (stillbirth[Title/Abstract] OR deliver*[Title/Abstract] OR terminat*[Title/Abstract] OR induction[Title/Abstract] OR abort*[Title/Abstract]))
	9	(((((("Analgesia"[Mesh]) OR "Conscious Sedation"[Mesh]) OR "Delivery, Obstetric"[Mesh]) OR "Parturition"[Mesh]) OR "Doulas"[Mesh]) OR "Labor, Obstetric"[Mesh]
	14	6 or 7 or 8 or 9
	15	(parents[Title/Abstract] OR mother*[Title/Abstract] OR father*[Title/Abstract] OR patient[Title/Abstract] OR woman*[Title/Abstract] OR migrant[Title/Abstract] OR immigrant[Title/Abstract] OR refugee*[Title/Abstract] OR "indigenous"[Title/Abstract] OR "torres strait islander*"[Title/Abstract] OR ATSI[Title/Abstract] OR aborigin*[Title/Abstract] OR islander*[Title/Abstract] OR remote*[Title/Abstract] OR "linguistically diverse"[Title/Abstract] OR "literacy"[Title/Abstract] OR "low income"[Title/Abstract] OR "cultural care"[Title/Abstract] OR elders[Title/Abstract] OR maori[Title/Abstract] OR whanau[Title/Abstract] OR cost[Title/Abstract] OR economic*[Title/Abstract])
	16	("health care"[Title/Abstract] OR healthcare*[Title/Abstract] OR practition*[Title/Abstract] OR professional*[Title/Abstract] OR nurs*[Title/Abstract] OR doctor*[Title/Abstract] OR physician*[Title/Abstract] OR midwi*[Title/Abstract] OR obstetric*[Title/Abstract] OR gynecolog*[Title/Abstract] OR carer[Title/Abstract] OR "care management"[Title/Abstract] OR "counsel*"[Title/Abstract] "counsel*")
	17	15 or 16
	18	5 and 14 and 17
Australian Indigenous HealthInfoNet		(("sorry business" OR death) AND baby)
Informit Indigenous Collection		([All Fields: death OR All Fields: dies OR All Fields: dead OR All Fields: 'sorry business']) AND ([All Fields: baby OR All Fields: stillb* OR All Fields: neonat* OR All Fields: child])

Figure 1. PRISMA flow diagram of screening evidence

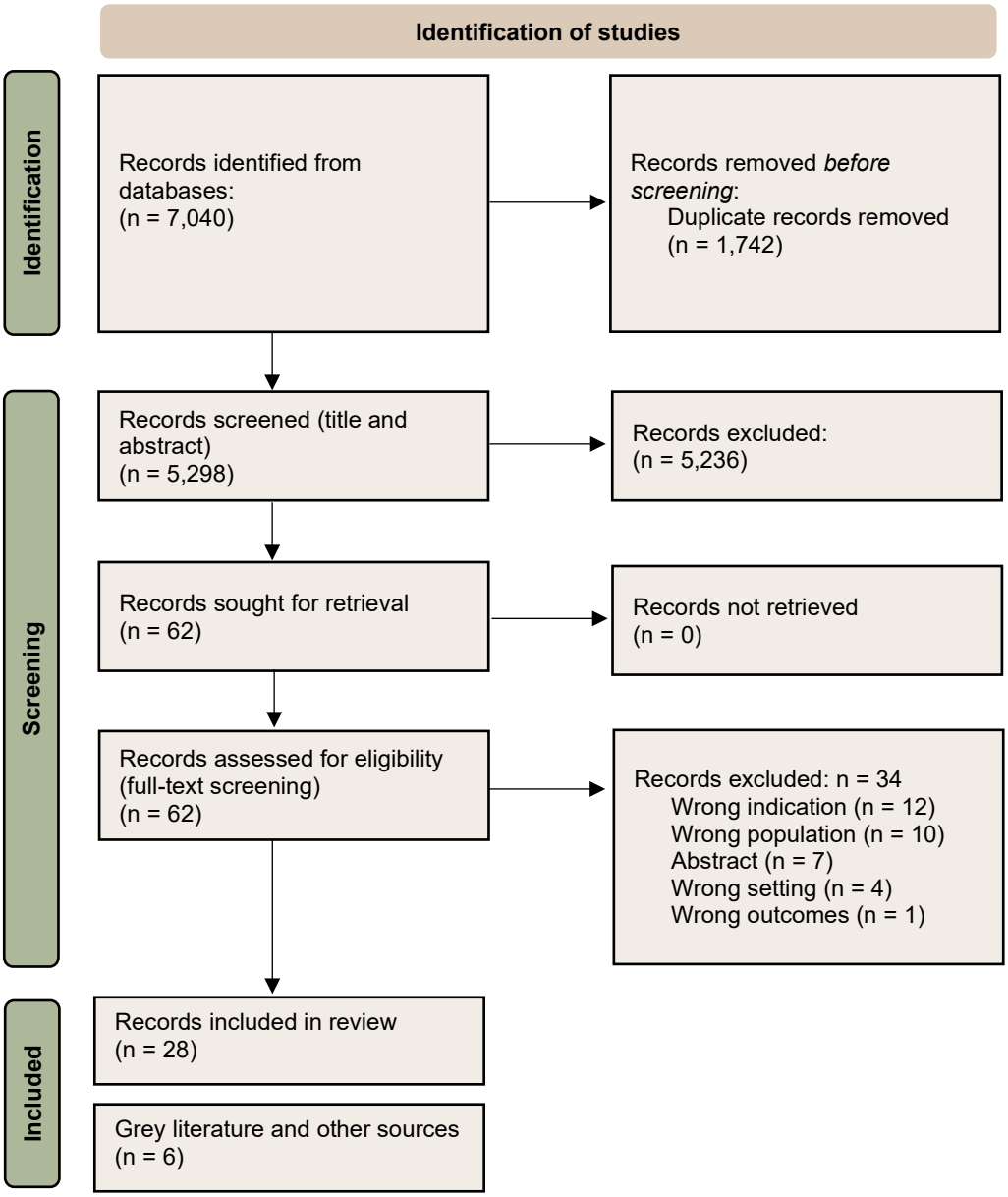

Table 5. Study characteristics

Study ID	Country (Period)	Locality (state/national / hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Amin et al. 2019	India (Jan-Nov 2015)	1 tertiary care centre in Mumbai	Hospital records	LMIC	Quantitative	NA	Prospective observational	100	Stillbirth	The most effective method of induction of labour in the case of intrauterine foetal death	Refusal of consent for inclusion in the study	Intrauterine foetal death after 20 weeks of gestation but not in labour; singleton pregnancy	Checklist for case series studies [a]
Bailey et al. 2022	Australia (2010-2015)	1 state-Western Australia	Population health datasets.	HIC	Quantitative	NA	Retrospective cohort	634	Stillbirth	Factors associated with c-section following antepartum stillbirth	NA	All singleton antepartum stillbirths ≥20 weeks gestation in Western Australia, 2010-2015	Checklist for cohort studies [b]
Boyle et al. 2017	USA (March 2006-Sept 2008)	59 hospitals in 5 geographically defined catchment areas	Hospital records	HIC	Quantitative	NA	Retrospective case series	611	Stillbirth	Delivery management of singleton stillbirths	Women with multiple gestations. Women were excluded if incarcerated or if informed consent could not be obtained	Women residing within one of the geographic catchment areas, with singleton stillbirths at or after 20 weeks gestation enrolled in the Stillbirth Collaborative Research Network study from March 2006-Sept 2008.	Checklist for case series studies
Brierley-Jones et al. 2018	England (2014-2015)	Three hospitals in Northeast England	Focus groups, semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	60	Stillbirth	Views of health professionals and healthcare staff across three hospitals in the	NA	Consultant obstetricians, trainees, midwives, midwife sonographers and chaplains	Checklist for qualitative research [c]

										management of stillbirth			
Christou et al. 2021	Afghanistan (Oct-Nov 2017)	3 high-volume referral maternity hospitals in Kabul and 2 lower-level health facilities and surrounding communities in 2 rural districts ~25–30 km west and north of Kabul city	Interviews	LIC	Qualitative	Deductive thematic analysis	NA	55 (21 mothers, 9 fathers, 3 female community elders, 20 healthcare professionals, 2 government officials)	Stillbirth	Parents' and healthcare professionals'experiences of care after stillbirth	NA	Women and men experiencing stillbirth, community female elders, healthcare professionals, and key informants including government officials, hospital directors, chiefs of wards	Checklist for qualitative research
Dathan-Stumpf et al. 2021	Germany (2016-2019)	University Hospital	Patient files	HIC	Quantitative	NA	Non-comparative study	164	TOPFA	Approaches to termination of pregnancies ≥21 weeks GA and complications.	Multiple pregnancies. In addition, one patient with an abnormally invasive placenta (s/p caesarean section), in whom the fetus and placenta were delivered after six weeks following a two-stage approach with preservation of	Termination of singleton pregnancies ≥21 weeks GA carried out at Leipzig University Hospital between 2016–2019.	Checklist for case series studies

											the uterus, was also excluded from the study.		
Hidalgo-Lopezosa et al. 2023	Spain (2016-2019)	Spain	Registry data	HIC	Quantitative	NA	Retrospective cohort study	3504 births	Stillbirth	Prevalence of stillbirth, and also risk factors for Caesarean delivery.	Births under 28 weeks gestational age.	If births resulting in a stillborn in gestations lasting for 28 weeks or more, between January 2016 and December 2019	Checklist for cohort studies
Horey et al. 2021	40 countries (Dec 2014-Feb 2015)	NA	Survey	HIC and MIC	Quantitative	NA	Descriptive	3041	Stillbirth	Bereavement care practices after stillbirth in high and middle-income countries	Stillbirth >5 years prior to completing the survey	Self-reported stillbirth ≤5 years prior to completing the survey	Checklist for studies reporting prevalence data [d]
Hvidtjørn et al. 2021	Denmark (2012-2018)	A midwifery-led specialised unit for bereaved parents at Aarhus University Hospital in Denmark	Hospital electronic health records	HIC	Quantitative	NA	Descriptive cross-sectional	579	Miscarriage (>14 weeks), missed abortion (>14 weeks), termination of pregnancy (>14 weeks), stillbirth, NND	Clinical characteristics of women admitted to a specialised unit for bereaved parents and characteristics of women who stayed more than 2 days	NA	All women who experienced spontaneous pregnancy loss after 14 weeks gestation, TOPFA, intrauterine death, or intrapartum death between 1 January 2012, and 31 December 2018. Women who experienced the death of a newborn in the NICU within the first 48 hours after birth and desired a stay in the unit were also included.	Checklist for studies reporting prevalence data

Monari et al. 2022	Italy (2014-2020)	Emilia Romagna, Italy	Surveillance data	HIC	Quantitative	NA	Retrospective cohort study	770 births	Stillbirth	To evaluate the different modes of birth in a stillbirth Italian population.	Birth under 22 weeks gestational age.	Babies stillborn and delivered at or after 22 weeks gestational age, between 2014 and 2020 in Italy with mode of delivery data.	Checklist for cohort studies
Ramseyer et al. 2021	USA: July 2015 to June 2019	Arkansas state (44 hospitals)	Secondary analysis of data from Ramseyer 2020 study	HIC	Quantitative	NA	Retrospective cohort	75	Stillbirth	Characteristics of women who underwent c-section for stillbirth management	NA	Women undergoing caesareans after stillbirth in Arkansas	Checklist for cohort studies
Ravaldi et al. 2018	Italy (2009-2015)	National (11 hospitals)	Hardcopy survey questionnaire	HIC	Quantitative	NA	Cross-sectional study	674	Stillbirth	Current practices of healthcare professionals caring for women experiencing a stillbirth and to explore their training needs	NA	Practicing midwives, obstetricians, nurses, and psychologists of the Obstetrics and Gynaecology wards in 11 Italian hospitals	Checklist for analytical cross-sectional studies [e]
Rossi 2019	USA (2014)	National	National Center for Health Statistics	HIC	Quantitative	NA	Retrospective cohort	16,160	Stillbirth	Rate of caesarean delivery in pregnancies complicated by antepartum stillbirth and characteristics associated with caesarean delivery	Multifetal gestations; if data on mode of delivery was missing; GA less than 16 weeks; if the patient was diagnosed with an intrapartum fetal demise or was in spontaneous labour at the time of	Stillbirths occurring at 16 weeks of gestation or greater	Checklist for cohort studies

											stillbirth diagnosis, or if the birthweight was less than 50 g		
Siassakos et al. 2018	UK (2013)	Three maternity hospitals	Interviews, focus groups, service provision data	HIC	Qualitative	Thematic analysis	NA	Parents of 16 stillborn babies, 22 maternity staff	Stillbirth	Views of bereaved parents and maternity staff to improve bereavement care for families	Twin pregnancy and loss, intrapartum stillbirth	Parents with a stillborn baby (gestational age more than 23 weeks, 6 days)- singleton stillbirths with the fetal death diagnosed before the onset of labour, maternity staff	Checklist for qualitative research
Smith et al. 2020	UK (Sept 2016- Aug 2017)	Two parent support organisations, 4 clinical sites	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	28 (10 couples, 18 mothers)	Miscarriage, stillbirth, NND, TOPFA	Parents' healthcare experiences before, during, and after their baby's death between 20 and 23+6 weeks of gestation	NA	Parents whose baby died before, during, or shortly after birth at 20+0 to 23+6 weeks of gestation.	Checklist for qualitative research
Tomlinson et al. 2018	UK (2013-2016)	13 maternity units in North West of England	Clinical audit questionnaire	HIC	Mixed methods	NA (no qual data presented)	Descriptive case study	89 (29 stillbirths audited in 2014, 29 in 2015 and 31 in 2016)	Stillbirth	Evaluation of integrated care pathway program for stillbirth management	NA	2 cases from each of 13 maternity units in Northeast England	Checklist for case report studies [f]
Warland et al. 2023	Australia (2020-2021)	Australia	Semi-structures virtual interviews	HIC	Qualitative	Grounded theory	NA	18 (14 mothers, 4 fathers)	Stillbirth	Parents	NA	English language proficient parents aged 18 years or older who had experienced	Checklist for qualitative research

												a fetal death in utero (FDIU) in Australia within the previous five years	
Wool & Catlin 2019	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND, miscarriage	Integrated system of care for perinatal bereavement	NA	NA	Checklist for text and opinion papers [g]

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall appraisal	Relevance
Brierley-Jones et al. 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Christou et al. 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Siassakos et al. 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	R
Smith et al. 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Warland et al. 2023	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Ravaldi et al. 2018	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Horey et al. 2021	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	NA	Include	R
Hvidtjørn et al. 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/sources logically defended?	Overall appraisal	Relevance

Wool & Catlin 2019	Yes	Unclear	Yes	Unclear	Yes	NA	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilized?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Bailey et al. 2022	Yes	Yes	Yes	No	No	Yes	Yes	NA	NA	NA	Yes	Include	R
Ramseyer et al. 2021	NA	NA	Yes	No	No	Yes	Yes	Yes	NA	NA	Yes	Include	R
Hidalgo-Lopezosa et al. 2023	Yes	Yes	No	Yes	Yes	Yes	No	Yes	No	No	Yes	Include	R
Monari et al. 2022	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	No	Include	R
Rossi 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Comments (including reason for exclusion)
Amin et al. 2019	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Include	R
Boyle et al. 2017	Yes	Yes	Yes	Unclear	No	Yes	Yes	Yes	No	Yes	Include	R
Dathan-Stumpf et al. 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case report studies

	1. Were patient's demographic characteristics clearly described?	2. Was the patient's history clearly described and presented as a timeline?	3. Was the current clinical condition of the patient on presentation clearly described?	4. Were diagnostic tests or assessment methods and the results clearly described?	5. Was the intervention(s) or treatment procedure(s) clearly described?	6. Was the post-intervention clinical condition clearly described?	7. Were adverse events (harms) or unanticipated events identified and described?	8. Does the case report provide takeaway lessons?	Overall appraisal	Comments (including reason for exclusion)
Tomlinson et al. 2018	No	No	Yes	Yes	No	Yes	No	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
3.9	Engage with parents to develop a detailed care plan that considers their values, preferences, wishes, and concerns. • Discuss advantages and disadvantages of options with parents and accompanying family/whānau or support person. • Provide appropriate information so that parents know what to expect and can make informed decisions about their care. • Ensure care plans are filed in medical records to ensure good communication between all healthcare professionals and members of multidisciplinary team.	Ten studies are included. Five are primary qualitative research, two prevalence studies, two retrospective cohort studies, and one narrative piece.	Moderate concerns of methodological limitation are noted. No or minor concerns of methodological limitations are noted in assessment of six of the included studies. Four included studies were assessed to have moderate concerns of methodological limitation. Two included qualitative studies, and the two included cohort studies. Concerns are noted due to both qualitative studies failing to mention the cultural position of the researcher and the impact of findings. One of the studies also was noted to have unclear methodology alignment with the stated philosophical perspective. One included cohort study failed to demonstrate reliable exposure and outcome measures that were valid. The other failed to identify confounders or to account for their effect through statistical analysis.	No or minor concerns of relevance are noted. Nine of the included studies are deemed directly relevant to birth planning around stillbirth and neonatal death. The remaining study is deemed partially relevant.	Minor concerns of coherence are noted due to differences in findings as a result of different population settings.	Minor concerns of data adequacy of included evidence are noted. Nine of the included studies source cohorts from high-income country populations. The remainder sources its population from a low-income country. The outcomes from the evidence included are stillbirth (n=7,486), and composite perinatal mortality (n=~617). Viewpoints include mothers (n=3041), parents (n=101), and healthcare professionals (n=60), as well as a medical record audit and literature review. Minor concerns of adequacy of evidence are noted as outcomes are predominantly relevant to stillbirth.	**Moderate confidence** *Minor concerns of relevance, coherence and adequacy of data. Moderate concerns of methodological limitation.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
3.10	For labour and birth, parents should be given as much time as they need to make decisions about options offered. • Advise parents that labour and vaginal birth may provide physical and emotional benefit, compared to a caesarean birth without obstetric indication. However, parents' values, preferences, and wishes need to be respected. • Ensure parents understand what usually happens when labouring with a baby who has died and what their baby may look and feel like following birth (for example physical appearance, size, tone, and temperature). • Advise parents that the full range of pharmacological and non-pharmacological pain relief options are available for them. • Offer strong pain relief/sedation with caution as this may	Six studies are included. Three are cohort studies, one case-series study, one cross-sectional study, and one narrative review.	Minor concerns of methodological limitation are noted through the assessment of the included studies. No or minor concerns of methodological limitation are noted through assessment of two included studies. Minor concerns are noted for one included study. Moderate concerns are noted through the assessment of the study methodology of three included studies. Two because the confounders were neither identified nor accounted for through analysis, and the case - series, because there was incomplete inclusion of participants and no reporting of site demographic information.	Minor concerns of evidence relevance are noted through assessment. Four of the included studies are deemed directly relevant to birth planning around stillbirth and neonatal death. One study is deemed to be partially relevant to planning of birth around stillbirth or neonatal death, and the remaining study is deemed to have unclear relevance.	Minor concerns of evidence coherence are noted.	Moderate concerns of data adequacy are noted for the included evidence. All included studies source their cohorts from high-income country settings. The outcome included is stillbirth (n=18154), and the viewpoint of mothers (n=611) is the only included view. The remaining studies examine existing literature or existing datasets. Moderate concern of data adequacy is noted due to the lack of healthcare professionals' and parents' view expressed in the literature.	**Moderate confidence** *Minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	interfere with opportunities for spending time with the baby.						

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 3: Perinatal loss care: space and surroundings

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

An important component of respectful and supportive perinatal loss care is the access to, and nature of, physical spaces and surroundings for bereaved parents/family. The physical environment for the care of bereaved parents will depend on the timing of the perinatal death and the setting and model of care. Across the continuum of care, from the time of breaking bad news, a quiet, private, and safe space is essential to provide parents with uninterrupted time to understand and process information and the opportunity to ask questions.

In settings where a designated bereavement suite is not available, suitable areas must be made available to ensure parents have privacy to support each other. Capacity for extended family members and other support persons to gather should also be considered.[1]

Methodology

The Guideline Development Committee identified two key research questions (Table 1) on which to focus the evidence for space and surroundings for perinatal loss care.

Table 1. Research questions

1	What physical and/or environmental space and surroundings do parents need around the birth of their stillborn baby, or around palliative care of their baby? How can healthcare providers best ensure the mother is attended by those she wishes to have around her?
2	How do healthcare providers negotiate the balance between parental request and safe/appropriate surrounding for mourning, birth, and/or palliative care (e.g. place of care)? How best to support staff to have these discussions with parents? (e.g. place of birth, environment, surroundings at birth; safety vs supportive care)

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 2. PICO criteria

PICO	Inclusion criteria

Population	Defined in Australia and Aotearoa New Zealand as:
	• Stillbirth
	  ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[2,3]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a

	live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth[2,3] • Inclusion of perinatal deaths following termination of pregnancy ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).
Intervention	Studies exploring perinatal loss care following stillbirth or neonatal death in maternal or newborn services.
Comparator	Not applicable – no comparator within research questions.
Outcomes	Outcomes, processes and experiences of parents, family members, healthcare professionals around the impact of the physical environment and provision of perinatal loss care. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Searches were conducted on 7 June 2022. A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and were restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- wrong *language*: The study was not published in English.
- wrong *publication dates*: The study was published prior to 2017.
- wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee

between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[4] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[5]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[6]
- Adequacy: The richness and quantity of data supporting the findings[7]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[8]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated, and details of any concerns were identified and listed.[9] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question one: What is the optimal physical environment for the care of bereaved parents/family in maternal and newborn services from the time of bad news, through labour and birth, postpartum, neonatal care, and bereavement?

The physical environment for the care of bereaved parents and family will depend on the timing of the perinatal death, the setting, and model of care. Regardless of the circumstances, physical spaces and surroundings are essential to support good communication and best practice care. The physical environment for the care of bereaved parents should provide “privacy not abandonment” in the form of spaces that balance the needs of the family need for privacy and comfort with their need for access to appropriately trained healthcare professionals.[1]

Appropriate spaces need to be available for conducting difficult conversations across the full spectrum of care.[10] Every service providing maternity care should have an appropriate safe space available 24/7 for parents from the time they come into the service and throughout their care. Specific spaces should be available for breaking bad news and all subsequent discussions with parents around care planning that allow for uninterrupted time.

Maternal and newborn service setting can often be a loud and busy place of care and is not considered an ideal environment for bereaved parents and family.[11] Families appreciate having the same environment, as well as care provider, from diagnosis to birth. Changes in locations and care provider intensify feelings of disorientation and shock.[12] An unsuitable hospital environment and lack of privacy (such as a noisy emergency department) for breaking bad news regarding pregnancy loss can exacerbate the distress felt by women and partners.[13,14] Inappropriate spaces for these conversations, such as hospital corridors, staff areas, or postnatal wards, can add to the distress and trauma experienced by bereaved parents and families. In the maternity emergency room, it may not be possible to differentiate women experiencing pregnancy loss (miscarriage or stillbirth) until a diagnosis is made, therefore these women may be in the waiting room together with labouring or postnatal women.[14,15]

It is important to create a space for families where they can be cared for and express their pain and grief without interruption. Being in the wider maternity area may increase parents' feelings of stress and isolation when being attended by healthcare professionals unfamiliar with their bereavement.[16] While it is recommended that quiet private environments for bereaved families, ideally in a dedicated room away from busy maternity unit wards or emergency department waiting rooms are made available, in both inpatient- and outpatient-settings, it is also important to ensure that parents do not feel isolated or abandoned.[14] Having individual consultation rooms to notify a woman of a stillbirth represents a challenge for many hospitals including in HICs.[17]

Around the time of birth, a designated bereavement suite for parents is considered ideal.[10] This should be a purpose-built room that is separate from busy birth suites and wards, but with access to staff for necessary physical and emotional care. Some mothers may prefer the option of care away from the maternity ward, but this should not be assumed suitable for all. For some mothers, being away from the maternity ward may be experienced as isolating or reinforce a sense of failure from a lack of recognition of status as a mother.[10] It is therefore important to establish what parents would prefer. In settings where a designated bereavement suite is not available, suitable areas must be made available to ensure parents have privacy to support each other.

In the hospital environment there are very few options for parents to manage the time before the birth is induced. After perinatal loss, mothers may be given medication to induce labour and asked to return home, or to wait on the ward with other mothers who are waiting to birth their live baby.[18] Care providers should be supported to prepare parents for the birth of their baby, by adequately explaining what to expect during birth. Parents should be given the option to induce labour immediately or return to the hospital later after spending some time at home. While some families appreciate having the time to return home for an evening, others may want to start the birthing process right away.[19]

Changes at different organisational levels are needed to accommodate parents' needs of being together and in a private space when their baby passes away, to allow adequate time to process the news.[20] Kindness and compassion, alongside out of the box thinking are integral to parents feeling supported in caring for their baby. Parents express frustration when their baby is ignored by hospital staff. It is appreciated when healthcare professionals treat their baby like any other baby by holding and talking to the baby.[21] Parents appreciated care providers' transparency in acknowledging their own uncertainty in providing care.[21]

Describing the period after perinatal loss, parents expressed their appreciation for clarity, time, an appropriate space, and directness from healthcare professionals on what procedures were going to be taking place [19]. Parents also expressed gratitude when allocated a room in a separate area away from the cries of other babies or the conversations of those after live birth.[14,15,19] Parents appreciate it when hospital staff make efforts to create a compassionate environment such as, by soundproofing grieving parents' rooms, displaying respectful signage on doors to indicate a baby has died, removal of posters with newborn photos, closing doors with crying babies, and facilitating the timing of discharge to avoid seeing other families with their living babies.[22] Sharing the same physical space with other women with healthy infants, the absence of information, monitoring, and psychological care make it difficult to overcome the loss.[16] Appropriate space should also be identified for all follow-up appointments and documented in care plans. Parents may find it distressing to return to the unit where their baby was born for follow-up meetings.[10] This should be considered when choosing the location of meetings with parents.

Considerations for low resourced settings

One study conducted in the Sub-Saharan African region showed that it was common for parents to be left unattended during birth in these settings.[20] Being left alone following the notification of their baby's death increased women and families' sense of vulnerability. Further, death was often disclosed in open spaces such as labour ward, obstetric theatre, radiology rooms, antenatal clinics, or the postnatal ward, where privacy could not always be guaranteed. Learning about their baby's death accidentally, in a place with limited privacy, exacerbated the distress felt by parents, particularly when the news could be heard by other families and health care workers. Parents who received the news in in a separate room, scanning room, or doctor's office appreciated having time to privately mourn. It is recommended that hospital management should consider innovative ways of finding private space for these families, including upgrading existing protocols to accommodate parents' needs to be together and in a private space during notification of death.[20]

Question two: How can healthcare professionals meet the wishes and preferences of parents/family while still ensuring a safe and appropriate place of care?

Acknowledging that respectful and supportive perinatal bereavement care is a responsibility shared between the organisation and individual healthcare professionals is critical to developing environments that enable and support sustainable best practice care.[10] Although healthcare professionals strive to provide private and supportive environments, many feel unsupported by their organisations to provide the adequate space and surroundings for newly bereaved parents and families. Many healthcare professionals acknowledged the difficulties of the busy clinical environment, but they also recognised the importance of finding the time and being with the mother.[23] The recent COVID-19 pandemic had significant implications on the ability of healthcare professionals to support parents and families with a safe and appropriate place of care and across the continuum of care. Safety precautions including personal protective equipment meant interactions between bereaved parents and healthcare professionals felt impersonal, and in some cases care was perceived as less than adequate.[24] Parents appreciate it when hospitals provide allowances such as flexibility with rules because of their unique situation such as, allowing parents to stay together overnight in the hospital, and to make room to accommodate religious ceremonies.[19]

Care planning

A care plan should be established with parents which is respectful of their perspectives, and facilitates their participation in decision-making, for example around neonatal resuscitation, analgesia, sedation and the treatment of other symptoms. It is important to establish different care plans for different possible scenarios. For example, if the neonate is expected to survive for more than one hour, palliative care plans should be developed with the parents.[22] Similar to end-of-life hospice planning, the act of therapeutic birth planning allows expectant parents the emotional space to discuss their needs with one another and plan for the anticipated death of their child.[25] Ensuring that parents are supported to discuss and engage in palliative care of their baby relies on the ability of healthcare professionals to provide appropriate space for planning and discussion. During neonatal palliative care, comparisons between the dedicated bereavement space and the ward emphasised environmental factors such as the lack of physical equipment, a quiet space away from the rest of the NICU and away from clinical surroundings.[11,14,26-28] Most parents want "a private room for recovery which was quiet and away from healthy newborns" but also a space where health care professionals are able to treat their baby like any other baby.[12]

Care of a stillborn baby is challenging for healthcare professionals where resources are not available to facilitate both care of the baby, and spending time with the parents and family/whānau.[29] Until recently, in many hospitals, standard practice was to place the stillborn baby in a refrigerator, in a cold storage room, or to transport the baby to a cold room during the night, and even during parts of the day when the parents are in the hospital.[19] This is especially challenging when in some cultures, it is, for example, unacceptable to leave a stillborn baby alone in the time leading up to the funeral.[30] Recently in the UK and Sweden, the use of a 'cold cot' or "Cubitus baby" has become widely available,[30,31] which allows the family to spend as much time as possible with their baby. In a study conducted with midwives in Sweden on their experiences of using Cubitus baby, midwives viewed changing the cooling blocks as part of the care of the baby and reported benefits of the families' involvement in this care routine,[30] although some concerns were noted about support being available for parents to maintain and use the cold cot. Families were able to take the cubitus baby home, enabling them to be close to their baby and to create a more natural parent-child situation.[30]

Few parents feel they have enough time and privacy with their baby before they die. Within the perinatal palliative care setting, parents report the speed of deterioration of the baby and business of the neonatal care unit as an obstacle to this.[32] It is vitally important to individualise the care plan for families, considering their individual needs and preferences.[33] In a study on the end-of-life decision making process, healthcare professionals noted that the absence of a separate room to accommodate parents and infants during the decision-making process and before, during, and after death was one of the key barriers to enabling a negotiation between parental request and hospital policy.[28] The balance between parental involvement in neonatal care and postpartum maternity care should be addressed by organisations to support health care professionals and staff. Facilitation of care pathways that allow the mother's care alongside care of their infant with a lethal diagnosis ensures family-centred postpartum care and maximises quality time together with their infant.[34] Parents should also receive support to perform, if they so wish, religious ceremonies or rituals according to their beliefs. Most parents value spending time with their child during ceremonies and rituals and perceive this as a positive life experience that they can cherish later.[22]

Flexibility and capacity for family support person(s)

Parents need to make a number of decisions which require support from family, and other healthcare professionals. Fathers frequently report lack of facilities for them to stay overnight or receive adequate support.[15] During the COVID pandemic, in a UK study, many women commented on instances of separation from their partners such as, during scans whereby partners had to remain in cars while women sought care. Restrictions such as these, made women fearful they might have to deliver their miscarried or stillborn baby alone.[24] While fathers and partners were usually able to stay during labour, some parents experienced difficulty negotiating the presence of their preferred birthing partners, which added to the distress of starting labour knowing their baby had died.[24] It is important that provisions are made to enable parents to stay together and to provide personalised care.[35,36]

Ways of integrating the deceased baby into the family history may help mourning processes. However, in a hospital environment, legal and administrative limits may restrict this.[37] Family support, friends, and the presence of other children can help minimise the pain and suffering of parents. Conversely lack of social support increases feelings associated with grief.[16] Parents express their need for friends and family members to be at the hospital, to be with the family, and meet the baby.[19] Some parents felt that involving the rest of the family enabled them to participate in something positive.[37] Parents are encouraged to include the newborn's life, however short, as a part of their family narrative, which includes honouring the family ties, and recognising a big brother and big sister role through family presence at the hospital.[25] These contacts with family and friends were also curtailed during the COVID-19 pandemic due to the lockdown restrictions.[24] Hospital management should consider innovative ways of findings private space for these families and their support networks, including upgrading existing protocols to enable parenting of the baby with family, if desired.[20]

Grey literature and other sources

Note. Grey literature is not included in the GRADE assessment of the evidence-based recommendations.

In addition to the published academic literature, both international and national government agency and parent support organisation (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to space and surroundings at the time of stillbirth or neonatal death. A targeted Google search was also conducted using a combination of the following keywords: space and surroundings following stillbirth; space and surroundings following neonatal death; space and surroundings following perinatal death; hospital spaces for parents following stillbirth. The findings of the grey literature are supported by both the current and previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*.

Parents should be well-informed and provided with information about the available options and places where they can choose to give birth. These places will vary depending on the woman's medical condition and history, and discussions should include the potential risks and benefits of each option.[38,39] Healthcare professionals should encourage women to involve anyone they wish in their planning and decision-making. This may include their partner, other family members, carers, friends or consumer advocates (e.g. social worker). Most health services will have liaison officers available such as Aboriginal and Torres Strait Islander liaison officers, who can help support parents and provide them with the appropriate information.[40]

In Australia and the UK, maternity care services should have a dedicated, private space for bereaved parents. Ideally, these rooms will be soundproof and away from other mothers and newborn babies who may be heard crying.[38,39] Healthcare professionals are encouraged to let parents have as much privacy and alone time in these spaces as they need (or for as long as what is possible). Dedicated spaces should also be able to accommodate any support people requested by the parents.[38] If quiet and private spaces are unavailable, healthcare professionals should prepare parents and let them know that they may encounter some distressing sights or sounds (e.g. live babies and babies crying) on the way to where they will receive care.[38] In Victoria, Australia, the state government are currently working with maternal health services to improve health outcomes for women, which may include additional bereavement spaces where new maternity facilities are being built, or in existing services where building upgrades are being planned.[41]

In some cases, parents may wish to continue with a pregnancy after their baby has been diagnosed with a life-limiting condition. During this time, parents will need special care and ongoing support, particularly during labour and birth. If possible, referrals should be made in advance to a local hospice or palliative care service.[38] This is essential for parents who wish to care for their baby at home once it is born.[40]

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies		GRADE-CERQual overall confidence rating of evidence	Guideline recommendations
		See Section 8: Technical report for organisational recommendations for evidence appraisal.	**Evidence-based recommendation 8.5:** Ensure a designated private and safe place is available for bereaved parents and family/whānau whose baby has died or is receiving palliative care. This includes capacity and resources to support: • parents to spend time with and create memories with their baby including mementos and other keepsakes • family/whānau members and other support people to gather • cultural, religious, and spiritual rituals or ceremonies.
Colwell 2017 Dombrecht 2020 Paize & MacWilliam 2020 Helps et al. 2020 Nuzum et al. 2017 Paraíso Pueyo et al. 2021	King et al.2021 Czynski et al. 2021 Berry 2021 Martín-Ancel 2022 Listermar et al. 2020 Smith et al. 2020	Moderate confidence *No or minor concerns of coherence, minor concerns of relevance and adequacy of data, moderate concerns of methodological limitation.*	**Evidence-based recommendation 3.14:** Enable parents and family/whānau to spend as much time as they wish in private with their baby who is dying or who has died, including the option to take their baby outside into the natural environment, home, or to another place important to family. • For a baby who has died, discuss practical matters with parents when they are ready, including care and transport of the baby's body, use of 'cold cots', and relevant legal issues. • For a baby with a life-limiting condition, consider and offer the option of perinatal palliative care in the family home, involving palliative care teams if available and ensuring parents have the support they need.

Table 4. Search strategy

Database	Search strategy	
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/
	2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.
	5	1 or 2 or 3 or 4
	6	*bereavement/ or *bereavement support/ or *social support/
	7	(Environment or surrounding* or privacy or "room in" or "rooming in" or ((separate or "purpose built" or dedicat* or adjacent or devot* or assign* or mourn*) adj4 (space or suite or ward or place or location or area)) or ((take or taking or go or going or tranf*) adj2 home)).ti,ab.
	8	6 or 7
	9	*birthing position/ or *birthplace/ or Delivery, Obstetric/ or Labor, Obstetric/ or Parturition/
	10	(peripartum or "peri partum" or ((during or undergo* or time or place or (environment* adj2 (of or for or around or contribut* or comfort or care or home*))) adj3 (deliver* or induction or labor or labour or parturition or birth* or childbirth or (uter* adj4 contraction*)))).ti,ab.
	11	("bad news" or "truth telling" or "difficult news" or "unexpected news" or prognosis or ((truth or disclo* or reveal or break* or give or communicat*) adj4 ("prenatal diagnosis" or "unexpected news" or death or loss or negative or prognosis))).ti,ab.
	12	(palliative or "end of life" or goodbye or mourn* or griev* or visit or cost* or econom* (("care for" or hold or attend) adj3 (baby or body or babies or deceased))).ti,ab.
	13	*terminal care/ or Health Communication/ or *transcultural care/ or *indigenous health care/ or *vulnerable population/ or *grief/ or *child parent relation/ or *palliative therapy/
	14	9 or 10 or 11 or 12 or 13
	15	5 AND 8 AND 14
	16	limit 15 to yr-=”2017-Current”
CINAHL	S23 S5 AND S8 AND S21	
	S22 S5 AND S8 AND S21	

	S21 S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20
	S20 (MM "Transcultural Care")
	S19 (MH "Grief") OR (MH "Complicated Grief") OR (MH "Disenfranchised Grief")
	S18 (MM "Special Populations")
	S17 (MM "Parent-Child Relations")
	S16 (MM "Health Services, Indigenous")
	S15 (MM "Palliative Care") OR (MM "Palliative Medicine")
	S14 (MM "Terminal Care") OR (MM "Terminally Ill Patients")
	S13 (MM "Delivery, Obstetric")
	S12 (MM "Birth Setting") OR (MM "Birth Place")
	S11 AB(palliative or "end of life" or goodbye or mourn* or griev* or visit or cost* or econom* (("care for" or hold or attend) N3 (baby or body or babies or deceased)))
	S10 AB("bad news" or "truth telling" or "difficult news" or "unexpected news" or prognosis or ((truth or disclo* or reveal or break* or give or communicat*) N4 ("prenatal diagnosis" or "unexpected news" or death or loss or negative or prognosis)))
	S9 AB(peripartum or "peri partum" or ((during or undergo* or time or place or (environment* N2 (of or for or around or contribut* or comfort or care or home*))) N3 (deliver* or induction or labor or labour or parturition or birth* or childbirth or (uter* N4 contraction*))))
	S8 S6 OR S7
	S7 (MM "Bereavement") OR (MM "Bereavement Support (Saba CCC)") OR (MM "Grief") OR (MM "Hospice Care") OR (MM "Complicated Grief") OR (MM "Personal Loss")
	S6 AB(Environment or surrounding* or privacy or "room in" or "rooming in" or ((separate or "purpose built" or dedicat* or adjacent or devot* or assign* or mourn*) N4 (space or suite or ward or place or location or area)) or ((take or taking or go or going or tranf*) N2 home))
	S5 S1 OR S2 OR S3 OR S4
	S4 AB ((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort)) or "prenatal diagnosis")
	S3 AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) N1 loss*) OR stillb*)
	S2 AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*)
	S1 (MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
Scopus	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*))

	OR (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)) OR (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*) AND (Environment or surrounding* or privacy or "room in" or "rooming in" or ((separate or "purpose built" or dedicat* or adjacent or devot* or assign* or mourn*) W/4 (space or suite or ward or place or location or area)) or ((take or taking or go or going or tranf*) W/2 home)) AND (peripartum or "peri partum" or ((during or undergo* or time or place or (environment* W/2 (of or for or around or contribut* or comfort or care or home*))) W/3 (deliver* or induction or labor or labour or parturition or birth* or childbirth or (uter* W/4 contraction*)))) OR ("bad news" or "truth telling" or "difficult news" or "unexpected news" or prognosis or ((truth or disclo* or reveal or break* or give or communicat*) W/4 ("prenatal diagnosis" or "unexpected news" or death or loss or negative or prognosis))) OR (palliative or "end of life" or goodbye or mourn* or griev* or visit or cost* or econom* (("care for" or hold or attend) W/3 (baby or body or babies or deceased)))
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Death] explode all trees #3 MeSH descriptor: [Perinatal Mortality] this term only #4 MeSH descriptor: [Abortion, Induced] this term only #5 (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mortalit*) #6 ((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) ADJ1 loss*) OR stillb*)):ab (Word variations have been searched) #7 ((((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") ADJ3 (terminat* or abortion or abort)) or "prenatal diagnosis")):ti,ab,kw #8 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 #9 ((Environment or surrounding* or privacy or "room in" or "rooming in" or ((separate or "purpose built" or dedicat* or adjacent or devot* or assign* or mourn*) ADJ4 (space or suite or ward or place or location or area)) or ((take or taking or go or going or tranf*) ADJ2 home))):ti,ab,kw #10 MeSH descriptor: [Bereavement] explode all trees

	#11	MeSH descriptor: [Social Support] this term only
	#12	#9 OR #10 OR #11
	#13	MeSH descriptor: [Parturition] explode all trees
	#14	MeSH descriptor: [Delivery, Obstetric] this term only
	#15	MeSH descriptor: [Labor, Obstetric] explode all trees
	#16	MeSH descriptor: [Palliative Care] this term only
	#17	MeSH descriptor: [Perinatal Care] explode all trees
	#18	MeSH descriptor: [Health Services, Indigenous] explode all trees
	#19	((peripartum or "peri partum" or ((during or undergo* or time or place or (environment* ADJ2 (of or for or around or contribut* or comfort or care or home*))) ADJ3 (deliver* or induction or labor or labour or parturition or birth* or childbirth or (uter* ADJ4 contraction*))))):ti,ab,kw
	#20	(("bad news" or "truth telling" or "difficult news" or "unexpected news" or prognosis or ((truth or disclo* or reveal or break* or give or communicat*) ADJ4 ("prenatal diagnosis" or "unexpected news" or death or loss or negative or prognosis)))):ti,ab,kw
	#21	((palliative or "end of life" or goodbye or mourn* or griev* or visit or cost* or econom* (("care for" or hold or attend) ADJ3 (baby or body or babies or deceased)))):ti,ab,kw
	#22	MeSH descriptor: [Grief] explode all trees
	#23	MeSH descriptor: [Vulnerable Populations] explode all trees
	#24	#13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23
	#25	#8 AND #12 AND #24
Informit Indigenous Collection	[All Fields: bereavement OR All Fields: mourn* OR All Fields: griev* OR All Fields: grief OR All Fields: place* OR All Fields: suround* OR All Fields: environment*] AND [All Fields: death OR All Fields: dies OR All Fields: dead OR All Fields: 'sorry business'] AND [All Fields: baby OR All Fields: stillb* OR All Fields: neonat* OR All Fields: child] AND Publication Date: (01/01/2017 TO 12/31/2018)	
PubMed	15	#14 AND #9 AND #5
	14	#10 OR #11 OR #12 OR #13
	13	"Birth Setting"[Mesh] OR "Palliative Care"[Mesh] OR "Parent-Child Relations"[Mesh] OR "Vulnerable Populations"[Mesh] OR "Transcultural Nursing"[Mesh] OR "Health Services, Indigenous"[Mesh] OR "Health Care Costs"[Mesh]
	12	(palliative[Title/Abstract] OR "end of life"[Title/Abstract] OR goodbye[Title/Abstract] OR mourn*[Title/Abstract] OR griev*[Title/Abstract] OR visit[Title/Abstract] OR (("care for"[Title/Abstract] OR hold[Title/Abstract] OR attend[Title/Abstract]) AND (baby[Title/Abstract] OR body[Title/Abstract] OR babies[Title/Abstract] OR deceased[Title/Abstract]))
	11	("bad news"[Title/Abstract] OR "truth telling"[Title/Abstract] OR "difficult news"[Title/Abstract] OR "unexpected news"[Title/Abstract] OR prognosis[Title/Abstract] OR ((truth[Title/Abstract] OR disclo*[Title/Abstract] OR reveal[Title/Abstract] OR break*[Title/Abstract] OR give[Title/Abstract] OR communicat*[Title/Abstract]) AND ("prenatal diagnosis"[Title/Abstract] OR

		"unexpected news"[Title/Abstract] OR death[Title/Abstract] OR loss[Title/Abstract] OR negative[Title/Abstract] OR prognosis[Title/Abstract]))) (peripartum[Title/Abstract] OR "peri partum"[Title/Abstract] OR (("environment of"[Title/Abstract]) AND (deliver*[Title/Abstract] OR induction[Title/Abstract] OR labor[Title/Abstract] OR labour[Title/Abstract] OR parturition[Title/Abstract] OR
	10	birth*[Title/Abstract] OR childbirth[Title/Abstract] OR "uterine contraction"[Title/Abstract]))
	9	#6 OR #7 OR #8
	8	("Bereavement"[Mesh]) OR ("Grief"[Mesh] OR "Disenfranchised Grief"[Mesh])
	7	("Environment"[Title/Abstract] OR "surrounding*"[Title/Abstract] OR "privacy"[Title/Abstract] OR "room in"[Title/Abstract] OR "rooming in"[Title/Abstract]) AND (english[Filter])
	6	("separate space"[Title/Abstract] OR "Separate ward"[Title/Abstract] OR "separate place"[Title/Abstract] OR "Separate location"[Title/Abstract] OR "separate area"[Title/Abstract] OR "purpose built"[Title/Abstract] OR ((dedicate*[Title/Abstract] OR adjacent[Title/Abstract] OR mourn*[Title/Abstract]) AND (space[Title/Abstract] OR suite[Title/Abstract] OR ward[Title/Abstract] OR place[Title/Abstract] OR location[Title/Abstract] OR area[Title/Abstract])) OR "take home"[Title/Abstract] OR "taking home"[Title/Abstract] OR "go home"[Title/Abstract] OR "going home"[Title/Abstract] OR "transfer home"[Title/Abstract])
	5	#1 OR #2 OR #3 OR #4
	4	(("fetal malformation"[Title/Abstract] OR "congenital abnormality"[Title/Abstract] OR "fetal anomaly"[Title/Abstract] OR "congenital anomaly"[Title/Abstract] OR "fetal anomalies"[Title/Abstract] OR "congenital anomalies"[Title/Abstract] OR "prenatal diagnosis"[Title/Abstract]) AND (terminat*[Title/Abstract] OR abortion[Title/Abstract] OR abort[Title/Abstract]))
	3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])
	2	("Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*" [Title/Abstract])
	1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]
Australian Indigenous HealthInfoNet	(grief OR mourning) AND (environment OR place) AND ("sorry business" OR baby)	

Table 5. Study characteristics

Study ID	Country (period)	Locality (state/ national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Amin 2019	India (Jan–Nov 2015)	Tertiary care centre in Mumbai	Hospital records	LMIC	Quantitative	NA	Prospective observational	100	Stillbirth	The most effective method of induction of labour in the case of intrauterine foetal death	Refusal of consent for inclusion in the study	Intrauterine foetal death after 20 weeks of gestation but not in labour; singleton pregnancy	Checklist for case series studies
Bailey 2022	Australia (2010-2015)	Western Australia	Population health datasets.	HIC	Quantitative	NA	Retrospective cohort	634	Stillbirth	Factors associated with c-section following antepartum stillbirth	NA	All singleton antepartum stillbirths ≥20 weeks gestation in Western Australia, 2010–2015	Checklist for cohort studies
Berry 2021	USA (2019)	Online website	Parent interviews	HIC	Qualitative	Grounded theory	NA	3 within this sub-analysis of a larger study	NND (n=3)	Palliative care following birth of a live neonate and subsequent	None	Parents able to communicate in English, over 18 years of age, and not	Checklist for qualitative research

										discharge home		currently pregnant. Parents who had previously experienced a pregnancy complicated by anencephaly	
Boyle 2017	USA (March 2006-Sept 2008)	59 hospitals in 5 geographically defined catchment areas	Hospital records	HIC	Quantitative	NA	Retrospective case series	611	Stillbirth	Delivery management of singleton stillbirths	Women with multiple gestations. Women were excluded if incarcerated or if informed consent could not be obtained	Women residing within one of the geographic catchment areas, with singleton stillbirths at or after 20 weeks gestation enrolled in the Stillbirth Collaborative Research Network study from March 2006-Sept 2008.	Checklist for case series studies

Brierley-Jones 2018	England (2014–2015)	Three hospitals in Northeast England	Focus groups, semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	60	Stillbirth	Views of health professionals and healthcare staff across three hospitals in the management of stillbirth	NA	Consultant obstetricians, trainees, midwives, midwife sonographers and chaplains	Checklist for qualitative research
Christou 2021	Afghanistan (Oct–Nov 2017)	3 high-volume referral maternity hospitals in Kabul and 2 lower-level health facilities and surrounding communities in 2 rural districts ~25–30 km west and north of Kabul city	Interviews	LIC	Qualitative	Deductive thematic analysis	NA	55 (21 mothers, 9 fathers, 3 female community elders, 20 healthcare professionals, 2 government officials)	Stillbirth	Parents' and healthcare professionals' experiences of care after stillbirth	NA	Women and men experiencing stillbirth, community female elders, healthcare professionals, and key informants including government officials, hospital directors, chiefs of wards	Checklist for qualitative research

Colwell 2017	UK	Northwest of England	4 Discussion sessions, and 2 simulation scenarios	HIC	Qualitative	Simulation	NA	Not reported	Neonatal death care training, building confidence in care during infant bereavement	The influence of simulation built into training programs	Not reported	Not reported	Checklist for qualitative research
Czynski 2021	USA (2019)	Tertiary Hospital	Feedback from staff (questionnaire)	HIC	Qualitative	Exploratory post-implementation acceptability	NA	2	NND	Description of the "Mother Baby Comfort Care Pathway" where mothers and families can room-share with their dying infant. Feedback from Nurses who attended training sessions and cared for families who opted into the	None mentioned	Aspects of the care pathway. Feedback from nurses who attended training sessions on the care pathway and cared for families who opted into the care model.	Checklist for qualitative research

										care model			
D'Angelo 2021	Multiple (2021)	International literature	Literature (Medline)	NA	Qualitative	Narrative review	NA	23 studies	Stillbirths	Effectiveness of caesarean section in preventing stillbirths in mothers with COVID-19.	Studies about biology, anaesthesiology, and necroscopy	Studies published in English regarding the mode of delivery in pregnant women infected with COVID-19 and neonatal outcomes	Checklist for text and opinion papers [d]
Dathan-Stumpf 2021	Germany (2016–2019)	University hospital	Patient files	HIC	Quantitative	NA	Non-comparative study	164	TOPFA	Approaches to termination of pregnancies ≥21 weeks' GA and complications.	Multiple pregnancies. In addition, one patient with an abnormally invasive placenta (s/p caesarean section), in whom the fetus and placenta were delivered after six	Termination of singleton pregnancies ≥21 weeks' GA carried out at Leipzig University Hospital between 2016 and 2019.	Checklist for case series studies

											weeks following a two-stage approach with preservation of the uterus, was also excluded from the study.		
Dombrecht 2020	Belgium (Dec 2017–Jul 2018)	Four tertiary hospital NICUs	Interviews & questionnaires	HIC	Qualitative	Thematic analysis	NA	30	NND	Barriers to and facilitators of end-of-life decision making by Neonatologists and Neonatal Nurses in neonates	None mentioned.	Neonatologists working as resident physicians at one of four Flemish NICUs (university hospitals of Ghent, Brussels, and Leuven, and general hospital Sint-Jan Bruges) between December 2017 and July 2018 who had	Checklist for qualitative research

											been the attending/ treating physician to at least one child who had died at the NICU where an ELD was made in the past year, and nurses who had been the most involved.	
Helps 2020	Ireland (2005-2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	Stillbirth, NND	Bereavement care provided to families following perinatal death/ pregnancy loss as described in national inquiry reports	None stated	National inquiries into perinatal deaths/ pregnancy loss services between 2005 and 2018.	Checklist for qualitative research
Horey 2021	40 countries (Dec 2014–Feb 2015)	NA	Survey	HICs and MICs	Quantitative	NA	Descriptive	3041	Stillbirth	Bereavement care practices after stillbirth in	Stillbirth >5 years prior to completin	Self-reported stillbirth ≤5 years prior to	Checklist for studies reporting prevalence data [e]

										high and middle-income countries	g the survey	completing the survey	
Hvidtjørn 2021	Denmark (2012-2018)	A midwifery-led specialised unit for bereaved parents at Aarhus University Hospital in Denmark	Hospital electronic health records	HIC	Quantitative	NA	Descriptive cross-sectional	579	Miscarriage (>14 weeks), missed abortion (>14 weeks), termination of pregnancy (>14 weeks), stillbirth, NND	Clinical characteristics of women admitted to a specialised unit for bereaved parents and characteristics of women who stayed more than 2 days	NA	All women who experienced spontaneous pregnancy loss after 14 weeks gestation, TOPFA, intrauterine death, or intrapartum death between January 1, 2012, and December 31, 2018. Women who experienced the death of a newborn in the NICU within the first 48 hours after birth and	Checklist for studies reporting prevalence data

												desired a stay in the unit were included.	
Kerns 2018	USA (2009-2013)	University of California, and University of Michigan	Interviews	HIC	Qualitative	Modified grounded theory	NA	36	TOPFA	Women's experiences of being counselled about the diagnosis and options for termination in the setting of fetal anomalies and pregnancy complications, factors associated with making their decision, how they experienced their decision process	None mentioned	Women undergoing termination of pregnancy at the University of California and the University of Michigan were eligible for the study if they were between 14- and 24-weeks' gestational age, over 18 years of age, and English speaking.	
King 2021	USA (dates not reported)	National	Interviews	HIC	Qualitative	IPA	NA	8 couples/ 16 individuals	Stillbirth	Experience of stillbirth and their	None mentioned	Intact couples, 18 years or older at	Checklist for qualitative research

										hospital encounter for couples		the time of stillbirth, married for at least 6 months at the time of stillbirth, biological parents of the stillborn, English-speaking, within 10 years of the stillbirth, and able to take part in the interview together	
Listermar 2020	Sweden (2014–2016)	40 maternity clinics in Sweden	Open-ended response on questionnaire	HIC	Qualitative	Content analysis	NA	110	Stillbirth	Midwives' experience of using cold cots	None mentioned	Midwives using cooling cot (Cubitus baby) while caring for parents of a stillborn child	Checklist for qualitative research
Martin-Ancel 2022	Spain (dates not reported)	National	Literature	HIC	Qualitative	Narrative review	NA	NA	Stillbirth, NND, TOPFA	Guidelines for perinatal	None mentioned	Characteristics of palliative	Checklist for

										palliative care		care for perinatal life limiting and life-threatening diseases	qualitative research
Nuzum 2017	Ireland (2008–2013)	1 tertiary maternity hospital	Interviews	HIC	Qualitative	IPA	NA	17 parents (12 mothers, 5 fathers)	Stillbirth	Communication of bad news to parents following a diagnosis of stillbirth	None mentioned	Parents of babies who had received a diagnosis of stillbirth were purposively sampled from three years - 2008, 2010 and 2013	Checklist for qualitative research
Paraíso Pueyo 2021	Multiple (2018–2019)	International literature	Literature: 4 databases	HIC	Qualitative	Scoping review	NA	9 papers	NND	Nursing interventions to help parents of neonates admitted to NICUs cope with perinatal loss	Studies relating to stillbirth, TOP for non-medical reasons, miscarriage	Studies published between 2000 and 2019 that included mothers and/or fathers and/or the immediate family who have experienced the death of	Checklist for systematic reviews and research syntheses

											an infant in the perinatal period in a NICU. Papers written in Spanish whose title and abstract had also been written in English.	
Paize 2020	UK (Jan 2010–Dec 2015)	Liverpool Women's Hospital	Postal survey	HIC	Mixed methods	Content analysis	Descriptive statistics (%s)	26	NND	Parents' experience of end of life and bereavement care in NICU	None mentioned	Parents whose baby died in the neonatal unit of the Liverpool Women's Hospital between Jan 2010 and Dec 2015	Checklist for qualitative research
Ravaldi et al. 2018	Italy (2009-2015)	National (11 hospitals)	Hardcopy survey questionnaire	HIC	Quantitative	NA	Cross-sectional study	674	Stillbirth	Current practices of healthcare professionals caring for women experienci	NA	Practicing midwives, obstetricians, nurses, and psychologists of the obstetrics and	Checklist for analytical cross-sectional studies [f]

										ng a stillbirth and to explore their training needs		gynaecology wards in 11 Italian hospitals	
Rossi 2019	USA (2014)	National	National Center for Health Statistics	HIC	Quantitative	NA	Retrospective cohort	16,160	Stillbirth	Rate of caesarean delivery in pregnancies complicated by antepartum stillbirth and characteristics associated with caesarean delivery	Multifetal gestations; if data on mode of delivery was missing; GA less than 16 weeks; if the patient was diagnosed with an intrapartum fetal demise or was in spontaneous labour at the time of stillbirth diagnosis, or if the birthweight was less than 50 g	Stillbirths occurring at 16 weeks of gestation or greater	Checklist for cohort studies

Siassakos et al. 2018	UK (2013)	Three maternity hospitals	Interviews, focus groups, service provision data	HIC	Qualitative	Thematic analysis	NA	Parents of 16 stillborn babies, 22 maternity staff	Stillbirth	Views of bereaved parents and maternity staff to improve bereavement care for families	Twin pregnancy and loss, intrapartum stillbirth	Parents with a stillborn baby (gestational age more than 23 weeks, 6 days)- singleton stillbirths with the fetal death diagnosed before the onset of labour, maternity staff	Checklist for qualitative research
Smith, Vasileiou & Jordan 2020	UK (Sept 2016–Aug 2017)	Two parent support organisations, 4 clinical sites	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	28 (10 couples, 18 mothers)	Miscarriage, stillbirth, NND, TOPFA	Parents' healthcare experiences before, during and after their baby's death between 20 and 23+6 weeks of gestation	None mentioned	Parents whose baby died before, during or shortly after birth at 20+0 to 23+6 weeks of gestation.	Checklist for qualitative research
Tomlinson 2018	UK (2013-2016)	13 maternity units in North	Clinical audit questionnaire	HIC	Mixed methods	NA (no qual data presented)	Descriptive case study	89 (29 stillbirths audited in 2014, 29 in 2015	Stillbirth	Evaluation of integrated care pathway	None mentioned	2 cases from each of 13 maternity units in	Checklist for case report studies

		West of England						and 31 in 2016)		program for stillbirth management		Northeast England	
Wool 2019	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND, miscarriage	Integrated system of care for perinatal bereavement	NA	NA	Checklist for text and opinion papers

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative resear; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data.

Figure 1. PRISMA flow chart of screening evidence

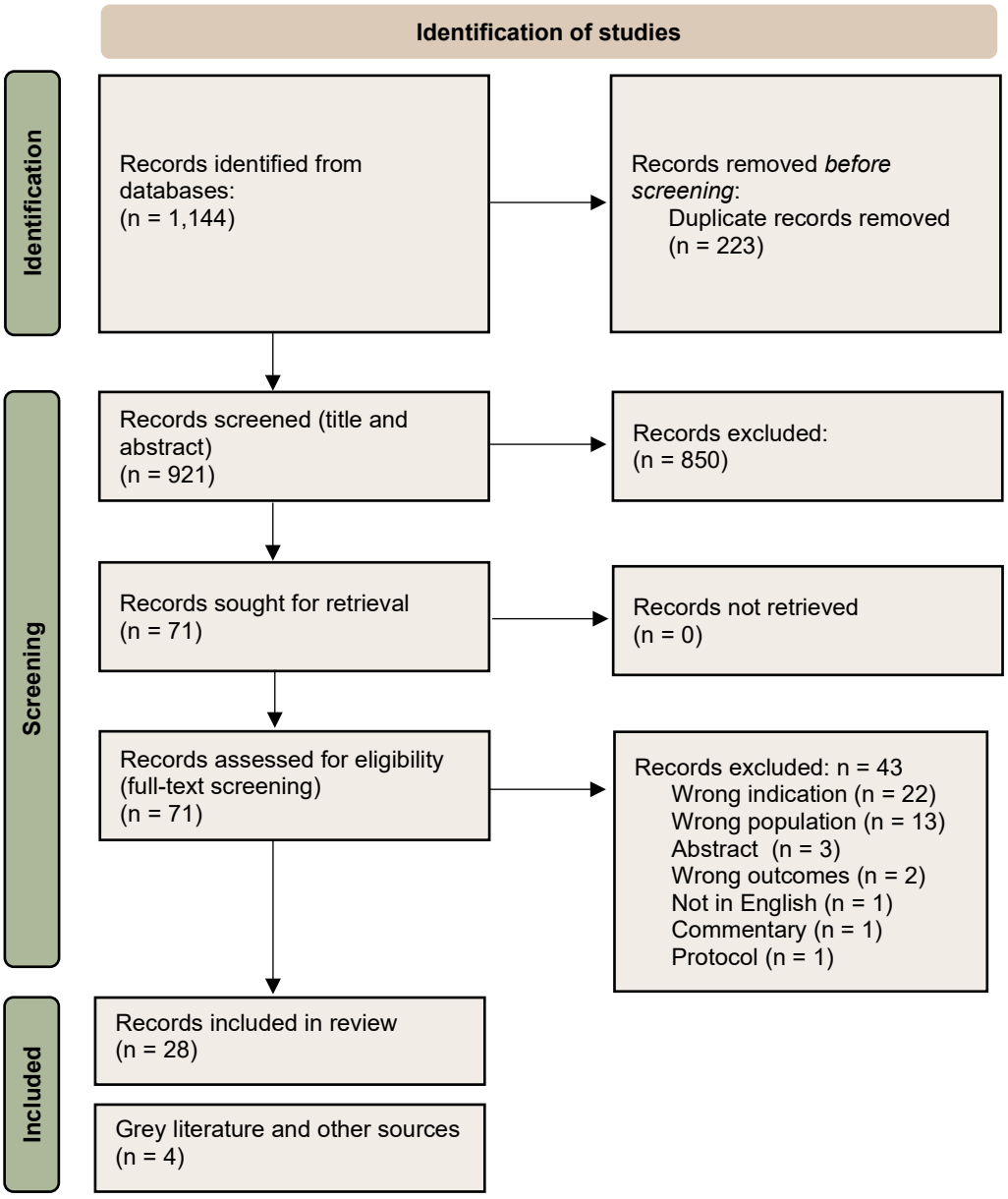

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall appraisal	Relevance
Berry 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Brierley-Jones 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Christou 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Colwell 2017	No	No	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	U
Czynski 2021	Unclear	No	Yes	No	No	No	No	No	Unclear	No	Include	U
Dombrecht 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	R
Helps 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R

Kerns 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
King 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Unclear	Yes	Include	R
Listermar 2020	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	P
Martin-Ancel 2022	Unclear	Yes	Yes	Yes	Yes	Unclear	No	NA	NA	Yes	Include	R
Nuzum 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Paige 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	R
Siassakos et al. 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	R
Smith 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Smith, Vasileiou & Jordan 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimize errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Paraíso Pueyo 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	No	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Ravaldi 2018	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Horey 2021	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	NA	Include	R
Hvidtjørn 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/sources logically defended?	Overall appraisal	Relevance
D'Angelo 2021	Yes	Unclear	Yes	Yes	Yes	NA	Include	U
Wool 2019	Yes	Unclear	Yes	Unclear	Yes	NA	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Bailey 2022	Yes	Yes	Yes	No	No	Yes	Yes	NA	NA	NA	Yes	Include	R
Rossi 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Na	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Comments (including reason for exclusion)
Amin 2019	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Include	R
Boyle 2017	Yes	Yes	Yes	Unclear	No	Yes	Yes	Yes	No	Yes	Include	R
Dathan-Stumpf 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case report studies

	1. Were patient's demographic characteristics clearly described?	2. Was the patient's history clearly described and presented as a timeline?	3. Was the current clinical condition of the patient on presentation clearly described?	4. Were diagnostic tests or assessment methods and the results clearly described?	5. Was the intervention(s) or treatment procedure(s) clearly described?	6. Was the post-intervention clinical condition clearly described?	7. Were adverse events (harms) or unanticipated events identified and described?	8. Does the case report provide takeaway lessons?	Overall appraisal	Comments (including reason for exclusion)
Tomlinson 2018	No	No	Yes	Yes	No	Yes	No	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
8.5	Ensure a designated private and safe place is available for bereaved parents and family/whānau whose baby has died or is receiving palliative care. This includes capacity and resources to support: • parents to spend time with and create memories with their baby including mementos, and other keepsakes • family members/whānau and other support people to gather • cultural, religious, and/or spiritual rituals or ceremonies.	Twelve studies are included. Of these, 11 are primary qualitative studies and one is a mixed-methods study.	Moderate concerns of methodological limitation through critical appraisal are noted. Seven of the included studies are note dot have no or minor concerns of methodological limitation. Five of the included studies are noted to have moderate concerns of methodological limitation through critical appraisal. Four are qualitative primary studies noted to lack a statement of researcher cultural position, and account for the influencer of the researcher on findings and analysis. Three furthermore are noted	Minor concerns of relevance are noted. Nine of the included studies are deemed relevant to organisational responsiveness to care around stillbirth and neonatal death, and three studies are deemed partially relevant.	Minor concerns of coherence are noted	Minor concerns of data adequacy are noted. Nine studies sourced their cohorts from high-income country populations, two from low-income countries and one from lower middle-income country. Outcomes of interest include stillbirths (n=218), neonatal death (n=30) and composite perinatal mortality outcomes (n=885). The viewpoints contained within the data included are from mothers (n=48), parents (n=161), and healthcare professionals (n=51).	*See Section 8: Technical report for organisational recommendations for evidence appraisal.*

			to lack congruity between the stated philosophical perspective and methods. The included mixed methods study was found to have minor concerns of quantitative methodology, but moderate concerns of the qualitative body of work due to the same reasons for the above studies.			Minor concerns of data adequacy are noted due to inadequate combined cohort size.	
3.14	Enable parents and family/whānau to spend as much time as they wish in private with their baby who is dying or who has died, including the option to take their baby outside into the natural environment, home, or to another place important to family. • For a baby who has died, discuss practical matters with parents when they are ready, including care and transport of the baby's body, use of 'cold cots', and relevant legal issues. • For a baby with a life-limiting condition, consider and offer the option of perinatal palliative care in the family home, involving palliative care teams if available and ensuring parents have the support they need.	Twelve studies were included. Eleven qualitative studies, one systematic review.	Moderate concerns were noted for four qualitative studies included, due to the lack of reported demographic or clinical details of the populations. Major concerns were noted for three of the included qualitative studies due to lack of clinical, demographic, inclusion, or outcome definition measures reported. Minor concerns were noted for the methodology of four of the included qualitative	No or very minor concerns were noted concerning study relevance to this recommendation. 10 of the included 12 studies were assessed to be relevant. Two qualitative studies were deemed to have unclear relevance -one due to the focus of the study findings concerning communication between parents and healthcare professionals during diagnosis, and the other due to the staff education focus of the study findings.	There were minor concerns regarding the coherence of the evidence synthesis and the recommendation. Concerns were attributed to different practices between included populations, concerning transport and legal issues following neonatal death in the separate included studies.	Ten included studies sourced data from high income countries, one from a low-income country, one systematic review included data from a mixture of high-, middle- and low-income countries. The combined populations included 61 neonatal deaths, eight stillbirths, and three studies reported perinatal death without stratification between stillbirth and neonatal death. Three studies report the viewpoint of 142 healthcare professionals, and one study reported including the viewpoint of	Moderate confidence *Moderate concerns of methodological limitations, no or minor concerns of adequacy of data, evidence coherence and relevance.*

		studies due to lack of reporting clinical participant details.		fathers/support person in their population. Two studies reviewed guidelines concerning care around neonatal death, and 2 guidelines were included in the reviews. Minor concerns were recorded concerning the small populations included across studies in forming this recommendation.

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 3: Perinatal loss care: recognition of parenthood

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

The grief experienced by families after the loss of a baby can be long lasting and exacerbated due to the lack of recognition and acknowledgment of the loss and parenthood. Recognition of parenthood includes acknowledgment of the baby, acknowledgment of the bond that parents may have established with their baby, and acknowledgement of their identity as parents.[1]

A unique aspect of perinatal bereavement is the little time, if any, that parents spend with their baby. Healthcare professionals take on a critical role in this context where they can significantly shape parent's grief journey through their actions. Several studies emphasise the importance of supporting parents to make tangible memories with their baby, to see and spend time with them, and engage in commemorative activities.[1] The benefits of these activities have been noted on mother's long-term psychological symptoms.[2-4] Ongoing discussions and consultation with parents are required to determine their needs throughout their bereavement care journey and to ensure families receive respectful, sensitive, and individualised cares. This is also important for parents who experience perinatal loss in twin and multiple pregnancies. Every effort must be made to give the parents and siblings opportunities to make memories with the deceased baby/ies.[5]

Parents will need to make "memories of a lifetime" in a very limited span of time.[6]

While parent's experience of loss is shaped by cultural norms and traditions,[7] all parents value the sensitivity and kindness of healthcare professionals, want their feelings validated, and appreciate when different options are made available to them.[8-10]

Methodology

The Guideline Development Committee developed key research questions around recognition of parenthood for perinatal loss care (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	In what ways can health care professionals acknowledge parenthood and help parents to create positive memories with their baby? Does this support bereavement for parents and families?
2	What mementoes do parents value and how should these be collected? Are there differences (e.g., cultural) between some parents and other parents?
3	What are the unique issues for multiple births where one or more babies has survived?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 2. PICO criteria

PICO	Inclusion criteria

Population	Defined in Australia and Aotearoa New Zealand as:
	• Stillbirth
	  ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion[11,12]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth[11,12]
	• Inclusion of perinatal deaths following termination of pregnancy
	  ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).

Intervention	Studies exploring perinatal loss care following stillbirth or neonatal death in maternal or newborn services.
Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes and experiences of parents, family members, healthcare professionals around perinatal loss care including care that specifically addresses and recognises the identity of parents (recognition of parenthood) following termination of pregnancy, stillbirth, or neonatal loss. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Searches were conducted on 22 August 2022. A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service

settings (e.g. remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus

In addition, the Technical Working Group conducted searches for grey literature, and committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, review (any), editorial, dissertation, or diagnostic evaluation.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- Wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth, or neonatal death as defined in Table 2.
- Wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- Wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- Wrong *language*: The study was not published in English.
- Wrong *publication dates*: The study was published prior to 2017.
- Wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations were drafted by the Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between

September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[13] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[14]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[15]
- Adequacy: The richness and quantity of data supporting the findings.[16]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[17]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated, and details of any concerns were identified and listed.[18] Table 3 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: In what ways can healthcare professionals acknowledge parenthood and support parents to create positive memories with their baby? Does this have a positive impact on bereavement for parents and families?

All parents should be offered the opportunity to parent and make memories with their baby. Memory making activities include opportunities to see, touch and hold the baby, and may also include encouraging parents to participate in typical parenting and caregiving activities, such as changing nappies, feeding, bathing and dressing their baby.[19-21] Parents may wish to engage with their babies through talking, reading, or singing, and taking time to study the details of their baby's appearance to form enduring memories.[21] Research has shown that holding a baby with visible fetal abnormalities was not associated with adverse psychological outcomes, including depression and PTSD up to 36 months after delivery,[22] suggesting that parents should not be discouraged from holding their baby in the presence of visible abnormalities.

Spending time with their baby helps parents create a social identity for their baby as a person, and for themselves as parents, while simultaneously providing an opportunity to say goodbye. Despite this being an intensely emotional experience and traumatic event, parents rarely express regret around spending time with their baby after death,[21,23] with many reporting positive feelings in the process of seeing and holding the baby.[24] Parents appreciate when healthcare professionals facilitate unrestricted, uninterrupted time with their baby.[20,21] Many parents have a desire to have their babies

acknowledged as irreplaceable individuals and appreciate when healthcare professionals use their baby's name, which serves as an acknowledgment of their baby and their unique relationship with them.[25-27] The acknowledgment of a baby as a person and of parenthood also helps validate the profound grief experienced by bereaved parents.[26,28] Acknowledgement of the baby as physically beautiful by healthcare professionals was also important in assuaging parents' fears about seeing their baby.[26,29]

> **"We were emotionally calm. [We] also talked with the baby in a gentle voice." [24]**

> **"I had held [and] touched the baby's hands and feet. Looking at her hands and feet... as [this was] the second pregnancy, [I] would compare [the baby] with [my] elder daughter. [She] had long hands and legs like her elder sister..."[24]**

Some parents can feel uncertain about being with their deceased baby after birth.[30,31]The role of healthcare professionals becomes even more critical in these instances due to the limited amount of time parents have available to create a lifetime of memories.[32,33] Parents may need advice, support, and guidance from healthcare professionals in making decisions about if and how they want to spend time with their baby.[32-35 36]

> **"After delivery the mothers glanced at what I was doing for the stillborn babies..., So, I cared for the stillborn baby slowly in order to allow the mothers to have more time to see... Such as wiping the baby and cleaning it up nicely. Because I had noticed that the parents gazed toward the baby, even they told me not to see the baby at admission, before delivery.... However, before transferring the baby to the mortuary, I would ask them again with respect, some of the parents changed their mind and hugged... In that moment, the stillborn baby to be loved is happiness, if mother missed this only opportunity they might regret in their whole life."[37]**

Parents highly value receiving guidance from healthcare professionals regarding making memories with their baby:

> **"Without her (the bereavement midwife) we wouldn't know how important creating memories of our baby boy were".[6]**

Parents who are not supported in creating positive memories with their baby often report distress.[28,36]

> **"We were so shocked we needed guidance on next steps and our options, and we weren't thinking straight. I wish I was told I could take pictures of him, that I could bathe him, that I could have more time with him...now I am filled with regret that I didn't spend more time with him and take more pictures of him. I wish a doctor/nurse/social worker told me I could do this as I know I would have said yes if given the option".[38]**

It is important that parents are always offered the opportunity to see their baby and make memories and their decisions should be respected no matter what they decide. [28] Parents may sometimes reconsider their initial decision not to see/hold the baby, therefore giving parents guidance, time, and

space is extremely important to avoid regret and guilt when considering their decisions in hindsight.[27,39,40]

Cooling options (e.g. cold cots, manaaki mats) give parents time to make decisions about spending time with and interacting with their baby.[41] Midwives in Sweden positively rated the use of cold cots because the practice allowed bereaved families to develop a bond with their child at the pace they wanted and the time they needed to say farewell to their baby.[42]

For mothers who experience perinatal loss, the ambiguity of giving birth but not having a living baby to love and care for can cause them to self-doubt and question the legitimacy of their role as mothers, putting the socially constructed notion of motherhood in jeopardy.[43] Recognising this complexity, the finite window of opportunity to interact with the baby, and the irreversibility of decisions made in that brief period,[26,27] perinatal bereavement literature and guidelines increasingly recommend bereavement interventions such as memory making interventions that recognise the significance of the loss of the baby as a person, while validating the role of bereaved parents.[21,26,35]Memento photography provides an avenue that helps affirm a baby's identity and promotes a view of the bereaved as parents.[35,44] Where such opportunities are missed, parents may have a sense of the baby only being "real" for them and this is often met with regret.[35,39]

Milk expression and donation has also received attention recently as a potential pathway to make memories and affirm maternal identity following bereavement. Research with bereaved mothers who chose to express and donate their breast milk has shown that it allows mothers to identify themselves as a mother in the absence of their baby.[45,46] Expressing milk sessions were described by mothers, as a time to connect with the memory of their babies and continue the emotional bond with them. It helped women to mourn their loss and create positive memories. It is therefore important that healthcare professionals discuss lactation with bereaved parents and provide options beyond suppression (e.g. keeping milk as memento or donating breast milk) that help honour their motherhood status, maintain connection with their deceased infant, or make meaning after their child's death.[47]

Research about the recognition of parenthood for fathers is sparse. Available evidence clearly highlights the need for fathers to "feel cared for or acknowledged" by healthcare professionals.[48] Similar to mothers, fathers begin to construct their identity as a father-to-be and modify their life plans accordingly. A perinatal death disrupts this new perception of self and the modifications of their life. Fathers are not only suffering the loss of the baby but also their identity as fathers. Several studies have recognised this and called on professionals to acknowledge paternal grief and recognise that they are much more than 'supporters' and 'comforters' of their partners.[49] Fathers appreciate the role of healthcare professionals in helping parents make decisions, such as holding their deceased child and collecting 'tokens of remembrance'.[49] Similarly, within NICU and palliative care settings, fathers appreciated the support healthcare professionals provided to encourage their meaningful and active involvement in infant feeding.[47] While most studies have included only bereaved parents' experience of memory making interventions, research also highlights the importance and value of involving grandmothers in memory making and spending time with the baby, where possible.[50]

The COVID-19 pandemic impacted opportunities for parents to engage in memory-making and parenting. Early research from the UK suggests that blanket changes to policies affecting maternity and bereavement care services are not helpful.[51] Data from Australia suggests that the COVID-19 pandemic may have contributed to lost opportunities for parents, such as introducing their baby to

significant others, opportunities for memory making due to lack of access to professional photographers, restrictions on cultural practices such as ritual washing, and restrictions on funerals and commemorative events.[41] It is important to prioritise quality care in the context of a "health system shock" such as the COVID-19 pandemic, which added to the isolation of an 'already isolating' experience. Some health services responded promptly to minimise these impacts on parents by making various adaptations such as using cold cots to facilitate time for parents to spend with their baby, health professionals taking on more active roles in memory making (e.g. by taking on the role of photographer for families), and providing families with informational resources regarding options for online rather than in-person commemorative events and services.[41] It is yet to be assessed how these adaptations were perceived by parents; however, it highlights the need for practices to be flexible in response to external circumstances so that optimal quality care can continue to be provided to minimise further harm to families.

Research suggests that most parents are overwhelmingly positive about opportunities to see and hold their baby, with positive psychological outcomes reported; however, a small number also describe negative experiences.[23,52] While parents will make different choices in bereavement care, all parents need to be presented with options to make the most appropriate choice for them.[8] All women and their partners should have opportunities to see and hold their babies and to keep linking objects, if they would like.[52] Parents appreciate when they are given choices and explanations by healthcare professionals, asked what they would like, and informed about what is possible in relation to their baby's care before their baby's death.[20,53]

Cultural considerations

While most of the research in this area has been conducted in high-income countries (HICs), different perceptions of stillbirth and neonatal death exist across different contexts. In some contexts, there are taboos around seeing or holding a deceased baby therefore, it is important to consider the cultural context and provide parents the option with adequate time to make the decision.

A couple of international surveys on parents' experiences of care following perinatal bereavement[8] and memory making needs showed that parents report high unmet needs in middle income countries (MICs) compared to HIC.[2] There were substantially more opportunities to make memories, including being able to take the baby home, and to see and hold the baby in HICs. Some differences could be attributed to financial barriers, whereas other differences may reflect cultural and religious beliefs and practices. For example, several studies conducted in LMICs demonstrated differences between parents' and healthcare professionals' perceptions of parents' memory making needs,[23,53,54] with many parents reporting a strong desire to see, hold, and have a memento of their stillborn child; however, they were not often permitted to do so because local practices did not allow the baby to be mourned. This often led to significant grief for bereaved parents. Similarly, some Asian cultures may prevent contact with the deceased baby in accordance with folk taboos.[55] In this context, rituals take on a significant role, allowing women to talk to or do something for their stillborn child, helping ease their guilt and restoring the identities of children and mothers.[55] In addition to opportunities for memory making and parenting their child, parents appreciate midwives' help in facilitating the farewell rituals in accordance with their culture and beliefs.[28,39]

In the context of different individual and cultural needs, it is important that healthcare professionals remain non-judgmental and open to the preferences of bereaved parents and offer information without bias. Parents who initially refuse to see the baby may change their mind. Therefore, healthcare professionals should approach individuals' needs and wishes mindfully and sensitively and

give parents time after first refusing to see or hold their deceased baby in case they change their mind.

Question 2: What mementoes do parents value and how should these be collected? Are there important considerations for healthcare professionals to be aware of when supporting parents and families to create memories with their baby?

Mementoes can help families create meaningful and lasting memories surrounding the death of their baby and are seen as an important aspect of care for bereaved parents.[34] For parents, mementoes can act as evidence of their baby's existence and of their own identity as parents. This can be of lasting importance to many parents and may help validate their experience and acknowledge their loss,[34,56] in the months, years, and decades after their loss.[57] Mementoes can include several different memory items provided to parents and families after the loss of their baby. Many of these items are low-cost or free, such as hospital records that include the baby's birth and weight, identification tags or bands, religious certificates, and birth and death certificates.[4]

Other memory items that are highly valued by parents include items of clothing worn by their baby, ink or plaster footprints or handprints, the blanket their baby was wrapped in, knit hats, locks of hair, and baby/family photographs.[6,34,36,39,58,59] Baby clothes and related textiles such as blankets and soft toys afford and legitimise rituals of sensing, touching, physical contact, caregiving, and intimacy,[60] and assert the identity of the baby as an individual.[34] Many parents also treasure the name card from their baby's cot as a memento, which is also a confirmation of their baby's identity.[35]

The baby's ink-based, clay, or plaster hand- and footprints are also highly valued mementoes by parents because they provide physical evidence of the baby's physicality and size.[35,61]

> **"they are the thing that I touch on a day to day basis the most. And they are definitely the most physical reminder…you can feel the little crevices in her footprints and the like."[35]**

Memory boxes including an assortment of different memory items, as mentioned above are also well received by parents[40,57,62] and should be offered to the families before hospital discharge, along with the contact details of support organisations.[62]

Some parent organisations also offer teddy bears as mementoes, to allow families to leave the hospital without empty arms following the loss of their baby. This can be comforting to some parents and can also be a lasting memento for the siblings who may not yet be at a developmental level to understand the intricacies of death.[4] However, it is important that all parents are supported to choose the options that are most meaningful for them. Not all parents appreciate all mementoes.

Bereavement photography

Several studies have established the high value bereaved parents place on photographs of their baby as a way of validating their experience, the existence of their baby, and their identity as parents.[35,63,64] Photographs also help validate the child's place in the family, create a family legacy, and help parents remember the small details of their child's appearance and family resemblance.[44,64,65]

"It's a validation of being a parent…that this person was here on this planet, and that he lived. He was here very briefly, he had a huge impact on our lives, and that presence is recognized and celebrated in the pictures." (bereaved mother).[64]

Parents also note the importance of photographs in providing permission to share their grief and experience, as they enable difficult conversations with members of the family who could not be present when the child was born.[36,64]

Additionally, the experience of taking the photographs creates positive memories, by providing a special occasion for the family, opportunities to hold the baby, and spend time together as a family.[64] Photographs help parents with the process of mourning,[65] and to cope with their loss by keeping the memory of the child alive,[64] facilitating their continuing bond over time.[57]

Photographs can also be used by midwives as a way of preparing some parents to see their baby .[36] Research capturing nurses' involvement in bereavement photography highlights that it is viewed as a positive and meaningful part of their work with bereaved families. Nurses describe this experience as something tangible to give to families and were satisfied knowing that this might play an important role in the family's healing.[66] Parents appreciate natural and candid photos rather than those that are clinical or staged, even when these captured parents' grief and pain.[35,63]

It is important to note that parents sometimes decline the offer of photography; however, they may request photographs at a later time.[36,39] When this option is not available, it is often a source of regret for parents.[35] Even when the parents choose not to opt for bereavement photography, there may be value in health professionals taking some photographs of the deceased baby and saving them for a specified period of time, in case the parents return when the option is no longer available to them.[4,63]

Breastmilk

For many bereaved mothers, lactation and breast milk hold great value and meaning after the loss of their baby.[67,68] Recent research conducted with bereaved mothers suggests that the ritual of pumping breast milk and milk donation provide comfort and meaning to some grieving families in the immediate postpartum period,[46,68] allowing "*mothers to accept their loss while forming a more integrative experience of their bond with their child*".[69] Some women may also wish to keep a container of milk as a memento.[70] Women can be advised that there are companies that turn breast milk into mementos for a fee, such as beads or pendants.[46]

Cultural considerations

It is also important to consider the diversity of cultural practices regarding the mourning process. Some cultures may have different views regarding the collection of mementoes and taking pictures of the deceased baby.[65] Health professionals must consult with families to ask about their wishes, afford parents opportunities to be leaders in the decision-making process, and enable conditions that allow them to construct mementoes that are important for them, such as including other family members or incorporating cultural or religious rituals.[65]

Studies conducted in different contexts have highlighted the heterogeneity in the cultural and healthcare needs of bereaved parents between and within countries.[4,71] Research conducted in African countries such as Nigeria, Malawi, Tanzania, Zambia, and Ghana suggest that although some women value the opportunity to see and connect with their baby, fewer are interested in taking

photographs or other mementoes.[7,54] Traditional beliefs play an important role in these settings, where there is a cultural ban of touching and keeping anything related to the stillborn baby due to the belief that this could affect future pregnancies. However, some women still desire to keep simple mementoes such as a hospital card and photos of their baby even when health professionals did not facilitate this process and these mementos are generally kept hidden from others including family members to avoid blame for having kept a memory of a stillborn baby.[54] Similarly, in Jordan, mothers were refused the opportunity to create memories with their deceased baby through memento photographs as it was not socially or culturally acceptable. Husbands and the extended families played an influential role in these decisions.[72]

While parents value different practices and mementos offered by healthcare professionals to remember their child, objects may have different meanings for different families. It can sometimes be complex to embed memories in material objects such as, a memory box for all families. For some families, accepting the silence might be as meaningful as words or memory boxes. Thus, it is important that healthcare professionals be attuned to and respectful of individual needs[73] and facilitate family-centred activities that create unique memories and experiences, as guided by the family.[43]

Question 3: What are the unique issues and considerations around care for parents with a twin/multiple pregnancy where one (or more) baby has died?

To date, there is limited research examining the unique experiences and challenges for multiple births where one or more babies has survived. Parents are faced with the task of caring for surviving sibling/s who may not be well while mourning the loss of their baby. A mother who has had a multiple pregnancy continues to think of herself as a mother of twins (or more)[74] and should be validated as such.

In a study conducted by Meaney et al.[75] examining parents' views on the impact of the death of one twin in the perinatal period, parents recounted their immense distress on being initially informed of a complication in pregnancy. Parents began a complex palliative journey when the diagnosis was made, grieving one baby while trying to ensure the welfare of the co-twin. Parents were often encouraged to focus on the surviving twin and felt a lack of validation of their loss. It was important for parents that their surviving twin would be identified as a twin and know of their sibling. However, this was also a reminder of their profound loss and resulted in feelings of deep sadness in parents.

Existing research clearly demonstrates the uniqueness of this type of loss, the need for recognition of their babies as separate individuals, and that the survival of one twin does not compensate or substitute for the loss that parents have experienced.[75]Healthcare professionals must make every effort to provide respectful and sensitive bereavement care to parents in this context, as for singleton stillbirth. Parents should be encouraged to spend extra time with the deceased baby/ies so that precious memories can be created. This includes opportunities to see and hold the baby, make mementoes, and take photographs. Several types of photographs could be taken, of the twins separately and together. When one twin dies in utero, a photograph of the ultrasound scan showing both babies may be a precious memory for parents as parents of twins. Spare photographs should always be kept with the medical records, for parents who initially refuse photographs but may later desperately want one.[74]

Mothers with multiple pregnancies emphasise the importance of emotional support, and acknowledgement and sensitivity of health professionals to their loss while their surviving baby was being cared for. Healthcare professionals, on the other hand reported feeling ill-equipped in dealing with the specific needs of parents in this situation.[76] Over a quarter of healthcare professionals providing support to parents who experienced a loss from a twin pregnancy reported feeling less confident about providing bereavement support compared to providing medical care to families; less than half reported receiving training for supporting parents; and over two-thirds felt more training and further guidelines were required:

> **"I think we quickly forget that the baby we care for is a surviving twin, as soon as the baby has a first name we omit to communicate in any way that this is a twin multiple pregnancy and parents are treated in the same way as those who had a singleton pregnancy. We have guidelines when there is a neonatal death but there are not specific to the loss of a twin." (Neonatal nurse)[76]**

The bereaved parents of a multiple pregnancy have the difficult task of grieving for a lost baby while continuing a pregnancy and after a live birth. Healthcare professionals need to consider the conflicting emotions that parents experience in this unique situation whereby they try to be strong to ensure the health and wellbeing of the surviving baby/ies, while simultaneously grieving the loss of another, and recognise their parenthood as parents of multiple babies.

Grey literature and other sources

In addition to the published academic literature, both international and national government agency and parent support organisation (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to recognition of parenthood following stillbirth or neonatal death. A targeted Google search was also conducted using a combination of the following keywords: recognition of parenthood following stillbirth; recognition of parenthood following neonatal death; and recognition of parenthood following perinatal death. The findings of the grey literature are supported by both the current and previous editions of *the Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*.

According to the World Health Organization and the Partnership for Maternal, Newborn and Child Health, many parents struggle with their sense of worth and identity following stillbirth.[77] Support is needed from both family and healthcare professionals during this time, however it is not always fulfilled. Healthcare professionals can support parents following the loss of their baby by collecting keepsakes that can contribute to memories of their baby. Healthcare professionals should not make assumptions about what should be kept or cleared away in the hospital. Baby equipment, clothes, and toys should be kept as these may be a comfort to parents, and they may want to go through them later at home. Gift tags, baby name bands, cards, and dried flowers should also be kept in case parents want to take them home. If parents are unsure about what they want to keep, healthcare professionals can put items away into a 'memory box' for parents to collect at a later time.[78,79] According to the Sands UK's *National Bereavement Care Pathway for Stillbirth* (2022)[80] and the *Loss and Grief* chapter of the Canadian Family-Centred Maternity and Newborn Care National Guidelines (2020),[81] keepsakes may include:

- handprints and footprints
- a record of baby's weight and measurements
- baby's scan picture
- baby's cot card
- baby's identification bracelet
- baby's cord clamp
- a lock of baby's hair
- an identical set of the clothes the baby has been dressed in
- cards and ribbons from any flowers received
- sympathy cards
- candles
- stuffed animals
- a copy of baby's certificate(s)
- the blanket baby has been wrapped in
- forget-me-not seeds to plant.

Maternity services should have access to facilities that enable framing keepsakes such as locks of hair, handprints, and footprints. Maternal and newborn services and healthcare professionals should also help facilitate photography and framing if parents wish to take photographs of their baby,.[78] Healthcare professionals should always ask the parents before taking photographs of the baby and if they would like the photos to include any visible anomalies or maceration. It should be documented in clinical records if parents decline photographs being taken.[82] For a multiple pregnancy where there

has been a loss, healthcare professionals should offer photographs of all the babies together, as well as with the parents.[82]

Some parents may want to take their baby home or to a special place of significance. Healthcare professionals should always offer and sensitively discuss these options with parents. In some cases, parents may not want to take their baby home, or are unable to (e.g. the death has been referred to the coroner). Parents who do not take their baby home, regardless of the reason, should always be offered a longer stay in hospital.[82]

Healthcare professionals can also support parents to see and hold their baby, as well as washing and dressing the baby. For a multiple pregnancy where there has been a loss, healthcare professionals should ask the parents if they would like to hold the living and dead babies together, if possible. Some parents may value the memory of their babies being together.[82]

Healthcare professionals should ask parents how they would like them to refer to their baby. Some parents will decide to name their baby, which may help them and their family talk about the baby in the future. If parents have named their baby, healthcare professionals should ask if it is okay to use the baby's name in discussions.[82]

It is important for healthcare professionals to remember that this is an overwhelming time for parents, and they will need to think about what activities they would like to do or what to keep, to help them remember their baby. Parents may keep changing their mind about what to do or keep or have different feelings and emotions to their partner. Time needs to be given to enable parents to make the decisions that are right for them.[82]

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Allocated studies		GRADE-CERQual overall confidence rating of evidence	Recommendations
Aiyelaagbe et al. 2017 Atkins et al 2022 Berry et al. 2021 Boyle et al. 2022 Camacho Ávila et al. 2019 Christou et al. 2021 Farrales et al. 2020 Fernández-Medina et al. 2022 Jones et al. 2017 Jones et al. 2019 Lin et al. 2021	Lockton et al. 2020 Noble-Carr et al. 2021 Nuzum et al. 2018 Pollock et al 2020 Salgado et al 2021 Steen, 2019 Thornton et al. 2020 Thornton et al. 2021 Tovey & Turner, 2020	Low confidence *No or minor concerns of coherence and data adequacy. Moderate concerns of methodological limitation and relevance*	**Consensus-based recommendation 3.11:** Validate parenthood and support memory making by: • discussing options and exploring parents' concerns and preferences around parenting activities • offering all parents the opportunity to see and hold their baby immediately after birth, including skin-to-skin contact with their baby and supporting them through the process • normalising and supporting parenting activities such as bathing and dressing their baby • using gentle and caring language and actions when interacting with the baby • asking parents how they would like you to refer to their baby (e.g. by name) • providing parents information about their baby (e.g. weight, length, hair colour) using the same tenderness and respect afforded to any baby • providing opportunities to involve siblings, grandparents, and other family/whānau members • offering parents and family/whānau the opportunity to engage in parenting activities and memory making more than once, while remaining respectful of their decisions.

			Consensus-based recommendation 3.12: Ask parents and family/whānau throughout care about cultural needs regarding perinatal loss practices and handling of their baby's body. Always ask parents and family/whānau permission before handling their baby.
Atienza-Carrasco et al. 2020 Aydin et al. 2019 Ceronsky et al. 2022	Farrales et al. 2020 Jørgensenet al. 2022 Smith et al. 2020	Low confidence *No or minor concerns of coherence and relevance. Moderate concerns of methodological limitation and data adequacy.*	**Consensus-based recommendation 3.13:** Prepare parents for seeing and holding their baby by giving information about the baby's physical appearance, size, tone, and temperature. • Sensitively answer parents and family/whānau members questions and explore concerns. • Discuss preferences for seeing their baby, including use of special blankets, hats, or clothing.
Atkins et al. 2022 Boyle et al. 2022 Hvidtjørn et al. 2021 Listermar et al. 2020 Martínez-Serrano et al. 2019 Murphy & Cacciatore 2017	Nuzum et al. 2018 Redshaw et al. 2021 Steen, 2019 Thornton et al., 2021	Moderate confidence *No or minor concerns of coherence, data adequacy, and relevance. Moderate concerns of methodological limitation.*	**Evidence-based recommendation 3.14:** Enable parents and family/whānau to spend as much time as they wish in private with their baby who is dying or who has died, including the option to take their baby outside into the natural environment, home, or to another place important to the family. • For a baby who has died, discuss practical matters with parents when they are ready, including care and transport of the baby's body, use of 'cold cots', and relevant legal issues. • For a baby with a life-limiting condition, consider and offer the option of perinatal palliative care in the family home, involving palliative care teams if available and ensuring parents have the support they need.
Lewis & Bryan 2018 LeDuff et al. 2017	Meaney et al. 2017 Rankin et al. 2021	Low confidence	**Consensus-based recommendation 3.15**: For parents of twins, triplets, or other multiple births:

		Moderate concerns of relevance, coherence and data adequacy. Minor concerns of methodological limitation.	• provide parents with opportunities to spend time with and make memories with their baby or babies that have died • support parents in their decision making and acknowledge that there may be mixed feelings around spending time with a baby who has died, while also caring for and spending time with the surviving baby or babies • provide parents with culturally and linguistically appropriate resources and support options for the loss of a baby or babies from a multiple pregnancy.
Aiyelaagbe et al. 2017 Camacho Ávila et al., 2020; Charrier & Clavandier, 2019; Hendriks et al., 2022 Jesus et al. 2022 Jones, 2022 Kalanlar 2020 LeDuff 2017 Martel & Ives-Baine, 2018 Martínez-Serrano et al., 2019	Paraíso Pueyo et al., 2021 Porch et al. 2022 Ramirez et al., 2019 Salgado et al 2021 Smith et al. 2020 Steen, 2019 Thornton et al. 2019 Thornton et al. 2020 Tovey & Turner, 2020 Wool et al 2017	Low confidence *Minor concerns of coherence and data adequacy. Moderate concerns of methodological limitation and relevance.*	**Consensus-based recommendation 3.16:** Offer and facilitate opportunities to gather tangible mementos of the baby (e.g. photographs, identification tags, cot cards, locks of hair, handprints and footprints). Memory making should be an option that is offered more than once to parents/family/whānau.
Kalanlar, 2020 LeDuff 2017 Lewis & Bryan, 2018	Martínez-Serrano et al., 2019; Smith et al., 2020	Low confidence *Moderate concerns of methodological limitation, relevance, coherence and data adequacy.*	**Consensus-based recommendation 3.17:** Be aware of local processes for supporting parents and family/whānau who initially choose not to keep mementos. Ensure mementos are stored securely and labelled appropriately in maternal or neonatal records for future access.
			Consensus-based recommendation 3.18: Support and facilitate parents to take a mix of photographs and videos of their baby, including with family/whānau.

			• Ensure photos are taken with sensitivity and are of highest possible quality. • Facilitate access to a professional photographer who has experience in compassionate bereavement photography, if desired by parents.
Atkins et al 2022 Boyle et al. 2022 Camacho-Ávila et al., 2019	Jørgensen et al. 2022 Wong & Ng 2021	Moderate confidence *No or minor concerns of methodological limitation, relevance, and coherence. Moderate concerns of data adequacy.*	Evidence-based recommendation 3.19: Offer and facilitate opportunities for commemorative rituals and acknowledge cultural, religious, and spiritual customs important to families/whānau.
			Consensus-based recommendation 3.20: Sensitively discuss with parents and family/whānau that burial or cremation is a legal requirement for a baby who dies at greater than 20 weeks gestation or weight of 400 g. Provide parents with: • information (including written) that includes the range of available options for burial, cremation, and funeral, and support parents/family/whãnau in their decision making • contact details for relevant services • information about available financial support.

Table 4. Search strategy

Database	Search strategy		
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR ("Abortion, Eugenic"[Mesh]) OR "Abortion, Legal"[Mesh]	Mesh
	#2	"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR “Neonatal loss*” OR “Neonatal mortalit*”OR “Neonatal death*” OR “Neonatal Demise*” OR “Newborn death*” OR “Newborn mortalit*” OR “pregnancy termination” or “termination of pregnancy” or (“fetal malformation” or “congenital abnormality” or “fetal anomaly” or “congenital anomaly” OR “fetal anomalies” or “congenital anomalies” AND (terminat* or abortion or abort))	Title/abstract
	#3	#1 OR #2	
	#4	"Indigenous Peoples"[Mesh] OR "Transients and Migrants"[Mesh] OR "Refugees"[Mesh] OR "Health Disparity, Minority and Vulnerable Populations"[Mesh] OR "Vulnerable Populations"[Mesh] OR "Culturally Competent Care"[Mesh]	Mesh
	#5	parents or mother* or father* or “patient understan*” or “patient need*” or “patient resource*” or “patient experience*” or “patient view*” or "patient decision-making" or "patient decision making" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or “cultural care” or elders or maori or whanau	Title/ abstract
	#6	#4 AND #5	
	#7	"Health Care Economics and Organizations"[Mesh]	Mesh
	#8	(cost* OR econom*)	Title/ abstract
	#9	#7 OR #8	
	#10	#9 OR #6	
	#11	"Palliative Care"[Mesh] or "Decision Making, Shared"[Mesh] or "Disenfranchised Grief"[Mesh]	Mesh
	#12	Regret or sedation or “pain relief” or “mode of birth” or “mode of delivery” or “timing” or “place of birth” or “place of delivery” or “birth plan” or “birth planning” or “birth option*” or “vaginal birth” or “vaginal delivery” or “caesarean” or “time to delivery” or “time to deliver” or “time to birth” or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or counselling or counselling or “funeral arrangements” or decisions or “values” or “palliative care” or “prenatal palliative care” or “grieving parent*” or “grieving families”	Title/ abstract
	#13	#11 OR #12	
	#14	#3 AND #10 AND #13	

Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/
	2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.
	5	1 OR 2 OR 3 OR 4
	6	exp transcultural care/ or exp vulnerable population/ or exp indigenous health care/ or exp health disparity/ or indigenous people/
	7	(parents or mother* or father* or "patient understan*" or "patient need*" or "patient resource*" or "patient experience*" or "patient view*" or "patient decision-making" or "patient decision making" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elders or maori or whanau or M#ori or wh#nau or Jew* or Muslim* or Hindu* or buddhist* or religio* or Christian* or orthodox or Uighur* or Rohingya*).ti,ab.
	8	6 OR 7
	9	*health care cost/
	10	(cost* or econom*).ti,ab.
	11	9 OR 10
	12	(Regret or sedation or "pain relief" or (("mode of" or "place of" or "timing") adj1 (birth or delivery)) or ((birth or deliver*) adj2 (plan or planning or option* or "time to")) or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or "funeral arrangements" or decisions or "palliative care" or "prenatal palliative care" or "grieving parent*" or "grieving" or grief or ((bereavement or "post-natal" or postnatal) adj4 (counselling or counselling)).ti,ab.
	13	*palliative therapy/ or *shared decision making/
	14	12 OR 13
	15	11 OR 14
	16	5 AND 8 AND 14

CINAHL	S15	S4 AND S14
	S14	S12 OR S13

	S13	AB ("telehealth" OR "tele health" OR "SMS" OR (("mobile" OR "phone") N3 ("app" OR "application")) OR (("written" OR "audio" OR virtual) N5 "infORmation") OR "pamphlet*" OR (("visit*" OR "attend*" OR "allow*" OR "transfer" OR "accompany") N4 ("mortuary" OR "morgue" OR "body" OR "imaging" OR "radiology" OR "computeri$ed tomography" OR "magnetic resonance imaging" OR "MRI" OR "CT")) OR ("community" N3 "outreach") OR ("community" N1 "care") OR (("decision making" OR "decision aid*" OR "written" OR "electronic" OR "community" OR online) N3 "resources") OR "virtual consultation" OR "shared decision" OR "timeline*" OR "decision making" OR "decision-making" OR "shared-decision" OR counselling OR counselling)
	S12	(MM "Telehealth") OR (MM "Decision Making, Patient") OR (MH "Decision Making, Family") OR (MM "Decision Making, Shared")
	S11	(S5 OR S6 OR S7 OR S8 OR S9 OR S10)
	S10	AB (cost* OR econom*)
	S9	(MH "Health Care Costs+")
	S8	AB (parents OR mother* OR father* OR (patient* N2 (understan* OR need* OR resource* OR experience* OR view* OR "decision-making" OR "decision making" OR "shared decision")) OR "women understand*" OR "women* need*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR family OR families OR refugee* OR "indigenous" OR "torres strait islander*" OR ATSI OR "aborigin*" OR "islander*" OR remote* OR "linguistically diverse" OR "literacy" OR "low income" OR cultural OR elders)
	S7	(MH "Parents+")
	S6	(MM "Health Services, Indigenous") OR (MM "Rural Health Personnel") OR (MM "Rural Health Centers") OR (MM "Hospitals, Rural") OR (MM "Rural Health Services")
	S4	S1 OR S2 OR S3
	S3	AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) N1 loss*) OR stillb*)
	S2	AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*)
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")

Scopus

(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*)

(pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal") W/1 (loss*))

(stillb*)

AND

parents OR mother* OR father* OR (patient* W/2 (understan* OR need* OR resource* OR experience* OR view* OR "decision-making" OR "decision making" OR "shared decision")) OR "women understand*" OR "women* need*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR family OR families OR refugee* OR "indigenous" OR "torres strait islander*" OR ATSI OR "aborigin*" OR "islander*" OR remote* OR "linguistically diverse" OR "literacy" OR "low income" OR cultural OR elders

AND

("telehealth" OR "tele health" OR "SMS" OR (("mobile" OR "phone") W/3 ("app" OR "application")) OR (("written" OR "audio" OR virtual) W/5 "information") OR "pamphlet*" OR (("visit*" OR "attend*" OR "allow*" OR "transfer" OR "accompany") W/4 ("mortuary" OR "morgue" OR "body" OR "imaging" OR "radiology" OR "computeri$ed tomography" OR

	"magnetic resonance imaging" OR "MRI" OR "CT")) OR ("community" W/3 "outreach") OR ("community" W/1 "care") OR (("decision making" OR "decision aid*" OR "written" OR "electronic" OR "community" OR online) W/3 "resources") OR "virtual consultation" OR "shared decision" OR "timeline*" OR "decision making" OR "decision-making" OR "shared-decision" OR counselling OR counselling) AND NOT ((*"genetic counseling"* OR *"genetic counselling"* OR *"contraceptive counselling"* OR *"contraceptive counseling"* OR *"prenatal counselling"* OR *"prenatal counseling"*))
Australian Indigenous HealthInfoNet	(sorry AND business) AND (stillborn OR baby OR newborn OR infant)
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Death] explode all trees #3 MeSH descriptor: [Perinatal Mortality] this term only #4 MeSH descriptor: [Abortion, Induced] this term only #5 (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mORtalit*) #6 #1 OR #2 OR #3 OR #4 OR #5 #7 MeSH descriptor: [Minority Health] explode all trees #8 MeSH descriptor: [Vulnerable Populations] explode all trees #9 MeSH descriptor: [Parents] explode all trees #10 MeSH descriptor: [Health Care Costs] this term only #11 (parents or mother* or father* or (patient* ADJ2 (understan* or need* or resource* or experience* or view* or "decision-making" or "decision making" or "shared decision")) or "women understand*" or "women* need*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or cultural or elders) #12 #7 OR #8 OR #9 OR #10 OR #11 #13 MeSH descriptor: [Telemedicine] this term only #14 (("telehealth" or "tele health" or "SMS" or (("mobile" or "phone") adj3 ("app" or "application")) or (("written" or "audio" or virtual) adj5 "information") or "pamphlet*" or (("visit*" or "attend*" or "allow*" or "transfer" or "accompany") adj4 ("mortuary" or "morgue" or "body" or "imaging" or "radiology" or "computeri$ed tomography" or "magnetic resonance imaging" or "MRI" or "CT")) or ("community" adj3 "outreach") or ("community" adj1 "care") or (("decision making" or "decision aid*" or "written" or "electronic" or "community" or online) adj3 "resources") or "virtual consultation" or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or counselling or counselling)):ti,ab,kw #15 #13 OR #14 #16 #6 AND #12 AND #15

Informit Indigenous Collection	"pregnancy terminat*" OR "Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mORtalit*" OR "Fetal demise*" OR "Foetal mORtalit*" OR "perinatal wast*" OR "perinatal mORtalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mORtalit*" OR "prenatal demise*" OR "Antenatal mORtalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mORtalit*" OR "Intrapartum Death*" OR "Neonatal loss*" OR "Neonatal mORtalit*" OR "Neonatal death*" OR "Neonatal Demise*" OR "NewbORn death*" OR "NewbORn mORtalit*"

Figure 1. PRISMA flow diagram of screening evidence

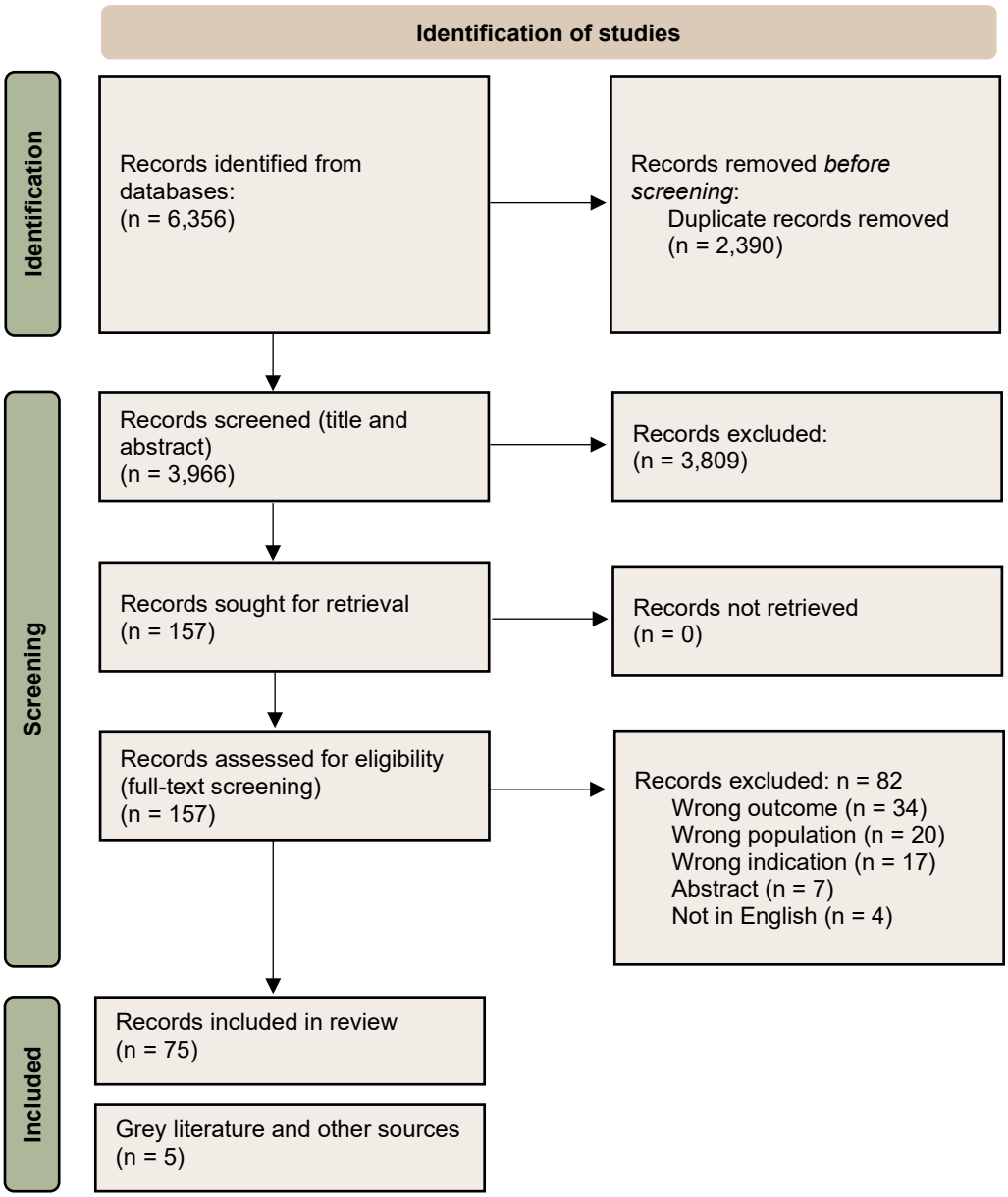


Table 5. Study characteristics

Study ID	Country (period)	Locality (state/ national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Abdel Razeq 2021	Jordan (NR)	2 NICUs	Semi-structured interviews	LMIC	Qualitative	Thematic analysis	NA	12 mothers	NND	Experience of mothers whose babies died in NICU	Not stated	Mothers of neonates born alive and then died in NICU	Checklist for qualitative research
Actis Danna 2023	Malawi, Tanzania, and Zambia	Women who had given birth at tertiary referral hospitals in Tanzania, Malawi and Zambia	Semi-structured interviews	LIC	Qualitative	Grounded theory (Symbolic interactionism)	NA	33 women	Stillbirth (within the preceding 12 months)	The purpose of this study was to understand how and when women became aware of the death of their babies.	Women <18 years of age	Women who had experienced a stillbirth in the preceding 12 months and had the capacity to consent.	Checklist for qualitative research
Aiyelaagbe 2017	UK (2014-2015)	St Mary's Hospital, Manchester UK	Interviews	HIC	Qualitative	Pilot Thematic analysis	NA	58	Stillbirths (antepartum and intrapartum), early neonatal deaths (n=NR)	Parents experience of bereavement care	None	Parents of stillborn babies, or babies that died in the delivery unit.	Checklist for qualitative research
Arocha 2021	USA (2016)	Facebook child loss groups	Online questionnaires	HIC	Quantitative	Descriptive cross-sectional	NA	66 women	Stillbirth	Experience of stillbirth and its association	2 women with miscarriages	Women who self-identified their loss as stillbirth	Checklist for qualitative research

										with depression			
Atienza-Carrasco 2020	Spain (2015-2017)	Costa del Sol Health Agency (Marbella, Spain)	Interviews, observations	HIC	Qualitative	Phenomenological	NA	27 interviews	Adverse antenatal diagnoses	receiving bad news	NA	Qualitative: 27 pregnant women of at least 18 years, with no mental disability and who can understand Spanish and express themselves correctly in Spanish.	Checklist for qualitative research
Atkins 2022	International (period not stated)	44 HIC and MIC	Online survey	HIC and MIC	Quantitative	NA	Cross-sec	3,769	Stillbirth	Parents reported experience of care during pregnancy and around the time of stillbirth, and the factors associated with reporting respectful care. Parental access to bereavement care practices.	Participants were excluded if the reported gestational age at stillbirth was below 20 weeks	Self-identified bereaved parents of stillborn babies	Checklist for analytical cross-sectional studies

Aydin 2019	Turkey (April-July 2017)	1 tertiary hospital	Interviews, hospital records	Upper-middle income setting	Qualitative	Thematic analysis	NA	10	Termination of pregnancy for medical indication	Experiences of women who have a termination of pregnancy for medical indication	None mentioned	Women hospitalised between April- July 2017 at the Akdeniz University Clinics of Obstetrics and Gynecology who were: over 18 years but below 45 years, free of chronic and psychiatric diseases, hospitalised because of pregnancy termination and without medical complications during hospitalisation, able to communicate in Turkish, and consented to participate	Checklist for qualitative research

Berry 2021 (2)	Multiple (2019-2020)	US, UK, Australia	Literature	HIC	Qualitative	Systematic review	NA	5	Stillbirth, NND, TOPFA	Parents' experiences of perinatal loss in a Western cultural context	Articles were excluded if they were reports of studies conducted in non-Western cultures, of twin pregnancies, or of the perinatal loss experiences of others (e.g., health care professionals, siblings, surrogate parents, grandparents, etc.). We also excluded quantitative studies, scale validation studies, and gray literature.	Peer-reviewed articles published in English within the last 10 years, about qualitative research conducted in Western countries (e.g., US, UK, Australia) that were focused on parents' experiences of perinatal loss (resulting from miscarriage, stillbirth, neonatal death, or termination of pregnancy related to fetal anomalies).	Checklist for systematic reviews and research syntheses
Bond 2018	Australia (2006-2011)	Sydney Hospitals	Postal surveys	HIC	Mixed methods	Thematic analysis	Cross sectional retrospective study	36	Stillbirth	Experience of care during and after stillbirth	Pregnancy loss prior to 32 weeks GA. Non-English-	Women who experienced stillbirth after 23 weeks and delivered at	Checklist for qualitative research Checklist for analytical

											speaking parents.	one of the seven tertiary maternity centres in Sydney NSW.	cross-sectional studies
Boyle 2020 (2)	Australia (2020)	NA	Author views and literature	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth	National approach to research to improve shared decision making in stillbirth care and other initiatives in this area	None mentioned	Shared decision-making literature and Stillbirth CRE initiatives	Checklist for text and opinion papers
Boyle 2022	Australia (April 2020)	National	Online survey	HIC	Qualitative	Content analysis	NA	35	Stillbirth, NND, TOPFA	Healthcare providers views of the impact of COVID-19 pandemic on provision of respectful care to parents and resulting practice changes	None specified	Healthcare providers who provided perinatal bereavement care in clinical settings or through support organisations in Australia	Checklist for qualitative research
Camacho Ávila 2020	Spain (Apr 2017-May 2018)	2 hospitals in Southeast Spain	Interviews	HIC	Qualitative	Hermeneutical phenomenology	NA	21 (13 mothers, 8 fathers)	Stillbirth (n=17), NND (n=4)	Parents' experiences in relation to professional and social support after	Spoke a language other than English or Spanish, or experienced	A mother or father 18 years and older at the time of perinatal	Checklist for qualitative research

										perinatal loss	a miscarriage, pregnancy termination due to genetic birth defect or multifetal pregnancy reduction.	loss, to have experienced a stillbirth or a neonatal death, and the loss had been suffered at least 2 years before the interview.	
Camacho Avila 2019	Spain (Apr 2016-May 2017)	2 hospitals in the South of Spain	Interviews	HIC	Qualitative	Thematic analysis	NA	21 (13 mothers, 8 fathers)	Stillbirth, NND	Experiences and perceptions of parents who have suffered a perinatal death	NA	(1) Being a mother or father who has suffered a loss through the perinatal death of their child, from the 22nd week of gestation to the first week of life. (2) The death occurring between 3 months and 5 years prior to the study (3) The mother or father had to speak Spanish or English. (4)	Checklist for qualitative research

												Signing the informed consent form.	
Cassidy 2018	Spain 2013-2016	National	Online self-completion questionnaire	HIC	Qualitative	Phenomenological	NA	796	Pregnancy loss stratified by GA (n=668 stillbirths >=20 wks GA)	Bereaved parents experience of care quality following intrauterine death	Respondents born outside of the Spanish national territory. Parents reporting neonatal deaths	Women who reported that their baby died within 60 months prior to survey completion.	Checklist for qualitative research
Censonsky 2022	US (2006-2009)	59 hospitals in five geographic regions	Secondary data from Stillbirth Collaborative Research Network longitudinal study	HIC	Quantitative	NA	Retrospective cohort	272	Stillbirth	Relationship between fetal appearance and abnormalities and the decision to hold a baby after stillbirth	Multiple births	Patients who (1) gave birth to a single, non-living fetus; (2) chose to hold their baby, see their baby, or do neither after the birth; and (3) completed a follow-up interview after delivery	Checklist for cohort studies
Charrier & Clavandier 2019	France (2013–2015)	Nine French cities (Lille, Lyon, Bron, Paris, Saint-Etienne, Tours,	Survey, interviews, opinion	HIC	Qualitative	Narrative	NA	Not specified	Stillbirth, TOPFA, NND	A place for stillborn infants/terminations in cemeteries	Not specified	Not specified (interviewed healthcare professionals, funeral	Checklist for text and opinion papers

		Rennes, Beziers, Grenoble)										industry workers and members of local administrations (civil records, cemetery management) and carried out observations in funeral parlours, crematoriums and cemeteries)	
Christou 2021	Afghanistan (Oct-Nov 2017)	3 high-volume referral maternity hospitals in Kabul and 2 lower-level health facilities and surrounding communities in 2 rural districts ~25–30 km west and north of Kabul city	Interviews	LIC	Qualitative	Deductive thematic analysis	NA	55 (21 mothers, 9 fathers, 3 female community elders, 20 HCPs, 2 govt officials)	Stillbirth	Parents' and healthcare professionals' experiences of care after stillbirth	None mentioned	Women and men experiencing stillbirth, community female elders, healthcare providers and key informants including govt officials, hospital directors, chiefs of wards	Checklist for qualitative research
Farrales 2020	USA (date not reported)	Unclear	Focus groups	HIC	Qualitative	Thematic analysis	NA	27	Stillbirth	Experiences of grieving parents	None mentioned	Participants were recruited	Checklist for qualitative research

											during their interaction with health care providers during/after the stillbirth of a baby		from a cohort of bereaved parents who participated in a two-day workshop on the topic of grief after stillbirth. 19 years of age or older. Consent obtained.	
Fernandez-Medina 2022	Spain (March–May 2021)	National	Interviews	HIC	Qualitative	Hermeneutical phenomenological approach	NA		13	Stillbirth, NND	How bereaved women perceive the expression and donation of their breastmilk	TOPFA and multiple pregnancies	18 years or older at the time of perinatal loss, have experienced a stillbirth or a neonatal death in the last 5 years, and have donated their breast milk to a nonprofit milk bank in Spain. Consent obtained.	Checklist for qualitative research
Fuller 2022	UK (2016–18)	National	Secondary data from interviews conducted	HIC	Qualitative	Narrative analysis	NA		20 (Stillbirth=9; TOPFA= 11)	Stillbirth, TOPFA	Aspects of memorialisation present in narratives	NA	Cis-gendered women who either	Checklist for qualitative research

			as part of another study							of pregnancy loss		experienced stillbirth or who had terminated their pregnancy following a diagnosis of fetal anomaly	
Helps 2020	Ireland (2005-2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	stillbirth, NND	Bereavement care provided to families following perinatal death/pregnancy loss as described in national inquiry reports	None stated	National inquiries into perinatal deaths/pregnancy loss services between 2005-2018.	Checklist for qualitative research
Horey 2021	40 countries (Dec 2014-Feb 2015)	NA	Survey	HIC and MIC	Quantitative	NA	Descriptive	3,041	Stillbirth	Bereavement care practices after stillbirth in high and middle-income countries	Stillbirth > 5yrs prior to completing the survey	Self-reported stillbirth ≤ 5 years prior to completing survey	Checklist for studies reporting prevalence data
Hvidtjørn 2021	Denmark (2012-2018)	A midwifery-led specialised unit for bereaved parents at Aarhus	Hospital electronic health records	HIC	Quantitative	NA	Descriptive cross-sectional	579	miscarriage (>14 weeks), missed abortion (>14 weeks), termination of pregnancy	clinical characteristics of women admitted to a specialised unit for bereaved	None mentioned	All women at Aarhus University Hospital who experienced spontaneous	Checklist for studies reporting prevalence data

		University Hospital in Denmark								(>14 weeks), stillbirth, NND	parents and characteristics of women who stayed more than 2 days		pregnancy loss after 14 weeks gestation, TOPFA, intrauterine death, or intrapartum death between January 1, 2012, and December 31, 2018. Women who experienced the death of a newborn in the NICU within the first 48 hours after birth and desired a stay in the unit were also included.	
Jesus 2022	Brazil (2017-ongoing)	1 tertiary hospital in the state of São Paulo, Brazil	Interviews	UMIC	Qualitative	Narrative paper	NA		3	Stillbirth, NND	Meaning of photography as a remembrance in the mourning process	None stated	Patients who were aware of the diagnosis of a life-limiting condition during pregnancy and had already	Checklist for qualitative research

											experienced stillbirth or the death of a newborn	
Jones 2017 (2)	Multiple (dates not reported)	International literature	Literature	NA	Qualitative	Meta-synthesis	NA	10 studies (581 women)	TOPFA	Women's experiences of labour and birth when having a TOPFA in the second trimester of pregnancy	Previously published literature reviews and systematic reviews	English language qualitative articles that were original research studies and published between 1996-2016, that were peer-reviewed and had full text available to view.	Checklist for systematic reviews and research syntheses
Jones 2019	Western countries/2000-2019	Mixed	Data from previous studies of mens grief	HIC	Qualitative	Scoping review	NA	27 studies	Stillbirth and NND	impact of perinatal death for men, meaning of loss and fathers identity, extent to which men were able to express grief and how grief was mediated by the support of health	Studies before 2000; studies from countries with likely substantial cultural, religious and health care differences; studies which exclusively looked at miscarriage, fetal loss before	Studies from 2000 exploring parental experiences of perinatal death and health care support following	Checklist for systematic reviews and research syntheses

											professionals	24weeks, lethal fetal abnormalities, and SIDS.	
Jørgensen 2022	Denmark (2015-2019)	Unclear	Online questionnaires	HIC	Quantitative	NA	Non-comparative study	173	stillbirth	The amount of time Danish parents spend with their stillborn baby in hospital settings; hypothesis of the reasons why Danish parents spend with their babies.	None mentioned	The cohort 'Life after the Loss' comprises mothers and their partners in Denmark who experienced a stillbirth from January 2015 till August 2019 (intrauterine death after gestational age 22 weeks).	Checklist for studies reporting prevalence data
Kalanlar 2020	Turkey (NR)	49 hospitals across Ankara, Istanbul, and Izmir	Postal questionnaires	UMIC	Quantitative	NA	Cross-sectional study	29	Perinatal death including stillbirth and neonatal death.	Managers, head physicians, head nurses, midwives, and specialist physicians caring for families following	dialysis, in vitro fertilisation, medical, physical the rapy, and rehabilitation centres. Hospitals which were shut down,	Purposive sampling to select provinces with the highest number of hospitals.	Checklist for analytical cross-sectional studies

											perinatal death	did not agree to take part, and did not have a maternity service were filtered out		
LeDuff 2017	Multiple (dates not reported)	Global	Literature (4 databases)	NA	Qualitative	Literature review	NA	NA	Miscarriage, Stillbirth, NND	Role of transitional objects to facilitate grieving following perinatal loss	None stated	full-text English language articles published between 2011-2016	Checklist for text and opinion papers
Lewis & Bryan 2018	UK (dates not reported)	NA	Opinion; Literature	HIC	Qualitative	Narrative piece	NA	NA	Stillbirth, NND	Management of perinatal loss of a twin	NA	NA	Checklist for text and opinion papers
Lewis 2019	UK (2016-2017)	National	Cross-sectional survey, interviews, focus groups	HIC	Qualitative	Thematic analysis	NA	439 free-text responses, 20 parent interviews, 25 HCPs	Miscarriage, Stillbirth, NND, TOPFA, Infant death	Parental decision making about post-mortem	None specified	Bereaved parents-including pregnancy loss, neonatal or infant death, HCPs from a range of clinical backgrounds involved in discussing or conducting post-mortem examinations with parents	Checklist for qualitative research

Lin 2021	Taiwan (dates not reported)	One regional teaching hospital in northern Taiwan	Reflective group sessions	HIC	Qualitative	Thematic analysis	NA	10 nurses participating in 8 group sessions	Stillbirth	Nurses' experiences of labour of a stillborn baby	None stated	Nurses with direct stillbirth nursing care experience in one hospital in Taiwan	Checklist for qualitative research
Listermar 2020	Sweden (2014-2016)	40 maternity clinics in Sweden	Open-ended response on questionnaire	HIC	Qualitative	Content analysis	NA	110	Stillbirth	Midwives' experience of using cold cots	None mentioned	Midwives using cooling cot (Cubitus baby) while caring for parents of a stillborn child	Checklist for qualitative research
Lizcano Pabón 2019	Colombia (2014-2015)	2 hospitals in northeastern Colombia	Semi-structured interviews, field diary, sociodemographic survey	UMIC	Qualitative	Thematic analysis	NA	15	Stillbirth, NND	Experience of perinatal death in a sample of fathers from Colombia	None stated	Men over 18 years of age who spoke Spanish, lived with their partners, experienced a perinatal death within a year at the beginning of the study, accepted to participate in the study, and signed an informed consent	Checklist for qualitative research
Lockton 2020	Australia (dates not reported)	National	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	14	Stillbirth, TOPFA	Grandmothers' experiences	None stated	Grandmothers from across	Checklist for qualitative research

										of loss and grief, following a child's pregnancy loss		Australia, whose child had experienced a pregnancy loss between six months and five years ago, and who were fluent in English	
Martel & Ives-Baine 2018	Canada (dates ns)	level 3/4 NICU	one focus group and one semi-structured interview	HIC	qualitative	IPA	NA	6 nurses (focus group); 1 semi-structured interview	NND	neonatal nurses' experiences with end-of-life photography	NA	Neonatal nurses- Inclusion in the study required participants to have worked in the NICU for at least two years and to have taken EOL photos at least twice preceding the interview.	Checklist for qualitative research
Martínez-Serrano 2019	Spain (2012-2017)	1 hospital and local pregnancy loss support organisation	Interviews	HIC	Qualitative	Thematic analysis	NA	11 parents (7 mothers, 4 fathers)	Stillbirth	Mothers' and fathers' experience of care received during delivery in	Those with psychological functional impairment and not fluent in Spanish?	Women and men over 18 years of age, who during a monitored low obstetric and	Checklist for qualitative research

										cases of stillbirth		neonatal risk pregnancy were attended for labour after stillbirth, through a vaginal birth.	
Meaney 2017	Ireland (dates not reported)	One hospital in Ireland	Interviews	HIC	Qualitative	IPA	NA	9 (5 mothers, 4 fathers)	Stillbirth, NND	Impact on parents of death of one twin in the perinatal period	None stated	Parents who had experienced a perinatal death during or after a twin pregnancy	Checklist for qualitative research
Meyer 2018	Ghana (2012)	One hospital in Kumasi, Ghana	Semi-structured Interviews	LMIC	Qualitative	Thematic analysis	NA	8	NND	Experience of infant loss for bereaved mothers in Ghana	mothers from the larger study for whom contact information or phone access was not available, lived more than 2 hours away from the hospital, were unreachable by phone (number disconnected, wrong number, no	mothers who were 18 or older, spoke English or Twi, lost a baby since participating in the larger study a year ago, lived within 2 hours of the hospital and could be reached by phone agreed to be interviewed	Checklist for qualitative research

											answer), and those who denied having received care at the hospital		
Murphy 2017	Multiple (dates not reported)	International	Literature	NA	Qualitative	Narrative review	NA	Not stated	Stillbirth	Psychological, social, and economic impact of stillbirth on families	NA	NA	Checklist for text and opinion papers
Noble-Carr 2021	Australia (2019)	3 large tertiary hospitals located in 3 Eastern states and territories	Interviews and focus groups	HIC	Qualitative	Thematic and interactional analysis	NA	113	Stillbirth, NND	Factors that shape the delivery of hospital-based lactation care for bereaved mothers	None mentioned	Professionals most likely to interface with bereaved families after stillbirth and infant death, and who may be called upon to offer lactation care. These included obstetricians, neonatologists, midwives, neonatal nurses, lactation consultants, social	Checklist for qualitative research

													workers or pastoral care workers, HMB staff, and specialist perinatal bereavement nurses.	
Nuzum 2018	Ireland/2008-2013	One tertiary university maternity hospital	Semi-structured interviews with mothers and fathers who experienced stillbirth	HIC	Qualitative	Interpretative Phenomenological Analysis	NA		17	Stillbirth	Comparison of lived experiences of bereaved parents with an expected or unexpected stillbirth, under the themes of maintaining hope, the importance of personhood, protective care, and relationships	NA	Parents who received a diagnosis in utero that their baby had a life-limiting condition and was unlikely to survive OR parents who experienced an unexpected stillbirth	Checklist for qualitative research
Paraíso Pueyo 2021	Multiple (2018-2019)	International literature	Literature (4 databases)	HIC	Qualitative	Scoping review	NA	9 papers		NND	Nursing interventions to help parents of neonates admitted to neonatal intensive care units	Studies relating to stillbirth, TOP for non-medical reasons, miscarriage	Studies published between 2000-2019 that included mothers and/or fathers	Checklist for systematic reviews and research syntheses

										cope with perinatal loss		and/or the immediate family who have experienced the death of an infant in the perinatal period in a NICU. Papers written in Spanish whose title and abstract had also been written in English.	
Parish 2021	UK (dates not specified)	NA	Opinion; literature	HIC	Qualitative	Narrative	NA	NA	NND	Management of lactation following the death of a baby	NA	NA	Checklist for text and opinion papers
Pollock 2020	Multiple (2018)	International literature	Literature (5 databases)	NA	Qualitative	Scoping review	NA	23 articles	Stillbirth	Current knowledge surrounding stillbirth stigma, specifically the extent, type and experiences of bereaved parents	Non-English articles; Articles not published at the time of this scoping review being submitted for publication (October 2018) were not included	The inclusion criteria for articles were; (1) written in English; (2) focused on stillbirth (3) the abstract or title included the words stigma OR silence.	Checklist for systematic reviews and research syntheses

Porch 2022	UK (dates not reported)	NA	Personal experiences of author	HIC	Qualitative	Auto ethnography	NA	NA	Stillbirth	Relationship between textiles and mourning stillbirth	NA	Bereaved parent of stillbirth loss	Checklist for qualitative research
Ramirez 2019	USA (dates not reported)	Seattle	Interviews	HIC	Qualitative	Grounded theory	NA	23 (6 bereaved parents, 8 photographers, 9 HCPs)	Stillbirth, NND	Role of professional bereavement photography in assisting the grieving process of bereaved parents	Participants with limited English proficiency	Inclusion criteria for bereaved parents included having experienced a third trimester fetal demise or loss of an infant within the first year of life and having received professional bereavement photography services while the child was alive or at the time of the loss. Photographers were recruited from 1 of 2 organizations that provide free,	Checklist for qualitative research

												professional photographs to families with children facing life-threatening conditions. Inclusion criteria for health care professionals included clinical or professional experience, in any of the health care–related professions, caring for families who had lost a fetus or infant within the first year of life.	
Rankin 2021	UK (2016)	National	Online survey	HIC	Quantitative	NA	Cross-sectional survey	293	Stillbirth, NND	Knowledge, training needs and self-rated confidence of health professionals in providing support to parents who have	None stated	Health professionals, including neonatal and fetal medicine doctors, neonatal nurses, and midwives involved in	Checklist for studies reporting prevalence data

										experienced a loss from a twin pregnancy.		supporting parents who have experienced a loss from a twin pregnancy whilst caring for a surviving sibling	
Redshaw 2021	England (dates not specified)	National	Questionnair es	HIC	Qualitative	Thematic analysis	NA	249	NND	Experience of women whose baby died in the neonatal period of their care in the perinatal period, on delivery suite, in the neonatal unit and afterwards.	None mentioned	Women aged 16 years and over in England who registered a stillbirth or neonatal death in two 3-month periods	Checklist for qualitative research
Shakespeare 2019	Multiple (2017)	International	Literature (6 databases)	LMIC	Mixed methods	Narrative synthesis	Meta-analysis	34 studies across 17 countries	Stillbirth	Parents' and healthcare professionals' experiences of care after stillbirth in LMIC	Studies explicitly addressing miscarriage, fetal anomaly, and neonatal death alone were excluded. Review articles, opinion	Qualitative, quantitative, and mixed method studies that addressed parents' or healthcare professionals' experience of care after	Checklist for systematic reviews and research syntheses

											pieces, and books were excluded.	stillbirth in LMIC	
Silverio 2021	UK (Nov–Dec 2020)	National	Interviews	HIC	Qualitative	Template analysis	NA	24	Late miscarriage - 14 to 23+6 weeks' gestation (n=5), Stillbirth (n=16), NND (n=3)	Bereaved parents' experience of care during COVID	None mentioned	Parents who experienced a late miscarriage, stillbirth or NND during COVID	Checklist for qualitative research
Smith 2020	UK (Sept 2016–Aug 2017)	Two parent support organisations, 4 clinical sites	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	38 (10 couples, 18 mothers)	Miscarriage, stillbirth, NND, TOPFA	Parents' healthcare experiences before, during and after their baby's death between 20 and 23+6 weeks of gestation	None mentioned	Parents whose baby died before, during or shortly after birth at 20+0 to 23+6 weeks of gestation.	Checklist for qualitative research
Steen 2019	USA	One hospital in Minneapolis, Minnesota	Feedback from staff and parent evaluations	HIC	Qualitative	Thematic analysis and narrative review	NA	NA	Stillbirth, NND	Description of a perinatal bereavement program	None mentioned	Different components of a perinatal bereavement program at one hospital	Checklist for qualitative research
Thornton 2019	Multiple (Jan 2019)	International	Literature (4 databases)	NA	Qualitative	Scoping review/ Thematic analysis	NA	25 articles	NND	Memory making in bereavement care for parents who experience the death of a newborn	Opinion pieces, news articles, editorials and review articles; Quantitative studies and	all original research articles available in English that Included parents of neonates as	Checklist for systematic reviews and research syntheses

											those published more than 30 years ago	research participants; included one or more memory making intervention as the focus of investigation or as a finding; and contained original data from the perspective of bereaved parents	
Thornton 2020	Australia (dates not reported)	National	Semi-structured interviews	HIC	Qualitative	Grounded theory	NA		18	NND	Significance of memory-making for bereaved parents and the impact of memory-making on parents' experience of loss following neonatal loss.	None stated	Parents who experienced the death of their infant in a neonatal unit in Australia, and were able to communicate in English without an interpreter	Checklist for qualitative research
Thornton 2021	Australia (dates not reported)	National	Interviews	HIC	Qualitative	Grounded theory	NA	18 (13 mothers, 5 fathers)		NND	Parent perceptions of memory making interventions in NICU	None specified	Parents who experienced the loss of their baby in NICU	Checklist for qualitative research

Tovey & Turner 2020	UK (2016-2018)	National	Stillbirth photographs published on websites and social media, insights from Death before Birth Project	HIC	Qualitative	Content analysis	NA	51 images	Stillbirth	Stillbirth memento photography	NA	Photographs where there was clear evidence they had been produced following a consistent procedure where a professional photographer external to the healthcare organisation had been given consent by the bereaved to produce a set of memento photographs	Checklist for qualitative research
Tseng 2017	Taiwan (dates not reported)	Teaching hospital, southern Taiwan	Questionnaires	HIC	Quantitative	NA	Longitudinal study	30 couples	Stillbirth	Post bereavement grief levels of parents	Couples <18 years old	Experienced a miscarriage or stillbirth in the previous month; signed informed consent	Checklist for analytical cross-sectional studies

Tseng 2018	Taiwan (dates not reported)	2 teaching hospitals in Taiwan	Interviews	HIC	Qualitative	Thematic analysis	NA	16	Stillbirth	Meaning of rituals after stillbirth	Unmarried mothers or pregnant adolescent	Women who experienced stillbirth during weeks 20 to 40 of pregnancy; had participated in rituals after diagnosed with a stillbirth; and consented to participate in the study	Checklist for qualitative research
Wool 2017	Multiple (Feb 2015)	Online survey	Online survey, distributed via email and posted on websites in February 2015 by webmasters that support families who have experienced a fetal life-limiting diagnosis	HIC	Quantitative	NA	Cross-sectional	405	Stillbirth, NND	To identify which quality indicators predict patient satisfaction with care in a prenatal setting when a fetus has been diagnosed with a life-limiting condition	None mentioned	Mothers or fathers >18-years who experienced a life-limiting fetal diagnosis and opted to continue the pregnancy living anywhere in the world. Participants needed to be able to communicate in English and access	Checklist for analytical cross-sectional studies

											and use a computer. Participants were welcome to contribute to the study regardless of the interval between the birth and survey.	
Wong 2021	Hong Kong / May-December 2019	Pamela Youde Nethersole Eastern Hospital, Hong Kong	Structured open-ended questions through self-administered questionnaire (n=26) or phone interview (n=25)	HIC	Qualitative	Thematic analysis	NA	51	Stillbirth, TOPFA, NND	Aimed to explore the views of Hong Kong Chinese women who experienced perinatal loss on seeing and holding the baby and on commemorating the baby	NA	Chinese women who experienced the loss of a baby or fetus (caused by miscarriage, TOPFA, stillbirth, or NND) perinatally (from second trimester [12gestational weeks] to 28 days of life after birth) within	Checklist for qualitative research

						5 years and had been under the care of the Bereavement Team at the hospital

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data.

Table 6. Study quality assessment

Qualitative studies

	Is there congruity between the stated philosophical perspective and the research methodology?	Is there congruity between the research methodology and the research question or objectives?	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice-versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Relevance
Abdel Razeq 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Actis Danna 2023	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	R
Aiyelaagbe 2017	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Atienza-Carrasco 2020	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	I
Aydin 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Bond 2018	Yes	Unclear	Yes	Yes	Unclear	No	No	Unclear	Yes	Yes	I
Boyle 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Camacho Ávila 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Camacho Avila 2019	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	P

Cassidy 2018	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P
Christou 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Farrales 2020	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	R
Fernandez-Medina 2022	Yes	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	R
Fuller 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	R
Helps 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Jesus 2022	Unclear	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Yes	I
Lewis 2019	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Lin 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	R
Listermar 2020	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	I
Lizcano Pabón 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Lockton 2020	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Martel 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Martínez Serrano 2019	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	R

Meaney 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	I
Meyer 2018	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	I
Noble-Carr 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P
Nuzum 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Porch 2022	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	R
Ramirez 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	I
Redshaw 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Silverio 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Smith 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	I
Steen 2019	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	No	Yes	R
Thornton 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Thornton 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Tovey & Turner 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Unclear	NA	Yes	I
Tseng 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R

Wong 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	Were the criteria for inclusion in the sample clearly defined?	Were the study subjects and the setting described in detail?	Was the exposure measured in a valid and reliable way?	Were objective, standard criteria used for measurement of the condition?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the outcomes measured in a valid and reliable way?	Was appropriate statistical analysis used?	Relevance
Atkins 2022	Yes	Yes	Yes	Yes	No	NA	Unclear	Yes	I
Bond 2018	Yes	Unclear	Yes	Yes	No	No	Yes	Yes	I
Kalanlar 2020	No	No	No	No	No	No	No	Unclear	I
Tseng 2017	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes	R
Wool 2017	Yes	Yes	Yes	Yes	No	No	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	Was the sample frame appropriate to address the target population?	Were study participants sampled in an appropriate way?	Was the sample size adequate?	Were the study subjects and the setting described in detail?	Was the data analysis conducted with sufficient coverage of the identified sample?	Were valid methods used for the identification of the condition?	Was the condition measured in a standard, reliable way for all participants?	Was there appropriate statistical analysis?	Was the response rate adequate, and if not, was the low response rate managed appropriately?	Relevance
Arocha 2021	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	R
Horey 2021	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	NA	R

Hvidtjørn 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Jørgensen 2022	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	NA	Yes	R
Rankin 2021	Unclear	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Unclear	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	Is the source of the opinion clearly identified?	Does the source of opinion have standing in the field of expertise?	Are the interests of the relevant population the central focus of the opinion?	Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	Is there reference to the extant literature?	Is any incongruence with the literature/sources logically defended?	Relevance
Boyle 2020 (2)	Yes	Yes	Yes	Unclear	Yes	NA	R
Charrier & Clavandier 2019	Yes	Yes	Yes	Unclear	Yes	NA	R
LeDuff 2017	Yes	Yes	Yes	Unclear	Yes	Unclear	R
Lewis & Bryan 2018	Yes	Unclear	Yes	Unclear	Yes	NA	R
Murphy 2017	Yes	Yes	Yes	Unclear	Yes	NA	I
Parish 2021	Yes	Unclear	Yes	Unclear	Yes	NA	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	Is the review question clearly and explicitly stated?	Were the inclusion criteria appropriate for the review question?	Was the search strategy appropriate?	Were the sources and resources used to search for studies adequate?	Were the criteria for appraising studies appropriate?	Was critical appraisal conducted by two or more reviewers independently?	Were there methods to minimise errors in data extraction?	Were the methods used to combine studies appropriate?	Was the likelihood of publication bias assessed?	Were recommendations for policy and/or practice supported by the reported data?	Were the specific directives for new research appropriate?	Relevance
Berry 2021 (2)	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	NA	Yes	Yes	R
Jones 2017 (2)	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	R
Jones 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	NA	Yes	I
Paraíso Pueyo 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	I
Pollock 2020	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Unclear	NA	Yes	I
Shakespeare 2019	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	R
Thornton 2019	Yes	Yes	Yes	Yes	NA	NA	Unclear	Yes	Unclear	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilized?	11. Was appropriate statistical analysis used?	Relevance
Cersonsky 2022	Yes	Yes	Unclear	Unclear	Unclear	Yes	Yes	Yes	Yes	NA	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
3.11	Validate parenthood and support memory making by: • discussing options and exploring parents' concerns and preferences around parenting activities • offering all parents the opportunity to see and hold their baby immediately after birth, including skin-to-skin contact with their baby and supporting them through the process • normalising and supporting parenting activities such as bathing and dressing their baby • using gentle and caring language and actions when interacting with the baby • asking parents how they would like you to refer to their baby (e.g. by name) • providing parents information about their baby (e.g. weight, length, hair colour) using the same tenderness and respect afforded to any baby • providing opportunities to involve siblings, grandparents, and other family/whānau members	19 studies are included. Of these, 14 are primary qualitative research, three are cross-sectional studies, and four are systematic reviews. One of the included studies is a mixed methods study, incorporating qualitative and cross-sectional methodology.	Moderate concerns of methodological limitation are noted. 10 of the included studies are deemed to have no or minor concerns of methodological limitation. Eight of the included studies have moderate concerns of methodological limitation, and one of the included studies are noted to have severe concerns affecting all aspects of study processes.	Moderate concerns of relevance are noted. 12 of the included studies are deemed directly relevant to recognition of parenthood during care around stillbirth and neonatal death. Two studies are deemed to be partially relevant, and 7 studies are deemed to be indirectly relevant.	Minor concerns of coherence are noted.	No concerns of data adequacy are noted. Of the included studies, 14 sourced their cohorts from high-income country populations. Two studies also included participants from middle-income countries in addition to high-income countries, two from lower-income countries and one from upper middle-income country. Three systematic reviews did not specify the income status of cohorts included in their analysis. Outcomes of interest include stillbirths (n=6849), neonatal deaths (n=249), termination of pregnancy for fetal anomaly, and composite perinatal mortality outcomes (n=1425). The viewpoints contained within the data included are from mothers (n=4,814), fathers (n=22), parents (n=4,175) and healthcare professionals (n=59).	Low confidence *No or minor concerns of coherence and data adequacy. Moderate concerns of methodological limitation and relevance.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	• offering parents and family/whānau the opportunity to engage in parenting activities and memory making more than once, while remaining respectful of their decisions.					No concerns of data adequacy are noted.	
3.12	Ask parents and family/whānau throughout care about cultural needs regarding perinatal loss practices and handling of their baby's body. • Always ask parents and family/whānau permission before handling their baby.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
3.13	Prepare parents for seeing and holding their baby by giving information about the baby's physical appearance, size, tone, and temperature. • Sensitively answer parents and family/whānau members questions and explore concerns. • Discuss preferences for seeing their baby, including use of special blankets, hats, or clothing.	Six studies are included. Of these, four are primary qualitative research studies, one is a prevalence study, and one is a cohort study.	Moderate concerns of methodological limitation are noted. Four of the included studies are deemed to have minor concerns of methodological limitation, and two studies have moderate concerns noted through critical appraisal.	Minor concerns of relevance are noted. Four of the included studies are deemed relevant to recognition of parenthood during care around stillbirth and neonatal death. Two of the included studies are deemed to be indirectly relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Five included studies sourced their cohorts from high income country populations and one from an upper middle-income country. Outcomes of interest include stillbirths (n=200), and composite perinatal mortality outcomes (n=75). The viewpoints contained within the data included are from mothers (n=55) and parents (n=492). Moderate concerns of data adequacy are noted due to inadequate combined cohort	Low confidence *No or minor concerns of coherence and relevance. Moderate concerns of methodological limitation and data adequacy.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
						size and inadequate outcomes included.	
3.14	Enable parents and family/whānau to spend as much time as they wish in private with their baby who is dying or who has died, including the option to take their baby outside into the natural environment, home, or to another place important to the family. • For a baby who has died, discuss practical matters with parents when they are ready, including care and transport of the baby's body, use of 'cold cots', and relevant legal issues. • For a baby with a life-limiting condition, consider and offer the option of perinatal palliative care in the family home, involving palliative care teams if available and ensuring parents have the support they need.	10 studies are included. Seven primary qualitative research, one narrative review, one cross-sectional study and a prevalence study.	Moderate concerns of methodological limitation are noted. Seven of the included studies are noted to have no or minor concerns of methodological limitation. Two included studies are noted to have moderate concerns of methodological limitation, and one study is deemed to have serve concerns through critical appraisal.	Minor concerns of relevance are noted. Seven of the included studies are deemed to be relevant to recognition of parenthood during care around stillbirth and neonatal death. The remaining three studies are deemed to be indirectly relevant.	No concerns of coherence are noted.	Minor concerns of data adequacy are noted. All included studies sourced their cohorts from high-income country populations. One study also included participants from middle-income countries in addition to high-income countries. Outcomes of interest include stillbirths (n=3780), neonatal deaths (n=249), and composite perinatal mortality outcomes (n=614). The viewpoints contained within the data included are from mothers (n=848), fathers (n=9), parents (n=3786) and health care professionals (n=145). Minor concerns of data adequacy are noted due to inadequate outcomes included.	**Moderate confidence** *No or minor concerns of coherence, data adequacy, and relevance. Moderate concerns of methodological limitation.*
3.15	For parents of twins, triplets, or other multiple births: • provide parents with opportunities to spend time with and make memories with their baby or babies that have died	Four studies are included. One primary qualitative study, one prevalence study, one literature review and an author opinion is included.	Minor concerns of methodological limitation are noted. Three of the included studies are assessed through critical appraisal to have minor concerns of	Moderate concerns of relevance are noted. Teo of the included studies are deemed to be directly relevant to recognition of parenthood during care	Moderate concerns of coherence are noted due to the complex nature of multiple pregnancy losses	Moderate concerns of data adequacy are reported. Three studies sourced their cohorts from high-income country populations, and one review did not specify the	**Low confidence** *Moderate concerns of relevance, coherence and data adequacy. Minor concerns of*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	• support parents in their decision making and acknowledge that there may be mixed feelings around spending time with a baby who has died, while also caring for and spending time with the surviving baby or babies • provide parents with culturally and linguistically appropriate resources and support options for the loss of a baby or babies from a multiple pregnancy.		methodological limitation. One included study is deemed to have moderate concerns due to a lack of a statement of the researchers cultural position, and the impact that this has on analysis and findings.	around stillbirth and neonatal death. The remaining two studies are deemed to be indirectly relevant.	and the differing perspectives through literature incorporating health care professional perspective, parent perspective and also an expert in the fields perspective.	income status of cohorts included in their analysis. Outcomes included across the data include stillbirths, neonatal deaths and composite perinatal mortality outcomes, however the sample sizes for these outcomes were not specified. The views of mothers (n=5), fathers (n=4), and health care professionals (n=293) were included. Moderate concerns of data adequacy are noted due to lack of information about the sample sizes for the outcomes of interest, and inadequate cohort size.	*methodological limitation.*
3.16	Offer and facilitate opportunities to gather tangible mementos of the baby (e.g. photographs, identification tags, cot cards, locks of hair, handprints and footprints). Memory making should be an option that is offered more than once to parents/family/whānau.	17 studies are included. Of the included studies, 11 are primary qualitative research, two are cross-sectional studies, two are systematic reviews, two are literature reviews.	Moderate concerns of methodological limitation are noted. Seven of the included studies are noted through critical appraisal to have no or minor concerns of methodological limitation. Six are noted to have moderate concerns, and two are noted to have severe concerns of methodological limitation affecting all aspects of the study processes.	Moderate concerns of relevance are noted. Nine of the included studies are deemed to contain evidence directly relevant to recognition of parenthood during care around stillbirth and neonatal death. One study is deemed partially relevant, and five of the included studies are deemed indirectly relevant.	Minor concerns of coherence are noted.	Minor concerns of data adequacy are noted. 15 of the included studies source their cohorts from high income countries and two from upper middle-income countries. Two reviews did not specify the income status of cohorts included in their analysis. Outcomes included across the data include stillbirth (n=28), neonatal deaths (n=4), termination of pregnancy for	**Low confidence** *Minor concerns of coherence and data adequacy. Moderate concerns of methodological limitation and relevance.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
						fetal anomaly (2 studies), and composite perinatal mortality outcomes (n=551). Viewpoints included across the primary data include that of mothers (n=28), fathers (n=48), parents (n=522) and healthcare professionals (n=45). Minor concerns of data adequacy are noted due to inadequate combined cohort size.	
3.17	Be aware of local processes for supporting parents and family/whānau who initially choose not to keep mementos. Ensure mementos are stored securely and labelled appropriately in maternal or neonatal records for future access.	Six studies are included. Three primary qualitative studies, one literature review, one cross-sectional study and an author opinion.	Moderate concerns of methodological limitation are noted. Four of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. One study is noted to have moderate concerns due to a lack of a statement of the researchers' cultural position, and the impact that this has on analysis and findings. One cross sectional study is noted to have severe concerns of methodological imitation due to lack of inclusion criteria and standard measured for measuring	Moderate concerns of relevance are noted. Three of the included studies are deemed relevant to recognition of parenthood during care around stillbirth and neonatal death. The three remaining studies are deemed to be indirectly relevant.	Moderate concerns of coherence are noted due to different cultural practices and facility policies reflected trough the evidence.	Moderate concerns of data adequacy are reported. Four of the included studies source their cohorts from high-income country populations, and one from upper middle-income country. One review did not specify the income status of cohorts included in their analysis. Outcomes included across the data include stillbirths (n=26) and composite perinatal mortality (n=67). The views of mothers (n=50), fathers (n=14), and health care professionals (n=29) were included through the data.	**Low confidence** *Moderate concerns of methodological limitation, relevance, coherence and data adequacy.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			exposures and outcomes. Confounders were furthermore neither identified or accounted for through analysis. The setting and participants of the research are also inadequately described.			Moderate concerns of data adequacy are noted due to inadequate combined cohort size and inadequate outcomes included.	
3.18	Support and facilitate parents to take a mix of photographs and videos of their baby, including with family/whānau. • Ensure photos are taken with sensitivity and are of highest possible quality. • Facilitate access to a professional photographer who has experience in compassionate bereavement photography, if desired by parents.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
3.19	Offer and facilitate opportunities for commemorative rituals and acknowledge cultural, religious, and spiritual customs important to families/whānau.	Five studies are included. Four primary qualitative research studies, one narrative review, and a prevalence study.	Minor concerns of methodological limitation are noted. Four of the included studies are noted through critical appraisal to have no or minor concerns of methodological limitation. One of the included studies is deemed to have moderate concerns.	Minor concerns of relevance are noted. Four of the included studies are deemed relevant to recognition of parenthood during care around stillbirth and neonatal death, and one study is deemed to be partially relevant.	No concerns of coherence noted.	Moderate concerns of data adequacy are noted. All included studies sourced their cohorts from high-income country populations. Outcomes of interest include stillbirth (n=200) and composite perinatal mortality outcomes (n=56). The viewpoints of mothers (n=36), fathers (n=12), parents (n=173) and health care professionals (n=35) were included.	**Moderate confidence** *No or minor concerns of methodological limitation, relevance, and coherence. Moderate concerns of data adequacy.*

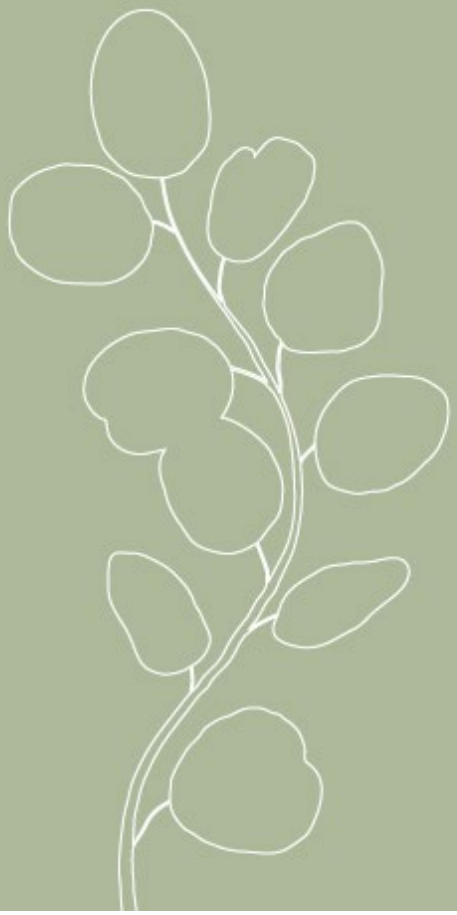
Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
						Moderate concerns of data adequacy are noted due to small, combined sample sizes, and inadequate outcomes included.	
3.20	Sensitively discuss with parents and family/whānau that burial or cremation is a legal requirement for a baby who dies at greater than 20 weeks gestation or weight of 400 g. Provide parents with: • information (including written) that includes the range of available options for burial, cremation, and funeral, and support parents/family/whānau in their decision making • contact details for relevant services • information about available financial support.	NA	NA	NA	NA	NA	**Consensus-based recommendation**

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report



Section 3: Perinatal loss care: effective support

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

The death of a baby during pregnancy or soon after birth is recognised as a unique type of bereavement. Respectful and supportive care should be provided to all parents.[1,2] Effective support addresses not only immediate but also ongoing emotional, informational, physical, and practical needs of parents and other family members.[2]

Immediate support is required to manage the initial stage of grief and to access support in the community once parents have left hospital.[2] Emerging evidence suggests that psychological interventions such as grief counselling may benefit some parents.[3,4] However, limited evidence exists to indicate who is most likely to benefit from different types of psychological support and not all parents will require formal interventions. While many parents feel satisfied with their care while in hospital, satisfaction with aftercare following discharge is much lower.[5] The responsibility of the health care team should therefore continue throughout the post-natal period. A critical area that is rarely addressed is supporting parents as they physically leave the hospital.

Existing social networks, including family members are an important source of support for many parents. However, bereaved grandparents are also impacted by grief and may benefit from informational support and acknowledgement of their grief.[6,7] Men also experience considerable grief but report feeling neglected.[8] Parent support groups and the support of those who have had similar experiences may be helpful for many parents. Some parents may benefit from specific supportive interventions or a combination of supports that will meet their needs at different times. A "flexible menu of support offerings" that recognises a continuum of support needs and the importance of collaboration between hospital, community, and families should be made available to all parents.[9,10]

Methodology

The Guideline Development Committee developed key research questions around provision of effective practical and emotional support for parents and families following the death of a baby (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	What physical care and support is needed by parents after birth and in the postnatal period, including support in making informed decisions regarding lactation management?
2	What are the psychosocial support needs of parents following stillbirth or neonatal death and what forms of psychosocial support are most beneficial?
3	How can healthcare professionals identify parents who may be at risk of experiencing complicated bereavement and ensure referral to appropriate care?
4	What support is needed by family members (including grandparents, siblings) following the death of a baby?
5	What is the optimal follow-up for parents after discharge from hospital?
6	What considerations are there in the provision of perinatal loss care and support for parents who have experienced a termination of pregnancy following diagnosis of fetal anomaly?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 1. PICO criteria

PICO	Inclusion criteria

Population	Defined in Australia and Aotearoa New Zealand as:
	• Stillbirth
	  ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[11,12]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[11,12]
	• Inclusion of perinatal deaths following termination of pregnancy
	  ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).

Intervention	Studies exploring perinatal loss care following stillbirth or neonatal death in maternal or newborn services.
Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes, and experiences of parents, family members, and healthcare professionals around perinatal loss care including care that specifically addresses the practical and emotional support needs of parents and families following termination of pregnancy, stillbirth, or neonatal loss. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Search strategies were conducted on 21 June 2022 and incorporated all PICO criteria and restricted to publications in English (Table 4). A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and were restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- wrong *population*: The study did not focus on stillbirth, neonatal death, or termination of pregnancy for fetal anomaly as defined in Table 2.
- wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- wrong *language*: The study was not published in English.
- wrong *publication dates*: The study was published prior to 2017.
- wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee

between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[13] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[14]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[15]
- Adequacy: The richness and quantity of data supporting the findings[16]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[17]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated and details of any concerns were identified and listed.[18] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

The Guideline Development Committee identified six key research questions on which to focus the evidence synthesis on the best possible outcomes through care for families during a pregnancy after stillbirth and neonatal death.

Evidence synthesis

Question 1: What physical care and support is needed by parents after birth and in the postnatal period, including support in making informed decisions around lactation management?

Mothers may experience different physical symptoms during the postnatal period including vaginal bleeding, lactation, stitches, and caesarean scarring and should be provided with information about postpartum physiology (including lactation and bleeding). It is important that parents are provided with information to help prepare them for what to expect both emotionally and physically, including when to seek medical advice and professional support.[19-21] Information sharing around physical changes following stillbirth or neonatal death including initiation of lactation is often inadequate.[19]

Bereavement lactation

The literature highlights the importance of empowering women to make informed choices regarding lactation by providing all options available to them.[22] The lactation needs of mothers are broadly

overlooked, which can lead to engorgement, mastitis, and psychological harm with many women feeling unprepared for lactation following bereavement.[19,22,23] Women described: "*having to lead myself blindly due to inexperience in the realm of lactation after perinatal loss"* and *"that was a complete shock [when the milk came in]*." Grief is an individual process, and every woman's experience of lactation following bereavement will be different. Thus, not all women will benefit from choosing the same option. When women can make these choices, this is often empowering for them.[22]

Healthcare professionals play a critical role in informing and sharing different options of lactation management, facilitating documentation for milk donation for mothers who are interested and eligible for this option, and providing access to breast pumps, where needed.[24,25] Mothers, however, note that the knowledge of many healthcare professionals about grieving lactation is insufficient.[22,26] Mothers report feeling abandoned, lonely, and misunderstood when they are not supported with knowledge of different lactation management options by healthcare professionals. This perceived lack of support can further hinder the grief process.[25] In a 2023 Australian study, parents noted that it would be beneficial to discuss and consider their options with the assistance of a specialist healthcare professional, such as a lactation consultant.[26]

Different options that can be presented to women include suppression of lactation by pharmacological or non-pharmacological means; donation of stored expressed breast milk; donation of expressed breast milk through expression as a method to wean their milk supply, and establishment or continuation of lactation.[22] The Lactation after Infant Death Framework[27] highlights the need to provide all bereaved parents with written information about lactation management. This should include anticipatory guidance on lactation and acknowledgement of different emotional responses and meanings that may be attached to this experience.

Donation of expressed breastmilk

Milk donation may be beneficial for some women[28], while others report that lactation is a reminder of what they have lost:

> **"expression brought an unexpected release… gave me purpose… my milk could benefit others while giving my baby's existence meaning"; "donating has helped us to heal"; and "people said I was generous to donate EBM from weaning my lactation, but I was the one who benefitted".[22]**

However, not all mothers will be suitable to donate due to various medical or lifestyle reasons, and sensitive counselling is essential to help with the disappointment of unrealised expectations. For example, many women choose to become pregnant within the year following the death of their baby and will require advice regarding how lactation affects their menstruation and planning a future pregnancy.[23]

Although research with bereaved mothers in lactation management is emerging, research on father's perspectives in relation to their partner's lactation is sparse. An Australian study[29] exploring fathers' perspectives of lactation found that fathers assumed a strong supporting role in their partner's lactation care and management practices when their partner had established lactation at the time of infant death or chose to continue lactation for the purpose of donation. Fathers were often involved in their partner's decision to donate and were integral to facilitating donations that sometimes lasted for many months. Fathers expressed pride in their partner's breastmilk donation and noted beneficial

effects of this on their family's grieving, especially in the early period after loss. Moreover, fathers expressed a high need to be presented with the full choice of lactation management options after the death of their baby, including the option of donation, and indicated a clear preference to be included in lactation care conversations with their partner.

Cultural considerations

It is also vital for healthcare professionals to be sensitive to different cultural and religious needs in this context. Alongside personal choice, cultural differences may also determine the way a woman chooses to suppress her milk. For example, Islamic law dictates that women may only donate to recipients that they know and therefore, may prefer informal milk sharing. Also, according to the concept of milk kinship, receiving milk from another mother creates kinship ties with any of her offspring, therefore prohibiting future marriage between them. An understanding of these cultural needs could assist discussions with bereaved Muslim mothers and the provision of informed choice.[23] Knowledge and awareness of society's diversity in an increasingly multicultural landscape is required for healthcare professionals to support all women in their care.[22] It is essential that healthcare professionals are trained in using person-centred approaches and evidence-based information to guide parents in lactation management.[25,30-32]

Question 2: What are the psychosocial support needs of parents following stillbirth or neonatal death and what forms of psychosocial support are most beneficial?

Following stillbirth or neonatal death, parents are at increased risk of negative psychosocial impacts including both short-term and long-term depression, anxiety, post-traumatic stress disorder (PTSD),[33,34] lower self-esteem,[35] stigma,[36] and attempted suicide within one year of birth.[37] Many parents report a high need for psychological and pharmacological interventions at this time.[38] There is a significant relationship between psychological impact of baby loss and support from caregivers and family members.[39]

> **Supportive social networks and compassionate communication by healthcare professionals can help to mitigate some of the distress experienced by parents when a baby dies. Thus, there is a need for greater awareness and sensitivity among healthcare providers, counsellors, and medical social workers about the psychological impact of loss.[1] Appropriate training in perinatal bereavement care including good communication, appropriate attitudes, and provision of meaningful information to grieving parents is recommended.[40]**

In a qualitative study conducted with bereaved parents,[19] parents noted that it was important providers realised how grief was experienced within health care and social support systems and expressed their desire for long-term, specialised support.

An Australian study by Bond et al.,[41] identified three key themes relating to hospital management of stillbirth: understanding the emotional response to grief, the educational importance of being guided through the grief process, and the environmental aspects of adequate time and appropriate physical space. Bereaved parents report that discussion with healthcare professionals about coping strategies following loss is helpful;[10] however, grieving parents do not always get the professional bereavement support they need.[1]

The hospital to home transition is a critical area of support need for families following a baby's death.[9] The transition for bereaved families from hospital to home should be seamless, allowing them to focus on their baby, their bereavement, and their family's wellbeing.[42]Parents' have a strong need for continuity of care and clear information about what to expect upon discharge from the hospital;[21,42,43] however, this is an area of care identified by parents as lacking and needing more support.[5,19,41,44-46]

> **"There's the hospital support and then there's the long-term support, how to survive in the community … once you leave that hospital you drop off the radar … how do we come up with solutions for these affected bereaved parents?[19]**

Parents have articulated their need for various information and resources to be provided in different formats in preparation for their transition from hospital to home. This includes verbal discussions with care providers, sufficient opportunity to ask questions, and written information.[41] Information and supports should be culturally sensitive and available in multiple languages, where possible.[46] Written information and resources should include information about funeral services, breast milk production, different lactation options; post-discharge physical and mental care, follow-up appointments, information about bereavement support groups, and psychological services.[47] Parents should also be provided with appropriate contacts for any ongoing questions/ clarifications about their baby's death, ideally within the same team in the hospital that were involved in their care.[43]

It is also important that parents are aware of possible grief reactions and different coping resources such as books, online resources, professional counselling, and support groups.[21,41,44-46] Supporting bereaved families to access professional groups, and encouraging participation of family or friends, midwives, and/or social workers to attend follow-up appointments may have a significant impact on satisfaction with care and long-term grief outcomes.[41]

Acknowledging fathers' experiences of grief

Partners are a key source of ongoing support for women, but also have support needs of their own. Bereaved fathers experience a double burden: their own pain of the loss and the physical and emotional suffering of their female partners. A study set in Brisbane, Australia, found that fathers are more likely to experience high levelsof distress, including self-harm, 3-4 months following the loss of their baby.[48] As fathers are expected to 'be strong and support the mother,' it is common for them to suffer alone while seeking ways of aligning with their partners' emotions to support them during the grieving process.[49]

Hospital support experiences are critical to fathers' support needs. Men often feel neglected and marginalised at hospitals while their partners are receiving treatment.[8] This also extends to emotional supports provided to parents after their baby's death, with some fathers reporting that they were unable to access hospital bereavement services as they were not officially recognised as a patient in the hospital.[5] In research conducted with Australian fathers, most fathers emphasised a need for individualised bereavement support that is separate and different to the support provided to the mother of the baby.[5]

Emotional care should take differences in the resolution of grief between mothers and fathers into consideration. Evidence suggests that both men and women are greatly affected psychologically and emotionally by the trauma of stillbirth and experience a broad range of symptoms with some gendered distinctions.[20] While men and women experience similar feelings, they cope differently.[50] Men's grief experiences are very diverse, and existing grief measures may not catalogue all the

challenges and complexities of grief for men such as a lack of social acknowledgment for their grief or the expectations to support female partners.[51,52]

> **"In men, grief is often a delayed reaction, this was especially true in me. At the six-month point, I felt a wave of deep grief. The first six months I was just trying to push through and make sure my wife was ok."[53]**

Overall, research shows that many fathers feel that those around them do not recognise their loss or provide adequate informal support; and emphasise the need to acknowledge their baby's life.[5] Healthcare professionals should recognise and acknowledge the pain of fathers who face perinatal death and include them as much as possible in the standard of care[54]. Anticipatory guidance about gender differences in grieving may also be helpful for bereaved parents who are partnered at the time of their loss.[20]

Professional support options

Research suggests that despite a clear value placed by parents in accessing different types of support, many parents are not told about available supports.[46] In certain contexts, this can be attributed to healthcare professionals' own lack of awareness of different support options and self-help groups.[55] This is something that should be addressed in healthcare professionals' ongoing training and development. While it is important to note that not all parents need psychological support, as grief can be a "normal" part of the bereavement process,[56] healthcare professionals are encouraged to discuss available resources and supports with each family and offer contact details of counselling and support groups.[46]

A systematic review summarising the efficacy of nursing interventions to facilitate the grieving process identified that the support of healthcare professionals, the expression of feelings and emotions, distraction methods, group sessions, social support, physical activity, and family education were helpful interventions for parents after the death of their baby.[57] Parents' participation in these activities led to improved anxiety, feelings of grief, sleep, and self-confidence.[57] The support interventions for families experiencing perinatal loss are effective if implemented both before (if foreseeable) and after the death of the baby.[51]

In intervention studies, grief counselling for parents following perinatal death reduced grief symptoms, prevented complicated grief,[3] and lead to statistically significant reductions in PTSD.[4] Grief counselling and bereavement programs should be considered and implemented at all institutions involved in maternal, fetal, and newborn care.[58] These programs may include opportunities for parents and families to create tangible memories as they relate to their child and their role as parents. Similarly, social and emotional interventions were found to be effective in reducing grief, depression, and anxiety among parents after perinatal loss.[59] Offers of psychological support are usually taken up by parents, as they imply recognition of loss, particularly to those parents at risk of disenfranchised grief. Offers of professional psychological support also enable parents to access appropriate support later when their mourning feels socially unrecognised. In one study psychological or psychiatric support was offered to 93% of parents and accepted immediately by 78%. A subsequent appointment with the medical team was offered to 80%.[60]

Online yoga and other physical activity have also been found to reduce depression, grief intensity, and post-traumatic stress among women post stillbirth.[61,62] An occupation-based residential retreat has also shown preliminary evidence in fostering positive change in depression, perceived social support, self-compassion, and trauma for mothers in the aftermath of losing a pregnancy or young infant. The

retreats provided women with the opportunity to participate in a physical temporal context that was separate from their everyday lives, thereby allowing them to focus on their own grieving process.[63]

Further, perinatal loss support groups provide parents with a unique opportunity to talk about the topic in an empathic environment where their loss is accepted without any kind of prejudice. Talking with other parents who have gone through the same or a similar situation makes parents feel more understood.[44,64]

> **"Talking with couples who have gone through the same thing as us helps us to realise that there are people who have been through the same as you..." [44]**

Support groups provide a sense of community and are valued by parents as a resource for additional support, empowerment, comfort, and hope.[65,66] Online support groups are popular for peer support, particularly for uncommon or stigmatised topics including pregnancy and infant loss.[67] In addition, some parents felt the need to support other parents with perinatal loss through their own experience, and this helped them overcome their own loss.

Some fathers in an Australian study reported that they did not engage in emotional supports, whereas others expressed a desire to connect with fathers who had experienced perinatal loss to make sense of their experience. This desire aligned with the limited social recognition fathers experienced regarding their loss.[5]

Rural women can also experience less social support due to geographic isolation. In rural communities, specific support groups for women who have lost an infant are difficult to locate and to maintain. In these communities, grief support groups are often general in nature and mixed with individuals addressing a variety of losses. The lack of specific grief services provides a limited opportunity for social connection and support and does not meet the unique and specific needs of the bereaved mother. In rural communities, support groups may take shape within the context of spiritual or religious affiliations.[68]

Question 3: How can healthcare professionals identify parents who may be at risk of experiencing complicated bereavement and how to ensure referral to appropriate care?

Grief is an expected normal response to perinatal loss; however, approximately 4 in 10 of women experience prolonged grief that persists over time,[69] and is characterised by high levels of anxiety,[70,71] depression,[70,71] and post-traumatic stress.[70,72] Various labels have been assigned to prolonged grief including prolonged grief disorder, complicated grief, and persistent complex bereavement disorder.[73] Factors associated with prolonged grief after perinatal loss include lack of social support,[74,75] relationship discord,[71,75-77] stigma,[36,78] pre-loss mental health issues,[70,76] maladaptive cognitions,[79] rumination,[80] and type of loss.

In an Australian study, women who experienced fetal death in utero were more likely to develop complicated grief than women who experienced termination of pregnancy, neonatal death, or intrapartum death.[69] Gender differences in the experience of grief after stillbirth have also been observed therefore the predictors of complicated grief may be different for men and women. Despite the psychological impact of complicated grief, there is a lack of randomised controlled studies in this

field of research.[75] Knowledge about the psychological comorbidities that may co-exist with complicated grief is also imperative to ensure appropriate care and referral.

Psychological comorbidities

A variety of comorbid conditions including major depressive disorder, generalised anxiety disorder, and PTSD are also associated with perinatal loss and may coexist in bereaved parents with complicated grief. Although women's response to perinatal loss is individual, bereaved mothers usually report feelings of anger, guilt, irritability, emptiness, loneliness, and depression.[25] Risk factors for these conditions include history of a psychiatric illness, childlessness, unknown cause of perinatal loss, negative cognitions (e.g. "I am worthless", "the world is unjust"), negative appraisals, limited social support, marital status (incl. marital/relationship discord), and variables related to care and management after stillbirth.[33,81] The risk of completed suicide has also found to be higher in women who experienced a stillbirth, miscarriage, or termination of pregnancy than in those who had a live birth.[37] The risk of suicide might increase in women who experience fetal loss within 1 year postnatally. Healthcare professionals and family members should enhance their sensitivity to care for possible mental distress, particularly for women who have experienced a stillbirth.[37]

Depression

Identified predictors of depression were marital status, educational status, time since stillbirth, professional and social support, negative cognitions (e.g. "I am worthless", "the world is unjust"), no future pregnancies, not having had the desired contact with the baby, birth order of the baby, and whether mothers experienced difficulty in becoming pregnant.[33] Longitudinal studies indicate that the highest risk of depression presents shortly after birth and although the symptoms decline with time, they remain higher than among controls.[33] Levels of depression were higher for parents who held back from sharing expressions of continuing bonds to avoid a negative response more frequently, and who felt more pressure from society to move on. Depression scores were lower for parents who thought they had made more meaning following their baby's death, and for those for whom more time had passed since their baby's death.[82] Similarly, depression was significantly lower in women who faced less social rejection during the postpartum period in India.[38] In another study, no significant differences were observed in grief and depression depending on the type of loss, no significant associations were found with the age of the mother, her socioeconomic level, or obstetric factors (week of gestation of the loss, having a child or having suffered a previous miscarriage).[83] The psychological and emotional symptoms of grief can sometimes be confused with or overlap with those of a major depression, although they are distinguished by symptomatic criteria and the duration of the episode.[83] Depression as measured by the Edinburgh Postnatal Depression Scale was associated with despair 6 weeks, 6 months, and 1 year after termination of pregnancy. Despair was measured on the perinatal grief scale and is representative of complicated grief.[71] Other studies reported that women who were single experienced more severe depression than those who were married. Difficulty getting pregnant after stillbirth and length of time between diagnosis and delivery were positively associated with depression.[84] Also, women reported significantly fewer symptoms of depression when they got to see their baby for as long as they wished compared to those who did not.[84]

Anxiety

Stillbirth is associated with anxiety symptoms in the postpartum period. The predictors include time since given diagnosis of death until the start of birth, seeing the child as long as desired, having tokens of remembrance, holding the baby after birth, time since stillbirth, and the wish to talk more about the baby.[33] Anxiety scores were higher for parents who reported lack of family support and understanding of their desire to share their continuing bonds with their baby, in comparison to

parents who reported more support and meaning following their baby's death [82]Anxiety symptoms in the first 6 weeks are associated with grief symptoms 6 and 12 months after termination of pregnancy.[71]

Post-traumatic stress

Women who suffered fetal death in utero were more likely to develop PTSD than those who had termination of pregnancy, neonatal death, or intrapartum death.[33,69] As with depression and anxiety, the symptoms appear to be highest in the immediate postnatal period, followed by a decline as time passes.[33,82,85] The predictors included cognitive factors (i.e. appraisals, dysfunctional strategies, locus of control, and posttraumatic cognitions), perceived social and professional support, time since stillbirth, and involvement in memory-making activities.[33] Additional risk factors for PTSD symptoms included younger age, lower income, and no previous pregnancies.[33] Women who rated perceived social support as high reported lower levels of re-experiencing symptoms at 3 and 6 months, indicating social support as a protective factor for PTSD.[33] Findings have also shown that some women who experience stillbirth will have a high risk for posttraumatic stress symptoms and experience poor sleep quality. Posttraumatic stress levels can often be higher in women than men after perinatal loss.[86] Following a perinatal loss, a high proportion of women had high PTSD scores and complicated grief despite utilising local bereavement services. In an Australian study examining the impact of bereavement services on the progression to complicated grief, 75% had a perinatal PTSD score which indicated the need for support from mental health services. Forty-three percent met the criteria for complicated grief.[69] Women whose PTSD scores were in the highest quartile were most likely to access services. Requests were made for grief training of hospital staff, and for referral to bereavement services to be offered after hospital discharge.[69] Further, PTSD scores were higher for parents who had a greater desire to talk more freely about their relationship with their baby with others, who agreed more strongly that they had avoided talking about their relationship with their baby with some people in case of a negative response, and who perceived their baby to be more integrated into their life.[82,85]

Fathers' experiences

Studies indicated that men reported less intense and enduring levels of psychological outcomes than women but were more likely to engage in avoidance and coping behaviours such as increased alcohol consumption.[87] Men felt their role was primarily as a 'supportive partner' and that they were overlooked by healthcare professionals.[87-91] One study found that while intense grief reactions and posttraumatic psychological sequelae diminished over time in mothers, it persisted in fathers who had experienced neonatal death.[92] In an Australian study,[93] men experienced significant grief across all loss types, with the average score sitting above the minimum cut-off considered to be a high degree of grief. The grief scores of men were linked to various factors, including their history of loss, satisfaction in their marriage, the extent of social support available to them, recognition of their grief by family and friends, the time they spent bonding with the baby before birth, and the conflict they felt between their role as a 'supporter' and their own grieving process. The factors contributing to grief differed based on the style of grief. Grief characterized by a focus on emotions (intuitive grief) was connected to the support they received from healthcare professionals. On the other hand, grief centred around activities (instrumental grief) was associated with the amount and quality of attachment to the baby during pregnancy, the availability of social support, recognition of their grief by their female partner, the interference of their role as a supporter with their grieving, and tendencies towards self-reliance. While better quality of attachment was mildly linked to lower grief scores, higher levels of time spent in attachment were related to increased grief. More instances of previous pregnancy losses or neonatal deaths correlated with higher levels of grief, as did lower

overall support, and extended time spent in attachment. Higher grief scores were also associated with lower levels of acknowledgement of grief from friends, as well as higher levels of agreement to the statement: "I was unable to grieve, because I was too busy supporting everyone else".[93] Men who saw their baby after birth had a lower psychological stress score compared with men who did not see their baby.[86]

Screening and referral pathways for parents at risk of complicated bereavement

Some scholars recommend all bereaved parents should be screened and offered support because of the significant relationship between perinatal loss and psychological impact.[38,39,76,94] Routinely implementing focused psychosocial assessments is necessary to identify parents at risk for developing complicated grief. A systematic review showed the most used screening tool for perinatal grief is the Perinatal Grief Scale (PGS).[76] Tools such as the Perinatal Grief Intensity Scale (PGIS), Patient Health Questionnaire (PHQ-9), General Anxiety Disorder-7 (GAD-7), the Munich Grief Scale, the Perinatal Bereavement Scale, the Dyadic Adjustment Scale, the Impact of Events scale, and the Center for Epidemiologic Studies Depression scale are other examples of validated and reliable instruments that may be beneficial in routine screening of persons experiencing perinatal loss. Screening should include both parents because the supporting partner's grief may be overlooked or neglected.[94] However, it is important that providers are conscious that some parents may feel uncomfortable when asked to respond to mental health assessments following a recent loss. They may see this as an attempt to quantify and pathologise their grief. For these individuals, targeted questions regarding their sleep quality and self-harm may be most appropriate.[95]

Parents currently experiencing or at risk of experiencing psychiatric symptoms should receive a comprehensive treatment plan that includes:

- Proactive clinical monitoring
- Evidence-based approaches to psychotherapy
- Discussion of the risks and benefits of, and alternatives to, medication treatment during preconception and pregnancy.

Healthcare professionals should focus on providing information and multidisciplinary care. Women should be encouraged to express feelings of grief and trauma to validate and give meaning to their loss. Additional interventions and professional follow up may assist in the processing of grief by providing a better assimilation of distressing unintegrated memories into coherent narratives.[71] Co-location of mental health services eliminates barriers to access care for women at risk of negative mental health outcomes.[96] Survey findings of a study conducted in Australia supported the continuation of current support services with some modifications, such as better collaboration and integration of hospital staff with specialised counsellors. Survey respondents also highlighted the need for better promotion of the services available in the community, not only while in hospital but also within the early post-discharge period.[69]

Addressing male-specific needs, such as balancing a desire to both support and be supported, requires tailored information and support.[97] It is therefore imperative that healthcare professionals are equipped to assist men to balance their desire and need to support their partner, while also addressing their grief and need for support. Intervention strategies should engage individually with men both immediately in hospitals, and in the weeks/months following a loss, to ensure they have access to tailored support and services where these are needed. Intervention, particularly for intuitive grievers, could include a formal brief assessment of men's grief and mental health in the hospital and in the weeks/months following discharge (e.g. the Edinburgh Postnatal Depression Scale).

Interventions for instrumental grievers could involve providing a follow-up telephone service specifically to men post-discharge from the hospital including referral to community-based supports where required or delivering couples-based psychoeducation sessions to foster positive communication, mutual understanding of individual grief styles, and information on supporting one another.[97] In addition, assessment of both partners' coping mechanisms should be conducted to identify maladaptive coping patterns, such as excessive alcohol use.[95] Increased hospital coordination and shorter waiting times are required since the delay in receiving psychological assistance aggravates the symptoms associated with grief.

> **"Expressing our feelings with a psychologist who had more knowledge of the subject would have helped us a lot. It would not have taken away the pain, but it would have guided us and gave advice. I don't understand why we were not offered psychological help at times when you are so lost.".[44]**

Research highlights the critical role that healthcare professionals can play in supporting and linking parents with appropriate services and supports, where appropriate. It is therefore imperative that healthcare professionals acknowledge and understand the psychological aspects of pregnancy loss, inquire about parents' emotional needs, identify risk factors for prolonged perinatal grief, and provide parents with information regarding grief and mental health referrals.[95,98] Provision of organised supportive healthcare, informational guidance, and active and timed follow-up of bereaved parents and family members is crucial in appropriate management of perinatal grief.[98]

Question 4: What support is needed by family members (including grandparents and siblings) following the death of a baby?

Family and community play a significant role in parents' coping after perinatal loss.[99,100] A social support system for families is necessary to avoid negative emotional consequences for bereaved parents.[44,101] Educating families and communities about grief and potential consequences of silent grief (i.e. depression, complicated grief, and emotion work) could mitigate the pressure of cultural expectations and help parents to feel supported. Bereavement support programmes for family members, including grandparents and siblings may be beneficial.[102,103] There is also some evidence on the effectiveness of family support programs in preventing post-traumatic stress symptoms for women with fetal abnormalities requiring termination.[104,105] Healthcare professionals might also need to challenge unhelpful behaviours with families and communities to avoid potential harm for parents, including blame, stigma, and social isolation.[40]

Grandparents play a significant role in supporting their children through perinatal loss, but also experience grief for the lost grandchild and often have support needs of their own.[6,7]

> **"It's like two lots of grief, because, but I don't want it to sound like it's as bad as um my daughter's loss, its different, it's a different grief, because you're grieving the loss of a grandchild, and you're also grieving for your daughter and her loss and it's like yeah you've been kicked in the guts twice instead of once."[6]**

Grandmothers described their experiences of pregnancy loss in terms that identified this as an ambiguous and compounded loss, with disenfranchisement of their grief leading to feelings of isolation and powerlessness. For first-time grandmothers, the symbolic loss of the role of grandparent

was an additional grief to bear. The grief experienced is influenced by individual differences and circumstances. Styles of grieving, personality, spirituality, family relationships, and the extent of prior losses also contribute to grandmothers' progression through grief.[6]

Grandfathers typically provided extensive support to their child and family; however, few supports were available to help grandfathers. While information via midwives has been reported as being highly valued and desired, this was not often available to grandparents.

> **"If there was someone at the hospital, I probably would have welcomed hearing from them before we left. We basically just walked out the door later that morning, um, but, had there been someone there who could have taken us aside and had a bit of a chat and made suggestions about how we could move forward that might have been useful."**[7]

Some grandfathers described how books and written information were their most useful sources of information.

> **"I got hold of a book on grieving. It was immensely helpful, and handy to have on hand. That sort of thing should be made available in case they need it."** [7]

Some grandfathers also noted that being well connected—or being associated with a supportive community group (e.g. church groups, hobby groups)—provided an avenue for good support, highlighting the importance of informal social connections. One participant encouraged those without such networks to seek and be open to support.

> **"Best place to be, if you can be in it. So do encourage people if they don't have support to find support and be open to support."**[7]

Grandparents desired more information from healthcare professionals and support organisations about the coping mechanisms their child might utilise and about how they could help their child. They indicated that this information would help them to understand their child's experience and, in turn, guide their actions.

> **"And just some, and just an understanding of the coping mechanisms that she would go through so I could be part of it and even in a passive way of just understanding what she's doing. Like if she rang up angry, then I could realise where that anger comes from, you know, like, there's a degree of common sense, per se about how we react to things, that I would have liked to have had the coping tools to better help her."** [7].

Question 5: What is the optimal follow-up for parents after discharge from hospital?

Research with bereaved parents indicates a strong need for structured and integrated follow-up care following the death of a baby,[69,106] yet this is an area of care that is often lacking.[107-109] Many parents report receiving no or delayed clinical follow-up, no professional intervention, and no social support beyond the immediate family.[107,110] The lack of care and follow-up support may interfere with parents' grieving process and may contribute to feelings of isolation and loneliness.[44,108] Follow-up

contact with bereaved parents provides healthcare professionals an opportunity to connect bereaved parents with additional support services and community resources if needed.[53]

A personalised approach to follow-up care is highly regarded given grief is an individualised process with parents having different needs at different times.[111] While it is important that parents are provided with information about various support options while at hospital in preparation for their transition to home, some parents may be too overwhelmed to process this information at that time, therefore follow-up after discharge can be immensely beneficial,[69] as described by one parent below.

> **"We were given information about bereavement services hours after delivering a stillborn. At that time, we couldn't even look at pamphlets…as it was too raw…We felt like we were never followed up once we left hospital, just left to drift in grief by ourselves in confusion"[69]**

Parents appreciate it when there is continuity in their care and the follow-up is made by a health professional who has been a part of the bereavement care journey during the family's time at the hospital and understands their individual needs.[53,108,112]The follow-up support can happen through various pathways including phone calls, midwife home visits, sending condolence card(s), or in the form of referral to further support such as, psychologists, community support groups, and online forums;[108] however, the research is not yet clear on the best method of follow-up contact and the length of time these services should remain available post-loss.[53] At a minimum, parents and families should be provided with written and online resources about "what to expect in the weeks and months after experiencing a loss, the signs of typical and complicated grief, when to seek out mental health services, strategies for establishing a daily routine, focusing on sustaining good self-care, and maintaining social connections".[53] Some parents appreciate follow-up phone calls during the first year of the bereavement process and this is also seen as a useful tool from the perspective of healthcare professionals in monitoring the well-being of parents during the grieving process.[19,20,113] Virtual follow-up and support options have also become more prevalent during the COVID-19 pandemic.[114] While the research is still emerging about how well-received these options are by parents, telehealth options provide opportunities for more effective and creative support for bereaved parents.[115] Bereavement outreach programs described in literature provide examples of how an integrated follow-up can be implemented in practice. In their perinatal palliative care and bereavement outreach program, Cole et al.[53] described a system of structured follow-up at three touch points throughout the first-year post-loss. At each timepoint, the contact included a handwritten condolence card with personalised messages and the contact information for the program clinical psychologist. Many parents appreciated this contact throughout the first-year post-loss, and that they were remembered at the one-year memorial of their loss. Similarly, in another perinatal bereavement program,[116] the author described that bereaved parents at their hospital receive a follow-up phone call and cards soon after the birth and again, after 3 months and are offered a monthly, face-to-face loss support group for those who desire ongoing support. An annual memorial service is also conducted, which has been an effective way to re-connect with families and offer continued support and encouragement.

It is not only important that follow-up with families takes place but the environment in which this happens is important for families too.[10,41] Private rooms, general practitioner clinics, and maternal fetal medicine units are favoured by parents for follow-up meetings as they are often quiet and secluded.[41] Antenatal clinics are viewed least favourably as a location for follow-up meetings.[41]

In terms of the content of these appointments, it is critical that along with the physical aspects of recovery, attention is also given to mental and emotional well-being and appropriate support options

such as, community bereavement services, professional, and peer groups are shared with parents and that referrals are facilitated, where needed. This can significantly impact on parents' satisfaction with care and long-term grief outcomes. Parents appreciate it when they are provided with opportunities to ask questions and can spend adequate time with the clinician.[41]

There is an urgent need to develop better collaborative care pathways at the interface between primary and secondary care [10]. There is a discrepancy between parents' experience of follow-up care and assumptions of healthcare staff. Contrary to parent experiences, it is often reported that health care practitioners assume that follow-up support automatically continues through primary care services such as general practitioners (GP) and community midwives after parents are discharged.[10] There is a strong need for establishing better healthcare communication pathways to improve continuity of care and support for parents following discharge from the hospital.[41,43,108,109]

Question 6: What considerations are there in the provision of perinatal loss care and support for parents who have experienced a termination of pregnancy following diagnosis of fetal anomaly?

Note. This Guideline provides guidance on care for parents who have experienced stillbirth, neonatal death, or termination of pregnancy. Termination of pregnancy specifically refers to parents who have made the decision to terminate a wanted pregnancy because of the diagnosis and/or prognosis. The decision to terminate is outside the scope of this evidence synthesis.

Psychosocial support needs

Women who experience termination of pregnancy are at increased risk of post-traumatic stress and depression compared with women who continue with pregnancy.[117,118] Risk factors for complicated bereavement include insufficient social support (odds ratio [OR] 6.5; 95% CI 2.0–21.0, P < 0.001), history of a mood disorder (OR 3.4; 95% CI 1.3–8.8, P < 0.01), and history of another termination of pregnancy (OR 6.2; 95% CI 1.2–31.0, P=0.01). Viewing the fetus after termination was not correlated with a significant reduction in complicated bereavement.[119] Another study found that higher self-judgment at the time of abortion was significantly associated with increased postabortion grief (b=2.5 and p=0.02).

Self-judgment was not associated with statistically significant differences in post-traumatic stress or mental health. There was no association between perceived community condemnation and psychological outcomes.[120] In a study in China of fathers who had experienced termination of pregnancy, there was no significant difference in the incidence of anxiety between fathers and mothers. For fathers, level of income, worry about the pregnancy, and perceived level of support were predictors of anxiety symptoms. Depression was more common in mothers (50.3%) than in fathers (24.9%). Predictors of paternal depression included worry about the pregnancy, perceived support, and maternal depression.[121]

Father's grief is often overlooked following termination of pregnancy.[122] In a survey, almost one-third of the partners had sought professional counselling outside the hospital for reasons including the grieving process (81%), understanding differences in coping between themselves and their partners (50%), depressive symptoms (40%), returning to normal life (40%), and coping with other children (30%).[123]

Regarding the psychosocial support received, the family usually plays a fundamental role as an element of support and accompaniment [107]. Receiving emotional support from family and close

friends is effective in restoring mental peace and decreasing the anxiety and stress of women. Women reported that family support is effective in providing empathy and decreasing the feeling of guilt and self-blame. A cooperation of the family members and close friends could be a significant help in balancing the situation and returning to normal condition. Peer support was also reported as beneficial[124] Religious beliefs are also seen as important*:*

> **"There are some people who just think that's God's will, and they accept it and they just cope with it" (Son 2) [125]**

According to the interview reports, many women received minimal to no clinical follow-up following termination of pregnancy. There was no social support beyond the immediate family and there was no professional counselling support (e.g. psychotherapist) offered [107].

Stigma

Stigma appears to play an important role in understanding psychological complications following a termination of pregnancy. As women can experience persisting symptoms of post-traumatic stress and depression as well as grief complications up to 7 years after a termination of pregnancy, short- and long-term psychological support should be made available for affected women.[78] Women described feelings of guilt and shame over their decision and thought how their situation would have been if the pregnancy had continued.

Internalised stigma is associated with long-term psychological distress following a termination of pregnancy. Perceived stigma at the time of the termination may contribute to increased trauma and grief symptomatology, but results need to be validated in longitudinal studies. Healthcare professionals and public initiatives should aim to reduce stigma among affected women and provide long-term psychological support for women after a termination of pregnancy.

Follow-up support for parents and families

Advances in antenatal diagnosis have created an opportunity to commence addressing psychosocial, emotional, and spiritual needs of families prior to the birth of their child.[126] Genetic counselling prior to termination of pregnancy has been shown to enhance coping afterwards.[127] Some parents may cope better after choosing to continue the pregnancy and receive palliative care if the infant survives, and so expectant parents should be presented with all options.[117,128-130] Recognition and respect of parental preferences concerning treatment options may facilitate the grieving process, potentially preventing long-term adverse psychosocial outcomes.[131,132] Parents expressed a preference for receiving support from a maternal-fetal medicine specialist to help them understand the severity and consequences of the anomalies found and to counsel them in their decision regarding termination. Support from mental healthcare professionals to help with their emotional responses was also prefered.[123] Embedded psychological services within multidisciplinary teams may be beneficial to women with a diagnosis of congenital anomaly.[133] Both parents experience grief and increased risk of adverse mental health impacts following termination of pregnancy and should be offered support including grief counselling and other psychological interventions.[105,134,135] During aftercare, attention should be paid to grief counselling, acknowledgement of the lost baby's existence, and possible future pregnancies.[123] However, women have reported a lack of aftercare following their termination of pregnancy.[136] This is especially concerning as grief complications were recognised in 2015 in the ICD-11 beta draft as a distinct psychological disorder (Prolonged Grief Disorder).[137]

In one survey, forty-one percent of women reported seeking support from a professional outside of the hospital, mostly on account of the following: their grieving process (65%), finding a balance

between grieving and returning to "normal life" (61%), depressive symptoms (32%), differences in coping between themselves and their partners (29%), "feeling like myself" again (26%), anxiety symptoms (23%), and PTSD symptoms (19%).[123]

An exploration of health professional's views found that healthcare professionals lacked insight into women's long-term coping processes and the potential for positive growth following termination of pregnancy, which is consistent with a lack of aftercare following termination reported by women.[125] In another study, aftercare was regarded as an important factor in women's coping processes but was recognised by a registrar as "patchy". Professionals commented on how isolated women may feel after the termination:

> **"I often feel when they have a termination and they just go home and they're left to deal with it…" (Specialist nurse).[125]**

This could contrast with the intense level of care women receive up to the termination:

> **"There is a sort of cliff-edge effect… you find a baby with an abnormality, and you see them every week in the fetal medicine unit, and you get counselled by 6,000 people and then you have a termination and then go home, and you don't see anyone anymore." (Consultant 1).[125]**

Aftercare was not routinely provided to parents following termination of pregnancy, highlighting a gap in the provision of healthcare services available. If aftercare is not available or easily accessible, healthcare professional should refer parents to support organisations.[45] When the women's expectations of the nurses were examined, 76.7% of the women expressed that they wanted to receive psychological counselling, 60.0% wanted to receive information about family planning, and 73.3% wanted to be informed about the infections that could develop after the procedure.[138]

Grey literature and other sources

In addition to the published academic literature, both international and national government agency and parent support organisations (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to effective support for parents following the loss of a baby. A targeted Google search was also conducted using a combination of the following keywords: effective support following pregnancy loss, effective support following stillbirth or neonatal death, effective support for parents following the loss of a baby. The findings of the grey literature are supported by both the current and previous edition of the Care Around Stillbirth and Neonatal Death Clinical Practice Guideline.

Bereavement care and support for parents following the loss of a baby should continue following discharge from hospital. The Red Nose Hospital to Home (H2H) Program (funded by the Australian Government Department of Health and Aged Care) has been designed to help parents and improve their transition from hospital to community for up to three months after they leave hospital. This is achieved through a trained Red Nose Bereavement Outreach Worker who provides individualised practical and emotional support. The H2H Program also includes tailored peer support from others who have lived experience of stillbirth or neonatal death. Overall, the H2H Program has been designed to:

- Provide early and targeted support to assist in ensuring healthy grieving
- Reduce isolation
- Validate the impact of grief
- Support healthy relationships by assisting partners to understand different grieving processes and encourage good communication
- Increase the understanding of family, friends, and community regarding the needs of bereaved families
- Identify emerging issues associated with complicated grief early so that additional supports can be put in place reducing the likelihood of ongoing mental health issues
- Increase productivity by supporting bereaved parents to return to their “normal” activities, including work.[139]

The support provided to parents varies depending on their individual needs, however, it encompasses both face-to-face and online support. Support may also include assistance with hospital discharge and accompanying parents to medical appointments (or other appointments to receive autopsy/investigation results). Parents may also need additional support when lodging paperwork such as birth and death registrations and re-integrating with their employment or other general activities.[139]

In 2021, the H2H Program was evaluated by the Institute for Social Science Research at The University of Queensland in partnership with Red Nose. Overall parents reported high levels of satisfaction with the support sessions provided by the program. However, most of the parents who participated in the evaluation were referred to the program by non-hospital sources, indicating the importance of building and enhancing relationships with maternity hospitals so immediate support can be accessed.[139]

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies		GRADE-CERQual Overall Confidence Rating of evidence	Guideline recommendations
		See Section 2: Technical report for cultural safety for evidence synthesis and GRADE-CERQual rating of this recommendation.	**Consensus-based recommendation 2.6:** Acknowledge the specific care and support needs of parent(s) who have experienced a termination of pregnancy and ensure perinatal loss care planning is across the continuum of care. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*
		See Section 2: Technical report for cultural safety for evidence synthesis and GRADE-CERQual rating of this recommendation.	**Consensus-based recommendation 2.7:** Normalise and validate parent(s) individual experience of grief and loss. Support parents to express their concerns by confirming their feelings and having open discussions about their needs. • Be aware of potential differences in how partners and family/whānau member express grief. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*
Azeez, Obst, Oxlad, Due, & Middleton, 2021 Cena et al., 2021	Lizcano Pabon et al 2019 McNeil et al 2021 Nguyen 2019	Low confidence	**Consensus-based recommendation 2.8:** Acknowledge father/partner's experience of loss and their identity as a parent. Provide tailored support services for

Cole et al., 2020 Fenstermacher & Hupcey, 2019	Obst, Due, Oxlad, & Middleton, 2020 Roberts et al 2017 Furtado-Eraso et al 2021	*Minor concerns of coherence moderate concerns of methodological limitation and relevance. Major concerns of data adequacy.*	fathers/partners including both formal and informal support options and referral to parent support organisations as required. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*
		See Section 2: Technical report for cultural safety for evidence synthesis and GRADE-CERQual rating of this recommendation.	Consensus-based recommendation 2.9: Acknowledge the grief and loss of other family members, especially grandparents and other children (siblings), and offer appropriate support options. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*
		See Section 2: Technical report for cultural safety for evidence synthesis and GRADE-CERQual rating of this recommendation.	Consensus-based recommendation 2.10 Offer parents culturally and linguistically appropriate information about perinatal grief and what to expect, to review when they are ready. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*
			Consensus-based recommendation 2.11: Provide parents and family/whānau members with information and

	See Section 2: Technical report for cultural safety for evidence synthesis and GRADE-CERQual rating of this recommendation.	opportunities for social and emotional support including peer support, professional counselling and psychology services, and other bereavement support services. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*
	See Section 2: Technical report for cultural safety for evidence synthesis and GRADE-CERQual rating of this recommendation.	Consensus-based recommendation 2.12: Establish and use referral pathways to ensure appropriate ongoing professional support for parents who may be at risk of developing mental health problems (e.g. post-traumatic stress), particularly parents who have pre-existing mental health conditions. *This recommendation has been drawn from the evidence synthesis in this report and evidence synthesis from *Section 2: Technical report for cultural safety.*
		Consensus-based recommendation 3.20: Sensitively discuss with parents and family/whānau that burial or cremation is a legal requirement for a baby who dies at greater than 20 weeks gestation or weight of 400 g. Provide parents with: • information (including written) that includes the range of available options for burial, cremation, and funeral, and support parents/family in their decision making

			• contact details for relevant services • information about available financial support.
Arach et al., 2022 Farrales et al 2020 Fenstermacher & Hupcey, 2019 Smith et al 2020		Low confidence *Minor concerns of coherence. Moderate concerns of methodological limitation, relevance and data adequacy.*	Consensus-based recommendation 3.21: Discuss expectations for postnatal care including lactation, vaginal bleeding, wound care, contraception, and physical activity. Provide all women with information about postnatal physical changes, postpartum care and potential complications that could occur, including when to seek medical advice and support.
Carroll et al., 2020 Cole et al., 2018 Dickens, 2020 Farrales et al. 2020 Fernandez-Medina et al., 2022 Kennedy et al., 2017	Noble-Carr et al., 2022 Oreg, 2020 Paraszczuk et al. 2022 Smith et al., 2020 Sweeney, 2020 Noble-Carr et al., 2021	Low confidence *No concerns of coherence, moderate concerns of methodological limitation, relevance, and data adequacy.*	Consensus-based recommendation 3.22: Provide information on the full scope of lactation management options to women and ask open ended and nondirective questions to understand and explore perspectives, while also considering cultural and individual variations.
			Consensus-based recommendation 3.24: Discuss the birth and death registration process with parents and family/whānau prior to their leaving hospital and ensure parents understand what is required of them. • Provide parents with written information about the registration process, including where, how, and when parents are required to register their baby's birth and death. • Ensure parents are aware that there is no fee to register, and they can choose to purchase a birth certificate at the time, or later.

			Consensus-Based Recommendation 3.25: Ensure parents are supported as they physically leave the hospital setting. For example, a healthcare professional or other support person should be available to accompany parents from the hospital to their mode of transport.
Abdel Razeq & Al-Gamal, 2021 Azeez et al., 2021 Bakhbakhi, 2017 Bond et al., 2018 Camacho Ávila et al, 2020 Cole et al., 2020 Helps et al., 2020 Inati et al., 2018	Durrmeyer et al., 2017 Due et al., 2018 Farrales et al., 2020 Fontaine, & Fockler, 2019 Heaney et al., 2022 Siassakos et al 2018 Smith et al., 2020 Watson et al., 2019 Ravaldi et al 2018	Low confidence *Minor concerns of relevance and data adequacy. Moderate7concerns of coherence and methodological limitation.*	**Consensus-based recommendation 3.26:** Ensure parents leave hospital with contact details for 24-hour follow-up support and are provided with culturally and linguistically appropriate information about ongoing sources of support including parent support organisations.
Atienza-Carrasco, Linares-Abad, Padilla-Ruiz, & Morales-Gil, 2020; Bond et al., 2018 Camacho Ávila et al., 2020 Cole et al., 2020 Due et al., 2018 Farrales et al., 2020; Fenstermacher & Hupcey, 2019	Horey et al 2021 Inati et al., 2018 Martínez-Serrano et al., 2019 Paraíso Pueyo et al., 2021 Pekkola et al. 2022 Shakespeare et al., 2019 Steen 2019 Tseng et al., 2018	Moderate confidence *Minor concerns of relevance, coherence and data adequacy. Moderate concerns of methodological limitation.*	**Evidence-based recommendation 3.27:** Ensure parents receive follow-up calls or visits, as required, from an appropriately skilled healthcare professional.
Acharya, 2018 Actis Danna et al., 2023 Arach, 2022 Berry 2021 Camacho Ávila et al., 2020 Cassaday 2018 Cassidy 2021	Hanschmidt, 2018 Obst & Due, 2021 Pachalla et al., 2021 Pollock et al., 2021 Ridaura et al 2017 Rodriguez et al. 2021 Sarkar 2022	Moderate confidence *No or minor concerns of methodological limitation, coherence and data adequacy. Moderate concerns of relevance.*	**Evidence-based recommendation 3.28:** Ask parents about their social and emotional wellbeing at all postnatal care appointments and appropriately refer to support services where needed.

Davoudian et al. 2021 Druguet 2018 Druguet 2019 Inati et al., 2018 Jones et al 2019 Kishimoto 2021 Köneş 2021 Kokou-Kpolou et al., 2018) Lockton, 2021 Gozuyesil et al., 2022 Güçlü et al. 2021	Setubal et al. 2021 Ssegujja 2021 Sun 2018 Sun 2020 Tseng et al., 2017 Xie, 2022 Marwah 2019 McNeil et al 2021 McSpedden 2017 Lockton et al., 2020	Ensure sufficient time is available in all follow-up appointments with bereaved parents to enquire about their social and emotional wellbeing. Provide information about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow-up, including family planning if desired. See Section 5: Care in subsequent pregnancies

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3

Table 4. Search strategy

Database	Search strategy	
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/
	2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.
	5	1 or 2 or 3 or 4
	6	*bereavement/ or *bereavement support/ or *social support/ or *indigenous health care/ or *vulnerable population or *transcultural care/ or *psychosocial care/
	7	*depression/ or *psychological aspect/ or *psychology/
	8	*emotion/
	9	(((support or support* or decision* or counsel* or cope* or coping) adj3 (regret* or guide or guidance or care or birth or social or clinic* or group* or intervention* or registrat* or practical or lactation or "vaginal bleeding" or "wound care" or "physical activit*" or "contraception")) or "follow up call" or bereave* or griev* or grief or emotion* or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness").ti,ab.
	10	6 OR 7 OR 8 OR 9
	11	*birthing position/ or *birthplace/ or Delivery, Obstetric/ or Labor, Obstetric/ or Parturition/ or *health care cost/ or *hospital discharge/
	12	(labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or (uter* adj4 contraction*) or ((during or undergo* or after) adj3 (stillbirth or deliver* or terminat*or induction))).ti,ab.
	13	(transition* or "leav* hospital" or "at home" or "general practitioner" or GP or discharge or ((community or "follow-up" or "follow up" or "after care" or postnatal or "post natal") adj3 (clinic* or care))).ti,ab.
	14	((diagnos* or detect or pronounce) adj3 (death or lethal or anomal* or congenital* or malform* or die*)).ti,ab.
	15	((support or counsel*) adj3 (Sibling* or grandparent* or grandfather* or grandmother* or famil*)).ti,ab.

	16	(cost* or econom*).ti,ab.
	17	11 OR 12 OR 13 OR 14 OR 15 OR 16
	18	5 AND 10 AND 17
CINAHL	S29	S5 AND S13 AND S27
	S28	S5 AND S13 AND S27
	S27	S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26
	S26	AB (cost* or econom*)
	S25	AB ((support or counsel*) N3 (Sibling* or grandparent* or grandfather* or grandmother* or famil*))
	S24	AB ((diagnos* or detect or pronounce) N3 (death or lethal or anomal* or congenital* or malform* or die*))
	S23	AB (transition* or "leav* hospital" or "at home" or "general practitioner" or GP or discharge or ((community or "follow-up" or "follow up" or "after care" or postnatal or "post natal") N3 (clinic* or care)))
	S22	AB (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or (uter* N4 contraction*) or ((during or undergo* or after) N3 (stillbirth or deliver* or terminat*or induction)))
	S21	(MM "Health Care Costs")
	S20	(MM "Transfer, Discharge")
	S19	(MM "Transcultural Care")
	S18	(MM "Health Services, Indigenous")
	S17	(MH "Labor+")
	S16	(MM "Delivery, Obstetric")
	S15	(MM "Birthing Positions")
	S14	(MM "Birth Place")
	S13	S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12
	S12	AB (((support or support* or decision* or counsel* or cope* or coping) N3 (regret* or guide or guidance or care or birth or social or clinic* or group* or intervention* or registrat* or practical or lactation or "vaginal bleeding" or "wound care" or "physical activit*" or "contraception")) or "follow up call" or bereave* or griev* or grief or emotion* or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness")
	S11	(MM "Psychology, Clinical")
	S10	(MM "Emotions")

	S9	(MM "Support, Psychosocial") OR (MM "Psychosocial Care (Saba CCC)")
	S8	(MM "Psychological Well-Being") OR (MM "Stress, Psychological")
	S7	(MM "Support, Social") OR (MM "Support, Psychosocial")
	S6	(MM "Bereavement Support (Saba CCC)") OR (MM "Bereavement")
	S5	(S1 OR S2 OR S3 OR S4)
	S4	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
	S3	AB (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort))
	S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
Scopus		((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)) OR (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)) OR (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*) AND (((support or support* or decision* or counsel* or cope* or coping) W/3 (regret* or guide or guidance or care or birth or social or clinic* or group* or intervention* or registrat* or practical or lactation or "vaginal bleeding" or "wound care" or "physical activit*" or "contraception")) or "follow up call" or bereave* or griev* or grief or emotion* or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness") AND (intrapartum or "intra partum" or peripartum or "peri partum" or (uter* W/4 contraction*) or ((during or undergo* or after) W/3 (stillbirth or deliver* or terminat* or induction or labor or labour or delivery or parturition or birth* or childbirth)))

		OR (transition* or "leav* hospital" or "at home" or "general practitioner" or GP or discharge or ((community or "follow-up" or "follow up" or "after care" or postnatal or "post natal") W/3 (clinic* or care))) **OR** ((diagnos* or detect or pronounce) W/3 (death or lethal or anomal* or congenital* or malform* or die*)) **OR** ((support or counsel*) W/3 (Sibling* or grandparent* or grandfather* or grandmother* or famil*)) **OR** (cost* or econom*) AND NOT (TITLE-ABS-KEY (*"genetic counseling"* OR *"genetic counselling"*))	
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]	Mesh
	#2	**"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*"** OR "Neonatal loss*" OR "Neonatal mortalit*"OR "Neonatal death*" OR "Neonatal Demise*" OR "Newborn death*" OR "Newborn mortalit*"	**Title/abstract**
	#3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])	**Title/abstract**
	#4	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "prenatal diagnosis") AND (terminat* or abortion or abort))	**Title/abstract**
	#5	#1 OR #2 OR #3 OR #4	
	#6	(((support or support* or decision* or counsel* or cope* or coping) AND (regret* or guide or guidance or care or birth or social or clinic* or group* or intervention* or registrat* or practical or lactation or "vaginal bleeding" or "wound care" or "physical activit*" or "contraception")) or "follow up call" or bereave* or griev* or grief or emotion* or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness")	Mesh

	#7	(((("Bereavement"[Mesh]) OR "Psychology"[Mesh]) OR "Emotions"[Mesh]) OR "Psychosocial Support Systems"[Mesh]	
	#8	#6 OR #7	
	#8	((support or counsel*) AND (Sibling* or grandparent* or grandfather* or grandmother* or famil*))	
	#9	((diagnos* or detect or pronounce) AND (death or lethal or anomal* or congenital* or malform* or die))	
		(transition* or "at home" or "general practitioner" or GP or discharge or ((“community care” or “community clinic*” or "follow-up clinic" or “follow-up care” or "follow up clinic" or “follow up clinic” or "after care" or “postnatal care” or "post natal") AND (clinic* or care)))	
		(parturition or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or “uterine contraction*” or “during delivery” or “during birth” or “during induction” or “during birth*” or “during labor” or “during labour” or “after delivery” or “after induction” or “after labor” or “after labour” or “after birth*”)	
	#7	"Birth Setting"[Mesh] OR "Vulnerable Populations"[Mesh] OR "Transcultural Nursing"[Mesh] OR "Health Services, Indigenous"[Mesh] OR "Birth Setting"[Mesh] OR "Labor, Obstetric"[Mesh]) OR "Health Care Costs"[Mesh] OR "Patient Transfer"[Mesh]	Title/ abstract
Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees	
	#2	MeSH descriptor: [Perinatal Death] explode all trees	
	#3	MeSH descriptor: [Perinatal Mortality] this term only	
	#4	MeSH descriptor: [Abortion, Induced] this term only	
	#5	((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mortalit*))	
	#6	(((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) ADJ1 loss*) OR stillb*))):ti,ab,kw	
	#7	#1 OR #2 OR #3 OR #4 OR #5 OR #6	
	#8	((((support or support* or decision* or counsel* or cope* or coping) NEAR/3 (regret* or guide or guidance or care or birth or social or clinic* or group* or intervention* or registrat* or practical or lactation or "vaginal bleeding" or "wound care" or "physical activit*" or "contraception")) or "follow up call" or bereave* or griev* or grief or emotion* or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness")):ti,ab,kw	

#9 MeSH descriptor: [Psychology] explode all trees

#10 MeSH descriptor: [Emotions] explode all trees

#11 MeSH descriptor: [Psychosocial Intervention] explode all trees

#12 MeSH descriptor: [Social Support] explode all trees

#13 MeSH descriptor: [Bereavement] explode all trees

#14 #8 OR #9 OR #10 OR #11 OR #12 OR #13

#15 ((labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or (uter* NEAR/4 contraction*) or ((during or undergo* or after) NEAR/3 (stillbirth or deliver* or terminat*or induction)))):ti,ab,kw

#16 ((transition* or "leav* hospital" or "at home" or "general practitioner" or GP or discharge or ((community or "follow-up" or "follow up" or "after care" or postnatal or "post natal") NEAR/3 (clinic* or care)))):ti,ab,kw

#17 (((diagnos* or detect or pronounce) NEAR/3 (death or lethal or anomal* or congenital* or malform* or die*))):ti,ab,kw

#18 (((support or counsel*) NEAR/3 (Sibling* or grandparent* or grandfather* or grandmother* or famil*))):ti,ab,kw

#19 ((cost* or econom*)):ti,ab,kw

#20 MeSH descriptor: [Labor, Obstetric] explode all trees

#21 MeSH descriptor: [Patient Discharge] explode all trees

#22 MeSH descriptor: [Transcultural Nursing] explode all trees

#23 MeSH descriptor: [Health Services, Indigenous] explode all trees

#24 MeSH descriptor: [Health Care Costs] explode all trees

#25 #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24

#26 #7 AND #14 AND #25

Australian Indigenous HealthInfoNet	Grief AND babies OR Baby AND bereavement
Informit Indigenous collection	All Fields: baby AND [All Fields: 'bereavement care' OR All Fields: 'palliative care' OR All Fields: 'death']

4

Figure 1. PRISMA flow diagram of screening evidence

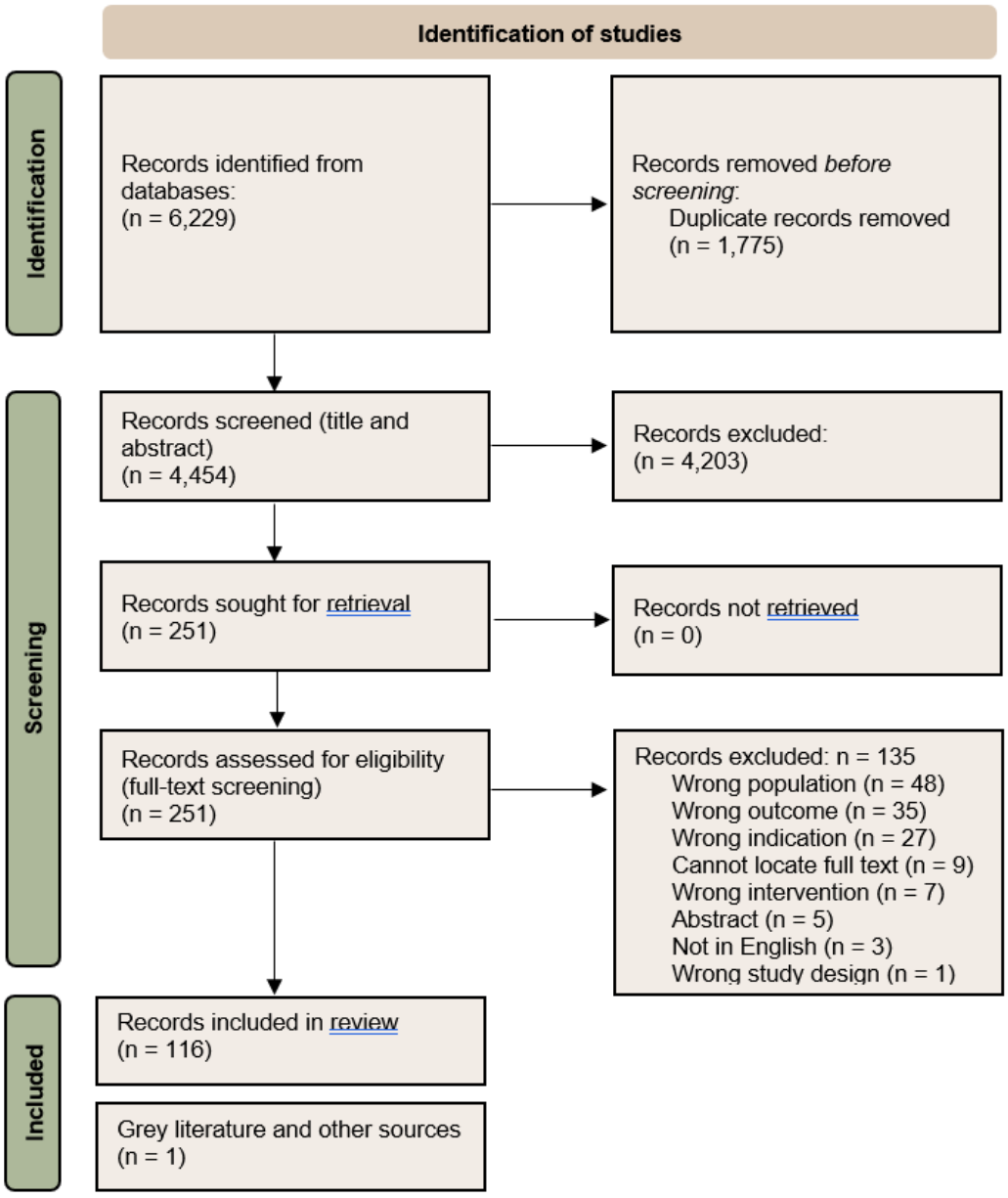

Table 5. Study characteristics

Study ID	Country/ period	Locality (state/national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Abdel Razeq 2021	Jordan (NR)	2 NICUs	Semi-structured interviews	LMIC	qualitative	Thematic analysis	NA	12 mothers	NND	Experience of mothers whose babies died in NICU	not stated	Mothers of neonates born alive and then died in NICU	Checklist for qualitative research
Acharya 2018	India (dates not reported)	National	Secondary data sources including National Family Health surveys and a multi-state study on social exclusion conducted by	LMIC	Qualitative	Narrative review	NA	NA	Stillbirth, NND	Disparities in bereavement experience of women in terms of demographic, social and economic characteristics	NA	NA	Checklist for text and opinion papers

			Indian Institute of Dalit Studies, Delhi										
Actis Danna 2023	Malawi, Tanzania, and Zambia	Women who had given birth at tertiary referral hospitals in Tanzania, Malawi, and Zambia	Semi-structured interviews	Low income	Qualitative	Grounded Theory (Symbolic Interactionism)	NA	33 women	Stillbirth (within the preceding 12 months)	The purpose of this study was to understand how and when women became aware of the death of their babies.	Women <18 years of age	Women who had experienced a stillbirth in the preceding 12 months and had the capacity to consent.	Checklist for qualitative research
Arach 2022	Uganda (Aug 2019-Sept 2020)	Lira District, Northern Uganda	In-depth interviews	LMIC	Qualitative	Thematic analysis	NA	32 (18 women; 14 men)	Stillbirth, NND	Lived experiences of parents following perinatal loss	Participants were excluded if they had migrated to distant places beyond the reach of the study team or were not willing to talk about the perinatal deaths.	Participants were women and partners of women who had had either a stillbirth or an early neonatal death within the past 2 years. Those who lived in the study area (Aromo, Agweng and Ogur sub counties) from atleast the third trimester (≥ 28 weeks of	Checklist for qualitative research

												gestation) until 6 months after perinatal death were included in the study. Married women had to have their partner's permission to participate.	
Arocha 2021	USA; 2016	Facebook child loss groups	Online questionnaires	HIC	Quantitative	Descriptive cross-sectional	NA	66 women	stillbirth	Experience of stillbirth and its association with depression	2 women with miscarriages	Women who self-identified their loss as stillbirth	Checklist for studies reporting prevalence data
Asare 2020	Ghana (dates not reported)	One public hospital & 2 private hospitals	Interviews	LMIC	Qualitative	Thematic analysis	NA	20 parents	stillbirth, NND, child death	Emotional, social, psychological, and economic experiences of child loss	NA	Parents experiencing child loss in past 8 years	Checklist for qualitative research

Asim 2022	Pakistan (June 2018-May 2019)	Rural villages of district Thatta Sindh	Interviews	LMIC	Qualitative	Thematic analysis	NA	8 women	stillbirth	Lived experience of multiple stillbirths	NA	Women experiencing multiple stillbirths, with last stillbirth occurring within the period of last 12 months from the date of interview	Checklist for qualitative research
Atienza-Carrasco 2020	Spain (2015-2017)	Costa del Sol Health Agency (Marbella, Spain)	Interviews, observations	High income	Qualitative	Phenomenological	NA	27 interviews	Adverse antenatal diagnoses	Receiving bad news	NA	27 pregnant women ≥18 years, with no mental disability and able to understand Spanish and express themselves correctly in Spanish.	Checklist for qualitative research
Aydin 2019	Turkey (April-July 2017)	1 tertiary hospital	Interviews, hospital records	Upper-middle income setting	Qualitative	Thematic analysis	NA	10	Termination of pregnancy for medical indication	Experiences of women who have a termination of pregnancy for medical indication	None mentioned	Women hospitalised between April- July 2017 at the Akdeniz University Clinics of Obstetrics and Gynaecology	Checklist for qualitative research

												who were: over 18 years but below 45 years, free of chronic and psychiatric diseases, hospitalised because of pregnancy termination and without medical complications during hospitalisation, able to communicate in Turkish, and consented to participate	
Azeez 2021	Australia 2020	National	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	10 fathers	NND	Father's experiences of support following neonatal death	NA	Men experiencing a neonatal death at least 6 months before the interviews	Checklist for qualitative research

Bakhbakhi 2017	Multiple (not dated)	NA	Published research, guidelines and best practice points	HIC	Qualitative	Descriptive review	NA	NA	Stillbirth	Best practice points in bereavement care research in high income countries	None mentioned	Published research, guidelines and best practice points in care following stillbirth in high income countries	Checklist for text and opinion papers
Baransel 2020	Turkey (Feb-Nov 2017)	Obstetrics and newborn departments of a public hospital and a university hospital in the Malatya Province	Questionnaires	UMIC	Quantitative	NA	Cross-sectional	154 couples	Stillbirth, NND	Posttraumatic stress levels and the factors affecting them in couples after a perinatal loss in Turkey	history of psychiatric problems or traumatic events (e.g., traffic accidents, earthquakes, floods, wars, torture, sexual harassment, etc.) before the perinatal loss	Women and men (husbands) who lost babies during the perinatal period in the obstetrics and newborn units of the hospitals participating in the study; being able to establish verbal communication	Checklist for analytical cross-sectional studies

BeggsIII 2018	USA (dates not reported)	International	Literature ; Opinion	HIC	Qualitative	Narrative review	NA	NA	NND	How mutual aid groups can support grieving parents	NA	NA	Checklist for text and opinion papers
Bernardes 2020	Brazil (May 2015-Sept 2016)	One tertiary fetal medical centre	Retrospective medical records of family conferences	UMIC	Qualitative	Content analysis	NA	50	TOPFA	Family conferences in prenatal palliative care follow-up after the diagnosis of life-limiting fetal condition	None mentioned	Participation in at least one family conference with the perinatal palliative group at the hospital and delivery at the hospital or another centre followed by participation in postnatal family conference	Checklist for qualitative research
Berry 2019	Multiple (Nov 2017-May 2018)	NA	Literature	NA	Qualitative	Systematic review	NA	NA	TOPFA	Impact of communication in discussing an intrauterine diagnosis of a fetal congenital anomaly on perinatal grief	Non-English articles, articles published prior to 2008, grey literature and those that did not focus on communication of an anomaly	Peer-reviewed articles on communication styles, techniques, and stances by healthcare professionals	Checklist for systematic reviews and research syntheses

												when communicating a fetal anomaly diagnosis detected in utero, published in English in last 10 years	
Berry 2021	USA (2019)	Online website	Parent interviews	HIC	Qualitative	Grounded Theory	NA	3 within this sub-analysis of a larger study	NND (n=3)	Palliative care following birth of a live neonate and subsequent discharge home	None	Parents able to communicate in English, over 18 years of age, and not currently pregnant. Parents who had previously experienced a pregnancy complicated by anencephaly	Checklist for qualitative research
Bond 2018	Australia (2006-2011)	Sydney Hospitals	Postal surveys	HIC	Mixed methods: Qualitative and Quantitative	Thematic analysis	Cross sectional retrospective study	36	Stillbirth	Experience of care during and after stillbirth	Pregnancy loss prior to 32 weeks GA. Non-English speaking parents.	Women who experienced stillbirth after 23 weeks and delivered at one of the seven tertiary maternity centres in Sydney NSW.	Checklist for qualitative research and Checklist for analytical cross-sectional studies

Boyle 2020	Australia	National	Guideline, literature	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth, NND	Perinatal bereavement care guidelines	None mentioned	Components of best practice perinatal bereavement care	Checklist for text and opinion papers
Boyle 2020 (2)	Australia (2020)	NA	Author views and literature	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth	National approach to research to improve shared decision making in stillbirth care and other initiatives in this area	None mentioned	Shared decision making literature and stillbirth CRE initiatives	Checklist for text and opinion papers
Brierley-Jones 2018	England (2014-2015)	Three hospitals in North East England	Focus groups, semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	60	Stillbirth	Views of health professionals and health care staff across three hospitals in the management of stillbirth	None mentioned	Consultant obstetricians, trainees, midwives, midwife sonographers and chaplains	Checklist for qualitative research
Brown 2017	US (dates not reported)	Sedgwick County, South Central Kansas	Interviews	HIC	Qualitative	Descriptive phenomenological study	NA	6	Stillbirth, NND	Experience of stress across the life course among Black women who reported a history of fetal or infant death	None mentioned	(1) non-Hispanic Black women, (2) aged 18–40 years, (3) resident of Sedgwick County, Kansas, and (4) experienced a fetal or infant death in the last 8 years	Checklist for qualitative research

Cacciatore 2017	USA (dates not reported)	Unclear	Online survey, open-ended question	HIC	Qualitative	Thematic analysis	NA	94	Stillbirth	Relationship between trait mindfulness in counsellors and parents' perceptions of its helpfulness	None mentioned	Bereaved parents of stillborn children who participated in counselling after perinatal death	Checklist for qualitative research
Cacciatore 2018	US/dates not reported	National	Online survey including open-ended responses	HIC	Mixed methods	Content analysis	Cross sectional	n=191 for quantitative component, n=39 for qualitative component	Stillbirth	Parent's value of volunteering experience related to their child's death and their perceptions on volunteering relating to their experience and trauma	Parents who volunteered before their child's death for qualitative analysis	Parents who experienced stillbirth for quantitative component; Parents who volunteered after stillbirth for qualitative component	Checklist for qualitative research and Checklist for analytical cross-sectional studies
Camacho Ávila 2020	Spain (Apr 2017-May 2018)	2 hospitals in Southeast Spain	Interviews	HIC	Qualitative	Hermeneutical phenomenology	NA	21 (13 mothers, 8 fathers)	Stillbirth (n=17), NND (n=4)	Parents' experiences in relation to professional and social support after perinatal loss	spoke a language other than English or Spanish, or experienced a miscarriage, pregnancy termination due to genetic birth defect or multifetal pregnancy reduction.	a mother or father 18 years and older at the time of perinatal loss, to have experienced a stillbirth or a neonatal death, and the loss had been suffered at least 2	Checklist for qualitative research

												years before the interview.	
Carlsson 2019	Sweden (2015)	National	Web-based open-ended questionnaire	HIC	Qualitative	Thematic analysis	NA	6	Prenatal diagnosis of fetal anomaly	Experiences of immigrants with Arabic or Sorani interpreter needs when presented with a prenatal diagnosis of foetal anomaly	None mentioned	participants needed to require interpreter services to understand information from health professionals at the time of diagnosis, and be able to read and write in either Arabic or Sorani	Checklist for qualitative research
Carroll 2020	Australia/ not specified	National	International evidence-based lactation and bereavement information	HIC	Qualitative	literature review for development of evidence-based framework	NA	Not specified	Stillbirth, NND	Lactation support recommendations following stillbirth or infant death,	NA	Guidelines, scholarly research, and grey literature considering health-policy and parent's experiences of lactation	Checklist for qualitative research

												after infant death	
Cassaday 2018	Multiple (not dated)	NA	Literature	NA	Qualitative	Narrative review	NA	NA	Miscarriage, stillbirth, NND	Impact of pregnancy loss on psychological functioning and grief outcomes	None mentioned	Risk factors of complicated grief, gender differences in the grieving process and impact on relationships and the role of HCP in screening and treatment of perinatal loss	Checklist for text and opinion papers
Cassidy 2021	Spain (2013-2016)	National	Online survey, interviews, and observations of an online support forum	HIC	Mixed methods	Thematic analysis	Descriptive	"Qualitative: 10 for interviews; 22 online forum observations 52 open-ended respons	Miscarriage, Stillbirth, TOPFA, NND	Disenfranchisement of perinatal grief and how it impacts parents	None mentioned	Interviews included all pregnancy losses (stillbirths or pregnancy terminations) and neonatal deaths; survey included only intrauterine and	Checklist for qualitative research and Checklist for studies reporting prevalence data

								es Quantitative surveys: 796"				intrapartum deaths from 16 weeks onwards, including TOPFA.	
Cena 2021	Multiple (2019)	International	Literature	Unknown/ Mixed	Qualitative	Evidence synthesis	NA	46 articles	Stillbirth	psychological effects of stillbirth on parents	Qualitative articles that did not describe any psychological aspects of stillbirth; quantitative articles	articles with any clinical material, theoretical consideration on psychological and behavioural effects on parents, published between 1999-2019	Checklist for systematic reviews and research syntheses
Christou 2021	Afghanistan (Oct-Nov 2017)	3 high-volume referral maternity hospitals in Kabul and 2 lower-level health facilities and surrounding communities in 2 rural districts ~25–	Interviews	LIC	Qualitative	Deductive thematic analysis	NA	55 (21 mothers, 9 fathers, 3 female community elders, 20 HCPs, 2 govt officials)	Stillbirth	Parents' and HCPs' experiences of care after stillbirth	None mentioned	Women and men experiencing stillbirth, community female elders, healthcare providers and key informants including govt officials,	Checklist for qualitative research

		30 km west and north of Kabul city									hospital directors, chiefs of wards	
Chung 2017	UK/	National	Surveys of women from stillbirth support groups	HIC	Quantitative	NA	Cross sectional; Paper surveys (by post) with the PTSD Diagnostic Scale, EPDS, Posttraumatic Cognitions Inventory, and Rotter's Locus of Control Scale,	Group 1 n=50; Group 2 n=50	Stillbirth	incidence of probable PTSD and psychiatric co-morbidities	Not specified	Group 1: first time stillbirth, spontaneous stillbirth after 24 weeks, no delivery of surviving twin, stillbirth at least one month prior to study. Group 2 - comparison group: experienced a healthy birth, no previous experience of stillbirth, miscarriage, abortion or neonatal death	Checklist for analytical cross-sectional studies

Cole 2017	USA	Tertiary Hospital	Case study	HIC	Qualitative	Case study	NA	1	NND and Stillbirth	Description of a perinatal palliative care program	None mentioned	Different components of a perinatal palliative care program at one hospital	Checklist for case report studies (reports of singular programs of care)
Cole 2018	USA, ns	Children's Hospital of Philadelphia	Telephone interviews	HIC	NA	qualitative	Case examples / narrative	2 women	Stillbirth, NND	experiences of donation of milk after perinatal loss	NA	women donating milk after perinatal loss	Checklist for qualitative research
Cole 2020	US/not specified	Hospital (Children's Hospital of Philadelphia)	Description of Bereavement Outreach program in a maternal-fetal care centre and words from patients from the perinatal palliative care and bereavement program including	HIC	Qualitative	Descriptive	NA	Not specified	Stillbirth, NND, TOPFA	Description of Bereavement Outreach program in a maternal-fetal care centre	NA	NA	Checklist for qualitative research

			those who delivered in the Special Delivery Unit										
Cote-Arsenault 2019	USA (dates not reported)	One perinatal hospice listserv extensively including perinatal palliative care providers	Online survey followed by telephone interviews of a subset of participants	HIC	Mixed methods	Case study analysis	Cross sectional	Survey n= 14 (11 mothers, 3 fathers), Interviews n=7	Life-limiting fetal condition; Stillbirth; NND	Parent characteristics, quality of perinatal palliative care (PPC) received and parent health outcomes	None mentioned	African American or Latino mothers who were: 1) English speaking, 2) indicated minority status of either themselves or their partner, 3) had experienced a perinatal death (fetal or neonatal) due to a prenatally diagnosed LLFC 6 to 36 months prior, 4) were a recipient of PPC for that perinatal	Checklist for qualitative research and Checklist for analytical cross-sectional studies

												death, 5) were at least 21 years of age at time of loss. Mothers recruited the father of the baby.	
Craven 2019	Multiple (2011-2018)	Online social media groups	Semi-structured interviews	HICs	Qualitative	Ethnography	NA	54	Miscarriage, Stillbirth	LGBTQ people's experiences of reproductive loss	None stated	Lesbian, gay, bisexual, transgender or queer (LGBTQ) people who had experiences with the loss of a child during pregnancy, birth, surrogacy, or adoption	Checklist for qualitative research
Das 2021 (3)	India (Sept 2018-Apr 2019)	One tertiary care Govt hospital in Delhi	Interviews, focus groups	LMIC	Qualitative	Thematic content analysis	NA	47 families with stillbirth / child death: 25 families with deceased children	Stillbirth, NND	Grief and coping experiences of North Indian bereaved parents following stillbirth and child death	Parents residing outside Delhi	Two categories of participants were included for interviews: (i) parents who had child or neonate death and stillbirths at the hospital	Checklist for qualitative research

	(neonates, n = 12 and >1month, n = 13, n = 49 parents and 21 family members) and 22 stillbirths (n = 44 parents and 20 family members) ; 12 community participants for interviews, 72 community participants for focus groups		and their family members; (ii) community representatives including influential community leaders, community health functionaries, and religious leaders. Four categories of participants were included for focus groups: mothers, fathers, elder family members including grandfathers and grandmothers with child under-five years, but not had child death or stillbirth.

Davoudian 2021	Multiple (2020)	International	Literature (3 databases)	NA	Qualitative	Narrative review	NA	NA	Stillbirth, NND, TOPFA	Psychological responses to perinatal loss and psychological interventions that may be helpful	Studies focused on grief unrelated to perinatal loss	NA	Checklist for text and opinion papers
deAndrade Alvarenge 2021	Canada (2015-2017)	7 regions of Quebec province in Canada	Secondary data analysis of interviews conducted with mothers experiencing perinatal death	HIC	Qualitative	Thematic analysis	NA	33	Stillbirth, NND, TOPFA	bereaved mothers' experience of hope following perinatal death	NA	women who experienced a perinatal death in the ten months preceding the interview, who received services from one of the participating establishments (hospitals, birthing centres, community organizations), and were able to understand and speak French.	Checklist for qualitative research

Dekkers 2019	Netherlands (2012-2015)	Rotterdam	Online questionnaire	High income	Quantitative	NA	Cross-sectional	76 women; 36 partners	psychosocial care for TOPFA	optimal time for psychosocial care	Women who were; treated from 2016 onwards, not fluent in Dutch, with intellectual disabilities, undergoing another TOP at the time of research invitation, or who underwent a TOP for maternal health issues.	cross-sectional: 76 women; 36 partners All women and partners, who underwent a TOP-by medical treatment-for fetal anomaly.	Checklist for analytical cross-sectional studies
Dempsey 2021	USA (dates not reported)	Global literature	Literature, opinion	HIC	Qualitative	Narrative review	NA	NA	Fetal anomaly	Challenges and behavioural health risks for expectant parents carrying a fetus with a birth defect and the unique role psychologists play to support patients and families within fetal care settings	NA	NA	Checklist for text and opinion papers

Dickens 2020	NA	NA	Literature	NA	Qualitative	Literature review	NA	NA	Stillbirth, NND	Management, support, and experiences of lactation after perinatal death	NA	NA	Checklist for text and opinion papers
Druguet 2018	Spain (2009-2012)	Maternity unit of the Vall d'Hebron University Hospital in Barcelona, Spain	Interviews; Questionnaires	HIC	Quantitative	NA	Cross-sectional	28	Stillbirth	Psychological effect on women of the loss of one or both fetuses during a monochorionic twin pregnancy and associated protective and risk factors	None stated	Women who lost one or both fetuses in a monochorionic twin pregnancy after fetal surgery because of complications, experienced the loss 1 to 3 years previously, were White and of Spanish nationality, and spoke and read Spanish sufficiently for them to complete the questionnaires	Checklist for analytical cross-sectional studies

Druguet 2019	Spain/not specified	Vall d'Hebron Hospital, Barcelona	Telephone survey and paper questionnaires	HIC	Quantitative	NA	Cross-sectional comparative correlational study	n=52	NND	Satisfaction with healthcare, demographics, psychological factors	Not specified	Mothers of monochorionic twin pregnancies that underwent intrauterine surgery and Education and language skills adequate to complete the surveys	Checklist for analytical cross-sectional studies
Due 2018	Australia (2013)	South Australia	Interviews	HIC	Qualitative	Thematic analysis	NA	15	Stillbirth	Women's experiences with the healthcare system following pregnancy loss in South Australia	None mentioned.	Women needed to be over 18 years old, fluent in English, resident in South Australia at the time of their loss, and have experienced at least one pregnancy loss at any stage between conception and birth. Women who had experienced	Checklist for qualitative research

											multiple losses were eligible for inclusion.	
Durrmeyer 2017	France (2011)	18 maternity units across 13 different regions in France	Questionnaire completed by professional caring for the baby	HIC	Quantitative	NA	Non comparative study	73	NND	Clinical course and management of neonates born between 22 and 26 weeks of gestation who died in the delivery room	Termination of pregnancy; stillbirth and birth in a non-participating centre	Infants born alive between 22 weeks+0 and 26 weeks+6 of gestation in one of the 18 participating maternity units	Checklist for case series studies
Farrales 2020	USA (date not stated)	Unclear	Focus groups	HIC	Qualitative	Thematic analysis	NA	27	Stillbirth	Experiences of grieving parents during their interaction with health care providers during/after the stillbirth of a baby	None mentioned	"Participants were recruited from a cohort of bereaved parents who participated in a two-day workshop on the topic of grief after stillbirth. 19 years of age or older. Consent obtained."	Checklist for qualitative research

Fenstermacher & Hupcey 2019	USA (dates not reported)	3 inner city hospitals in Pennsylvania	Interviews at 3 time points	HIC	Qualitative	Constant comparative analysis	NA	8	Stillbirth, NND	Bereavement support needs of black urban women in late adolescence after perinatal loss	None mentioned	Non-Hispanic, unmarried, English speaking black urban women ranging in age from 18 to 21 years (late adolescence) with a recent perinatal loss, with no prolonged hospital stay after their loss	Checklist for qualitative research
Fernandez Ferez 2021	Multiple (2020)	International literature	Literature (4 databases)	NA	Qualitative	Narrative synthesis	NA	4 articles	Stillbirth, NND	Efficacy of nursing interventions to facilitate the process of grief because of perinatal death	(1) studies on interventions in women who are less than 14 weeks pregnant; (2) studies that do not describe specific interventions in a group of women.	(1) studies published in the last 5 years; (2) studies published in English or Spanish; (3) quasi-experimental studies or randomised clinical trials (RCTs).	Checklist for systematic reviews and research syntheses

Fernandez Medina 2022	Spain (March-May 2021)	National	Interviews	HIC	Qualitative	Hermeneutical phenomenological approach	NA	13	Stillbirth, NND	How bereaved women perceive the expression and donation of their breastmilk	TOPFA and multiple pregnancies	18 years or older at the time of perinatal loss, have experienced a stillbirth or a neonatal death in the last 5 years, and have donated their breast milk to a non-profit milk bank in Spain. Consent obtained.	Checklist for qualitative research
Ferreira Paris 2021	Brazil, Canada (dates not reported)	Maringa in Southern Brazil; Gatineau in Canada	Semi-structured interviews	UMIC; HIC	Qualitative	Thematic analysis	NA	44 (26 Brazilian women, 18 Canadians)	Stillbirth	Professional care for maternal grief following stillbirth	NA	Mothers whose address was in Maringa after authorisation by the municipal health department of deaths investigated by the mortality committee, and mothers who participated	Checklist for qualitative research

												in the grief support group at CERIF in Gatineau	
Furtado-Eraso 2021	Multiple (2020)	International literature	Literature (4 databases)	NA	Qualitative	Narrative synthesis	NA	22 studies	Stillbirth, NND	Emotional care following perinatal loss	Theoretical reports, case studies, clinical cases and grey literature	original research published articles between January 2015 and January 2020, including quantitative and qualitative studies written in either English or Spanish with the full text available	Checklist for systematic reviews and research syntheses
Gilmour 2017	Australia (1 Jan 2012 to 30 June 2014)	Royal Brisbane and Women's Hospital, Brisbane, Queensland	Medical charts and death certificates	HIC	Quantitative	NA	Retrospective cohort study	46	NND	End-of-life care provided in an Australian tertiary neonatal centre, where paediatric palliative care was accessible via a consultative service	Stillborn, pre-viable infants (<400g/<23 weeks GA), aged>1 year, no opportunity for palliative care intervention	Liveborn infants, born 01/01/2012-30/06/2014, neonatal admission at RBWH, died<=1year	Checklist for studies reporting prevalence data

Gold 2018	US (dates not reported)	Michigan	Mail survey	HIC	Quantitative	NA	Non comparative study	311	Stillbirth, NND	Demographic, psychosocial, and reproductive factors associated with guilt in perinatally bereaved mothers	None stated	Women experiencing Stillbirth or NND in Michigan over the first 2 years after delivery	Checklist for case series studies
Gold 2021	US (dates unclear)	State/Michigan	Questionnaires from bereaved mothers, semi structured interviews	HIC	Qualitative	Thematic analysis	NA	n=30	Stillbirth, NND	Experiences of using online support groups for bereaved mothers (either named or anonymous)	not specified	Bereaved mothers, living in Michigan, 18 or older, able to read English, gave birth to a stillbirth baby or had an infant death in the first month and had a loss in 2011 or 2012	Checklist for qualitative research
Goldstein 2020	Multiple (2013-2016)	International	Survey questionnaires	HICs	Quantitative	NA	Cross-sectional	294	SIDS	Transitional objects of grief and their relation to Prolonged Grief Disorder	None stated	Mothers bereaved by SIDS 2–36 months post-loss	Checklist for analytical cross-sectional studies

Gozuyesil 2022	Turkey, June 2018-2019	university hospital, Adana	Questionnaires	UMIC	quantitative	NA	Longitudinal study	70 mothers	Stillbirth, NND	levels of grief and ruminative thought style in women after perinatal loss	Women who had previously had a psychological disorder	women who experienced pregnancy loss in any trimester of pregnancy, could speak and write in Turkish and did not have any psychological disorders	Checklist for cohort studies
Güçlü 2021	Turkey/Nov 2017-March 2018	Hospital/Gynaecology Clinic of Istanbul University Cerrahpasa Faculty of Medicine	Survey/questionnaires	UMIC	Quantitative	NA	Cross-sectional	n=46	TOPFA	Perinatal grief, depression, impact of event scale-revised, Beck anxiety inventory, Multidimensional relationship questionnaire, Adult attachment scale, following TOPFA, at 6 weeks, 6 months and 1 year	Under 18, illiteracy, dementia or other organic mental disorders	Experienced TOPFA	Checklist for studies reporting prevalence data
Hanschmidt 2018	Germany/ October 2015-Feb 2016	Hospital/Department of Obstetrics of the University of Leipzig	Questionnaires	HIC	Quantitative	NA	cross-sectional survey	n=148	TOPFA	Help-seeking intentions following TOPFA and actual help-seeking behaviour	Not specified	Previous TOPFA 1 - 7 years before study, 18 or older	Checklist for analytical cross-sectional studies

Hanschmidt 2018 (3)	Germany/ Oct 2015 - Feb 2016	Hospital/Department of Obstetrics of the University of Leipzig	Questionnaires	HIC	Quantitative	NA	cross-sectional survey	n=148	TOPFA	Individual Level Abortion Stigma following TOPFA	Not specified	Previous TOPFA 1 - 7 years before study, 18 or older	Checklist for analytical cross-sectional studies
Harden 2018	USA (dates not reported)	NA	Opinion, literature	HIC	Qualitative	Narrative	NA	NA	Miscarriage, stillbirth, NND	Factors impacting grief after perinatal loss	NA	NA	Checklist for text and opinion papers
Heaney 2022	Sweden, Spain, Thailand, USA, The Netherlands, UK, Canada, Iran, France, Finland, Israel, Australia, China, Taiwan, Poland / (published between 2010-2021)	NA (Systematic review)	Medline, Embase, PsycINFO, CINAHL, Web of Science, and Cochrane (plus grey lit search)	HIC & LMIC	Qualitative	Thematic analysis	NA	30 articles (inclusive of 1227 women and 114 men)	TOPFA	What are the healthcare experiences and needs of parents who undergo a termination of pregnancy following an antenatal diagnosis of a fetal anomaly?	Non-empirical studies, such as case reports, opinion pieces or reviews; and studies reporting experience of TOP for a reason other than fetal anomaly. Studies were also excluded if they only reported health professionals' or other family members' experiences of TOPFA	Qualitative, quantitative or mixed methods designs reporting the results of primary data on the healthcare experiences or healthcare needs in relation to TOPFA for either or both parents published between (1 Jan 2010 and 6 August 2021)	Checklist for systematic reviews and research syntheses

Hendriks 2022	Switzerland (not dated)	Tertiary perinatal centre of a Swiss University Hospital	Participatory observations in the perinatal centre; interviews	HIC	Qualitative	Content analysis	NA	10	TOPFA	Communication with HCPs, end-of-life decisions and parents' wishes and preferences during late termination of pregnancy	None mentioned	"Parents: Parents who had a TOPFA ≥20 weeks gestation at a tertiary perinatal centre of a Swiss University Hospital one or more year before the onset of the study. HCPs: Perinatal HCPs working in a discipline relevant to perinatal end-of-life decision-making (i.e. midwife, nurse, obstetrician, neonatologist, clinical director) at the tertiary perinatal centre of a Swiss University Hospital"	Checklist for qualitative research

Helps 2020	Ireland (2005-2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	stillbirth, NND	Bereavement care provided to families following perinatal death/pregnancy loss as described in national inquiry reports	None stated	National inquiries into perinatal deaths/pregnancy loss services between 2005-2018.	Checklist for qualitative research
Hennegan 2018	UK (2012)	National	Secondary data from another study collected using postal questionnaires	HIC	Quantitative	NA	Cross-sectional	455	Stillbirth	Effects on partners' health and well-being of holding a stillborn baby, from the perspective of mothers	None stated	Women aged 16 and older who experienced a stillbirth in England in 2012	Checklist for analytical cross-sectional studies
Hollins Martin 2022	Multiple (dates not reported)	International	Literature (4 databases)	NA	Qualitative	Scoping review	NA	23 papers	Stillbirth, NND	Effectiveness of therapies for treating psychological trauma post perinatal bereavement and post-childbirth	None	(1) Studies consisting of a therapeutic intervention used to treat women experiencing psychological trauma post perinatal bereavement or childbirth; (2) Papers that addressed Acute Stress Disorder	Checklist for systematic reviews and research syntheses

												(ASD), Post Traumatic Stress Syndrome (PTSS), PTSD, and Complex-PTSD; (3) the paper was published in English; and (4) full-text paper was available for review	
Horey 2021	40 countries (Dec 2014-Feb 2015)	NA	Survey	HIC and MIC	Quantitative	NA	Descriptive	3041	Stillbirth	Bereavement care practices after stillbirth in HIC and MICs	Stillbirth > 5yrs prior to completing the survey	Self-reported stillbirth ≤ 5 years prior to completing survey	Checklist for studies reporting prevalence data
Huberty 2017	Multiple (2016)	International literature	Literature	NA	Qualitative	Narrative review	NA	2 articles	Stillbirth	Systematic review of experimental interventions for women after stillbirth	Stillbirth not defined or if paper was a meta-analysis or review	Articles were eligible if they were: (1) published in English, (2) published in a peer-reviewed journal, (3) published in 1980 or later, (4) an intervention that evaluated	Checklist for systematic reviews and research syntheses

												(qualitative or quantitative methods) mental and/or physical health, and (5) included women who had experienced a stillbirth (in utero fetal death at more than 20 weeks of gestation).	
Huberty 2017 (2)	US/not specified	National	Questionnaires/Interviews	HIC	Mixed methods	Semi-structured interviews	Cross-sectional survey	n=52	Stillbirth	Experiences of yoga intervention following stillbirth	Already practicing yoga regularly, suicidal ideation, currently taking psychotropic medications	Stillbirth >20weeks within the last 24 months, 18 or older, living in the US, able to read/write/understand English, could exercise safely	Checklist for qualitative research and Checklist for analytical cross-sectional studies

Huberty 2018	US/not specified	National	Questionnaires	HIC	Quantitative	NA	cross-sectional cohort study	n=74	stillbirth	Effect of yoga intervention on; Mindful Attention Awareness Scale, Impact of Event Scale-Revised, COPE inventory, Pittsburgh Sleep Quality Index, Brief Resilience Scale	Already practicing yoga regularly, suicidal ideation, currently taking psychotropic medications	Stillbirth >20weeks within the last 24 months, 18 or older, living in the US, able to read/write/understand English, could exercise safely	Checklist for cohort studies
Huberty 2020	US/ July 2017 - September 2018	National	Questionnaires	HIC	Quantitative	NA	Randomised control feasibility trial	n=90	Stillbirth	Feasibility of yoga intervention; effect of yoga on PTSD symptoms, anxiety, depression, grief, self-compassion, emotional regulation, mindfulness, sleep quality, and subjective health	Unstable psychiatric condition, pregnant at time of enrolment, practiced yoga at least 60 min/week, severe depression, at risk for suicide	experienced a stillbirth within 6 weeks to 24 months, clinic level of posttraumatic stress syndrome, 18 or older, able to read/understand/speak English, underactive, willing to be randomised, regular internet access, can safely participate in exercise	Checklist for randomised controlled trials

Hvidtjorn 2021	Denmark (2012-2018)	A midwifery-led specialised unit for bereaved parents at Aarhus University Hospital in Denmark	Hospital electronic health records	HIC	Quantitative	NA	Descriptive cross-sectional	579	miscarriage (>14 weeks), missed abortion (>14 weeks), termination of pregnancy (>14 weeks), stillbirth, NND	clinical characteristics of women admitted to a specialised unit for bereaved parents and characteristics of women who stayed more than 2 days	None mentioned	All women at Aarhus University Hospital who experienced spontaneous pregnancy loss after 14 weeks gestation, TOPFA, intrauterine death, or intrapartum death between January 1, 2012, and December 31, 2018. Women who experienced the death of a newborn in the NICU within the first 48 hours after birth and desired a stay in the unit were also included.	Checklist for studies reporting prevalence data

Inati 2018	Australia (2014)	ACT, NSW	Questionnaire including open-text responses	HIC	Mixed methods	Thematic analysis	Retrospective descriptive	47	Stillbirth, NND	Types of bereavement services utilised by families who have experienced a perinatal loss, and the impact of these services on the families' bereavement journey	Parents with changed addresses, or who returned a blank survey or completed a 'request for withdrawal' form	Women in the ACT and surrounding NSW who had experienced a perinatal loss between January 2009 to December 2012	Checklist for studies reporting prevalence data and Checklist for qualitative research
Irani 2019	Iran (Apr 2017-Jan 2018)	2 referral centres for fetal anomaly in Mashhad, Iran	Semi-structured interviews	LMIC	Qualitative	Conventional content analysis	NA	25	Prenatal diagnosis of fetal anomaly	Emotional and cognitive experiences of pregnant women following prenatal diagnosis of fetal anomalies	Lack of willingness to participate in the study	Persian-speaking parents with prenatal diagnosis of fetal anomalies at the gestational week of 12-27	Checklist for qualitative research
Jones 2017 (2)	Multiple (dates not reported)	International literature	Literature	NA	Qualitative	Meta-synthesis	NA	10 studies (581 women)	TOPFA	Women's experiences of labour and birth when having a TOPFA in the second trimester of pregnancy	Previously published literature reviews and systematic reviews	English language qualitative articles that were original research studies and published between 1996-2016, that were peer-reviewed and	Checklist for systematic reviews and research syntheses

												had full text available to view.	
Jones 2019	Western countries/ 2000-2019	Mixed	Data from previous studies of men's grief	HIC	Qualitative	Scoping review	NA	27 studies	Stillbirth and NND	impact of perinatal death for men, meaning of loss and fathers identity, extent to which men were able to express grief and how grief was mediated by the support of health professionals	Studies before 2000; studies from countries with likely substantial cultural, religious and health care differences; studies which exclusively looked at miscarriage, fetal loss before 24weeks, lethal fetal abnormalities, and SIDS.	Studies from 2000 exploring parental experiences of perinatal death and health care support following	Checklist for systematic reviews and research syntheses
Jones 2021	Multiple (Australia, Canada, US, UK)/ Dec 2016-June 2017	4 countries	Online Questionnaire	HIC	Quantitative	NA	Cross-sectional	170	Stillbirth	Parents' continuing bond with their stillborn baby and bereavement adaptation	None stated	Parents 18 + years old, whose baby died at 24 weeks' gestation or later, over 1 year ago, and who felt they had an	Checklist for analytical cross-sectional studies

											ongoing relationship with their stillborn baby	
Jorgensen 2022	Denmark (2015-2019)	Unclear	Online questionnaires	HIC	Quantitative	NA	Non-comparative study	173	stillbirth	The amount of time Danish parents spend with their stillborn baby in hospital settings; hypothesis of the reasons why Danish parents spend with their babies.	None mentioned	The cohort 'Life after the Loss' comprises mothers and their partners in Denmark who experienced a stillbirth from January 2015 till August 2019 (intrauterine death after gestational age 22 weeks).	Checklist for studies reporting prevalence data
Kalanlar 2020	Turkey (NR)	49 hospitals across Ankara, Istanbul, and Izmir	Postal questionnaires	UMIC	Quantitative	NA	Cross-sectional study	29	Perinatal death including stillbirth and neonatal death.	"Managers, head physicians, head nurses, midwives, and specialist physicians caring for families following perinatal death"	"dialysis, in vitro fertilization, medical, physical therapy, and rehabilitation centres. Hospitals which were shut down, did not agree to take part, and did not have a maternity service were filtered out"	Purposive sampling to select provinces with the highest number of hospitals.	Checklist for analytical cross-sectional studies

Kamranpour 2019	Iran/2017-2018	State, Rasht, Iran health centres	In-depth semi-structured interviews	UMIC	Qualitative	content analysis	NA	42	TOPFA	Parents' feelings around TOPFA and what needs they had after	no diagnosed psychological disorders	at least 1 year after termination	Checklist for qualitative research
Kamranpour 2020	Iran (Oct 2017-Apr 2018)	Hospitals in one city in Iran	Interviews, field notes	LMIC	Qualitative	Thematic analysis	NA	40 (25 women, 2 spouses, 13 HCPs)	TOPFA	Psychological experiences of women due to TOPFA	None mentioned	Women with pregnancy termination due to fetal anomalies referred to hospitals in Rasht, two of their spouses and 13 healthcare providers (two forensic medicine specialists, three gynaecologists, one perinatologist, one psychologist, two reproductive health specialists, three midwives and one nurse). Inclusion criteria	Checklist for qualitative research

												included participants' willingness to participate in the study and informed consent, the ability to understand questions and having reading and writing literacy, a maximum of 1 year elapsed since pregnancy termination, and the absence of any known psychological illness.	
Kamranpour 2020 (2)	Iran (Oct 2017-Apr 2018)	Rasht city	Semi-structured interviews; field notes	LMIC	Qualitative	Conventional content analysis	NA	40 (25 women, 2 husbands, 13 HCPs)	TOPFA	Health system needs of women with experience of pregnancy termination due to fetal anomalies	None stated	Participants were women with experience of pregnancy termination due to fetal anomalies, their husbands, and healthcare providers	Checklist for qualitative research

who had experiences in caring or treating these women in Rasht city, Iran. The inclusion criteria were absence of any psychological disease, willingness to participate in the study, providing informed consent, having the ability to understand questions, and a maximum of 1 year has passed since the termination of pregnancy

Kecir 2021	France (Apr-Dec 2016)	Maternity Department of the Nancy University Hospital	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	8	TOPFA	Fathers' experiences of TOPFA, their caregivers and coping	Minor father; Known genetic illness in the family responsible for the TOP indication; Intellectual deficit' Chronic psycho-pathological problems; Inability to express themselves fluently in French	Partner of a woman having a TOP for foetal abnormality after 22 weeks of amenorrhea (WA)	Checklist for qualitative research
Kennedy 2017	UK (dates not reported)	Global	Published literature, blogs, charity websites, online news articles and milk bank websites	HIC	Qualitative	Narrative review	NA	NA	Stillbirth, NND	experience of bereaved mothers regarding milk donation following perinatal loss	NA	NA	Checklist for text and opinion papers

Kishimoto 2021	Japan (Jan-Apr 2019)	National Center for Child Health and Development	Medical records	HIC	Quantitative	NA	Retrospective cohort study	50	Stillbirth, NND, TOPFA	Medical and psychosocial risk factors, including inter- and intrapersonal factors affecting the development of complicated grief following perinatal loss	None stated	Women referred for treatment of grief due to perinatal loss by the Center for Maternal–Fetal, Neonatal and Reproductive Medicine of the study institution between April 2017 and March 2019	Checklist for cohort studies
Köneş 2021	Turkey/ Feb 2016-Oct 2016	Istanbul University Faculty of Medicine Hospital perinatology outpatient clinic	Face to face or phone interview	UMIC	Quantitative	NA	Cross-sectional	215	Stillbirth, NND, TOPFA	Perinatal grief in women with pregnancy loss	Women with past history or current treatment for a psychiatric disorder	Women who experienced perinatal loss due to intrauterine fetal death (IUFD), pregnancy termination, abortion (early, late) and stillbirth	Checklist for analytical cross-sectional studies

Kothari 2022	Australia (2013-2015)	One public teaching hospital in Brisbane	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	24	Stillbirth, TOPFA	Emotional and behavioural responses and coping strategies of fathers or expectant fathers who faced a significant traumatic event during a partner's pregnancy, labour, or the postpartum period	None stated	Male partners who experienced a traumatic event during the pregnancy, labour or postpartum period. A "traumatic event" was defined as a medical incident resulting in serious risk to the mother and the unborn child, termination of pregnancy, intrauterine fetal death or stillbirth.	Checklist for qualitative research
Kokou-Kpolou 2018	France, Feb to April 2017	groups for bereaved individuals on Google	Online survey	HIC	Quantitative	NA	cross-sectional	98 bereaved mothers	Stillbirth, NND	loss-related variables relating to the death of the child, acute grief reactions and depression, and negative cognitions	male respondents (n=5); 14 participants who had been bereaved for 10 years or longer	98 bereaved mothers, all of French nationality	Checklist for analytical cross-sectional studies

Lafarge 2017	England (May-July 2013)	3 Hospitals	Interviews	HIC	Qualitative	Inductive and deductive thematic analysis	NA	15 HCPs	TOPFA	Healthcare professionals' perceptions of women's coping with TOPFA and to what extent these perceptions are congruent with women's accounts.	Consent withheld.	Healthcare professionals involved in the pregnancy management of women in three hospitals in England. Women - Aged over 18 years old, had experienced a TOPFA, recruited through a support organisation for parents who face/undergo TOPFA. Data from 27 interviews with women reported elsewhere.	Checklist for qualitative research
LeDuffIII 2017	Multiple (dates not reported)	Global	Literature (4 databases)	NA	Qualitative	Literature review	NA	NA	Miscarriage, Stillbirth, NND	Role of transitional objects to facilitate grieving following perinatal loss	None stated	Full-text English language articles published between 2011-2016	Checklist for text and opinion papers

Leithner 2021	Austria (dates not reported)	Medical University Vienna	Questionnaire; Medical records	HIC	Quantitative	NA	Retrospective cohort study	40 (n=10 for women underwent fetal reduction; n=30 for women who delivered triplets)	Multifetal pregnancy reduction	Decision making for or against multifetal pregnancy reduction (MFPR) and psychological outcome in women with a triplet pregnancy	None stated	Women with triplet pregnancies attending the study institution between 2005-2014	Checklist for cohort studies
Lewis 2018 (4)	Not specified	NA	NA	Unknown	Qualitative	Narrative	NA	NA	Stillbirth	Generation of a tool to support childbirth educators support women in experiencing pregnancy loss following domestic violence	NA	NA	Checklist for text and opinion papers
Lizcano Pabon 2019	Colombia (2014-2015)	2 hospitals in northeastern Colombia	Semi-structured interviews, field diary, sociodemographic survey	UMIC	Qualitative	Thematic analysis	NA	15	Stillbirth, NND	Experience of perinatal death in a sample of fathers from Colombia	None stated	Men over 18 years of age who spoke Spanish, lived with their partners, experienced a perinatal death within a year at the beginning of the study,	Checklist for qualitative research

												accepted to participate in the study, and signed an informed consent	
Lockton 2020	Australia (dates not reported)	National	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	14	Stillbirth, TOPFA	Grandmothers' experiences of loss and grief, following a child's pregnancy loss	None stated	Grandmothers from across Australia, whose child had experienced a pregnancy loss between six months and five years ago, and who were fluent in English	Checklist for qualitative research
Lockton 2021	Australia (dates not reported)	National	Interviews	HIC	Qualitative	Thematic analysis	NA	10	Stillbirth, NND, TOPFA	Grandfathers' experiences of grief and support following the loss of a grandchild in pregnancy or the neonatal period	None stated	Australian grandfathers, fluent in English, whose child/ren had experienced a pregnancy loss or neonatal death between 6 months and 5	Checklist for qualitative research

												years previously	
Lord 2022	Canada (dates not reported)	NA	Opinion; Literature	HIC	Qualitative	Narrative paper	NA	NA	Prenatal diagnosis of fetal anomaly	Role of palliative care in the face of uncertainty	NA	NA	Checklist for text and opinion papers
Lou 2017	Multiple (March-April 2016)	Anglophone and European countries	PubMed, EMBASE, CINAHL, PsycINFO	NA	qualitative	Systematic review	NA	28 studies (591 women, 182 men, 595 affected pregnancies of which 232 were terminated)	TOPFA	parental response to severe or lethal antenatal diagnosis	"Exclusion criteria were as follows: (1) parental response to screening results prior to actual diagnosis, (2) expected behaviour in case of future diagnosis, (3) parental response to postnatal diagnosis and (4) clinicians experiences of parents' response"	Qualitative studies reporting on parental responses to severe prenatal diagnosis in any trimester	Checklist for systematic reviews and research syntheses

Martinez-Serrano 2019	Spain (2012-2017)	1 hospital and local pregnancy loss support organisation	Interviews	HIC	Qualitative	Thematic analysis	NA	11 parents (7 mothers, 4 fathers)	Stillbirth	Mothers' and fathers' experience of care received during delivery in cases of stillbirth	Those with psychological functional impairment and not fluent in Spanish?	Women and men over 18 years of age, who during a monitored low obstetric and neonatal risk pregnancy were attended for labour after stillbirth, through a vaginal birth.	Checklist for qualitative research
Marwah 2019	India (Sep 2016-Aug 2016)	1 hospital in Delhi	Questionnaire based on EPDS	LMIC	Quantitative	NA	Non comparative study	645	Stillbirth	Psychosocial impact of stillbirth among mothers and its contributing factors	Patients who did not wish to discuss about stillbirth	All patients delivering a stillborn fetus in the hospital who consented to participate in the study	Checklist for case series studies
McNeil 2021	Multiple (2019)	International	Literature (4 databases)	NA	Qualitative	Narrative synthesis	NA	21 articles	NND	Grief and bereavement experiences of fathers after the death of a child	Studies describing paternal bereavement after the death of a child aged older than 21 years, stillbirth, miscarriage, or studies that did not specify age of death	English language articles published between 2007 and 2019 that evaluated the grief and bereavement experiences of fathers	Checklist for systematic reviews and research syntheses

												after the death of their child	
McSpedden 2017	Australia (dates not reported)	3 regions of eastern Australia	Questionnaires	HIC	Quantitative	NA	Cross-sectional	121	Stillbirth, NND	Presence and possible predictors of complicated grief symptoms in perinatally bereaved mothers	Fathers	Bereaved mothers who were clients of SIDS and Kids in three regions of eastern Australia	Checklist for analytical cross-sectional studies
Mills 2021	Kenya and Uganda (July 2017-May 2019)	5 facilities in Nairobi and Western Kenya, Kampala and Central Uganda	Interviews	LIC, LMIC	Qualitative	Thematic analysis	NA	75 women, 59 men	Stillbirth	Parents' experience of care and support after stillbirth	NA	Women and men >18 years of age who had experienced the stillbirth of their baby (≤1 year previously) and received care in the included facilities.	Checklist for qualitative research

Murphy 2017	Multiple (dates not reported)	International	Literature	NA	Qualitative	Narrative review	NA	Not stated	Stillbirth	Psychological, social, and economic impact of stillbirth on families	NA	NA	Checklist for text and opinion papers
Musodza 2021	Australia / not applicable	UK, Australia, Sweden, USA)	Scoping review (OVID, EBSCO host, Google Scholar, Research Direct Western Sydney University , Research Gate and Google)	HIC	Qualitative (scoping review)	Scoping review, thematic analysis	NA	10	Stillbirth	The experiences of female maternity healthcare professionals when they return to work following a personal pregnancy loss or neonatal death	Papers which set out to address the experiences of HCPs not working in maternity units (e.g., sonographers), or HCPs still in training (e.g., student midwives). Other exclusions were blog entries, articles in non-professional journals, magazines or websites, and papers not written in English.	Papers written in English which were directly related to the research question: "What are the experiences of maternity HCPs who work in a maternity setting when they return to work following a personal pregnancy loss or perinatal loss". Grey literature was also included, such as personal stories,	Checklist for systematic reviews and research syntheses

												videos and book chapters	
Navidian 2017	Iran/May-September 2016	"Hospital/Central Maternity Hospital affiliated with Zahedan University of Medical Sciences"	Pre-post questionnaires	LMIC	Quantitative	NA	Pre-post study	200 (100 in each group, Control/ intervention)	Stillbirth	Prenatal Posttraumatic Stress Questionnaire pre and post 4 educational psychological counselling sessions	Failure to complete more than one counselling session, possible incidence of crisis or loss of relatives during the study	>18, literacy, no history of stillbirth or miscarriage in previous pregnancies, no history of mental disorders, absence of other stressful events in past year, perinatal loss at >22 weeks	Checklist for cohort studies
Navidian 2018	Iran / May-September 2016	Central Maternity Hospital, Zahedan, Iran	Self-administered questionnaire	LMIC	Quantitative	NA	Prospective cohort study	100	Stillbirth	To determine the impact of psychological counselling on the severity of grief symptoms in mothers after stillbirth	Lack of participation in more than one grief and crisis counselling session or possible loss during the study	Patients over 18 years old, being literate, with no history of still-birth or miscarriage in previous pregnancies, no history of mental disorders, and no other stressful	Checklist for cohort studies

												events during the past year	
Nguyen 2019	Australia / published during or after 2000	Australia, Switzerland, USA. Sweden, South Africa, Israel, Ireland,	Scoping review (Medline (Ovid), PsycINFO (Ovid), CINAHL (EBSCO), and Families and Societies (EBSCO)	HIC	Qualitative (scoping review)	Thematic analysis	NA	100	Stillbirth and NND	Lived experiences of men whose partner has experienced a stillbirth or miscarriage	Men whose partner has experienced a neonatal death, undergone a voluntary abortion, Studies where qualitative data do not distinguish between type of pregnancy loss, i.e. includes miscarriages, stillbirth and neonatal death without specifying which loss is being commented on, Focus on the experiences of women or health professionals, experiences of men and women but analysed data together, e.g. as a couple or family, Articles in languages other than English with no sufficient	Men of any age or country whose partner has experienced a miscarriage or stillbirth, Focus on miscarriage, stillbirth and neonatal death but analysed data separately, focus on the experiences of men in relation to miscarriages or stillbirth. This can be told by men themselves, their partners, family members or health professionals, The sample included experiences of men and women but	Checklist for systematic reviews and research syntheses

											translation, Secondary analysis of primary data, review of the literature, Book chapters, theses/dissertations, Quantitative studies or mixed design studies, Studies conducted before 2000	analysed data separately, Articles in English or with sufficient translation, Collected primary data on the experiences of men or personal recollections from the author, Journal articles, industry reports, grey literature conducted after 2000	
Noble-Carr 2021	Australia (2019)	3 large tertiary hospitals located in 3 Eastern states and territories	Interviews and focus groups	HIC	Qualitative	Thematic and interactional analysis	NA	113	Stillbirth, NND	Factors that shape the delivery of hospital-based lactation care for bereaved mothers	None mentioned	Professionals most likely to interface with bereaved families after stillbirth and infant death, and who may be called upon to offer lactation care. These included obstetricians,	Checklist for qualitative research

											neonatologists, midwives, neonatal nurses, lactation consultants, social workers or pastoral care workers, HMB staff, and specialist perinatal bereavement nurses.	
Noble-Carr 2022	Australia / November 2019-April 2020	Three tertiary hospitals in three eastern Australian states and territories	Semi-structured in-depth interviews (hour-long semi-structured interview, or a written survey of approximately 15 open-ended questions).	HIC	Qualitative	Thematic analysis	NA	7	Stillbirth and NND	Whether the support role that fathers often assume in relation to infant bereavement and infant feeding remains consistent in the context of bereavement and bereaved lactation care and will highlight if the specific needs of non-birthing parents are being considered	Not specified	Potential non-birthing parent participants were identified via interviews with bereaved mothers, who at the end of their interview, agreed to provide their partner with an invitation pack, including participant information	Checklist for qualitative research

												and consent forms.	
O'Connell 2019	Ireland (2017)	1 maternity teaching hospital	Semi-structured interviews	HIC	Qualitative	IPA	NA	4	Prenatal diagnosis of anomaly	Lived experience of mothers who continued with their pregnancies after prenatal diagnosis of anencephaly	None mentioned	Mothers, whose babies were diagnosed with anencephaly antenatally and chose to continue with the pregnancy; mothers were more than one year post bereavement and were not pregnant at the time of the interviews	Checklist for qualitative research

Obst 2020	Multiple (1998-2018)	International	4 databases; Qualitative, quantitative or mixed methods studies with data on men's grief or predictors of grief following a pregnancy or neonatal loss	NA	Qualitative	Narrative synthesis	NA	46 studies	Stillbirth/neonatal death	Primary data on men's grief and/or predictors of grief after a pregnancy loss or neonatal death;	Articles not published in English, abstracts, editorials, opinion pieces, discussion or review articles or those with no primary data; studies using a comparator that didn't present men's data separately; studies investigating grief after a termination for viable foetal anomaly or elective abortion.	Qualitative, quantitative or mixed methods studies published from 1998 to October 2018 with primary results of men's grief following pregnancy or neonatal loss	Checklist for systematic reviews and research syntheses
Obst 2021	Australia (Oct 2019-March 2020)	National	Semi structured interviews	HIC	Qualitative	Thematic analysis	NA	10	TOPFA	To explore men's experiences and needs for support following TOPFA	None mentioned	Heterosexual men over 18 years of age who experienced TOPFA with a female partner between 6 months and 11 years ago	Checklist for qualitative research

Obst 2021 (2)	Australia/ 2000 - 2021	National	Web-based survey	HIC	Quantitative	NA	Cross sectional	n=228	Stillbirth, NND, TOPFA	Development of a model to quantify men's grief and find factors associated with grief intensity; participant characteristics, Paternal Antenatal Attachment Scale, Perinatal Grief Scale-33, Grief Patterns Inventory-Revised, Crisis Support Scale, Conformity to Masculine Norms Inventory, and Male Role Norms Inventory-Short Form.	NA		18 or older with an experience of pregnancy loss or neonatal death in Australia within the last 20 years,	Checklist for analytical cross-sectional studies
Obst 2021 (3)	Australia/ 2017	National/Australia	Semi-structured interviews	HIC	Qualitative	Thematic Analysis	NA	n=7	Stillbirth	Health provider's experiences supporting men following stillbirth and their views on current support and options for future support	NA		Over 18, fluent in English, HCPs with experience providing formal care or grief support to men who have experienced a pregnancy	Checklist for qualitative research

												loss, in the last 5 years	
Oreg 2020	US/2017-2019	National	Personal testimonials of mothers posted on HMBANA milk bank websites, mothers' Facebook pages and personal blogs; in-depth interviews	HIC	Qualitative	Thematic analysis	NA	88 (80 personal testimonies; 8 interviews)	Stillbirth, NND, TOPFA	The grief ritual of extracting and donating human milk after perinatal loss	None stated	Mothers who experienced perinatal loss and chose to extract and donate their human milk to nonprofit milk banks.	Checklist for qualitative research
Osman 2017	Somalia 2015	Eight villages in a district in Somaliland	Interviews	LIC	Qualitative	Phenomenological	NA	10	Stillbirth (10)	Maternal experience of stillbirth	pregnant or unmarried women	Women who had given birth in a health facility to a baby with no signs of life at or after 28 weeks GA within 6	Checklist for qualitative research

												months prior to interview.	
Pachalla 2021	US/Oct 2018	National/US	Scoping review of publications relating to bereavement support for extended family following perinatal loss	HIC	Qualitative	Scoping review	NA	39 articles for full-text	Stillbirth, NND	efficacy of bereavement services	case studies, books, theses, articles about healthcare provider support or education, impact of childhood death, adult death, peri-death activities, abstracts for posters or conferences, studies from outside the US	Articles about the efficacy of bereavement services for people following the death of a child	Checklist for systematic reviews and research syntheses
Paraíso Pueyo 2021	Multiple (2018-2019)	International literature	Literature (4 databases)	HIC	Qualitative	Scoping review	NA	9 papers	NND	Nursing interventions to help parents of neonates admitted to neonatal intensive care units cope with perinatal loss	Studies relating to stillbirth, TOP for non-medical reasons, miscarriage	Studies published between 2000-2019 that included mothers and/or fathers and/or the immediate family who have	Checklist for systematic reviews and research syntheses

												experienced the death of an infant in the perinatal period in a NICU. Papers written in Spanish whose title and abstract had also been written in English.	
Paraszczuk 2022	US (July 2020-Apr 2021)	National	Interviews	HIC	Qualitative	Thematic analysis	NA	21	Stillbirth, NND	Experience of women choosing to continue to express milk after a perinatal loss for donation to a nonprofit milk bank	None stated	Participants were eligible if they were English speaking, donated to an HMBANA milk bank during the previous 2 years and specifically continued to pump milk for the purpose of milk donation following a perinatal loss.	Checklist for qualitative research

Parish 2021	UK (dates not specified)	NA	Opinion; literature	HIC	Qualitative	Narrative	NA	NA	NND	Management of lactation following the death of a baby	NA	NA	Checklist for text and opinion papers
Pekkola 2022	Finland/2016-2020	Hospital/Helsinki University Hospital, Helsinki	Postal questionnaires	HIC	Quantitative	NA	Cross-sectional	57 mothers, 46 partners	Stillbirth	Stillbirth diagnosis, delivery, information on postmortem examinations, aftercare at the ward, follow-up appointments, all assessed using researcher created statements with a 5-point Likert scale for response (agree- disagree)	Not specified	Antepartum singleton stillbirth at or after 22 weeks, language of communication of Finnish or Swedish	Checklist for studies reporting prevalence data
Pereira 2018	Brazil (Jul 2012-Jul 2014)	One city in Northeast Brazil	Semi-structured interviews	UMIC	Qualitative	Thematic analysis	NA	15	NND	Communication of a child's death and grief support provided to women who lost a newborn	Women with mental impairment	Mother living in the city of São Luís who lost a child at gestational age equal to or higher than 32 weeks, and weight at birth equal to	Checklist for qualitative research

												or higher than 2500 g.	
Pollock 2020	Multiple (2018)	International literature	Literature (5 databases)	NA	Qualitative	Scoping review	NA	23 articles	Stillbirth	Current knowledge surrounding stillbirth stigma, specifically the extent, type and experiences of bereaved parents	Non-English articles; Articles not published at the time of this scoping review being submitted for publication (October 2018) were not included	The inclusion criteria for articles were; (1) written in English; (2) focused on stillbirth (3) the abstract or title included the words stigma OR silence.	Checklist for systematic reviews and research syntheses
Pollock 2021	HIC (Australia, UK, USA, NZ); May-Sept 2018	International	Online survey	HIC	Quantitative	NA	Prevalence study	889 bereaved mothers	Stillbirth	Prevalence of stillbirth stigma, and relationship between the extent of stigma experienced and constructs such as grief and self-esteem	None stated	stillbirth 20 weeks and/or 400 g; and 18 years or over	Checklist for studies reporting prevalence data

Popoola 2021	Nigeria (2017)	Saki	Interviews, social network diagrams	LMIC	Qualitative	Thematic analysis	NA	20	Stillbirth	Social networks of women who have experienced a stillbirth in Nigeria and the factors influencing their social networks	None mentioned	Women who experienced a stillbirth was more than six months but less than three years ago	Checklist for qualitative research
Popoola 2022	Nigeria (Jan-June 2017)	Saki town in Nigeria	Interviews, focus groups	LMIC	Qualitative	Phenomenography	NA	n=20 for interviews; n=7 for focus groups	Stillbirth	Beliefs and strategies for coping with stillbirth	Women who were below the age of 18 years, those who were pregnant at the time of recruitment, or whose loss was less than six months	Yoruba women who had experienced stillbirth after the 28th week of pregnancy	Checklist for qualitative research
Popoola 2022 (2)	Nigeria (2017)	Saki	Semi-structured interviews	LMIC	Qualitative	Thematic analysis	NA	20	Stillbirth	Nigerian women's experiences of grief after stillbirth	Women who were pregnant at the time of recruitment	To be eligible for study participation, the participant must be a Yoruba living in Saki, and at least 6 months must have passed since stillbirth to minimise causing distress	Checklist for qualitative research

Qian 2019	China (Jan-Apr 2019)	1 tertiary public hospital in China	Expressive writing	UMIC	Qualitative	Thematic analysis	NA	20	TOPFA	Psychological trajectories of women undergoing pregnancy termination for foetal abnormality	Women who had postpartum complications (e.g. postpartum massive haemorrhage) or serious mental disorders (e.g. schizophrenia), which may interfere with their participation in the study.	Women who (a) were pregnant for more than 14 weeks, (b) decided to terminate their pregnancies due to foetal abnormality or stillbirth, (c) were able to write Chinese and willing to express their emotions through writing and (d) had access to WeChat (a chatting software) and were able to complete the follow-up research	Checklist for qualitative research

Qian 2020	China (Jan-Apr 2019)	One tertiary hospital	Expressive writing at 4 different time points from diagnosis through to 1 month after discharge	UMIC	Qualitative	Thematic analysis	NA	20	TOPFA	Psychological trajectories of women undergoing pregnancy termination for foetal abnormality	Women who had postpartum complications (e.g. postpartum massive haemorrhage) or serious mental disorders (e.g. schizophrenia)	Women who (a) were pregnant for more than 14 weeks, (b) decided to terminate their pregnancies due to foetal abnormality or stillbirth, (c) were able to write Chinese and willing to express their emotions through writing and (d) had access to WeChat (a chatting software) and were able to complete the follow-up research	Checklist for qualitative research
Qin 2019	China (May-Sept 2017)	Three general hospitals and one special hospital in Changsha, Hunan, China	Interviews	UMIC	Qualitative	Grounded theory	NA	41	TOPFA	Cognition, emotions, and behaviour of women who had recently undergone termination due	Pregnant women with severe complications (e.g., heart failure, severe pre-eclampsia, eclampsia,	1. Pregnant women who had decided to undergo TOP due to a foetal anomaly; 2.	Checklist for qualitative research

										to a foetal anomaly	and/or massive haemorrhage) or diagnosed with a severe mental illness (e.g., psychosis, schizophrenia)	Able to write and speak Chinese; 3. Had access to the Internet and telephone; and 4. Able to complete the follow-up surveys.	
Ravaldi 2018	Italy (2009-2015)	National (11 hospitals)	Hardcopy survey questionnaire	HIC	Quantitative	NA	Cross-sectional study	674	Stillbirth	Current practices of health care providers caring for women experiencing a stillbirth and to explore their training needs	None mentioned	Practising midwives, obstetricians, nurses, and psychologists of the ob/gyn wards in 11 Italian hospitals	Checklist for analytical cross-sectional studies
Redshaw 2021	England (dates not specified)	National	Questionnaires	HIC	Qualitative	Thematic analysis	NA	249	NND	Experience of women whose baby died in the neonatal period of their care in the perinatal period, on delivery suite, in the neonatal unit and afterwards.	None mentioned	Women aged 16 years and over in England who registered a stillbirth or neonatal death in two 3-month periods	Checklist for qualitative research

Rich 2018 (2)	US/not specified	not specified	Literature ; Opinion	NA	Qualitative	Narrative review	NA	NA	Stillbirth/NND	integration of findings from prominent theory to build an evidence based framework for patient care after perinatal loss	NA	NA	Checklist for text and opinion papers
Ridaura 2017	Spain/not specified	Hospital/Vall d'Hebron Maternal and Infant-care Hospital in Barcelona	Surveys with validated measures	HIC	Quantitative	NA	Cross-sectional	70	stillbirth, NND, TOPFA	grief and depression following loss, Perinatal Grief Scale - reduced version, and Beck's Depression Inventory	Not specified	Perinatal loss anytime during pregnancy, or in the 28 days following birth, and a minimum level of education and understood Spanish	Checklist for studies reporting prevalence data
Roberts 2017	India (dates not reported)	2 villages in central India	Structured interview including validated questionnaires	LMIC	Mixed methods	Content thematic analysis	Cohort study	n=28 men (18 with a history of stillborn ; 10 without a history of stillborn); n=5 key	Stillbirth	Men's perceptions, attitudes and behaviours related to reproductive choices linked to stillbirth; father's experiences related to stillbirth; and men's opinions regarding a women's	None stated	Key informants including one doctor, one nurse and three community members with an experience of stillbirth; adult males (18 years of age or older)	Checklist for qualitative research and Checklist for cohort studies

								informants		mindfulness-based intervention for perinatal grief after stillbirth in their communities in rural, central India.		of various ethnicities in two villages in Chhattisgarh, India	
Roberts 2021	India: 2012; 2020	Mungeli district in Chhattisgarh; Mumbai	Surveys conducted via structured interviews	LMIC	Quantitative	NA	Cross-sectional	217 rural & 149 urban women	stillbirth	comparison of poor rural and urban women's experience of perinatal grief	NA	rural women from Chhattisgarh and urban slum-dwelling women in Mumbai, of childbearing age (18– 49), who reported perinatal loss	Checklist for analytical cross-sectional studies
Roberts 2021 (2)	India/not specified	City/Mumbai	focus group interviews; Survey using validated scales	LMIC	Mixed methods	Thematic analysis	Cross-sectional	focus group n=7, surveys n=260	Stillbirth, NND	mental health among women living in Mumbai slums with a history of childbirth, stillbirth, or neonatal death	Not specified	Community health workers and women living in Mumbai slums; women who were pregnant in the last 12 months	Checklist for analytical cross-sectional studies

Rocha Catania 2017	Multiple (upto 31 Dec 2015)	International literature	Literature	NA	Qualitative	Systematic review	NA	29 articles	TOPFA, palliative care	Palliative care in the prenatal period	Case reports, studies restricted to only one aspect of care, parent interviews with less than 10 participants	articles published in English, palliative care during prenatal period	Checklist for systematic reviews and research syntheses
Rodriguez 2021	US/Jan 2017 - Dec 2019	Hospital/Department of Obstetrics and Gynaecology, The University of Texas Southwestern Medical Center	Medical records of women screened for depression and associated follow-up rates	HIC	Quantitative	NA	retrospective cohort study	25,425 patients screened, 978 positive screen EPDS result	Stillbirth, NND	EPDS Score antenatal, referral to mental health counsellors with a 'positive screen', demographics and maternal/infant outcomes for women with positive screens, comparison of this cohort to a 2008-2010 historic cohort to see changes in mental health referral rates and outcomes associated	Not specified	Women who delivered from Jan 2017 to Dec 2019 and underwent universal postpartum depression screening	Checklist for cohort studies
Rymaszewska 2019	Poland/Not specified	National	recommendations of the Polish Psychiatric Association	HIC	Qualitative	Recommendations piece	NA	NA	Stillbirth	recommendations for women experiencing pregnancy loss and health professionals caring for them, recommendations	NA	NA	Checklist for text and opinion papers

										on care provisions and support			
Sarkar 2022	India (March 2019-Jun 2020)	1 tertiary care public hospital in Northern India	Questionnaires	LMIC	Quantitative	NA	Prospective cohort study	300 couples (150 each with a recent stillbirth and live birth)	Stillbirth	Prevalence of depression, anxiety, stress, and domestic violence among parents after a stillbirth vs. livebirths and the need for psychological and pharmacological interventions for the affected individuals	Participants with a known history of any psychiatric disorder	All deliveries occurring at the study hospital during the study period were followed and out of them, 150 consecutive couples with a recent stillbirth (group 1) and 150 random couples with a recent live birth (group 2) in the same time period were enrolled, after due informed consent	Checklist for cohort studies

Schoonover 2022	Multiple (2020)	International	Literature	NA	Qualitative	Scoping review	NA	52 articles	Stillbirth, NND, child death	Helpful and unhelpful characteristics of informal support given by the support network of bereaved parents from the perspective of parents	Nonclinical based articles such as reflection papers; studies focused on grief in the setting of non-bereavement settings such as divorce, study populations not focused on parents or only focused on healthcare professionals, and studies focused on bereavement interventions run by healthcare professional	Clinical studies published in English between 2000 to 20/4/2020 on informal bereavement support of adult bereaved parents of stillborn to adult children	Checklist for systematic reviews and research syntheses
Senechal 2022	Canada (2018)	Tertiary hospital specialising in maternal and fetal health	Medical records	HIC	Quantitative	NA	retrospective case series	151	TOPFA	Evaluation of the counselling and TOPFA process and bereavement of women following TOPFA at a tertiary Canadian hospital specialising in maternal and fetal health	None mentioned	Women who underwent TOPFA at the study centre (a tertiary Canadian hospital specialising in maternal and fetal health) in 2018	Checklist for case series studies

Setubal 2021	Multiple (2018)	International	Literature (3 databases)	NA	Qualitative	Narrative synthesis	NA	67 papers	Stillbirth, NND, TOPFA	Instruments measuring grief after perinatal loss and factors that could moderate grief reactions	Articles written in languages other than English or measuring health care providers perceptions of grief were excluded	Articles in English, which used standardised measures to assess perinatal grief after any kind of perinatal loss. Articles reporting translation and validation of any perinatal grief instrument to other languages were included.	Checklist for systematic reviews and research syntheses
Shakes 2021	Australia (not stated)	Lismore, NSW	Narrative	HIC	Qualitative	Narrative analysis	NA	1	TOPFA	Review of medical records and photos to recall moments of the experience and prompt reflection	NA	NA	Checklist for text and opinion papers

Shakespeare 2019	Multiple (2017)	International	Literature (6 databases)	LMIC	Mixed methods	Narrative synthesis	Meta-analysis	34 studies across 17 countries	Stillbirth	Parents' and healthcare professionals' experiences of care after stillbirth in LMIC	Studies explicitly addressing miscarriage, fetal anomaly, and neonatal death alone were excluded. Review articles, opinion pieces, and books were excluded.	Qualitative, quantitative, and mixed method studies that addressed parents' or healthcare professionals' experience of care after stillbirth in LMIC	Checklist for systematic reviews and research syntheses
Shaohua 2021	Multiple (2019)	International	Literature (8 databases)	NA	Mixed methods	Narrative synthesis	Meta-analysis	17 studies	Stillbirth, NND, TOPFA	Effectiveness of psychosocial interventions in reducing depression, anxiety, and grief among parents after perinatal loss	Studies were excluded if it: 1) included parents below 18 years old; 2) included parents who were pregnant and intending to continue the pregnancy; 3) included parents whose child died beyond the neonatal phase (first 28 days of life); or 4) involved intervention programs for family members of the bereaved couple.	Studies with a randomised controlled trial study design published in the English language. Studies were included if it: 1) involved heterosexual parents (both father and mother or either parent) who had lost a child due to miscarriage, stillbirth, neonatal death, ectopic	Checklist for systematic reviews and research syntheses

							pregnancy, or termination of pregnancy (TOP) due to detection of fetal health problems or fetal abnormality; 2) involved parents who were in the post-partum period of less than two years; 3) included psychosocial interventions for parents; 4) included depression, anxiety or grief as one of their primary or secondary outcome measures; and 5) utilised no treatment, a waiting list, or usual supportive care as their control group.

Siassakos 2018	UK 2013	Three maternity hospitals	Interviews, focus groups, service provision data	HIC	Qualitative	Thematic analysis	NA	Parents of 16 stillborn babies, 22 maternity staff	Stillbirth	Views of bereaved parents and maternity staff to improve bereavement care for families	Twin pregnancy and loss, intrapartum stillbirth	Parents with a stillborn baby (gestational age more than 23 weeks, 6 days)- singleton stillbirths with the fetal death diagnosed before the onset of labour, maternity staff	Checklist for qualitative research
Silverio 2021	UK (Nov-Dec 2020)	National	Interviews	HIC	Qualitative	Template analysis	NA	24	Late miscarriage - 14 to 23+6 weeks' gestation (n=5), Stillbirth (n=16), NND (n=3)	Bereaved parents' experience of care during COVID-19 pandemic.	None mentioned	Parents who experienced a late miscarriage, stillbirth or NND during COVID	Checklist for qualitative research

Smith 2020	UK (dates not stated)	3 hospital settings in South West of England	Interviews	HIC	Qualitative	cross-sectional qualitative study; Thematic analysis	NA	33	Stillbirth, NND	Experiences and perceptions of healthcare professionals using a cold cot following the loss of a paper	None mentioned	NICU and CDS staff who have had experience of caring for bereaved parents. A maximum variation sampling in terms of participants disciplines (i.e., medical, nursing, midwifery, chaplaincy) was also attempted to represent differing perspectives in bereavement care provision.	Checklist for qualitative research
Smith 2021	USA (Aug 2018 - Jan 2019)	3 private online support groups	Online survey	HIC	Quantitative	NA	Cross-sectional study	124	TOPFA	Factors that lead to women to accept of decline genetic counselling prior to TOPFA; The impact of genetic counselling on women's coping mechanisms and	Participants who were unsure as to whether they saw a genetic counsellor prior to TFA, and/or did not complete the COPE and/or PGS surveys.	English-speaking women who had undergone a TFA within the last 10 years in the United States and were at	Checklist for analytical cross-sectional studies

										grief following TOPFA, assessed with the brief COPE survey and short version of the PGS.		least 18 years of age at that time, recruited through three private online support groups.	
Smorti 2021	Italy/1 May 2018 - 31 January 2019	Hospital/metropolitan Tuscany	Questionnaires	HIC	Quantitative	NA	Cross-sectional	208 pregnant women	Stillbirth	anxiety related to health of child-to-be (Pregnancy related anxiety questionnaire (PRAG-R), prenatal depression (EPDS), delivery expectancy (Wijma Delivery Expectancy/Experience Questionnaire - DEQ)	History of abortion, twin pregnancy, foetal pathologies, maternal pathologies occurring before or during pregnancy, previous mental health issues	>18, able to speak and read Italian, currently pregnant, at >32 weeks.	Checklist for analytical cross-sectional studies
Ssegujja 2021	Uganda / January-May 2019	Mukuno district, Uganda	Interview questionnaire	LMIC	Quantitative	NA	Cross-sectional study	17	Stillbirth	To document the nature of available social support within existing networks for women experiencing a stillbirth and to characterize providers and recipients as well as the networks	Not being available for interview during the study period and those mothers who had delivered within one month prior to the study	18 years or older, having experienced a stillbirth within six months before the study and consented to participate. Delivered in a district health	Checklist for analytical cross-sectional studies

										they belonged to inform how best these could be strengthened for community-level stillbirth prevention strategies.		facilities (Health center III and above)	
Steen 2019	USA	One hospital in Minneapolis, Minnesota	Feedback from staff and parent evaluations	HIC	Qualitative	Thematic analysis and narrative review	NA	NA	Stillbirth, NND	Description of a perinatal bereavement program	None mentioned	Different components of a perinatal bereavement program at one hospital	Checklist for qualitative research
Sullivan 2017	Multiple (dates not reported)	International	Medical literature	NA	Qualitative	Narrative literature review	NA	10 studies	TOPFA	Psychological impact of abortion due to fetal anomaly	None stated	Studies examining psychological sequelae of pregnant women following prenatal diagnosis of life limiting conditions	Checklist for qualitative research
Sun 2018	Taiwan (Aug 2012 - July 2014)	Tertiary hospital	Interviews	HIC	Qualitative	Phenomenological	NA	20	TOPFA	How fathers experience TOPFA while their spouses are hospitalised in Taiwan	None mentioned	Partners of women who were hospitalised for TOPFA at a maternity unit in a teaching hospital in Taoyuan and:	Checklist for qualitative research

												aged ≥ 20 years, married, able to communicate in Mandarin or Taiwanese, and agreed to audio recording of personal interviews.	
Sun 2018 (2)	China / Nov 2016-June 2017	Women's Hospital School of Medicine, Zhejiang University	Self-reported questionnaries	UMIC	Quantitative	NA	RCT	124	TOPFA	The effects of a family-support programme for pregnant women with foetal abnormalities in terms of family support, depression, and post-traumatic stress symptoms	NA	A foetal anomaly diagnosis in the medical diagnostic centre of a tertiary hospital, acceptance of early induced labour as suggested by physicians, age at least 18 years, gestational age more than 14 weeks, a willingness to participate in this study as shown by signing an	Checklist for randomised controlled trials

											informed consent form, and no history of psychosomatic disease	
Sun 2020	China / March 2016-September 2017	Women's Hospital School of Medicine, Zhejiang University	Self-reported questionnaire and semi-structured in-depth interviews	UMIC	Mixed methods	Semi-structured in-depth interviews (Colaizzi's phenomenological seven-step analysis)	Cross sectional	214	TOPFA	The importance and influencing factors of family support for pregnant women with foetal abnormalities requiring pregnancy termination and the correlation between family support and women's post-traumatic stress symptoms	A history of psychosomatic disease, any type of postpartum complication, intellectual disability, or illiteracy and/or could not understand the content of the questionnaires	Foetal abnormality confirmed by Zhejiang Provincial Prenatal Diagnosis Center, decision to terminate a pregnancy for a foetal abnormality (including stillbirth, lethal defect, chromosomal or genetic defect and structural pathologies), older than 18 years of age, gestational week >14weeks, and voluntary participation	Checklist for qualitative research and Checklist for analytical cross-sectional studies

												in the study and signed informed consent	
Sun 2022	Sun 2022	China/Nov 2016 - Oct 2020	Hospital/ Women's Hospital School of Medicine, Zhejiang University	Surveys of parents	UMIC	Quantitative	NA	Cross-sectional survey	169 couples	stillbirth, TOPFA	Anxiety (Self-rating Anxiety Scale), depression (Self-rating depression scale for fathers; EPDS for mothers), Social Support Rating Scale	history of psychosomatic disease or other traumatic event, intellectual disability or illiteracy, inability to understand the content of the questionnaires	Checklist for analytical cross-sectional studies
Sweeney 2020	Australia (2018)	National	websites addressing infant death, lactation and/or milk donation	HIC	Qualitative	Content analysis	NA	21 websites	NND	health information or support related to infant death, lactation and/or milk donation	NA	NA	Checklist for qualitative research

Teefey 2020	NA (review)	International literature	Literature review	NA	Qualitative	Literature review	NA	NA	Stillbirth, NND, TOPFA	Psychological implications in expectant parents after a prenatal diagnosis	NA	NA	Checklist for text and opinion papers
Thomas 2021	UK (Sept 2016-Dec 2018)	St Mary's Hospital, Wythenshawe Hospital, Manchester and Royal Preston Hospital	Validated questionnaires	HIC	Quantitative	NA	Non comparative study	112 women	Stillbirth, NND	anxiety, depression, stress, quality of life in the antenatal and perinatal period following perinatal loss	women <16 years; unable to consent; diagnosed with pregnancy complications, received treatment for an acute mental health issue in the current pregnancy	women attending antenatal care in a pregnancy after stillbirth or neonatal death	Checklist for case series studies
Tseng 2017	Taiwan/ns	teaching hospital, southern Taiwan	Questionnaires	HIC	Quantitative	NA	Longitudinal study	30 couples	Stillbirth	Post bereavement grief levels of parents	Couples <18 years old	Experienced a miscarriage or stillbirth in the previous 1 month; signed informed consent	Checklist for analytical cross-sectional studies

Tseng 2018	Taiwan (dates no reported)	2 teaching hospitals in Taiwan	Interviews	HIC	Qualitative	Thematic analysis	NA	16	Stillbirth	Meaning of rituals after stillbirth	unmarried mothers or pregnant adolescent	women who experienced stillbirth during weeks 20 to 40 of pregnancy; had participated in rituals after diagnosed with a stillbirth; and consented to participate in the study	Checklist for qualitative research
Watson 2019	Canada (2017)	Ontario, Canada	Online survey including one open-ended question	HIC	Mixed methods	Thematic analysis	Descriptive cross-sectional	596 for quantitative survey, 269 for qualitative component	Stillbirth, NND, TOPFA	How families access existing care and supports around the time of their loss and their experiences of receiving such care	Participants were excluded if they did not live in Ontario at the time of their loss	People who lived in Ontario and had a pregnancy loss at any gestation of pregnancy (i.e. the person who carried the pregnancy or their intimate partner(s)), or who had experienced the death of an infant	Checklist for qualitative research and Checklist for studies reporting prevalence data

Weng 2018	Taiwan (2001-2011)	National	Records from the Health and Welfare Data Science Centre (HWDC), Ministry of Health and Welfare, Taiwan	HIC	Quantitative	NA	Case control	485 and 350 cases of attempted and completed suicide respectively; Controls n=4850 for attempted suicide and n=3500 for completes suicide	Stillbirth, TOPFA	Risks of attempted and completed suicide in women who experienced a stillbirth, miscarriage, or termination of pregnancy within 1 year postnatally and compare this risk with that in women who experienced a live birth	Women with missing age data or with an age of < 18 or > 50 years	Women who experienced a live birth, stillbirth, miscarriage or termination of pregnancy in Taiwan from 2001 to 2011.	Checklist for case control studies
Westby 2021	Multiple (2020)	International	Literature (2 databases)	NA	Qualitative	Systematic review	NA	13 articles	Stillbirth	Depression, anxiety, PTSD, and obsessive-compulsive disorder (OCD) in parents after stillbirth	Articles were excluded if (1) the women were currently pregnant subsequent to a previous loss, (2) studies investigating elective abortions after the 20th week of gestation due to fetal anomalies,	1) peer-reviewed, quantitative, English-language articles published from 1980; (2) studies investigating depression, anxiety, PTSD, or OCD among	Checklist for systematic reviews and research syntheses

				(3) if the sample included twin births with two stillborn or if the stillborn baby had a live-born twin (4) intervention studies and case studies, articles without primary data (systematic reviews and meta-analysis), and articles that did not isolate results for SB from other forms of perinatal loss (i.e., miscarriage, neonatal death, and sudden infant death syndrome), (5) dissertations, letters, conference abstracts, and editorials	parents following stillbirth; and (3) studies defining stillbirth as equal to or after 20 weeks of gestation.	

Wonch Hill 2017	US (dates not reported)	National	National Survey of Fertility Barriers dataset	HIC	Quantitative	NA	Retrospective cross-sectional	3847 (n= 2,042 for women who had never experienced a pregnancy loss, stillbirth, or death of a child; n= 1,363 for women who had experienced miscarriage only; n= 124 for women who had experienced stillbirth but not the death of	Stillbirth, NND	Effect of miscarriage, stillbirth, and child death on maternal self-esteem	Women who placed their only children for adoptions, as well as women who had abortions and no other living children	Women aged 25–45 who had ever been pregnant and responded to survey items assessing self-esteem	Checklist for analytical cross-sectional studies

								a child; n= 72 women who had experienced the death of a child)					
Xie 2022	Multiple (2020-2021)	International	Literature (9 databases)	NA	Qualitative	Narrative synthesis	NA	37 studies	TOPFA	Psychosocial interventions for psychological distress among women undergoing termination of pregnancy for fetal anomaly	Studies with repeated publication data and conference abstracts	Randomised controlled trials (RCTs) and quasi-experimental studies which included women who decided to terminate their pregnancy because of fetal anomaly or had experienced pregnancy termination following a fetal anomaly diagnosis. Interventions included any PSI, including psychotherapy, counselling,	Checklist for systematic reviews and research syntheses

												psychoeducation, various support, or any combination of these interventions. Outcomes included depression, anxiety or PTSD as measured by a validated measurement tool or evaluated through interviews.	
Youngblut 2018	USA (dates not stated)	four referral hospitals	Secondary data from 2 separate studies	HIC	Quantitative	NA	Cross-sectional	32 mothers and 32 grandmothers of 32 deceased children	NND	Physical and mental health of mothers compared with matched grandmothers	Mothers and grandmothers were not eligible if 1) the deceased newborn was from a multiple gestation pregnancy, 2) the deceased infant/child was living in a foster home before PICU admission, 3) the deceased's injuries involved child abuse, or 4)	Mothers (> 18 years old) and grandmothers of infants and children admitted to NICU or PICU at least 1 h before their death and who spoke (but not necessarily read) English or Spanish	Checklist for analytical cross-sectional studies

a parent or sibling died because of the same event (e.g., motor vehicle crash, childbirth). Additional exclusion criteria for grandmothers were: living in an extended care or skilled nursing facility because of diminished physical and/or cognitive capacity or scoring ≤20 on the telephone Mini-Mental Status Examination

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data.

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice- versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Relevance
Abdel Razeq 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Actis Danna 2023	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	P
Arach 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	I
Asare 2020	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Yes	Yes	R
Asim 2022	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	P
Atienza-Carrasco 2020	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	R

Aydin 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P
Azeez 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Bernardes 2020	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Berry 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	U
Bond 2018	Yes	Unclear	Yes	Yes	Unclear	No	No	Unclear	Yes	Yes	R
Brierley-Jones 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Brown 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Cacciatore 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Cacciatore 2018	Unclear	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	R
Camacho Ávila 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Carlsson 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	I
Carroll 2020	Unclear	Yes	Yes	Yes	Unclear	Unclear	Yes	Not applicable	Unclear	Yes	R
Cassidy 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	P
Christou 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	I

Cole 2018	Unclear	Yes	Unclear	Unclear	Unclear	Unclear	No	Unclear	No	Yes	P
Cole 2020	Not applicable	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	P
Côté-Arsenault 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	P
Craven 2019	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	U
Das 2021 (3)	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	U
de Andrade Alvarenga 2021	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	P
Due 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	P
Farrales 2020	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	R
Fenstermacher 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	U
Fernandez-Medina 2022	Yes	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	I
Ferreira Paris 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P
Gold 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Hendriks 2022	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R

Helps 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Huberty 2017 (2)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	R
Inati 2018	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	R
Irani 2019	Unclear	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	R
Kamranpour 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Kamranpour 2020	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	P
Kamranpour 2020 (2)	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	P
Kecir 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	I
Kothari 2022	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Lafarge 2017	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Yes	Unclear	P
Lizcano Pabón 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Lockton 2020	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Lockton 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	I

Martinez-Serrano 2019	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	R
Mills 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	I
Noble-Carr 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P
Noble-Carr 2022	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
O'Connell 2019	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	R
Obst 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	R
Obst 2021 (3)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Oreg 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Osman 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Paraszczuk 2022	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Pereira 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Popoola 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	P
Popoola 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Popoola 2022 (2)	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	P

Qian 2019	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Qian 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Qin 2019	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	R
Redshaw 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Roberts 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Siassakos 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	R
Silverio 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Smith 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Steen 2019	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	No	Yes	P
Sun 2018	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	R
Sun 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Sun 2021	Yes	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	R
Sweeney 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Not applicable	Yes	Yes	R
Tseng 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P

Watson 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Relevance
Baransel 2020	Yes	Yes	Not applicable	Yes	No	No	Yes	Yes	P
Bond 2018	Yes	Unclear	Yes	Yes	No	No	Yes	Yes	R
Cacciatore 2018	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	R
Chung 2017	Yes	Yes	Yes	Yes	No	No	Yes	Yes	I
Cote-Arsenault 2019	Yes	Yes	Not applicable	Not applicable	No	No	Yes	Yes	P
Dekkers 2019	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	R
Druguet 2018	Yes	Yes	Not applicable	Not applicable	No	No	Yes	Yes	U
Druguet 2019	Yes	Yes	Yes	Yes	No	No	Yes	Yes	R
Goldstein 2020	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Yes	R

Hanschmidt 2018	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	R
Hanschmidt 2018 (3)	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	R
Hennegan 2018	Yes	Yes	Unclear	Yes	Unclear	Unclear	No	Yes	P
Huberty 2017 (2)	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	R
Jones 2021	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	P
Kalanlar 2020	No	No	No	No	No	No	No	Unclear	P
Köneş 2021	Yes	Yes	Unclear	Yes	No	Not applicable	Yes	Yes	R
Kokou-Kpolou 2018	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	P
McSpedden 2017	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	R
Obst 2021 (2)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Ravaldi 2018	Yes	Yes	Yes	Yes	No	Not applicable	Yes	Yes	R
Roberts 2021	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Yes	I
Roberts 2021 (2)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Smith 2021	Yes	Yes	Yes	Yes	No	Not applicable	Yes	Yes	I

Smorti 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Ssegujja 2021	Yes	Yes	Yes	Yes	No	No	Yes	Yes	P
Sun 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Sun 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Tseng 2017	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes	P
Wonch Hill 2017	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	U
Youngblut 2018	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimize errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Relevance
Berry 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	P
Cena 2021	Unclear	Yes	Yes	Unclear	Not applicable	Not applicable	Unclear	Yes	Unclear	Yes	Yes	P

Fernandez-Ferez 2021	Unclear	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	No	Yes	Unclear	R
Furtado-Eraso 2021	Unclear	Yes	Yes	Unclear	Not applicable	Not applicable	Unclear	Yes	Unclear	Yes	Yes	R
Heaney 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	R
Hollins Martin 2022	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Unclear	Yes	Unclear	Not applicable	Yes	R
Huberty 2017	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Not applicable	No	Yes	Yes	R
Jones 2017 (2)	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	P
Jones 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Not applicable	Yes	P
Luo 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
McNeil 2021	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	P
Musodza 2021	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Unclear	Not applicable	Not applicable	Yes	Yes	R
Nguyen 2019	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Not applicable	Not applicable	Not applicable	Yes	P
Obst 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Pachalla 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Not applicable	Yes	R

Paraíso Pueyo 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	R
Pollock 2020	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Unclear	Not applicable	Yes	I
Rocha Catania 2017	Yes	Yes	Yes	No	Unclear	Unclear	Unclear	Yes	No	Yes	Yes	R
Schoonover 2022	Unclear	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	P
Setubal 2021	Unclear	Yes	Yes	Unclear	Not applicable	Not applicable	Yes	Yes	Unclear	Yes	Not applicable	P
Shakespeare 2019	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	R
Shaohua 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Westby 2021	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	R
Xie 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Not applicable	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Relevance
Arocha 2021	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	R

Cassidy 2021	Yes	Yes	Unclear	Yes	Unclear	Unclear	No	Yes	Unclear	P
Gilmour 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	I
Güçlü 2021	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	P
Horey 2021	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	NA	R
Hvidtjorn 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Inati 2018	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Unclear	R
Jorgensen 2022	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	NA	Yes	U
Pekkola 2022	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Unclear	R
Pollock 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Ridaura 2017	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	P
Watson 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/sources logically defended?	Relevance
Acharya 2018	Yes	Unclear	Yes	Unclear	Yes	Not applicable	R
Bakhbakhi 2017	Yes	Yes	Yes	Unclear	Yes	Not applicable	R
Beggs Iii 2018	Yes	Unclear	Yes	Unclear	Yes	Not applicable	P
Boyle 2020	Yes	Yes	Yes	Yes	Yes	Not applicable	R
Boyle 2020 (2)	Yes	Yes	Yes	Unclear	Yes	Not applicable	R
Cassaday 2018	Yes	Yes	Yes	Yes	Yes	Not applicable	P
Davoudian 2021	Yes	Unclear	Yes	Yes	Yes	Not applicable	R
Dempsey 2021	Yes	Unclear	Yes	Unclear	Yes	Not applicable	I
Dickens 2020	Yes	Yes	Yes	Yes	Yes	Not applicable	R
Harden 2018	Yes	Unclear	Yes	Unclear	Yes	Not applicable	R
Kennedy 2017	Yes	Unclear	Yes	Yes	Yes	Not applicable	R

LeDuff III 2017	Yes	Yes	Yes	Unclear	Yes	Unclear	P
Lewis 2018 (4)	Yes	Unclear	Yes	Yes	Yes	Unclear	U
Lord 2022	Yes	Unclear	Yes	Unclear	Yes	Not applicable	R
Murphy 2017	Yes	Yes	Yes	Unclear	Yes	Not applicable	R
Parish 2021	Yes	Unclear	Yes	Unclear	Yes	Not applicable	R
Rich 2018 (2)	Yes	Unclear	Yes	Unclear	Yes	Not applicable	I
Rymaszewska 2019	Yes	Yes	Yes	Yes	Yes	Yes	R
Shakes 2021	Yes	Yes	Yes	Yes	Yes	Not applicable	I
Teefey 2020	Yes	Yes	Yes	Yes	Yes	Not applicable	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough	9. Was follow up complete, and if not, were the reasons to loss to follow up described	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Relevance

		unexposed groups?						for outcomes to occur?	and explored?			
Gozuyesil 2022	Not applicable	Not applicable	Unclear	No	No	Yes	Yes	Yes	Yes	Unclear	Yes	P
Huberty 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	R
Kishimoto 2021	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Not applicable	Yes	P
Leithner 2021	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No	No	Yes	P
Navidian 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	I
Navidian 2018	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Not applicable	Yes	P
Roberts 2017	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Not applicable	Yes	Not applicable	Yes	R
Rodriguez 2021	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Not Applicable	Yes	R
Sarkar 2022	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case report studies

	1. Were patient's demographic characteristics clearly described?	2. Was the patient's history clearly described and presented as a timeline?	3. Was the current clinical condition of the patient on	4. Were diagnostic tests or assessment methods and the results clearly described?	5. Was the intervention(s) or treatment procedure(s) clearly described?	6. Was the post-intervention clinical condition clearly described?	7. Were adverse events (harms) or unanticipated events identified and described?	8. Does the case report provide takeaway lessons?	Relevance

			presentation clearly described?						
Cole 2017	Yes	No	Yes	Yes	Yes	Yes	No	Yes	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Relevance
Durrmeyer 2017	Yes	Yes	Yes	Unclear	No	Yes	Yes	Yes	No	Yes	R
Gold 2018	Yes	Yes	Yes	Yes	No	Yes	Unclear	Yes	No	Yes	P
Marwah 2019	Yes	Yes	Yes	Unclear	No	Yes	Yes	Yes	Unclear	Yes	R
Sénéchal 2022	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	No	Yes	R
Thomas 2021	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case-control studies

	1. Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?	2. Were cases and controls matched appropriately?	3. Were the same criteria used for identification of cases and controls?	4. Was exposure measured in a standard, reliable and valid way?	5. Was exposure measured in the same way for cases and controls?	6. Were confounding factors identified?	7. Were strategies to deal with confounding factors stated?	8. Were outcomes assessed in a standard, valid and reliable way for cases and controls?	9. Was the exposure period of interest long enough to be meaningful?	10. Was appropriate statistical analysis used?	Relevance
Weng 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

RCT studies

	1. Was the true randomisation used for assignment of participants to treatment groups?	2. Was allocation to treatment groups concealed?	3. Were treatment groups similar at the baseline?	4. Were participants blind to treatment assignment?	5. Were those delivering treatment blind to treatment assignment?	6. Were outcome assessors blind to treatment assignment?	7. Were treatment groups treated identically other than the intervention of interest?	8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	9. Were participants analysed in the groups to which they were randomised?	10. Were outcomes measured in the same way for treatment groups?	11. Were outcomes measured in a reliable way?	12. Was appropriate statistical analysis used?	13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?	Relevance

Huberty 2020	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Sun 2018 (2)	Yes	Yes	Yes	Yes	Unclear	No	Yes	No	Yes	Yes	Yes	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

REF	RECOMMENDATION	STUDIES CONTRIBUTING	METHODOLOGICAL LIMITATIONS	RELEVANCE	COHERENCE	ADEQUACY OF DATA	GRADE-CERQUAL APPRAISAL
2.6	Acknowledge the specific care and support needs of parent(s) who have experienced a termination of pregnancy and ensure perinatal loss care planning is across the continuum of care	NA	NA	NA	NA	NA	*See Section 2: Technical report for cultural safety for evidence appraisal.*
2.7	Normalise and validate parent(s) individual experience of grief and loss. Support parents to express their concerns by confirming their feelings and having open discussions about their needs. • Be aware of potential differences in how partners and family/whānau member express grief.	NA	NA	NA	NA	NA	*See Section 2: Technical report for cultural safety for evidence appraisal.*
2.8	Acknowledge father/partner's experience of loss and their identity as a parent. Provide tailored support services for fathers/partners including both formal and informal support options and referral to parent support organisations as required.	10 studies are included. Of the included studies, 5 are systematic review. Four primary qualitative studies are included, and one mixed method study incorporating both qualitative and quantitative analysis is included.	Moderate concerns of methodological limitation are noted. Six of the included studies are deemed to have no or minor concerns of methodological limitation through critical appraisal.	Moderate concerns of relevance are noted. Five studies are deemed to have direct relevance to effective support. Four studies are partially relevant to effective support, and one study has unclear relevance.	Minor concerns of coherence are noted.	Major concerns of data adequacy are noted. Four of the included studies source their cohorts from high-income country populations, one from lower middle-income country, and one from upper middle-income country.	Low confidence *Minor concerns of coherence moderate concerns of methodological limitation and relevance. Major concerns of data adequacy.*

			Four of the included studies are deemed to have moderate concerns of methodological limitation.			Four systematic reviews did not specify the income status of cohorts included in their analysis. Outcomes included across the data include stillbirths (n=18) and composite perinatal mortality (n=123). The views of mothers (n=8), fathers (n=53), parents (n=100), health care professionals (n=2) and community members (n=3) were included through the data. Major concerns of data adequacy are noted due to small, combined sample of outcomes and viewpoints contained within the data, and limited data relevant to high-income country settings such as Australia.	
2.9	Acknowledge the grief and loss of other family members, especially grandparents and other children	NA	NA	NA	NA	NA	*See Section 2: Technical report for cultural safety for evidence appraisal.*

	(siblings), and offer appropriate support options.						
2.10	Offer parents culturally and linguistically appropriate information about perinatal grief and what to expect, to review when they are ready.	NA	NA	NA	NA	NA	*See Section 2: Technical report for cultural safety for evidence appraisal.*
2.11	Provide parents and family/whānau members with information and opportunities for social and emotional support including peer support, professional counselling and psychology services, and other bereavement support services.	NA	NA	NA	NA	NA	*See Section 2: Technical report for cultural safety for evidence appraisal.*
2.12	Establish and use referral pathways to ensure appropriate ongoing professional support for parents who may be at risk of developing mental health problems (e.g. post-traumatic stress), particularly parents who have pre-existing mental health conditions.	NA	NA	NA	NA	NA	*See Section 2: Technical report for cultural safety for evidence appraisal.*
3.20	Sensitively discuss with parents and family/whānau that burial or cremation is a legal requirement for a baby who dies at greater than 20 weeks gestation or weight of 400 g. Provide parents with: • information (including written) that includes the range of available options for burial, cremation, and funeral,	NA	NA	NA	NA	NA	Consensus-based recommendation

	and support parents/family in their decision making • contact details for relevant services • information about available financial support.						
3.21	Discuss expectations for postnatal care including lactation, vaginal bleeding, wound care, contraception, and physical activity. Provide all women with information about postnatal physical changes, postpartum care and potential complications that could occur, including when to seek medical advice and support.	5 studies are included. 4 studies are primary qualitative studies, and one is a narrative review.	Moderate concerns of methodological limitation are noted. Three of the included studies are deemed to have minor concerns of methodological limitation. Two primary qualitative studies are noted to have moderate concerns of methodological limitation through critical appraisal. Both are noted to lack a statement of researcher cultural position, or to take the impact of the researcher's cultural position into account on findings and analysis. One further lacks congruity between intended methodology and actual methodology.	Moderate concerns of relevance are noted. Three of the included studies are deemed directly relevant to effective support. One study is deemed indirectly relevant, and one study is deemed of unclear relevance to effective support.	Minor concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Three included studies sourced their cohorts from high-income country populations, two studies from lower middle-income country populations. Outcomes of interest include stillbirths (n=27), and composite perinatal mortality outcomes (n=73). The viewpoints contained within the data included are from mothers (n=26), fathers (n=14), parents (n=27) and health care professionals (n=33). Moderate concerns of data adequacy are noted due to inadequate combined cohort	Low confidence *Minor concerns of coherence. Moderate concerns of methodological limitation, relevance and data adequacy.*

						size, inadequate outcomes included, and the lack of data relevant to high-income country settings such as Australia.	
3.22	Provide information on the full scope of lactation management options to women and ask open ended and nondirective questions to understand and explore perspectives, while also considering cultural and individual variations.	12 studies are included. Of the included studies, 10 are primary qualitative research studies, one is a narrative review, and another is an author opinion.	Moderate concerns of methodological limitation are noted. Five included studies are noted to have no or minor concerns of methodological limitation. Seven primary qualitative studies are deemed to have moderate concerns of methodological limitation, all lack a statement of research cultural position, and fail to account for the researchers cultural influence on findings and analysis. Four also lack congruity between the stated philosophical perspective, and the methods and analysis performed.	Moderate concerns of relevance are noted. Four of the included studies are deemed relevant to effective support, two are deemed to be partially relevant, and one indirectly relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are reported. All included studies sourced their cohorts from high income country populations. Outcomes of interest across the data include stillbirth (n=27), and composite perinatal mortality outcomes (n=189). Viewpoints included across the primary data include that of mothers (n=124), fathers (n=7), parents (n=27) and health care professionals (n=146). Moderate concerns of data adequacy are noted due to inadequate combined cohort size and inadequate outcomes included.	**Low confidence** *No concerns of coherence, moderate concerns of methodological limitation, relevance, and data adequacy.*
3.24	Discuss the birth and death registration process with parents	NA	NA	NA	NA	NA	**Consensus-based recommendation**

	and family/whānau prior to their leaving hospital and ensure parents understand what is required of them. • Provide parents with written information about the registration process, including where, how, and when parents are required to register their baby's birth and death. • Ensure parents are aware that there is no fee to register, and they can choose to purchase a birth certificate at the time, or later.						
3.25	Ensure parents are supported as they physically leave the hospital setting. For example, a healthcare professional or other support person should be available to accompany parents from the hospital to their mode of transport.	NA	NA	NA	NA	NA	Consensus-based recommendation
3.26	Ensure parents leave hospital with contact details for 24-hour follow-up support and are provided with culturally and linguistically appropriate information about ongoing sources of support including parent support organisations.	17 studies are included. Of these, 10 are primary qualitative research, two are prevalence studies, one is cross-sectional, one is a narrative review, one is a systematic review, and one is a case series. One of	Moderate concerns of methodological limitation are noted. Ten of the included studies are note dot have no or minor concerns of methodological limitation.	Minor concerns of relevance are noted. 15 of the included studies are noted to be directly relevant to effective support. Two included studies are partially	Moderate concerns of coherence are noted due to qualitative evidence detailing barriers to effective follow-up and support in resource limited areas.	Minor concerns of data adequacy are noted. Fifteen of the included studies sourced their cohorts from high-income country populations. One study also included participants from lower middle-income	Low confidence *Minor concerns of relevance and data adequacy. Moderate concerns of coherence and methodological limitation.*

		the included studies is a mixed methods study, incorporating qualitative and cross-sectional methodology.	Seven of the included studies (four primary qualitative studies, one mixed methods, one prevalence and one case series) are note dot have moderate concerns of methodological limitation through critical appraisal.	relevant to effective support.		countries in addition to high-income countries, one from lower middle-income country and another from upper middle-income country. Outcomes of interest include stillbirths (n=94), neonatal deaths (n=100) and composite perinatal mortality outcomes (n=976). The viewpoints contained within the data included are from mothers (n=1352), fathers (n=124), parents (n=913) and health care professionals (n=729). Minor concerns of data adequacy are noted due to inadequate outcomes included.	
3.27	Ensure parents receive follow-up calls or visits, as required, from an appropriately skilled healthcare professional.	17 studies are included. 10 studies are primary qualitative studies. Two systematic reviews and one narrative review is included. Two prevalence studies are included. Two	Moderate concerns of methodological limitation are noted. Ten of the included studies are deemed to have no or minor concerns of methodological	Minor concerns of relevance are noted. 12 included studies are deemed directly relevant to effective support. Four studies are deemed to be partially relevant, and one	Minor concerns of coherence are noted.	Minor concerns of data adequacy are reported. Of the included studies, 16 sourced their cohorts from high income country populations. One study also included participants from	Moderate confidence *Minor concerns of relevance, coherence and data adequacy. Moderate concerns of methodological limitation.*

		mixed method studies are included incorporating both qualitative and quantitative analysis, one is a cross-sectional and another is a prevalence study.	limitation through critical appraisal. Six included studies (four primary qualitative research, one prevalence, and one mixed methods study) are deemed to have moderate concerns of methodological limitation through critical appraisal. One included primary qualitative research study is deemed to have major concerns of methodological limitation through critical appraisal. The study is noted to lack congruity between the stated research methodology and philosophical perspective, and analysis. Participants voices are inadequately heard, and no statement of ethical approval is provided. Cultural position of researcher is also missing, along with accounting for the impact of the position on analysis and findings.	study is deemed to be of unclear relevance to effective support.		middle-income countries in addition to high-income countries, and another from lower middle-income countries. Outcomes of interest include stillbirths (n=3162), neonatal deaths (n=3) and composite perinatal mortality outcomes (n=127). The viewpoints contained within the data included are from mothers (n=3254), fathers (n=50), and parents (n=72). Minor concerns of data adequacy are noted due to inadequate outcomes included.	
3.28	Ask parents about their social and emotional wellbeing at all postnatal care appointments and appropriately refer to support services where needed.	34 studies are included. Of the included studies, 8 are cross-sectional studies,	Minor concerns of methodological limitation are noted.	Moderate concerns of relevance are noted.	No concerns of coherence are noted.	Minor concerns of data adequacy are noted.	**Moderate confidence** *No or minor concerns of methodological*

	Ensure sufficient time is available in all follow-up appointments with bereaved parents to enquire about their social and emotional wellbeing. Provide information about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow-up, including family planning if desired. See Section 5: Care in subsequent pregnancies	seven are primary qualitative research, five are systematic reviews, three are narrative reviews, four are cohort studies, three are prevalence studies and one is a case series. Three mixed methods studies incorporating qualitative and quantitative analysis, one cross-sectional study and two prevalence studies are included.	23 of the included studies are noted to have no or minor conerns of methodological limitation through critical appraisal. 12 of the included studies are noted to have moderate concerns of methodological limitation through critical appraisal.	18 of the included studies are deemed directly relevant to effective support. 14 are deemed to have partial relevance to effective support, one with indirect relevance, and two with unclear relevance.		19 of the included studies source their cohorts from high income countries. Five studies source their cohorts from lower middle-income countries, four from upper middle-income countries, and one from low-income country. Five reviews did not specify the income status of cohorts included in their analysis. Outcomes included across the data include stillbirth (n=1701), neonatal deaths (n=3), termination of pregnancy for fetal anomaly (n=428) and composite perinatal mortality outcomes (n=1195). Viewpoints expressed through the data are mothers' views (n=2353), fathers' views (n=34), parents' views (n=1755), and the views of grandmothers (n=14) and grandfathers (n=10). Minor concerns of data adequacy are noted due to the small, combined number of	*limitation, coherence and data adequacy. Moderate concerns of relevance.*

						outcomes included across studies.	

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 3: Perinatal loss care: communication between healthcare professionals

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Continuity of care comprises of seamless and personalised provision of quality care to families by an individual or team of healthcare professionals, which is maintained throughout their bereavement care journey, from the time the family engages with the health service through to follow-up care and support.[1] Provision of appropriate bereavement support, care interventions and follow-up care are critical and fundamental for enabling continuity of care for bereaved families.[2] Poor communication between specialised and primary healthcare teams can cause a lack of continuity of care.[3] Lack of a single point of contact is commonly reported by parents and adds to frustration and feelings of distress.[1] Organisations can facilitate and aid communication between healthcare professionals to prevent additional distress for families. One way to facilitate this communication is by providing universal markers or symbols for medical charts and parent room doors to communicate the loss across clinical and non-clinical teams to make everyone aware of the loss and prevent inappropriate communication, comments, and disturbance.[4,5] Coordination of care planning is also critical to fostering good communication within and between teams, and with parents. An integrated system of care increases quality and safety and contributes to patient satisfaction.[5]

Methodology

The Guideline Development Committee developed key research questions around best practice communication between healthcare professionals in the provision of perinatal loss care (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	How do you ensure healthcare professionals are appropriately resourced to provide the best possible care to bereaved parents and families?
2	How does an organisation ensure continuity of experienced carer and continuity of care planning during the perinatal loss experience?
3	Does use of a universal symbol or other identifier (in clinical charts, physical spaces) of a perinatal loss care plan improve outcomes and satisfaction with care for parents and families?
4	What are the responsibilities for sharing information with other healthcare professionals to ensure appropriate handover to community-based care and support?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 1. PICO criteria

PICO	Inclusion criteria
Population	Defined in Australia and Aotearoa New Zealand as: • Stillbirth ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR

	where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[2,11] • Neonatal death ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[2,11] • Inclusion of perinatal deaths following termination of pregnancy Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).
Intervention	Studies exploring perinatal loss care following stillbirth or neonatal death in maternal or newborn services.
Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes and experiences of parents, family members, healthcare professionals around communication between healthcare professionals in the provision of perinatal loss care to parents and families following termination of pregnancy, stillbirth, or neonatal death. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Search strategies were conducted on 11 July 2022. A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and were restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection

- PubMed
- Scopus

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- wrong *language*: The study was not published in English.
- wrong *publication dates*: The study was published prior to 2017.
- wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior

to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual [8]. The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[9]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[10]
- Adequacy: The richness and quantity of data supporting the findings[11]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[12]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence supporting the synthesis findings was formulated following this review, and details of any concerns were identified and listed.[13] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: How do you ensure healthcare professionals are appropriately resourced to provide the best possible care to bereaved parents and families?

Experienced staff should always be available to provide immediate support and counselling to bereaved families, allowing parents and families the opportunity to understand and process information at and around the time of a pregnancy loss.[1] Having a healthcare team member who can compassionately deliver a terminal prognosis may help alleviate the feelings of abandonment and negativity often experienced by parents.[2] Parents have indicated a need for proactive professionals who engender trust, provide accurate information, are prepared for appointments, and avoid medical jargon and patronising language.[14] Healthcare professionals can make a significant difference to families' experience of end-of-life care by facilitating psychosocial, emotional, and spiritual supports, in addition to medical care.[15,16] These actions of healthcare professionals help parents feel valued and respected.[14]

To elevate the standard of care for patients, support must be given to their healthcare professionals. A plan should be in place for healthcare professionals working with bereaved families that provides near immediate access to a chaplain, social worker, palliative care team member, ethics committee member, or employee assistance counsellor.[4,5]

In the medical profession, the expression of emotions in distressing situations is often perceived as unprofessional, which results in many medical doctors learning to suppress and ignore their feelings [17]. In one study conducted in China, the majority (85%) of nurses and midwives had not received training in perinatal bereavement care.[18] Nurses may find it extremely difficult to meet the needs of the bereaved family while caring for another family who is celebrating a new life. Nurses may not be able to 'flip their emotional switches'. At times, nursing leadership may need to be reminded of the complexity involved in caring for families who have lost a baby.[19]

In a qualitative study of Australian early career midwives' clinical encounters with perinatal loss, midwives noted that while type and degree of support was a contributing factor to how effective they were when providing care to families experiencing perinatal loss, support was not always consistently available. Those who received support considered themselves to be 'fortunate' or 'lucky'. Formal supports provided by management and institutional processes were regarded by most as hard to access. While participants desired interactions with managers, these were reported to be largely absent [20]. Supports desired by early career midwives included working with an experienced and kind midwife during initial encounters with perinatal loss, having empathetic midwifery colleagues who provide guidance and practical support, access to timely debriefing, adequate staffing and skill mix, and receiving recognition from management.[20] Organisational support in the form of education, formalised debriefing and mentoring, institutional philosophies which promote collegial ethics of care, and the expansion of continuity of midwifery care models could improve new midwives' experiences.[20]

In a mixed methods American study evaluating formal bereavement debriefing programs for NICU staff following infant death, Hawes et al[21] found that healthcare professionals' ability to manage grief improved when attending routine debriefing sessions. Additionally, it was found that healthcare professionals benefit from expressing their feelings of grief and other emotional responses following the loss of a patient. Overall, formal bereavement debriefing sessions may reduce the emotional

impact for healthcare professionals and help them feel better prepared to provide care to future patients.

There are potentially moral and ethical decisions imposed on the sonographer about communicating results to a pregnant patient which are different to that of any other type of scan. Sonographers communicate to patients with no prior knowledge of their disposition or history, and yet they are the starting point of the grieving process for patients upon hearing the adverse outcome.

In a study conducted with sonographers working in a tertiary referral public hospital,[22] sonographers believed that there is ambiguity among all stakeholders (radiologists, sonologists, referrers, and patients) on the role of a sonographer in communicating with a pregnant patient. This was frustrating and stressful for sonographers, as they felt vulnerable and poorly recognised for the important role they play in not only diagnosing the patient's condition, but also being the frontline practitioner in communicating findings to the patient. There were differing opinions on what sonographers thought should be part of their role. Some sonographers expected the radiologist/ sonologist to "step up" and impart the results if there was bad news, while others believed it was "their call" and "judgement" and part of a sonographer's role. Further, sonographers felt that working in a multidisciplinary team with geneticists and having access to midwives and counsellors made for a more supportive environment and helped to reduce their stress levels. Practice sites that achieved the best results were those that had the greatest direct collaboration between the sonographer and the sonologist, which was demonstrated in obstetrician-sonologist-run practices.[22]

Question 2: How does an organisation ensure continuity of experienced carer and continuity of care planning during the perinatal loss experience?

Continuity of care and carer is vitally important to parents[23] and is an essential part of bereavement care.[1] Continuity of care entails provision of quality care to families by an individual healthcare professional or a team, which is maintained during the entire time the family engages with the health service.[1] With good continuity of care, the transition for bereaved families from diagnosis through the hospital stay to discharge and follow-up should be seamless, allowing them to focus on their baby, their bereavement, and their family's wellbeing.[1]

Unfortunately, however the lack of a single point of contact for parents appears to be common. It can be difficult for families to direct their questions at the appropriate personnel when they do not know who to contact or approach,.[1] In a scoping review of parents' perspectives on children's unmet palliative care needs, parents described communication and organisation between healthcare professionals often to be poor, particularly in emergency situations, mentioning understaffing and poorly resourced and poorly coordinated services. This included issues around communication and interpersonal skills, including having to retell their story.[14] Poor communication between specialised and primary care can cause a lack of continuity of care, including follow-up care.[3,23,24] Parents also report that they feel services are 'not joint up' due to the lack of communication between the various services they used, and even within services due to a lack of communication and coordination among staff.[14]

In a study aimed at developing global consensus on core principles of bereavement care after stillbirth,[23] one of the eight key principles refers to the importance of "including a point of contact for ongoing support". The NICE Guidelines for Infants, Children and Young People in their quality standards for end-of-life care mention that a named medical specialist should be made available to each family who leads and coordinates their care.[25]

The role of clinical midwife specialists in bereavement can provide a single point-of-contact for the bereaved families.[1] Parents have expressed the need for key workers and nurse-led care coordinators to provide proactive care coordination, cohesion, and continuity of care for families.[14] Therefore, organisations can ensure continuity of care planning by training and allocating specific roles to care coordination.[21]

Question 3: Does use of a universal symbol or other identifier (in clinical charts, physical spaces) of a perinatal loss care plan improve outcomes and satisfaction with care for parents and families?

Parents highly value healthcare professionals' acknowledgement of their baby, their parenthood, and their grief.[26] Further, systemic acknowledgement in the form of structural policies and procedures relating to access to support, and attention to environmental factors within healthcare settings also impacts parents' coping both in the immediate period after loss and in the long-term.[26] In a qualitative study conducted with bereaved parents, parents reported a number of environmental factors that negatively impacted on their grief experience.[26] These included sounds of babies crying, pictures on walls with images of live babies, and interactions with hospital staff who assumed that parents had a live baby. Conversely, parents highly valued when hospital staff made efforts to create a compassionate environment by soundproofing grieving parents' rooms, using respectful signage on doors to indicate a baby has died, and removal of posters with newborn photos, as described by a parent below:

> **"The hospital I was at also had signs on the door with a teddy bear and a tear. I don't know if all hospitals have that. But, that helped. The people taking blood and bring [ing] the food, you know, to be sensitive and I think that probably helped prevent a lot of situations. So that helped."[26]**

A recognisable marker that designates pregnancy loss may be used on the doors, stretcher, bed, medical record, or any other item deemed appropriate and accepted by parents.[4] All healthcare personnel including both clinical and non-clinical staff (e.g. medicine, nursing, social work, chaplaincy, pathology laboratory, ultrasonography, radiology, patient transport) should be taught to recognise this marker and provide sensitive care in response.[4] From the housekeeper to the pharmacist dispensing medications, expressing condolences for a pregnancy loss is an important comfort measure.[4,5]

Question 4: What are the responsibilities for sharing information with other healthcare professionals to ensure appropriate handover to community-based care and support?

Clear care pathways are required at the interface between primary and secondary care.[3,23] When this doesn't happen, it can cause a lack of continuity of care.[3] This can lead to parents feeling left out and abandoned, as described by one parent below:

> **"There's the hospital support and then there's the long-term support, how to survive in the community … once you leave that hospital you drop off the radar … how do we come up with solutions for these affected bereaved parents?".[26]**

Linking with primary care, including postnatal home visits facilitates implementation of good bereavement care for families.[23]

Clear, easily understandable and structured information given sensitively at appropriate times, helps parents through their experience.[27] In an Australian study conducted with healthcare professionals regarding factors that shape the delivery of hospital-based lactation care for bereaved mothers, healthcare professionals explained bereaved mothers would rarely receive any lactation information, advice, or support from them that extended beyond the hospital setting. The exceptions to this were mothers who were eligible to receive home visits from a hospital midwife (due to the model of pregnancy or birthing care they were enrolled in) or those who had been referred to the human milk bank. Social workers or pastoral care workers appeared to have the most flexibility in extending care beyond hospital settings. Healthcare professionals assumed that mothers requiring further lactation support would most likely consult their general practitioner (GP).[28]

In most cases, GPs provide health care to the woman after discharge. Therefore, it is important that discharge protocols are in place to ensure prompt communication with the woman's GP or other primary care provider to advise of the baby's death and recommendations for follow-up care and support.[29,30] When the death occurs in the emergency department, the healthcare team needs to identify and notify the obstetric provider (if one exists) of the death or impending death of the baby. This is important for follow-up obstetric care and to avoid having the woman continuing to receive communications from the provider regarding prenatal screening tests and pregnancy classes when she is no longer pregnant.[4]

In Spain, healthcare centres have the Connect 72 program to facilitate follow-up communication between healthcare professionals and parents.[3] In this program, physicians and nurses automatically receive an alert for a telephone consultation within 72 hours after a patient is discharged. Although the system does not directly notify primary healthcare midwives, some cases are further referred onto them.[3] Thus, protocols, policies, and systems are needed to facilitate care continuity through the improvement of communication between specialised and primary healthcare.

Grey literature and other sources

In addition to the published academic literature, both international and national government agency and parent support organisation (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to best practice to enable appropriate communication between healthcare professionals at the time of stillbirth or neonatal death. A targeted Google search was also conducted using a combination of the following keywords: communication between healthcare professionals following stillbirth; communication between healthcare professionals following neonatal death; communication between healthcare professionals following perinatal death; communication between healthcare providers following perinatal death; communication between healthcare teams following perinatal death; handover from hospital to community following perinatal death. The findings of the grey literature are supported by both the current and previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline.*

For care during labour and birth, particularly when parents arrive for a scheduled induction, labour ward staff should be available to welcome parents without seeking an explanation for why they are there. All healthcare staff should ensure that they have read the woman's medical records and birth plan (if one has been developed). Additionally, healthcare staff that are working but are not assigned to the birth should be informed about the baby's death or expected death, which will help to prevent inappropriate comments being made. Patient boards/medical records should also be marked with an identifier or something similar to identify that a woman is in labour whose baby has died or is expected to die.[31] All staff, including administrative staff, cleaning staff, and support staff, should be familiar with this identifier. This will help to reduce the level of noise, chatter, and laughter from nearby rooms and corridors.[32]

After seeking parental consent, hospital staff should promptly inform all key and primary healthcare staff (e.g. GP or community midwife) of the loss so existing appointments and appointment reminders (e.g. antenatal and immunisation) can be cancelled.[32,33] This also ensures continuity of follow-up care.[31,33] Additionally, hospital staff are encouraged to discuss with parents the benefits and importance of receiving support from the woman's primary healthcare team, while also providing referrals and advice on where additional support and care can be received.[32] According to the Australian Commission on Safety and Quality in Healthcare's *Stillbirth Clinical Care Standard* (2022)[31], referrals may need to be made to:

- parent support organisations and programs (and other community supports)
- a counsellor or qualified social worker with expertise or experience in perinatal bereavement care
- a psychologist or psychiatrist, especially if the women is assessed as having pre-existing mental health risk factors.

Where multidisciplinary care is being provided, effective communication between all key and primary healthcare staff is essential.[34-39] All members of the team have a responsibility to share relevant information with other team members and document discussions with parents, as well as the decisions made. This will ensure that everyone involved in caring for the parents and family is aware of their preferences, wishes, and decisions, and are kept up to date with accurate and current information.[32] If there is a transfer between teams, units, or services, all medical records (including specific decisions, requests, and details of investigations and test results) should also be immediately

transferred.[40] It is also equally as important to facilitate a clear and consistent handover of care to the community.[40] Where possible, a dedicated bereavement lead/team should be assigned to families while in hospital who can offer consistent support and guidance in hospital and remain a point of contact for parents after leaving hospital.[41]

Upon discharge, a letter/discharge summary outlining the nature of the loss, treatment, and ongoing care needs should be made available to the woman's GP and other primary healthcare staff.[31,33] Information about the death of a baby should also be passed on to Centrelink so parents do not have to publicly explain why their baby has died.[42]

Continuity of care in transition from hospital to home is one area that is currently lacking in perinatal bereavement care. To address this gap, the Australian Government Department of Health and Aged Care has recently funded the Hospital to Home Program delivered by Red Nose, which aims to improve the transition from hospital to community for bereaved parents. The is achieved through a bereavement outreach worker providing individualised practical and emotional support, as well as tailored peer support for up to three months after parents leave hospital. A program evaluation by Boyle and Dean[43] has shown promising results, with parents placing high value on the continuity of care they received throughout the program.

According to the Australian Commission on Safety and Quality in Health Care's *Stillbirth Clinical Care Standard* (2022), healthcare services should ensure that systems are in place to enable appropriate communication between healthcare professionals involved the woman's care.[31] Refer to *Section 8: Organisational recommendations* for further information and best practice recommendations.

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies		GRADE-CERQual Overall Confidence Rating of evidence	Guideline recommendations
Catlin 2018 Constantinou 2019 Gilmour 2017 Kalanlar 2020 Actis Danna 2023	Alaradi 2021 Bakari 2021 Boyle 2022 Fenstermacher 2019 Rent 2022	Low Confidence *Minor concerns of coherence and data adequacy. Moderate concerns of methodological limitation and relevance.*	**Consensus-based recommendation 2.1:** A multidisciplinary team should oversee care across the continuum from diagnosis through birth and death planning to transition from hospital to community. The team should: • provide continuity of care and carer • hold regular meetings with parents and family/whānau • ensure medical records include a care plan (e.g. a perinatal palliative care plan) that has been developed with the parents and the plan is accessible to all team members, parents and family/whānau • consider supports that may be required to meet the cultural, religious, and/or spiritual needs of parents and family/whānau • engage other relevant healthcare workers and interpreters, where needed. **This recommendation is cross-cutting across several technical reports. For additional evidence synthesis, see Section 2: Cultural safety and Section 4: Perinatal palliative care.*
Berry 2021 Constantinou 2019 Farrales 2020	Hawes 2022 Helps 2020 Shakespeare 2020	Low Confidence	**Consensus-based recommendation 2.2:** To ensure continuity of carer, designate a lead contact person with

Fernández-Basanta 2021	No concerns of coherence, minor concerns of data adequacy. Moderate concerns of methodological limitation and relevance.	training in perinatal loss care, ideally a bereavement midwife or Lead Maternity Carer in Aotearoa New Zealand, to be a known point of contact for parents, family/whānau and other members of the care team (including hospital volunteers). *This recommendation is cross-cutting *across several technical reports. For additional evidence synthesis, see Section 4: Perinatal palliative care and Section 8: Organisational recommendations.*
Wool & Catlin 2019 Catlin 2018 Farrales 2020	Low Confidence *No concerns of coherence, minor concerns of relevance and data adequacy, and moderate concerns of methodological limitation.*	Consensus-based recommendation 2.3: Use an identifier in medical records to show there is a perinatal loss care plan in place outlining parents' values, preferences, and wishes for care and support. • Ensure care plans are accessible to all members of the multidisciplinary team and available to parents and family/whānau.
Catlin 2018 Farrales 2020 Fernández- Alcántara2020 Noble-Carr 2021 Serafim 2021	Low Confidence *No or minor concerns of study relevance, and coherence. Moderate concerns were noted for methodological limitation and data adequacy.*	Consensus-based recommendation 3.23: Discuss with parents prior to hospital discharge, their preferences for advising relevant healthcare professionals involved in their care (e.g. general practitioner [GP], other community-based services) of the baby's death or impending death so that existing appointments are cancelled, and other types of appropriate follow-up are activated. • Document processes and decisions to ensure handover is contemporaneous and accurate.

Table 4. Search strategy

Database		Search strategy
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/
	2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.
	5	1 or 2 or 3 or 4
	6	(exp transcultural care/ or exp indigenous health care/ or exp health care personnel/ or exp obstetrics/ or gyneacology/ or exp neonatology/ or newborn intensive care/ or *palliative therapy/) and (*personnel management/ or exp health care planning/)
	7	(("health care" or healthcare* or (health adj3 care) or bereavement or "health service" or practition* or professional* or nurs* or doctor* or physician* or midwi* or therapist* or obstetric* or gynecolog* or neonatolog* or paediatric* or "social work*" or "intensive care" or interdisciplin* or carer or "cross discipline" or "cross-discipline" or community or "care management" or outpatient or GP or "general practitioner" or "counsel*") adj8 (integrate* or interact* or relation or communicat* or collaborat* or coordinat* or considerat* or continuity or "continuous care" or rotat* or roster* or staff or staffing or "shared decision" or "staff manage*" or cooperat* or "hand-over" or "hand over" or handover or refer or referral* or resource* or readiness) or "continuity of care" or "continuity of carer*").ti,ab
	8	((chart or symbol* or sticker* or alert*) adj4 (loss or stillb* or death* or palliative)).ti,ab.
	9	6 OR 7 OR 8
	10	5 AND 9
CINAHL	S18	S5 AND S17
	S17	(S14 OR S15 OR S16)
	S16	AB ((chart or symbol* or sticker* or alert*) N4 (loss or stillb* or death* or palliative))

S15	AB (("health care" or healthcare* or (health N3 care) or bereavement or "health service" or practition* or professional* or nurs* or doctor* or physician* or midwi* or therapist* or obstetric* or gynecolog* or neonatolog* or paediatric* or "social work*" or "intensive care" or interdisciplin* or carer or "cross discipline" or "cross-discipline" or community or "care management" or outpatient or GP or "general practitioner" or "counsel*") N8 (integrate* or interact* or relation or communicat* or collaborat* or coordinat* or considerat* or continuity or "continuous care" or rotat* or roster* or staff or staffing or "shared decision" or "staff manage*" or cooperat* or "hand-over" or "hand over" or handover or refer or referral* or resource* or readiness) or "continuity of care" or "continuity of carer*")
S14	S12 AND S13
S13	(S6 OR S7 OR S8 OR S9 OR S10 OR S11)
S12	(MM "Personnel Management") OR (MM "Personnel Staffing and Scheduling") OR (MM "Personnel Shortage") OR (MM "Quality Management, Organizational")
S11	(MM "Palliative Care")
S10	(MM "Neonatology")
S9	(MM "Gynecology")
S8	(MM "Obstetrics")
S7	(MM "Multidisciplinary Care Team") OR (MM "Health Care Costs") OR (MM "Health Personnel")
S6	(MM "Intensive Care, Neonatal") OR (MM "Neonatal Intensive Care Nursing")
S5	(S1 OR S2 OR S3 OR S4)
S4	AB (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort))
S3	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")

Scopus	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)) OR (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)) OR (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*) AND ((("health care" or healthcare* or (health W/3 care) or bereavement or "health service" or practition* or professional* or nurs* or doctor* or physician* or midwi* or therapist* or obstetric* or gynecolog* or neonatolog* or paediatric* or "social work*" or "intensive care" or interdisciplin* or carer or "cross discipline" or "cross-discipline" or community or "care management" or outpatient or GP or "general practitioner" or "counsel*") W/8 (integrate* or interact* or relation or communicat* or collaborat* or coordinat* or considerat* or continuity or "continuous care" or rotat* or roster* or staff or staffing or "shared decision" or "staff manage*" or cooperat* or "hand-over" or "hand over" or handover or refer or referral* or resource* or readiness) or "continuity of care" or "continuity of carer*")) OR ((chart or symbol* or sticker* or alert*) W/4 (loss or stillb* or death* or palliative))
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Death] explode all trees #3 MeSH descriptor: [Perinatal Mortality] this term only #4 MeSH descriptor: [Abortion, Induced] this term only #5 ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mortalit*)) #6 (((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) ADJ1 loss*) OR stillb*))):ti,ab,kw #7 #1 OR #2 OR #3 OR #4 OR #5 OR #6 #8 MeSH descriptor: [Transcultural Nursing] explode all trees #9 MeSH descriptor: [Health Services, Indigenous] explode all trees #10 MeSH descriptor: [Health Personnel] this term only #11 MeSH descriptor: [Obstetrics] this term only

	#12	MeSH descriptor: [Gynecology] this term only
	#13	MeSH descriptor: [Neonatology] explode all trees
	#14	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
	#15	MeSH descriptor: [Palliative Care] this term only
	#16	MeSH descriptor: [Health Planning Support] explode all trees
	#17	MeSH descriptor: [Personnel Management] this term only
	#18	MeSH descriptor: [Health Planning Guidelines] explode all trees
	#19	#8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15
	#20	#16 OR #17 OR #18
	#21	#19 AND #20
	#22	((("health care" or healthcare* or (health NEAR/3 care) or bereavement or "health service" or practition* or professional* or nurs* or doctor* or physician* or midwi* or therapist* or obstetric* or gynecolog* or neonatolog* or paediatric* or "social work*" or "intensive care" or interdisciplin* or carer or "cross discipline" or "cross-discipline" or community or "care management" or outpatient or GP or "general practitioner" or "counsel*") NEAR/8 (integrate* or interact* or relation or communicat* or collaborat* or coordinat* or considerat* or continuity or "continuous care" or rotat* or roster* or staff or staffing or "shared decision" or "staff manage*" or cooperat* or "hand-over" or "hand over" or handover or refer or referral* or resource* or readiness) or "continuity of care" or "continuity of carer*")):ab
	#23	(((chart or symbol* or sticker* or alert*) NEAR/4 (loss or stillb* or death* or palliative))):ab
	#24	#21 OR #22 OR #23
	#25	#24 AND #7
Pubmed	1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]
	2	"Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract]
	3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])
	4	(("fetal malformation"[Title/Abstract] OR "congenital abnormality"[Title/Abstract] OR "fetal anomaly"[Title/Abstract] OR "congenital anomaly"[Title/Abstract] OR "fetal anomalies"[Title/Abstract] OR "congenital anomalies"[Title/Abstract] OR "prenatal diagnosis"[Title/Abstract]) AND (terminat*[Title/Abstract] OR abortion[Title/Abstract] OR abort[Title/Abstract]))

	5	#1 OR #2 OR #3 OR #4
	6	(((((("Transcultural Nursing"[Mesh]) OR "Health Services, Indigenous"[Mesh]) OR "Health Personnel"[Mesh]) OR "Obstetrics"[Mesh]) OR "Gynecology"[Mesh]) OR "Neonatology"[Mesh]) OR "Intensive Care, Neonatal"[Mesh]) OR "Palliative Care"[Mesh]
	7	("Health Care Rationing"[Mesh] OR "Advance Care Planning"[Mesh]) OR "Personnel Management"[Mesh]
	8	#6 AND #7
	9	("health care"[Title/Abstract] OR healthcare*[Title/Abstract] OR bereavement[Title/Abstract] OR "health service"[Title/Abstract] OR practition*[Title/Abstract] OR professional*[Title/Abstract] OR nurs*[Title/Abstract] OR doctor*[Title/Abstract] OR physician*[Title/Abstract] OR midwi*[Title/Abstract] OR therapist*[Title/Abstract] OR obstetric*[Title/Abstract] OR gynecolog*[Title/Abstract] OR neonatolog*[Title/Abstract] OR paediatric*[Title/Abstract] OR "social work*"[Title/Abstract] OR "intensive care"[Title/Abstract] OR interdisciplin*[Title/Abstract] OR carer[Title/Abstract] OR "cross discipline"[Title/Abstract] OR "cross-discipline"[Title/Abstract] OR community[Title/Abstract] OR "care management"[Title/Abstract] OR outpatient[Title/Abstract] OR GP[Title/Abstract] OR "general practitioner"[Title/Abstract] OR "counsel*"[Title/Abstract] "counsel*")
	10	(integrate*[Title/Abstract] OR interact*[Title/Abstract] OR relation[Title/Abstract] OR communicat*[Title/Abstract] OR collaborat*[Title/Abstract] OR coordinat*[Title/Abstract] OR considerat*[Title/Abstract] OR continuity[Title/Abstract] OR "continuous care"[Title/Abstract] OR rotat*[Title/Abstract] OR roster*[Title/Abstract] OR staff[Title/Abstract] OR staffing[Title/Abstract] OR "shared decision"[Title/Abstract] OR "staff manage*"[Title/Abstract] OR cooperat*[Title/Abstract] OR "hand-over"[Title/Abstract] OR "hand over"[Title/Abstract] OR handover[Title/Abstract] OR refer[Title/Abstract] OR referral*[Title/Abstract] OR resource*[Title/Abstract] OR readiness[Title/Abstract] OR "continuity of care"[Title/Abstract] OR "continuity of carer*"[Title/Abstract] OR "continuity of carer*")
	11	#9 AND #10
	12	(chart[Title/Abstract] OR symbol*[Title/Abstract] OR sticker*[Title/Abstract] OR alert*[Title/Abstract])
	13	(loss[Title/Abstract] OR stillb*[Title/Abstract] OR death*[Title/Abstract] OR palliative[Title/Abstract])
	14	#12 AND #13
	15	#8 OR #11 OR #14
	16	#15 AND #5
Australiana Indigenous HealthInfoNet	Stillbirth OR “baby death” or “neonatal death”	
Informit Indigenous Collection	Stillb* OR “neonatal death”	

Figure 1. PRISMA flow diagram of screening evidence

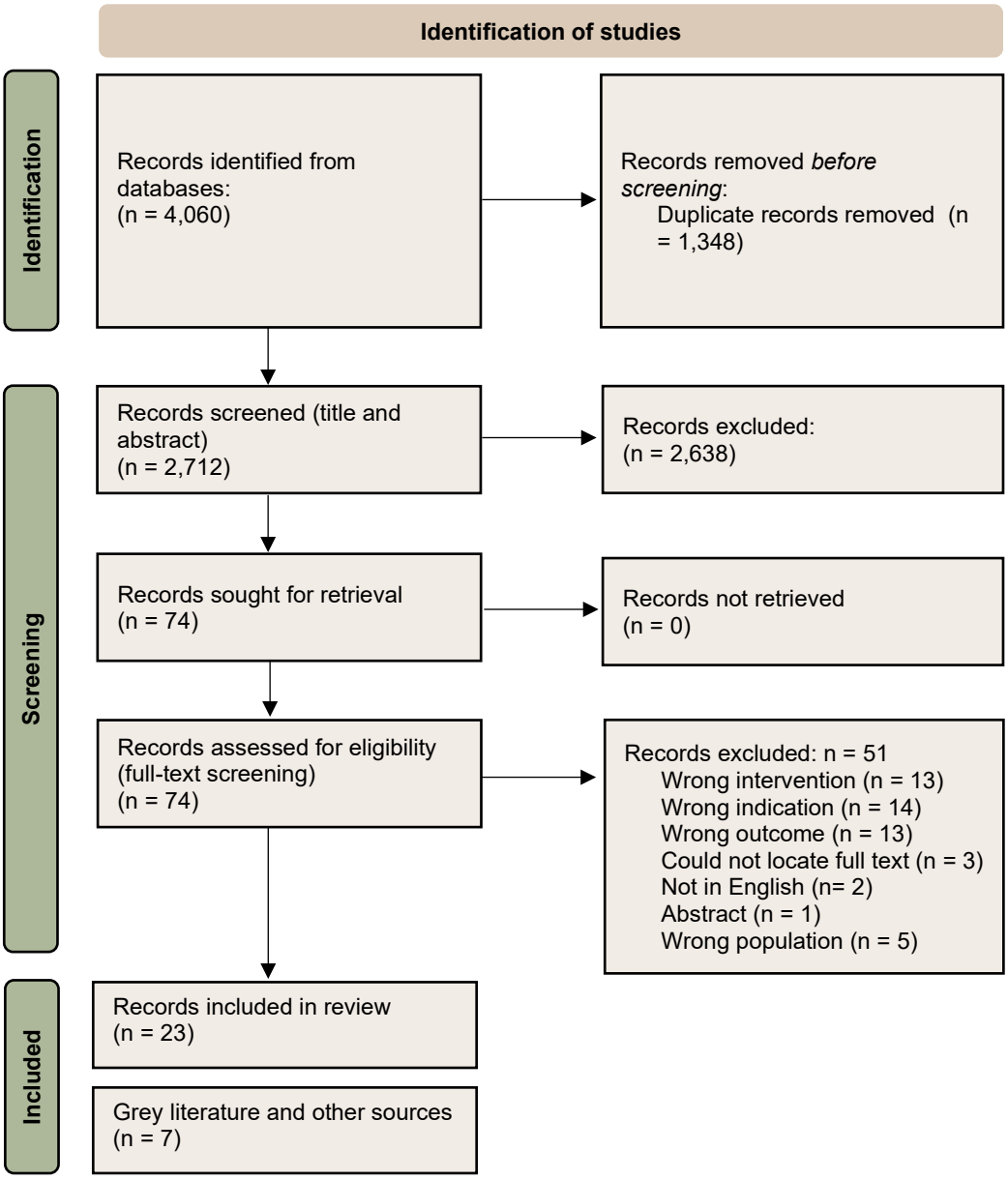


Table 5. Study characteristics

Study	Country (period)	Locality (state/ national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Actis Danna 2023	Malawi, Tanzanie and Zambia	Women who had given birth at tertiary referral hospitals in Tanzania, Malawi and Zambia	Semi-structured interviews	Low income	Qualitative	Grounded Theory (Symbolic Interactionism)	NA	33 women	Stillbirth (within the preceding 12 months)	The purpose of this study was to understand how and when women became aware of the death of their babies	Women <18 years of age	Women who had experienced a stillbirth in the preceding 12 months and had the capacity to consent	Checklist for qualitative research
Alaradi 2021	USA (June 2017-Aug 2019)	Two large mosques in Louisville, KY	Questionnaire	HIC	Quantitative	NA	Cross-sectional study	79	Miscarriage (n=12), Stillbirth (n=4), NND (n=5)	Arab Muslims' perception of perinatal loss care in the USA	None mentioned	Arab Muslims over 18 years of age. Not a requirement to have had experienced perinatal loss	Checklist for analytical cross-sectional studies
Berry 2021 (2)	Multiple (2019-2020)	Western cultural countries (US, UK, Australia)	Literature	HIC	Qualitative	Systematic review	NA	5	Stillbirth, NND, TOPFA	Parents' experiences of perinatal loss in a Western cultural context	Non-Western cultures, twin pregnancies	Peer-reviewed articles published in English within the last 10 years,	Checklist for systematic reviews and research syntheses

Boyle 2022	Australia (April 2020)	National	Online survey	HIC	Qualitative	Content analysis	NA	35	Stillbirth, NND, TOPFA	Healthcare professional views of the impact of COVID-19 on provision of respectful care to parents and resulting practice changes	None specified	Healthcare professionals who provided perinatal bereavement care in clinical settings or through support organisations in Australia	Checklist for qualitative research
Catlin 2018	USA (2016)	Texas	Interdisciplinary summit / Delphi study	HIC	Qualitative	Narrative	NA	32	Stillbirth	The needs of women who present with actual or potential pregnancy loss to the emergency department	NA	NA	Checklist for text and opinion papers
Constantinou 2019	Multiple (2019)	International literature	Literature (4 databases)	NA	Qualitative	Scoping review	NA	55 papers	Children with life-limiting condition	Unmet needs of children with life-limiting conditions and their families, from the perspective of parents	Non-English, not primary research, and stillbirth or unexplained death	papers from the perspective of parents of children aged 0–19 years, who have a life-limiting condition and are receiving palliative care.	Checklist for systematic reviews and research syntheses
Farrales 2020	USA (date not stated)	Unclear	Focus groups	HIC	Qualitative	Thematic analysis	NA	27	Stillbirth	Experiences of grieving parents during their interaction with healthcare professionals during/after the stillbirth of a baby	None mentioned	Participants were recruited from a cohort of bereaved parents who participated in a two-day workshop on the topic of grief after stillbirth. 19 years of age or older. Consent obtained.	Checklist for qualitative research

Fenstermacher 2019	USA (dates not reported)	3 inner city hospitals in Pennsylvania	Interviews at 3 time points	HIC	Qualitative	Constant comparative analysis	NA	8	Stillbirth, NND	Bereavement support needs of black urban women in late adolescence after perinatal loss	None mentioned	non-Hispanic, unmarried, English speaking black urban women ranging in age from 18 to 21 years (late adolescence) with a recent perinatal loss, with no prolonged hospital stay after their loss	Checklist for qualitative research
Fernández-Alcántara2020	Spain (Feb - Sep 2016)	3 public hospitals in province of Granada	Interviews	HIC	Qualitative	Thematic analysis	NA	16	Stillbirth, NND, TOPFA	Experiences and practices of experienced professionals attending to perinatal loss in the hospital context in Spain	Consent withheld	Inclusion criteria for participation were (i) being a professional in a discipline (health care or other) regularly involved in intervening in cases of perinatal loss and (ii) having at least 5 years of professional experience in attending to perinatal losses. Consent obtained.	Checklist for qualitative research
Fernández-Basanta 2021 (2)	Spain (Feb - April 2019)	10 primary healthcare centres in northern Spain	Interviews	HIC	Qualitative	Phenomenological hermeneutic approach	NA	11	Stillbirth	The experiences of primary healthcare midwives who care for parents who have suffered an involuntary pregnancy loss	None mentioned.	Primary healthcare midwife and having experience in providing care to parents who have suffered an involuntary pregnancy loss.	Checklist for qualitative research
Gilmour 2017	Australia / (01/01/2012-30/06/2014)	Royal Brisbane and Women's Hospital, Brisbane,	Medical charts and death certificates	HIC	Quantitative	NA	Retrospective cohort study	46	NND	End-of-life care provided in an Australian tertiary neonatal centre, where paediatric palliative care was	Stillborns, pre-viable infants (<400g/<23 weeks GA), aged >1 year, no	Liveborn infants, born 01/01/2012-30/06/2014, neonatal admission at RBWH, died ≤1year	Checklist for studies reporting prevalence data

		Queensland								accessible via a consultative service	opportunity for palliative care intervention		
Hawes 2022	USA (2015-17)	1 level 111 NICU in a major teaching hospital in the north-eastern US	Surveys; observations	HIC	Mixed methods	Thematic analysis	Pre-post intervention	115 pre-intervention; 39 post-intervention; unclear for qualitative component	NND	Impact of formal bereavement debriefing sessions after infant death on NICU staff	None mentioned	Multidisciplinary NICU staff including attending physicians, neonatal perinatal medicine fellows, nurses, nutritionists, occupational therapists, neonatal pharmacist, case managers, nurse practitioners, respiratory therapists, clinical social workers, chaplains, lactation consultants, and assistant nurse managers	Checklist for quasi-experimental studies (non-randomised experimental studies) and Checklist for qualitative research
Helps 2020	Ireland (2005-2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	Stillbirth, NND	Bereavement care provided to families following perinatal death/pregnancy loss as described in national inquiry reports	None stated	National inquiries into perinatal deaths/pregnancy loss services between 2005-2018.	Checklist for qualitative research
Kalanlar 2020	Turkey (NR)	49 hospitals across Ankara, Istanbul, and Izmir	Postal questionnaires	UMIC	Quantitative	NA	Cross-sectional study	29	Perinatal death including stillbirth and neonatal death.	Managers, head physicians, head nurses, midwives, and specialist physicians caring for families following perinatal death	dialysis, in vitro fertilisation, medical, physicaltherapy, and	Purposive sampling to select provinces with the highest number of hospitals.	Checklist for analytical cross-sectional studies

											rehabilitation centres.	
Khader 2022	Jordan (2018)	4 hospitals in different geographical areas of Jordan	Focus groups	UMIC	Qualitative	Thematic analysis	NA	80	Stillbirth, NND	Determinants of perinatal deaths in Jordan from healthcare professional's perspective	None mentioned	HCPs including paediatricians, obstetricians, senior postgraduate trainees, registered nurses, and midwives	Checklist for qualitative research
Lappeman 2019	South Africa (dates not reported)	1 large metropolitan hospital in an impoverished area of the Western Cape	Interviews	UMIC	Qualitative	Thematic analysis	NA	8	Stillbirth	Emotional experiences of medical practitioners dealing with stillbirths	None mentioned	Medical doctors including consultants, who had worked in the labour ward for at least four months and cared for at least one stillborn birth	Checklist for qualitative research
Muin 2021 (2)	Austria (2020)	National	Online survey with one open ended question	HIC	Mixed methods	Content analysis	Cross sectional study	369 for quantitative component, 74 responded to open-ended question	Stillbirth	Facilitators and strategies used by obstetricians when communicating IUFD to parents	NA	Austrian obstetricians and gynaecologists registered with the Austrian Society of Obstetrics and Gynaecology	Checklist for qualitative research and Checklist for analytical cross-sectional studies
Noble-Carr 2021	Australia (2019)	3 large tertiary hospitals located in 3 Eastern states and territories	Interviews and focus groups	HIC	Qualitative	Thematic and interactional analysis	NA	113	Stillbirth, NND	Factors that shape the delivery of hospital-based lactation care for bereaved mothers	None mentioned	Professionals most likely to interface with bereaved families after stillbirth and infant death, and who may be called upon to offer lactation care. These	Checklist for qualitative research

											included obstetricians, neonatologists, midwives, neonatal nurses, lactation consultants, social workers or pastoral care workers, HMB staff, and specialist perinatal bereavement nurses.	
Power 2021	Ireland (June-Aug 2019)	Seven voluntary organisations in Ireland delivering support for pregnancy loss and perinatal deaths related to fatal fetal anomaly	Interviews	HIC	Qualitative	Thematic analysis	NA	17	Stillbirth, NND	Experience of volunteers supporting parents following a diagnosis of fatal fetal anomaly	None mentioned	volunteers who offered supports to parents who experience a pregnancy with a FFA	Checklist for qualitative research
Qian 2022	China (March-May 2021)	tertiary maternity hospital, Zheijang University	Semi-structured interviews	UMIC	Qualitative	Thematic analysis	NA	6 nurses, 13 midwives, 7 women	Stillbirth, TOPFA	how women who have experienced pregnancy loss and obstetric nursing staff perceive their interactions, what influencing factors impacted their experiences	Women who had a multifetal pregnancy reduction were not included	Nurses and midwives qualified to participate if they worked in the obstetric ward or delivery room and had experiences caring for women who had experienced pregnancy loss. Women were included if they (1) were	Checklist for qualitative research

											pregnant for more than 14 weeks; and (2) had already completed termination of pregnancy due to miscarriage, stillbirth or fatal foetal anomaly.	
Rent 2022	Ethiopia and Ghana / 2018	3 hospitals in Addis Ababa, Ethiopia, and Kumasi, Ghana	Interviews	LIC, LMIC	Qualitative	Grounded theory	NA	40 HCPs	NND	Provider perceptions on bereavement following newborn death	NA	Nurses, midwives, medical trainees, and senior physicians with at least 1 month experience in caring for newborn infants in their hospital	Checklist for qualitative research
Serafim 2021	Sao Paulo countryside, Brazil; periods	hospitals; family health unit	Interviews	LMIC	qualitative	Thematic content analysis	NA	11 health professionals	Stillbirth	experiences of health professionals dealing with fetal death	Professionals who were away or on vacation during data collection	Healthcare professionals who worked directly in women's health care and obstetric care (physicians, nurses, obstetric nurse, midwife, technicians and nursing assistants and psychologist) with at least one year experience	Checklist for qualitative research
Shakespeare 2020	Global (September 2017 - October 2018)	26 countries	Systematic reviews, meetings & online surveys	NA	Mixed methods (policy-Delphi methodology)	Thematic analysis	Descriptive (Likert scale)	Round 1 n = 23 Round 2 n = 19 Round 3 n = 236 Round 4 n =	Bereavement care after stillbirth	Global consensus on a set of feasible and evidence-based core principles for best practice bereavement care after stillbirth	None mentioned	International clinical and academic experts and healthcare workers with experience in providing bereavement care	Checklist for qualitative research and Checklist for analytical cross-sectional studies

								30 Round 5 n = 143					
Sheehy 2022	UTS, Sydney, Australia (June 2021)	NSW	indepth interviews	HIC	qualitative	Thematic analysis	NA	15 midwives	perinatal loss	Early career midwives' experiences of clinical encounters of perinatal grief, loss, and trauma	NA	Midwives who had undertaken their pre-registration education and had commenced working as a registered midwife in Australia, and were within their first five years of practice, were eligible to participate.	Checklist for qualitative research
Steen 2019	USA	One hospital in Minneapolis, Minnesota	Feedback from staff and parent evaluations	HIC	Qualitative	Thematic analysis and narrative review	NA	NA	Stillbirth, NND	Description of a perinatal bereavement program	None mentioned	Different components of a perinatal bereavement program at one hospital	Checklist for qualitative research
Thomas 2017	Australia (no period stated)	Metropolitan Sydney, NSW (n=9). 1 rural based.	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	10 (9 Sydney metropolitan, 1 rural)	Stillbirth, TOPFA	Views, experiences, and practices of Australian sonographers in communicating an adverse outcome to pregnant patients in different departmental settings in public and private sector practice	None stated	Participants who performed ultrasounds on obstetric patients were accepted from public and private practice settings	Checklist for qualitative research
Wool & Catlin 2019	USA (datesns)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND, miscarriage	Integrated system of care for perinatal bereavement	NA	NA	Checklist for text and opinion papers

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall appraisal	Relevanc
Actis Danna 2023	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	P
Boyle 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Farrales 2020	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	R
Fenstermacher 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Fernández-Alcántara2020	Yes	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Fernández-Basanta 2020	Yes	Yes	Yes	No	Yes	Yes	No	Unclear	Yes	Unclear	Include	R
Hawes 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I

Helps 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Khader 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Lappeman 2019	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Muin 2021 (2)	Unclear	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Yes	Include	R
Noble-Carr 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Power 2021	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Qian 2022	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	I
Rent 2022	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	R
Serafim 2021	yes	yes	yes	yes	yes	Yes	No	Yes	Yes	Yes	Include	P
Shakespeare 2020	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Include	I
Sheehy 2022	yes	yes	yes	yes	yes	No	yes	yes	yes	Yes	include	P
Steen 2019	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	No	Yes	Include	U
Thomas 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Alaradi 2021	Yes	Yes	Unclear	No	No	No	Yes	Yes	Include	R

Kalanlar 2020	No	No	No	No	No	No	No	Unclear	Include	I
Muin 2021 (2)	Yes	Yes	Unclear	No	No	Not applicable	Yes	Yes	Include	R
Shakespeare 2020	Yes	No	Unclear	No	No	Not applicable	Yes	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic reviews

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimize errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Berry 2021 (2)	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Not applicable	Yes	Yes	Include	U
Constantinou 2019	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Quasi experimental studies

	1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e., there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?	Overall appraisal	Comments (including reason for exclusion)
Hawes 2022	Yes	Yes	Yes	No	Yes	No	Not applicable	No	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Gilmour 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/ sources logically defended?	Overall appraisal	Relevance
Catlin 2018	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Wool & Catlin 2019	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
2.1	A multidisciplinary team should oversee care across the continuum from diagnosis through birth and death planning to transition from hospital to community. The team should: • provide continuity of care and carer • hold regular meetings with parents and family/whānau • ensure medical records include a care plan (e.g. a perinatal palliative care plan) that has been developed with the parents and the plan is accessible to all team members, parents and family/whānau • consider supports that may be required to meet the cultural, religious, and/or spiritual needs of parents and family/whānau • engage other relevant healthcare workers and interpreters, where needed. **This recommendation is cross-cutting across several technical reports. For additional evidence synthesis, see Section 2: Cultural safety and Section 4: Perinatal palliative care.*	Nine studies are included. Of these, four are primary qualitative studies, two are cross-sectional studies, two reviews (one systematic and one narrative review) and one prevalence study.	Moderate concerns of methodological limitation are noted Three of the included studies are deemed to have minor or no concerns of methodological limitation through critical appraisal. Three primary qualitative studies, one systematic review and one cross sectional study are all noted to have moderate concerns of methodological concern through critical appraisal. The cross-sectional study fails to identify confounders of to adjust for confounder effects through analysis. The exposure measure is also poorly described. The systematic review through critical appraisal is noted to have concerns for the criteria appraising studies, methodology and lack of publication bias assessment. All qualitative studies are noted to lack a statement of researcher cultural position and influence on analysis and findings. Two further demonstrated unclear	Moderate concerns of study relevance were noted through assessment. Five of the included studies are deemed relevant to HCPs communication through care around stillbirth and neonatal death. Two studies were deemed to be partially relevant and one was deemed to be indirectly relevant to HCPs communication. One prevalence study was assessed to be of unclear relevance to HCPs communication during care around stillbirth and neonatal death.	Minor concerns of coherence are noted.	Minor concerns of data adequacy were noted through assessment. Five of the included studies sourced their cohorts from high-income countries, one from lower middle-income country, one from upper middle-income country, and one from low-income country. One systematic review did not state the income levels of the study cohorts included in their review. Outcomes of interest in the evidence included stillbirth (n=49), neonatal death (n=51), termination of pregnancy for fetal anomalies (one study) and composite perinatal mortality outcomes (n=92). The views of mothers and parents were included across three studies, and those of HCPs (n=49) and community were also included in the evidence. There are minor concerns regarding the lack of data	**Low confidence** *Minor concerns of coherence and data adequacy. Moderate concerns of methodological limitation and relevance.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			methodological processes and one lacked congruity between the stated philosophical perspective and the methods. One included study is deemed to have major concerns of methodology through critical appraisal of all aspects of the study methods.			adequacy due to small, combined cohort sizes of viewpoints and outcomes included.	
2.2	To ensure continuity of carer, designate a lead contact person with training in perinatal loss care, ideally a bereavement midwife or Lead Maternity Carer in Aotearoa New Zealand, to be a known point of contact for parents, family/whānau and other members of the care team (including hospital volunteers). *This recommendation is cross-cutting *across several technical reports. For additional evidence synthesis, see Section 4: Perinatal palliative care and Section 8: Organisational recommendations.*	Seven studies are included. Three of the included studies are primary qualitative research, two are mixed methodology with a qualitative component, and one cross -sectional, one quasi-experimental. Two systematic reviews are included.	Moderate concerns of methodological limitation are noted through assessment. Two of the included studies are note dot have no or minor concerns of methodological limitation. Five of the included studies are noted to have moderate concerns of methodological limitation. Two qualitative studies, one mixed methods study, and two systematic reviews. The qualitative studies and the mixed methods study all demonstrated moderate concerns to the qualitative component of work due to lack of a statement of researcher cultural position, and failure to account for this through analysis	Moderate concerns of study relevance were noted through assessment. Four of the included studies are deemed relevant to HCPs communication through care around stillbirth and neonatal death. Two Mixed methods were deemed to be indirectly relevant to HCPs communication and one systematic review was assessed to be of unclear relevance to HCPs communication during care around stillbirth and neonatal death.	Overall assessment of coherence results in no concerns.	Minor concerns of data adequacy were noted through assessment. Five included studies sourced their cohorts from high-income countries. Two studies did not state the income levels of their study cohorts. Outcomes of interest in the evidence included stillbirth (n=489), neonatal death (n=154), and composite perinatal mortality outcomes (n=15). Viewpoints included in the evidence included are parents (n=32), healthcare professionals (n=126), national inquiries (n=10) and clinical and academic experts.	**Low confidence** No concerns of coherence, minor concerns of data adequacy. Moderate concerns of methodological limitation and relevance.

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			and findings. Unclear congruity between methodology and philosophical perspective. The mixed methods concerns highlight inadequate representation of participants voices, unclear inclusion measures, poor study setting descriptions, and unclear exposure measures. The systematic review is moted to lack criteria for appraising studies, unclear critical methodology, and unclear assessment of publication bias.			There are minor concerns of data adequacy due to lack of termination of pregnancy for fetal anomaly or life-limiting diagnosis data. The viewpoints predominantly contain healthcare professional perspective, but this is appropriate given the focus of this topic.	
2.3	Use an identifier in medical records to show there is a perinatal loss care plan in place outlining parents' values, preferences, and wishes for care and support. • Ensure care plans are accessible to all members of the multidisciplinary team and available to parents and family/whānau.	Three studies were included. One qualitative primary research, and two qualitative narrative reviews.	Minor concerns were noted through assessment of methodological limitations. No and minor concerns were noted on assessment of narrative review methodology. Moderate concerns were noted through assessment of the qualitative study included due to lack of a researcher statement of culture, and the impact of this on analysis and results.	No concerns of relevance were noted.	No concerns of coherence were noted.	Severe concerns of data adequacy are noted. All included studies source evidence from high-income country populations. Outcomes in the studies include stillbirth (n=59) and composite perinatal mortality outcomes. The viewpoints in the evidence include parents. There are severe concerns regarding the lack of data adequacy due to small cohort sizes, the quality of evidence source, and the poor diversity of viewpoints included.	**Low confidence** *No or minor concerns of methodological limitation, relevance and coherence. Severe concerns of data adequacy.*

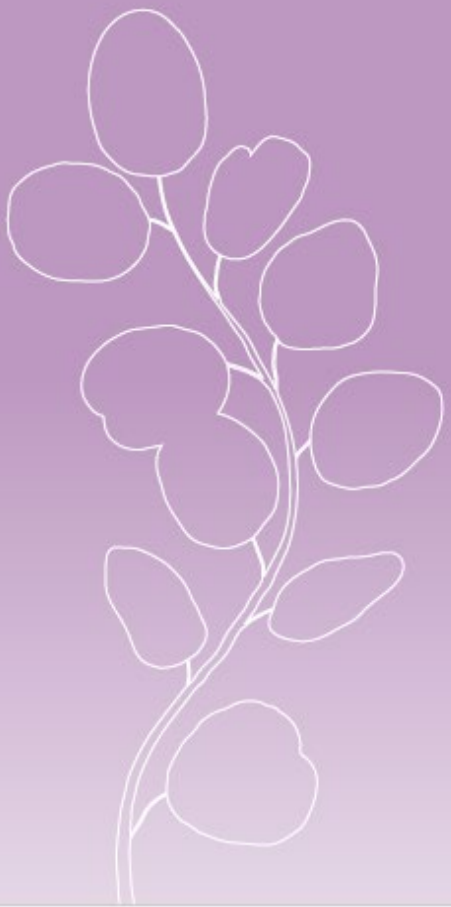
No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
3.23	Discuss with parents prior to hospital discharge, their preferences for advising relevant healthcare professionals involved in their care (e.g. general practitioner [GP], other community-based services) of the baby's death or impending death so that existing appointments are cancelled, and other types of appropriate follow-up are activated. • Document processes and decisions to ensure handover is contemporaneous and accurate.	Five studies are included. Four of the included studies are primary qualitative research, and the final is a narrative review.	Moderate concerns of methodological limitation are noted. The are no or minor concerns or methodological limitation of the narrative review and one of the qualitative studies. Moderate concerns were noted of methodological limitation of the remaining three qualitative studies. All lacked a statement of researcher cultural position and fail to report the influence that this may have on the findings and analysis. Two were noted to also lack congruity between the philosophical perspective and the stated research methodology.	No or minor concerns of study relevance were noted. Four of the included studies were deemed to have direct relevance to communication between HCPs during care around stillbirth and neonatal death. The remaining qualitative study was deemed to be partially relevant.	There were no concerns of coherence noted across the included evidence.	Moderate concerns are noted of data adequacy. All but one of the included studies sources cohorts from high-income country populations. The remaining qualitative study encompasses a cohort from a lower-middle-income country. Outcomes of the evidence include stillbirth (n=70), and composite perinatal mortality (n=129). The views of parents and HCPS were included from the literature. Moderate concerns are noted of data adequacy due to outcomes not including neonatal death, or termination of pregnancy for fetal anomaly/life-limiting diagnosis.	Low Confidence *No or minor concerns of study relevance, and coherence. Moderate concerns were noted for methodological limitation and data adequacy.*

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report



Section 4: Perinatal palliative care

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Perinatal palliative care is a right for all babies with a life-threatening or life-limiting illness and their parents and families. It is a coordinated care strategy to maximise quality of life and comfort for newborns with conditions considered to be life-limiting in early infancy.[1] The World Health Organization identifies perinatal palliative care as an ethical responsibility[2] for unborn babies with major health problems who may not live through birth; infants who may survive for only a few hours/days; infants with birth anomalies that may threaten vital functions; and infants for whom intensive care has been appropriately applied but developed an incurable disease.[2,3]

"Palliative care for a fetus, neonate, or infant with a life-limiting condition is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, at the time of death and beyond. It embraces physical, emotional, social, and spiritual elements and focuses on the enhancement of quality of life for the neonatal infant and support for the family. It includes the management of distressing symptoms, the provision of short breaks, and care through death and bereavement."[3,4]

Methodology

The Guideline Development Committee developed research questions for perinatal palliative care (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	What are the information and support needs of parents and families/whānau who choose a palliative care approach following diagnosis of a life-limiting condition either before or after birth?
2	Who are the *right people* to have in the *right team* and what is the *right place* for a perinatal palliative care approach?
3	What barriers are experienced by parents in accessing and engaging with palliative care? What barriers are experienced by healthcare professionals in providing perinatal palliative care services?
4	What forms of psychosocial support benefit parents and families/whānau?
5	What are the training and support needs of healthcare professionals providing perinatal palliative care?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 1. PICO criteria

PICO	Inclusion criteria

Population	Defined in Australia and Aotearoa New Zealand as:
	• Stillbirth
	  ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[5,6]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[5,6]
	The definition of stillbirths and neonatal deaths includes the death of a baby following a termination of pregnancy of 20 or more completed weeks of gestation or of 400 g or more birthweight.

Intervention	Studies exploring perinatal palliative care in maternal or newborn services including pregnancy, birth, postnatal, neonatal and bereavement care planning.
Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes and experiences of parents, family members, healthcare professionals in the context of perinatal palliative care. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Searches were conducted on 26 August 2022. A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL

- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- Wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- Wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- Wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- Wrong *language*: The study was not published in English.
- Wrong *publication dates*: The study was published prior to 2017.
- Wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and

consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[7] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[8]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[9]
- Adequacy: The richness and quantity of data supporting the findings[10]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[11]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated, and details of any concerns were identified and listed.[12] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: What are the information and support needs of parents and families who choose a palliative care approach following diagnosis of a life-limiting condition either before or after birth?

Perinatal palliative care is an approach to healthcare services that addresses the needs of the baby and parents beginning at the time of diagnosis and extending through the birth, through the possible death of the baby, and into the bereavement period.[13]

Knowing when to discuss a palliative approach with parents and family/whānau can be challenging; however, providing options and support services as early as possible maximises the time available for parents and family/whānau to consider options and make choices.[14]

The decision to take a palliative approach to perinatal care needs to be jointly made by the parents, any chosen support people (e.g., family/whānau), and the multidisciplinary team of healthcare professionals supporting the parents and the baby.[14] Factors such as education level, family dynamics, financial resources, religion, and available care options all influence decision making in the context of a life-limiting diagnosis.[15]

Perinatal palliative care can be considered for babies in three main categories:

- babies at the threshold of viability
- babies with complex congenital anomalies considered to be incompatible with long-term survival
- babies with severe clinical conditions not responding to aggressive cure-oriented treatments, for whom continuation of intensive care is no longer helpful.[16]

Perinatal palliative care is carefully planned to minimise the physical, psychological, social, emotional, and spiritual suffering that families face throughout the pregnancy and birth.[16,17] Semi-structured interviews with women who received care from a perinatal palliative care program during pregnancies with life-limiting fetal diagnoses revealed four overarching themes: (1) importance of memorabilia to cope with the death and documentation of pregnancy, (2) acceptance of death as part of the pregnancy experience, (3) continued life without a child, and (4) importance of empathy throughout the process.[18]

Supporting families and families to identify information and support needs is a crucial component of care. A content analysis[19] of medical records of family conferences found five main themes during prenatal palliative care follow-up after the diagnosis of a life-limiting fetal condition: (2) talking about the fetal condition, (2) understanding the context of the moment, (3) preparing care, (4) childbirth and the period after birth, and (5) about the GAI group and the importance of the family conferences (GAI refers to a support group for pregnant women and families of babies with a malformation). The results highlighted wide variation in emotional responses and values among parents during prenatal palliative care follow-up. Synthesis of the findings gave rise to the development of the "ACE of Care" framework for supporting parents and families in identifying their values and creating a birth plan.

The steps of the ACE of Care framework are:

1. Approach the subject
2. Contextualise
3. Establish goals
4. Organise birth
5. Follow-up (after birth, in the neonatal period, and beyond).

> **"We provided care and talked about the possibility of anaesthesia because the patient fears that she might experience pain during childbirth"** [19]

Support resources

Parents also benefit from well-designed handouts, written in simple language, that provide useful information about procedures, genetic testing, transfer options, end-of-life protocols, and follow-up options with social work, cultural and spiritual support. An Australian study evaluated the acceptability and usefulness of a handbook and web-based resources (Caring Decisions) and found the resource filled a gap by supporting and enabling families and healthcare professionals to communicate effectively around end-of-life care for children.[20]

All care options should be discussed including antenatal and postnatal intervention intended to promote survival, as well as palliative care, which may include interventions to promote comfort and improve quality of life without intending to promote survival.[21-24]

Best practices for palliative care planning discussions include:

- using a private room
- ensuring that there are enough chairs for all attendees
- inviting all interested/involved participants
- silencing mobile phones/devices or passing these to colleagues not in the room
- introducing each attendee
- declaring statement of the purpose of the meeting
- sitting at eye level with parents and family
- reviewing the baby's current condition
- avoiding medical jargon
- listening to the patient and families without interruption
- asking questions for clarification
- repeating what the parents/family said
- using the words death/dying if applicable
- offering specific recommendations for care going forward
- inviting questions
- allowing silence if grief or other strong emotions are expressed
- summarising key points from the meeting.

Making difficult decisions are rarely possible after a single meeting. Parents need time to digest the information privately, formulate follow-up questions, and discuss their feelings and concerns with family members or spiritual leaders. Most advanced care planning requires repeated discussions over several days or weeks, depending on the urgency of the decision.[25]

Family-centred care planning

Three key areas should be the focus of perinatal palliative care to ensure that families feel respected and empowered to make decisions through their and their baby's care:[26] care, choice, and legacy.[16] Further details are described below.

CARE

Perinatal palliative care programs generally include: a formal antenatal consultation; development of a birth plan; access to other neonatal and paediatric specialties, as needed; and support and care during the prenatal, birth, and postnatal periods, including bereavement counselling.[24,27] Currie et al.[28] suggest renaming "birth plan" to "parenting plan" to better integrate recognition of parenthood through palliative care.

Specific strategies related to care include:

- Provide detailed birth planning and ensure that the birth plan is accessible to all members of the perinatal palliative care team.
- Empower all members of the perinatal palliative care team to support families as they process the diagnosis and care plan throughout the pregnancy.
- Embrace flexibility when the care plan is changing and communicate this openly to parents.
- Embed routine newborn care as much as possible: e.g., bathing, handprints, family visits, pictures.
- Use alternative phrasing and avoid stating that the diagnosis is "incompatible with life" as appropriate.
- Be sensitive to, and try to limit reminders about care of healthy babies in the vicinity
- Schedule repeat visits so that questions can be answered as frequently as needed and information can be delivered in manageable amounts.

CHOICE

Resources to help parents understand the complex and difficult ethical questions concerning their baby or assist them to participate in conversations in written or web-based form are limited. Use of such materials relies on healthcare professionals telling families about the resources, deciding when is the right time to raise the issue and working within the healthcare team to identify who is best placed to initiate conversations and make decisions.[29]

'What's the right thing for this family to do is whatever is going to give them peace in an otherwise horrible situation. And that's the right decision.'

Specific strategies related to choice include:

- Provide resources early to parents and families, particularly local and online parent support groups.
- Encourage parents to identify a primary care provider when the baby is likely to survive to hospital discharge.
- Provide all options (including termination of pregnancy for medical reasons, palliative care, and end-of-life care) as well as subspecialty consultation early to support informed maternal decision making.

LEGACY

Perinatal palliative care teams should raise legacy formation (e.g., organ donation or donating funds to research) from diagnosis, or through pregnancy as well as after birth. Conventional bereavement and counselling protocols are not sufficient for families whose children have life-limiting fetal conditions, which may involve multistage, anticipated antenatal losses. Even less appropriate is routine care with no attention to anticipatory grief, extinguished dreams, and loss of future life events, which are much different from those of parents expecting a healthy child. For families given the news of a life-limiting condition, the joyful expectation of a healthy new baby is often replaced with sorrow and periods of uncertainty, in anticipation of losing a loved child.[30]

Some services may provide families with resources that:

- describe the process and options at birth, memory-making at the time of birth, autopsy and genetic testing, managing grief, physical and emotional recovery, funeral planning, talking with siblings (if any), subsequent pregnancy after a loss, and specific pregnancy loss books and online resources for both adults and children
- include procedure and postoperative instructions if required, managing complex grief, connecting with the surviving co-twin (if any), support for the remainder of the pregnancy and preparing for birth, and additional complicated monochorionic twin resources if appropriate
- contain a 'comfort' kit that encourages self-care for parents.[31]

Anecdotal evidence from a two-year pilot perinatal palliative care pathway in Toronto indicated that take-home kits for legacy creation were appreciated by families. These kits contained information on the benefits of legacy creation alongside materials and instructions, and enabled mothers to develop legacy with other family members in the home during the COVID-19 pandemic-related restrictions.[32]

'Avoid having families need to tell their story over and over; consolidate and provide continuity.'

'Helping families to minimise regret, and so helping them to make informed decisions and to have the information that they need and the support to make those decisions … it's their decision, not our decision … and we can provide guidance and support.'[33].

Honest, continued, and open communication with the parents and family is crucial. Discussions about the baby's diagnosis and prognosis need to take place in an appropriate and safe setting, considering the culture of the child and the family. Parents wish to:

- feel supported and heard
- comprehend the fetal condition and care options
- have their needs and wishes known and met
- feel that their care is seamless
- feel like good parents
- have no regrets at the end of their journey.[33]

The healthcare team should carefully consider the wording and terminology they use when communicating with parents and families and agree upon terms to avoid. Some parents may experience discomfort with certain phrases or terminology including "end-of-life" care.[34] The phrase "diagnosis is incompatible with life" should be avoided.[26]

Parents may be uncertain about legal rights, including (1) on the available options regarding their child's healthcare after birth; (2) whether healthcare professionals will accept a decision against life-sustaining measures; (3) whether they will accept the wish for their baby to die in peace without suffering; (4) what will happen if the baby survives pregnancy and birth for a longer time than expected; and (5) who will support them at home in such a situation.[35]

It is important to have sufficient time for the decision-making process, for understanding the diagnosis, to get all the information needed, to talk about all options, time to decide, time to mourn, and time to be accompanied for as long as needed. Support exists, but it may be fragmented and uncoordinated, with limited access to counselling services for families.[35]

> **"[it] is often not what you say, but [in] the things not said—the non-verbal communication [and] body language, sitting with the family, holding their hand, crying with them, sitting in silence, and meeting them where they are."[36]**

A so-called 'good death' for infants – as suggested by neonatal intensive care unit (NICU) nurses – includes having the child die unattached to technology, being held, and out of pain.[37]

> **"… parents just need to be able to do things that they would do with their baby if it was at home" (nurse).[38]**

Parents experience progressive patterns of emotional reaction, knowledge acquisition, diagnostic acceptance, and decision making. Perinatal palliative care specialists understand these stages and have expert skills to engage with families with active listening, modification of conversation, and needs-directed supportive interactions that are crucial for optimal partnership during the perinatal and neonatal parental experience.[39]

After a life-limiting diagnosis, healthcare professionals see that parents may be unable to adequately express their concerns. At this point, healthcare professionals report offering parents enough time to empathetically listen to them and to speak openly about the situation.[35]

Specialised childbirth classes are needed to prevent unintentional harm to parents and families who know that they will be losing a child, and to inform them about birth scenarios specific to their situation.[40]

Healthcare professionals raised the following as needs: counselling and parental support during the decision-making process; fragmented or missing support infrastructure for parents; and challenges, hesitations, and barriers, particularly from the different stakeholders.

Planning includes reserving a private room, making sure the parents are present, that death is not rushed, and creating memories with parents. Healthcare professionals mentioned the negative effect of lack of a separate room for privacy, shortage of available trained personnel, and differences in expertise across NICUs.

> **"…the nurses for the other children didn't really realise that the child was dying and the father said: one image still sticks in my mind: that is those laughing nurses walking past the desk…."[41]**

When a family opts for newborn rooming-in, the neonatal and palliative care teams should visit the family to ensure the baby's comfort and to provide practical and emotional support to the parents,

while also respecting the family's privacy. These visits are intended to provide newborn palliative care at the bedside, to educate, to offer emotional support, and to minimise stress [24].

The birth plan or parenting plan needs to include plans for assessment and care of the baby and cover considerations such as newborn bonding and skin-to-skin contact, warmth, hydration, feeding and lactation, management of respiratory distress, and pain control.[24] If parents desire comfort measures for their infant – oxygen, feeding, medications, pain relief (if indicated), and wound dressings – parents should be assured that these will be provided.[30] Assessment of family needs should begin at the initiation of perinatal palliative care and be extended up to bereavement after the baby's death.[1,2] Following the birth plan at the parents and families pace can help to effectively address their worries and concerns without eliciting traumatic stress.[42] Birth plans should be reviewed/updated at each antenatal visit.[43]

A mixed-methods, descriptive study identified six themes from parents' overall experience of creating and using a birth plan: (1) sense of control, (2) therapeutic, (3) memory making, (4) effective communication, (5) feeling prepared, and (6) unexpected events. Four themes from physicians were as follows: (1) importance of birth plans, (2) need for meetings, (3) follow-through and communication, and (4) key components are needed with flexibility.[43]

The palliative care birth plan should remain available in the woman's medical record to inform decisions related to fetal monitoring, preference for mode of birth and surgical birth for fetal distress, or the wish to donate breast milk after the baby's death.[42] In describing her final milk donation, one bereaved mother stated *"That was the last piece of her in my body*". Other women may find that donating milk worsens their grief.

Elements of care plans:[44]

Birth

- Place
- Timing
- Mode
- Monitoring in labour
- People to be present at birth
- Care provided at birth
- Which (if any) diagnostic interventions to be done
- Postnatal care
- Skin-to-skin

Palliative care

- Pain
- Medical system access and quality
- Family oriented care
- Dignity and respect
- Decision making
- Psychosocial
- Spiritual symptoms treatment plan
- Family support (siblings and grandparents)

Bereavement care

- Arranging for spiritual/cultural care
- Psychosocial support
- Supporting memories

Important elements of a **perinatal palliative care plan** have been adapted into an example perinatal palliative care plan– See Appendix 4B.[39]

Question 2: Who are the *right people* to have in the *right team* and what is the *right place* for a perinatal palliative care approach?

The right people

Active listening, modification of conversation, and needs-directed supportive interactions are crucial for optimal partnership during the perinatal and neonatal parental experience. Parents experience predictable and progressive patterns of emotional reaction, knowledge acquisition, diagnostic acceptance, and decision making inherent to the perinatal experience. Perinatal palliative care specialists must understand these stages and be experienced in assessment of parental journey through them. Such specialists rely on their insights into parental medical decision making and their expert communication skills to facilitate families' progress through emotional and developmental stages.[39]

The right team

Perinatal palliative care teams should include parents, families, those providing primary care, a social worker, and a nurse with training in bereavement. Generally, as the care evolves, mental health professionals, neonatologists, anaesthesiologists, genetic counsellors, psychiatrists, psychologists, lactation specialists, chaplains, a local priest/pastor, bereavement counsellors, labour nurses, midwives, neonatal nurses, sonographers, and child life specialists may be added.[15,24,30,40]

Because the family may interact with many different healthcare professionals, grieving parents report significant benefits from having a perinatal palliative care coordinator, often a nurse, who helps to coordinate care between providers, teams, and families.[33] A palliative care coordinator ensures that care from every member of the team is well coordinated, continuous and complementary. Child life specialists work at a developmentally appropriate level with siblings to provide support during the pregnancy and birth. Geneticists are involved during pregnancy and after birth to confirm the diagnosis by using genetic testing, a postmortem examination, and/or cytogenetic testing. Genetic counsellors are often underused in perinatal palliative care. Genetic counsellors are an integral part of the team with the ability to offer support because they are trained to clarify the families' understanding of the diagnosis in a nonbiased fashion, answer questions, and take the time to provide accurate information about all of their options.[40] Nurses' roles are recognised as fundamental, providing support, clarifying doubts, meeting needs, and individualising care for the baby and the family.[45]

Psychosocial team members (e.g., social workers, psychologists, chaplains) should be an integrated part of the palliative care team to support grieving parents, connect them with community grief resources, and provide continuity of services throughout the perinatal period and ongoing

assessment for emotional and social risk factors that may potentially challenge a family's grief process.[42]

Healthcare professionals are encouraged to model effective, compassionate communication that respects cultural beliefs and values and to promote shared decision making with parents and families, which includes[24,46]:

- Feeling supported and heard
- Being able to comprehend fetal condition and care options
- Having their needs and wishes known and met
- Feeling that their care is seamless
- Feeling like good parents
- Having no regrets at the end of their journey.[33]

One nurse said, "We prolong suffering too long. Make a decision earlier and faster." Other nurses described their desire to stop care sooner to decrease the infant's pain."[37].

"Many teams don't always share the same diagnosis and/or treatment the other physician presented to the family. This [lack of consistency] causes serious conflict among the family. When physicians don't present a united front, it causes conflict with staff as well as families."[37]

The right place

For most babies with life-limiting and life-threatening conditions comfort care measures are initiated in the NICU setting.[47] This may necessitate separating the mother from her ill baby so that she can receive postnatal care in traditional postnatal care units. Where possible, services may be adapted so that postpartum women and ill babies can receive care in the same location. The Mother Baby Comfort Care Pathway is one example, which focuses on providing flexible care to enable mothers, babies, and families to experience as normal a postnatal period as possible, within the context of life-limiting and life-threatening neonatal conditions.[23]

Broader health systems and service delivery considerations are essential in providing perinatal palliative care, including healthcare personnel, training, and infrastructure. The time-intensive nature of providing end-of-life care requires a level of staffing that is not always available, which can lead to substandard care.[37] Nurses have suggested that they look after one patient at a time, not two.[37] An understanding and appreciation of the experience of grief and the emotional stages seen in families facing severe fetal diagnoses is central to providers' roles.[39]

Any hospital or healthcare organisation providing perinatal palliative care should have in place multidisciplinary collaboration between professionals from obstetrics, neonatology, and other specialties.[27] The role of community health workers, volunteer clinicians, home care nurses, and midwives is also crucial.[2] Reports consistently mention that more ancillary staff are needed in current models of perinatal palliative care – with 24 hour availability from social work, chaplain, secretarial support.[37] Access to professional interpreters is essential when there are language barriers.[48]

Adopting some form of patient chart/record identifier of impending/likely perinatal loss may help to prevent healthcare providers from inadvertently communicating insensitively or inappropriately with parents (e.g., asking how the baby is doing).[33]

It is advisable to have regular multidisciplinary team meetings including all healthcare professionals, routinely implementing palliative care planning in severely ill babies to make important decisions beforehand, creating privacy for difficult conversations with parents, and reviewing the complex legal framework of perinatal end-of-life decision making. When an end-of-life decision is made, physicians need to assess if withholding or withdrawing treatment is sufficient rather than actively ending life with lethal medication.[49]

> **"I actually see as a blessing to be able to be there when they go through that profound experience. I feel honoured that I can know their baby's life." (Social worker)[50]**

Question 3: What barriers are experienced by parents in accessing and engaging with palliative care? What barriers are experienced by healthcare professionals in providing perinatal palliative care services?

Factors contributing to insufficient perinatal palliative care include family access issues, and physician education and training barriers.[24] Barriers to the provision of perinatal palliative care practices in NICUs include the time-intensive nature of a comprehensive and integrative care plan and lack of adequate staffing across a multidisciplinary team.[37] When a multidisciplinary care team is not available due to organisational issues or very limited resources, perinatal palliative care should be delivered by healthcare professionals with the highest possible levels of training.[2,51]

To examine institutional and individual barriers to and facilitators of palliative care, Kain[52] developed the Neonatal Palliative Care Attitude Scale (NiPCAS) survey and identified five facilitators to neonatal palliative care as perceived by neonatal nurses:

- support for a neonatal palliative model of care by the healthcare team
- the ability to express values, opinions, and beliefs
- the availability of counselling support for caregivers
- the presence of clinical guidelines to support practice
- the support of parents by the healthcare team.

The barriers to neonatal palliative care include:

- inadequate staffing
- a physical environment not conducive to palliative care practice
- technological imperatives and parental demands.[53]

Prognostic uncertainty is one of the most challenging issues to communicate with families in the NICU, made more difficult by the fact that both practitioners and families tend to be overly optimistic about the effectiveness of NICU procedures. The skill with which the palliative care team navigates this tension affects the team's ability to integrate the parents' goals of care with complex decision making, and may delay the family from recognising that their time with their baby may be shorter than hoped for.[25] Just under half of healthcare professionals felt adequately prepared to participate in advanced care discussions for paediatric advanced care planning. Following

simulation-based education, 90% felt confident to participate in advanced care planning discussions.[54]

Healthcare professionals have identified the following gaps and barriers: (1) counselling and parental support during the decision-making process; (2) fragmented or missing support infrastructure for parents; and (3) challenges, hesitations, and barriers, particularly from the different stakeholders, regarding a Perinatal Palliative Care framework. They highlighted the importance of the integration of perinatal palliative care in existing structures, a multi-professional approach, continuous coordination of care and education for all healthcare professionals involved.[35]

Barriers to incorporating palliative care practices in NICUs include:

- inadequate staffing to care for dying babies
- environmental factors not conducive to end-of-life care such as lack of rooms, small spaces, and loud environment
- technological advances leading to futile care
- parental expectations being unrealistically high about long-term outcomes
- parental demands to continue life extending care.[37]

Barriers to efficient and humanised care include institutional rules, pre-established routines, physical barriers, such as lack of adequate infrastructure and lack of interest in being flexible and readjusting care.[45] While neonatologists manage the short lives of many newborns (given the relatively high mortality rates associated with prematurity and birth defects), addressing the continuum of multidisciplinary palliative care, end-of-life care, and bereavement care has varied widely.[3] NICU nurses suggested that providing consistent information to families was a high priority and that communications need to be realistic and honest.[37]

Although the physical environment in which end-of-life care is provided can be difficult to manipulate, nurses can modify the existing environment by moving infants to more private corners or ends of rooms so that dying infants and families can have increased privacy. When new units are being built or remodelled, NICU nurses should be on planning committees providing input on unit design to facilitate privacy and adequate space for appropriate end-of-life care.[37] Services may also be built or adapted to negate the need to separate mothers from babies in order for them each to receive postnatal and palliative care, respectively.[23]

In the case of a cardiac diagnosis, “If your first conversation is with a paediatric cardiologist, you are probably not going to get the termination option. You’re going to get potentially a palliative care, but you’re going to get a surgical or medical route. If your first experience is with an obstetrician, you’re going to get termination as one of the first options.” Parents reported little or no discussion of palliative care as an option, describing that there was “an illusion of choice”.[29]

Parents and families coping with a life-limiting fetal condition report experiencing fragmented care and feeling “utterly alone” when left to navigate their care.[33] Without a perinatal palliative care plan in place, the default treatment for infants with diagnosed life-limiting conditions during antenatal care is likely to be invasive and painful, with minimal likelihood of long-term survival.[26]

Question 4: What forms of psychosocial support benefit parents and families?

Bereaved parents have higher mortality rates and psychiatric hospitalisations when compared with parents who have not experienced the death of a child. Twenty-nine percent of parents (of NICU and PICU patients) report stress-related hospitalisations, newly diagnosed chronic health conditions, clinical depression (35% of mothers and 24% of fathers), and clinical post-traumatic stress disorder (35% of mothers and 30% of fathers). Grief is an individualised and normal experience. Bereaved parents and family members (including grandparents and siblings) may experience a range of emotional and physical reactions including worry/anxiety, intense sadness, anger, hopelessness, loneliness, disrupted sleep and lack of energy.[28]

> **"How things evolve for that family is going to impact them for the rest of their lives. If it [child's death] goes well it's going to serve them for a lifetime and if it goes poorly, it could have an impact for a very, very long time."[55]**

Family centred care is a core principle of perinatal palliative care where the child, family, and healthcare professional work in partnership to meet the ever-changing physical, psychosocial, developmental, emotional, spiritual, and practical needs.[55] Healthcare professionals need to feel supported in their role to support parents to face their fears.[42] The process of care planning can help support families to express their fears, values, hopes and wishes.[17] Affected/bereaved mothers and fathers may have different needs, which may threaten their relationship.[35] Nurses have suggested environment/design improvements such as improving privacy, adding to limited space, and the need for special family areas/private rooms and a garden outside the NICU[37] to offer physical support to families. One descriptive study found that, although all parents in one cohort had access to free infant loss grief support through the children's hospital where their infant was hospitalised prior to death, none of the parents utilised this resource.[28] Accessibility, functionality, and the appropriateness of resource format needs further research for each family member, as support needs are unique for each parent and family.

Bereaved parents may refuse to accept the reality of their baby's death, with ambiguous loss leading to unresolved grief. They may show signs of complicated grief and experience spousal neglect (e.g., sexual relationship), self-blame and emotional pain, as well as anxiety and depression. Symptoms may include sense of anger, hatred, and guilt,[56] as well as physical and psychological exhaustion.[57] The grief accompanying perinatal loss of a wanted child may be more intense compared with loss of another family member. The lack of physical contact, minimal amount of time with the infant, and the small number of others mourning may prevent connection within the family and minimise the feelings of loss.[30]

Perinatal palliative care may be provided in the delivery room, post-partum ward, in the NICU, at home, or wherever is thought to be most appropriate and provided this approach is consistent with family goals of care.[2] The assessment of family needs should begin at the initiation of perinatal palliative care and be extended up to bereavement care after the child's death. The families' needs should be included in the development of the perinatal palliative care plan and addressed, when possible, by multidisciplinary team members skilled in active listening and communication and respectful of each family member's dignity.[2] The needs of family members (parents, siblings, grandparents, other persons if necessary) should be evaluated throughout the child's illness trajectory.[2]

Family members should be offered the opportunity to share and discuss their personal feelings and thoughts and receive appropriate support from compassionate professionals with advanced communication skills. Honest ongoing communication with the family is crucial. Communication and discussions about the child's diagnosis and prognosis should take place in an appropriate and safe setting, taking into account the culture of the child and the family.[2] The SORROWFUL model, developed based on documented evidence as well as experience in providing bereavement care to families of newborns at the perinatal referral centre at Charité Universitätsmedizin Berlin, advocates for an individualised approach, ensuring care is provided with respect, understanding, and an open mind.[58] The SORROWFUL acronym stands for:

- Steadfast support
- Offer gentle and compassionate prompts
- Realising and comprehending death with all senses
- Room for bonding
- Owning a new life-situation
- Walk beside and guide
- Forget-me-not
- Utilising resources and assessing risks
- Leveraging support systems.

Potential situations of conflict should be identified early, prevented, and managed. Trained members of the interdisciplinary team should offer psychological support to family members, and when possible, by specialised mental health professionals, especially when distress is very high, abuse occurs, and/or dysfunctional family dynamics perpetuate over time. Psychological support should be available to all family members after the death of the child and, when possible, for as long as needed.[2] Parents may also experience "social suffering" wherein they feel exposed or uncomfortable when questioned by strangers in their everyday lives about how the pregnancy is progressing.[2]

For some families, it is not possible to talk about the fetal condition with the other children,[42] often as a consequence of trying to protect the children from suffering. Where these conversations do occur, it is important to provide age-appropriate, honest, and concrete explanations to siblings to help them understand the finality of death and begin coping with the loss.[42] Some parents refrain from bonding with the baby, believing that bonding will increase their suffering. There were also couples who prefer not to build memories during gestation. For other women, bonding feels natural and desired, and many families want to participate in pregnancy rituals, such as baby showers. Some families report not knowing if they would like to see and hold their babies, particularly in cases of fetal death. On the other hand, for some families, it is very important to see the baby and the malformation.[2]

After birth, nurses can model bonding behaviours and support families to feel more comfortable with holding, seeing, and touching their baby before and after the death and calling the baby by name. Ample time is needed for a gradual goodbye to promote healthy grief and potentially reduce the risk of trauma at the time of birth. Taking photographs, hands-on bonding, bathing, and dressing are all important activities that can help to normalise the experience and celebrate the birth.[42] In qualitative studies, many families emphasise the importance of having had the opportunity to bond with their babies and take care of them, exercising their parental role and therefore gaining something positive from the tragic experience of bereavement.[59] Creating memorabilia to cope with the death and documentation of pregnancy is particularly salient,

providing parents and families with something tangible to represent mark the pregnancy and existence of the child.[18]

> **"And even providing material things that you could have after the baby had passed away. That, I think, is an enormous, huge, huge thing because, especially for me, it was my first, and my body had showed all the symptoms of being a mother..."[18]**

Following up with families at 1 month, 6 months, and the 1-year anniversary of their baby's death is suggested. This includes contact with the family, initially by card, and then by follow-up telephone calls at 1 month, 3 months, 6 months, and 1 year after death. These calls may be completed by a nurse who had a close relationship with the family or the palliative care coordinator. The conversations provide support to the family and allow for any additional resources to be given.[40]

Question 5: What are the training and support needs of healthcare professionals providing perinatal palliative care?

Training needs

Most practising physicians, nurses, and other healthcare professionals have not received training to engage in paediatric palliative care discussions with patients and families.[60] Healthcare professionals providing perinatal palliative care have reported lower confidence including having conversations with families about the possibility of their infant dying (55%) and knowing and accessing community palliative care resources (32%) concerning topics such as communication with families, managing symptoms, pain management and ethical issues being priorities.[61] Increasing self-awareness, practising specific responses via role-play activities, improving eye contact and body language, and learning to mirror a patient's own language are key components of providing quality perinatal palliative and family care.[36]

Barriers to perinatal palliative care engagement among healthcare professionals include inability to express values and beliefs regarding palliative care, environmental constraints, engagement in technology, demands from parents, and lack of education.[37]

> **"Increased education about what to say, what words or phrases to avoid, and words or phrases to use to convey genuine compassion."[37]**

In a study conducted in Switzerland, authors highlighted that most neonatal healthcare professionals reported the need for more training in perinatal palliative care in their centres to enable them to deal more confidently with palliative care circumstances.[62] An education program of a single 4-hour workshop with groups of multiple professionals demonstrated that a relatively short training intervention changed attitudes to palliative care among participants, increasing both knowledge of services and confidence to refer patients appropriately. The voice of the bereaved parents had a strong impact on participants and was perceived as a particularly valuable aspect of the workshop.[63]

The ELNEC Pediatric Palliative Care (ELNEC-PPC) project is a train-the-trainer educational program and evidence-based curriculum to provide nurses and others healthcare providers with the

knowledge and skills needed to provide palliative care and support families through decision making and perinatal bereavement.[64] The ELNEC-PPC curriculum includes 9 modules: (1) introduction to paediatric palliative nursing care; (2) perinatal and neonatal palliative care; (3) communication; (4) ethics and legal issues; (5) cultural consideration; (6) pain management; (7) symptom management; (8) care at the end of life; and (9) loss, grief, and bereavement. The project was initiated in 2001 and has been implemented in 100 countries.

Support needs

In the absence of resilience-building practices, healthcare professionals may find the emotional strain of providing palliative care and supporting bereaved parents to be unsustainable.[36] Many healthcare professionals do not practise self-care and report to not having education on self-care, yet most would consider self-care plans if training was provided.[36] Facilitators of self-care practices may include supportive environments, self-assessment, prioritisation, and an ongoing planning process. Barriers include overwhelming workload and excessive busyness, stigma against self-care at the workplace, low self-worth or self-criticism, and lack of planning.[36]

"...debriefing is essential. It can be a formal debrief or decompressing with a co-worker about what happened, how I feel about it, etc. The process of 'talking things through' not only helps me digest the situation, learn from it and grow as a nurse." [36]

Even though NICU colleagues generally support each other in difficult end-of-life decisions, more psychological support such as professional ad hoc counselling or standard debriefings is needed.[49] Healthcare professionals, such as neonatologists and nurses, are at risk of developing compassion fatigue and/or burnout, which could have an influence not only on their personal life but also on their ability to care for babies, parents and families.[49]

**"There are no resources for someone with expert skills in specialist palliative care on the ward; aftercare for the core healthcare team in stressful situations is unsatisfactory; doctors only partly deal with the latest findings in neonatal palliative care; and training for the healthcare team has limited resources."
(Nurse, 13–20 years of work experience).[62]**

Grey literature and other sources

In addition to the published academic literature grey literature from international membership organisations (American College of Obstetricians and Gynaecologists and British Association of Perinatal Medicine), Australian government agencies (Safer Care Victoria and Queensland Health), perinatal loss support organisations (Stillbirth Foundation Australia and Together for Short Lives), and websites (WebMD) were searched for information and reports on perinatal palliative care. A targeted Google search was also conducted using a combination of the following keywords: perinatal palliative care, neonatal palliative care, palliative care during pregnancy and life-limiting diagnosis during pregnancy.

In Australia, if a life-limiting condition is diagnosed during the antenatal period, an experienced healthcare professional or a perinatal palliative coordinator (as the role is referred to in the USA) should discuss the aims and plans for maternal and neonatal care during delivery, as well as following the birth.[65,66] These discussions should take place during the pregnancy and also consider any cultural or religious needs and/or preferences the parents may have.[66] In some cases, the term "Advanced Care Planning" will be used to refer to antenatal care planning and birth plans and is an approach that provides space and enables families to share their wishes and hopes for the care that their baby will receive.[67] Shared decision making between parents and healthcare professionals is encouraged during this time .[24]

During the birth, an experienced healthcare professional should be present at the birth to confirm the gestational age and diagnosis.[66] Bereavement care and support for the parents should begin as soon as the life-limiting condition is diagnosed and continue after the baby has died.[68] Bereavement care should include offering the parents and family professional support (social workers, chaplains, grief counsellors) and peer support (parents who experienced similar loss) and educating parents about grief.[68] Also, with the mother's agreement, a universal bereavement symbol (e.g., a teardrop or butterfly), which should be recognised by hospital staff may be placed discreetly in the woman's room and on medical records to indicate a baby has died or is expected to die.[69] Another important recommendation is to collect birth mementoes and compile them in booklets.[69] Birth mementoes may include handprints and footprints or impressions, a lock of hair or the mother and baby's hospital tags.[70]

Finally, when the baby dies, perinatal palliative guidelines in the UK encourage parents to be their baby's primary caregiver "by ensuring the very first cuddle, direct physical contact and bonding opportunity can be achieved at the very beginning of life."[65] This is essential to nurture and enhance the family experience.[65] In some cases, if the baby is expected to live longer than a few days, parents can be provided with the option of caring for and taking their baby home.[66,68]

Considering the demands of providing perinatal palliative care, it is imperative for the healthcare staff to be fully equipped and supported.[21] Perinatal/neonatal palliative care education should be commenced at undergraduate and postgraduate levels. Innovative and multi-modal approaches that include "buddying" with an experienced colleague and opportunities for reflection and debriefing should be incorporated in the curricula.[67,71]

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also include methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies		GRADE-CERQual overall confidence rating of evidence	Guideline recommendations
Abdelbasit 2019 Aidoo 2018 (narrative) Bolognani 2021 Cole 2017 Cortezzo & Meyer 2020 Glass 2019 Grauerholz 2020	Guimarães 2019 (narrative) Kamrath 2019 Locatelli 2020 Martin-Ancel 2022 Power 2020 Wool & Catlin 2019	Low confidence *Moderate concerns of methodological imitation, data adequacy and coherence. Minor concerns of relevance.*	**Consensus-based recommendation 4.1:** When a life-limiting perinatal condition is diagnosed in pregnancy, arrange a formal consultation with parents and family/whānau and the lead healthcare professionals to openly discuss the diagnosis and available options and begin to develop a detailed palliative care plan. A follow-up meeting should be held once parents have had the opportunity to consider and discuss with others the information received.
ACOG 2019 Bolognani 2021 Buskmiller 2021 Carter 2018 Cole 2018 Cortezzo, Ellis 2020 Czynski 2021	Falke 2020 Humphrey 2022 Kilcullen 2017 Lago 2020 Locatelli 2020 Marc-Aurele 2020 Wool & Catlin 2019	Low confidence *Moderate concerns of methodological limitation, coherence and data adequacy. Minor concerns of relevance.*	**Consensus-based recommendation 4.2:** Parallel planning related to potential outcomes should be considered to provide comprehensive information to parents and family/whānau (for example antepartum stillbirth, intrapartum stillbirth, very early neonatal death, survival). Develop a detailed perinatal palliative care plan that includes all phases and transitions of care: • antenatal care plan • birth care plan • newborn care plan • perinatal loss care plan.
Benini 2022 Bernardes 2020 Bolognani 2021 Camilo 2019 Cortezzo 2019 Delany 2017	Grauerholz 2020 Humphrey 2022 Jaaniste 2020 Lago 2020 Martin-Ancel 2022 Sieg 2019	Moderate confidence *Moderate concerns of methodological limitation. Minor concerns of relevance, coherence and data adequacy.*	**Evidence-based recommendation 4.3:** Provide perinatal palliative care within a parent-centred decision-making framework involving parents and family/whānau and the multidisciplinary care team. .

Marc-Aurele 2020	Thornton 2019		
ACOG 2019 Benini 2022 Cole 2017 Crawford 2021 Dahò 2020 Falke 2020 Garten 2018 Glass 2019	Haxel 2019 Humphrey 2022 Kain 2017 Kuchemba-Hunter 2019 Marc-Aurele 2020 Wool & Catlin 2019	Moderate confidence *Moderate concerns of methodological limitation, minor concerns of relevance, coherence and data adequacy.*	**Evidence-based recommendation 4.4:** Discuss the option of community-based perinatal palliative care and ensure community-based practical, social, and emotional support is available, including care at home, outreach, hospice, generalist palliative care services with support from the multidisciplinary team so they can accommodate babies.
			Consensus-based recommendation 4.5: Discuss and provide all required documentation to the parents, family/whānau and community care team members when a baby is to be transferred to community-based care including care at home, outreach, hospice, or generalist palliative services (for example birth registration, letters for transport).
			Consensus-based recommendation 4.6: When a baby has died, provide parents with the option to take their baby home or to cultural, religious, or spiritual places that hold meaning for their family/whānau. Discuss these options with parents and provide accurate information about caring for the deceased baby at home.

Table 4. Search strategy

Database		Search strategy
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/
	2	((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "life limiting" or "life limiting") adj3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term")).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) adj1 loss*) or abortus* or stillb* or (palliative adj5 (pregnancy or newborn or neonate or fetus or feotus))).ti,ab.
	5	1 or 2 or 3 or 4
	6	((palliative or "end of life" or "life limiting" or "life-limiting" or hospice) and (care or treatment or counsel* or carer or diagnosis or prognosis or condition or barrier* or poor or imped* or alternat* or "re-nam*" or reinvent* or "different term" or "different label" or change or "referring to" or "reference to" or training or educat* or mentor* or intern* or conversation* or discussion*)).ti,ab.
	7	((right or appropriate or prefer* or best) adj4 (place or people or person or support or place or environment or ward or room or team)).ti,ab.
	8	(((patient* or parent* or mother* or father* or family or families) adj4 (understan* or need* or resource* or experience* or view* or information or support)) and (palliative or hospice or "end of life" or "life limiting" or "life-limiting")).ti,ab.
	9	((interven* or approach* or support* or support or group* or counsel*) adj8 (grief or bereavement or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness" or psychiatri* or medical)).ti,ab.
	10	*psychosocial care/ or *social support/ or *bereavement/ or *bereavement support/ or *psychological aspect/ or *psychology/ or *major depression/
	11	*hospice care/ or *hospice/ or *hospice nursing/ or *hospice patient/ or exp palliative therapy/
	12	*training/ or *staff training/ or *education/
	13	6 or 7 or 8 or 9 or 10 or 11 or 12
	14	(parent* or mother* or father* or patient or family or "family's" or families or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elder or maori or whanau or cost or economic* or sibling).ti,ab.
	15	(practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or chaplain or "health care team" or team or psychologist or psychiatrist or specialist or "fetal medicine").ti,ab.
	16	*pediatrician/ or *physician/ or *parent/
	17	14 or 15 or 16
	18	5 and 13 and 17

CINAHL	S21	(S5 AND S14 AND S20)
	S20	(S15 OR S16 OR S17 OR S18 OR S19)
	S19	(MM "Parent-Infant Bonding")
	S18	(MM "Physicians") OR (MM "Neonatologists")
	S17	(MM "Pediatricians")
	S16	AB (practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or chaplain or "health care team" or team or psychologist or psychiatrist or specialist or "fetal medicine")
	S15	AB (parent* or mother* or father* or patient or family or "family's" or families or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elder or maori or whanau or cost or economic* or sibling)
	S14	S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
	S13	(MM "Palliative Care") OR (MM "Hospice and Palliative Nursing") OR (MM "Palliative Medicine")
	S12	(MM "Bereavement") OR (MM "Hospice Care") OR (MM "Grief") OR (MM "Depression, Reactive") OR (MM "Complicated Grief") OR (MM "Bereavement Support (Saba CCC)")
	S11	(MM "Support, Social")
	S10	(MM "Stress, Psychological") OR (MM "Models, Psychological") OR (MM "Human Needs (Psychology)") OR (MM "Psychological Well-Being")
	S9	AB ((interven* or approach* or support* or support or group* or counsel*) N8 (grief or bereavement or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness" or psychiatri* or medical))
	S8	AB (((patient* or parent* or mother* or father* or family or families) N4 (understan* or need* or resource* or experience* or view* or information or support)) and (palliative or hospice or "end of life" or "life limiting" or "life-limiting"))
	S7	AB ((right or appropriate or prefer* or best) N4 (place or people or person or support or place or environment or ward or room or team))

	S6	AB ((palliative or "end of life" or "life limiting" or "life-limiting" or hospice) and (care or treatment or counsel* or carer or diagnosis or prognosis or condition or barrier* or poor or imped* or alternat* or "re-nam*" or reinvent* or "different term" or "different label" or change or "referring to" or "reference to" or training or educat* or mentor* or intern* or conversation* or discussion*))
	S5	(S1 OR S2 OR S3 OR S4)
	S4	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb* or (palliative N5 (pregnancy or newborn or neonate or fetus or feotus)))
	S3	AB (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term"))
	S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
Scopus		((TITLE-ABS-KEY (((fetus* OR antenatal OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*)))) OR (TITLE-ABS-KEY ((("fetal malformation" OR "congenital abnormality" OR "fetal anomaly" OR "congenital anomaly" OR "fetal anomalies" OR "congenital anomalies" OR "life limiting" OR "life limiting") W/3 (condition OR diagnosis OR diagnoses OR terminat* OR abortion OR abort OR continue OR continuing OR "to term")))) OR (TITLE-ABS-KEY ((((foetal OR fetal OR fetus OR perinatal OR "peri natal" OR neonatal OR newborn) W/1 loss*) OR abortus* OR stillb* OR (palliative W/5 (pregnancy OR newborn OR neonate OR fetus OR feotus)))))) AND ((TITLE-ABS-KEY (((palliative OR "end of life" OR "life limiting" OR "life-limiting" OR hospice) AND (care OR treatment OR counsel* OR carer OR diagnosis OR prognosis OR condition OR barrier* OR poor OR imped* OR alternat* OR "re-nam*" OR reinvent* OR "different term" OR "different label" OR change OR "referring to" OR "reference to" OR training OR educat* OR mentor* OR intern* OR conversation* OR discussion*)))) OR (TITLE-ABS-KEY(((right OR appropriate OR prefer* OR best) W/4 (place OR people OR person OR support OR place OR environment OR ward OR room OR team)))) OR (TITLE-ABS-KEY((((patient* OR parent* OR mother* OR father* OR family OR families) W/4 (understan* OR need* OR resource* OR experience* OR view* OR information OR support)) AND (palliative OR hospice OR "end of life" OR "life limiting" OR "life-limiting")))) OR (TITLE-ABS-KEY (((interven* OR approach* OR support* OR support OR group* OR counsel*) W/8 (grief OR bereavement OR guilt OR psychosocial OR psychotherap* OR compassion* OR psychology* OR psychological OR wellbeing OR "wellbeing" OR "well-being" OR mindfulness OR "mindfulness" OR psychiatri* OR medical))))) AND ((TITLE-ABS-KEY ((parent* OR mother* OR father* OR patient OR family OR "family's" OR families OR migrant OR immigrant OR refugee* OR "indigenous" OR "torresstraitislander*" OR atsi OR aborigin* OR islander* OR remote* OR "linguistically diverse" OR "literacy" OR "low income" OR "cultural care" OR elder OR maori OR whanau OR cost OR economic* OR sibling))) OR (TITLE-ABS-KEY ((practition* OR professional* OR nurs* OR doctor* OR physician* OR midwi* OR obstetric* OR chaplain OR "healthcare team" OR team OR psychologist OR psychiatrist OR specialist OR "fetalmedicine"))))
Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees
	#2	MeSH descriptor: [Perinatal Death] explode all trees
	#3	MeSH descriptor: [Perinatal Mortality] explode all trees

	#4	MeSH descriptor: [Abortion, Induced] explode all trees	
	#5	((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) NEAR/2 (death* OR wast* OR demise* OR mortalit*)):ti,ab,kw	
	#6	(((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) NEAR/1 loss*) OR stillb* OR (palliative NEAR/5 (pregnancy or newborn or neonate or fetus or feotus))))):ti,ab,kw	
	#7	(((((“fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "life limiting" or "life limiting") NEAR/3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term"))))):ti,ab,kw	
	#8	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7	
	#9	(((palliative or "end of life" or "life limiting" or "life-limiting" or hospice) and (care or treatment or counsel* or carer or diagnosis or prognosis or condition or barrier* or poor or imped* or alternat* or "re-nam*" or reinvent* or "different term" or "different label" or change or "referring to" or "reference to" or training or educat* or mentor* or intern* or conversation* or discussion*))):ti,ab,kw	
	#10	(((right or appropriate or prefer* or best) NEAR/4 (place or people or person or support or place or environment or ward or room or team))):ti,ab,kw	
	#11	((((patient* or parent* or mother* or father* or family or families) NEAR/4 (understan* or need* or resource* or experience* or view* or information or support)) and (palliative or hospice or "end of life" or "life limiting" or "life-limiting"))):ti,ab,kw	
	#12	(((interven* or approach* or support* or support or group* or counsel*) NEAR/8 (grief or bereavement or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness" or psychiatri* or medical))):ti,ab,kw	
	#13	MeSH descriptor: [Psychology] explode all trees	
	#14	MeSH descriptor: [Hospice Care] explode all trees	
	#15	MeSH descriptor: [Palliative Care] this term only	
	#16	MeSH descriptor: [Grief] explode all trees	
	#17	MeSH descriptor: [Prolonged Grief Disorder] explode all trees	
	#18	#9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17	
	#19	((parent* or mother* or father* or patient or family or "family's" or families or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elder or maori or whanau or cost or economic* or sibling)):ti,ab,kw	
	#20	((practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or chaplain or "health care team" or team or psychologist or psychiatrist or specialist or "fetal medicine")):ti,ab,kw	
	#21	MeSH descriptor: [Physicians] this term only	
	#22	MeSH descriptor: [Pediatricians] explode all trees	
	#23	#19 OR #20 OR #21 OR #22	
	#24	#23 AND #18 AND #8	
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR "Abortion, Induced"[Mesh]	Mesh
	#2	"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal	Title/abstract

	death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR "Neonatal loss*" OR "Neonatal mortalit*"OR "Neonatal death*" OR "Neonatal Demise*" OR "Newborn death*" OR "Newborn mortalit*"	
#3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])	Title/abstract
#4	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "prenatal diagnosis" OR "life limiting" or "life-limiting") AND (terminat* or abortion or abort))	Title/abstract
#5	#1 OR #2 OR #3 OR #4	
	((palliative or "end of life" or "life limiting" or "life-limiting" or hospice) and (care or treatment or counsel* or carer or diagnosis or prognosis or condition or barrier* or poor or imped* or alternat* or "re-nam*" or reinvent* or "different term" or "different label" or change or "referring to" or "reference to" or training or educat* or mentor* or intern* or conversation* or discussion*))	Title/abstract
	("right place" OR "right people" OR "right person" OR "right support" OR "right environment" OR "right ward" OR "right team" OR "appropriate place" OR "appropriate people" OR "appropriate person" OR "appropriate support" OR "appropriate environment" OR "appropriate ward" OR "appropriate room" OR "appropriate team" OR "best room" OR "best team" OR "best place" OR "best people" OR "best person" OR "best support")	Title/abstract
	((understan* or resource* or view* or support) AND (palliative or hospice or "end of life" or "life limiting" or "life-limiting"))	Title/abstract
	((interven* or approach* or support* or support or group* or counsel*) AND (grief or bereavement or guilt or psychosocial or psychotherap* or compassion* or psychology* or psychological or wellbeing or "well being" or "well-being" or mindfulness or "mind fulness" or psychiatri*))	Title/abstract
	"Hospice Care"[MeSH Terms] OR "Hospice and Palliative Care Nursing"[MeSH Terms] OR "Grief"[MeSH Terms] OR "Prolonged Grief Disorder"[MeSH Terms] OR "Bereavement"[MeSH Terms] OR "Social Support"[MeSH Terms] OR "Psychosocial Support Systems"[MeSH Terms] OR "depression, postpartum"[MeSH Terms]	Mesh
11	#6 OR #7 OR #8 OR #9 OR #10	
12	(parent* or mother* or father* or patient or family or "family's" or families or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elder or maori or whanau or cost or economic* or sibling)	Title/abstract
13	(practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or chaplain or "health care team" or team or psychologist or psychiatrist or specialist or "fetal medicine")	Title/abstract
14	((("Parents"[Mesh]) OR "Physicians"[Mesh]) OR "Pediatricians"[Mesh]) OR "Neonatologists"[Mesh]	Mesh
	#12 OR #13 OR #14	
	#5 AND #15 And #11	

Australian Indigenous HealthInfoNet	“perinatal palliative care”
Informit Indigenous Collection	"perinatal palliative care" or ((neonate or pregnancy) AND (palliative or hospice))

Figure 1. PRISMA flow diagram for screening process

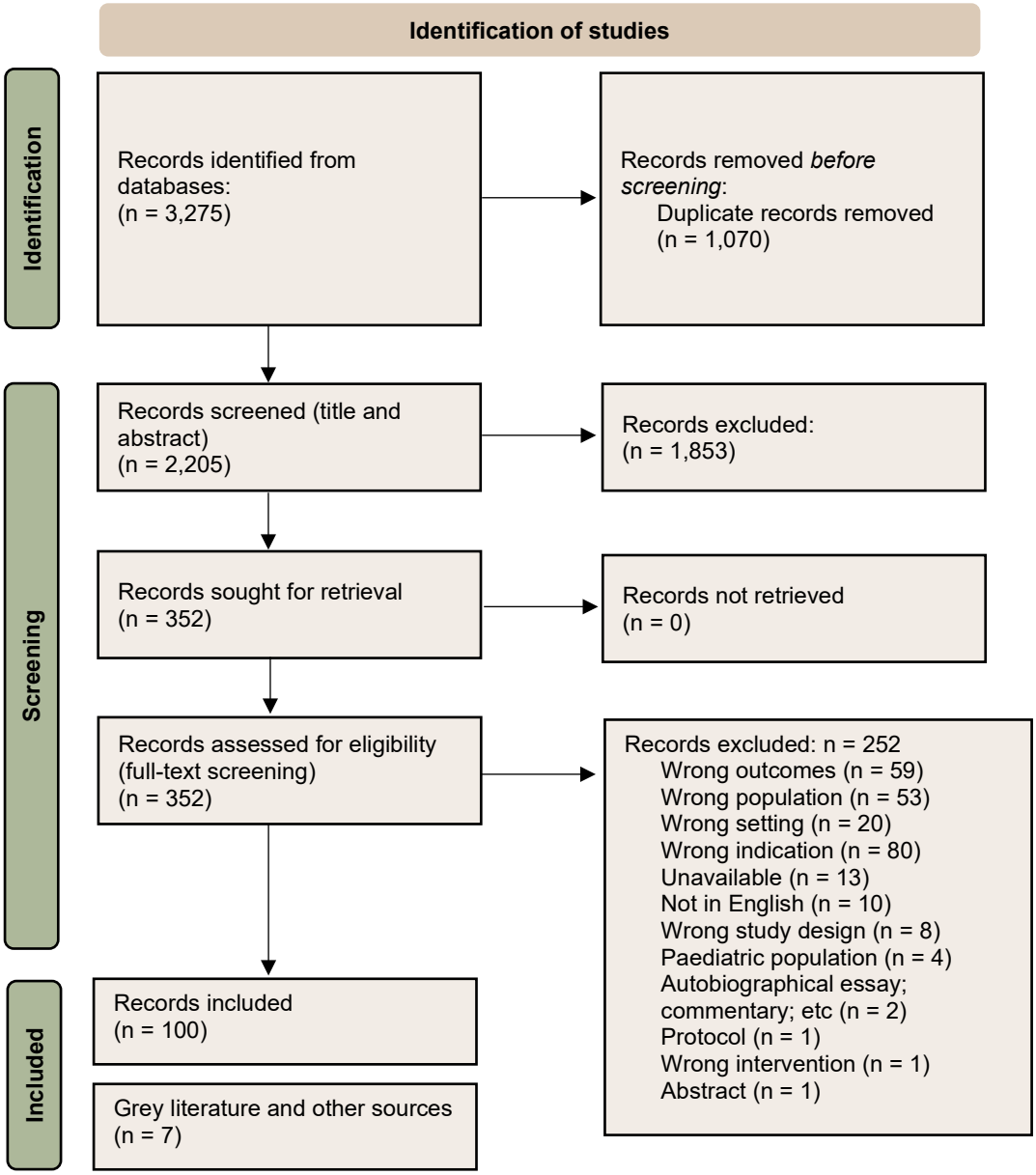

Table 5. Study characteristics

Study	Country (period)	Locality (state/ national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool[a]
Abdelbasit 2019	Saudi Arabia, (2001–2016)	Security Forces Hospital, Riyadh	Hospital records	HIC	Quantitative	NA	Prospective observational study	384 fetuses with lethal congenital malformations	Stillbirth, NND	Palliative care for babies born with lethal congenital malformations	NA	Fetuses diagnosed with lethal congenital malformations	Checklist for analytical cross-sectional studies
Abdel Razeq 2021	Jordan (dates not reported)	2 NICUs	Semi-structured interviews	LMIC	Qualitative	Thematic analysis	NA	12 mothers	NND	Experience of mothers whose babies died in NICU	Not stated	Mothers of neonates born alive and then died in NICU	Checklist for qualitative research
ACOG 2019	USA (2019)	NA	Committee opinion	HIC	Qualitative	Descriptive review	NA	NA	TOPFA	Perinatal palliative comfort care	None mentioned	Patients appropriate for perinatal palliative comfort care, essential components of care, challenges and benefits for patients, HCPs and health care entities, and ethical	Checklist for text and opinion papers

												considerations	
Aidoo 2018	UK (dates not reported)	National	Opinion	HIC	Qualitative	Narrative	NA	NA	NND, end of life care	Summary of NICE guideline for end-of-life care for infants, children and young people with life limiting conditions	NA	NA	Checklist for text and opinion papers
Ainscough 2019	Multiple	International literature	Literature (4 databases)	NA	Qualitative	Narrative synthesis	NA	9 papers (8 studies)	Stillbirth, NND, child death	effectiveness of bereavement support interventions (BSIs) for parents of an infant or a child who has died from a medical condition or in unforeseen circumstances	Studies that (i) focused on supporting pregnancy loss before viability (24 weeks gestation); (ii) evaluated a BSI for parents and other family members (e.g. siblings and grandparents) but did not report effects for each separately; (iii) were a case report,	Studies were eligible for inclusion if they reported (i) primary research, (ii) were published in a peer-reviewed journal and (iii) evaluated the effectiveness of a BSI(s) for the parents of a child who died between 24 weeks gestation	Checklist for systematic reviews and research syntheses

											case series, case study, discussion article or review article; (iv) conducted in a non-OECD country; (v) offered a BSI for the parents of children who were dying but still alive; (vi) tested a BSI for the parents of (adult) children who died while serving in the military.	and 30 years of age	
Akard 2018	USA (dates not reported)	NA	Literature, author's own work	HIC	Qualitative	Narrative review	NA	NA	Palliative care	Components of paediatric palliative nursing care	NA	NA	Checklist for text and opinion papers
Alaradi 2021	USA (June 2017-Aug 2019)	Two large mosques in Louisville, KY	Questionnaire	HIC	Quantitative	NA	Cross-sectional study	79	Miscarriage (n=12), Stillbirth(n=4), NND (n=5)	Arab Muslims' perception of perinatal loss care in the USA	None mentioned	Arab Muslims over 18years of age. Not a requirement to have had experienced perinatal loss.	Checklist for analytical cross-sectional studies

Al Mutair 2019	Saudi Arabia, (Jul–Nov 2018)	1 private hospital in Riyadh	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	13	NND	Staff experience of providing care to dying infants/ children and their families	Not specified	NICU/PICU staff who cared for at least one child who had died	Checklist for qualitative research
Asare 2020	Ghana (dates not reported)	1 public hospital and 2 private hospitals	Interviews	LMIC	Qualitative	Thematic analysis	NA	20 parents	Stillbirth, NND, child death	Emotional, social, psychological, and economic experiences of child loss	NA	Parents experiencing child loss in past 8 years	Checklist for qualitative research
Bae 2022	Korea, (Jan 2019–Aug 2021)	Pediatric Palliative Care Center, Kyungpook National University Children's Hospital	Hospital records	HIC	quantitative	NA	Cross-sectional	10 babies under 1 year	NND	Considerations in the process of initiating palliative care services	NA	Children/ youth with life-limiting conditions (up to 24 years) registered at the study site	Checklist for analytical cross-sectional studies
Beckstrand 2019	USA (dates not reported)	National	Mailed survey including 4 open-ended questions	HIC	Qualitative	Thematic analysis	NA	121 nurses	NND	NICU nurses' suggestions for improving obstacles in EOL care in NICUs	None stated	NICU nurses who were members of National Association of Neonatal Nurses, read English, and had cared for at least one dying newborn were eligible	Checklist for qualitative research

												to participate.	
Benini 2022	International (2016–2020)	International	literature review	Mixed	Qualitative	literature review	NA	Not specified	NND	Standards for paediatric palliative care	None stated	Not specified	Checklist for text and opinion papers
Bernardes 2020	Brazil (May 2015–Sept 2016)	One tertiary fetal medical centre	Retrospective medical records of family conferences	UMIC	Qualitative	Content analysis	NA	50	TOPFA	Family conferences in prenatal palliative care follow-up after the diagnosis of life-limiting fetal condition	None stated	Participation in at least one family conference with the perinatal palliative group at the hospital and delivery at the hospital or another centre followed by participation in postnatal family conference	Checklist for qualitative research
Blakeley 2019 (2)	Multiple (2017–2018)	International	Literature (13 databases)	NA	Qualitative	Thematic synthesis	NA	22 papers	TOPFA	Influencing factors for parents considering termination or continuation of pregnancy following identification of lethal, life-limiting or	Quantitative papers, book reviews, opinion pieces, conference posters or abstracts, literature reviews	Qualitative primary studies in any language examining or considering in any manner parents' decision-making and the factors	Checklist for systematic reviews and research syntheses

										severely debilitating fetal abnormalities		influencing their decision following the diagnosis of a lethal, life-limiting, or severely debilitating disorder, prior to termination or birth	
Boan Pion 2021	Switzerland (Apr–Nov 2019)	National. Swiss tertiary NICUs	Online survey	HIC	Quantitative	NA	Cross-sectional electronic survey	436	NND	Describe perinatal palliative care services, education and training; illustrate availability and awareness of perinatal palliative care guidelines; assess satisfaction with palliative care in general and in particular with perinatal	None stated	All healthcare professionals working in one of the nine level 3 NICUs in Switzerland	Checklist for analytical cross-sectional studies

										palliative care guidelines at participating sites			
Bolognani 2021	Italy (1 Jan 2016–31 May 2020)	Hospital/ Trentino II Level perinatal centre	hospital case records	HIC	Quantitative	NA	Retrospective case records audit	45	NND, Stillbirth	Describe the model of perinatal palliative care	Not specified	Infants eligible for palliative care; newborns at threshold of viability (birth weight <500g or <24 weeks, newborns with life limiting or life-threatening disease diagnosed in utero or at the postnatal ward, newborns not responding to intensive care intervention with high health care needs or medical complexity	Checklist for studies reporting prevalence data

Bourdens 2017	France (1 Jan 2006–31 Dec 2014)	2 French regions (Aquitaine & Marseille; three French prenatal diagnostic centres)	Medical records	HIC	Quantitative	NA	Retrospective data audit	140	TOPFA	outcome of continued pregnancy after a diagnosis of severe fetal abnormality	Any TOP requested for maternal reasons	Continuing pregnancies with a fetal pathology qualifying for a TOP	Checklist for cohort studies
Boyle 2022	Australia (April 2020)	National	Online survey	HIC	Qualitative	Content analysis	NA	35	Stillbirth, NND, TOPFA	Healthcare providers views of the impact of COVID on provision of respectful care to parents and resulting practice changes	None specified	Healthcare providers who provided perinatal bereavement care in clinical settings or through support organisations in Australia	Checklist for qualitative research
Buskmiller 2021	Multiple (2001–2020)	NA	Literature	NA	Qualitative	Narrative review	NA	NA	Fetal anomaly	Scoping review of perinatal palliative care	None mentioned	Background, quality and benefits of offering PPC and ethical principles that support it being offered	Checklist for text and opinion papers
Camilo 2022	Brazil (Dec 2018–Feb 2019)	3 hospitals in Sao Paulo	Semi-structured interviews	UMIC	Qualitative	Thematic analysis	NA	17	NND	Experiences of nurses in neonatal intensive care units in the face of the process	Nurses who were away or on vacation	Nurses working in the neonatal ICU and with experience related to the provision	Checklist for qualitative research

										of communicating bad news to the family of newborns in palliative care.		of direct care to the newborn in palliative care and their family during and after the process of communicating bad news	
Carter 2018	USA (NA)	Multiple	Literature	NA	Qualitative	Literature review	NA	Unclear	NND	Needs for palliative care in NICU	NA	NA	Checklist for systematic reviews and research syntheses
Chong 2017	Singapore (Apr–Jul 2014)	Members of the Asia Pacific Hospice Network	survey	HIC	Qualitative	Content analysis	NA	59 responses from 16 countries	Paediatric palliative care	Service models	NA	NA	Checklist for qualitative research
Cobb 2019	Unclear	NA	Hypothetical case	NA	qualitative	Narrative	NA	NA	Diagnosis of fetal anomaly	trisomy 18	woman undergoing routine 20-week ultrasound	NA	Checklist for text and opinion papers
Cole 2017	USA	Tertiary Hospital	Case study	HIC	Qualitative	Case study	NA	1	NND and Stillbirth	Description of a perinatal palliative care program	None mentioned	Different components of a perinatal palliative care program at one hospital	Checklist for case report studies
Cole 2018	USA (date not reported)	Children's Hospital of Philadelphia	Telephone interviews	HIC	NA	qualitative	Case examples/ narrative	2 women	Stillbirth, NND	experiences of donation of milk after perinatal loss	NA	women donating milk after perinatal loss	Checklist for qualitative research

Cole 2020	USA (date not reported)	Children's Hospital of Philadelphia	Description of bereavement outreach program in a maternal-fetal care centre and words from patients from the perinatal palliative care and bereavement program including those who delivered in the special delivery unit	HIC	Qualitative	Descriptive	NA	Not specified	Stillbirth, NND, TOPFA	Description of bereavement outreach program in a maternal-fetal care centre	NA	NA	Checklist for qualitative research
Cortezzo 2019	USA (1 Jan 2015–31 Dec 2016)	Hospital	Surveys including open-ended questions	HIC	Mixed methods	Thematic analysis	Descriptive cross sectional	20 parents; 116 healthcare professionals	NND	Discover important components of a birth plan, understand the experience of parents and providers with the birth plan	nNt specified	Families enrolled in the institution's perinatal hospice and women seen at the institution's fetal care centre with a diagnosis of severe congenital diaphragmatic hernia,	Checklist for qualitative research Checklist for studies reporting prevalence data

	Trisomy 13 or 18, renal agenesis, anencephaly, holoprosencephaly, severe skeletal dysplasia, limb-body wall complex, encephalocele, hypoplastic left heart syndrome, and potentially life-limiting anomalies, between 1 Jan 2015 and 31 Dec, 2016, with an active email address; and Neonatal Care Association members, a group of neonatologists, and paediatrician

												s who cover delivery hospitals and all OBs and MFMs at hospitals NCA covers who had identifiable emails	
Cortezzo & Meyer 2020	USA (no dates reported)	NA	Literature	HIC	Qualitative	Narrative review	NA	NA	NND	Neonatal end of life symptom management	NA	NA	Checklist for text and opinion papers
Cortezzo, Ellis 2020	Not specified	International	Review of studies	Mixed	Qualitative	Literature review	NA	NA	NND	Perinatal palliative care birth planning as advance care planning	Not specified	Not specified	Checklist for text and opinion papers
Cote-Arsenault 2021	USA (date not reported)	National	Interviews	HIC	Qualitative	Iterative thematic analysis	NA	13	NND	HCPs communication skills, philosophy of care, birth planning, and essential aspects of care	not specified	PPCCs with at least 3 years' experience, deemed experts by colleagues, limited to one participant per site	Checklist for qualitative research
Crawford 2021	USA (2006–2016)	Intermountain West region	Semi-structured interviews	HIC	Qualitative	Thematic content analysis	NA	12	NND	Women's experiences in the perinatal palliative	not specified	Women who had used the service in the last 10 years; 18 or	Checklist for qualitative research

										care program		older, had diagnoses of life-limiting fetal anomalies, English as primary language	
Currie 2019	USA (2009)	University of Alabama, Birmingham	Interviews	HIC	Qualitative	Thematic analysis	NA	10	NND	Parents' coping experiences following NICU hospitalisation and neonatal end of life care	<19 years old, non-English speaking	neonatal death <=15 months prior to interview.	Checklist for qualitative research
Czynski 2021	USA (2019)	Tertiary Hospital	Feedback from staff (questionnaire)	HIC	Qualitative	Exploratory post-implementation acceptability	NA	2	NND	Description of the "Mother Baby Comfort Care Pathway" where mothers and families can room-share with their dying infant. Feedback from Nurses who attended training sessions and cared for	None mentioned	Aspects of the care pathway. Feedback from nurses who attended training sessions on the care pathway and cared for families who opted in to the care model.	Checklist for qualitative research

										families who opted in to the care model			
Dahò 2021	New York (2007)	Hospital	Semi-structured interviews	HIC	Qualitative	linguistic-textual analysis	NA	10	NND	experiences of providers who work in Perinatal Hospice	Not specified	Staff employed at a non-faith-based New York hospital in 2007	Checklist for qualitative research
Dahò 2020	America and Italy (2013–2016)	Hospitals: 2 Italian, 2 American	Postal questionnaires	HIC	Qualitative	Thematic analysis	NA	35	NND	experience of parents with children in perinatal hospice care	not specified	Parents who elected perinatal hospice, at least three months after the event but not more than a year	Checklist for qualitative research
de Barbeyrac 2022	France (Jan 2015–Dec 2016)	Nine Multidisciplinary Centres for Prenatal Diagnosis associated with 10 maternity units and 8 NICUs	Hospital records	HIC	Quantitative	NA	Prospective cohort	736 continuing pregnancies with a diagnosis of a severe fetal condition eligible for TOP; 106 infants where limiting life-sustaining treatments were considered	NND	Prenatal decision-making processes and birth plans in pregnancies amenable to planning perinatal palliative care	Pregnant mothers were not considered for inclusion if the mother refused to participate or opted to terminate pregnancy before any discussion regarding birth planning	Expectant mothers whose fetuses presented with a major and incurable congenital anomaly were eligible when limitation of life-sustaining treatments for the baby	Checklist for cohort studies

								for the newborn in the antenatal period				was discussed among health professionals and with the parents at least once in the antenatal period. All cases continuing with the pregnancy were considered for inclusion.	
Delaney 2022	USA (Nov 2017–Apr 2019)	4 academic medical centres across USA	Focus groups	HIC	Qualitative	Thematic analysis	NA	10 FGDs with 56 parents	TOPFA	Parents' decision-making for their foetus or neonate with a severe congenital heart defect	None stated	Parents who had a foetus or neonate diagnosed within the last 6 months to 5 years with a severe CHD, who chose between one or more of three viable treatment options (i.e., termination, palliative care, or surgery),	Checklist for qualitative research

Delany 2017	Australia (Nov 2014–June 2015)	Royal Children's Hospital in Melbourne	Interviews	HIC	Qualitative	Thematic analysis	NA	18 HCPs	NND	Clinicians' views on the acceptability and usefulness of a paediatric end of life decision making resource	None stated	Health professionals who were closely involved in clinical decision-making and/or provision of care to parents of children who face life-limiting illnesses, including 5 physicians (2 neonatologists, 1 cardiologist, 1 paediatrician, 1 paediatric intensivist) with an average of 21 years' experience, 9 nurses (4 paediatric intensive care unit (PICU) nurses, 1 organ and tissue	Checklist for qualitative research

												donation nurse coordinator, 3 clinical nurse consultants) with an average of 18 years' experience, 2 educational play therapists (with 5 years' experience each), 1 chaplain (8 years' experience) and 1 social worker (15 years' experience).	
Doherty 2021	Canada (Oct 2007–Dec 2017)	The Children's Hospital of Eastern Ontario, The Ottawa Hospital and Roger Neilson House	Retrospective chart review	HIC	Quantitative	NA	Descriptive	85	Stillbirth, NND	Characteristics of the infants and families referred for perinatal palliative care and the context for referrals	Unexpected inter-uterine fetal demise	Antenatal referrals included all cases when a pregnant woman was referred and seen by the palliative care team prior to the birth of the	Checklist for studies reporting prevalence data

												child. Postnatal referrals included cases when the referral occurred after the child's birth even though diagnosis of a life-limiting condition was made prior to birth.	
Dombrecht 2020 (2)	Belgium (May 2017)	8 NICUs in Flanders	Survey	HIC	Quantitative	NA	Population - based study	272 (n=52 neonatologists, n=250 neonatal nurses)	NND	Attitudes of neonatologists and nurses towards perinatal end of life decisions	NA	All neonatologists and neonatal nurses in all eight NICUs in Flanders, Belgium	Checklist for studies reporting prevalence data
Dombrecht 2020 (3)	Belgium (May 2017)	Flanders, Belgium (8 Flemish NICUs)	Self-administered questionnaire (mail survey)	HIC	Quantitative	NA	Non-comparative study	302 (250 neonatal nurses, 52 neonatologists)	NND	Stress in relation to end-of-life decisions, perceived colleague and professional psychological support and whether or not this support is	NA	All neonatologists and neonatal nurses in all eight Flemish neonatal intensive care units	Checklist for studies reporting prevalence data

										sufficient in neonatologists and nurses working in neonatal intensive care units and examines whether psychological support differs between socio-demographic or professional groups.			
Dombrecht 2021	Belgium (Sept 2016–Dec 2017)	Flanders and Brussels	Questionnaire	HIC	Quantitative	NA	Descriptive cross-sectional	229	NND	Prevalence and characteristics of continuous deep sedation until death in neonates on a population level	None stated	All infants under 1 year who died in the inclusion period in Flanders or Brussels whose mother was a Flemish resident	Checklist for studies reporting prevalence data

Dombrecht 2020	Belgium (Dec 2017–Jul 2018)	Four Tertiary Hospital NICUs	Interviews & questionnaires	HIC	Qualitative	Thematic analysis	NA	30	NND	Barriers to and facilitators of end-of-life decision making by Neonatologists and Neonatal Nurses in neonates	None mentioned.	Neonatologists working as resident physicians at one of four Flemish NICUs (university hospitals of Ghent, Brussels, and Leuven, and general hospital Sint-Jan Bruges) between December 2017 and July 2018 who had been the attending/treating physician to at least one child who had died at the NICU where an ELD was made in the past year, and nurses who had been the most involved.	Checklist for qualitative research

Donovan 2019	Australia (2016–2017)	Specialist tertiary and regional services in Australia	Interviews	HIC	Qualitative	Phenomenological study	NA	16	NND	Healthcare providers and educators perspectives on paediatric palliative care	<18 years of age, cognitive impairment, intellectual disabilities, or mental illness.	Healthcare providers and educators involved in paediatric palliative care	Checklist for qualitative research
Falke 2020	USA (2017)	Nebraska	Hospital Consultants	HIC	Qualitative	Opinion piece	NA	1 program implementation review	NND	Establishment of a palliative care program	NA	NA	Checklist for text and opinion papers
Ferrell 2020	USA (2003)	End of life nursing education consortium - Paediatric palliative care. California	Program review	HIC	Qualitative	Program review	NA	1	Palliative care	Educational content for health care providers for palliative care.	NA	NA	Checklist for text and opinion papers
Flaig 2019	Germany (2015)	NR	Interviews	HIC	Qualitative	Grounded theory	NA	10 HCPs from pregnancy counselling services	Pregnancy counselling with parents	The need for a structured perinatal palliative care program and how framework of such a program should be conceived.	Lack of professional expertise.	Professionals of pregnancy counselling, experience, interest in the research question.	Checklist for qualitative research
Forman 2020	NR	NR	Literature	HIC	Qualitative	Narrative review	NA	NA	NND	Palliative care	None	None	Checklist for text and opinion papers

Fortney 2020	USA (2017-2019)	Midwestern, level IV regional referral NICU	Paper-pencil survey	HIC	Quantitative	NA	Longitudinal cohort study	593 Nurse-infant pairs	neonatal care and suffering of infants and nursing staff	NND - care and suffering	Nurses caring for infants with neonatal abstinence syndrome.	Nurses caring for infant who had been born >23 weeks GA, had one parent >18 years who could speak English.	Checklist for cohort studies
Fry 2020	USA (2010–2016)	Children's Hospital Neonatal Database	Medical records	HIC	quantitative	NA	retrospective cohort	6299 non-surviving infants in 32 NICUs	infants who die in regional NICUs	impact of inter-centre variation and patient factors on end-of-life practices	Deceased infants admitted during 2010-16 to participating CHND centres	Incomplete infant records; readmitted prior to death; or death occurred before admission/referral	Checklist for cohort studies
Gandino 2020	Italy (date no specified)	16 Italian hospitals	Questionnaire including open-ended qs	HIC	qualitative	linguistic analysis	NA	485 healthcare professionals	Stillbirth, NND	impact of perinatal loss	NS	physicians, nurses, midwives, ward assistants	Checklist for qualitative research
Garten 2018	Germany (Jan 2009–Dec 2013)	Charite University Medical Center, Berlin	retrospective chart review	HIC	quantitative	NA	cross-sectional	149 neonates designated as comfort care (death anticipated within hours to weeks)	NND	need for planning transition out of NICU	NS	neonates with a life-limiting or life-threatening condition	Checklist for analytical cross-sectional studies

Ghoshal 2017	India (dates not specified)	Tata Memorial Centre, Mumbai	Narratives	LMIC	qualitative	narrative	NA	staff/parents and family (exact numbers not stated)	NICU palliative care	experience of care	NA	NA	Checklist for text and opinion papers
Gibelli 2021	Brazil (Jan 2015–31 Dec 2017)	Child and Adolescent Institute, Ho spital das Clinicas HCFMUSP, Faculdade de Medicina, Universidade de Sao Paulo, Sao Paulo r	Medical records	UMIC	quantitative	NA	retrospectiv e cohort	74 hospitalised newborns with major congenital anomalies	newborns with congenital anomalies	parental decision-making on limiting therapeutic interventions (LTI)	NS	newborns with congenital anomalies	Checklist for cohort studies
Gilmour 2017	Australia (1 Jan 2012–30 Jun 2014)	Royal Brisbane and Women's Hospital, Brisbane, Queensland	Medical charts and death certificates	HIC	Quantitative	NA	Retrospectiv e cohort study	46	NND	End-of-life care provided in an Australian tertiary neonatal centre, where paediatric palliative care was accessible via a consultative service	Stillborn, pre-viable infants (<400g/<23 weeks GA), aged>1 year, no opportunity for palliative care intervention	Liveborn infants, born 01/01/2012-30/06/2014, neonatal admission at RBWH, died<=1year	Checklist for studies reporting prevalence data
Glass 2019	USA (NA)	NA	Literature	HIC	qualitative	narrative	NA	NA	paediatric palliative care	operative or diagnostic procedures requiring anaesthesia	NA	NA	Checklist for text and opinion papers

Grauerholz 2020	US (2020)	International for scoping review. 4 cities in US for interviews.	Literature (4 databases); Semi-structured Interviews	HIC	Qualitative	Scoping review; Content analysis	NA	6 for interviews (4 RNs, 2 physicians); 21 articles for scoping review	NND	Barriers and facilitators of professional resiliency in perinatal palliative care	NA	Systematic reviews, qualitative case studies, and quantitative survey studies that had been published between January 2009– January 2020 for scoping review. Four registered nurses and two physicians involved in various perinatal palliative and hospice care programs or interviews.	Checklist for qualitative research
Greydanus 2021	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	NND	Basic principles of newborn palliative care	NA	NA	Checklist for text and opinion papers
Guimarães 2019	Portugal (dates not reported)	1 level 3 NICU in Portugal	Case studies	HIC	Qualitative	Narrative	NA	2	Prenatal palliative care for	Overview of a perinatal palliative care	NA	Prenatal diagnosis of fetal anomaly	Checklist for case report studies

									severe fetal anomaly	program following prenatal diagnosis of severe fetal anomaly at a NICU in Portugal			
Hancock 2018	USA (Apr 2013–Aug 2015)	One university hospital	Pre-post Questionnaires	HIC	Quantitative	NA	RCT	38 (n=18 intervention group, n=20 standard care)	NND	Early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease	Neonates born at less than 32 weeks of gestation requiring management in the neonatal ICU and neonates diagnosed with major non-cardiac anomalies requiring additional surgery beyond cardiac surgery in the neonatal period	English-speaking mothers pregnant with fetuses with single-ventricle heart disease planned to undergo the first stage of single-ventricle palliative surgery during the neonatal period	Checklist for randomised controlled trials
Haxel 2019	USA (2008–2017)	1 tertiary cardiac centre	Electronic medical records	HIC	Quantitative	NA	Retrospective case series	75	NND	Outcomes of fetuses and neonates with the diagnosis of severe or	NA	Pregnant women and fetuses or neonates followed by the Neonatal	Checklist for case series studies

											complicated congenital heart disease treated with Neonatal Palliative Care		comfort care team at the study institution from 2008 to 2017 in the setting of a prenatal diagnosis of single ventricle CHD or another CHD with multiorgan dysfunction and/or severe genetic syndrome	
Hildenbrand 2021	USA (Sept–Nov 2020)	National	Online survey	HIC	Mixed methods	Content analysis	Cross sectional	131	NND	Roles of psychologists in delivering paediatric palliative care (PPC) services, barriers and facilitators of psychologists' PPC, and strategies to improve psychology integration into PPC.	NA	Participants were eligible if they reported that they (a) were currently employed at a hospital that serves paediatric patients located in the United States, (b) were involved in	Checklist for qualitative research Checklist for analytical cross-sectional studies

												delivering PPC services at their hospital, and (c) were a licensed independent practitioner (i.e., not currently in the process of completing professional training).	
Humphrey 2022	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	NND	Longitudinal Perinatal Palliative Care for Severe Fetal Neurologic Diagnoses	NA	NA	Checklist for text and opinion papers
Hutti 2019	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND, TOPFA	Application of Hutti Perinatal Grief Intensity theoretical framework and guided participation to nursing care for bereaved families	NA	NA	Checklist for text and opinion papers
Jaaniste 2020	Australia	NA	Literature	HIC	Qualitative	Narrative review	NA	NA	NND	Communication between	NA	NA	Checklist for text and

	(dates not reported)									parents and well-siblings in the context of living with a child with a life-threatening or life-limiting condition			opinion papers
Kachlova 2021	Czech Republic (Apr–Sep 2020)	5 perinatology centres in the Czech Republic	Standardised questionnaire	HIC	Quantitative	NA	Cross sectional	109	NND	Attitudes of nurses to providing perinatal palliative care	NA	Nurses with a minimum of 1 year experience working at a neonatological ICU	Checklist for analytical cross-sectional studies
Kain 2017	Australia (dates not reported)	1 tertiary level hospital in SE Australia	Pre-post questionnaires	HIC	Quantitative	NA	RCT	40 (n=25 intervention n=15 waitlist control)	NND	Evaluation of an online educational program to improve neonatal palliative care	NA	Members of a multidisciplinary team at a tertiary level hospital in South-east Queensland, Australia who provide care to neonates who may not be expected to survive and their families.	Checklist for randomised controlled trials

Kain 2021	Multiple (2020)	International	Literature (5 databases)	NA	Qualitative	Literature review	NA	14 studies	NND/ Palliative care	Cultural, spiritual, and religious practices of parents and how this might impact neonates who are born with a life-limiting fetal diagnosis	None stated	All empirical and research studies published in English that focus on the cultural and religious needs of parents who opted to continue a pregnancy in which the fetus had a life-limiting condition or had received perinatal palliative care. Gray literature from religious leaders about the Great Religions were also considered	Checklist for systematic reviews and research syntheses
Kamrath 2019	USA (2011–2014)	1 public university-based medical centre in the Midwest	Electronic medical records; FGDs and interviews	HIC	Mixed methods	Thematic analysis	Case series	27 mother-infant pairs for quantitative component; 7 mothers for	NND/ Palliative care	Maternal experience after being offered perinatal palliative care	NA	Mothers of infants with a life-limiting condition who were offered perinatal	Checklist for qualitative research Checklist for case series studies

								qualitative component				palliative care	
Katz 2020	Australia (15 Feb–17 Mar 2019)	1 quaternary paediatric referral centre	Learning needs survey; Program evaluation survey	HIC	Mixed methods	Thematic analysis	Before-after study	157 for learning needs survey; 19 for evaluation surveys	NND	Clinicians' experience, attitudes and confidence with advance care planning and its application to the development of a simulation-based education program	NA	Hospital staff providing continuing care for children with life-limiting conditions	Checklist for qualitative research Checklist for quasi-experimental studies
Kilcullen 2017	Australia (dates not reported)	Townsville Hospital	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	8	NND	perceptions of neonatal nurses about facilitators and barriers to delivery of palliative care and the impact of the regional location of the unit	None mentioned	part-time and full-time neonatal nurses who had experience providing palliative care in the neonatal context	Checklist for qualitative research
Knighting 2019	UK (2012–2015)	1 children's hospital in UK	Pre-post questionnaires, interviews	HIC	Mixed methods	Thematic analysis	Pre-post intervention	70 for quantitative component; 4 for interviews	NND	Evaluation of a palliative care education workshop	NA	Staff from neonatal units in the 9 hospitals of the Neonatal Clinical Network and	Checklist for qualitative research Checklist for quasi-

												other appropriate professionals working across the area including those from the children's hospices who attended the workshop	experimental studies
Kuchemba-Hunter 2019	USA (2015)	NA	Personal narrative	HIC	Qualitative	Narrative illustration	NA	NA	Stillbirth	Compassion and community in perinatal palliative care	NA	NA	Checklist for text and opinion papers
Kuebelbeck 2020	US (no dates reported)	NA	Literature, personal narrative	HIC	Qualitative	Narrative	NA	NA	NND	Perinatal hospice for palliative care	NA	NA	Checklist for text and opinion papers
Kukora 2017	USA (Apr 2012–Oct 2014)	Fetal Diagnostic Center (FDC) at the University of Michigan	Hospital database	HIC	Quantitative	NA	Retrospective cohort	44 (n=23 mothers with 24 fetuses APCC group, n=21 mothers with 24 fetuses no APCC group)	NND	Antenatal palliative care consultation (APCC) and its implications for decision making and perinatal outcomes	Women lost to follow-up after neonatology consultation	Mothers/ fetus pairs receiving and not receiving APCC	Checklist for cohort studies

Kyc 2020	USA (2017)	1 level 4 NICU in US	Electronic survey	HIC	Quantitative	NA	Cross-sectional	139 (n=50 medical staff, n=89 nursing staff)	NND	Institutional and individual barriers to and facilitators of neonatal palliative care from medical and nursing perspectives	NA	Medical (attending physicians, neonatology fellows, nurse practitioners, and physician assistants) and nursing (registered nurses) staff working in a 64- bed level IV NICU in the United States	Checklist for analytical cross-sectional studies
Lago 2020	Multiple/ no dates reported	International	Literature, position statements, guidelines	HIC	Qualitative	Narrative review	NA	36 papers	NND	Summary of the key concepts and principles in the development of a perinatal palliative care program	NA	Literature, position statements and guidelines on perinatal palliative care	Checklist for text and opinion papers
Laing 2020	Australia/ 2012-2014	National	Personal Inventory Questionnaire, group blog activity, FGDs, email interviews	HIC	Qualitative	Thematic analysis	NA	17 midwives	NND	Midwives' experiences of caring through, and learning from,	None stated	Current registration with the Australian Health Practitioner Regulation	Checklist for qualitative research

										perinatal death		Agency (AHPRA) as a Registered Midwife or Midwifery Student; experience in caring for a minimum of one mother whose baby died during the perinatal period; and access to a computer with internet and a telephone to be able to take part in data collection activities.	
Leitao 2021	Ireland (2019, 2020)	National for pilot workshop; 3 maternity units for second workshop	Paper feedback questionnaires completed after the two program workshops	HIC	Quantitative	NA	Descriptive	36 for first workshop; 47 for second workshop	Stillbirth, NND, TOPFA	Evaluation of a perinatal bereavement care training program for HCPs	None stated	HCPs participating in the training workshops	Checklist for studies reporting prevalence data
Lin 2022	US/ no dates reported	International	Literature	HIC	Qualitative	Narrative review	NA	NA	NND	Ethical concept of "the equivalence	NA	Summary of the history, philosophy, and clinical	Checklist for text and opinion papers

										thesis" in neonatology		significance of ET, situating ET within empiric outcomes research on neonatal mode of death, and review of perspectives and experiences of neonatologists and parents on EOL care in the NICU.	
Linebarger 2020	US/ no dates reported	NA	Opinion	HIC	Qualitative	Narrative	NA	NA	NND/ Stillbirth	Pregnancy accompanied by palliative care	NA	NA	Checklist for text and opinion papers
Listermar 2020	Sweden (2014-2016)	40 maternity clinics in Sweden	Open-ended response on questionnaire	HIC	Qualitative	Content analysis	NA	110	Stillbirth	Midwives' experience of using cold cots	None mentioned	Midwives using cooling cot (Cubitus baby) while caring for parents of a stillborn child	Checklist for qualitative research
Locatelli 2020	Italy/ 2013-2020	Sant'Orsola Hospital in Bologna	Program description	HIC	Qualitative	Case study	NA	1	NND	Description of a perinatal palliative care	NA	Different components of a perinatal palliative	Checklist for case report studies

										program in Italy		care program at one hospital	
LoGiudice 2018	US	NA	Literature,	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth, NND, TOPFA	A model of perinatal palliative care in a United States midwifery education program	None mentioned	Components of a perinatal palliative care model, and implementation of the model, taught in the Fairfield University midwifery program.	Checklist for text and opinion papers
Lord 2022	Canada (dates not reported)	NA	Opinion; Literature	HIC	Qualitative	Narrative paper	NA	NA	Prenatal diagnosis of fetal anomaly	Role of palliative care in the face of uncertainty	NA	NA	Checklist for text and opinion papers
Macauley 2019	US/ no dates reported	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Palliative care	Negative connotations of using the terminology 'life limiting' in paediatric palliative care	NA	NA	Checklist for text and opinion papers
Marc-Aurele 2020	US/ no dates reported	NA	Literature	HIC	Qualitative	Narrative review	NA	NA	Stillbirth, TOPFA	Shared decision making when parents are faced with life-limiting	NA	NA	Checklist for text and opinion papers

										fetal diagnoses			
Marc-Aurele 2017	US/ no dates reported	NA	Literature, opinion	HIC	Qualitative	Narrative review	NA	NA	NND	Trends in neonatology and barriers to implementing palliative care in intensive care settings	NA	NA	Checklist for text and opinion papers
Martin-Ancel 2022	Spain (not dated)	National	Literature	HIC	Qualitative	Narrative review	NA	NA	Stillbirth, NND, TOPFA	Guidelines for perinatal palliative care	None mentioned	Characteristics of palliative care for perinatal life limiting and life-threatening diseases	Checklist for qualitative research
McLaughlin 2020	US/ Jan 2015-Dec 2016	1 children/s hospital in Georgia	Medical records	HIC	Quantitative	NA	Retrospective cohort	64 infants	NND	Description of palliative care services for seriously ill infants at a hospital and association between palliative care consultations and less aggressive interventions near the end of life	Infants who were admitted and died within 24 hours of admission, and infants who transferred to another hospital, were discharged home, or died outside the hospital	Infants who were initially admitted to the NICU and died at the hospital between January 1, 2015, and December 31, 2016	Checklist for cohort studies

McNeil 2020	Multiple (Dec 2019)	International	Literature	LMICs	Qualitative	Narrative review	NA	11 papers	Stillbirth, NND	Grief and bereavement support for parents after the death of a child	None mentioned	Articles were included if they specifically evaluated the bereavement experience of parents after the death of a child in a LMIC	Checklist for systematic reviews and research syntheses
Mendes 2017	Multiple (Jan-June 2015)	International	Web data from perinatalhospice.org (comments from parent advocates, clinicians and researchers)	NA	Qualitative	Content analysis	NA	Unclear	Perinatal palliative care	Ethical considerations in perinatal palliative care	None mentioned	Comments around ethical considerations in PPC by members of the private lists of the international website perinatalhospice.org	Checklist for qualitative research
Parravicini 2017	US/ no dates reported	NA	Literature	HIC	Qualitative	Narrative review	NA	NA	NND/ Neonatal palliative care	Review of literature regarding neonatal palliative care	NA	NA	Checklist for text and opinion papers
Paraíso Pueyo 2021	Multiple (2018-2019)	International literature	Literature (4 databases)	HIC	Qualitative	Scoping review	NA	9 papers	NND	Nursing interventions to help parents of neonates admitted to	Studies relating to stillbirth, TOP for non-medical	Studies published between 2000-2019 that included mothers	Checklist for systematic reviews and research syntheses

										neonatal intensive care units cope with perinatal loss	reasons, miscarriage	and/or fathers and/or the immediate family who have experienced the death of an infant in the perinatal period in a NICU. Papers written in Spanish whose title and abstract had also been written in English.	
Power 2020	Ireland (dates not specified)	National	Survey	HIC	Quantitative	NA	Modified Delphi, descriptive study	n = 12 round 1 Delphi; n = 7 round 2 Delphi	TOPFA, Stillbirth, NND	Education needs of voluntary organisations supporting parents experiencing perinatal loss	None mentioned	Support organisations who provide care to parents and families who experience pregnancy loss or perinatal death	Checklist for analytical cross-sectional studies
Sieg 2019	Multiple (dates not reported)	International	Literature (2 databases)	NA	Qualitative	Narrative review	NA	15 articles	Neonatal palliative care	What does neonatal palliative care entail, how parents perceive	Articles that focused on palliative care for specific diagnoses	Full-text articles published in English from 2012 that articles	Checklist for systematic reviews and research syntheses

										healthcare providers' actions, what they potentially need at the end of their infant's life, and what bereavement interventions are most supportive for parents	(i.e. life-limiting conditions)	focused on the best interests of neonates and best practices in neonatal palliative care	
Thornton 2019	Multiple (Jan 2019)	International	Literature (4 databases)	NA	Qualitative	Scoping review/ Thematic analysis	NA	25 articles	NND	Memory making in bereavement care for parents who experience the death of a newborn	Opinion pieces, news articles, editorials and review articles; Quantitative studies and those published more than 30 years ago	All original research articles available in English that Included parents of neonates as research participants; included one or more memory making intervention as the focus of investigation or as a finding; and contained original data	Checklist for systematic reviews and research syntheses

												from the perspective of bereaved parents	
Wool & Catlin 2019	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND, miscarriage	Integrated system of care for perinatal bereavement	NA	NA	Checklist for text and opinion papers

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data.

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall appraisal	Relevance
Abdel Razeq 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Al Mutair 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Asare 2020	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Yes	Yes	Include	U
Beckstrand 2019	Unclear	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Include	R
Bernardes 2020	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Boyle 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Camilo 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	R

Chong 2017	unclear	Yes	Yes	Yes	Yes	No	No	Yes	unclear	Yes	Include	R
Cole 2018	unclear	Yes	unclear	unclear	Unclear	Unclear	No	unclear	No	Yes	Include	P
Cole 2020	Not applicable	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	Include	P
Cote-Arsenault 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	R
Crawford 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	R
Currie 2019	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Include	R
Czynski 2021	Unclear	No	Yes	No	No	No	No	No	Unclear	No	Include	R
Dahò 2021	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	Unclear	Yes	Include	P
Dahò 2020	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	Include	R
Delaney 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Delany 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Dombrecht 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	Include	R
Donovan 2019	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	I
Flaig 2019	Unclear	Yes	No	No	No	Unclear	No	Unclear	Yes	Unclear	Include	R

Gandino 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Grauerholz 2020	Unclear	Yes	Yes	Unclear	Yes	No	No	Yes	Unclear	Yes	Include	R
Hildenbrand 2021	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	Include	R
Kamrath 2019	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	R
Katz 2020	Unclear	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Include	U
Kilcullen 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Knighting 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Laing 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	U
Martin-Ancel 2022	Unclear	Yes	Yes	Yes	Yes	Unclear	No	Not applicable	Not applicable	Yes	Include	R
Mendes 2017	Unclear	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Abdelbasit 2019	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	P
Alaradi 2021	Yes	Yes	Unclear	No	No	No	Yes	Yes	Include	I
Bae 2022	Unclear	Yes	Yes	Yes	No	No	Unclear	Yes	Include (marginal)	P
Boan Pion 2021	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Yes	Include	R
Garten 2018	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	Include	P
Hildenbrand 2021	Yes	Yes	Unclear	Unclear	No	Not applicable	Unclear	Yes	Include	R
Kachlova 2021	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes	Include	R
Kyc 2020	Yes	Yes	Unclear	Yes	No	Not applicable	Yes	Yes	Include	R
Power 2020	Yes	Yes	Not applicable	Yes	Not applicable	Not applicable	Yes	Not applicable	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Bolognani 2021	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Cortezzo 2019	Yes	Yes	Unclear	Yes	Yes	Unclear	Unclear	Yes	Unclear	Include	R
Doherty 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Dombrecht 2020 (2)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Include	I
Dombrecht 2020 (3)	Yes	Yes	Yes	Yes	No	Unclear	Yes	No	No	Include	I
Dombrecht 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	U
Gilmour 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Include	R
Leitao 2021	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/sources logically defended?	Overall appraisal	Relevance
ACOG 2019	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	R
Aidoo 2018	Yes	Yes	Yes	Unclear	Yes	Yes	Include	P
Akard 2018	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	R
Benini 2022	Yes	Yes	Yes	Yes	Yes	Unclear	Include	R
Buskmiller 2021	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Cobb 2019	No	Yes	Yes	Unclear	Yes	Not applicable	Include	P
Cortezzo & Meyer 2020	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	I
Cortezzo, Ellis 2020	Yes	Unclear	Yes	Yes	Yes	Yes	Include	R
Falke 2020	Yes	Yes	No	No	Yes	Unclear	Include	R
Ferrell 2020	Yes	Yes	No	Yes	Yes	Yes	Include	R
Forman 2020	Yes	Unclear	Yes	No	Yes	No	Include	R
Ghoshal 2017	unclear	Yes	Yes	Yes	Yes	Not applicable	Include	P

Glass 2019	unclear	unclear	Yes	Unclear	Yes	Unclear	Include	I
Greydanus 2021	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	R
Humphrey 2022	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	R
Hutti 2019	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	I
Jaaniste 2020	Yes	Unclear	Yes	Yes	Yes	Not applicable	Include	R
Kuchemba-Hunter 2019	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	R
Kuebelbeck 2020	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	P
Lago 2020	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Lin 2022	Yes	Yes	Unclear	Yes	Yes	Not applicable	Include	U
Linebarger 2020	Yes	Yes	Yes	No	No	Not applicable	Include	P
LoGiudice 2018	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	R
Lord 2022	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	P
Macauley 2019	Yes	Yes	No	Unclear	Yes	Not applicable	Include	P
Marc-Aurele 2020	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	R

Marc-Aurele 2017	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	R
Parravicini 2017	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Wool & Catlin 2019	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimise errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Ainscough 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Not applicable	Yes	Include	I
Blakeley 2019 (2)	Unclear	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Not applicable	Include	I
Carter 2018	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Not applicable	No	Unclear	Unclear	Include	R
Kain 2021	Unclear	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Unclear	Yes	Not applicable	Include	R
McNeil 2020	Unclear	Yes	Yes	No	Unclear	Unclear	Unclear	Yes	No	Unclear	Yes	Include	U
Paraíso Pueyo 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Include	U
Sieg 2019	Unclear	Yes	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Include	R
Thornton 2019	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Unclear	Yes	Unclear	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Bourdens 2017	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
de Barbeyrac 2022	Not applicable	Not applicable	Unclear	No	Not applicable	Yes	No	No	Unclear	Unclear	Yes	Include	I
Fortney 2020	Not applicable	Yes	Yes	No	No	No	Yes	Yes	Yes	Unclear	Yes	Include	I
Fry 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	NA	Yes	Include	R
Gibelli 2021	yes	no	yes	unclear	unclear	NA	Yes	Yes	NA	NA	Yes	Include	I
Kukora 2017	Yes	Yes	Unclear	No	Not applicable	Yes	Unclear	Yes	Yes	Not applicable	Yes	Include	P
McLaughlin 2020	Yes	Yes	Unclear	No	Not applicable	Yes	Unclear	Yes	Yes	Not applicable	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

RCT studies

	1. Was true randomisation used for assignment of participants to treatment groups?	2. Was allocation to treatment groups concealed?	3. Were treatment groups similar at the baseline?	4. Were participants blind to treatment assignment?	5. Were those delivering treatment blind to treatment assignment?	6. Were outcomes assessors blind to treatment assignment?	7. Were treatment groups treated identically other than the intervention of interest?	8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	9. Were participants analysed in the groups to which they were randomized?	10. Were outcomes measured in the same way for treatment groups?	11. Were outcomes measured in a reliable way?	12. Was appropriate statistical analysis used?	13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?	Overall appraisal	Comments (including reason for exclusion)
Hancock 2018	Unclear	No	Yes	No	Unclear	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Kain 2017	Yes	No	Unclear	No	Not applicable	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Quasi experimental studies

	1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/ exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?	Overall appraisal	Comments (including reason for exclusion)
Katz 2020	Yes	Not applicable	Not applicable	Not applicable	No	Yes	Not applicable	Unclear	Yes	Include	U
Knighting 2019	Yes	Yes	Yes	No	Yes	Yes	Not applicable	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Comments (including reason for exclusion)
Haxel 2019	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Include	P
Kamrath 2019	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case report studies

	1. Were patient's demographic characteristics clearly described?	2. Was the patient's history clearly described and presented as a timeline?	3. Was the current clinical condition of the patient on presentation clearly described?	4. Were diagnostic tests or assessment methods and the results clearly described?	5. Was the intervention(s) or treatment procedure(s) clearly described?	6. Was the post-intervention clinical condition clearly described?	7. Were adverse events (harms) or unanticipated events identified and described?	8. Does the case report provide takeaway lessons?	Overall appraisal	Comments (including reason for exclusion)
Cole 2017	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Include	R
Guimarães 2019	Unclear	No	Yes	Yes	Yes	Yes	No	Yes	Include	R
Locatelli 2020	No	No	Yes	Yes	Yes	Yes	No	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
4.1	When a life-limiting perinatal condition is diagnosed in pregnancy, arrange a formal consultation with parents and family/whānau and the lead healthcare professionals to openly discuss the diagnosis and available options and begin to develop a detailed palliative care plan. A follow-up meeting should be held once parents have had the opportunity to consider and discuss with others the information received.	13 studies are included. Three assessments of programs of care, two cross sectional studies, one prevalence studies, four reviews/opinion pieces, two qualitative primary research studies and one mixed methods study.	Moderate concerns of methodological limitation re noted. Minor concerns are noted through critical appraisal of eight included studies. Five included studies are noted to have moderate concerns of methodological limitation through critical appraisal due to lack of clear methodology, patient demographics and lack of adverse event reporting of three program evaluation reports. Two included qualitative research studies are noted to lack a statement of the researcher's cultural position, or account for it through analysis and findings. Both are further noted to have unclear congruity between research intent and methodology.	Minor concerns of relevance are noted through critical appraisal of the included studies. Nine of the included studies are deemed to be directly relevant to perinatal palliative care. Two studies are deemed to be partially relevant; one study is deemed to be indirectly relevant, and one study is of unclear relevance to perinatal palliative care.	Moderate concerns of coherence are noted due to the differences between opinions facilitation of, and who should be included, in the discussions and family perinatal palliative care plan.	Moderate concerns of data adequacy are noted. All included studies source their data from high-income country populations with the exception of one that includes data from a mixture of low-, middle- and high-income country populations. Outcomes of interest include neonatal death (eight studies) and composite perinatal mortality outcomes (5 studies). All included studies source data from published literature, or hospital records. Moderate concerns of data adequacy are noted due to the lack of family or health care professional viewpoint contained within the evidence.	**Low confidence** *Moderate concerns of methodological imitation, data adequacy and coherence. Minor concerns of relevance.*
4.2	Parallel planning related to potential outcomes should be considered to provide comprehensive information to parents and family/whānau (for example antepartum	14 studies are included. Eight are narrative literature reviews, one	Moderate concerns of methodological limitation are noted.	Minor concerns of relevance are noted.	Moderate concerns of coherence are noted. The over	Moderate concerns of data adequacy are noted.	**Low confidence** *Moderate concerns of methodological*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	stillbirth, intrapartum stillbirth, very early neonatal death, survival). Develop a detailed perinatal palliative care plan that includes all phases and transitions of care: • antenatal care plan • birth care plan • newborn care plan • perinatal loss care plan.	program review, one prevalence study, three primary qualitative research studies, and one systematic review.	Seven of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. Four of the included studies are deemed to have moderate concerns of methodological limitation. Two qualitative research studies due to lack of a researcher statement of cultural position, alongside failure to account for the impact of researcher cultural position on findings and analysis. two reports of care programs fail to adequately describe the patients' demographics and history, or adverse events associated with the program. Three of the included studies are noted to have major concerns of methodological limitation due to all aspects of methodology through critical appraisal.	12 of the included studies are deemed to be directly relevant to perinatal palliative care. One included study is partially relevant. One included study is deemed to be indirectly relevant to perinatal palliative care.	all body of evidence differs in findings and recommendations for policy due to differences in settings, resources available, and the impact of opinion pieces/narrative reviews included that differ in views on care planning.	All included studies source their evidence form high income country populations with the exception of one narrative review, and one systematic review that are unclear in their data source. Outcomes of interest included are neonatal deaths (9 studies), termination of pregnancy for fetal anomaly (1 study, cohort size not reported), and composite perinatal mortality outcomes (four studies (n=47). The view of mothers exclusively is contained in one study, parents collectively is included in data from one study, and the view of health care providers is contained in three of the studies. Moderate concerns of data adequacy are noted due to the small combined sample sizes or both outcomes, and viewpoints from primary research.	*limitation, coherence and data adequacy. Minor concerns of relevance.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
4.3	Provide perinatal palliative care within a parent-centred decision-making framework involving parents and family/whānau and the multidisciplinary care team.	15 studies are included. Five narrative reviews are included, one prevalence study, three systematic reviews, five primary qualitative studies and one mixed methods study.	Moderate concerns of methodological limitation are noted through critical appraisal. 10 of the included studies are deemed to have no or minor concerns of methodological limitation. Four of the included studies are noted to have moderate concerns of methodological limitation, three primary qualitative research studies due to lack of a statement of researcher cultural position, and failure to account of the researcher cultural position through findings and analysis. One systematic review it noted to have major concerns of methodological limitation due to concerns of all aspects of methodology noted through critical appraisal.	Minor concerns of relevance are noted. 14 of the included studies are deemed to be directly relevant to perinatal palliative care. One study is deemed to be of unclear relevance to perinatal palliative care.	Minor concerns of coherence are noted. All studies deemed it necessary to include a decision-making framework through delivery of perinatal palliative care. Differing outcomes of parental involvement were noted in few studies.	Minor concerns of data adequacy are noted. 10 of the included studies reportedly source their data from high-income country settings. Two studies source their data from upper middle income country settings, and one study reports sourcing data from a mixture of income setting countries. Two included studies do not clearly report the setting of the data sourced. Outcomes of interest included within the evidence are neonatal deaths (10 studies, n=171), termination of pregnancy for fetal anomaly (n=50), and composite perinatal mortality outcomes (four studies, n=56). The view of parent is included across four studies (n=81), and health care professionals across four studies (n=151).	**Moderate confidence** *Moderate concerns of methodological limitation. Minor concerns of relevance, coherence and data adequacy.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
						Minor concerns of data adequacy are noted.	
4.4	Discuss the option of community-based perinatal palliative care and ensure community-based practical, social, and emotional support is available, including care at home, outreach, hospice, generalist palliative care services with support from the multidisciplinary team so they can accommodate babies.	14 studies are included. Eight included studies are narrative reviews, two are qualitative primary research studies, one case series, one program of care review, one randomised controlled trial, and one cross-sectional study.	Moderate concerns of methodological limitation are noted through critical appraisal. 10 of the included studies are deemed to have minor concerns of methodological limitation through critical appraisal. Four of the included studies are noted to have moderate concerns of methodological limitation. Three due to a lack of researcher cultural position statement and lack of adjustment for the influence through findings and analysis. One program review narrative lacks clear patient history and lacks a clear timeline. Adverse events associated with the program of care are also not adequately reported. One included randomised controlled trial is noted to have moderate concerns of methodological limitation due to lack of blinding, and differences in the groups at baseline.	Minor concerns of relevance are noted. 11 of the included studies are deemed directly relevant to perinatal palliative care. two of the included studies are deemed to be partially relevant to perinatal palliative care. One study is indirectly relevant to perinatal palliative care.	Minor concerns of coherence are noted. Although community based palliative care is preferred, the available resources effect delivery and sustainability within populations.	Minor concerns of data adequacy are noted. 13 of the included studies source their data from high income country populations, and one study doesn't describe the income setting of populations included. Outcomes of interest include neonatal death (12 studies, n=311), termination of pregnancy for fetal anomaly (one study), and composite perinatal mortality outcomes (three studies). The view of mother is included in one study, parents across two studies, and health care providers views are included in data from three studies. Minor concerns of data adequacy are noted.	**Moderate confidence** *Moderate concerns of methodological limitation, minor concerns of relevance, coherence and data adequacy.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
4.5	Discuss and provide all required documentation to the parents, family/whānau and community care team members when a baby is to be transferred to community-based care including care at home, outreach, hospice, or generalist palliative services (for example birth registration, letters for transport).	One primary qualitative study is included.	Moderate concerns of methodological imitation are noted due to a lack of statement of researcher cultural position, and failure to account for the researchers' cultural position through methods and findings.	No concerns of relevance, the included study is deemed relevant to perinatal palliative care.	NA	The included study sources data from a high-income country population. Outcomes of interest include neonatal death (n=8) and the view of health care professionals is included. Major concerns of data adequacy are noted.	**Consensus based recommendation.**
4.6	When a baby has died, provide parents with the option to take their baby home or to cultural, religious, or spiritual places that hold meaning for their family/whānau. Discuss these options with parents and provide accurate information about caring for the deceased baby at home.	One narrative review is included.	Minor concerns of methodological imitation are noted.	The included study is deemed to be directly relevant to perinatal palliative care.	NA	Major concerns of data adequacy are noted. The included narrative review cites research conducted in high-income country populations.	**Consensus based recommendation.**

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 5: Care in subsequent pregnancies

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

The death of a baby during pregnancy or soon after birth is a devastating outcome with long-lasting psychological, social, and economic consequences which extend into subsequent pregnancies.[1] Many parents will become pregnant again within 12 months of the death of their baby.[1,2]

Women with a history of stillbirth are at high risk of adverse pregnancy outcomes in a subsequent pregnancy including preterm birth, low birthweight, placental abruption, pre-eclampsia, and gestational diabetes.[3-8] Parents who have experienced the tragedy of stillbirth are up to five times more likely to have a stillborn baby in their next pregnancy.[9]

Parents require additional psychological and emotional support during a subsequent pregnancy. Becoming pregnant again can be a daunting prospect for parents and family members and a period of intense anxiety and fear.[10,11] Parents often experience mixed emotions and are at increased risk for anxiety, depression, and post-traumatic stress.[12-14] Parents also report delayed bonding/attachment with their baby as a coping mechanism for psychological distress and fear.[1,4,6,10,15]

Methodology

The Guideline Development Committee identified key research questions (Table 1) about care for families during a pregnancy after stillbirth or neonatal death.

Table 1. Research questions

1	What approaches/models of care and referral pathways benefit parents in a subsequent pregnancy following stillbirth or neonatal death?
2	What is the role of preconception counselling and does this support parents' decision-making around interventions in future pregnancies?
3	What is the role of antepartum surveillance in a subsequent pregnancy following stillbirth or neonatal death, including additional antenatal care visits and additional ultrasound scans?
4	What targeted interventions and preventative strategies are available for parents with risk factors for adverse outcomes including risk factors based on previous cause of death?
5	What considerations will impact on timing and mode of birth in a subsequent pregnancy following stillbirth or neonatal death? What resources are helpful for healthcare professionals and parents to make these decisions?
6	What are the psychosocial needs of parents during a subsequent pregnancy following stillbirth or neonatal death and what forms of support improve psychosocial outcomes?

Criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 2. PICO criteria

PICO	Inclusion criteria
Population	Defined in Australia and Aotearoa New Zealand as: • Stillbirth ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It

	is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[16,17]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[16,17]
	• Inclusion of perinatal deaths following termination of pregnancy
	  ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).

Intervention	• Care during subsequent pregnancies
Comparator	Not applicable – no comparator within research question
Outcomes	Outcomes, processes, and experiences of care during pregnancy subsequent to stillbirth or neonatal loss including: • models of care • optimal therapy and support • referral/handover and discharge • surveillance/monitoring during pregnancy • interventions for families specific to pregnancy subsequent to stillbirth or neonatal death • wellbeing and support needs of families, parents, healthcare professionals • considerations that should be addressed specific to pregnancy after stillbirth or neonatal death. Outcomes, processes, and experiences of care during pregnancies subsequent to stillbirth or neonatal death for: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families.

Literature search

Searches were conducted on 11 October 2022. Search strategies incorporated all PICO criteria and restricted to publications in English (Table 4). Studies from low- and middle-income countries were

included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- Wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- Wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- Wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- Wrong *language*: The study was not published in English.
- Wrong *publication dates*: The study was published prior to 2017.
- Wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[18] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[19]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[20]
- Adequacy: The richness and quantity of data supporting the findings[21]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[22]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence supporting the synthesis findings was formulated following this review, and details of any concerns were identified and listed[23]. Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: What approaches/models of care and referral pathways benefit parents in a subsequent pregnancy following stillbirth or neonatal death?

Parents face a range of challenges when considering and embarking on a subsequent pregnancy after stillbirth including increased engagement with antenatal services for both fetal surveillance and parental reassurance of fetal wellbeing.[4,15,24] Given women with a history of stillbirth are at increased risk for adverse pregnancy and mental health outcomes, families need individualised care plans by a known multidisciplinary healthcare team who can provide continuity of physical and psychological care, ideally from the time of the index stillbirth or neonatal death.[10,11,25-27]

A continuum of respectful and supportive care around stillbirth and neonatal death should be provided—from the time a baby dies through to a subsequent pregnancy.[28]

The paucity of high-level evidence to direct care in pregnancies following stillbirth results in substantial variation in care for parents and families.[11] Guidance for care during subsequent pregnancy to stillbirth or neonatal death needs to incorporate a consistent approach that encourages acknowledgment and recognition of previous pregnancies, and that cares for the families psychosocial, emotional, physical and medical wellbeing.[11,29] In an international survey in 2018, Wojcieszek and colleagues found additional antenatal care visits and ultrasound scans were provided for 67% and 70% of all parents, although there was wide variation across geographic regions. Yet care addressing psychosocial needs was less frequently provided than antenatal visits or ultrasounds scans, such as additional visits to a bereavement counsellor (10%) and access to named healthcare professional's phone number (27%). Specialist antenatal classes for bereaved parents were rarely provided, despite the benefits of group-based/peer antenatal support and education programmes for parents who have experienced loss.[2] In a retrospective cohort study in Ireland, a history of stillbirth was associated with increased surveillance and intervention. The average number of antenatal appointments for women in a subsequent pregnancy was twice than expected, and the average number of ultrasound scans was five times higher than expected. Higher than national rates of induction of labour, caesarean and preterm birth for multiparous women were also observed.[24] The guidelines of The Society of Obstetricians and Gynaecologists of Canada recommend that women attend consultant-led antenatal appointments, with specialised care provided by a multidisciplinary team.[15]

Specialised services and clinics

There is increasing evidence that parents and families appreciate and value continuity of care and carer in pregnancies after stillbirth or neonatal death. Specialised care provided by dedicated clinical services have demonstrated positive outcomes for parents who are pregnant following stillbirth.[10,25] The following paragraphs provide an overview of specialised care services and dedicated clinics in Australia, Canada, and the UK.

In Australia, the Mater Mothers' Bereavement Support Service in Brisbane, developed a Pregnancy After Loss Clinic (PALC).[30] This is a public midwifery-led clinic developed in response to the unique needs of local women in a pregnancy after stillbirth or neonatal death. A multidisciplinary team including PALC midwife, registrar, sonographer, midwives, counsellor, and consultant obstetrician provide emotional and clinical care to parents and families.[30] All PALC midwives have loss and grief

training, and women typically have 13 scheduled appointments and two to six ultrasound appointments during pregnancy. Women have access to antenatal pregnancy after loss parenting classes, dedicated telephone number for access to a PALC midwife (during clinic hours), and 24-hour care through the hospital. Parents can access additional supportive counselling (individual or couples) through the hospital's bereavement service. In an interview study of 10 women attending this service, all women reported their experience of the PALC as overwhelmingly positive. Women who received care at the PALC appreciated the availability and flexibility of the care they received, the emotionally supportive relationships they developed with the PALC midwives, and perceived that their partners, children, and other family members also benefited from the care received. For example: "I just don't think I would've stayed sane into my pregnancy without it.".[30] Mothers attending this specialised clinic appreciated the recognition by PALC midwives of their unique and individual care needs during a subsequent pregnancy: "Everybody was…understanding that you weren't just a normal mum anymore, you were a…pregnant mum coming in with a lot of mixed emotions".

In Australia, the STAR (Stillbirth and Reproductive Loss) Clinic in Melbourne provides care for women who are pregnant again after a mid- or late trimester loss, as well as women who experience recurrent early pregnancy loss (three or more consecutive miscarriages). The STAR Clinic offers pre-pregnancy advice, investigation, and extra support during a subsequent pregnancy through obstetric care, midwifery care, point-of-care ultrasound, and perinatal care. The clinic also offers ongoing care for severe life-limiting conditions.[31]

In Canada, the Subsequent Pregnancy Program at Sunnybrook Health Sciences Centre in Toronto provides parents and families with individualised care plans with women reporting increased satisfaction when given the option of primary care or regular input from knowledgeable and specialised providers (including obstetricians, nurses, midwives).[25] The program offers preconception counselling in addition to care during pregnancy, which includes an individualised prenatal visit schedule, birth plan preparation, peer support, drop-in fetal heart rate checks, breastfeeding consultations, and individualised postpartum follow-up for up to six weeks. The program also provides access to several peer and community supports including Ontario's Healthy Babies Healthy Children Program.[32]

In the UK, a specialist pregnancy after loss service (the Rainbow Clinic) was established in 2014 at a tertiary maternity unit in Saint Mary's Hospital in Manchester, UK.[3] This service focuses on continuity of care provided by an experienced multidisciplinary team with access to specialist perinatal bereavement counselling. Care is individualised and based on circumstances of the previous stillbirth (i.e., history of loss), maternal risk factors and ultrasound scans conducted throughout the subsequent pregnancy. Care follows the international consensus statement for care in pregnancies after stillbirth.[15] A qualitative interview study of 20 women attending the specialised antenatal service was conducted between 2016 and 2018 to explore their experiences of care.[3] All women reported a heightened "awareness of risk" and expressed that navigating their pregnancy relied on them "expecting the worst and hoping for the best" in terms of pregnancy outcomes. Women viewed the provision of specialist care in a dedicated clinical service favourably and reported that this model of care helped to control their anxiety, which was increased due to their awareness of risk.[3] In 2022, a feasibility study of this continuity of midwifery care model (Rainbow Clinics) for women with a history of stillbirth or neonatal death was conducted. Women who received increased midwifery continuity of care reported positive impacts on their pregnancy experience.[33] The continuity of midwifery care model was supported as a beneficial strategy to improve care and support in pregnancy after the death of a baby by parents and professionals.[33] Models of multidisciplinary continuity of care have

been associated with improved clinical outcomes, particularly a reduction in preterm birth and improved patient experience.[11] Based on the UK Rainbow Clinic specialised services, a recommended pathway for care has been developed.[11] In this pathway, care is initiated from the time of the index stillbirth including postmortem investigations and follow-up at a postnatal/preconception appointment. Initial antenatal care is shown in the green boxes and includes commencing appropriate treatment early in the subsequent pregnancy and implementation of screening for small for gestational age/fetal growth restriction with involvement of other relevant specialist services (e.g., maternal medicine clinics, fetal medicine unit). As pregnancy progresses, a plan for birth should be developed that addresses the wishes of the parents and families.[11]

At the initial booking visit, if the previous stillbirth was not adequately investigated, currently no universal tests are recommended.[34] Clinical history and workup at the time of stillbirth should be used to guide testing on a case-by-case basis.

The availability of increased and flexible appointments, opportunity to contact healthcare professionals between appointments (e.g. telephone contact), individualised preparation for birth, and education and postnatal support for parents are common elements of care that have shown to be beneficial to parents in a subsequent pregnancy.[25] However, these elements of care have important implications for clinical services in terms of staff and economic resources.[24] Lack of the necessary infrastructure, staff and expertise, as well as competing demands on resources and service pressures (including shift and roster changes) have been reported as barriers to providing a continuity of care model for parents in a subsequent pregnancy.[2,30,33] The COVID-19 pandemic has also impacted provision of maternity care. Care changes may not necessarily meet the additional care needs of parents and families in a subsequent pregnancy, in turn, leading to unintended consequences or indirect costs of COVID-19.[35] All maternity units should facilitate service requirements, ideally through the development of a dedicated antenatal clinic, to better meet the physical and psychosocial care needs of parents in a subsequent pregnancy following stillbirth or neonatal death while using maternity service resources efficiently.[24]

Effective referral pathways between services and healthcare professionals can improve parent experiences of care in a subsequent pregnancy. Thorough investigation of parents' health and obstetric history allows healthcare professionals to anticipate and provide necessary care including targeted support and referrals.[25] Coordination of referrals between services and healthcare professionals can spare parents the pain of having to disclose their previous pregnancy loss multiple times.[36]

Question 2: What is the role of preconception counselling and does this support parents' decision-making around interventions in future pregnancies?

Postnatal or preconception counselling following stillbirth or neonatal death involves addressing the results of postmortem investigations, parents' medical history, and parents' expectations and management plans for a subsequent pregnancy.[25] Understanding why a baby died is an important step in determining the likelihood of a recurrent stillbirth and identifying preventive strategies in future pregnancies.[37,38] Tsakiridis et al.'s [39] review of guidelines found consensus that medical history and postmortem examination are crucial and that determining the aetiology may improve care in a subsequent pregnancy. If the results of investigations are unavailable, a verbal autopsy may be appropriate to understand what may have been the most likely cause of the index stillbirth.

Most parents will conceive again within a year of a stillbirth, which highlights the need for an organised plan of care during the postnatal period of the index stillbirth.[2] A postnatal/preconception consultation provides an opportunity to address modifiable risk factors prior to conception through interventions such as dietary and supplementation advice, smoking cessation, and weight loss.[11,37] Assisted reproductive technologies can also be discussed and considered given the increased stillbirth risk associated with multiple gestations.[37]

Addressing management of future pregnancies is an important component of postnatal care following a stillbirth.[37]

While limited, evidence suggests that there is no optimal interpregnancy interval to reduce adverse outcomes in a subsequent pregnancy. The risk of stillbirth and other adverse pregnancy outcomes in high-income settings is not altered by short or long interpregnancy intervals.[11,40] An international cohort study investigated the association between interpregnancy interval after stillbirth and birth outcomes in the subsequent pregnancy.[40] There was no associated increased odds of subsequent stillbirth (pooled adjusted OR 1·09 [95% CI 0·63–1·91] for <6 months; 0·90 [0·47–1·71] for 6–11 months), preterm birth (0·91 [0·75–1·11] for <6 months; 0·91 [0·74–1·11] for 6–11 months), or small for gestational age birth (0·66 [0·51–0·85] for <6 months; 0·64 [0·48–0·84] for 6–11 months) for an interpregnancy interval of less than 12 months compared to an interval of 24–59 months. There were also no clear differences in association between interpregnancy interval and birth outcomes by gestational length of the previous stillbirth.[40]

Termination of pregnancy for medical reasons (i.e. fetal anomaly) is associated with long-lasting psychosocial consequences that extend into subsequent pregnancies. Most women perceived genetic counsellors to have a positive impact on their coping by providing information and resources, non-judgemental care and emotional support, and follow-up care. These aspects of support enhanced personal decision-making and hope for the future.[41] Almost half the participants (47%; 46/97) indicated that they would see a genetic counsellor in future pregnancies, and an additional 13% (13/97) reported they had already seen a genetic counsellor in a subsequent pregnancy. The role and expectations for genetic counsellors in future pregnancies included organising genetic testing (57%; 55/97), providing information about genetic testing (56%; 54/97), and reviewing recurrence risk (48%; 47/97).[41] For some population groups, particularly those where consanguineous unions are common, there is a need for proactive genetic counselling and education from the multidisciplinary team, addressing language barriers and cultural beliefs to optimise reproductive outcomes.[42]

Question 3: What is the role of antepartum surveillance in a subsequent pregnancy following stillbirth or neonatal death, including additional antenatal care visits and additional ultrasound scans?

It is difficult to determine precise estimates of risk of stillbirth recurrent according to specific causes of death for the index stillbirth. Also, few interventions are available for healthcare professionals to assist parents in a subsequent pregnancy, which results in wide variation in care and pregnancy management.[11,43] Because there is no reliable way to accurately predict risk, there is a need for increased monitoring in all pregnancies after stillbirth.[7]

In a prospective cohort study in Norway, women in a pregnancy after stillbirth accessed more healthcare services. Women reported more frequent antenatal visits (mean 10.0; 95% CI 9.4–10.7) compared with women with a previous live birth (mean 6.0; 95% CI 5.8–6.2) and previously nulliparous women (mean 6.3; 95% CI 6.1–6.6). Induced labour and caesarean section were also more prevalent in mothers who had experienced stillbirth.[44] While additional antenatal appointments and ultrasound scans may be provided, access to psychological care is less frequently supplied. In another study, parents whose stillbirth occurred at more than 30 weeks' gestation were more likely to receive additional care such as options for early birthing.[8] An international survey of 2,716 parents found that 67% received additional antenatal visits and 70% received additional ultrasound scans; however, only 10% had access to a bereavement counsellor.[2]

Parents with a history of stillbirth may be at risk for fetal growth restriction in the subsequent pregnancy and may benefit from serial growth ultrasound. Serial fetal biometry measurements, as opposed to a single measurement, are recommended for detecting small for gestational age and fetal growth restriction.[10] Other screening methods that may benefit high-risk populations include measuring blood flow through the umbilical or uterine arteries by Doppler ultrasound and assessing placental structure through ultrasound.[11]

Antenatal surveillance strategies include nonstress tests, biophysical profiles, and fetal movement assessment; however, there is no clear guidance on how best to use these tests in pregnancies following a stillbirth.[37] Ultrasound scans may conversely be an extremely stressful event for parents in pregnancy after stillbirth and therefore a tailored approach to offer scans with consideration given to obstetric history and maternal preference is advised.[24]

Fetal movement monitoring is a low-cost test that may identify placental dysfunction and has been shown to reduce stillbirth rates when combined with consistent messaging and appropriate medical follow-up.[15] Healthcare professionals should educate parents about normal variations in fetal movement to help minimise anxiety caused by this surveillance.[25]

Question 4: What targeted interventions and preventative strategies are available for parents with risk factors for adverse outcomes including risk factors based on previous cause of death?

Women with a history of stillbirth are at increased risk of stillbirth in any subsequent pregnancy, even when a live birth has since occurred. Women with a history of stillbirth are also at a higher risk of other adverse pregnancy outcomes, such as preterm birth, low birthweight, and placental abruption.[15] Strategies to prevent recurrent stillbirth include addressing modifiable risk factors, antenatal surveillance, and birth planning.[37]

The risk of recurrent stillbirth depends on the timing of the index stillbirth. A retrospective cohort study including 308,478 women found that previous intrapartum stillbirth was associated with a particularly high risk of recurrence (36/1,000 births, RR 36.50, 95% CI 20.17–66.05). Most of the index intrapartum stillbirths occurred at pre-viable gestations. The recurrence risk of antepartum stillbirth was lower and appeared to be only increased to a clinically significant degree among women with a previous small for gestational age stillbirth.[45] In another retrospective cohort study conducted in the Netherlands including 252,827 women with two consecutive pregnancies between 1999 and 2007, Nijkamp and colleagues[46] found that a history of stillbirth remains an important risk factor for recurrent stillbirth. Compared to women with a live birth in their first pregnancy, women with a prior

stillbirth had a two-fold higher risk of recurrence (adjusted odds ratios (aOR) 1.96, 95% CI 1.07-3.60). Risk was highest in women with an early gestation stillbirth between 22 and 28 weeks (aOR 2.25, 95% CI 0.62–8.15) and decreased for women with a stillbirth after 32 weeks' gestation. For risk of neonatal death, the risk was higher after 34 weeks' gestation for women with a history of stillbirth (aOR 6.48, 95% CI 2.61–16.1) and with expectant obstetric management (aOR 10.0, 95% CI 2.43–41.1).[46]

Risk factors for stillbirth include obesity, smoking, advanced maternal age, fetal growth restriction, hypertension, and diabetes.[11,25] Optimal management of maternal medical disorders is essential to reducing risk of recurrent stillbirth.[37,47] Smoking cessation, discontinuation of any illicit drug use, and weight loss are preconception strategies that should begin as early as the postpartum/preconception counselling visit.

Care for a subsequent pregnancy should commence with investigation of the index stillbirth given increased risk of complications resulting from recurrent placental pathologies, genetic conditions, or persistent maternal disease.[11] A genetic survey, autopsy, and autoimmune and diabetes screening should be performed. Thorough investigation of a woman's health and obstetric history allows healthcare professionals to anticipate and provide necessary care, including targeted supports and referrals. Cases where the index stillbirth is known to be obviously of a nonplacental, nonrecurrent cause, such as cord accident or TORCH (toxoplasmosis, other infections, rubella, cytomegalovirus, herpes simplex) infection, may not require additional treatment or increased frequency of monitoring and ultrasound, although mothers may benefit from the reassurance of knowing their babies' growth is normal. Individualised treatment plans based on the circumstances surrounding the previous loss should be created with consideration for the woman's wishes.[15]

Placental pathology merits consideration in all cases. Women with an unexplained pregnancy loss after 10 weeks' of gestation may warrant testing for antiphospholipid syndrome (APS).[25] At the initial booking visit, if the previous stillbirth was not adequately investigated, currently no universal tests are recommended.[15] Clinical history and workup at the time of stillbirth should be used to guide testing on a case-by-case basis. Pharmacological interventions that are effective and safe during pregnancy may optimise maternal health and reduce risk of placental disorders.[11]

Low dose aspirin and low molecular weight heparin

The use of low-dose aspirin (LDA) to prevent pre-eclampsia is well established, showing early initiation reduced the risk of perinatal death among women at risk for placental insufficiency.[37,48] Current Australian recommendations define low dose aspirin for prevention of pre-eclampsia as 150mg.[49] Routine use of LDA is not indicated for history of stillbirth without other risk factors for pre-eclampsia.

In a Cochrane review, Hamulyák and colleagues assessed the effects of aspirin or heparin, or both, for improving pregnancy outcomes in women with persistent antiphospholipid antibodies and recurrent pregnancy loss.[50] For aspirin versus placebo, it was uncertain whether:

- aspirin has any effect on live birth compared to placebo (risk ratio (RR) 0.94, 95% confidence interval (CI) 0.71 to 1.25, 1 trial, 40 women, very low-certainty evidence)
- compared to placebo, aspirin has any effect on the risk of adverse events including pre-eclampsia, pregnancy loss, preterm delivery of a live infant, intrauterine growth restriction or adverse events in the child.
- compared to placebo, aspirin has any effect on adverse events in the mother (RR 1.29, 95% CI 0.60 to 2.77, 1 study, 40 women).

There is currently no high-grade evidence for use of low-molecular-weight heparin (LMWH) with the primary aim to prevent fetal complications among women with a history of stillbirth.[51] However, it should be considered for women at high risk of maternal venous-thromboembolism due to antiphospholipid syndrome (APS).[51] APS is an autoimmune disorder causing miscarriage and late pregnancy complications.[51] Close surveillance during pregnancy is needed with frequency and modality to monitor women determined according to maternal and/or fetal status. Risk factors should be individually assessed, including the antiphospholipid antibodies (aPL) profile.[51]

In the Cochrane review,[50] Hamulyak and colleagues found heparin plus aspirin versus aspirin may increase the number of live births (RR 1.27, 95% CI 1.09 to 1.49, 5 studies, 1295 women, low-certainty evidence). However, it was uncertain whether:

- compared to aspirin alone, heparin and aspirin have any effect on risk of adverse events including pre-eclampsia, preterm live infant, or intrauterine growth restriction; or adverse events for the mother (e.g., bleeding) (RR 1.65, 95% CI 0.19 to 14.03, 1 study, 31 women).

Due to several factors including imprecision, low numbers of women involved, wide confidence intervals, and risk of bias, the certainty of evidence for these outcomes was very low. Authors concluded that more research is needed to further evaluate potential risks and benefits of this treatment strategy, especially among women with aPL and recurrent pregnancy loss, to gain consensus on the ideal prevention for recurrent pregnancy loss, based on a risk profile.

There is also uncertainty about the safety of heparin and aspirin for mothers and infants because adverse events were frequently not, or not uniformly, reported in the included studies. There is some indication that LMWH may reduce the risk of placenta-mediated complications among women with a history of placental abruption, but further evaluation is needed. Women with thrombotic conditions should pause warfarin and move to LMWH as soon as a subsequent pregnancy is confirmed because warfarin can cause fetal malformations.[51]

Question 5: What considerations will impact on timing and mode of birth in a subsequent pregnancy following stillbirth or neonatal death? What resources are helpful for healthcare professionals and parents to make these decisions?

Early birth is an opportunity for stillbirth risk reduction, but this must be balanced with the risks of prematurity. A retrospective cohort study including 308,478 women found that previous intrapartum stillbirth was associated with a particularly high risk of recurrence (36/1,000 births, RR 36.50, 95% CI 20.17–66.05). Most of the index intrapartum stillbirths occurred at pre-viable gestations. The recurrence risk of antepartum stillbirth was lower and appeared to be only increased to a clinically significant degree among women with a previous small for gestational age stillbirth.[45]

Mode and timing of delivery should be determined through a conversation with the family, balancing the risks of prolonging the pregnancy with issues around late prematurity and early term births. Counselling for elective induction in the subsequent pregnancy should occur around 37–38 weeks' gestation to decrease the risk of perinatal death.[46] Healthcare professionals should openly discuss the possible stresses women may experience, including procedures and tests but also complications of early birth such as neonatal jaundice and breastfeeding challenges.[25]

Decisions around timing of birth should incorporate the circumstances surrounding the previous stillbirth, the clinical picture of the current pregnancy, and the emotional state of the woman and her family, while considering the known risks of birth prior to 39 weeks.[8] In select cases, there may be a role for early term (37–39 weeks) birth. There is no evidence for birth before 37 weeks based on the risk factor of previous stillbirth alone. For the general obstetric population, the optimal time for delivery is at 39 weeks' gestation,.[11] The American College of Obstetricians and Gynecologists (ACOG) and Royal College of Obstetricians and Gynaecologists (RCOG) agree that in the absence of coagulopathies, expectant management should be considered to encourage vaginal birth, but each suggest different labour induction protocols and different management in subsequent pregnancies.

Question 6: What are the psychosocial needs of parents during a subsequent pregnancy following stillbirth or neonatal death and what forms of support improve psychosocial outcomes?

Subsequent pregnancies following stillbirth or neonatal death are typically characterised by mixed emotions including joy, happiness, fear, worry and uncertainty.[52,53] Parents are also at increased risk of anxiety, depression, and post-traumatic stress during pregnancy and the postnatal period.[5,12,54]

A cohort study conducted in the UK explored anxiety, depression, stress, and quality of life among women who were pregnant following perinatal death. Of the 112 participants, self-reported anxiety and depressive symptoms decreased from the highest levels at 15 weeks' gestation to 6 weeks postpartum (e.g. mean GAD-7: 15 weeks 8.2 ± 5.5, 6 weeks postnatal 4.4 ± 5.0, $p<0.001$). A cohort study in Germany found that higher levels of pregnancy-specific distress and tiredness in women with a history of perinatal loss persist and possibly worsen as pregnancy progresses.[55]

Key factors that predict symptoms of depression and anxiety in subsequent pregnancies include a history of severe depression or other psychiatric problems, experiencing three or more stressful events from mid-pregnancy, inadequate social support, history of termination of pregnancy, and history of abuse.[54] A longitudinal cohort study of 2,854 mothers from Canada and Australia identified three distinct longitudinal trajectory patterns of depressive and anxiety symptoms reflecting low (54%), sub-clinical (34%), and clinical symptoms (12%).[54] Women with a history of pregnancy loss, regardless of gestational age of loss, are also more likely to experience symptoms of post-traumatic stress disorder[56] and report higher levels of pregnancy-specific distress in early as well as late pregnancy.[55] Healthcare professionals need simple, accurate, and standardised clinical screening tools to identify parents experiencing psychological distress in the context of previous perinatal bereavement. Understanding factors predictive of long-term sub-clinical or clinical depressive and anxiety symptoms will also improve the capacity of healthcare professionals to identify parents who may benefit from immediate or ongoing monitoring and professional or peer-based support during pregnancy after loss.[54] Parents experiencing complex bereavement and intense grief responses following perinatal loss are likely to benefit from professional follow-up and support.[57]

Mother-baby attachment and bonding

A cohort study in France found women who experienced a termination of pregnancy for fetal anomaly displayed heightened emotional symptoms during the first 20 weeks' gestation, which correlated with reduced prenatal attachment.[58] Despite the emotional symptoms reducing after 20 weeks' gestation, women experienced lower prenatal attachment in the second half of pregnancy than expectant women with a baby at the same gestational age.[58] Parents may also experience parenting-related

stress following a healthy live birth[59] such as perceiving their infant as having more problematic behaviours and having greater difficulty establishing routines with sleeping and eating.[54]

To optimise maternal-fetal attachment, the final ultrasound in the subsequent pregnancy could be an opportunity to screen for attachment problems and provide support where needed.[58] Many families benefit from open discussions with healthcare professionals about the possibility of a difficult attachment process and the potential for conflicting emotions during pregnancy and after the birth of a subsequent child.[25] Healthcare professionals should ask women about their preparations for the baby and acknowledge the unique challenges of pregnancy and parenting after previous stillbirth.[25,54] O'Leary and Henke suggest parents may benefit from support in a therapeutic educational group setting focused on continued bond/attachment theories that suggest parents have an ongoing relationship with both their deceased baby, which began during that pregnancy and is now developing, and with the new baby in the current pregnancy.[57] On the initial visit, a therapist should ask parents to share the story of the deceased baby; how much they weighed, their name, who they looked like, and ask the parents if they would like to share photos of their baby. Unless the parents do not want to share information, the deceased baby's name should be used during future visits. One benefit of participating in a supportive group versus individual therapy is the feeling of universality from being with others who are struggling with similar issues.[57]

A recently published randomised controlled trial[60] found that progressive muscle relaxation exercises may have a positive effect on reducing maternal pregnancy-related anxiety during pregnancies following perinatal loss. Another study suggests that journalling to express thoughts and emotions in a non-judgemental space may enhance women's coping ability.[61]

Supporting parents and building positive parent-provider relationships

An international survey of 2,716 parents found that care addressing psychosocial needs, such as additional visits to a bereavement counsellor (10%) and access to named healthcare professional's phone number (27%), was less frequently provided than medical/physical care such as additional antenatal visits or ultrasounds scans.[2] Further, specialist antenatal classes for bereaved parents were rarely provided, despite the benefits of group-based/peer antenatal support and education programmes for parents who have experienced loss.[2]

Goldblatt Hyatt and colleagues[43] described a Double RAINBOW approach to counselling parents experiencing a pregnancy after stillbirth. This approach encourages strength-based foundations for care that builds on previous experiences and strengthens the relationship between the family and the healthcare professionals.

The Double RAINBOW approach uses prompts of:

- Remember: all previous pregnancies; distinguish each prior pregnancy
- Rehearse and anticipate: use exposure therapy; prepare for anniversaries, due dates
- Attach and internalise: identify safety points and allow for growing attachment
- Interrogate decision: re-visit decision-making to help affirm prior decision
- Neutralise: incorporate cognitive based therapy principles
- Normalise: incorporate acceptance and commitment principles
- Bond: Support celebrations of safe point accomplishments and growing connection to the baby
- Breathe and observe: progressive muscle relaxation and deep breathing

- Optimise health: attend to growing physical endurance, strength, and efficacy
- Weave: use storytelling with positive outcomes as pregnancy persists
- Whole story: develop the coherent narrative: review the entire pregnancy post-birth.

Healthcare professionals can provide trauma-informed care for parents and their families who have experienced a previous perinatal loss.[36] Acknowledging that there was another baby signals to the parents that their care providers are comfortable with the topic and offers them time and space when they may honour all of their babies in the context of the new one.[36] The eight A's mnemonic[36] is a useful way to remember key aspects of perinatal loss care:

- Awareness: learn about each woman's obstetric history and their experiences with previous perinatal loss
- Ask: ask a woman what she wants to talk about
- Acknowledge: acknowledge a woman's previous pregnancy history
- Anxiety: assess a woman's level of anxiety
- Address others' concerns: Address the concerns of other family members as well
- Attachment: be aware that attachment may be delayed
- Appropriate fears: deal with both appropriate (or unwarranted) fears as valid
- Afterward: after the birth, remember that the family may need help with parenting.

Healthcare professionals can begin dialogues with parents by asking "I understand from your history that this isn't your first baby. Is this experience different than you expected?" or "This must be an overwhelming moment. What kinds of feelings are you having?".[36] After confirming that the parent feels it is acceptable to talk about their deceased baby, a compassionate follow-up could be to ask, "Would you like to tell me about that baby?"[62] Using the baby's name is appropriate and appreciated by parents (unless parents indicate otherwise). It is important that nurses and other care providers know what not to say, such as suggesting that this baby can replace the previous child.[36]

Unanticipated events in a pregnancy after loss, such as preterm birth, admission to the neonatal intensive care unit, or resuscitation of baby at birth may trigger a range of negative emotions and increase the parents' need for reassurance and support. Chichester and colleagues suggest that healthcare professionals use cognitive reframing to appropriately reassure parents that their newborn will be closely cared for by the neonatal intensive care unit team and that they may visit, see, and touch their baby as much as they like. Parents demonstrating a delay in attachment or being cautiously optimistic about the health of their baby, may need encouragement to do so.[36]

Ongoing support

After the birth, parents should be provided with information on local parenting support groups and a list of resources before leaving the hospital. Perinatal loss support groups tend to focus on bereavement care; therefore, these groups may not be appropriate unless the parents have unresolved grief from their prior loss.[36] A new parents' support group or a list of available counsellors and psychologists in the area may be more appropriate depending on individual needs.

Summary

Women and families who have experienced prior stillbirth or neonatal death often need additional emotional support, and the entire family should be provided with opportunities for support during pregnancy and the postnatal period. Healthcare professionals should promote family strengths and provide psychosocial screening, targeted follow-up, referrals, and treatment as appropriate. Providing

and encouraging access to a range of bereavement support options is recommended to meet the varying needs of individuals.[63]

Grey literature and other sources

In addition to the published academic literature, websites of international and national government agency and parent support organisations (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) were searched for relevant information relating to care in subsequent pregnancy following a stillbirth or neonatal death. A targeted Google search was also conducted using a combination of the following keywords: care in subsequent pregnancy, managing pregnancy after stillbirth, pregnancy following stillbirth and subsequent pregnancy care after perinatal loss.

Pregnancy after stillbirth or neonatal death can be a difficult, overwhelming, and anxious time and parents are encouraged to seek support from their general practitioner, consultant, or midwife to help manage anxiety or other negative feelings.[64,65] Healthcare professionals should also offer parents access to psychosocial and other support services in line with their concerns, needs and preferences.[66] In addition to psychosocial risks, most pregnancies following stillbirth are categorised as high risk for adverse pregnancy outcomes, with extra care and scans undertaken more frequently to carefully monitor the baby's health and development.[15,64,66-68]

In the UK, not-for-profit organisation Tommy's has established Rainbow Clinics across the country for families who are pregnant again after experiencing a stillbirth or neonatal death.[64] At a Rainbow Clinic, parents are offered specialist care and support including:

- an ultrasound scan at 23 weeks and then at intervals throughout pregnancy
- continuity of consultant-led care with midwifery support
- discussion regarding timing and mode of birth.

Between 2015 and 2017, the Rainbow Clinic conducted a Social Return on Investment study to understand the impacts of its service and how much social value has been created.[69] The methodology of this study involved identifying and comparing the social and environmental impacts of the clinic to its financial costs. The study found that for every pound spent, the Rainbow Clinic created £6.10. This suggests that treating women with a specialist and empathetic model of care is cost-effective and has the potential to reduce pressures felt by health services.

In Australia, subsequent pregnancy care should include preconception review by local healthcare professionals, and early referral to specialist care (i.e., during the first trimester). A review of all available information and results from investigations should guide a subsequent pregnancy care plan to minimise the risk of stillbirth or neonatal death.[66,70,71] Women who have previously experienced a stillbirth with evidence of a small for gestational age baby should be provided with a routine assessment of growth by ultrasound/fetal biometry in their subsequent pregnancy.[70]

Generally, discussions about timing of birth take place towards the end of pregnancy (close to 36 weeks' gestation); however, these discussions should occur sooner if there are any concerns about the baby's health and development. Parents' preferences should also be considered during timing of birth discussions, including any cultural or religious considerations.[66]

Beyond friends, family and professional support that is offered in a pregnancy after loss, many parents will benefit from peer support provided by other parents who are pregnant again after experiencing stillbirth or neonatal death.[72] Several online communities (Instagram, Twitter, blogs etc.) for baby loss welcome expectant parents seeking peer support following the loss of a baby. For one mother in the US, having a "network of mums was critical to [her] emotional health during her subsequent pregnancy". These mothers formed an informal support group and checked in with each other constantly throughout their pregnancies.[72] Peer support is also provided in the form of published books and podcasts.[64]

Royal College of Obstetricians and Gynaecologists

The first edition of the *Royal College of Obstetricians and Gynaecologists (RCOG) Guideline* was published in 2010 with the primary purpose of providing guidance to obstetricians and midwives around the time of a stillbirth. One of the main aims of the guideline is to "incorporate information on general care before, during and after birth, and care in future pregnancies." This guideline has recently been updated.

The RCOG recommendations for subsequent pregnancy care following stillbirth highlight the importance of identifying risk factors for the subsequent pregnancy based on previous history. These risk factors should guide the subsequent pregnancy's antenatal care plan. Screening and assessments should include:

- fetal growth assessments (small for gestational age infants are commonly 2–3 times more frequent in women who have had a previous stillbirth)
- screening for gestational diabetes (women who have had a previous stillbirth are at a higher risk of developing gestational diabetes in a subsequent pregnancy).

Additionally, RCOG's *Late Intrauterine Fetal Death and Stillbirth Green-top Guideline No. 55* recommends the use of low dose aspirin in a subsequent pregnancy following stillbirth, particularly for women with a history of placental insufficiency or pre-eclampsia.

At 39 weeks' gestation, RCOG recommend offering women in subsequent pregnancies following stillbirth an induction of labour. This is due to an increased risk of recurrence secondary to a placental cause. Induction of labour should be offered with specific medical and emotional needs taken into consideration.

It is likely that both parents will have increased psychological needs in a subsequent pregnancy following stillbirth and should be provided with the appropriate supports.

American College of Obstetricians and Gynaecologists

The *Management of Stillbirth Consensus* by the American College of Obstetricians and Gynaecologists (ACOG)[73] was developed in 2020 to review the current information on stillbirth, the evaluation of a stillbirth, and strategies for prevention.

The ACOG recommendations for subsequent pregnancy care following stillbirth are outlined across five key time periods:

- pre-pregnancy or initial prenatal visit
- first trimester

- second trimester
- third trimester
- birth.

The ACOG recommendations support those made by RCOG, with several key additions. Subsequent pregnancy care should be guided by detailed medical and obstetric history, reviewed at the initial pre-pregnancy and prenatal visit, which will help to determine stillbirth recurrence risk. Smoking cessation and weight loss counselling (pre-pregnancy only) should be discussed at initial consultations, with screening for diabetes and thrombophilia testing conducted alongside genetic counselling (if a family genetic condition exists).

- The first trimester should include dating ultrasonography, and first-trimester screening for pregnancy-associated plasma protein A, human chorionic gonadotropin, and nuchal translucency, or cell-free fetal DNA testing.
- In the second trimester, fetal sonographic anatomic survey should be conducted between 18 and 20 weeks, and genetic screening offered if not performed in the first trimester. If genetic screening is performed in the first trimester, single marker alpha fetoprotein testing should be offered in the second trimester.
- Screening for fetal growth restriction should be conducted after 28 weeks in the third trimester, with antepartum fetal surveillance starting at 32 weeks of gestation (1–2 weeks earlier than previous stillbirth).
- Maternal or fetal comorbid conditions should guide the plans for delivery and timing of birth. Planned birth at 39 0/7 weeks' gestation is recommended; however, in the case of severe anxiety, early term birth (37 0/7 weeks to 38 6/7 weeks) may be offered. If early term birth is decided, there must be an understanding of the risk of neonatal complications compared to the potential benefits needs to be considered.

Society of Obstetricians and Gynaecologists of Canada

The *SOGC Clinical Practice Guideline—No. 369 Management of Pregnancy Subsequent to Stillbirth* was developed for healthcare professionals to help guide obstetric management and care in subsequent pregnancies following stillbirth, including antenatal care, intrapartum care, and psychosocial care.

The guideline contains 12 recommendations, including the importance of determining recurrence risk based on the cause of the index stillbirth and other known risk factors. In addition to stillbirth, women who have had a previous loss are at higher risk of experiencing other adverse pregnancy outcomes, such a preterm birth, low birth weight, and placental abruption. Determining risk factors can help reduce all adverse outcomes.

Women who have had a previous stillbirth may benefit from screening for fetal growth restriction through serial growth ultrasound. Some women may also benefit from low-dose aspirin, which may reduce the risk of stillbirth in women at risk for placental insufficiency.

Timing of birth should (generally around 39 weeks) be guided by the current clinical circumstances, as well as the circumstances surrounding the previous stillbirth. Parents' emotions, particularly the woman's, should also be taken into consideration when developing a birth plan. In some cases, early term birth (37–39 weeks) may be offered.

The parents and all family members should be provided with the appropriate psychosocial information and psychosocial support during pregnancy and postpartum. Many parents experience depression, post-traumatic stress, and anxiety. Services should adequately address the diverse grief reactions and needs of parents following stillbirth to help support parents during subsequent pregnancies.

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also includes methodology citations and grey literature.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies	GRADE-CERQual overall confidence rating of evidence	Guideline recommendations
Bakhbakhi 2017 Fockler 2017 Graham, Stephens 2021 Ladhani 2018 Meredith 2017 O'Leary 2017 Page 2020	Moderate confidence *Minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*	**Evidence-based recommendation 5.1:** Offer bereaved parents postpartum/preconception consultation(s) to discuss future pregnancy planning. • Provide information about the types of specialised care and support available that may benefit parents in a subsequent pregnancy.
Fockler 2017 Meaney 2017 Ordóñez 2018 Page 2020 Regan 2019 Roseingrave 2022	Moderate confidence *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*	**Evidence-based recommendation 5.2:** Support parents to plan the timing of a subsequent pregnancy, taking into consideration physical and emotional recovery and the circumstances of the previous birth.
Bakhbakhi 2017 Chichester 2022 Fockler 2017 Graham, Stephens 2021 Gravensteen 2018 Ladhani 2018 Lazarides 2021 Lee 2017 Meaney 2017 Pollock 2021 Roseingrave 2022 Smith 2022 Thomas 2021 Tsakiridis 2022 Wojcieszek, Boyle 2018 Wojcieszek, Shepherd 2018 Wojcieszek 2019	Moderate confidence *No or minor concerns of coherence, relevance and methodological limitation. Moderate concerns of adequacy of the data.*	**Evidence-based recommendation 5.3:** Provide care in a subsequent pregnancy within a continuity of care and carer model with a multidisciplinary focus and appropriate to cultural, religious, and spiritual needs of each family/whānau.

Meredith 2017 Mills 2022 Moore 2018			
Beauquier-Maccotta 2022 Charrois 2022 Chichester 2022 Duman 2022 Faleschini 2021 Fockler 2017 Goldblatt Hyatt 2022 Graham, Stephens 2021 Gravensteen 2018 Ladhani 2018	Lazarides 2021 Lee 2017 Meaney 2017 Meredith 2017 Mills 2022 O'Leary 2017 Ordóñez 2020 Smith 2022 Thomas 2021 Wojcieszek, Boyle 2018 Wojcieszek, Shepherd 2018 Wojcieszek 2019	Moderate confidence *No concerns of relevance or coherence. Minor concerns of methodological limitation and moderate concerns of data adequacy.*	Evidence-based recommendation 5.4: Acknowledge parents' previous loss, including if and how they would like healthcare professionals to refer to their previous baby (for example by name).
Chichester 2022 Duman 2022 Fockler 2017	Ladhani 2018 Shepherd 2018 Wojcieszek,	Moderate confidence *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*	Evidence-based recommendation 5.5: Ensure effective referral pathways and appropriate handover and documentation processes are in place, with previous loss identifiable in medical records.
Fockler 2017 Graham, Stephens 2021 Ladhani 2018	Roseingrave 2022 Smith 2021 Tsakiridis 2022	Moderate confidence	Evidence-based recommendation 5.6: Review maternal risk factors and results of investigations from the previous pregnancy, with detailed clinical history and information from

Meany 2017		*No or minor concerns of methodological limitations, relevance and coherence. Moderate concerns of data adequacy.*	parents, to identify risks and opportunities to improve outcomes. Be aware of and respectful of cultural, religious, and spiritual-based decisions around care following the death of their previous baby including (if any) postmortem investigations. • Be aware of and respectful of cultural, religious, and spiritual-based decisions around care following the death of their previous baby including (if any) postmortem investigations.
Antovic 2018 Bakhbakhi 2017 Fockler 2017 Graham, Stephens 2021 Grandone 2021 Gravensteen 2018 Hamulyák 2020 Ladhani 2018 Meaney 2017 Mone 2021 Moore 2018 Nijkamp 2022 Page 2020	Pollock 2021 Regan 2019 Roseingrave 2022 Schreiber 2017 Shepherd 2018 Smith 2021 Tsakiridis 2022 Van Eerden 2018 Wojcieszek, Wood 2021 Yusuf 2023	High confidence *No concerns of coherence. Minor concerns of methodological limitation, data adequacy and relevance.*	**Evidence-based recommendation 5.7:** At the initial antenatal care visit, explore parents' expectations, concerns, and support needs including: • risk of recurrent perinatal death • number and timing of appointments • availability of support outside appointments and out of hours • need for and access to additional ultrasound scans, investigations, and monitoring • pregnancy milestones and settings that may evoke a heightened emotional response and require additional support • parents' discomfort being around other pregnant women • options relating to timing and mode of birth.

Fockler 2017 Graham, Stephens 2021	Grandone 2021 Roseingrave 2022	Moderate confidence *No or minor concerns of methodological limitation, relevance and coherence are noted. Moderate concerns of data adequacy are noted.*	**Consensus-based recommendation 5.8:** Consider early screening for gestational diabetes mellitus (GDM) in addition to routine screening at 26–28 weeks for women with a previous unexplained stillbirth.
Fockler 2017 Graham, Stephens 2021 Ladhani 2018	Page 2020 Roseingrave 2022 Wood 2021	Low confidence *Moderate concerns of methodological limitations, study adequacy of data, and relevance of the evidence. Minor concerns of coherence.*	**Consensus-based recommendation 5.9:** Determine fetal monitoring frequency based on obstetric history, the circumstances surrounding the index stillbirth or neonatal death, screening findings, and parental preferences. • Consider fetal biometry, amniotic fluid, and fetal Doppler every 4 weeks from 24 weeks' gestation. • Consider additional support requirements for parents at significant milestones.
Ladhani 2018 Page 2020 Wojcieszek, Shepherd 2018		Low confidence *Moderate concerns of methodological limitations, study adequacy of data, and relevance of the evidence. Minor concerns of coherence.*	**Consensus-based recommendation 5.10:** Consider the use of low dose aspirin (LDA) prophylaxis in a pregnancy following loss if preterm pre-eclampsia, or other forms of placental dysfunction, was evident. • Suitable LDA dose is 100–150 mg from 12–36 weeks' gestation. • LDA prophylaxis is not recommended for preventing early pregnancy loss, spontaneous preterm birth or in the context of prior unexplained stillbirth.

Antovic 2018 Graham, Stephens 2021 Grandone 2021	Schreiber 2017 Wojcieszek, Shepherd 2018 Tsakiridis 2022	Low confidence *Moderate concerns of methodological limitations, study adequacy of data, and relevance of the evidence. Minor concerns of coherence.*	**Consensus-based recommendation 5.11:** It is not recommended to routinely offer women low-molecular-weight heparin (LMWH) in pregnancies following stillbirth, unless there are other medical considerations or thrombophilia is present.
Bakhbakhi 2017 Fockler 2017 Ladhani 2018 Nijkamp 2022 Pollock 2021	Roseingrave 2022 Tsakiridis 2022 Wojcieszek, Shepherd 2018 Wood 2021	Moderate confidence *No concerns of relevance or coherence. Minor concerns of data adequacy, and moderate concerns of methodological limitation.*	**Evidence-based recommendation 5.12:** To support parent-centred decision making, discuss timing and mode of birth and consider the circumstances of the previous stillbirth or neonatal death, current pregnancy, and emotional state of parents: • individualise counselling concerning timing and mode of birth • discuss planned birth from 39 weeks' gestation • discuss the potential harm of early planned birth (such as increased chance of neonatal and longer-term adverse outcomes) before 39 weeks' gestation.
Graham, Stephens 2021 Fockler 2017 Ladhani 2018	Meredith 2017 O'Leary 2017 Smith 2022 Tsakiridis 2022	Moderate confidence *No concerns of coherence, minor concerns of methodological limitation and relevance. Moderate concerns of data adequacy.*	**Evidence-based recommendation 5.13:** Offer parents individualised preparation for birth including: • a birth plan that details the likely location of the birth (for example avoiding birthing rooms where the previous baby died) • antenatal classes specific to pregnancy after loss including tailored education (such as on fetal movement) and support • an identifier in medical records to indicate parents have experienced a previous stillbirth or neonatal death.

Beauquier-Maccotta 2022 Charrois 2022 Chichester 2022 Fockler 2017 Lazarides 2021 Lee 2017 Meredith 2017	Mills 2022 Moore 2018 Ordóñez 2018 Ordóñez 2020 Smith 2022 Thomas 2021	Moderate confidence *No concerns of coherence or relevance. Minor concerns of data adequacy. Moderate concerns of methodological limitation.*	**Evidence-based recommendation 5.14:** Engage parents in open discussions about the challenges of pregnancy and parenting after loss by: • anticipating and supporting parents through points in pregnancy and after birth that may be particularly distressing, such as pregnancy milestones and certain settings • acknowledging the mixed emotions relating to the joy of having a baby and the ongoing grief of previous loss • asking about preparations for the baby to help identify and support parents who may experience impediments to parenting such as delayed attachment and bonding.
Azogh 2018 Bakhbakhi 2017 Beauquier-Maccotta 2022 Charrois 2022 Chichester 2022 Duman 2022 Faleschini 2021 Fockler 2017 Goldblatt Hyatt 2022 Graham, Stephens 2021 Gravensteen 2018	Ladhani 2018 Lazarides 2021 Lee 2017 Meaney 2017 Meredith 2017 Mills 2022 Moore 2018 O'Leary 2017 Ordóñez 2018 Ordóñez 2020 Roseingrave 2022 Thomas 2021 Wojcieszek, Shepherd 2018 Wojcieszek, Boyle 2018	Moderate confidence *No concerns of relevance or coherence. Moderate concerns of methodological limitation and data adequacy.*	**Evidence-based recommendation 5.15:** Ask parents about their social and emotional wellbeing and support needs at all antenatal and postnatal care appointments, in addition to routine mental health screening. Appropriately refer to support services where needed. • Provide information on how to access outpatient peer support, professional counselling and psychology services and other local and national perinatal mental health and parenting support services.

Table 4. Search strategies

Database	Search strategy	
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/
	2	((fetal or foetal or fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal") adj1 loss*) or stillb*).ti,ab.
	5	("pregnanc* after" or "next pregnanc*" or recurrent or "care following" or rainbow or ((subsequent or next or following) adj4 (birth or pregnanc*))).ti,ab.
	6	1 or 2 or 3 or 4
	7	5 and 6
	8	((model or models or framewor* or type or types or optimal or optimise or best) adj3 (care or referral or healthcare or "health care" or therapy or interventio*)).ti,ab.
	9	(referral or "hand over" or handover or discharge or (pathway* adj4 care)).ti,ab.
	10	(((psych* or emotio* or preconcept* or genetic) adj4 (care or support or pathwa* or counse*)) or wellbeing or "well being" or "well-being" or posttraumatic or "post-traumatic" or (maternal adj4 (stress or depression or fear or grief or anxiety))).ti,ab.
	11	(surveillance or ((appointmen* or visit or visits or monitor or monitor* or ultrasound or scan*) adj3 (additional or extra or increas*))).ti,ab.
	12	(((plan* or mode* or time or timing or type* or expect* or engage* involve* or pool or bath or submersion) adj2 (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* adj4 contraction*))) or ((while or undergo* or during) adj2 (stillbirth or deliver* or terminat*or induction or abort*))).ti,ab.
	13	(Interven* or therap* or treat or treatment or pathway or counse* or "fetal medicine" or "foetal medicine").ti,ab.
	14	((improv* or better or benefi*) adj3 (outcomes or health or state or result or results or result or results)).ti,ab.
	15	8 or 9 or 10 or 11
	16	14 and 15
	17	(considera* or (decision adj4 (making or make or share or shared))).ti,ab.
	18	10 or 12
	19	17 and 18
	20	7 and 16
	21	7 and 19
	26	(13 or 14) and 7
	27	10 and 7
	28	20 or 21 or 26 or 27

CINAHL	S25	(S20 OR S21 OR S22 OR S23)
	S24	(S20 OR S21 OR S22 OR S23)
	S23	S10 AND S7
	S22	(S13 OR S14) AND S7
	S21	S7 AND S19
	S20	S7 AND S16
	S19	S17 AND S18
	S18	S10 OR S12
	S17	AB (considera* or (decision N4 (making or make or share or shared)))
	S16	S14 AND S15
	S15	S8 OR S9 OR S10 OR S11
	S14	AB ((improv* or better or benefi*) N3 (outcomes or health or state or result or results or result or results))
	S13	AB (Interven* or therap* or treat or treatment or pathway or counse* or "fetal medicine" or "foetal medicine")
	S12	AB (((plan* or mode* or time or timing or type* or expect* or engage* involve* or pool or bath or submersion) N2 (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* N4 contraction*))) or ((while or undergo* or during) N2 (stillbirth or deliver* or terminat*or induction or abort*)))
	S11	AB (surveillance or ((appointmen* or visit or visits or monitor or monitor* or ultrasound or scan*) N3 (additional or extra or increas*)))
	S10	AB (((psych* or emotio* or preconcept* or genetic) N4 (care or support or pathwa* or counse*)) or wellbeing or "well being" or "well-being" or posttraumatic or "post-traumatic" or (maternal N4 (stress or depression or fear or grief or anxiety)))
	S9	AB (referral or "hand over" or handover or discharge or (pathway* N4 care))
	S8	AB ((model or models or framewor* or type or types or optimal or optimise or best) N3 (care or referral or healthcare or "health care" or therapy or interventio*))

	S7	S5 AND S6
	S6	S1 OR S2 OR S3 OR S4
	S5	AB ("pregnanc* after" or "next pregnanc*" or recurrent or "care following" or rainbow or ((subsequent or next or following) N4 (birth or pregnanc*)))
	S4	AB (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort))
	S3	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
	S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Perinatal Death") OR (MM "Abortion, Induced")
Scopus	((TITLE-ABS-KEY((((psych* or emotio* or preconcept* or genetic) W/4 (care or support or pathwa* or counse*)) or wellbeing or "well being" or "well-being" or posttraumatic or "post-traumatic" or (maternal W/4 (stress or depression or fear or grief or anxiety))))) AND (((TITLE-ABS-KEY(((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)))) OR (TITLE-ABS-KEY((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)))) OR (TITLE-ABS-KEY((((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*)))) AND (TITLE-ABS-KEY(("pregnanc* after" or "next pregnanc*" or recurrent or "care following" or rainbow or ((subsequent or next or following) W/4 (birth or pregnanc*))))))) OR (((TITLE-ABS-KEY(((improv* or better or benefi*) W/3 (outcomes or health or state or result or results or result or results)))) AND (TITLE-ABS-KEY((Interven* or therap* or treat or treatment or pathway or counse* or "fetal medicine" or "foetal medicine")))) AND (((TITLE-ABS-KEY(((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)))) OR (TITLE-ABS-KEY((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)))) OR (TITLE-ABS-KEY((((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*)))) AND (TITLE-ABS-KEY(("pregnanc* after" or "next pregnanc*" or recurrent or "care following" or rainbow or ((subsequent or next or following) W/4 (birth or pregnanc*))))))) OR ((((TITLE-ABS-KEY(((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)))) OR (TITLE-ABS-KEY((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)))) OR (TITLE-ABS-KEY((((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*)))) AND (TITLE-ABS-KEY(("pregnanc* after" or "next pregnanc*" or recurrent or "care following" or rainbow or ((subsequent or next or following) W/4 (birth or pregnanc*)))))) AND (((TITLE-ABS-KEY((((psych* or emotio* or preconcept* or genetic) W/4 (care or support or pathwa* or counse*)) or wellbeing or "well being" or "well-being" or posttraumatic or "post-traumatic" or (maternal W/4 (stress or depression or fear or grief or anxiety))))) OR (TITLE-ABS-KEY((((plan* or mode* or time or timing or type* or expect* or engage* or involve* or pool or bath or submersion) W/2 (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* W/4 contraction*))))))) AND (TITLE-ABS-KEY((considera* or (decision W/4 (making or make or share or shared))))))) OR ((((TITLE-ABS-KEY(((model or models or framewor* or type or types or optimal or optimise or best) W/3 (care or referral or healthcare or "health care" or therapy or interventio*)))) OR (TITLE-ABS-KEY((referral or "hand over" or handover or discharge or (pathway* W/4 care)))) OR (TITLE-ABS-KEY((((psych* or emotio* or preconcept* or genetic) W/4 (care or support or pathwa* or counse*)) or wellbeing or "well being" or "well-being" or posttraumatic or "post-traumatic" or (maternal W/4 (stress or depression or fear or grief or anxiety))))) OR (TITLE-ABS-KEY((surveillance or ((appointmen* or visit or visits or monitor or monitor* or ultrasound or scan*) W/3	

	(additional or extra or increas*)))))) AND (TITLE-ABS-KEY(((improv* or better or benefi*) W/3 (outcomes or health or state or result or results or result or results))))) AND (((TITLE-ABS-KEY(((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)))) OR (TITLE-ABS-KEY((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)))) OR (TITLE-ABS-KEY((((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*)))) AND (TITLE-ABS-KEY(("pregnanc* after" or "next pregnanc*" or recurrent or "care following" or rainbow or ((subsequent or next or following) W/4 (birth or pregnanc*)))))))
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Death] explode all trees #3 MeSH descriptor: [Perinatal Mortality] this term only #4 MeSH descriptor: [Abortion, Induced] this term only #5 ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) NEAR/2 (death* or wast* or demise* or mortalit*)) #6 (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) NEAR/1 loss*) or stillb*) #7 (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") NEAR/3 (terminat* or abortion or abort)) #8 (((subsequent or nex* or following) NEAR/4 (birth or pregnan*)) or "pregnan* after" or "next pregnanc*" or recurrent or "care following" or rainbow) #9 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 #10 #9 AND #8 #11 (((model or models or framewor* or type or types or optimal or optimise or best) NEAR/3 (care or referral or healthcare or "health care" or therapy or interventio*))):ti,ab,kw #12 ((referral or "hand over" or handover or discharge or (pathway* NEAR/4 care))):ti,ab,kw #13 ((((psych* or emotio* or preconcept* or genetic) NEAR/4 (care or support or pathwa* or counse*)) or wellbeing or "well being" or "well-being" or posttraumatic or "post-traumatic" or (maternal NEAR/4 (stress or depression or fear or grief or anxiety)))):ti,ab,kw #14 ((surveillance or ((appointmen* or visit or visits or monitor or monitor* or ultrasound or scan*) NEAR/3 (additional or extra or increas*)))):ti,ab,kw #15 (((plan* or mode* or time or timing or type* or expect* or engage* involve* or pool or bath or submersion) NEAR/2 (labor or labour or delivery or parturition or birth* or childbirth or intrapartum or "intra partum" or peripartum or "peri partum" or caesarean or (uter* NEAR/4 contraction*))) or ((while or undergo* or during) NEAR/2 (stillbirth or deliver* or terminat*or induction or abort*))) #16 ((Interven* or therap* or treat or treatment or pathway or counse* or "fetal medicine" or "foetal medicine")):ti,ab,kw #17 ((improv* or better or benefi*) NEAR/3 (outcomes or health or state or result or results)) #18 #11 OR #12 OR #13 OR #14 #19 #17 AND #18 #20 ((considera* or (decision NEAR/4 (making or make or share or shared)))):ti,ab,kw #21 #13 OR #15 #22 #20 AND #21 #23 #19 AND #10 #24 #10 AND #22 #25 ((#16 OR #17) AND #10) #26 #10 AND #13

	#27	#23 OR #24 OR #25 OR #26
PubMed	25	#20 OR #21 OR #22 OR #23
	24	#20 OR #21 OR #22 OR #23
	23	#7 AND #10
	22	#13 AND #14 AND #7
	21	#7 AND #19
	20	#16 AND #7
	19	#18 AND #17
	18	#10 OR #11
	17	(considera*[Title/Abstract] OR "decision making"[Title/Abstract] OR "make decisio*"[Title/Abstract] OR "share decision"[Title/Abstract] OR "shared decision"[Title/Abstract])
	16	#14 AND #15
	15	#8 OR #9 OR #10 OR #11
	14	("improve outcom*"[Title/Abstract] OR "improve health"[Title/Abstract] OR "improved state"[Title/Abstract] OR "improve resul*"[Title/Abstract] OR "better outcom*"[Title/Abstract] OR "better health"[Title/Abstract] OR "better state"[Title/Abstract] OR "better resul*"[Title/Abstract] OR "beneficial outcome*"[Title/Abstract] OR "health benefi*"[Title/Abstract] OR "beneficial health"[Title/Abstract] OR "beneficial state"[Title/Abstract] OR "beneficial resul*")
	13	((Interven*[Title/Abstract] OR therap*[Title/Abstract] OR treat[Title/Abstract] OR treatment[Title/Abstract] OR pathway[Title/Abstract] OR counse*[Title/Abstract] OR "fetal medicine"[Title/Abstract] OR "foetal medicine"[Title/Abstract]))
	12	(((plan*[Title/Abstract] OR mode*[Title/Abstract] OR time[Title/Abstract] OR timing[Title/Abstract] OR type*[Title/Abstract] OR expect*[Title/Abstract] OR engage* involve*[Title/Abstract] OR pool[Title/Abstract] OR bath[Title/Abstract] OR submersion) AND (labor[Title/Abstract] OR labour[Title/Abstract] OR delivery[Title/Abstract] OR parturition[Title/Abstract] OR birth*[Title/Abstract] OR childbirth[Title/Abstract] OR intrapartum[Title/Abstract] OR "intra partum"[Title/Abstract] OR peripartum[Title/Abstract] OR "peri partum"[Title/Abstract] OR caesarean[Title/Abstract] OR (uter*[Title/Abstract] AND contraction*[Title/Abstract]))) OR ((while[Title/Abstract] OR undergo*[Title/Abstract] OR during[Title/Abstract]) AND (stillbirth[Title/Abstract] OR deliver*[Title/Abstract] OR terminat*[Title/Abstract] OR induction[Title/Abstract] OR abort*[Title/Abstract])))
	11	((surveillance[Title/Abstract] OR ((appointmen*[Title/Abstract] OR visit[Title/Abstract] OR visits[Title/Abstract] OR monitor[Title/Abstract] OR monitor*[Title/Abstract] OR ultrasound[Title/Abstract] OR scan*[Title/Abstract]) AND (additional[Title/Abstract] OR extra[Title/Abstract] OR increas*[Title/Abstract])))
	10	((((psych*[Title/Abstract] OR emotio*[Title/Abstract] OR preconcept*[Title/Abstract] OR genetic[Title/Abstract]) AND (care[Title/Abstract] OR support[Title/Abstract] OR pathwa*[Title/Abstract] OR counse*[Title/Abstract])) OR wellbeing[Title/Abstract] OR "well being"[Title/Abstract] OR "well-being"[Title/Abstract] OR posttraumatic[Title/Abstract] OR "post-traumatic"[Title/Abstract] OR "maternal stress"[Title/Abstract] OR "maternal depression"[Title/Abstract] OR "maternal fear"[Title/Abstract] OR "maternal grief"[Title/Abstract] OR "maternal anxiety"[Title/Abstract]))
	9	((referral[Title/Abstract] OR "hand over"[Title/Abstract] OR handover[Title/Abstract] OR discharge[Title/Abstract] OR (pathway*[Title/Abstract] AND care[Title/Abstract])))
	8	(((model[Title/Abstract] OR models[Title/Abstract] OR framewor*[Title/Abstract] OR type[Title/Abstract] OR types[Title/Abstract] OR optimal[Title/Abstract] OR optimise[Title/Abstract] OR best[Title/Abstract]) AND (care[Title/Abstract] OR referral[Title/Abstract] OR healthcare[Title/Abstract] OR "health care"[Title/Abstract] OR therapy[Title/Abstract] OR interventio*[Title/Abstract])))
	7	#5 AND #6

	6	#1 OR #2 OR #3 OR #4
	5	(((subsequent[Title/Abstract] OR next[Title/Abstract] OR following[Title/Abstract]) AND (birth[Title/Abstract] OR pregnan*[Title/Abstract])) OR "pregnancy after"[Title/Abstract] OR "next pregnanc*"[Title/Abstract] OR recurrent[Title/Abstract] OR "care following"[Title/Abstract] OR rainbow[Title/Abstract])
	4	(("fetal malformation"[Title/Abstract] OR "congenital abnormality"[Title/Abstract] OR "fetal anomaly"[Title/Abstract] OR "congenital anomaly"[Title/Abstract] OR "fetal anomalies"[Title/Abstract] OR "congenital anomalies"[Title/Abstract] OR "prenatal diagnosis"[Title/Abstract]) AND (terminat*[Title/Abstract] OR abortion[Title/Abstract] OR abort[Title/Abstract]))
	3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])
	2	"Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract]
	1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]
Australian Indigenous HealthInfoNet	Stillbirth OR “baby death” or “neonatal death”	
Informit Indigenous Collection	Stillb* OR “neonatal death”	

Figure 1. PRISMA flow diagram of screening evidence

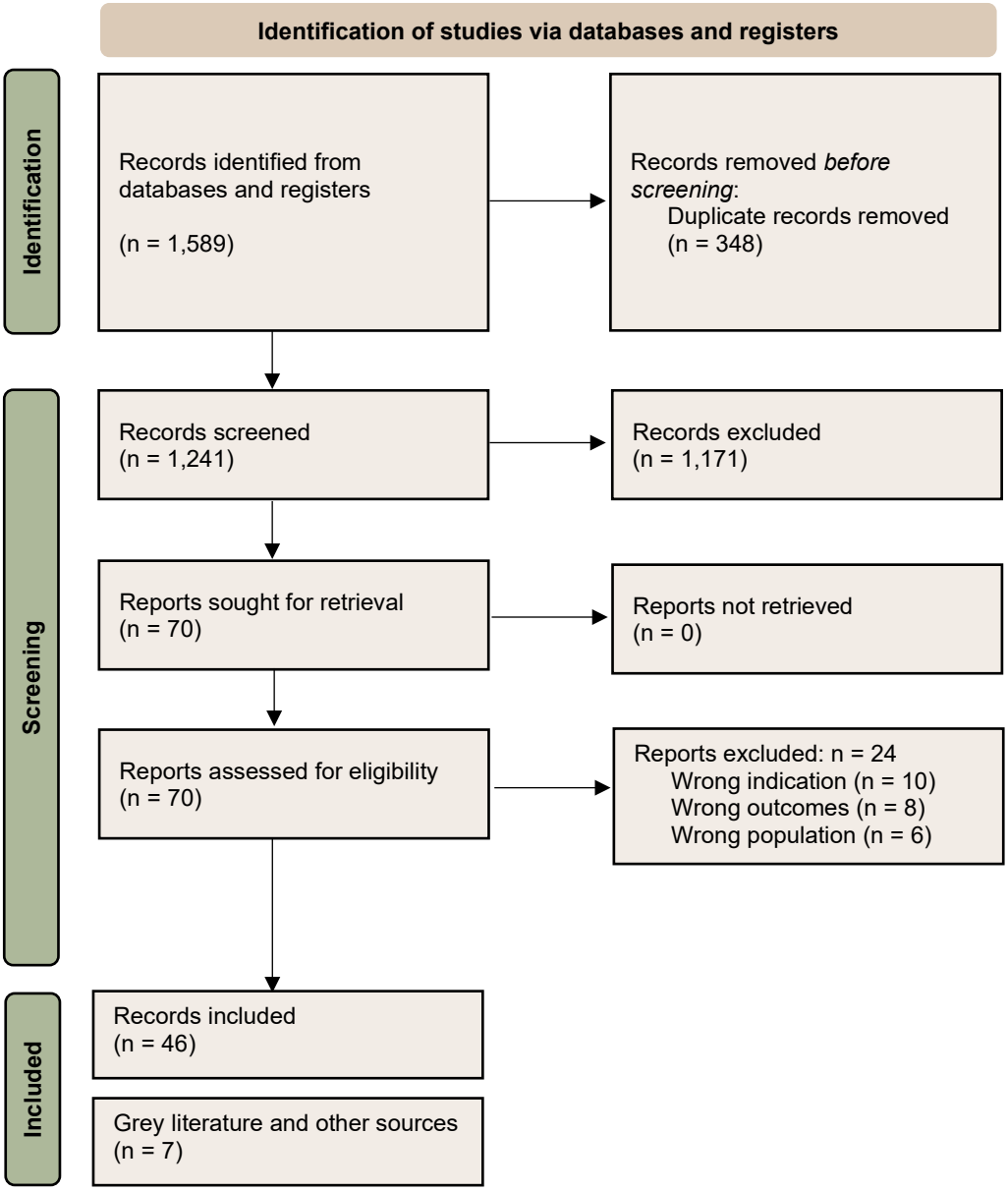

Table 5. Study characteristics

Study ID	Country (period)	Locality (state/national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality appraisal tool
Antovic 2018	Sweden (dates not reported)	NA	Literature	HIC	Qualitative	Narrative review	NA	NA	Stillbirth, NND	Risk factors and risk estimations for adverse pregnancy outcomes before and during pregnancy,	NA	NA	Checklist for text and opinion papers
Azogh 2018	Iran (2017)	Healthcare centres affiliated with a university of medical sciences in SE Iran	Questionnaires	LMIC	Quantitative	NA	Quasi experimental study	100 (n=50 each INT and Control group)	Stillbirth	Effect of psychoeducation on anxiety in subsequent pregnancy following stillbirth	Pregnancy complications hospitalisation, pregnancy termination, and absence from more than one educational session.	Women with a history of stillbirth, who were pregnant again and visited healthcare centres affiliated to the study institution in 2017 to receive prenatal care services. Age >18 years, less than 12 months between	Checklist for quasi-experimental studies (non-randomised experimental studies)

												stillbirth and the subsequent pregnancy, natural pregnancy, and lack of high-risk pregnancy, singleton pregnancy, lack of experience of stillbirth or miscarriage more than once, gestational age of ≥20 weeks, no recognised mental problems, no addiction, no psychosocial crisis, such as death of a relative, and no physical problems or serious diseases.	
Bakhbakhi 2017	Multiple (dates not reported)	NA	Published research, guidelines and best	HIC	Qualitative	Descriptive review	NA	NA	Stillbirth	Best practice points in bereavement care	None mentioned	Published research, guidelines and best	Checklist for text and opinion papers

			practice points						research in high income countries		practice points in care following stillbirth in high income countries	
Beauquier-Maccotta 2022	France (dates not reported)	Necker-Enfants Malades Hospital	Interviews, questionnaires	HIC	Quantitative	NA	Longitudinal Cohort	25	TOPFA	Prenatal attachment, anxiety, and grief during subsequent pregnancy after medical termination of pregnancy	Women <18 years of age, fetal abnormality in the current pregnancy, severe maternal psychiatric disorders, predictable monitoring difficulties, and non-French-speaking patients	Women aged 18 years and older in a subsequent pregnancy after a medical termination of pregnancy for foetal abnormality	Checklist for cohort studies
Charrois 2022	UK (1991–1992)	Avon in Southwest England	Secondary data from the Avon Longitudinal Study of Parents and Children	HIC	Quantitative	NA	Longitudinal Cohort	2854	Stillbirth	Patterns and predictors of depressive and anxiety symptoms in mothers affected by previous prenatal loss	Women who indicated they had a previous baby that was born alive and died after birth, women with recurrent losses	Pregnant women who experienced previous miscarriage or stillbirth	Checklist for cohort studies

Chichester 2022	USA (dates not reported)	NA	Literature	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND	Nursing Care of Childbearing Families After Previous Perinatal Loss	NA	NA	Checklist for text and opinion papers
Douglas Wilson 2021	Canada (2021)	National	Literature	HIC	Qualitative	Narrative synthesis	NA	NA	Congenital anomaly	Prevention, screening, diagnosis, and management of fetal neural tube defects	NA	NA	Checklist for text and opinion papers
Duman 2022	Turkey (2017–2018)	Obstetrics clinic of a university hospital in Eastern Turkey	Questionnaires	UMIC	Quantitative	NA	RCT	104 (n=52 INT group, n=52 Control group)	Stillbirth, NND	Effect of relaxation exercises training on pregnancy-related anxiety after perinatal loss	Illiterate in the Turkish language, having risky current pregnancy, the mother's chronic illness and her receiving medical treatment	Healthy pregnant women who had at least one experience of perinatal loss, multiparous, being pregnant voluntarily, age between 18 and 35, literate in the Turkish language.	Checklist for randomised controlled trials
Faleschini 2021	Canada (dates not reported)	One Canadian city	Online Questionnaires	HIC	Quantitative	NA	Cross-sectional	178 (55 reported perinatal loss)	Miscarriage, Stillbirth	Relation between perinatal loss and mothers'	None stated	Parents from intact families having a 6-	Checklist for analytical cross-

										and fathers' psychological symptoms and parenting stress 6-months after the birth of a healthy child		month-old biological infant, living with the infant at the time of recruitment, full-term pregnancy, and the absence of any known physical or mental disabilities or severe developmental delays in the infant	sectional studies
Fockler 2017	Canada (2017)	NA	Literature	HIC	Qualitative	Narrative review	NA	NA	Stillbirth	Medical and psychosocial aspects of care in pregnancy subsequent to stillbirth	NA	NA	Checklist for text and opinion papers
Goldblatt Hyatt 2022	USA (2021)	NA	Literature	HIC	Qualitative	Narrative	NA	NA	TOPFA	Counselling people experiencing a subsequent pregnancy after TOPFA using the double RAINBOW approach	NA	NA	Checklist for text and opinion papers

Graham, Stephens 2021	UK (2020)	NA	Literature	HIC	Qualitative	Narrative review	NA	NA	Stillbirth	Care in pregnancies subsequent to stillbirth or perinatal death	NA	NA	Checklist for text and opinion papers
Grandone 2021	Italy (2012–2019)	12 hospitals in 3 countries	Medical data collected at hospital stay, routine follow-up visits or via telephone interviews	HIC	Quantitative	NA	Prospective cohort	265	Stillbirth, miscarriage	Reproductive outcomes in women with unexplained recurrent pregnancy loss	Personal history of venous and/or arterial thromboembolism; chromosomal abnormalities in parents; documented haemorrhagic disease; allergy to LMWH or ASA; uterine abnormalities; cervical incompetence	All consecutive pregnant women with recurrent pregnancy loss or at least one IUFD	Checklist for cohort studies
Gravenstee n 2018	Norway (1999-2008)	National	Secondary data from another study and information from the Medical Birth Registry of Norway (MBRN)	HIC	Quantitative	NA	Prospective cohort	n=197 women who experienced stillbirth, n=394 women with a live birth in previous pregnancy, n=394	Stillbirth	Healthcare use, induced labour, and caesarean section in the pregnancy after stillbirth	Women not responding to the first questionnaire, with missing MBRN data, or participating more than	Women who were pregnant after a stillbirth and two reference groups: women with at least one	Checklist for cohort studies

								nulliparous women			once were excluded	live birth and no previous stillbirth and nulliparous women.	
Hamulyák 2020	Multiple (2019)	International	Literature	NA	Qualitative	Systematic review	NA	11 studies	Stillbirth	Effects of aspirin or heparin, or both for improving pregnancy outcomes in women with persistent antiphospholipid antibodies and recurrent pregnancy loss	Cross over trials	Randomised, cluster-randomised and quasi-randomised controlled trials that assessed the effects of aspirin, heparin, or a combination of aspirin and heparin compared with no treatment, placebo or another, on pregnancy outcomes in women with persistent aPL and recurrent pregnancy loss were eligible	Checklist for systematic reviews and research syntheses
Ladhani 2018	Canada, UK (2018)	International	Literature: 3 databases	HIC	Qualitative	Consensus statement/ narrative review	NA	Not stated	Stillbirth	Management of pregnancy subsequent to stillbirth	NA	Women and families presenting for care	Checklist for text and opinion papers

												following a pregnancy affected by stillbirth or other causes perinatal loss	
Lazarides 2021	Germany (dates not reported)	Institute of Medical Psychology and the Department of Obstetrics at the Charité Universitaetsmedizin Berlin, Germany	Structured interviews, medical records, Ecological momentary assessment of maternal stress and mood	HIC	Quantitative	NA	Cohort	155 (n=40 with a history of prenatal loss)	Stillbirth	History of prenatal loss and maternal psychological state in a subsequent pregnancy	Twin pregnancies, uterine, placental/cord anomalies, fetal congenital malformations, and systemic corticosteroid intake	Women with a singleton, intrauterine pregnancy were recruited prior to 16 weeks gestation.	Checklist for cohort studies
Lee 2017	Multiple (2015)	International	Literature (7 databases)	NA	Qualitative	Integrative review	NA	15 articles	Stillbirth	Maternal-fetal relationships in pregnancy following miscarriage and stillbirth, whether and how psychological distress because of perinatal loss and associated coping impacts on maternal-	Non-research-based articles, language other than English, books and articles which did not examine maternal-fetal relationships in subsequent pregnancy following perinatal loss	Articles published in English in peer-reviewed journals, which explicitly discussed, reviewed, or empirically studied maternal-fetal relationships in subsequent pregnancy following	Checklist for systematic reviews and research syntheses

										fetal relationships		perinatal loss.	
Meaney 2017	Ireland (dates not reported)	1 large tertiary maternity hospital in Ireland	Semi-structured interviews	HIC	Qualitative	IPA	NA	15 parents (10 mothers, 5 fathers)	Stillbirth	Parents' concerns about future pregnancy after stillbirth	NA	Parents who experienced a previous stillbirth	Checklist for qualitative research
Meredith 2017	Australia (2015)	Mater Mothers' Hospital in Brisbane	Semi-structured interviews	HIC	Qualitative	Thematic content analysis	NA	10	Stillbirth, NND	Support service for women who are pregnant subsequent to perinatal loss	Fathers	Mothers who had previously experienced perinatal loss and who attended the Mater Mothers' Pregnancy After Loss Clinic during their subsequent pregnancy	Checklist for qualitative research
Mills 2022	UK (Mar 2018–Jul 2020)	2 Northwest England Maternity Units	Pre-post questionnaires, Interviews	HIC	Mixed methods	Thematic analysis	Quasi Experimental study	n=54 for quantitative component (n=38 INT group, n=16 pre-INT group); 33 for interviews (n=20 women, 5 partners, 8 midwives)	Stillbirth, NND	Effectiveness of different maternity care pathways in pregnancies after stillbirth or NND	None stated	Pregnant women ≥ 16 years, who had experienced the stillbirth or neonatal death of any previous baby and booked for care in the included sites.	Checklist for quasi-experimental studies (non-randomised experimental studies) and Checklist for qualitative research

	Women were also required to be ≤ 20 weeks pregnant at recruitment and not previously referred to an existing medical/obstetric clinical service (e.g., cardiac disease, diabetes clinics). Additionally, participants were required to have sufficient command of English to complete study questionnaires and qualitative interviews without the assistance of a translator.

Mone 2021	UK (2008–2019)	1 tertiary prenatal centre	Clinical notes, genetic laboratory notes	HIC	Quantitative	NA	Cohort study	n = 280 (62 consanguineous pregnancies; 218 non-consanguineous pregnancies)	Congenital anomaly	Background characteristics, uptake of prenatal and postnatal investigation and, diagnostic outcomes of UK consanguineous couples and non-consanguineous couples presenting with a fetal structural anomaly.	None mentioned	Couples referred to the West Midlands Regional Genetics Service with a history or current fetal structural anomaly	Checklist for cohort studies
Moore 2018	USA (2007–2009)	Central and Western New York obstetrical offices and a perinatal loss support group	Diaries of study participants	HIC	Qualitative	Thematic analysis	NA	19	Stillbirth, NND	Women's experiences of pregnancy subsequent to prior perinatal loss	If women or their fetus had a medical diagnosis that precluded their chance of delivering a healthy infant, had an uncontrolled medical or mental health condition, or had a	Healthy women aged 21 years and over pregnant again after a prior spontaneous, nonelective perinatal loss (miscarriage, stillbirth, or neonatal death), fluent in written and spoken English, and	Checklist for qualitative research

											multiple gestation	in either their first or second trimesters of pregnancy	
Nijkamp 2022	The Netherlands (1999–2007)	National	National Perinatal Registry	HIC	Quantitative	NA	Retrospective cohort	25,827 women with two consecutive pregnancies, 2,058 women with a previous stillbirth	Stillbirth, NND	Risks of recurrent stillbirth	Fetal deaths associated with a congenital anomaly, all multiple gestations and pregnancies exceeding 43 + 0 weeks of gestation (in the first and/or second pregnancy)	All women who delivered from 22 weeks onwards, two subsequent singleton pregnancies (first and second delivery) in the Netherlands between 1 Jan 1999 and 31 Dec 2007.	Checklist for cohort studies
O'Leary 2017	USA (2017)	NA	Literature, case and clinical examples	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND	Supporting parents during their pregnancy that follows a perinatal loss	NA	NA	Checklist for text and opinion papers
Ordonez 2018	Spain (Sept 2018)	5 public hospitals in Malaga	Questionnaire	HIC	Quantitative	NA	Cross-sectional	115	Stillbirth, NND, TOPFA	Prevalence of post-traumatic stress disorder (PTSD) among post-	women who were pregnant and those who did not have mastery in Spanish	Women 18 and over who had given birth in one of the public hospitals of	Checklist for analytical cross-sectional studies

										partum women who give birth after having suffered a previous perinatal loss		the province of Malaga, having previously suffered a gestational loss	
Ordonez 2020	Multiple	International	Literature/Medline	NA	Qualitative	Systematic review	NA	15 articles	Stillbirth, NND, TOPFA	Post-traumatic stress and related symptoms in subsequent pregnancy after loss	studies published. more than 10 years ago, in a language other than English or Spanish	Articles in English or Spanish published in the last 10 years	Checklist for systematic reviews and research syntheses
Page 2020	USA (date not reported))	NA	Literature	HIC	Qualitative	Review of literature and current practice	NA	NA	Stillbirth	Stillbirth evaluation and follow-up	None mentioned	NA	Checklist for text and opinion papers
Pollock 2021	Australia, Ireland, USA (2020)	International	Literature, Opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND	Pregnancy after loss during the COVID19 pandemic	NA	NA	Checklist for text and opinion papers
Regan 2019	Finland, Norway, Australia (1980–2016)	International	Medical Birth Register of Finland, the Medical Birth Registry of Norway, and the Midwives Notification System in Western Australia	HIC	Quantitative	NA	Retrospective cohort	14552 births in women with previous stillbirths	Stillbirth	Interpregnancy interval and adverse birth outcomes in women with a previous stillbirth	Births with missing data for gestational age, birthweight, sex, date of birth, parity, or maternal age at delivery	Consecutive singleton pregnancies in women whose most recent pregnancy had ended in stillbirth of at least 22 weeks' gestation	Checklist for cohort studies

Roseingrave 2022	Ireland (Apr 2019)	1 tertiary referral university maternity teaching hospital	Electronic and paper medical records	HIC	Quantitative	NA	Retrospective cohort		145	Stillbirth	Maternal and fetal outcomes and health service utilisation in pregnancy after stillbirth	None stated	All pregnancies after stillbirth at the study institution	Checklist for cohort studies
Schreiber 2017	UK, Denmark, Italy (2017)	NA	Literature	HIC	Qualitative	Narrative review	NA	NA		Stillbirth	Clinical manifestations and management of obstetric antiphospholipid syndrome	NA	NA	Checklist for text and opinion papers
Smith 2021	USA (Aug 2018–Jan 2019)	3 private online support groups	Online survey	HIC	Quantitative	NA	Cross-sectional study		124	TOPFA	Factors that lead to women to accept of decline genetic counselling prior to TOPFA; The impact of genetic counselling on women's coping mechanisms and grief following TOPFA, assessed with the	Participants who were unsure as to whether they saw a genetic counsellor prior to TFA, and/or did not complete the COPE and/or PGS surveys.	English-speaking women who had undergone a TFA within the last 10 years in the United States and were at least 18 years of age at that time, recruited through three private online support groups.	Checklist for analytical cross-sectional studies

										brief COPE survey and short version of the PGS.			
Smith 2022	UK (Sept 2016–Dec 2018)	Saint Mary's Hospital and Wythenshawe Hospital, Manchester	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	20 women	Stillbirth, NND	Women's experiences of pregnancy whilst attending a specialist antenatal service for pregnancies after a perinatal death	Women less than 16 years of age, lacked capacity to consent, had been diagnosed with pregnancy complications, or were receiving treatment for an acute mental health issue in this pregnancy.	Pregnant women were eligible for inclusion if they were attending the specialist antenatal service for care in a pregnancy after a stillbirth or neonatal death	Checklist for qualitative research
Thomas 2021	UK (Sept 2016–Dec 2018)	St Mary's Hospital, Wythenshawe Hospital, Manchester and Royal Preston Hospital	Validated questionnaires	HIC	Quantitative	NA	Non comparative study	112 women	Stillbirth, NND	anxiety, depression, stress, quality of life in the antenatal and perinatal period following perinatal loss	women <16 years; unable to consent; diagnosed with pregnancy complications, received treatment for an acute mental health issue in the	women attending antenatal care in a pregnancy after stillbirth or neonatal death	Checklist for case series studies

											current pregnancy		
Tsakiridis 2022	Multiple (not dated)	NA	International guidelines	NA	Qualitative	Descriptive review	NA	NA	Stillbirth	Synthesis and comparison of recommendations from influential guidelines on stillbirth investigation and management	None mentioned	Guidelines included from the American College of Obstetricians and Gynecologists, the Royal College of Obstetricians and Gynaecologists, the Perinatal Society of Australia and New Zealand and the Society of Obstetricians and Gynaecologists of Canada	Checklist for qualitative research
van Eerden 2018	The Netherlands (2000–2019)	National	Medical charts	HIC	Quantitative	NA	Retrospective cohort	79	TOP, Stillbirth, NND	Outcome of subsequent pregnancies after termination of pregnancy for preeclampsia	TOP for other maternal indications, fetal congenital anomalies or intra-uterine fetal demise prior to the decision to	Women who underwent TOP for preeclampsia in The Netherlands between 2000 and 2009	Checklist for cohort studies

											terminate the pregnancy		
Wojcieszek, Shepherd 2018	Multiple (Jun 2018)	International	Literature	NA	Quantitative	NA	Meta-analysis	10 studies including 222 women	Stillbirth, NND	Effects of different interventions or models of care prior to and during subsequent pregnancies following stillbirth on maternal, fetal, neonatal and family health outcomes, and health service utilisation	Cross-over trials	RCTs and quasi-randomised controlled trials	Checklist for systematic reviews and research syntheses
Wojcieszek, Boyle 2018	Multiple (dates not reported)	International	Web-based Survey	HICs and MICs	Quantitative	NA	Epidemiological	2,716 parents	Stillbirth	Parents' perceptions of care, in pregnancies subsequent to stillbirth	None stated	Parents who had a subsequent pregnancy following stillbirth	Checklist for studies reporting prevalence data
Wojcieszek 2019	Multiple (Jun–Aug 2018)	International	Web-based survey	HIC mainly	Mixed methods	Thematic analysis	Descriptive	79	Stillbirth	Research priorities and potential methodologies to inform care in subsequent pregnancies following a stillbirth	NA	Stillbirth researchers, care providers and individuals involved in clinical practice, support	Checklist for qualitative research and Checklist for studies reporting prevalence data

												and/or advocacy around stillbirth	
Wood 2021	Canada (1992–2017)	Alberta	Alberta Perinatal Health Program Database	HIC	Quantitative	NA	Retrospective cohort study	308478 women with more than one birth, n= 3698 women experiencing stillbirth	Stillbirth	Risk of recurrent stillbirth	Births with congenital anomalies	All singleton births in Alberta, Canada, between 1992 and 2017	Checklist for cohort studies
Yusuf 2023	Ireland (Mar 2019–Apr 2021)	Perinatal History Clinic	Hospital database	HIC	Quantitative	NA	Retrospective cohort	n=96 women with subsequent birth (n=20 with adverse outcomes in subsequent pregnancy; n=76 with healthy outcomes)	Stillbirth	Chances of a woman having a healthy subsequent pregnancy after a pregnancy loss	Women without adequately documented previous pregnancies	Women with subsequent pregnancies after a history of fetal demise from 16 weeks	Checklist for cohort studies

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data.

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall appraisal	Relevance
Meaney 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Meredith 2017	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Moore 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	R
Smith 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	R
Tsakiridis 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Unclear	NA	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Faleschini 2021	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Include	R
Ordonez 2018	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Include	R
Smith 2021	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Wojcieszek, Boyle 2018	Yes	Unclear	Yes	Yes	Yes	Unclear	Unclear	Yes	Unclear	Include	R
Wojcieszek 2019	Unclear	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion pieces

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/ sources logically defended?	Overall appraisal	Relevance
Antovic 2018	Yes	Yes	Yes	Unclear	Yes	NA	Include	P
Bakhbakhi 2017	Yes	Yes	Yes	Unclear	Yes	NA	Include	P
Chichester 2022	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
Douglas Wilson 2021	Yes	Yes	Yes	Yes	Yes	NA	Include	R
Fockler 2017	Yes	Yes	Yes	Unclear	Yes	Unclear	Include	R
Goldblatt Hyatt 2022	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
Graham, Stephens 2021	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
Ladhani 2018	Yes	Yes	Yes	Yes	Yes	NA	Include	R
O'Leary 2017	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
Page 2020	Yes	Yes	Yes	Unclear	Yes	NA	Include	I
Pollock 2021	Yes	Yes	Yes	Unclear	Yes	NA	Include	R

Schreiber 2017	Yes	Yes	Unclear	Unclear	Yes	NA	Include	R					

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimize errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Hamulyák 2020	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Lee 2017	Unclear	Yes	Yes	Yes	NA	NA	Unclear	Yes	No	Yes	Yes	Include	R
Ordóñez 2020	Unclear	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	NA	Include	R
Wojciesze k, Shepherd 2018	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	NA	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilized?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Yusuf 2023	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	NA	Yes	Include	R
Beauquier-Maccotta 2022	Not applicable	Not applicable	Unclear	No	NA	Unclear	Yes	Yes	Unclear	Unclear	Yes	Include	R
Charrois 2022	NA	NA	Unclear	Unclear	Unclear	Unclear	Yes	Yes	No	Yes	Yes	Include	R
Grandone 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NA	Yes	Include	P
Gravenstee n 2018	Yes	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	No	No	Yes	Include	R
Lazarides 2021	Unclear	Unclear	Unclear	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Include	R
Mone 2021	No	Yes	No	No	NA	Yes	Yes	NA	NA	NA	Yes	Include	P
Nijkamp 2022	No	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes	Yes	NA	Yes	Include	R
Regan 2019	Not applicable	Not applicable	Unclear	Yes	Yes	No	Unclear	Yes	Yes	Not applicable	Yes	Include	R

Roseingrave 2022	Not applicable	Not applicable	Unclear	No	Not applicable	Unclear	Unclear	Yes	Yes	Not applicable	Yes	Include	R
van Eerden 2018	Not applicable	Not applicable	Unclear	No	Not applicable	Yes	Unclear	Yes	Yes	Unclear	Yes	Include	R
Wood 2021	Not applicable	Unclear	Unclear	Unclear	Unclear	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Quasi experimental studies

	1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?	Overall appraisal	Comments (including reason for exclusion)
Azogh 2018	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Include	R
Mills 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

RCTs

	1. Was true randomisation used for assignment of participants to treatment groups?	2. Was allocation to treatment groups concealed?	3. Were treatment groups similar at the baseline?	4. Were participants blind to treatment assignment?	5. Were those delivering treatment blind to treatment assignment?	6. Were outcomes assessors blind to treatment assignment?	7. Were treatment groups treated identically other than the intervention of interest?	8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	9. Were participants analysed in the groups to which they were randomized?	10. Were outcomes measured in the same way for treatment groups?	11. Were outcomes measured in a reliable way?	12. Was appropriate statistical analysis used?	13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?	Overall appraisal	Comments (including reason for exclusion)
Duman 2022	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	No	Yes	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Comments (including reason for exclusion)
Thomas 2021	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. Detailed GRADE-CERQual assessment

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
5.1	Offer bereaved parents postpartum/preconception consultation(s) to discuss future pregnancy planning. • Provide information about the types of specialised care and support available that may benefit parents in a subsequent pregnancy.	Seven studies are included. Six studies are qualitative literature reviews, and one study is a primary qualitative research study.	Minor concerns of methodological limitation are noted. All seven included studies are deemed to have no or minor concerns of methodological limitations through critical appraisal.	Minor concerns of relevance are noted. Five of the included studies are deemed relevant to care during a subsequent pregnancy. One study is deemed to be partially relevant, and the remaining literature review is deemed to be indirectly relevant.	Minor concerns of coherence are noted.	Moderate concerns of data adequacy are noted. All included studies source their data from high income country populations. Of the included studies, six are literature reviews, and one includes primary data. Outcomes included are composite perinatal mortality outcomes (n=10) and the viewpoint of fathers is included (n=10).	**Moderate confidence** *Minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*
5.2	Support parents to plan the timing of a subsequent pregnancy, taking into consideration physical and emotional recovery and the circumstances of the previous birth.	Six studies are included. Two literature reviews, two cohort studies, one primary qualitative study and one cross-sectional study.	Minor concerns of methodological limitation are noted. Four of the included studies are noted to have no or minor methodological limitation through critical appraisal. Two cohort studies are noted to have moderate concerns of methodological limitation. One due to the groups not assessed as free from exposures at the start of the study, and unclear outcome and exposure	Minor concerns of relevance are noted. Five of the included studies are deemed to be relevant to care in a pregnancy subsequent to stillbirth or neonatal death. One study is deemed to be indirectly relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. All of the included studies source their data and cohorts from high income country populations. Outcomes of interest included across the literature include stillbirth (n=14,712), and composite perinatal mortality outcomes (n=115).	**Moderate confidence** *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			measures. The other due to confounders not being identified or accounted for through analysis, as well as unclear exposure and outcomes measures.			The views of parents are included from 2 primary research studies. Moderate concerns are noted due to the lack of parents' viewpoints contained within the evidence.	
5.3	Provide care in a subsequent pregnancy within a continuity of care and carer model with a multidisciplinary focus and appropriate to cultural, religious, and spiritual needs of each family/whānau.	20 studies are included. Six narrative reviews. Three systematic reviews including one review of guidelines, two mixed methods studies, five primary qualitative research studies, three cohort studies, one case series, and one quasi-experimental study.	Minor concerns of methodological limitation are noted. 14 of the included studies are assessed to have no or minor concerns of methodological limitation through critical appraisal. Six of the included studies are deemed to have moderate concerns of methodological limitation. One qualitative study is noted to lack a statement of the researchers' cultural position, and the influence that this has on analysis and findings. Methodology is also unclear. Three cohort studies are noted to have moderate concerns due to issues concerning follow-up, confounders and measures of exposures and	No or minor concerns of relevance are noted. 18 of the included studies are deemed directly relevant to care during subsequent pregnancy. Two included studies are deemed partially relevant.	There are no issues of coherence of the included evidence.	Moderate concerns of data adequacy are noted. All included studies source their cohorts from high income studies, along with two systematic review and one review of guidelines. Prior pregnancy outcomes include stillbirth (n=3,307), and composite perinatal mortality outcomes (n=248). Across the evidence, the view of birthing and non-birthing parents is represented, and one study only includes the view of non-birthing parents. In addition to these views, one study presents the research priority setting of researchers, and health care professionals.	**Moderate confidence** No or minor concerns of coherence, relevance and methodological limitation. Moderate concerns of adequacy of the data.

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			outcomes. One systematic review raised concerns due to publication bias, unclear methods and unclear research questions, and one mixed methods study had notable concerns associated with qualitative methodology.			Moderate concerns of the included evidence relate to the lack of health care professional view across the included evidence, and the absence of neonatal death included in previous pregnancy outcomes.	
5.4	Acknowledge parents' previous loss, including if and how they would like healthcare professionals to refer to their previous baby (for example by name).).	23 studies are included. Six are narrative reviews. Three primary qualitative research studies, four cohort studies, three systematic review, two mixed methods studies, one case series, one randomised controlled trial, and one cross sectional study.	Minor concerns of methodological limitation. 14 of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. Eight of the included studies are noted to have moderate concerns of methodological limitation. Of the eight studies, four cohort studies are noted to have concerns of confounder identification and also unclear follow-up and strategies to address incomplete follow-up. One cohort study was also noted to include incomparable groups, and the measures of exposure and outcomes were unclear.	No concerns of relevance are noted. All included studies are deemed relevant to care in a subsequent pregnancy.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Ten of the included studies source their cohorts from high income countries. Two from high-income countries combined with middle-income countries, and one from upper middle-income countries. In addition to this, there are two systematic reviews included. Prior pregnancy outcomes include stillbirth (n=6016), termination of pregnancy for fetal anomaly (n=25), and composite perinatal mortality outcomes (n=511). The view of parents and in particular birthing parents is included across 11 of the included studies. In addition, one study includes the view	**Moderate confidence** *No concerns of relevance or coherence. Minor concerns of methodological limitation and moderate concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			One mixed methods study is noted to have concerns associated with the included qualitative component. One randomised controlled trial is noted to have moderate concerns due to incomplete follow-up and unclear blinding of participants, researchers and assessors. Two systematic reviews are noted to have moderate concerns of methodological limitation due to unclear research questions, sources, appraisal criteria, independent review and methods to minimise errors.			of researchers and health care professionals. Moderate concerns of data adequacy are noted due to the lack of health care professional viewpoint.	
5.5	Ensure effective referral pathways and appropriate handover and documentation processes are in place, with previous loss identifiable in medical records.	Five studies are included. One primary quantitative randomised controlled trial, three literature reviews, and one systematic review.	Minor concerns of methodological limitation are noted. Five of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. The included randomised controlled trial has moderate concerns of methodological limitation. Incomplete follow-up, difference in follow-up between groups, and unclear	No concerns of relevance are noted. All included studies are deemed to be relevant to care in a pregnancy subsequent to stillbirth or neonatal death.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Three of the included studies source their cohorts and evidence from high income country populations. One sourced evidence from upper middle income country populations, and the last study does not report the source of data. Outcomes of interest included across the studies	**Moderate confidence** *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			blinding were all noted through appraisal.			are stillbirth (3 studies), and composite perinatal mortality outcomes (2 studies). The view of mothers is included through evidence of one included study. Moderate concerns of data evidence are noted due to lack of health care professional view, as well as lack of combined outcomes included across the studies.	
5.6	Review maternal risk factors and results of investigations from the previous pregnancy, with detailed clinical history and information from parents, to identify risks and opportunities to improve outcomes. Be aware of and respectful of cultural, religious, and spiritual-based decisions around care following the death of their previous baby including (if any) postmortem investigations. • Be aware of and respectful of cultural, religious, and spiritual-based decisions around care following the death of their previous baby including (if any) postmortem investigations.	Seven studies are included. Studies include three included literature reviews, and one review of guidelines. Three primary research studies are included, one cohort study, one cross-sectional study and one primary qualitative research study.	Minor concerns of methodological limitation are noted. Five of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. Two studies are noted to have moderate concerns of methodological limitation. The included cohort study fails to identify and account for confounders, and it noted to have unclear measures of exposure and outcome. One primary qualitative study lacks a statement of researcher cultural position and fails to	Minor concerns of relevance are noted. Five of the included studies are deemed to be directly relevant to care in a subsequent pregnancy, two studies are deemed to be partially relevant.	No concerns of coherence are noted. All included evidence concurred with the recommendation to review previous investigation results.	Moderate concerns of data adequacy are noted. Six of the included studies source their data from high income country populations. One study is a review of guidelines. Outcomes of interest include stillbirth (6 studies), and termination of pregnancy for fetal anomaly (n=124). The view of mothers and parents is included through evidence from 2 studies. Moderate concerns are noted due to inadequate	**Moderate confidence** *No or minor concerns of methodological limitations, relevance and coherence. Moderate concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			account for culture in analysis of findings. Outcomes are also noted to be reported unclearly.			combined data adequacy of viewpoints across the evidence, and lack of neonatal death as an outcomes included through the evidence.	
5.7	At the initial antenatal care visit, explore parents' expectations, concerns, and support needs including: • risk of recurrent perinatal death • number and timing of appointments • availability of support outside appointments and out of hours • need for and access to additional ultrasound scans, investigations, and monitoring • pregnancy milestones and settings that may evoke a heightened emotional response and require additional support • parents' discomfort being around other pregnant women • options relating to timing and mode of birth.	23 studies are included. Nine cohort studies, one cross sectional, one mixed methods study, three primary qualitative research studies, eight narrative reviews and one systematic review.	Minor concerns of methodological limitation are noted. Of the included studies, 15 were noted to have no or minor concerns of methodological limitation. Seven of the cohort studies and one qualitative study were noted to have moderate concerns of methodological limitation. The cohorts studies were noted to predominantly lack confounder identification, and unclear exposure and outcome measures. The qualitative study was noted to lack a statement of researchers cultural position and failed to account for this influence through analysis and findings. The outcomes were also noted to be unclearly reported.	Minor concerns of relevance noted. 15 of the included studies are deemed relevant to care in a subsequent pregnancy, four studies are deemed partially relevant to care in a subsequent pregnancy, and two included studies are deemed to be indirectly relevant.	No issues of coherence.	Minor concerns of data adequacy are noted. All of the included studies sources cohort from high-income countries. Outcomes include stillbirth (n=14,887), termination of pregnancy for fetal anomaly (n=404), and composite perinatal mortality outcomes (n=26,190). The view of parents is included across eight of the include studies. In addition researchers and health care professionals view is included in one study. Minor concerns are noted due to the lack of health care professional view included.	**High confidence** *No concerns of coherence. Minor concerns of methodological limitation, data adequacy and relevance.*
5.8	Consider early screening for gestational diabetes mellitus (GDM) in addition to routine screening at 26–28 weeks for	Four studies are included.	Minor concerns of methodological limitation are noted.	Minor concerns of relevance are noted.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted.	**Moderate confidence** *No or minor concerns of methodological*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	women with a previous unexplained stillbirth.	Two literature reviews are included, and two quantitative cohort studies.	Three of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. One included cohort study is noted to have moderate concerns of methodological limitation due to lack of confounder identification, and unclear exposure and outcomes measures.	Three o the included studies are deemed to be directly relevant to care in a pregnancy subsequent to stillbirth. One study is deemed to be partially relevant.		All included studies source their data from high income country populations. Outcomes of interest include stillbirth (3 studies) and composite perinatal mortality outcomes (n=265). The view of mothers is included through one study, and the remaining primary research study sources data directly from medical records. Moderate concerns of data adequacy are noted due to the small, combined cohort sizes included, as well as the lack of health care professional view from primary sources.	*limitation, relevance and coherence are noted. Moderate concerns of data adequacy are noted.*
5.9	Determine fetal monitoring frequency based on obstetric history, the circumstances surrounding the index stillbirth or neonatal death, screening findings, and parental preferences. • Consider fetal biometry, amniotic fluid, and fetal Doppler every 4 weeks from 24 weeks' gestation. • Consider additional support requirements for parents at significant milestones.	Six studies are included. Five literature reviews, and two cohort studies.	Minor concerns of methodological limitation are noted Four of the included studies are noted to have no or minor concerns of methodological limitation. Both included cohort studies have moderate concerns of methodological limitation. One	Minor concerns of relevance are noted. Five of the included studies are deemed to be directly relevant to care during a pregnancy subsequent to stillbirth or neonatal death. One included study is deemed to be indirectly relevant.	Minor concerns of coherence are noted.	Moderate concerns of data adequacy are noted. All of the included studies source their cohorts and data from high income country populations. Outcomes of interest include stillbirth (4 literature reviews, and cohort study data n=3,843).	Low confidence *Moderate concerns of methodological limitations, study adequacy of data, and relevance of the evidence. Minor concerns of coherence.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			due to lack of confounder identification, and unclear measures of exposure and outcomes. The other due to incomplete follow-up, and unclear outcome and exposure measures.			The view of parents of health care professionals is not contained within the evidence. Major concerns of data adequacy are noted due to the inclusion of 4 opinion literature pieces, and lack of parent viewpoint.	
5.10	Consider the use of low dose aspirin (LDA) prophylaxis in a pregnancy following loss if preterm pre-eclampsia, or other forms of placental dysfunction, was evident. • Suitable LDA dose is 100–150 mg from 12–36 weeks' gestation.	Three studies are included. Two are literature reviews, and one is a mixed methods qualitative and prevalence study	Minor concerns of methodological limitation are noted. All of the included studies are noted to have no or minor concerns of methodological limitation.	Moderate concerns of relevance are noted. Two of the included studies are seemed to be directly relevant to care during a pregnancy subsequent to stillbirth or neonatal death. One study is deemed to be indirectly relevant.	No issues of coherence are noted.	Major concerns of data adequacy are noted. Two of the included studies report sourcing their data from high income country populations. The outcome of interest include through the evidence is care following a pervious stillbirth (2 reviews, and 1 primary research study (n=79)). Through evidence in one mixed methods study, the view of 79 researchers and care providers is expressed. Major concerns of data adequacy are noted due to the small, combined sample size, and the lack of parents	Low confidence *Moderate concerns of methodological limitations, study adequacy of data, and relevance of the evidence. Minor concerns of coherence.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
						and healthcare provider viewpoints.	
5.11	It is not recommended to routinely offer women low-molecular-weight heparin (LMWH) in pregnancies following stillbirth, unless there are other medical considerations or thrombophilia is present.	Seven studies are included. Four literature reviews, one review of guidelines, one prevalence study, and one primary qualitative research studies.	Minor concerns of methodological limitation are noted. Five of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. One included review of guidelines is noted to have moderate concerns of methodological limitation due to a lack of the researchers cultural influence being accounted for through analysis and discussion, and also poorly reported outcomes.	Minor concerns of relevance are noted. Three of the included studies are deemed directly relevant to care during pregnancy subsequent to stillbirth or neonatal death. Three included study is deemed to be partially relevant.	Minor concerns of coherence are noted.	Major concerns of data adequacy are noted. Four of the included studies report sourcing their study data from high income country populations. The prevalence study included high- and middle-income country populations. The included review of guidelines did not specify the population included. Outcomes of interest included are stillbirth (4 studies), and composite perinatal mortality outcomes (3 studies). The view of mothers is included through data from one study, and the view of fathers is included from another study. Major concerns of data adequacy are noted as most of the included data are included in opinion pieces, and the combined studies result in a small cohort of primary data.	Low confidence *Moderate concerns of methodological limitations, study adequacy of data, and relevance of the evidence. Minor concerns of coherence.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
5.12	To support parent-centred decision making, discuss timing and mode of birth and consider the circumstances of the previous stillbirth or neonatal death, current pregnancy, and emotional state of parents: • individualise counselling concerning timing and mode of birth • discuss planned birth from 39 weeks' gestation • discuss the potential harm of early planned birth (such as increased chance of neonatal and longer-term adverse outcomes) before 39 weeks' gestation.	Nine studies included. Three are cohort studies, four are narrative reviews, and one mixed methods including a qualitative and prevalence design.	Moderate concerns of methodological limitation are noted. Of the included studies, five were noted to have minor or no concerns of methodological limitation. The remaining four (cohort studies) are deemed to have moderate concerns due to unclear exposure and outcome measures, incomplete follow-up and one study including two groups that were deemed incomparable.	No concerns of relevance. Six of the included studies are deemed relevant to care in a subsequent pregnancy, and two are deemed partially relevant.	No issues of coherence are noted.	Minor concerns of data adequacy are noted. Seven included studies source their cohorts from high income country populations, one from a mix of high- and middle-income country populations, and one study did not disclose the income state of the populations included. Outcomes include stillbirths (n= 6,749) and composite perinatal mortality outcomes (n=25,827). Two of the included studies use registry data, one includes the view of birthing parents, and the other includes the view of mothers (n=25,827). Minor concerns are noted due to the lack of view from non-birthing parents and also health care professionals.	**Moderate confidence** *No concerns of relevance or coherence. Minor concerns of data adequacy, and moderate concerns of methodological limitation.*
5.13	Offer parents individualised preparation for birth including: • a birth plan that details the likely location of the birth (for example	Seven studies are included. Four literature revies, one review of guidelines, and two	Minor concerns of methodological limitation are noted.	Minor concerns of relevance are noted. Six of the included studies are relevant to	No issues of coherence are noted.	Moderate concerns of data adequacy are noted. Six of the included studies reported sourcing their data	**Moderate confidence** *No concerns of coherence, minor concerns of*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	avoiding birthing rooms where the previous baby died) • antenatal classes specific to pregnancy after loss including tailored education (such as on fetal movement) and support • an identifier in medical records to indicate parents have experienced a previous stillbirth or neonatal death.	primary qualitative research studies.	Six of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. One study is noted to have moderate concerns of methodological limitation notes owing to	care after stillbirth or neonatal death. One included study was deemed to be partially relevant to care during a pregnancy subsequent to stillbirth or neonatal death.		from high income country populations, and one primary qualitative study did not report the data source. Outcomes of interest include stillbirth (4 studies), and composite perinatal mortality (3 studies). The viewpoint of mothers is included through data of one study (n=20). Moderate concerns of data adequacy are noted due to small, combined samples of views and outcomes.	*methodological limitation and relevance. Moderate concerns of data adequacy.*
5.14	Engage parents in open discussions about the challenges of pregnancy and parenting after loss by: • anticipating and supporting parents through points in pregnancy and after birth that may be particularly distressing, such as pregnancy milestones and certain settings • acknowledging the mixed emotions relating to the joy of having a baby and the ongoing grief of previous loss • asking about preparations for the baby to help identify and support parents who may experience	13 studies are included. Three literature reviews, three cohort studies, two systematic reviews, three primary qualitative research studies, one mixed methods study, and one case series study.	Moderate concerns of methodological limitation are noted through critical appraisal. Seven of the included studies are noted to have minor concerns of methodological limitation. Six studies are noted to have moderate concerns of methodological limitation including three cohort studies without confounders identified or accounted for through analysis. Unclear outcome and	No concerns of relevance are noted. All studies included are deemed to be directly relevant to care during a pregnancy subsequent to stillbirth or neonatal death.	No issues of coherence are noted.	Minor concerns of data adequacy are noted. 11 of the included studies reported sourcing data from high-income country populations. The remaining two studies didn't report the source of data. Previous pregnancy outcomes of interest included through the evidence include stillbirths (n=3,009), termination of pregnancy for fetal anomaly (n=25), and composite	**Moderate confidence** *No concerns of coherence or relevance. Minor concerns of data adequacy. Moderate concerns of methodological limitation.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	impediments to parenting such as delayed attachment and bonding.		exposure measures, and incomplete follow-up. Two systematic reviews are noted to have moderate concern of methodological limitation through critical appraisal. Concerns are primarily due to unclear research questions, unclear independent review and methods to minimise errors and bias, and publication bias. The included mixed methods study is noted to have moderate concerns of methodology associated with the qualitative component of work. A statement of the researcher's cultural position is not provided for or accounted for through analysis and findings. There is also unclear congruity noted between the methods and intent.			perinatal mortality outcomes (n=363). The view of mothers is included through the evidence (n=3,354), as well as fathers (n=10). Minor concerns of data adequacy are noted.	
5.15	Ask parents about their social and emotional wellbeing and support needs at all antenatal and postnatal care appointments, in addition to routine mental health screening. Appropriately refer to support services where needed.	26 studies are included. Of the included studies, five are cohort studies, two are cross-sectional studies, three are primary qualitative research studies, one	Moderate concerns of methodological limitation are noted. Of the included studies 17 were deemed to have no or minor concerns of	No issues of relevance are noted, all included studies are relevant to care in a subsequent pregnancy.	No issues of coherence are identified between the included studies.	Moderate concerns of data adequacy are noted. 20 of the included studies sourced their cohorts from high-income population countries, one from a mixture of high- and middle-	**Moderate confidence** *No concerns of relevance or coherence. Moderate concerns of methodological*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	• Provide information on how to access outpatient peer support, professional counselling and psychology services and other local and national perinatal mental health and parenting support services.	quasi-experimental study, one mixed methods study, one randomised controlled trial, seven narrative reviews and three systematic reviews.	methodological limitation through critical appraisal. Nine were noted to have moderate concerns of methodological limitation. All three cohort studies are noted to have concerns of unidentified confounders, and lack of strategies to deal with confounders through analysis. Unclear exposure and outcomes measures were noted, as well as incomplete follow-up for two of the studies. The mixed methods study was noted to have moderate concerns of the qualitative component of analysis. Two systematic reviews are noted to have moderate concerns or publication bias, unclear methods and critical appraisal, and also unclear research questions.			income countries, one from a lower middle-income country, and one from an upper middle-income country. In addition, three systematic reviews were included. Outcomes included are stillbirth (n=6,261), termination of pregnancy for fetal anomaly (n=25) and composite perinatal mortality outcomes (n=625). The view of parents is included across 12 of the included studies (disproportionately birthing parents), the view of health care providers is not included. Moderate concerns are noted due to the lack of health care provider viewpoint, and also the small sample of non-birthing partners included through analysis.	*limitation and data adequacy.*

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 6: Investigations for perinatal death: communication and decision making

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Making decisions about investigations can be the hardest and most confronting decisions that parents will need to make following the death of a baby. When approaching decision-making about investigations for their baby, parents may feel strongly for or against, or somewhere in between and many will feel overwhelmed.[1] Parents often have a strong need to understand why their baby died, and this can also help with planning for future pregnancies. However, there are many influences on parents' decisions about whether to have certain investigations, particularly autopsy.[2] The way in which investigations are discussed by healthcare professionals is one major influence on parents' decision making.[3]

All investigations to understand why a baby has died, aside from a very small proportion of perinatal deaths where a coronial autopsy is required, will require parental consent. Parental decision not to have an autopsy is a major driver for the low autopsy rates in Australia and Aotearoa New Zealand. Parents may base their decision on cultural and religious beliefs and practices, lack of rapport with healthcare professionals, or their degree of emotional distress. Healthcare professionals may be reluctant to discuss autopsy with parents if they feel this could cause more distress,[4] and healthcare professional's opinion about the lack of value of the autopsy also contributes. Yet many parents later regret not having an autopsy to help understand why their baby died.[5-7] It is important for healthcare professionals to provide appropriate counselling about investigation options available to them including autopsy and to help them make the decision that is right for them.

Finding out where parents are on the decision spectrum and exploring with them their views and concerns can assist healthcare professionals to provide information and support that matches parents' needs. Parents who choose not to have an autopsy for their baby may experience later regret.[8,9] Ensuring parents feel fully informed and adequately involved in the decision-making process may minimise regret, regardless of the decision made.[1,8] Where individual, religious, and cultural beliefs make some investigations unacceptable to parents, these beliefs and the decision should be respected.[10] Parents should be assured that everything possible will be done to understand the cause of their baby's death and that this will include standard investigations and a review of the care provided to facilitate improvements to future care.[2] Clear information should be given regarding how and when parents will receive the results of investigations that take place.

Methodology

The Guideline Development Committee identified key research questions (Table 1) about communication and decision-making considerations for investigations after perinatal death.

Table 1. Research questions

1	What strategies and considerations improve communication with parents about the option of an autopsy examination for their baby?
2	How can shared decision-making around investigations of the baby's death be effectively offered and achieved?
3	What types of information should healthcare professionals provide to meet the individual needs (e.g. literacy level, culturally appropriate) and preferences (e.g. written, audio) of parents?

4	What information should be provided to parents about the range of investigation options available to them, and who should provide information about which, if any, investigations are most likely to be useful?
5	Are telehealth reviews an acceptable option for providing parents with information about investigation options? Is this an acceptable option for discussing results of investigations with parents?
6	What is the optimal content of consent forms for perinatal autopsy and other investigations?
7	What is the value of providing a plain language summary of the perinatal autopsy to parents?
8	What information should be provided to parents when their baby needs to be transported to another service/setting for investigations (such as autopsy and medical imaging)?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 1. PICO criteria

PICO	Inclusion criteria

Population	Defined in Australia and Aotearoa New Zealand as:
	• Stillbirth
	  ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[11,12]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[11,12]
	• Inclusion of perinatal deaths following termination of pregnancy
	  ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).

Intervention	• Any intervention to support effective communication and shared decision-making about investigations to understand why a baby has died including resources (e.g., written) and counselling.
Comparator	• Not applicable—no comparator within research questions

Outcomes	Outcomes and needs of healthcare professionals and parents concerning communication and decision-making about investigations following perinatal death. Outcomes and needs specific to the following populations were searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families.

Literature search

Searches were conducted on 9 March 2022. A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and were restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- wrong *language*: The study was not published in English.
- wrong *publication dates*: The study was published prior to 2017.
- wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual [13]. The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings? [14]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings? [15]
- Adequacy: The richness and quantity of data supporting the findings [16]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline [17].

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain

- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence supporting the synthesis findings was formulated following this review, and details of any concerns were identified and listed [18]. Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: What strategies and considerations improve communication with parents about the option of an autopsy examination for their baby?

The ways in which healthcare professionals interact with parents, as well as how the autopsy process is presented and explained, can heavily influence the decision that parents make regarding investigations for their baby.[9,19,20] Information is sometimes provided to parents in an inaccessible or insensitive way.[1] There can also be assumptions that the cause of death is already known, or that the consent process will be too onerous and distressing, for both parents and healthcare professionals. Suggestions for healthcare professionals when discussing and seeking consent for autopsy include: interacting unambiguously and professionally, imparting information about autopsy in an unbiased way, and giving families enough time to reflect and begin grieving.[19] Consent for autopsy should be sought in an unambiguous, parent-centred way, which also allows for considerations of differences between diverse groups.[19]

It is important that discussions relating to autopsy and sensitive and/or complex clinical situations take place in a quiet and private space with no interruptions. Information must be provided in a clear, kind, and sensitive manner. Parents must also be provided with enough time to understand and process the information that they have been given, with an opportunity to ask questions.[21,22] Unsuitable spaces for discussing investigation options, such as a hospital corridor or busy postnatal wards where other babies can be heard crying, have been reported to increase the distress and trauma felt by parents and families at this emotionally difficult time.[23] Parents in the UK, Australia and Aotearoa New Zealand have indicated that they want to receive information from healthcare professionals who are experienced, knowledgeable, and can answer their questions clearly (e.g., pathologist).[1,21,24-26] Healthcare professionals should always be available to provide support to bereaved parents and families, including helping them to understand all the investigations and autopsy information provided to them following their loss.[23] Where possible, a pathologist should discuss the autopsy and its results with parents.[27]

Healthcare professionals should be mindful about the level of detail and information shared with parents about the autopsy process, as too much can cause more distress. While it is widely accepted as “good practice” to offer all parents the option of an autopsy, pre-existing stereotypes and perceptions can mean that not all parents and families are given this option. For example, in one UK study, ethnicity and/or religion was found to influence healthcare professionals’ approach to autopsy. In some cases, assumptions made based on previous experiences and scenarios relating to cultural and religious practices meant that autopsy was not offered in similar circumstances.[4,6] In other cases, healthcare professionals wanted to remain respectful and not be responsible for adding to parents’ distress. Additional influences regarding the ways in which healthcare professionals approached autopsy in the UK included: emotional connections that had been developed with families, as well as the discussion around autopsy being a “tick-box” exercise. Both of these scenarios meant that parents were not provided with the right information about autopsy, and were more likely to decline.[6] Healthcare professionals should always enquire about parents’ needs and preferences relating to cultural, spiritual and/or religious matters concerning investigations and autopsy and respond respectfully. Interpreters should be sought if required.[28] Refer to *Technical report*: *Investigations for perinatal death* for more information on cultural considerations around consent for investigations.

It is important that healthcare professionals’ approach to autopsy is timed sensitively, as some parents have reported that they were asked about it too soon following the death of their baby.

Other parents reported that they were asked at an inappropriate time (e.g., only one parent was present during the conversation). Parents in the UK acknowledged that there is "never a good time" to be asked about autopsy. However, during this difficult time, the likelihood of a "knee-jerk" reaction to decline autopsy is more likely if the subject is raised too soon (e.g., during labour or soon after birth).[6]

The time at which written information about autopsy is provided to parents should also be carefully considered by healthcare professionals. Studies in the UK have shown that parents value materials that they can read and digest at their own pace.[6]

Before signing consent forms in the UK, parents noted that they appreciated a "conversation where time was spent talking through the process" with a healthcare professional who allowed "adequate space for questions and consideration before signing the consent forms." For parents to make an informed decision about autopsy, healthcare professionals must be sensitive to individuals needs regarding the amount of detail that is given, as well as being attentive to both verbal and nonverbal communication.[6]

Recommendations for practice in the UK from Lewis et al.[6] include:

Phase 1: The initial approach (planting the seed)

- Routinely approach every family
- Initiate when both parents are present, any medication has worn off and distress is contained
- Ideally approach is made by healthcare professionals who have an established relationship with the family

Phase 2: Adjustment and deliberation

- Provide time/space for decision to be considered
- Provide written material from leading support charities

Phase 3: Detailed discussion about procedure

- Present autopsy as a key component of the ongoing care of the child/baby
- Explain autopsy is the most valuable tool to try and establish cause of death and inform recurrence risk, although this cannot be guaranteed
- Individualise the care to provide the appropriate level and depth of information required by each family
- Offer consultation with religious leaders where appropriate
- Sensitivity, confidence, and knowledge of the procedure is key
- Avoid sharing person opinions/prejudices
- Reassure that baby/child will be treated with respect

Phase 4: Formal consent

- Use of Sands consent form
- Formal consent conducted with a trained healthcare professional who is able to answer any questions that may arise.

Improving communication and support surrounding autopsy consent in the UK:

- Sands Lothians have developed the animation "Parent to Parent Post-Mortem (autopsy) Authorisation" (https://vimeo.com/272820256), which has been created with parents to dispel some of the myths surrounding autopsy procedure and to ensure parents have clear and accurate information to enable them to make an informed decision about autopsy.

- NHS Education for Scotland has developed training videos specifically to support staff breaking bad news as well as to have discussions around autopsy examination. These are available at www.sad.scot.nhs.uk.
- The new National Bereavement Pathway currently being piloted in England and Scotland also includes professional guidance around consenting for autopsy at any stage of loss and is available at www.nbcpathway.org.uk.

Question 2: How can shared decision-making around investigations of the baby's death be effectively offered and achieved?

Appropriate bereavement care following perinatal death is essential to minimise the negative socio-economic impact on parents and their families.[10] Stillbirth investigations should be offered to parents to help explain the cause of the stillbirth, and may guide the management of future pregnancies.[10]

Consenting to an autopsy is a difficult decision for parents with possible long-lasting consequences. Discussion about autopsy should involve a trusted and knowledgeable healthcare professional who is empathetic to the parents' situation and able to provide the information needed to assist them in reaching their decision.[9] Sufficient time must be allocated to explain the options available, including less invasive and stepwise examinations, and to explore concerns and answer questions.[2]

Finding out where parents are on the decision spectrum[1] can assist healthcare professionals to provide information and support that matches parents' needs. In a qualitative study conducted in UK, when asked to decide about stillbirth investigations, parents tended to fall into one of three decisional groups:

- "Not open to postmortem examination": parents who were not open, under any circumstances, to a postmortem investigation
- "Consenting regardless of concerns": parents for whom the need for answers overrode any concerns about the procedure
- "Initially undecided": parents who were ambivalent towards post-mortem and for whom careful management and counselling by the healthcare professional team was key in supporting them towards the right choice for them.[6]

One of the decisional drivers that were important to the 'Initially undecided' group included the initial approach of healthcare professionals, which involved offering autopsy to all families and avoiding stereotypes and preconceptions based on parents' ethnicity or religion. Many parents who decline autopsy do so early in the discussion process, particularly if the timing of the approach is poor. A sensitively timed discussion about autopsy was an important component of the initial approach, as was having an established relationship with the staff member bringing up the discussion. Further, allowing parents time to consider their decision was important, which sometimes meant healthcare professionals conducting follow-up phone calls or house visits to give parents time to reflect on their decision.[6]

In a study by Schirmann and colleagues,[1] analysis of survey findings from 454 parents who had a stillborn baby across Australia and Aotearoa New Zealand identified the attributes of parent-centred decision-making about autopsy. To create a supportive decision-making environment, healthcare professionals are required to:

Recognise:

- Autopsy consent as a difficult decision with long-lasting consequences: support is essential at the time of the decision but doesn't end there.
- Parents may feel strongly for or against, or somewhere in between and many will feel overwhelmed. Finding out where parents are on the decision spectrum is an entry point for tailoring information.

Expect:

- A wide range of views: elicit from parents what they see as important, including future pregnancies, the baby's legacy. Share what other parents have found important.

Avoid:

- Making assumptions: decision drivers may operate in unexpected ways.
- Imposing values, opinions, or decisions on parents. Helping parents to make informed autonomous decisions may minimize regret. The healthcare professional's cues can be subtle, and it is important to be mindful of tone, timing, and content. Allow parents to guide the level of detail.

Acknowledge:

- Parents in the same way as parents who have delivered a living baby, with strong needs to protect their baby from any further harm. Allow parents to spend time with their baby and to engage in parenting activities.
- Feelings of self-blame and questions about preventability. Consideration of these issues may help clarify concerns.

Assure:

- Parents that their baby will be treated with care and respect: allow parents to know where their baby will be and who will provide care.

Prevent:

- Unnecessary distress arising from poor communication of results. Establish clear processes and timelines for informing parents of results and ensure settings for the delivery of results are appropriate.

Parents may regret their decision about autopsy, and this may be due to inadequate information or poor communication. Parents find it helpful when staff explain the respectful nature and purpose of the examination. Sometimes, parents' may decline an autopsy due to their perception that they already know the cause of death.[10] Discussions with staff influence the parents' decision (about autopsy) more than staff may think. However, in a UK study, fewer than half of the parents felt involved in the decision-making process after stillbirth and one third did not feel listened to.[29] When parents are supported in their decision-making by empathetic staff, and have time to deliberate, they are more likely to consent to autopsy.[6]

Parents also need clear information about how and when they will receive results of investigations. Uncertainty around timeframes and lengthy waiting times for results are a commonly reported source of distress for many parents.[1,20,29] Parents need to be assured that they will receive results as soon as they are available; preliminary results may be available within days but other results may take longer.[2]

Where individual, religious, and cultural beliefs make autopsy unacceptable to parents, these beliefs and parents' decisions regarding autopsy should be respected.[10] Attempts to persuade parents to choose a post-mortem should be avoided. However, less invasive approaches may be more acceptable to those who decline autopsy and these options should be discussed with parents.[2] Less invasive approaches may include limited autopsies that take an organ-specific approach, minimally

invasive autopsies that use a laparoscopic or keyhole approach to obtain organ samples, or non-invasive autopsies that use detailed external, placental and umbilical cord examinations and external measurements, skin/needle blood sampling, clinical photography, and radiological investigations.[2]

Question 3: What types of information should healthcare professionals provide to meet the individual needs (e.g., literacy level, culturally appropriate) and preferences (e.g., written, audio) of parents?

The information provided to parents about their options following perinatal death should be clear and consistent and provided in a timely and sensitive way. Healthcare professionals should be knowledgeable and well prepared to discuss investigations, invite questions from parents and respond to any concerns that they may have, and seek consent for autopsy from parents. It is important that healthcare professionals are aware that parents' ability to process new information and to make decisions may be greatly affected by the stress and grief that they are experiencing.[1,21]

Verbal information was reported as a common method of information delivery in the UK. A 2017 study found that influences on parents' decision-making include the ways in which investigations are discussed, the healthcare professional leading the discussion, and the timing of the discussion.[20] In some circumstances, parents reported inadequate information provision and insensitive communication. Parents need to feel supported during this time, and find it helpful when staff can explain the respectful nature and purpose of the investigation while being mindful about their tone and the level of detail being provided during the discussions.[29]

Schirmann et al.[1] found that information about investigations had been poorly communicated across Australia and Aotearoa New Zealand, reiterating the importance of tone (including being mindful of other nonverbal body language) and the timing of the discussion. For example:

> **"The doctor was really horrible with explaining the autopsy … she went into great detail about what and how they would do it, right in front of me while I was holding my baby and it made me sick to my stomach".[1]**

Written resources alongside verbal information was suggested to provide families with information for their reference. Providing written information can help women and families with their decision-making following discussions about investigations, as some studies have shown that it can be difficult to remember conversations at the time of perinatal death.[30]

To help facilitate and ensure that information is kept consistent throughout Aotearoa New Zealand, a national perinatal postmortem information pamphlet is available for staff to give to families.[5] Even with this information, Cronin et al.[5] found that women of Māori and Pacific ethnicity were more likely to decline autopsy for late stillbirth. The main reasons for declining autopsy were around 'not wanting baby to be cut' and 'already knowing the reason why baby had died.' However, no women in the study who chose to have an autopsy regretted their decision, in comparison to 10% of women who declined autopsy and stated that they would not make the same decision again.

In the UK, most healthcare professionals also reported providing written information to accompany verbal discussions. Of the women who received written information in the UK, the majority agreed to a full autopsy for their baby as they felt 'sufficiently informed' to make the decision.[20]

In Australia, translations of information for women in their native language are needed to ensure that women understand their options, any concerns are addressed, and to obtain informed consent. A clear and concise handout explaining the rationale and providing a strong reminder for women that the choice of management remains with her [is offered by midwives].[31]

Following information delivery in Australia, Aboriginal and Torres Strait Islander parents reported not having enough time to think about their decision. Additionally, parents reflected on the ways in which they were approached and asked about autopsy, with most reporting that the approach was made in an insensitive manner at such an overwhelming and distressing time.[32] In some cases, parents felt unprepared after healthcare professionals only included one parent in the discussion. All these factors influenced parents' final decision about autopsy and other investigations. Delay and uncertainty around the timeframe for receiving results also had a negative influence on parents. Transparency about timeframes can be particularly difficult in regional, rural, and remote hospitals. Follow-up with families during this time helped to relieve some of the distress felt by parents[9].

Timing of information delivery differed by healthcare professional across Ireland and the UK. In a survey of 98 neonatal healthcare professionals in the UK (including consultant neonatologists and advanced neonatal nurse practitioners), 73.5% indicated that they "always" provided information to parents about investigations. However, those who "rarely" or "never provided" information were usually nurses. In almost two-thirds of responders (63.4%), information was provided in the hours after death. Almost one-quarter of responders (22.6%), stated that they provide information before the baby's death, in the minutes after death (11.8%), and in the days after death (2.2%). In just over two-thirds of cases (71.0%), investigations were discussed one to two times. In almost one-third of cases (25.8%), investigations were only discussed once. Most responders (90.4%) stated that another staff member was present for these discussions, often to provide support. Verbal information was reported as the most common method of information delivery (98.9%), with written resources also provided in most cases (73.4%). Just over half of responders (54.6%) were "satisfied" or "very satisfied" with the information that parents were given following perinatal death and half (49.5%) reported that they were satisfied.[4]

The consent process for investigations, particularly autopsy, has developed to involve increased transparency and clear guidance. In 2013, Sands UK (stillbirth and neonatal death charity) launched the Sands Post-Mortem Consent Package. This package was developed to be used by both healthcare professionals and bereaved families and was designed to provide information and guidance about investigations. During the development of the package, hospital consent forms were made to be more succinct and were changed to focus on the priorities of parents. The medical terminology and wording on the forms was changed to be more compassionate and easier to understand. Following the launch of this package, the Human Tissue Authority introduced codes of practice for postmortem examination. These codes of practice help to maintain healthcare professional skills, as well as practices around investigations, including guidance around handling tissue following the examination(s), healthcare professional training around seeking consent, and regular assessments of competency.[33]

Decision aid tools help patients by listing possible outcomes, risks, and benefits, and can often increase confidence around the decision. There is currently no decision aid tool for autopsy; however, development of a tool could help parents make an informed decision that is best for them and their baby and aligns with their personal values, beliefs, and needs.[34]

In some low-and-middle-income settings, such as Ghana, Malawi, Tanzania and Zambia, there is limited information available for healthcare professionals to provide to parents, which often limits autopsy consent and uptake [35]. In these countries, healthcare professionals often have to rely on verbal autopsies when investigating the cause of perinatal death.[36] However, verbal autopsies are often inaccurate and have poor specificity.[37] Additionally, women in these countries perceive communication about investigations and stillbirth in general as being poor.[38] Bedwell et al.[38] state various reasons for this including limited confidence and communication skills, and discomfort in discussing death. Healthcare professionals have expressed the need for education and training to help manage communication in challenging situations.[38,39] According to Bedwell et al[39], community awareness and support for parents are also important factors for increasing the uptake of investigations in low-and-middle income settings.

Religious beliefs also limit and influence parents' decision-making and acceptance of investigations.[37] In a study in India, an information sheet in Hindi and verbal explanation was used. Visual or pictorial tools were not used in the counselling and consenting process for minimally invasive tissue sampling.[36] Refer also to Appendix 6A: *Technical report: Investigations for perinatal death* for information around how diverse cultural and religious backgrounds may influence autopsy consent.

Question 4: What information should be provided to parents about the range of investigation options available to them, and who should provide information about which, if any, investigations are most likely to be useful?

Information provided about the range of investigations that may be useful, and how and where they are performed was examined in the UK through a qualitative exploration of parents' ability to make informed choices about investigations including 477 women.[20] Most women (85%) who received information about investigations felt sufficiently informed and like they had enough time to decide (81%).[20] However, some women mentioned that they were concerned about how they had interpreted the information provided, and were worried that they had not correctly understood the medical terminology:

> **"... we are not doctors, we are not technical people, so having to explain that, things get lost in translation." [40]**

The cost of investigations following perinatal death have implications for parental decisions, and in the USA, one study concluded that accurate information about the out-of-pocket costs and fees of investigations should be made available for parents' consideration.[41] Additionally, referrals to programs and organisations that can help with the associated costs should also be made available. In Australia, the costs of investigations are usually paid by the facility caring for the family, with a gap paid by Medicare. A cost of up to A$8,000 has been estimated per perinatal death in Australia.[42]

In the UK, the main people to discuss investigations and engage in these difficult conversations are senior obstetricians.[20] In other countries in Europe and across the US and, a team based, family-centred approach that is individualised and led by a clinician who has an established rapport with the parents and family should guide discussions about autopsy and investigations.[6]

Other members of the healthcare team may also be involved. A survey of 46 chaplains in Ireland and the UK found that almost two-thirds had been asked for advice by parents as they faced decisions about investigations. Almost all felt that they should engage with parents in discussions about investigations if requested, but most did not feel sufficiently informed to support parents and provide needed advice.[28]

Healthcare professionals should be mindful of their influence on parents' decision-making. For autopsy, ambivalence about the value of the procedure from a healthcare professional perspective, belief that the cause of death is already known, and assumptions about parents' needs including concerns about adding further distress, are among the most common barriers to consent following perinatal death.[1,3] It is important to convey to parents an understanding of the value of each investigation available to them and that they are useful and respectful.[29]

Healthcare professionals must be considerate of parents' needs when discussing consent for autopsy or investigations. The amount and level of detail parents require to engage in shared decision-making about autopsy or investigations differs between families. Verbal and nonverbal communication should be observed to ascertain parent's comfort with the discussion.[6,23] Parents have reported finding it useful in their decision-making when discussions include the purpose of the examination, and the information that may be learnt from the investigation.[29] In some cases, the cause of death is classified as unknown. However, the value of not finding a cause should still be discussed when providing parents with their options for investigations. Having no definitive cause of death can be helpful when planning and managing future pregnancies.[43-46]

Healthcare professionals in low-and-middle-income countries, such as Ghana, have indicated that helpful information for parents regarding autopsy and investigations includes who should perform the counselling, the costs associated with the examination, what usually happens during an autopsy, and how much time is needed to receive the results and final report.[35]

Question 5: Are telehealth reviews an acceptable option for providing parents with information about investigation options? Is this an acceptable option for discussing results of investigations with parents?

Telehealth has been viewed as an acceptable way to provide information to parents following perinatal death. However, face-to-face support is optimal for most parents (REF). While some parents prefer telehealth, it is important to recognise the challenges for both parents and healthcare professionals. These include difficulty accessing the appropriate technology, lack of technical knowledge and skills, and lack of internet access.[22] In addition to common telehealth services (i.e. appointment by phone), information and resources about investigations, such as pamphlets, are available online or via phone apps for parents to view.[34]

Question 6: What is the optimal content of consent forms for perinatal autopsy and other investigations?

In 2013, Sands launched its consent package for perinatal autopsy, which incorporated major changes to some perinatal autopsy consent forms being used in the UK.[6] The priority was to align content with the priorities of parents, and to remove medicalised terminology. The Human Tissue Authority in 2016 (UK) introduced clear consent form processes concerning retention of tissues and organs. Less

invasive methods of investigations were also introduced to inform and help parents to decide on the appropriate autopsy and investigation process for their needs.[6] This consent form is currently used in the UK and encompasses:

- the extent of examination permitted (full, limited to a body cavity, laparoscopic autopsy with biopsy sampling or external examination only)
- taking and examination of tissues for histology
- genetic investigations and other laboratory tests
- and whether images or tissues may be used for audit, research, and teaching.

Radiology and photography are performed for all perinatal deaths with parental consent.[44]

> **"With the Sands consent form the wording of it is just more straightforward, it's a little bit softer, it acknowledges the fact that it is somebody's baby."** Bereavement midwife.[6]

Question 7: What is the value of a plain language summary of the perinatal autopsy for parents?

In the UK, parents valued written information about the diagnosis.[21] Further, this information should be clear and consistent, with limited use of medical jargon. Helps et al. found that lack of clear information regarding interventions, paired with medical jargon, caused confusion, discomfort and anxiety. Clear information helped eased distress.[23]

> **"This (poor communication and language skills using unexplained medical jargon) left parents feeling intimidated and unclear as to what was being said to them and some of them felt inadequate and uncomfortable about asking for a clearer explanation."** Report 7 in [23]

Question 8: What information should be provided to parents when the baby needs to be transported for investigations (including autopsy and medical imaging)?

In an Australian qualitative study, it was evident that parents wanted to know where their baby was at all times following the birth, regardless of their decision about investigations.[1] Healthcare professionals should be informed about this information and update parents where possible. Healthcare professionals should also be aware that timeframes and processes relating to investigations can be affected by various factors. For example, during the COVID-19 pandemic, babies were unable to be returned to the parents' room once taken to the mortuary or other isolation room.[22] If possible, parents should be provided with the opportunity to accompany their baby to the mortuary if they wish.[9]

Grey literature and other sources

Note. Grey literature is not included in the GRADE assessment of the evidence-based recommendations. References for grey literature that are synthesised in this report are marked with an asterisk (*) in the reference list.

In addition to the published academic literature, both international and national government agency and parent support organisations (Red Nose/Sands, Bears of Hope, Stillbirth Foundation Australia) websites were searched for relevant information relating to decisions about investigations following stillbirth or neonatal death. A targeted Google search was also conducted using a combination of the following keywords: stillbirth investigations; neonatal death investigations; perinatal death investigations; stillbirth investigations decision-making; neonatal death investigations decision-making; perinatal death investigations decision-making; parent decision-making following stillbirth. The findings of the grey literature, particularly in Australia, are drawn from and supported by the previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*.

Across several states in Australia, it is emphasised that experienced healthcare professionals are best placed to discuss and inform parents about their options for stillbirth investigations.[47,48] Parents may find verbal, electronic and written information helpful when deciding whether they should have investigations and/or an autopsy performed to help find out why their baby died.[48] To support healthcare professionals in their discussions with parents, both Red Nose (2023)[49] and Stillbirth Foundation Australia (2022)[50] have developed written parent-facing resources explaining autopsy and other investigations in more detail. In some cases, services might also have their own resources for healthcare professionals that contain helpful information about investigations, and more specifically, around obtaining consent for an autopsy.[51] Parents must provide their written consent for an autopsy following an informed discussion.[48,52]

In South Australia, several projects have been undertaken by SA Health in response to the National Stillbirth Action and Implementation Plan including the development of investigations decision-making resources and fact sheets for bereaved families that are 'fit for purpose.'[53] These resources and fact sheets include:

- *Pre-admission information for families experiencing perinatal loss* fact sheet
- *Stillbirth investigations*: *Information for parents* fact sheet – to be used as below:
    - As a pre-emptive prior to the conversation regarding stillbirth investigations
    - To guide clinicians through a discussion about stillbirth investigations and autopsy
    - Following a discussion as a resource to help parents remember information
- Consumer video: *The perinatal postmortem examination: An information resource for families*
- *Postnatal care following stillbirth* fact sheet
- *Community bereavement support groups in South Australia following stillbirth* brochure.

The fact sheets are available in seven languages and are accessible via the SA Health webpage: www.sahealth.sa.gov.au/stillbirth

In the UK, written information is also available and provided to parents to help them decide whether they should have any investigations performed following the death of their baby. This information should be provided following a discussion with a doctor, midwife, or nurse. Parents are also encouraged to discuss their options for investigations with their family and friends.[47,54] Parents may also wish to reach out to people who can provide spiritual or religious support.[47]

During discussions, healthcare professionals should ask parents about their personal wishes, as well as any cultural or religious preferences or needs that may influence their decisions about investigations.[47] If there are any cultural considerations, an interpreter, Aboriginal or Torres Strait Islander health worker and/or liaison officer or cross-cultural health worker should join the discussion.[47] Parents should also be provided with an opportunity to discuss any concerns, and if there is anything that they think may have contributed to the stillbirth. This may include different aspects of care throughout the pregnancy.[47]

Healthcare professionals who understand the case should arrange a follow-up meeting with the parents and their family (or other support people) to discuss the results of the investigations. Nationally, telehealth is an appropriate way of providing interpretation of investigation results if required, particularly if the family live in a rural or remote area.[47]

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies		GRADE-CERQual overall confidence rating of evidence	Guideline recommendations
Avagliano 2022 Boyle 2022 Cronin 2018 Das, Arora, Debata, et al. 2021 Feroz 2019 Henderson 2017 Lewis, Riddington, Hill, Bevan, et al. 2019 Schirmann 2018 Siassakos 2018 Spierson 2019 Swarray-Deen 2022		Low confidence *Minor concerns of data adequacy, moderate concerns of methodological limitation, relevance and coherence are noted.*	**Consensus-based recommendation 6.1:** Counselling parents about options for investigations (including the option of a full autopsy or less invasive options) should be conducted within a parent-centred decision-making framework by an experienced healthcare professional who has established rapport with the parents. • Discussions should include the value and limitations of the investigations in their circumstances. Parents should be given multiple opportunities to discuss their options according to their needs.
			Consensus-based recommendation 6.2: Ideally, counselling parents on their options for investigations (including autopsy) is informed by a clinical case review by a multidisciplinary team, including a perinatal/paediatric pathologist, the lead obstetrician or paediatrician, and radiologist.
Aiyelaagbe 2017 Avagliano 2022 Boyle 2022 Cassidy 2019 Cronin 2018 Das, Arora, Debata, et al. 2021 Das, Arora, Kaur, et al. 2021	Kilcullen 2020 Lewis, Riddington, Hill, Arthurs, et al., 2019 Page & Silver 2020 Riches 2023 Schirmann 2018 Shelmerdine 2020 Siassakos 2018	High confidence *No concerns of coherence or data adequacy, minor concerns of relevance. Moderate concerns of methodological limitation.*	**Evidence-based recommendation 6.3:** Information (written and verbal) and counselling for parents about all investigations, including autopsy, should include: • the possibility that the cause of death may not be determined despite all investigations being undertaken

Evans 2020 Helps 2020 Henderson 2017	Silverio 2021 Spierson 2019		• that, while a cause may not be found, excluding some potential causes of death may be helpful • a full investigation, including autopsy, provides the best possible information to help understand why the baby died and to plan future pregnancies • when and how they will be provided with the outcome of the investigations undertaken • whether the baby will need to be transported to another centre for the investigations, how the transport is organised, when the baby will be returned to them. • how their baby will look after the autopsy • any costs to them related to investigations.
Lewis 2017 Lewis, Riddington, Hill, Bevan, et al., 2019 Schirmann 2018		Low confidence *No concerns of relevance and coherence. Moderate concerns of methodological limitation. Major concerns of data adequacy.*	Consensus-based recommendation 6.4: Assure parents that, throughout the process of autopsy and other investigations, their baby will be cared for by highly trained healthcare professionals who will treat their baby with respect as they do all possible to understand the cause of death.
			Consensus-based recommendation 6.5: Explain to parents that the placenta can be returned to them following examination by the pathologist. The pathology service should be notified of the parents' wishes when the placental examination is requested. Advice should be given to families/whānau about any relevant health and safety precautions when handling the placenta.
		See Section 2: Technical report for cultural safety for evidence	Evidence-based recommendation 6.6: Healthcare professionals must respectfully ask parents and

	synthesis and GRADE CERQual rating of this recommendation.	family/whānau throughout their care if they have cultural, religious, or spiritual care needs including preferences for discussing and making decisions about investigations to understand why their baby died. • Healthcare professionals should avoid making assumptions and must work in partnership with families/whānau to ensure care is individualised and that their needs are met, seeking further guidance where needed.

Table 4. Search strategy

Database	Search strategy		
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh]	Mesh
	#2	"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal emise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR “Neonatal loss*” OR “Neonatal mortalit*”OR “Neonatal eath*” OR “Neonatal Demise*” OR “Newborn death*” OR “Newborn mortalit*”	Title/abstract
	#3	#1 OR #2	
	#4	"Indigenous Peoples"[Mesh] OR "Transients and Migrants"[Mesh] OR "Refugees"[Mesh] OR "Health Disparity, Minority and Vulnerable Populations"[Mesh] OR "Vulnerable Populations"[Mesh] OR "Culturally Competent Care"[Mesh] OR "Rural Health Services"[Mesh] OR "Parents"[Mesh]	Mesh
	#5	(parents or mother* or father* or “patient understan*” or “patient need*” or “patient resource*” or “patient experience*” or “patient view*” or "patient decision-making" or "patient decision making" or "women understand*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or “cultural care” or elders)	Title/ abstract
	#6	#4 AND #5	
	#7	"Health Care Economics and Organizations"[Mesh]	Mesh
	#8	(cost* OR econom*)	Title/ abstract
	#9	#7 OR #8	
	#10	#9 OR #6	
	#11		Mesh
	#12	("telehealth" or "tele health" or "SMS" or "mobile app" or “mobile application” or “digital application” or "phone app" or “phone application” or "audio information" or “virtual information” or "pamphlet*" or “visit body” or “visit imaging” or (Transfer AND ("mortuary" or "morgue" or "body" or "imaging" or "radiology" or "computerised tomography" or "magnetic resonance imaging" or "MRI" or "CT")) or “community outreach” OR “community care” or "decision making" or "decision aid*" or "written resources" or "electronic resources" or "community" or “online resources” or "virtual consultation" or “virtual care” or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or counselling or counselling)	Title/ abstract
	#13	#11 OR #12	
	#14	#3 AND #10 AND #13	
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *newborn death/ or *induced abortion/ or *pregnancy termination/	
	2	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.	
	3	(((pregnancy or foetal or fetal or fetus or perinatal or "peri natal" or neonatal) adj1 loss*) or stillb*).ti,ab.	
	4	1 OR 2 OR 3	
	5	exp transcultural care/ or exp vulnerable population/ or exp rural health care/ or exp indigenous health care/ or exp health disparity/ or indigenous people/	
	6	(parents or mother* or father* or (patient* adj2 (understan* or need* or resource* or experience* or view* or "decision-making" or "decision making" or "shared decision")) or "women understand*" or "women* need*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant	

	or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or cultural or elders).ti,ab. 7 5 OR 6 8 *health care cost/ 9 (cost* OR econom*).ti,ab. 10 8 OR 9 11 ("telehealth" or "tele health" or "SMS" or (("mobile" or "phone") adj3 ("app" or "application")) or (("written" or "audio" or virtual) adj5 "information") or "pamphlet*" or (("visit*" or "attend*" or "allow*" or "transfer" or "accompany") adj4 ("mortuary" or "morgue" or "body" or "imaging" or "radiology" or "computeri$ed tomography" or "magnetic resonance imaging" or "MRI" or "CT")) or ("community" adj3 "outreach") or ("community" adj1 "care") or (("decision making" or "decision aid*" or "written" or "electronic" or "community" or online) adj3 "resources") or "virtual consultation" or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or counselling or counselling).ti,ab. 12 *telehealth/ or exp telemedicine/ 13 11 OR 12 14 10 AND 13 15 4 AND 7 AND (13 OR 14)
CINAHL	S17 S4 AND S15 AND S16 S16 S8 OR S12 S15 S13 OR S14 S14 AB ("telehealth" OR "tele health" OR "SMS" OR (("mobile" OR "phone") N3 ("app" OR "application")) OR (("written" OR "audio" OR virtual) N5 "infORmation") OR "pamphlet*" OR (("visit*" OR "attend*" OR "allow*" OR "transfer" OR "accompany") N4 ("mortuary" OR "morgue" OR "body" OR "imaging" OR "radiology" OR "computeri$ed tomography" OR "magnetic resonance imaging" OR "MRI" OR "CT")) OR ("community" N3 "outreach") OR ("community" N1 "care") OR (("decision making" OR "decision aid*" OR "written" OR "electronic" OR "community" OR online) N3 "resources") OR "virtual consultation" OR "shared decision" OR "timeline*" OR "decision making" OR "decision-making" OR "shared-decision" OR counselling OR counselling) S13 (MM "Telehealth") OR (MM "Decision Making, Patient") OR (MH "Decision Making, Family") OR (MM "Decision Making, Shared") S12 S8 AND S11 S11 S9 OR S10 S10 AB (cost* OR econom*) S9 (MH "Health Care Costs+") S8 (S5 OR S6 OR S7)

	S7 AB (parents OR mother* OR father* OR (patient* N2 (understan* OR need* OR resource* OR experience* OR view* OR "decision-making" OR "decision making" OR "shared decision")) OR "women understand*" OR "women* need*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR family OR families OR refugee* OR "indigenous" OR "torres strait islander*" OR ATSI OR "aborigin*" OR "islander*" OR remote* OR "linguistically diverse" OR "literacy" OR "low income" OR cultural OR elders) S6 (MH "Parents+") S5 (MM "Health Services, Indigenous") OR (MM "Rural Health Personnel") OR (MM "Rural Health Centers") OR (MM "Hospitals, Rural") OR (MM "Rural Health Services") S4 S1 OR S2 OR S3 S3 AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal" OR neonatal) N1 loss*) OR stillb*) S2 AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*) S1 (MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
SCOPUS	((TITLE-ABS-KEY ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*)))) OR ((TITLE-ABS-KEY ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*)))) OR ((TITLE-ABS-KEY ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*)) AND ALL (stillb*))) AND TITLE-ABS-KEY ((parents OR mother* OR father* OR (patient* W/2 (understan* OR need* OR resource* OR experience* OR view* OR "decision-making" OR "decision making" OR "shared decision")) OR "women understand*" OR "women* need*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR family OR families OR refugee* OR "indigenous" OR "torres strait islander*" OR atsi OR "aborigin*" OR "islander*" OR remote* OR "linguistically diverse" OR "literacy" OR "low income" OR cultural OR elders)) AND TITLE-ABS-KEY (("telehealth" OR "tele health" OR "SMS" OR (("mobile" OR "phone") W/3 ("app" OR "application")) OR (("written" OR "audio" OR virtual) W/5 "information") OR "pamphlet*" OR (("visit*" OR "attend*" OR "allow*" OR "transfer" OR "accompany") W/4 ("mortuary" OR "morgue" OR "body" OR "imaging" OR "radiology" OR "computeri$ed tomography" OR "magnetic resonance imaging" OR "MRI" OR "CT")) OR ("community" W/3 "outreach") OR ("community" W/1 "care") OR (("decision making" OR "decision aid*" OR "written" OR "electronic" OR "community" OR online) W/3 "resources") OR "virtual consultation" OR "shared decision" OR "timeline*" OR "decision making" OR "decision-making" OR "shared-decision" OR counselling OR counselling)) AND NOT ((*"genetic counseling"* OR *"genetic counselling"* OR *"contraceptive counselling"* OR *"contraceptive counseling"* OR *"prenatal counselling"* OR *"prenatal counseling"*))
Australian Indigenous HealthInfoNet	(sorry AND business) AND (stillborn OR baby OR newborn OR infant)

Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees
	#2	MeSH descriptor: [Perinatal Death] explode all trees
	#3	MeSH descriptor: [Perinatal Mortality] this term only
	#4	MeSH descriptor: [Abortion, Induced] this term only
	#5	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mORtalit*)
	#6	#1 OR #2 OR #3 OR #4 OR #5
	#7	MeSH descriptor: [Minority Health] explode all trees
	#8	MeSH descriptor: [Vulnerable Populations] explode all trees
	#9	MeSH descriptor: [Parents] explode all trees
	#10	MeSH descriptor: [Health Care Costs] this term only
	#11	(parents or mother* or father* or (patient* ADJ2 (understan* or need* or resource* or experience* or view* or "decision-making" or "decision making" or "shared decision")) or "women understand*" or "women* need*" or "women* view*" or "women* experience*" or "woman* understand*" or "woman experience*" or migrant or immigrant or family or families or refugee* or "indigenous" or "torres strait islander*" or ATSI or "aborigin*" or "islander*" or remote* or "linguistically diverse" or "literacy" or "low income" or cultural or elders)
	#12	#7 OR #8 OR #9 OR #10 OR #11
	#13	MeSH descriptor: [Telemedicine] this term only
	#14	(("telehealth" or "tele health" or "SMS" or (("mobile" or "phone") adj3 ("app" or "application")) or (("written" or "audio" or virtual) adj5 "information") or "pamphlet*" or (("visit*" or "attend*" or "allow*" or "transfer" or "accompany") adj4 ("mortuary" or "morgue" or "body" or "imaging" or "radiology" or "computeri$ed tomography" or "magnetic resonance imaging" or "MRI" or "CT")) or ("community" adj3 "outreach") or ("community" adj1 "care") or (("decision making" or "decision aid*" or "written" or "electronic" or "community" or online) adj3 "resources") or "virtual consultation" or "shared decision" or "timeline*" or "decision making" or "decision-making" or "shared-decision" or counselling or counselling)):ti,ab,kw
	#15	#13 OR #14
	#16	#6 AND #12 AND #15
Informit Indigenous Collection	"pregnancy terminat*" OR "Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mORtalit*" OR "Fetal demise*" OR "Foetal mORtalit*" OR "perinatal wast*" OR "perinatal mORtalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mORtalit*" OR "prenatal demise*" OR "Antenatal mORtalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mORtalit*" OR "Intrapartum Death*" OR "Neonatal loss*" OR "Neonatal mORtalit*" OR "Neonatal death*" OR "Neonatal Demise*" OR "NewbORn death*" OR "NewbORn mORtalit*"	

Figure 1. PRISMA flow diagram of evidence screening process

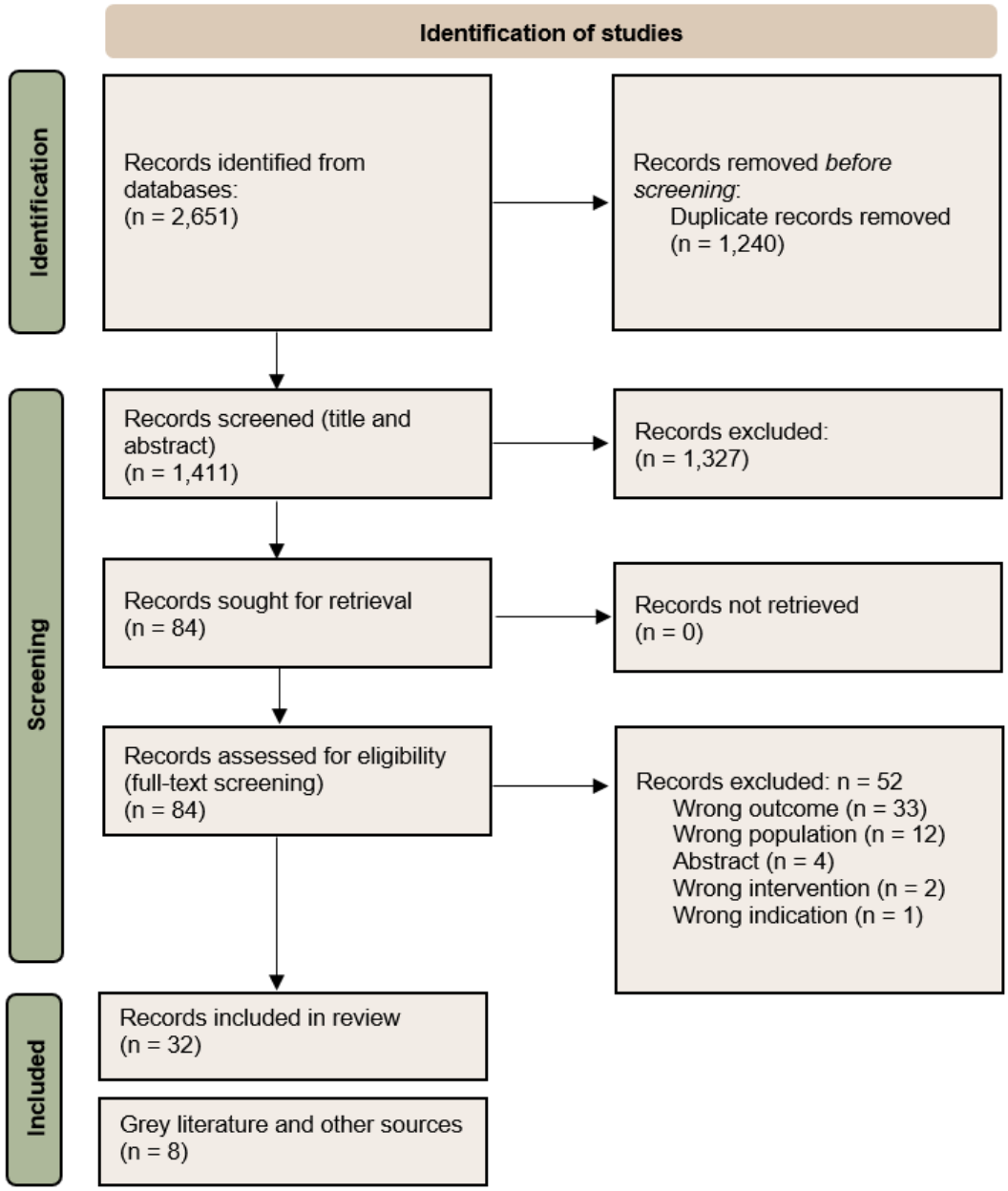

Table 5. Study characteristics

Study ID	Country (period)	Locality (state/ national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Avaglian o 2022	Italy (dates not reported)	1 third level Italian university care centre	Online anonymous questionnaire	HIC	Quantitative	NA	Prospective cross sectional	34 clinicians	Stillbirth	Clinicians' knowledge about fetal autopsy	NA	Healthcare staff of the obstetrics unit of the study institution	Checklist for case control studies
Bakhbakhi 2017	UK (2015)	Southwest England	Focus group discussions with bereaved parents	HIC	Qualitative	Narrative Analysis	NA	11 (8 female, 3 male)	Stillbirth, NND, TOPFA	Parents' views on involvement in the perinatal mortality review process	None specified	Women and their partners who had experienced a perinatal death more than 6 months prior to the study	Checklist for qualitative research
Boyle 2022	Australia (April 2020)	National	Online survey	HIC	Qualitative	Content analysis	NA	35	Stillbirth, NND, TOPFA	Healthcare professional views of the impact of COVID-19 on provision of respectful care to parents and	None specified	Healthcare professionals who provided perinatal bereavement care in clinical settings or through support organisati	Checklist for qualitative research

										resulting practice changes		ons in Australia	
Cassidy 2019	USA 1994-2009	University of California, San Francisco	Medical charts	HIC	Quantitative	NA	Comparative diagnostic accuracy	385	Pregnancy loss or termination for anomalies and other complications	Correlation between ultrasound and autopsy diagnosis	Babies that lived >6 hours, autopsies for reasons other than terminations or pregnancy, partial autopsy only, missing antenatal records, cases from elsewhere, no identified maternal or fetal indication for termination.	All autopsies performed at the University of California, San Francisco in cases of intrauterine fetal demise, termination for anomalies or fetuses delivered but not resuscitated.	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Cronin 2018	Aotearoa New Zealand 2012-2015	20 Aotearoa New Zealand District Health Boards	Face-to-face interviews, and maternity and postmortem records	HIC	Quantitative	NA	Case Series	169	Stillbirth (n=169)	Exploration of factors influencing decision-making about postmortem	Pregnancies with a known congenital abnormality at recruitment.	Women with singleton pregnancies that ended in late stillbirth (≥28	Checklist for case series studies

										examination.		weeks GA) without known congenital abnormality.	
Das 2021	India (Sept 2018–April 2019)	Tertiary care hospital in Delhi	Observations and interviews	LMIC	Qualitative	Thematic content analysis	NA	13	Stillbirth (n=1), NND (n=7)	Process of counselling and obtaining consent for MITS	None specified	Parents and family members of deceased children and stillbirths, MITS research staff and healthcare providers	Checklist for qualitative research
Das 2021	India (2018–2019)	At and around a tertiary care hospital in Delhi	Observations, interviews and focus groups	LMIC	Qualitative	Thematic content analysis	NA	104	Stillbirth (n=44 parents of 22 stillbirths), NND (n=24 parents of 12 NND)	Perceptions of parents, community and religious leaders on acceptability of MITS	Parents from outside Delhi were excluded	Parents of deceased children, neonates or stillbirths, community members and religious leaders	Checklist for qualitative research
Evans 2020	UK (2013–2017)	National	Medical records	HIC	Quantitative	NA	Non-comparative study	25,316	Stillbirth, NND	Factors associated with the offer of and consent to	Cases of perinatal deaths with missing information on offer	Cases of perinatal deaths of babies born between 2013-2017	Checklist for case series studies

										perinatal PM	of post-mortem and socioeconomic deprivation. Terminations of pregnancy.	with data collected by MBRRACE-UK	
Feroz 2019	Pakistan (Jul–Aug 2018)	National Institute of Child Health, Karachi, Pakistan	Focus groups and interviews	LMIC	Qualitative	Thematic analysis	NA	45 (40 for focus groups, 5 interviews)	Views and opinions of parents of newborns concerning MITS for stillbirth and neonatal death.	Parents' and religious leaders' perceptions related to MITS	Parents and/or families that experienced a recent neonatal death/stillbirth or who were in-patients	Parents of newborns who were visiting the OPD and well-baby clinics of NICH hospital for regular growth monitoring, postnatal check-ups and vaccinations were purposively sampled for focus group discussions. Religious leaders, including Sunni Ulemas and Shia	Checklist for qualitative research

												Muftis were purposively sampled for key-informant interviews.	
Helps 2020	Ireland (2005-2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	stillbirth, NND	Bereavement care provided to families following perinatal death/pregnancy loss as described in national inquiry reports	None stated	National inquiries into perinatal deaths/pregnancy loss services between 2005-2018.	Checklist for qualitative research
Henderson 2017	UK (2013)	National	Postal survey	HIC	Mixed-methods	Thematic analysis	Cross-sectional descriptive study	477	Stillbirth	Experience of parents in relation to postmortem following stillbirth	None specified	Women who experienced a stillbirth in 2013	Checklist for qualitative research and Checklist for studies reporting prevalence data
Kilcullen 2020	Australia (2005-2015)	Townsville Hospital	Semi-structured interviews with women	HIC	Qualitative	Thematic analysis	NA	5	Stillbirth	Aboriginal and Torres Strait Islander women's decisions to consent for	Women with active mental health difficulties	Aboriginal and Torres Strait Islander women who experienced stillbirth	Checklist for qualitative research

										autopsy after stillbirth		between 2005–2015	
Lewis 2017	UK (Dec 2015, Aug 2016)	International literature	Published literature	HIC	Qualitative	Systematic review	NA	34 papers	Stillbirth, NND, TOPFA, Child death	Factors affecting uptake of prenatal/ perinatal/ paediatric postmortem examination	(a) Included adult PM examination; focus on verbal, social or psychological PM; bereavement studies; (b)Non-English papers; (c)Editorials, letters, abstracts or commentaries, non-research articles or case reports.	Studies included: (a) Bereaved parents with experience of termination of pregnancy for fetal abnormality, stillbirth, neonatal or childhood death (<16 years), or health professionals or general public; (b)where a diagnosis was known as well as where there was	Checklist for systematic reviews and research syntheses

												no confirmed diagnosis; (c) Factors affecting uptake or decline of perinatal/ paediatric postmortem examination; (d) Qualitative, quantitative or mixed methods; in English and peer reviewed.	
Lewis 2019	UK (2016–2017)	National	Cross-sectional survey, interviews, focus groups	HIC	Qualitative	Thematic analysis	NA	439 free-text responses, 20 parent interviews, 25 HCPs	Miscarriage, Stillbirth, NND, TOPFA, Infant death	Parental decision making about postmortem	None specified	Bereaved parents-including pregnancy loss, neonatal or infant death, HCPs from a range of clinical backgrounds involved in discussing or conductin	Checklist for qualitative research

												g postmortem examinations with parents	
Lewis 2019	UK (2016–2017)	7 hospitals in England, 4 parent support organisations	Surveys and phone interviews	HIC	Mixed methods	Thematic analysis	Cross-sectional survey	859 survey responses, 20 interviews (18 women)	Stillbirth, NND, TOPFA, miscarriage, infant death	Acceptability and uptake of less invasive autopsy methods by parents	None specified	Bereaved parents who had experienced pregnancy loss or a neonatal or infant death	Checklist for qualitative research and Checklist for studies reporting prevalence data
Nuzum 2021	UK and Ireland	National	Online survey	HIC	Quantitative	NA	Cross-sectional descriptive study	46	Stillbirth	Role of maternity healthcare chaplains in providing decision making-information and support around perinatal postmortem with bereaved parents	None specified	Maternity healthcare chaplains	Checklist for studies reporting prevalence data

Page & Silver 2020	USA (dates not reported)	NA	Literature	HIC	Qualitative	Review of literature and current practice	NA	NA	Stillbirth	Stillbirth evaluation and follow-up	None mentioned	NA	Checklist for text and opinion papers
Riches 2023	USA (dates not reported)	1 university hospital	Interviews	HIC	Qualitative	Thematic content analysis	NA	19 parents	Stillbirth	Postmortem decision-making needs and preferences of parents of a stillborn	NA	Patients who received stillbirth care at the University of Utah in the last 5 years, aged ≥18 years, and an English speaker.	Checklist for qualitative research
Schirmann 2018	Australia and Aotearoa New Zealand (Dec 2015-Feb 2016)	National	Online survey	HIC	Qualitative	Framework analysis	NA	454	Stillbirth (n=454)	Mothers' decision-making needs for autopsy consent following stillbirth	Male respondents and mothers experiencing a loss earlier than 20 weeks	Mothers residing in Australia or Aotearoa New Zealand who reported a stillbirth after 20 weeks' gestation were included	Checklist for qualitative research
Shelmerdine 2020	UK (June 2007–2013)	Great Ormond Street Hospital	Hospital medical records	HIC	Quantitative	NA	Diagnostic accuracy	81	TOPFA, Stillbirth, NND	Additional yield from autopsy following	Cases were excluded where the	Sequential cohort of fetuses and	Quality Assessment for Diagnostic

										prenatal ultrasound and postmortem MRI	prenatal imaging findings or autopsy reports were not available for re-review	children referred to Great Ormond Street Hospital over a 6-year period where parents consented for traditional autopsy and PMRI	Accuracy Studies (QUADAS)
Siassakos 2018	UK (2013)	Three maternity hospitals	Interviews, focus groups, service provision data	HIC	Qualitative	Thematic analysis	NA	Parents of 16 stillborn babies, 22 maternity staff	Stillbirth	Views of bereaved parents and maternity staff to improve bereavement care for families	Twin pregnancy and loss, intrapartum stillbirth	Parents with a stillborn baby (gestational age more than 23 weeks, 6 days)- singleton stillbirths with the fetal death diagnosed before the onset of labour, maternity staff	Checklist for qualitative research

Silverio 2021	UK (Nov–Dec 2020)	National	Interviews	HIC	Qualitative	Template analysis	NA	24	Late miscarriage 14 to 23+6 weeks' gestation (n=5), Stillbirth (n=16), NND (n=3)	Bereaved parents' experience of care during COVID	None mentioned	Parents who experienced a late miscarriage, stillbirth or NND during COVID-19.	Checklist for qualitative research
Spierson 2019	UK (May 2011–Jun 2012)	National (through British Association of Perinatal Medicine)	Online survey	HIC	Quantitative	NA	Cross-sectional study	98	NND	Healthcare professionals' practices and views on neonatal postmortem	Did not work with neonates and/or did not complete most of the survey	Neonatal healthcare professionals in UK	Checklist for analytical cross-sectional studies
Swarray-Dean 2022	Ghana (dates not reported)	Korle-Bu Teaching Hospital	Interviews, surveys	LMIC	Mixed methods	Thematic analysis	Cross sectional	99 healthcare professionals (n=12 for interviews)	Stillbirth, NND	Healthcare professionals' views and perceptions of perinatal autopsy in Ghana	NA	Healthcare professionals working at the Obstetrics Department of the Korle-Bu Teaching Hospital	Checklist for qualitative research and Checklist for analytical cross-sectional studies

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data.

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Overall appraisal	Relevance
Bakhbakhi 2017	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Boyle 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Das 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	I
Das 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	U
Feroz 2019	Unclear	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	No	Include	P
Helps 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	
Henderson 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R

Kilcullen 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Lewis 2019	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Lewis 2019	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Riches 2023	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Schirmann 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Siassakos 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	R
Silverio 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	I
Swarray-Dean 2022	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Avagliano 2022	Yes	Yes	Unclear	Yes	Not applicable	Not applicable	Unclear	Yes	Include	R
Spierson 2019	Yes	Yes	Unclear	Yes	No	No	Yes	No	Include	R
Swarray-Dean 2022	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Henderson 2017	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	R
Lewis 2019	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Include	P
Nuzum 2021	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes	No	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Relevance
Cronin 2018	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	No	Yes	Include	R
Evans 2020	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic reviews

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimise errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Lewis 2017	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	No	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/ sources logically defended?	Overall appraisal	Relevance
Page & Silver 2020	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Diagnostic accuracy studies

The QUADAS-2 was used to assess the following diagnostic accuracy studies:

- Cassidy 2019
- Shelmerdine 2020

Please contact the Stillbirth CRE for more information on quality assessment for these studies (e: stillbirthcre@mater.uq.edu.au)

Table 7. GRADE-CERQual detailed assessment

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
6.1	Counselling parents about options for investigations (including the option of a full autopsy or less invasive options) should be conducted within a parent-centred decision-making framework by an experienced healthcare professional who has established rapport with the parents. • Discussions should include the value and limitations of the investigations in their circumstances. Parents should be given multiple opportunities to discuss their options according to their needs.	Eleven studies are included. Six primary qualitative research studies, two cross sectional studies, one case series, and two mixed-method studies.	Moderate concerns of methodological limitation are noted. Seven of the included studies are deemed to have no or minor concerns of methodological limitation through critical appraisal. Four of the primary qualitative studies are deemed to have moderate concerns of methodological limitation due to a consistent lack of statement of the researcher's cultural position, and the impact of analysis and findings. One also demonstrated unclear methodology, and three lacked congruence between the methods and the intent. One mixed methods study is deemed to have moderate concerns of methodological limitation due to confounders neither identified nor adjusted for through analysis.	Moderate concerns of relevance are noted. Eight of the included studies are deemed directly relevant to decision making of post-mortem investigations. Three included studies are deemed partially relevant.	Moderate concerns of coherence are noted due to few reports of distress and negative outcomes for parents following some discussions of autopsy with pathologists.	Minor concerns of data adequacy are noted. Eight of the included studies source cohorts from high income populations and three from lower middle-income populations. Outcomes included are stillbirth (n=1,116), neonatal death (n=98) and composite perinatal mortality outcomes (n=577). The view of parents is included across evidence from seven studies, and that of healthcare professionals is included from six studies. One study also contains the viewpoint of religious groups.	Low confidence *Minor concerns of data adequacy, moderate concerns of methodological limitation, relevance and coherence are noted.*
6.2	Ideally, counselling parents on their options for investigations (including autopsy) is informed by a clinical case review by a multidisciplinary team, including a	NA	NA	NA	NA	NA	Consensus-based recommendation

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	perinatal/paediatric pathologist, the lead obstetrician or paediatrician, and radiologist.						
6.3	Information (written and verbal) and counselling for parents about all investigations, including autopsy, should include: • the possibility that the cause of death may not be determined despite all investigations being undertaken • that, while a cause may not be found, excluding some potential causes of death may be helpful • a full investigation, including autopsy, provides the best possible information to help understand why the baby died and to plan future pregnancies • when and how they will be provided with the outcome of the investigations undertaken • whether the baby will need to be transported to another centre for the investigations, how the transport is organised, when the baby will be returned to them.	19 included studies contribute to this recommendation. 10 primary qualitative studies, two mixed methods studies, two case series, two cross sectional, two assessments of diagnostic tools and one literature review.	Moderate concerns of methodological limitation Eight of the included studies are assessed to have no or minor concerns of methodological limitation. Fourteen of the included studies are noted to have moderate concerns of methodological limitation, primarily due to qualitative literature consistently lacking a statement of the researcher's cultural position, and the resultant impact on analysis and findings. In addition to qualitative methodological limitations, one included assessment of a diagnostic tool analysis was noted to have concerns of the referencing standard, unclear flow and timing through the study and unclear enrolment and inclusions. The included cross-sectional study failed to identify and account for confounders and reported use of an inappropriate statistical method.	Minor concerns of study relevance are noted. Thirteen of the included studies are deemed relevant to decisions about investigations following stillbirth or neonatal death. Three of the included studies are deemed partially relevant, two studies are deemed indirectly relevant, and one study is deemed to be of unclear relevance to decisions about investigations following stillbirth or neonatal death.	No concerns of coherence.	No concerns of data adequacy are noted. 17 of the included studies source their cohorts from populations in high-income countries. Two studies examine cohorts from low- and middle-income countries. Outcomes included are stillbirth (n=1,143), neonatal death (n=110), and composite perinatal mortality outcomes (n=26,801). The view of mothers, parents and healthcare professionals is included across 14 included studies, and specifically those of Aboriginal and Torres Strait Islander women in one study.	**High confidence** *No concerns of coherence or data adequacy, minor concerns of relevance. Moderate concerns of methodological limitation.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	• how their baby will look after the autopsy • any costs to them related to investigations.						
6.4	Assure parents that, throughout the process of autopsy and other investigations, their baby will be cared for by highly trained healthcare professionals who will treat their baby with respect as they do all possible to understand the cause of death.	Three studies are included, one systematic review and two primary qualitative research studies.	Moderate concerns of methodological limitation are noted. One of the included studies was noted to have minor concerns of methodological limitation, and the other moderate due to lack of a statement of cultural position of the researchers and the impact on analysis and findings.	Minor concerns of relevance are noted. Two of the included studies are deemed relevant to decisions about investigations and one is partially relevant.	No issues of coherence are noted.	Moderate concerns of data adequacy are noted. All included studies source data from high income countries. The outcomes of interest included through the evidence is stillbirth (n=454) and composite perinatal mortality outcomes (n=484). The view of mothers and parents is included across the evidence. Moderate concerns of data adequacy are noted due to limited outcomes included, lack of healthcare professionals' viewpoints and also small, combined sample sizes.	**Low confidence** *No concerns of relevance or coherence. Moderate concerns of methodological limitation and data adequacy are noted.*
6.5	Explain to parents that the placenta can be returned to them following examination by the pathologist. The pathology service should be notified of the parents' wishes when the placental examination is requested. Advice should be given to families/whānau about any relevant health and safety	NA	NA	NA	NA	NA	**Consensus-based recommendation**

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	precautions when handling the placenta.						
6.6	Healthcare professionals must respectfully ask parents and family/whānau throughout their care if they have cultural, religious, or spiritual care needs including preferences for discussing and making decisions about investigations to understand why their baby died. • Healthcare professionals should avoid making assumptions and must work in partnership with families/whānau to ensure care is individualised and that their needs are met, seeking further guidance where needed.	NA	NA	NA	NA	NA	*See Section 2: Technical report for cultural safety for evidence synthesis and GRADE CERQual rating of this recommendation.*

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 6: Investigations for perinatal death

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Accurate identification of the cause of stillbirth and neonatal death (perinatal deaths) through postmortem investigation is the cornerstone of prevention. Findings of investigations can be critically important to helping parents understand why their baby died and for planning future pregnancies.[1] The high proportion of unexplained stillbirths reported globally is an impediment to these goals and is often related to suboptimal investigation.[2] A wide variety of investigations are available for perinatal deaths. Given their economic cost and their potential to add further emotional burden to parents, approaches to investigation of perinatal deaths need to consider outcomes for parents as well as diagnostic yield.[3]

The approach to investigations for perinatal deaths should focus on the most common causes within the particular setting of these deaths.[4] The perinatal death rate for Australia and for Aotearoa New Zealand is approximately 1% in both countries.[5,6] Most perinatal deaths are stillbirths. In 2020, Australia recorded 3,004 perinatal deaths, of which 76% (2,273) were stillbirths and 24% (731) were neonatal deaths.[6] Aotearoa New Zealand recorded 642 cases of perinatal death (babies who died after 20 weeks of pregnancy or within the first four weeks of life).[5] The most frequent causes of all perinatal deaths in Australia[6] and Aotearoa New Zealand[5] are congenital abnormality, spontaneous preterm labour or rupture of membranes. Congenital anomalies account for around one-third of perinatal deaths in Australia and Aotearoa New Zealand,[6,7] Perinatal autopsy rates for Australia and Aotearoa New Zealand are 41%[6] and 34%[8] for stillbirths and 27%[6] and 24% for neonatal deaths,[8] respectively. In Australia in 2020, 13% of stillbirths were classified as unexplained.[6]

Autopsy remains the gold standard investigation for most perinatal deaths. However, perinatal autopsy rates are low globally even across well-resourced settings. In Australia in 2020, the autopsy rate was 41% (847) for stillbirth and 27% (176) for neonatal deaths.[6] In Aotearoa New Zealand in 2018, the autopsy rate was 34% (108) for stillbirths and 24% (37) for neonatal deaths.[8] There is wide variation in perinatal autopsy rates across jurisdictions in Australia. The highest rates are in Western Australia (57%)[9] and South Australia (56%),[10] compared to 38% in Queensland and in Tasmania.[11,12]

The literature search in this section found limited studies of investigations for neonatal deaths alone. This concurs with the findings of another recent search.[13] As neonatal deaths result from disorders of the fetus or neonate, placenta, or mother, they often share causal pathways with stillbirth. The Guideline Development team therefore took the approach that core investigations for stillbirth also apply to neonatal deaths.

Methodology

The Guideline Development Committee identified key research questions (Table 1) about investigations for perinatal death.

Table 1. Research questions

1	What is the value of individual or groups of investigations for stillbirth and/or neonatal death including partial/limited autopsy compared with full autopsy?
2	What is the value of performing genome sequencing for high-risk neonates and does specific medical situations determine the need for genome sequencing for high-risk neonates?

3	Does a non-selective vs. selective or sequential approach to stillbirth and/or neonatal death investigations result in improved understanding of causes, parents' satisfaction with adequacy of investigation, and better planning for future pregnancies?
4	What is the value of performing skin swabs for high-risk neonates (including rectal, skin, surface, ear, nose, mouth, wound or throat) and do specific medical situations determine the need for skin swabs of high-risk neonates?
5	What trends are apparent and which interventions assist in improving understanding of local practices around perinatal autopsy?
6	What are the barriers to undertaking autopsies?
7	How should transfer of a baby for autopsy be carried out? How will this differ for regional and remote settings?
8	Which aspects of the autopsy examination are valuable in determining the cause of death?
9	What are minimum standards and important elements of a quality autopsy examination following a perinatal death?
10	What training/expertise is required to undertake a high-quality perinatal autopsy?
11	What is the optimal reporting format for a perinatal autopsy?
12	What is the appropriate timeframe for results of a perinatal autopsy to be made available?
13	What are minimum standards for autopsy examination in the event of Sudden Unexpected Death in Infancy or death with suspected genetic metabolic disorders?
14	What are the educational and training needs of healthcare professionals around investigations for perinatal death?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 2. PICO criteria

PICO	Inclusion criteria

Population	• Stillbirth
	  ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[7,14]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[7,14]
	• Inclusion of perinatal deaths following termination of pregnancy

	○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).
Intervention	Any investigation to understand the cause of stillbirth or neonatal death including: • Autopsy • Clinical examination and history • Forensic analysis • Genetic analysis • Histological examination • Minimally invasive tissue sampling • Placental investigations • Radiographic imaging
Comparator	• Not applicable – no comparator within research question
Outcomes	• Value or yield of investigations individually or grouped. • Comparison of investigations and results in determining a cause of death • Parents satisfaction and adequacy of investigations • Investigation findings in assisting in planning for future pregnancies • Approaches to investigations to better improve understanding of causes. Outcomes and needs concerning perinatal autopsy including • Optimal aspects of autopsy • Barriers to undertaking autopsy • Local practices concerning perinatal autopsy • Minimum standards for perinatal autopsy • Training and expertise needed to perform and report a perinatal autopsy • Timeframe for results of a perinatal autopsy • Transfer and relocation for autopsy needs. Outcomes specific to the following populations were searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families.

Literature search

Searches were conducted 3–10 March 2022. A top-up search was conducted on 12 September 2023. Search strategies incorporated all PICO criteria and restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus.

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- wrong *language*: The study was not published in English.
- wrong *publication dates*: The study was published prior to 2017.
- wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flowchart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical*

Practice Guideline for Care Around Stillbirth and Neonatal Death. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[15] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[16]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[17]
- Adequacy: The richness and quantity of data supporting the findings[18]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[19]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence supporting the synthesis findings was formulated following this review, and details of any concerns were identified and listed.[20] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Questions 1 and 2: What is the value (yield) of individual or groups of investigations for stillbirth and/or neonatal death, including partial or limited autopsy compared with full autopsy? What is the value of performing genome sequencing for high-risk neonates and does specific medical situations determine the need for genome sequencing for high-risk neonates?

A review of relevant available guidelines about stillbirth investigation and management[21] (including the American College of Obstetricians and Gynaecologists,[22,23] Royal College of Obstetricians and Gynaecologists [RCOG] in the UK,[24] Perinatal Society of Australia & New Zealand,[2] and Society of Obstetricians and Gynaecologists in Canada[25]) outlines agreement and divergent views on investigations. All guidelines recommend the following core investigations with additional testing based on the specific scenario and findings from core investigations.

As neonatal deaths and stillbirths often have similar causal pathways, and studies specifically addressing investigations for neonatal deaths are limited, we have taken the approach that the core investigations for neonatal deaths are the same as for stillbirths. However, investigations for neonatal deaths (and liveborn at high risk of neonatal death) are more often guided by the clinical condition. Specific scenarios will be addressed later in this document.

The recommended stillbirth core investigations for which there is consensus across international guidelines[21] are:

- a structured personal, obstetric, and family medical history of the mother
- physical examination of the baby
- Kleihauer–Betke test to detect feto-maternal haemorrhage
- histopathological examination of the placenta
- microbiology of fetal and placental tissues
- genetic testing
- autopsy
- offering less invasive techniques when autopsy is declined.

All the above guidelines discourage routine screening for inherited thrombophilias. Discrepancies exist among the reviewed guidelines on the usefulness of routine thyroid function tests, maternal viral screening, and testing for diabetes. Further, a systematic approach to gaining parents feedback about their summary of events around the deaths is now recognised as an important part of the history.[26]

The value of tests with an investigation protocol

In a prospective study conducted in the US, 512 stillbirths (≥20 weeks) from 59 hospitals underwent a systematic stillbirth investigation protocol through the Stillbirth Collaborative Research Network. Each test was evaluated to determine if it was useful in establishing or refuting a cause of death. The most useful tests were placental pathology in 330 cases (65%), autopsy in 217 (40%), followed by genetic testing in 58 cases (12%), testing for antiphospholipid antibodies in 51 cases (11%) and feto-maternal haemorrhage in 14 cases (6.4%). After stratification by gestational age, fetal autopsy and placental pathology remained the most useful tests at all gestations. Fetal autopsy was the most useful at early gestational ages. Placental pathology became more useful with increasing gestational age, whereas other tests did not vary significantly by gestational age at stillbirth.[27]

In another study in United States,[28] all stillbirth cases from a single institution over a five-year period (2009–2013) were reviewed in a stepwise approach, to quantify the specific contributions of placental pathology and autopsy in identifying a cause of death and to identify how often clinical management for subsequent pregnancies is changed due to these results: Step 1, clinical history and laboratory results; Step 2, placental pathologic evaluation; Step 3, autopsy. At each step, a cause of death and the certainty of that aetiology were coded. Clinical changes that would be recommended by information available at each step were also recorded. Step 1 identified a cause of death in 35 (24%). The addition of placental pathologic examination identified a cause in 88 (61%) and step 3; autopsy in 78 (74%) cases having an identifiable probable cause of death. Placental examination alone changed clinical management in 52 (36%) cases. Autopsy led to additional clinical management changes in 6 (6%) cases.

In Thailand all autopsy reports at a single institution over a 20-year period (2001–2020) were reviewed as part of a study to determine value of an investigation protocol for stillbirths.[29] Causes of 330 stillbirths (126 antepartum and 204 intrapartum deaths) were analysed in a sequential manner: step 1: clinical history and laboratory results; step 2: placenta; and step 3: autopsy; and classified at each step according to the International Classification of Diseases Perinatal Mortality Classification system (ICD-PM). Step 1 identified a cause in 176 (86%) intrapartum deaths and 64 (51%) antepartum deaths. The addition of placental pathology (step 2) changed the cause of death in 12% of cases, with causes now identified in 190 (93%) intrapartum and 89 (71%) antepartum deaths. Adding step 3 did not identify any additional causes of death. A placental cause of death was found in 96 (46%), non-placental causes in 28% and the cause of death was unknown in 26%. Of those 96 placentas, 44% were categorised as inflammatory immune, 30% maternal stromal-vascular, 13% fetal stromal-vascular, 7% umbilical cord complications and 6% other.

Clinical photographs are commonly recommended as part of the investigation of perinatal deaths,[2,21,23,24] which can help to identify a cause of death through guiding further investigation.[21,30] In perinatal deaths with neural tube defects, the importance of careful photographic and radiographic documentation of fetal malformations and dysmorphism can assist in genetic counselling.[31]

The Wisconsin Stillbirth Service Program (WiSSP) indicated that, in a series of 1,000 stillbirths, 28% of had observable abnormalities identifiable on photographs and photographs were critical in establishing a diagnosis in approximately 5% of cases. WiSSP has also reported that external examination identified abnormalities in 26% of cases.[32]

Perinatal autopsy

Perinatal autopsy is consistently reported as one of the most useful diagnostic tests to determine cause of death.[21,25,33,34] A wider importance of autopsy is its value for quality control for antenatal diagnosis, teaching, and research.[35] It is not uncommon in stillbirth autopsies for there to be a range of anomalies that, when taken as isolated findings, would not have caused the death of the baby, but when considered as part of a wider whole, may have contributed towards death.[30] Some stillbirths remain unexplained even after a full autopsy examination.[34] The value of a negative observation cannot be underestimated; this may still provide useful information that can help plan and manage future pregnancies and provide reassurance for parents.[30]

The diagnostic value of an autopsy may be defined as “the ratio of major change in the diagnosis/new diagnosis or additional major findings”.[36] Neşe and Bülbül[36] reviewed 486 antenatal autopsy reports

from a Turkish university medical facility to determine the diagnostic value of each autopsy. Most cases were miscarriages (226; 46.5%) or fetuses terminated for anomalies detected by antenatal ultrasonography (227; 46.7%). Thirty-three autopsies were investigations into neonatal deaths, of which the most frequently identified causes were pulmonary immaturity followed by cardiovascular anomalies. The authors divided the neonatal death autopsies into three groups for analysis and considered how diagnostically valuable each group was. Autopsy was perceived as valuable (provided a different diagnosis or major change in diagnosis) for 9/33 (27.3%) of the neonatal death investigations. In a study conducted in India, autopsy was found to be superior to antenatal ultrasound in the diagnosis of congenital anomalies of the kidney and urinary tract. There was complete agreement in 26.2% of cases, 35.7% with partial agreement and 38.1% with complete discordance in findings. Autopsy changed the diagnosis in 60% of cases.[37]

In a large study conducted in the US, autopsy contributed to diagnosis by proving, strongly suggesting or confirming a cause in 710/2,363 (30%) of cases (second trimester miscarriages, stillbirths, and early neonatal deaths).[38]

A retrospective cohort study in the US examined the value of autopsy over antenatal diagnosis in 385 stillbirths ranging from 14 weeks to 41 weeks gestation (mean 24 weeks). The main reason for autopsy being structural anomalies (40%) or intrauterine fetal demise (28%). Autopsy added information that resulted in a change in recurrence risk in a small proportion (2.3%) of cases with a antenatal diagnosis for those with a known antenatal diagnosis.[39] In a study conducted in India at a single institution, structural anomalies were found in 24% of perinatal autopsies.[35]

Two systematic review articles have reviewed the literature to investigate the association between antenatal findings and fetal or neonatal autopsy, to inform counselling of parents about risk of fetal malformations in subsequent pregnancies.[40,41] Approximately 22% of fetal anomalies were missed by routine antenatal ultrasound.[40] The reasons for missing an anomaly include low gestational age at the time of the scan, the experience and skill of the sonographer, the quality of equipment used, an abnormal amount of amniotic fluid, and a chromosomal or genetic diagnosis that does not demonstrate any identifiable morphological features on the scan. Some minor malformations are not detectable by ultrasound scan at any time in pregnancy, and some important major malformations are not detectable early due to organs not yet fully developed, structurally or functionally. An example of this might be a cardiac anomaly such as coarctation of the aorta that may only become obvious in the second half of pregnancy, after the time of the routine morphology scan. Compared with antenatal ultrasound findings, in only 2–3% of stillbirths did additional autopsy findings lead to a different diagnosis or genetic counselling.[40,41]

A single hospital study in India found central nervous system anomalies in 17/50 stillbirths (>22 weeks' gestation). Autopsy confirmed routine antenatal ultrasound findings in 40 (80%) of the stillborn babies. Significant additional findings were observed in seven (14%) autopsies. Ultrasound diagnosis completely changed in three (6%) cases following autopsy.[42]

Placental examination

A detailed gross and microscopic examination of the placenta, fetal membranes and umbilical cord can identify pathologies associated with perinatal deaths such as placental abruption, infarcts, calcifications, and velamentous cord insertion.[21,23,25,43] Placental examination has been shown consistently to have high value as a stillbirth investigation; it reduces the likelihood of an unexplained stillbirth and provides prognostic information for subsequent pregnancies.[43] For this reason,

histopathological investigation of the placenta is one of the most cost-effective tests.[44] Placental examination includes evaluation for signs of viral or bacterial infection, and provided additional information in around 30% of cases in one study.[25]

In a retrospective review of stillbirth cases in a large region, placental pathology was the most frequent investigation performed for stillbirths (94%) and was a valuable investigation revealing placental insufficiency in 22.8% of cases, umbilical cord causes 14.2% and other placental anomalies (mainly retroplacental hematomas) 12.5%.[45]

In a study conducted at a single institution in Thailand, a placental cause of death was found in 46% of cases, non-placental causes in 28% and the cause of death was unknown in 26%.[46] In a study conducted at a single institution in Italy, placentas from obese women showed pathological lesions in placentas from all gestations, mostly at term.[47] In a study in South Africa, clinical information together with the placental examination was used to determine a probable cause of death attributed to the placental in 40/47 (85%) of cases, a maternal cause in 4/40 (8.5%) and no cause of death in 3/47 (6.4%).

A study in South Africa[48] demonstrated the value of placental histopathology over a clinical diagnosis alone in 210 stillbirths. For initially unexplained stillbirths (56% of the sample) histopathological examination of the placenta revealed chorioamnionitis in 34.6% of cases (n=56), followed by maternal vascular malperfusion (32.1% of cases) and placental abruption (31.5% of cases). Evidence of distal villous immaturity was found in 17.8% of the unexplained stillbirths and TORCH infections (toxoplasmosis, rubella, cytomegalovirus, herpes, and other agents) accounted for 6.2% of the cases (n=10), the majority of which included treponemal infection. Only five cases of unexplained stillbirths (3.1%) were without pathological findings.

In a study of 147 stillbirths in Tunisia, placental pathology was able to ascertain the cause of stillbirth in 95% of cases. Placental lesions were the main cause of stillbirth and were predominantly of vascular type. Placental causes 89 (61%), maternofetal causes 23 (16%), fetal causes 14 (9%), multiple causes 13 (9%), unknown 8 (5%). Almost half of stillbirths were diagnosed at a gestational age of less than 22 weeks gestation, suggesting early stillbirths are often related to placental causes.[49]

A systematic review reported the proportion of stillbirths attributed to a placental cause ranged from 11 to 65%.[50]

Genetic analyses

A genetic diagnosis in stillbirth is particularly relevant for the purpose of counselling regarding future pregnancies.[51] Specific genetic analysis approaches include karyotyping, quantitative fluorescent polymerase chain reaction (QF-PCR), and chromosome microarray (CMA). The most common types of CMAs are comparative genomic hybridisation array and single nucleotide polymorphism (SNP) array.[52] These tests detect copy number changes (deletions and duplications), long continuous stretches of homozygosity, ploidy status and chromosomal aberrations. Cytogenetic testing is by either conventional karyotyping or by CMA—whichever is available in the given setting. CMA is the preferred method of evaluation; however, because of cost, logistic concerns and interpretation that can be time-consuming, karyotype may be the only method readily available for some patients.[53] A success rate of 78% has been reported for karyotyping performed on the placenta.[54]

In one study including 136 stillbirths undergoing cytogenetic analysis, test success rate was 100% (38/38) for CMA, 99% (65/66) for QF-PCR and 66% (65/98) for karyotyping.[54] CMA is fast becoming standard practice because it detects a substantial number of pathological changes not seen with standard karyotyping, although balanced chromosomal translocations and triploidy may not be detected (Talkowski et al. in [55,56]). Where placental pathology does not explain the cause of stillbirth, microarray analysis of fetal DNA has been reported to provide further diagnostic information in 3% of cases but can also add further diagnostic confusion.[57]

In a meta-analysis of seven studies involving 903 stillbirths with normal karyotype, the test success rate achieved by conventional cytogenetic analysis was 75%, while that for CMA was 90%. The incremental yield of CMA over conventional karyotyping based on the random-effects model was 4% (95% CI, 3–5%) for pathogenic CNVs (pCNVs) and 8% (95% CI, 4–17%) for variants of unknown significance. Subgroup analysis showed a 6% (95% CI, 4–10%) incremental yield of CMA for pCNVs in structurally abnormal fetuses and 3% (95% CI, 1–5%) incremental yield for those in structurally normal fetuses. The pCNV found most was del22q11.21. CMA, incorporated into the stillbirth panel of investigations, improves both the test success rate and the detection of genetic anomalies compared with conventional karyotyping.[51]

Molecular testing

Fetal DNA extraction and storage should be done whenever possible and can be performed from the same tissue as cytogenetics above. Refrigerated unfixed placenta has been shown to be the most suitable source of high-quality DNA during perinatal investigations. Organs such as thymus and spleen were significantly more likely to yield good quality DNA than the liver in one study.[52] Using parental DNA can identify additional genes known to cause embryonic or perinatal lethality.[58]

The material can be helpful in further testing, such as point mutation tests, gene panel analysis, and exome or genome sequencing. In addition, some centres can now perform trio analysis (mother, baby, father) on the next generation platform, which is known to improve diagnostic yield in perinatal loss investigation. Next generation sequencing technologies (gene sequencing; whole exome sequencing [WES] and whole genome sequencing [WGS]) improve diagnostic yield and have become more easily available to investigate perinatal deaths. WES involves sequencing of all the protein-coding genes, which comprise 1–2% of the genome. WGS includes sequencing the non-coding regions of the genome that may contain regulatory elements. Although substantially more expensive, WGS may detect variants not found by WES.[55] The first application of WGS in perinatal death investigations was published in 2018. Armes et al. used WGS to analyse 16 fetal, perinatal, and early infant deaths that had undergone a full autopsy. WGS detected variants with likely implications to cause of death in 50% (8/16) of the cohort.[59]

Families have reported benefits from having targeted genomic testing of their newborn in ICU.[60,61] Almost all parents (91%, 60/66) said they would want genomic sequencing if given the option for their newborn. This included 98% of parents with genetic testing experience, 88% of those who were currently pregnant, and 85% of parents who experienced a recent birth.[62] Diagnostic findings of genome sequencing could alleviate guilt for some parents[63] if they were fearful that they could have prevented their baby's death.

Healthcare professionals can use findings from genome sequencing to inform their clinical recommendations about therapeutic or palliative treatment[63] and potentially avoid unnecessary or risky treatment, medical procedures, or surgical interventions in favour of palliative 'comfort care'.[64]

Results from genome sequencing can inform decision-making discussions with parents.[62,65] Full results of rapid WES (R-WES) may be available after 5–14 days.[66] There is scant evidence to show if specific medical situations can determine the need for genome sequencing in high-risk neonates. In some cases, genome sequencing is not recommended. For example, rapid exome sequencing is not appropriate for patients whose features suggest a trisomy or other chromosomal anomaly. CMA is more appropriate in this situation.[67]

Clinically, the measure of value of performing genome sequencing is diagnostic yield. A range of diagnostic yields from genome sequencing have been reported, including 20–60%,[67] 21–58%,[68] 28%,[60] and 72.2%.[66] Diagnostic yield rates vary by genome sequencing technique and genetic condition under investigation. The NSIGHT2 randomised controlled trial found ultra-rapid or rapid WGS was superior to rapid WES/WGS in terms of diagnostic rate (46% vs 20%), and median time to positive report (2.3 days v 11.6 days).[61] In another study, referring clinical geneticists rated ultra-rapid sequencing reports as 'very useful' or 'useful' in 52 of 55 cases (95%).[69] Using fetal clinical exome sequencing, Marangoni et al.[70] found an overall diagnostic yield (an underlying genetic cause) in 13% (24/183 prospective) and 29% (35/120) retrospective cases of pregnancies that had anomalies detected by ultrasound. Zhou et al.[71] found trio-exome sequencing gave a diagnostic yield of 36% in recurrent non-immune hydrops fetalis. Byrne et al.[72] investigated genomic investigations as an adjunct to standard autopsy including 22 babies who died during the neonatal period. The study found a higher yield of LP/P variants in the neonatal death group (45%) than among terminations of pregnancy (24%) and stillbirths (19.5%). Yang et al.[73] used WES to investigate the genetic causes of newborns who died in hospital or within one week of discharge from a neonatal intensive care unit in China. Analysis of WES results revealed 42 single nucleotide variants (SNVs) and four copy number variants (CNVs) in 223 patients (19.7%). The authors concluded that a key benefit of using WES to investigate neonatal deaths is that the technique is not limited to a specific set of genes because it does not require assumptions about specific genetic defects.

Genome sequencing may be conducted antenatally. When used for clinical reasons such as for women with a prior pregnancy with similar fetal anomalies (without a known genetic diagnosis) or a history of consanguinity, the yield may range from 10–50%.[74] In a study by de Koning,[65] antenatal exome sequencing had a diagnostic yield of 53% (10/19).

Clinical limitations and considerations relating to genome sequencing include:

- variant databases are based on data from people of European ancestry, which limits applicability to people of non-European ancestry[74]
- direct-to-consumer sequencing is not recommended for diagnosis or screening of newborns[74]
- decision-making aids may help guide decision-making with parents, particularly for parents with lower health literacy[75]
- parents and healthcare professionals perceive more risk with genome sequencing than with newborn screening[76]
- healthcare professionals may have concerns relating to privacy and discrimination related to genome sequencing[76]
- it is unclear how equitable access to genome-wide sequencing will be achieved[68]
- it is unclear how supportive a healthcare system will be of genome-wide sequencing.[64]

Alternatives to autopsy

If parents decline a full autopsy, less invasive alternative options include a limited autopsy (where only specific organs are examined)[77] and tissue sampling.[38] Non-invasive options include external examination by a trained perinatal pathologist, clinical photographs, X-ray imaging (babygram), postmortem ultrasonography and magnetic resonance imaging (MRI).[38,78] These may be more acceptable to parents because they does not require any incisions to the body; however, a limitation is that no tissues are available for analysis.[79] Postmortem MRI measurement of the brain:liver weight ratio in perinatal deaths provides reasonable correlation with autopsy results and may be used when autopsy is not offered to identify FGR.[80]

Prenatal ultrasound combined with postmortem fetal MRI can offer a less invasive option to conventional autopsy. A retrospective study conducted in the United States compared the findings from the two imaging techniques and full body conventional autopsy conducted on 50 fetuses. Conventional autopsy provided additional information for 9/50 fetuses (18%): 2 were major abnormalities of cardiac malformation and 7 were minor abnormalities. Conversely, the imaging techniques identified some abnormalities not detected using conventional autopsy. As such, the less invasive and potentially more acceptable investigations of prenatal ultrasound and postmortem fetal MRI could replace conventional full-body autopsy, with the exception of fetal heart autopsy.[81] A study conducted in Belgium also found support for using postmortem MRI as an alternative to conventional autopsy for some anomalies, particularly involving the central nervous system (CNS). Correlation between PMMR and conventional autopsy showed correlation in 67.6% of cases with discrepancies in 32.4%. Of the discrepant cases, 20.6% showed PMMR was superior to conventional autopsy due to autolysis of the brain.[82]

In a study conducted in the Netherlands, concordance between PMMR and conventional autopsy ranged from 76.3% to 100% for various abdominal structures with an average of 81.3% for non-cardiac thoracic abnormalities.[83] Discordance was observed in cases of oedematous and haemorrhagic liver and spleen abnormalities.
In one large study from the Wisconsin Stillbirth Service Program (WiSSP), a community-based program for etiologic evaluation of over 3,000 second trimester miscarriages, stillbirths, and early neonatal deaths (with a high proportion of birth defects), cases without autopsy had nearly the same overall rate of diagnosis as those with traditional autopsy (56% vs. 58%).[38] The authors concluded that a targeted or less invasive protocol to investigate perinatal deaths, with integration of clinical data, selective imaging, and genetic testing has merit over a traditional autopsy.

Three recent reviews[84-86] have presented the available evidence for non-invasive options for perinatal deaths. There is consensus across these reviews on the following:

- autopsy remains the diagnostic method of choice for most perinatal deaths and should be offered to all parents
- non-invasive or minimally invasive approaches should be offered to parents who decline an autopsy
- the imaging technique of choice is postmortem MRI (PM-MRI)
- PM-MRI should be considered as an adjunct to autopsy particularly in the presence of maceration where brain and spinal cord abnormalities are suspected.

The lack of histology is an important limitation of all postmortem imaging techniques. Tissue sampling may be required in a small proportion of perinatal deaths following imaging (with parental consent) and is best achieved by image guided laparoscopic tissue sampling; however, this may be difficult for

small fetuses. Image-guided needle tissue biopsy can overcome this limitation and should be considered as an option where autopsy is declined[87] where appropriate services are available.

All three reviews[84-86] highlighted the importance of training in imaging for perinatal deaths. Kang et al.[84] noted that the results of imaging studies to date have come from postmortem imaging expert centres, with more than 10 years' experience in these techniques. The importance of multidisciplinary team involvement, including (maternal-fetal medicine specialists, pathologists, and radiologists), in developing an individualised approach to investigation of perinatal deaths is also highlighted.[84,87]

The systematic review from the Dutch guideline group included a practice-based flowchart for radiology in non-forensic fetal and neonatal deaths[85] (see Figure 2). The authors concluded that MRI is the imaging modality of choice. However, they stated that "in most cases, conventional autopsy will remain the diagnostic method of choice". Three-dimensional printing and augmented reality may make imaging findings more accessible to parents, colleagues, and trainees.[85]

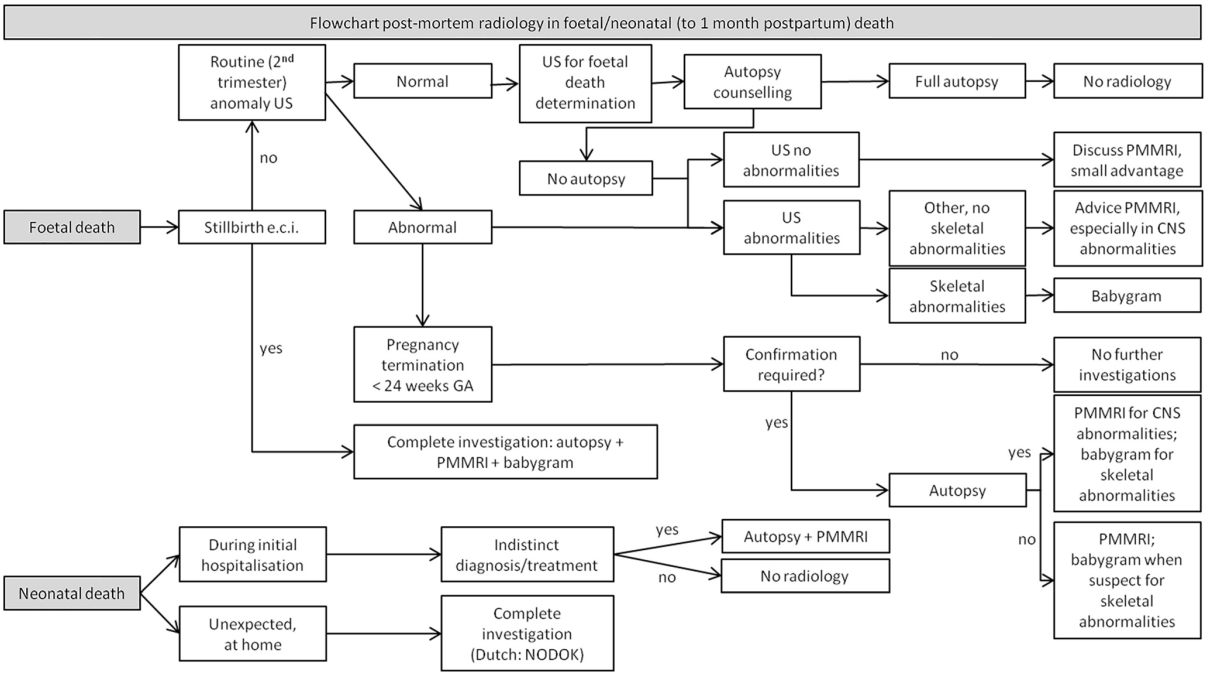

Figure 2. Flowchart for post-mortem radiology in foetal and neonatal deaths. Adapted from the Dutch guideline for clinical foetal, neonatal, and paediatric postmortem radiology. CNS: central nervous system; GA: gestational age; NODOK: the Dutch 'Nader Onderzoek naar de DoodsOorzaak van Kinderen' (i.e., 'further examination of cause of death in children') procedure is a stepwise approach to investigate the cause of death in children with an assumed natural unexpected and unexplained death; PMMRI: postmortem magnetic resonance imaging; US: ultrasonography. The 'routine 2nd trimester ultrasound' is a standard prenatal US in all growing foetuses. The 'US for foetal death determination' is a second, separate antenatal US by the gynaecologist to confirm death.

The review by Kang et al.[84] summarised the performance of imaging (MRI and ultrasound) for perinatal deaths. The performance of MRI was better than that of ultrasound irrespective of the state of maceration, except for the abdomen, for which there was no significant difference between imaging techniques when the fetus was macerated. Microfocus computed tomography (micro-CT) is a promising approach for the small fetus that warrants further research. The authors proposed a stepwise diagnostic approach for fetal examination where imaging is undertaken prior to decision

about autopsy may reduce the need for autopsy. However, further research is needed to test this application in routine practice.[84]

Shelmerdine and Arthurs[86] presented a narrative review of the evidence for imaging techniques for stillbirths and early neonatal deaths and mentions the role of less invasive autopsy or a minimally invasive autopsy where image-guided or laparoscopic surgical guided biopsies of organs may be performed. Where parents have declined autopsy and appropriate services are available, an imaging decision tree is suggested based on the clinical circumstances.

While a full autopsy remains the optimal investigation into the cause of death in most perinatal deaths, the authors present the growing body of evidence on the value of alternative imaging techniques that provides parents, who do not wish to have an autopsy, with options that can provide valuable diagnostic information particularly for brain and spinal cord abnormalities in the presence of maceration. Imaging should be undertaken within 3 days of the death and optimally within 24 hours where practicable. Figure 3 shows typical estimated gestational ages and the approximate postmortem weights (g) at which various postmortem imaging modalities would provide diagnostic quality examinations.

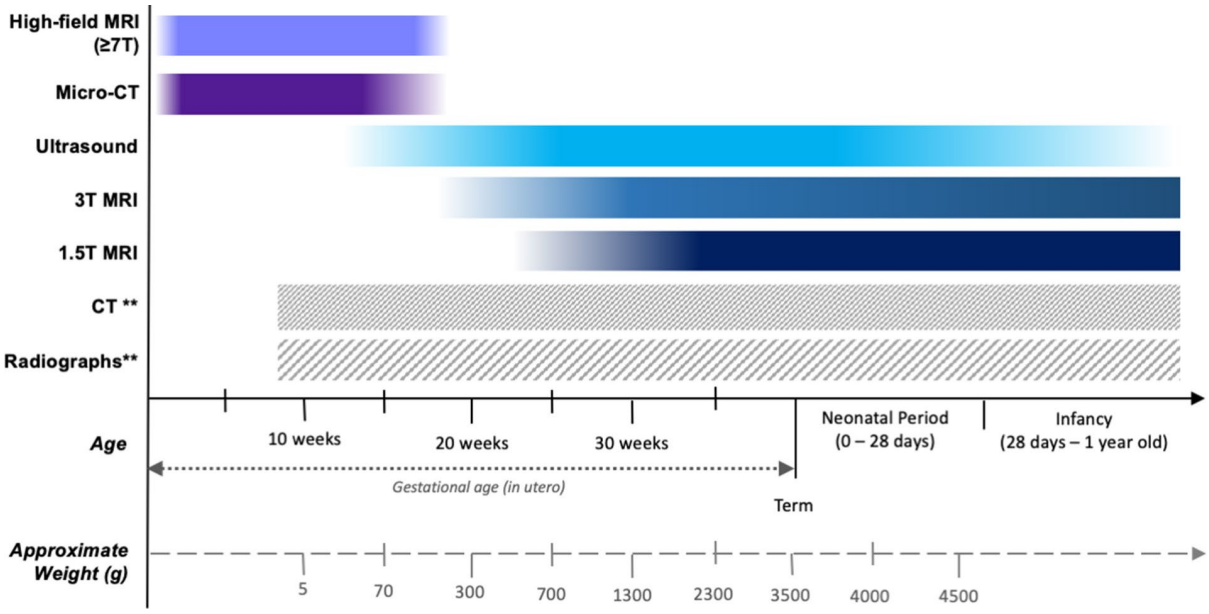

Figure 3. Typical estimated gestational ages and the approximate postmortem weights (g) at which various postmortem imaging modalities would provide diagnostic quality examinations. Note. Technically, radiographs and CT can be performed at any age after 8 weeks gestation (when the foetal skeleton beings to ossify), but in practice they are best reserved for specific clinical situations, such as for suspected skeletal abnormalities or trauma (Arthurs et al., 2013). *Reproduced from Shelmerdine SC et al. Insights into Imaging 2021*

Additional information from individual studies

The advantages and disadvantages of different imaging modalities (radiographs, ultrasound, CT, micro-CT, MRI (3 T or 1.5 T), ultra-high-field MRI [UHF-MRI]) for investigating perinatal deaths are summarised in the following paragraphs.

Radiographs are a standard part of an autopsy and are helpful in estimation of fetal gestational age and diagnosis of skeletal and limb abnormalities.[88] However, radiographs do not provide internal soft tissue detail and may be useful in as few as <5% of cases.[86]

For stillbirths, the degree of maceration can impact on the yield particularly with ultrasound. When the ultrasound imaging is of diagnostic quality, a 73% sensitivity and 97% specificity has been reported[89] with the highest sensitivity for brain imaging (84%) and lowest for cardiothoracic abnormalities (51%).

In one large study, MRI had >90% concordance for overall diagnosis compared to standard autopsy (sensitivity 89.7%, specificity 95%). This was particularly high for abnormalities of the heart, brain, and musculoskeletal system. MRI can give clinically useful information over autopsy for neuropathology in the presence of maceration.[90] Antenatal (fetal) brain MRI is better for diagnosing complex neurological conditions than postmortem MRI.[91] A study of 3Tesla MRI provided high diagnostic accuracy for the detection of fetal congenital heart defects with a sensitivity of 87.8%, a specificity of 97.9%, and concordance with autopsy of 95.3%.[92]

A recent systematic review of micro-CT and ultra-high-field MRI (UHF-MRI)[93] identified three small studies in which high-field MRI showed some promise. In one study, there was complete agreement between UHF-MRI and standard autopsy. However, UHF-MRI has a long scanning time.[94]

CT has low accuracy so is not recommended for investigation of perinatal deaths. High-field MRI and micro-CT imaging show particular promise for smaller and earlier gestation fetuses.[87] When compared to standard autopsy, micro-CT has a high sensitivity and specificity rates for overall diagnosis (94–100% sensitivity, 90–100% specificity).[95,96] However, the techniques require pre-imaging tissue preparation (staining), which has disadvantages including potential delays to obtaining results. Currently, there is limited availability and expertise to perform this technique.[94]

Postmortem MRI compared with autopsy. Shruthi et al.[97] compared postmortem MRI with conventional autopsy (examination of all internal organs by an experienced pathologist working to a standard protocol by Mudher et al.[98]) in a series of 40 stillbirths of >20 weeks' gestation (including terminations of pregnancy for fetal abnormality) without maternal or fetal reasons for the death In five cases (82%), the final diagnosis based on MRI was in agreement with autopsy. The remaining eight cases, in which conventional autopsy was required for the final diagnosis, involved either cardiovascular or gastrointestinal malformations. In this study, parental consent rate was 97% for MRI and 83% for autopsy. The authors concluded that MRI and other minimally invasive investigations can be an acceptable alternative to conventional autopsy when the latter is declined by the parents and can provide additional diagnostic information on brain and spinal cord malformations.

Postmortem MRI can provide additional diagnostic information on brain and spinal cord malformation as it can be examined in situ without anatomical and hydrostatic disturbances that can occur as a result of a termination,[39,97] but has poor sensitivity for cardiovascular malformations and provided partial diagnosis in complex congenital malformations.[97] In a study of fetal deaths with an antenatal ultrasound diagnosis of a brain abnormality, overall success rate of investigation (autopsy) of the brain was about 40%, with concordance of 84% between in utero MRI and autopsy.[99]

Autopsy compared with postmortem ultrasound: A study in France compared postmortem ultrasound results with autopsy findings in 70 stillbirths. Gestational age ranged from 15 to 38 weeks' gestation; 42 (56%) ≤24 weeks and 33 (44%) 24 weeks; 59 were terminations of pregnancy, three miscarriages

and 13 were unexplained intrauterine deaths. In detecting brain abnormalities, ultrasound had a sensitivity of 82% and a specificity of 98%. Specificities for the diagnosis of thoracic, cardiac, urinary tract, spinal and bone abnormalities were 100%. The authors concluded that postmortem ultrasound shows high sensitivity and specificity for the diagnosis of congenital structural abnormalities as compared to conventional autopsy, except for congenital cardiac diseases.[100]

Autopsy compared with antenatal ultrasound and postmortem MRI: To investigate less invasive methods of investigation than autopsy, Shelmerdine et al.[101] compared the concordance between findings of antenatal ultrasound and postmortem MRI. Scans were conducted of 81 fetuses. Findings were concordant in 44/81 (54.3%) cases. Based on the additional yield from autopsy (19/81; 23%), the authors suggest that autopsy adds little value when ultrasound and postmortem MRI are concordant.

Minimally invasive fetal autopsy combines imaging with laparoscopic or image-guided tissue sampling.[79] In view of declining consent rates for autopsies, a health technology assessment in the UK[102] investigated the feasibility of MRI and endoscopic examination following perinatal and unexpected paediatric deaths. Researchers consulted parents and healthcare professionals about the acceptability and likely uptake for different types of autopsies, analysis of existing autopsy data to determine the efficacy of less invasive autopsy and to assess the clinical utility. They concluded that "although extensive tissue and organ sampling is currently recommended, in most cases such sampling does not significantly contribute to determination of the cause of death or the major diagnosis. Therefore, a more limited and targeted tissue sampling protocol could be introduced without significant reduction in accuracy of final diagnosis. Further health economic, performance and implementation studies are now required to assess the viability of offering these alternatives in routine clinical care". In a UK study, a relevant condition to determine cause of death was identified in 90% of stillbirths (43/48) with MRI and placental pathology providing important clinical information.[103]

UK healthcare professionals and coroners identified the following advantages of minimally invasive approaches:

- improved diagnostic accuracy in some circumstances
- potential for faster turnaround times
- parental familiarity with imaging and laparoscopic approaches
- benefits to parents and faith groups who object to invasive approaches.[102]

In a study in the UK,[104] Minimally Invasive Autopsy with Laparoscopically assisted sampling (MinImAL) autopsy was successfully performed in 97.8% (91/93) of the cases undergoing a complete procedure. Histological sampling was satisfactory for most major organs; heart (100%, 91 cases), lung (100%, 91 cases), kidney (100%, 91 cases), liver (96.7%, 88 cases), spleen (94.5%, 86 cases), adrenal glands (89.0%, 81 cases), pancreas (82.4%, 75 cases) and thymus (56.0%, 51 cases). The rate of unexplained stillbirths for fetal deaths that underwent MinImAL autopsy was not significantly different from that following standard autopsy.[104]

In a study conducted in Zurich, postmortem magnetic resonance imaging with computed tomographic-guided biopsy (Virtopsy®) a cause of death was found in 92% (93/101) cases, compared with 94% (95/101) cases.[105] The CT biopsies yielded adequate histological samples in 53% of cases, providing limited additional diagnostic value.

Considerations for low-resourced settings

Minimally invasive tissue sampling (MITS) using needle biopsies of multiple tissues to obtain tissue for histological examination and organism identification with PCR has been developed and promoted to determine cause of death in low-resource areas where autopsy is often unacceptable to families or not available to them.[106] In Pakistan, a qualitative study with healthcare professionals including doctors, nurses, trainees, clinicians, bioethics experts and public health experts showed that generally, MITS was considered as a positive development for the health system. Diagnostic accuracy and identification of less common causes of death were highlighted as two main benefits of the MITS procedure and being non-disfiguring, quicker and cheaper compared to complete diagnostic autopsy or standard autopsy is more acceptable than full autopsy.[106] In India, the most common reasons for refusing MITS for both stillbirths and preterm neonatal deaths were cultural concerns, while in Pakistan the most common reason for MITS refusal was a potential delay in the funeral. The primary reason for accepting MITS was that the parents wanted to understand the cause of death. MITS was more commonly accepted in India than in Pakistan.[107]

MITS is feasible in high-burden resource-limited settings.[108,109] In a study from Kazakhstan, MITS determined cause of death was concordant with complete diagnostic autopsy diagnosis in 83% (93% of stillbirths and 67% of neonatal deaths) of 24 stillbirths/neonatal deaths. Diagnostic performance of MITS and concordance with the complete diagnostic autopsy diagnosis increased significantly when clinical information and the results of laboratory tests were used as part of the evaluation to identify the immediate and underlying causes of death. However, concordance rates decreased to 63% overall when only histological features were used. MITS requires less time to perform, is less costly and more acceptable to pathologists and relatives of deceased children. complete diagnostic autopsy still remains the gold standard, but MITS can be employed in the majority of cases when complete diagnostic autopsy is either not possible or not consented by relatives.[110] In a study conducted in India, MITS had good diagnostic yield in 100% of neonates studied (n=16) who had neurological insults.[111] In India and Pakistan, Guruprasad et al.[112] found a high yield (92%) of lung disease in the 453 stillbirths and 352 neonatal deaths they studied using MITS. In a study performed in South Africa, a cause of death was identified in 91% of stillbirths using MITS.[113] In a study conducted in Mozambique, a cause of death was identified in 83% using MITS compared to 100% with conventional autopsy.[114] In an Ethiopian study of 105 stillbirths, the sampling success for liver and lung was 84% and 100% respectively. A cause of death was determined in 84% of cases when MITS was performed, compared to 99% of cases with conventional autopsy.[109] In a study conducted in India and Pakistan, the maternal clinical history, placental pathology, the external examination of the fetus and comparison of placental weight and birthweight to recognised standards were the most informative to determine the cause of death. MITS specimens of the lungs, and pathogens in the blood and brain/cerebrospinal fluid were useful tests.[115]

A verbal autopsy may be used to identify the causes of stillbirth and neonatal death across some low-income and middle-income countries where access to pathology services is limited.[107] Verbal autopsy consists of interviews with care providers and support people to determine causes without examination of the baby.[3] The findings are subsequently interpreted and coded by physicians or by computerised methods. The method has shown to provide inconsistent results over time and place. Diagnostic accuracy is higher when the cause of death has a characteristic and well-defined set of signs and symptoms, but much lower for conditions with unspecific symptoms. Neither computer-coded verbal autopsy nor physician-certified verbal autopsy techniques have been validated against the complete diagnostic autopsy.[116]

While verbal autopsy has shown to be able to identify a cause of death in about 50% of stillbirths, the current system of verbal autopsy does not provide consistent information about the possible underlying risk factors for stillbirth.[117,118] A study conducted in India and Pakistan identified the limitations of this approach as incomplete data, recall bias, and subjectivity of physicians who assign the cause of death based on verbal autopsy. These findings were based on an interview with a mother or family members about the clinical events leading to stillbirth and neonatal deaths.[107] In a review from Ghana, they report the use of open histories , training and skill of data collectors and the timing of the verbal autopsy to be key lesions is conducting a successful verbal autopsy program.[119]

If verbal autopsy is used, it should be complemented by healthcare record and case note review to establish cause of death more accurately improve quality of care and reduce preventable stillbirths.[120] After verbal autopsy to explore the medical causes of a death along with the associated factors and delays, a social autopsy with community members may be conducted.[121]

Question 3: Does a non-selective vs. selective or sequential approach to stillbirth and/or neonatal investigations result in improved understanding of causes, parents' satisfaction with adequacy of investigation, and better planning for future pregnancies?

There is limited evidence on the role of selective or sequential investigation of perinatal deaths based on individual clinical circumstances.[3] Ideally, an individualised approach to investigation of perinatal deaths should be undertaken. This is best achieved on a case-by-case basis, involving a multidisciplinary team that includes maternal-fetal medicine specialists, pathologists, and radiologists.[84,87]

There is general agreement across major guidelines for a core set of investigations to be performed, followed by additional testing based on the specific scenario and findings from core investigations (including clinical examination and history).

One was a small study conducted in Ireland that examined the introduction of a placental examination pathway providing parents with timely information about the potential cause of stillbirth, which reduced the need for an autopsy examination. Most parents (68%; n=17/25) knew the likely cause of death of their baby by the next working day, and this information helped their decision-making regarding autopsy. Findings of the macroscopic placental examination are now discussed with parents very soon after the stillbirth.[122]

Many centres in the US that perform postmortem imaging now use results to triage cases into two groups—cases that could benefit from further invasive examination and cases that would not. This is particularly important when considering that the perinatal autopsy examination comprises many parts (e.g., placental examination, clinical history, microbiology testing, etc)—each of which could provide a plausible explanation for cause of death before the body is examined. In at least two large recent cohort studies,[27,123] the most useful component of the perinatal autopsy (with respect to providing overall cause of death or main diagnosis) was placental pathology (32–65%).[124]

The review by Kang et al.[84] summarised the performance of imaging (MRI and ultrasound) for perinatal deaths and proposed a stepwise diagnostic approach where imaging is undertaken prior to decision about autopsy. The authors suggested that this approach may reduce the need for autopsy. However, further research is needed to test this application in routine practice.

Best practice recommendations for additional investigations have been suggested for various clinical scenarios. These include unexplained stillbirth; suspected congenital abnormality; possible infective aetiology (e.g. chorioamnionitis); preterm rupture of the membranes, preterm labour; fetal growth restriction; maternal hypertension/pre-eclampsia; intrapartum stillbirth,[22,23] fetal hydrops; maternal drug abuse,[24] fetal macrosomia, suspected cholestasis; and personal or family history of thrombosis.[2] Specific additional scenarios relating to neonatal death include severe cardiorespiratory depression at birth, suspected metabolic disorders and infections and Sudden Unexpected Death in Infancy (SUDI).

Specific consideration for women with RhD negative blood group

The RCOG guideline[24] includes consideration of a sensitising bleed days prior to diagnosis of stillbirth for women who are RhD-negative and which may compromise the window for optimal administration of anti-RhD immunoglobulin (72 hours).[125] There is reduced benefit of anti-RhD immunoglobulin when given beyond 72 hours for up to 10 days after a sensitising event.[126-128]

RCOG highlights the importance of distinguishing between persistent Kleihauer–Betke positivity which usually occurs because the baby's blood group is also RhD-negative but can also occur with very large RhD-positive feto-maternal haemorrhage. The baby's blood type can be typed using conventional serology on cord blood. If a fetal blood sample is not available or obtainable, typing with ffDNA from maternal blood is now widely available and in antenatal setting is highly accurate in predicting the RhD type of the fetus.[129] In a prospective cohort study, 50 participants with fetal demise were analysed with the average clinical gestational age 16.9 weeks. Cell-free DNA was present in the maternal plasma (with fetal fractions greater than 3.7%) in more than three-quarters of cases with an ultrasonographic gestational age of 8 weeks or more.[130] RCOG[127] recommend the following:

- Women who are Rhesus D (RhD) negative should be offered a Kleihauer–Betke test undertaken urgently to detect large FMH that might have preceded late IUFD. Anti-RhD should be administered as soon as possible after presentation.
- If there has been a large FMH, the dose of anti-RhD should be adjusted and the Kleihauer–Betke test should be repeated at 48 hours to ensure the fetal red cells have cleared.
- Anti-RhD immunoglobulin should be given within 72 hours of FMH but has beneficial effects up to 10 days.
- Fetal blood group should be determined by cell free fetal DNA testing of maternal blood when required.

Question 4: What is the value of performing skin swabs for high-risk neonates (including rectal, skin, surface, ear, nose, mouth, wound or throat) and do specific medical situations determine the need for skin swabs of high-risk neonates?

There is scant evidence to show if skin swabs are useful for assessing microbiological conditions in high-risk neonates. A systematic review into the benefits of routine microbiological screening of neonatal body surface to predict and prevent sepsis included eight studies, all of which had high or unclear risk of bias (as assessed using the QUADAS-2 tool). The studies were conducted in six countries in Europe, Asia, and North America (N=4,829) and provided limited evidence for the prognostic value of neonatal screening for late-onset sepsis. Based on the limited evidence of low quality, the authors recommend conducting prospective trials to confirm the clinical value of routine microbiological screening.[131] A retrospective study conducted in Haiti investigated the similarity in phenotypes between rectal swab isolates and blood culture for Gram-negative bacteria in samples

from neonates suspected to have sepsis. The study found low concordance rates.[132] However, rectal screening swabs had a higher negative predictive value (81.6%) than blood cultures with respect to detecting Gram-negative bacteria. Rectal swabs had a negative predictive value of 92.6% for extended-spectrum β-lactamase-positive Gram-negative bacteria. This suggests results of rectal swabs may be useful to inform decisions about antibiotic treatment during sepsis outbreaks. A study conducted in Italy compared detection of pathogen species in blood culture with those cultured on rectal and nose/pharyngeal swabs. Pathogen matching was moderate, and results varied by swabbing site, number of sites, and pathogen species.[133]

A retrospective cohort study in Mexico compared SARS-CoV-2 detection methods to investigate the potential for vertical transmission even in asymptomatic mothers. The study found more than one neonate sample should be tested because cases may be undetected if only one swab (oral or rectal) is tested.[134,135]

Question 5: What trends are apparent and which interventions assist in improving understanding of local practices around perinatal autopsy?

In Quebec, fetal and infant autopsy rates decreased by 41% between the periods of 1981–1992 and 2005–2015. The decrease was largest for stillbirths and early neonatal deaths. Among non-autopsied deaths, however, the likelihood of having an undetermined cause of death increased for stillbirths only. In 2005–2015, non-autopsied stillbirths had 1.6 times the chance of having an undetermined cause of death compared with 1981–1992, equivalent to nearly seven extra stillbirths with an undetermined cause per 100. In contrast, among non-autopsied early, late, and post neonatal deaths the chance of having an undetermined cause did not increase and remained low in all study periods. These results suggest that the proportion of stillbirths with an undetermined cause of death could be reduced if autopsies were performed more systematically in fetuses. It is unlikely, however, that higher use of autopsy would impact the proportion of early, late, or post neonatal deaths with an undetermined cause. Guidelines for use of fetal autopsy are lacking, and institutional strategies for increasing use of this procedure are needed.[135]

Another study by Auger et al.[136] showed a tendency towards less use of autopsy at early neonatal ages. Despite decreasing autopsy rates, the proportion of non-autopsied infants with an undetermined cause of death did not increase. In fact, very few non-autopsied infants had an undetermined cause of death. These findings suggest that infant autopsies are less commonly performed for trivial reasons or that care providers feel confident the cause has been sufficiently evaluated prior to death or through other routes.[136]

In a study performed in France over a 10-year period, the fetal autopsy was performed in 74% of cases and placental pathology in 94% of cases.[45] Over the study period, an increase in placental pathology was observed while fetal autopsies were conducted less often due to a significant increase in parents declining the procedure.

In a study performed in the United States from 2014-2016, fetal autopsy was performed in 20.9% of stillbirths. Non-Hispanic black women had the highest rate of autopsy at 22.9% compared to non-Hispanic white women 20.4% and Hispanic women at 19.6%.[137] There was a higher uptake with increasing gestational age and maternal education. Lower uptake was observed in older women. The reason for the decline in autopsy rates could not be determined in this study.

Question 6: What are the barriers to undertaking autopsies?

Deciding whether to have an autopsy examination can be difficult for parents, who want clarity about the cause of death but also wish to protect their child from any further intervention.[138] A study in the UK highlighted parental dislike of the invasiveness of the procedure of autopsy, poor communication between professionals and parents about the procedure, ambivalence about the value of the procedure from healthcare professionals themselves, and religious objections have been identified as key barriers to uptake.[139] A parent advocate in one focus group in this UK study noted:

> **"A lot of our parents … will say something like 'the midwife said I shouldn't consent because it's not worth it and it's very unlikely to tell me anything', so you are very influenced by the professional who's consenting you.".[140]**

Parent barriers to autopsy for stillbirths include concerns regarding invasiveness of the procedure, timing and transport, organ retention issues, emotional distress, and poor understanding of the value of the procedure. There also may be cultural or religious concerns about autopsies and misconceptions regarding the procedure.[4] The main reasons for parents declining an autopsy include being afraid of what the baby would look like, cultural and/or religious beliefs,[135,141]wanting to limit the number of people who touched the baby, anxiety about more trauma or disrespect to the baby and advice that it would not be helpful,[141] concern of funeral delays, desire for the body to remain intact, fear of blame[135] and feeling overwhelmed or unable to take things in.[142]

In a study from New Zealand, the decision to decline a postmortem investigation was more common among Māori women than European women. The main reasons for declining were that women 'did not want the baby cut' followed by they 'already knew why baby had died'.[143]

Autopsy consent rates can be impacted by negative news stories. In the UK, an organ retention scandal in 1998 was followed by decline in autopsy consent rates. Stillbirth autopsy rates fell from 67% in 2000 to 49% in 2009 (Centre for Maternal and Child Enquiries 2009 in [144]) to the current rate of 48%. Neonatal autopsy rates fell from 59% in 2000 to 48% in 2009 (Centre for Maternal and Child Enquiries 2009 in [144]) to the current rate of 36%.

The type of perinatal death (stillbirth or neonatal), level of deprivation where the parent lives, and the parent's ethnicity may all influence perinatal autopsy rates. In a UK study of over 26,500 perinatal deaths, only 44.5% of parents consented to a postmortem examination.[144] Autopsy offer rates were higher following stillbirth than following neonatal death. The authors suggest that healthcare professionals may see more value in autopsy following stillbirth if they see the cause of stillbirth as less 'known' (obvious) than the cause of neonatal death. Likelihood of consent was higher among parents from the least deprived areas than among parents from the most deprived areas (RR=0.76 95% CI; 0.71 to 0.80). Consent increased with increasing gestation, possibly because death at earlier gestation may be seen as inevitable. Consent rates were much lower among mothers of Asian Pakistani (20%) and Asian Bangladeshi (18%) ethnicity than among mothers of other ethnicities (43–47%).

Religious or cultural practices may also influence perinatal autopsy consent rates, especially those who have requirements for burial to occur within a specified time from death. Where possible, delays due to transfer of body for autopsy should be minimised. In the UK, Muslim and Jewish religious and faith-based authorities agreed that non-invasive autopsy with imaging was religiously permissible because it did not require incisions or interference with the body. A minimally invasive approach was

less acceptable as it still required incisions to the body, although in those circumstances where it was required by law it was more acceptable than a full autopsy. During focus group discussions with community members, most participants indicated they might consent to a non-invasive autopsy if the body could be returned for burial within 24 hours, or if a family had experienced multiple fetal/pregnancy losses and the information gained might be useful in future pregnancies.[145]

The lower rates of consent among mothers from deprived areas or of Asian ethnicity means less may be known about causes of perinatal death in these populations. This presents a challenge for policy makers and impacts the design of interventions to reduce mortality.[144]

A paradoxical finding from an Australian study was stillbirths that occurred in late gestation (28 weeks gestation or more) that were unexplained at the time of completing the death certificate and prior to many stillbirth investigations being completed, were less likely to have an autopsy. The reason for this is not immediately clear. It was not possible to determine which investigations besides autopsy were conducted. However, among stillbirths that were described as unexplained on the death certificate, the leading categories after subsequent investigation and classification were: unexplained antepartum fetal death (55.8%), spontaneous preterm (11.7%), antepartum haemorrhage (9.0%) and fetal growth restriction (5.5%). Classification to the latter three categories was less likely to rely on autopsy findings. These findings may reflect barriers to autopsy consent that have been observed in surveys of healthcare professionals' views and practices. These include gaps in knowledge and training and an underestimation of the value of autopsy.[146]

Healthcare professionals and coroners in the UK viewed less invasive autopsy as having a number of procedural and psychological benefits over full autopsy, which include improved diagnostic accuracy in some circumstances, potential for faster turnaround times, parental familiarity with imaging and laparoscopic approaches, and benefits to parents and faith groups who object to invasive approaches.[79]

Financial cost of investigations

Stillbirth investigations incur healthcare costs that may be a barrier to a high-quality investigation. However, these investigations are necessary to provide information to help reduce the risk of a recurrent stillbirth and advice regarding family planning and future pregnancies.[147] An Australian study[147] examined costs of investigations according to the recommended tests in the previous edition of the CASaND Guideline.[2] In this series, 200 (28.7%) stillbirths were unexplained and 76.8% of these had between five and eight core investigations. Unexplained stillbirths were twice as likely to have eight core investigations as explained stillbirths (16.5% vs 7.7%). The estimated aggregated cost of stillbirth investigations for 697 stillbirths was A$2.13 million (mean A$3,060, median A$4,246). The main cost drivers were autopsies or cytogenetic screening. Mean costs were similar when stillbirths had known or unknown causes and by reason for stillbirth among cases with definable causes.

Statistical extrapolation indicates Australia pays A$8.8 million per year in stillbirth investigations or A$28 per live birth (based on 315,000 annual live births). Stillbirth investigations have a high diagnostic yield and can identify diagnoses that are amenable to change and could inform clinical management of subsequent pregnancies. Preventing future stillbirths may have cost benefits given the full economic burden of stillbirth may be as high as A$7,900 per case.[147] Despite no cost to families in a disadvantaged French district with a high migrant population, just over a third of families agreed to an autopsy.[148]

Question 7: How should transfer of a baby for autopsy be carried out? How will this differ for regional and remote settings?

Transfer of the baby and placenta to larger centres from remote and rural settings, where specialist paediatric pathologists and geneticists are available to perform a high-quality autopsy, is common in Australia. Transfer of the baby has been identified as a barrier to healthcare professionals attempting to gain consent for autopsy,[144,149] and also to parents who are uncomfortable with the transfer of their baby from the hospital of birth.[149]

Transfer of the baby away from the family to a tertiary centre is seen as a complex barrier that prevents healthcare professionals' confidence in reassuring families that their baby will be well cared for and respected while away from the parents.[144] Review of barriers to autopsy in Queensland found non-significantly decreased association between remote living and autopsy rates after 24 weeks gestational age.[146]

It has been recommended that in remote settings where autopsy in unavailable, communication with paediatric pathologists and geneticists at tertiary centres should be established to ensure that any opportunities to gather information or investigations that can be performed locally are not missed.[25]

Considerations for low-resourced settings

Many perinatal deaths occur outside of healthcare systems, and transport for transfer to healthcare facilities is unavailable. This contributes to the low autopsy rates in low-income countries.[150]

Questions 8–11: Which aspects of the autopsy examination are valuable in determining the cause of death? What are minimum standards and important elements of a quality autopsy examination following a perinatal death? What training/expertise is required to undertake a high-quality perinatal autopsy? What is the optimal reporting format for a perinatal autopsy?

A review of relevant guidelines,[21] including ACOG,[22,23] RCOG,[24] Perinatal Society of Australia & New Zealand (PSANZ),[2] and Society of Obstetricians and Gynaecologists in Canada (SOGC),[21] showed consistency in recommendations for the following: autopsy including gross and histologic examination of the placenta, umbilical cord, and membranes; and genetic evaluation.[53]

The SOGC[149] recommends that a full autopsy should include measurements to establish gestational age, such as foot length and body weight, estimation of the interval between death and delivery, such as identification of intrinsic abnormalities and developmental disorders, and investigation for evidence of infection. It is preferable to use a pathologist who is experienced in perinatal autopsy and to have a physician who is experienced in genetics and dysmorphology examine the fetus.

It is widely accepted that perinatal autopsy should be performed and reported by trained perinatal or paediatric pathologists.[4,149] External physical examination, medical photographs, and standard radiographic or computed tomography should be offered in all cases of fetal anomaly(ies) of non-chromosomal etiology. The need for additional sampling is guided by the results of previous antenatal and/or genetic investigations, as well as the type of anomalies identified in the fetus.[149]

In the US, no widespread, evidence-based standardisation of pathological practice has been established. Even when protocols are in place, the utility of the various components has not been

systematically examined, with the potential for non-judicious use of resources and the delay of final autopsy reports.[151]

The quality of autopsy varies; and improved quality of autopsy as well as reporting and interpretation was found when performed by a perinatal pathologist. Furthermore, a significant barrier to improving the quality of information on cause of death is a shortage of perinatal pathologist. It is unclear which clinical scenario results in the highest yield of information for autopsy following stillbirth.

Nevertheless, autopsy together with placental examinations could contribute to decreasing the rate of unexplained stillbirths.[146]
The importance of examining the central nervous system using specific autopsy protocols including histological, immunohistochemical, genetic investigations has been highlighted, particularly when a clear cause of death is not found at routine examination.[152]

Question 12: What is the appropriate timeframe for results of a perinatal autopsy to be made available?

Healthcare professionals and parents report lengthy delays between hospital discharge and follow-up consultations including information on autopsy results. The delays are characterised by a lack of information and support.[153] A national survey, in the UK, reported that fewer than half of parents had the results of their baby's autopsy within eight weeks.[153,154]

Clear timelines for when the parents can expect results and reports of investigations should be made in conjunction with the entire care team, including pathologists prior to hospital discharge.[149,153]

Question 13: What are minimum standards for autopsy examination in the event of Sudden Unexpected Death in Infancy (SUDI) or death with suspected genetic metabolic disorders?

SUDI requires a thorough investigation that includes a history using a specific protocol, death scene investigation and autopsy by an appropriately trained pathologist. One qualitative exploration of paediatricians' experience in taking the history found that of 234 responders, only 36 had attended a SUDI previously, and that across all cases, only 58% had completed the full history protocol required. Many provided feedback relating to the application of the protocol in a meeting with distressed families. These include comments about the length, format and structure of the history protocol but also the tone of some questions, which paediatricians report are "intrusive, accusatory or forensic".[155]

A novel autopsy approach is presented through one study of "neuropathological analysis procedures combined with energy dispersive spectroscopy/field emission gun environmental scanning electron microscopy investigations" that was implemented in a study of 10 cases of sudden infant death syndrome/sudden intrauterine unexplained death syndrome (SIDS/SIUDS). Although developmental abnormalities of the brain were associated with the presence of foreign bodies, nanoparticles were also present in control samples, unassociated with histological brain anomalies, as was the case in SIDS/SIUDS.[156]

Reyes, Somers[157] analysed full-body autopsy reports of sudden unexpected death in neonates (SUD-N) cases and identified a cause of death in 46 cases (44%). Over 50% of SUD-N were asymptomatic

before death. Given the diversity of underlying pathologies, the authors recommended routine referral of SUD-N to pathologists skilled in paediatric autopsies.

Question 14: What are the educational and training needs of healthcare professionals around investigations for perinatal death?

Training of staff is important. Of the respondents in a UK survey of neonatal healthcare professionals, 69.4% had observed an autopsy; these professionals had improved satisfaction with their training and confidence in counselling but not knowledge of the procedure. Healthcare professionals reported conservative estimates of the likelihood that an autopsy would identify significant information regarding the cause of death. Confidence of neonatal staff in counselling could be improved by observing an autopsy. Training for staff in developing a rapport with parents and addressing emotional distress may also overcome significant barriers to consent for an autopsy.[158] Healthcare professionals may contribute to low autopsy rates because of feelings of lack of qualification to discuss autopsy. Also, they fear that the discussion may increase stress for the family, and they may want to avoid an uncomfortable conversation.[4] In an Irish survey of perinatal staff in a hospital, 64% had discussed perinatal autopsy with a mother and 67% of the staff found it to be a difficult conversation. Self-reported levels of understanding were low, with 10% reporting excellent understanding of perinatal autopsy.[159]

A high-quality autopsy is one of the most useful steps in determining the cause of the baby's death, and healthcare professionals in conjunction with paediatric pathologists should emphasise this value in their communication.[25,149] Where a perinatal pathologist performs a methodical complete autopsy of the baby and placenta in consultation with a geneticist, identification of the cause of death has been confirmed in up to 42.2% stillbirths of previously unexplained cause.[25] Due to a shortage of perinatal pathologists trained to perform paediatric autopsies to a very high standard, some countries have considerable wait times.[144] Local access to pathologists and autopsy may improve consent rates and the quality of autopsy due to removal of transfer needs, and time constraints.[144] Where a pathologist may not be available following a perinatal death, protocols should be in place to prompt healthcare professionals to record the baby's gestational age and biometry, photographs (baby and placenta). X-rays should be taken, and tissue sampling should be performed. Communication with a medical genetics service or paediatric pathologist (on-call service available in tertiary care centres) can help coordinate further evaluations and ensure that vital information and details are not missed.[25,149]

Coronial autopsy investigations

Healthcare professionals should know consent requirements for perinatal autopsies. For example, in Ireland, parental consent is not required for a coronial autopsy. Although the coronial process is independent from the hospital, the bereaved parents need explanations regarding what it involves and the length of time it can take. Lack of support through the coronial process was reported to contribute to further feelings of anger and upset.[138] "The families seemed particularly angry at their treatment in the process (coronial)—a process that they understood to be there to provide them with the answers to some of their questions. They described their surprise and discomfort at the extent of the adversarial nature of the process." (Report 6 in [138]). At times, families had to wait many months or even years for reviews to be completed. Delays can have negative impacts.[138]

In some trusts in the UK, all neonatal deaths are referred to the coroner as part of local clinical guidelines or as mandated by local coronial offices. Not all neonatal deaths are coroner's cases;

however, there is inconsistency between settings. It is important to note that staff should refer to the coroner referral process in their setting before completing a medical certificate of cause of death. For a baby who dies on the neonatal unit, the criteria may be harder to apply and the most likely reason for referral would be 'cause of death is unknown'. Following discussion with the family and, if the cause of death is known and no concerns are raised, the coroner can allow the certificate to be issued by the treating team without a formal investigation. The wording on the certificate must agree with the coroner's paperwork.[160]

Coroners in England and Wales have wide ranging power to inquire into the circumstances of a death; however, they do not have the power to investigate a stillbirth. Coronial legislation relating to the investigation of stillbirth differs in Northern Ireland, where the *Coroners Act (Northern Ireland) 1959* includes a 'fetus in utero capable of being born alive' as part of the definition of 'deceased person'. This is considered to permit explicitly the coroner to investigate stillbirths (babies >24 weeks gestation but who are subsequently stillborn). In Scotland, the Procurator Fiscal has powers to investigate infant deaths that occur as a sudden, unexpected, and unexplained perinatal death; where the body of a newborn is found, and it is unclear if the baby was liveborn or stillborn; and deaths arising following a concealed pregnancy. Currently in England and Wales, there is debate about expanding coroner's roles in the investigation of stillbirth, with a Bill proceeding through parliament. This proposed change is supported by charitable bodies including the UK Stillbirth and Neonatal Death Charity (Sands). There may be grounds for a coronial investigation if the parental view is that hospital reviews have been inadequate or not undertaken or whether there were considered to be gaps in maternity care that could have resulted in the stillbirth.[30]

Grey literature and other sources

Note. Grey literature is not included in the GRADE assessment of the evidence-based recommendations.

MBRRACE-UK: The Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) collaboration collects, analyses, and reports national surveillance data about maternal and baby healthcare. Of the perinatal deaths that occurred in the UK between 1 January and 31 December 2020, postmortem examinations were offered for 98% of stillbirths and 86% of neonatal deaths. Parent acceptance rates were 53% for stillbirth and 34% for neonatal deaths.[161]

Clinical utility of investigations in stillbirths in Australia: A cohort study of 695 stillbirths across 18 maternity services in Australia from 2013–2018. The yield of investigations undertaken were assessed and classified using a purpose-built tool by an expert panel blinded to the cause of death as: useful-confirmed cause of death, useful-excluded cause of death, not useful, not performed. A three-phase stepwise approach was used:

- Phase 1: assessment of clinical and laboratory investigations
- Phase 2: placental pathology
- Phase 3: autopsy examination.

The change in classification of the cause of death according to the PSANZ-PDC was assessed at the end of each phase. Subgroup analyses by presenting clinical scenario was undertaken. Clinical utility was defined by usefulness of the investigation in contributing to identification of the cause of death and, for each investigation, was assigned to one of six categories. The term 'useful' was defined as being practically applicable to confirm or exclude cause of death. When an investigation was performed it was categorised as useful-assigned cause of death; partially useful-confirmed cause of death; partially useful-excluded cause of death and not useful. When an investigation was not performed, it was categorised as not performed (should have been performed), or not performed (not necessary).

The most useful investigations were placental pathology (87%), comprehensive maternal history (82%), genetic analysis (75%), maternal blood investigations for infection (64%), feto-maternal haemorrhage (57%) and fetal autopsy (47%). The least useful investigations were maternal full blood count (62%), liver function tests (59%), renal function tests (55%), blood group and antibody screen (41%), and thyroid function tests (33%). Imaging investigations were performed in a limited number of cases (40 cases) with MRI most useful at 98% (39/40) followed by babygram at 79% (198/251). Placental pathology and genetic analysis were useful in all clinical scenarios. Autopsy examination was most useful in an unknown clinical scenario. A cause of death was determined in 310 cases (47%) once the placenta had been examined.

The most useful investigations in stillbirths are placental pathology, comprehensive maternal history, genetic analysis, maternal blood investigations for infection, feto-maternal haemorrhage, and fetal autopsy.[1,162,163]

Clinical utility of investigations in stillbirths: a systematic review and meta-analysis: This review[162] examines the clinical utility of investigations in determining the causes and important contributing factors of stillbirth. The search yielded 3,414 articles for screening, from which 41 studies were identified for full review. Six studies were eligible for inclusion. Meta-analysis was performed for clinical utility of autopsy and placental pathology in determining cause of death. Thirteen studies specifically

looked at value of investigations in stillbirths. All studies assessed autopsy examination in conjunction with other investigations. Two studies only looked at autopsy. Three studies examined a comprehensive investigation protocol including all ancillary investigations. A comprehensive protocol involved a detailed review of maternal and obstetric history, maternal laboratory investigations for infection (cytomegalovirus, parvovirus, toxoplasmosis, syphilis), acquired thrombophilia and feto-maternal haemorrhage, external examination of fetus including radiography, microbiology, histological sampling, genetic analysis, and placental examination including microbiology and genetic analysis. A meta-analysis was performed with six articles with significant heterogeneity seen. The most clinically useful investigations in stillbirths are placental pathology, autopsy, and genetic testing. Further evaluation of a comprehensive investigation protocol according to gestational age and clinical scenario is required to guide a stillbirth investigation protocol.

Evaluation of diagnostic tests for determining the underlying cause of fetal death in stillbirth with attention to the underlying pathophysiological mechanism and contributing risk factors. The author[13] searched the past 10 years of literature for evidence-based investigations to review existing opinions on evaluation of stillbirth. The review found the diagnostic work up should depend on the specific clinical features per care. A standardised assessment must consist of the clinical context with details on maternal history, obstetric history and the course of the current pregnancy combined with investigations. Placental examination, cytogenetic evaluation, fetal autopsy, and investigation for fetal maternal haemorrhage are recommended for all perinatal deaths. If an autopsy is declines by the parents, they should be informed of alternative approaches such as minimally invasive autopsy or postmortem MRI are good alternatives in specific circumstances. Routine testing for inherited thrombophilias for stillbirth investigation is not supported by the evidence. Testing for antiphospholipid antibodies may be considered in cases of stillbirth with additional clinical features of anti-phospholipid syndrome accompanied by placenta-mediated complications or if cause of death.

When results are available, it is important to combine the findings of the investigations with the clinical review to determine the most probable cause of death, preferably in a multidisciplinary panel with parental input. Future directions of research should consider whole genome sequencing in unexplained stillbirth because it could uncover more information on the pathophysiology of stillbirth.

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This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence is indicated in the reference list by an asterisk (*) and also include methodology citations and grey literature.

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159. Cullen, S., et al., An audit of healthcare professionals' knowledge regarding perinatal autopsy. *Irish Journal of Medical Science*, 2019. **188**(2): p. 583–585 doi: 10.1007/s11845-018-1907-x.

160. Aladangady, N. and P. Chisholm, When should a neonatal death be referred to the coroner? Initiation of a guideline to aid decision making. *Infant*, 2021. **17**(4): p. 138-140

161. Draper ES, et al. *MBRRACE-UK perinatal mortality surveillance report, UK perinatal deaths for births from January to December 2020*. 2020; Available from: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2020/MBRRACE-UK_Perinatal_Surveillance_Report_2020.pdf

162. Marsden T, et al., Clinical utility of stillbirth investigations in Australia. Manuscript under review

163. Marsden T, et al., Clinical utility of investigations in stillbirths: a systematic review and meta-analysis. Manuscript under review

Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies	GRADE-CERQual Overall confidence Rating of evidence	Guideline recommendations
		Consensus-based recommendation 6.5 Explain to parents that the placenta can be returned to them following examination by the pathologist. The pathology service should be notified of the parents' wishes when the placental examination is requested. Advice should be given to families/whānau about any relevant health and safety precautions when handling the placenta.
		Evidence-based recommendation 6.6 *See Section 2 Technical report for cultural safety for evidence synthesis and GRADE-CERQual rating of this recommendation*
Siassakos 2018 Henderson 2017 Cullen 2019 Schirmann 2018 Lewis 2018a	**Moderate confidence** *No concerns of relevance, minor concerns of coherence and data adequacy. Moderate concerns of methodological limitation.*	**Evidence-based recommendation 6.7:** Provide parents with a clear timeline for receiving results of investigations and reports prior to discharge. The timeline should be made in conjunction with the multidisciplinary care team, including pathologists.
ACOG 2020 Leduc 2020 Page 2017 Page 2021 Tsakiridis 2022 Bakhbakhi 2018 Dalton 2023 RCOG 2010	**Moderate confidence** *No concerns of coherence, minor concerns of relevance and methodological limitation. Moderate concerns of data adequacy.*	**Evidence-based recommendation 6.8:** The recommended core set of investigations, with further investigations based on the clinical circumstances, should be considered routine practice for all perinatal deaths. • In some circumstances it may not be appropriate to undertake all core investigations (for example where cause has been unequivocally determined antenatally).

Page 2018			• Ideally, an individualised approach should be developed through multidisciplinary team discussion including the lead obstetrician, neonatologist/paediatrician, pathologist, radiologist, and geneticist, considering the clinical circumstances and the parents' wishes. Refer to *Appendix 6A: Stillbirth investigations flowchart* and *Appendix 6B: Neonatal death investigations flowchart.*
ACOG 2020 Leduc 2020 Holden 2019 Tsakiridis 2022 RCOG 2010 Miller 2016 Page 2018	Nijkamp 2017 Page 2017 Lou 2020 Madhi 2019 Mcpherson 2017 Facchinette 2023 Marsden 2023 Scalise 2022 Soltanghoraee 2022	High confidence *No concerns of coherence, minor concerns of methodological limitation, relevance and data adequacy.*	Evidence-based recommendation 6.9: A comprehensive clinical summary should be completed for all perinatal deaths to inform the investigations required. This summary should be completed as soon as possible after the death and include the following: • medical, social, family, and pregnancy history • antenatal ultrasound results • antenatal testing • initial findings of maternal, baby, and placental examination • parent's summary of the events surrounding the death.
			Consensus-based recommendation 6.10: A formal ultrasound for fetal anomalies, biometry and amniotic fluid index should be offered. The ultrasound should be carried out by an appropriately trained healthcare professional as soon as possible following diagnosis of a fetal death if not recently performed (within the past 4 weeks) and especially if there has been no second trimester morphology scan.
Page 2017 Leduc 2020 ACOG 2020 Page 2018 RCOG 2010 Facchinette 2023	McPherson 2017 Tsakiridis 2022 Wojcieszek 2018	High confidence *No concerns of coherence, minor concerns of data adequacy, methodological imitation and relevance.*	Evidence-based recommendation 6.11: A Kleihauer–Betke test to detect feto-maternal haemorrhage (with follow-up flow cytometry for quantification if any feto-maternal haemorrhage is detected) should be performed following the death of an unborn baby, preferably prior to birth.

ACOG 2020 Leduc 2020 Tsakiridis 2022 RCOG 2010 Facchinette 2023 Scalise 2022		Low confidence *No concerns of relevance and coherence. Moderate concerns of methodological limitation and major concerns of data adequacy.*	**Consensus-based recommendation 6.12:** External examination of the baby should be undertaken by an appropriately trained healthcare professional using *Appendix 6E: Examination of baby checklist.*
Holden 2019 Tsakiridis 2022 Schoner 2017		Low confidence *No concerns of coherence, minor concerns of relevance, moderate concerns of methodological limitation and major concerns of data.*	**Consensus-based recommendation 6.13:** Clinical photographs, following consent from parents, should be taken for later review, particularly for births that occur in non-tertiary hospital settings and where an autopsy is declined or delayed. • These photos are additional to the bereavement photographs and should not be given to the parents. • They should be clearly labelled and filed in the medical record.
Leduc 2020 ACOG 2020 Tsakiridis 2022 Roberts 2023		Low confidence *No concerns of coherence and minor concerns of relevance and methodological limitation. Major concerns of data adequacy.*	**Consensus-based recommendation 6.14:** Examination of the placenta and cord should be undertaken by the attending healthcare professional at the time of birth following the *Indications for placental examination (Appendix 6N*); *Placental examination for healthcare professionals (Appendix 6D)*. • If offered locally (and after parental consent), sample placenta for cytogenetic testing, including request to extract and store DNA for subsequent investigations. *Appendix 6D: Placental examination for healthcare professionals.*
Kang 2020 Holden 2019 Nijkamp 2017 Reid 2020	Tsakiridis 2022 Sonnemans 2018 Schoner 2017 Shelmerdine 2022	Low confidence *Minor concerns of relevance and coherence. Moderate concerns of methodological limitation and data adequacy.*	**Consensus-based recommendation 6.15:** Full body X-ray imaging of the baby (also known as a 'babygram') should be included in the routine investigations for perinatal deaths.

Cullen 2021 Graham 2020 Holden 2019 Hyde 2020 ACOG 2020 Mahdi 2019 Darouich 2020 Jones 2017 Tsakiridis 2022 Avagliano 2020 Scalise 2022 RCOG 2010	Taweevisit 2022a Taweevisit 2022b Nijkamp 2017 Miller 2016 Leduc 2020 Page 2017 Ptacek 2014 Facchinette 2023 Manjee 2023 Marsden 2023 Soltanghoraee 2022 Page 2018	High confidence *No concerns of coherence or relevance. Minor concerns of methodological limitation and data adequacy*	**Evidence-based recommendation 6.16:** Histopathology of the placenta and umbilical cord should be undertaken for all perinatal deaths by a perinatal pathologist. Microbiological culture may be required as directed by pathologist.
Graham 2020 Malusi 2019 Mahdi 2019 Page 2017 Leduc 2020 RCOG 2010	Cullen 2021 McPherson 2017 ACOG 2020 Taweevisit 2022 Matsika 2019 Roberts 2023	Moderate confidence *Minor concerns of methodological limitation, coherence and data adequacy. Moderate concerns of relevance.*	**Evidence-based recommendation 6.17:** Following a stillbirth or birth of a high-risk newborn, the placenta, membranes, and cord should be kept refrigerated and sent fresh and unfixed for macroscopic and histological examination by a perinatal pathologist as soon as possible (ideally within 48 hours of the birth).
Leduc 2020 Page 2017 Page 2018 ACOG 2020 Nijkamp 2017 McPherson 2017 Wojcieszek 2018	Tsakiridis 2022 Facchinette 2023 Odendaal 2022 RCOG 2010	High confidence *No concerns of relevance. Minor concerns of methodological limitation, coherence and data adequacy.*	**Evidence-based recommendation 6.18:** Cytogenetic testing should be performed for all perinatal deaths by either conventional karyotyping or by chromosomal microarray. • Snap freezing a piece of chorionic plate or muscle (if baby is not very macerated) is worth considering for all cases should a genetic condition need to be investigated).
Armes 2017 Byrne 2023 Dalton 2023	Schoner 2017 Tsakiridis 2022	Low confidence	**Consensus-based recommendation 6.19:** In perinatal deaths where there may be a genetic cause, parents should be referred to a multidisciplinary team with

RCOG 2010 R Nijkamp 2017 Quinlan-Jones 2019		*No concerns of coherence, minor concerns of relevance, moderate concerns of methodological limitation, and major concerns of data adequacy.*	expertise in clinical genetics to discuss the option of genomic sequencing where this option is available.
Leduc 2020 Nijkamp 2017 McPherson 2017 Page 2017 ACOG 2020 Page 2018 RCOG 2010 Mudda 2019 Lavezzi 2019 Jones 2017	Wojcieszek 2018 Kang 2020 Tsakiridis 2022 Sonnemans 2018 Neşe & Bülbül 2018 Moeremans 2023 Facchinette 2023 Ganesen 2023 Scalise 2022 Soltanghoraee 2022	High confidence *Minor concerns of methodological limitation, relevance, coherence and data adequacy.*	Evidence-based recommendation 6.20: Autopsy should be offered to all parents with an explanation of the likely value of the examination, including any limitations, in their specific circumstances.
Feroz 2019 Henderson 2017 Holden 2019	Lewis 2019d Tsakiridis 2022	Low confidence *Minor concerns of relevance and coherence.* *Moderate concerns of methodological limitation and data adequacy.*	Consensus-based recommendation 6.21: Consent for autopsy must clearly outline the extent of the investigations to be undertaken and should be recorded on an approved consent form, relevant to the jurisdiction.
Feroz 2019 Lewis 2019		Low confidence *Minor concerns of coherence, moderate concerns of methodological limitation and*	Consensus-based recommendation 6.22: When consent is obtained for specific organ/s to be retained for further examination at autopsy, parents should be offered the option of either delaying the funeral until the organs can be returned to the body or specifying their preference for how their baby's

		relevance. Major concerns of data adequacy.	retained organs are to be taken care of and their preferred method of organ disposal.
Dandona 2017 Das 2021a Menendez 2020 Tikmani 2021 Wojcieszek 2018 Holden 2019	Biswas 2018 ACOG 2020 Sauvegrain 2020 Taweevisit 2022a Tsakiridis 2022 McPherson 2017	Moderate confidence *No concerns of coherence, minor concerns of relevance and data adequacy. Moderate concerns of methodological limitation.*	Evidence-based recommendation 6.23: A comprehensive clinical summary should accompany the baby for autopsy and imaging to guide the procedure, including maternal, medical, social, family and pregnancy history, and results of antenatal investigations and imaging. Ideally, the cord and placenta should be sent with the baby for autopsy examination. Complete the following documents: • *Appendix 6D: Placental examination for healthcare professionals* • *Appendix 6E: Examination of baby checklist* • *Appendix 6G: Autopsy clinical summary form* • *Appendix 6M: Exemplar placental histopathology request form*
ACOG 2020 Evans 2020 Henderson 2017 Holden 2019 Leduc 2020 Pacheco 2017	McPherson 2017 Page 2017 Spierson 2019 Tsakiridis 2022 Wojcieszek 2018	High confidence *No concerns of data adequacy, relevance or coherence, minor concerns of methodological limitation*	Evidence-based recommendation 6.24: A perinatal/paediatric pathologist should perform or supervise all perinatal postmortem examinations.
Evans 2020 Fernandes 2019 Ibiebele 2017 Jones 2017		Moderate confidence *Minor concerns of coherence, data adequacy and methodological limitation. Moderate concerns of relevance.*	Evidence-based recommendation 6.25: If local autopsy is unavailable, transport for the baby to a centre with appropriate expertise should be arranged per local procedures.
Leduc 2020			Consensus-based recommendation 6.26: In remote settings, where autopsy is unavailable, communication with a multidisciplinary team (obstetrician and/or neonatologist/paediatrician, perinatal pathologists, and geneticist) at tertiary centres should be established to ensure that any opportunities to gather information or investigations that can be performed locally are not missed.

Lewis 2019 Siassakos 2018		**Low Confidence** *No concerns of coherence, minor concerns of relevance and moderate concerns of methodological limitation and data adequacy.*	**Consensus-based recommendation 6.27**: Ideally the final autopsy report should be forwarded to the referring healthcare professional within six weeks of the autopsy where the brain is not examined or 14 weeks if the brain is examined. (This is an aspirational target noting that reports may take longer due to resource limitations.) Healthcare professionals should consult with the perinatal pathology service available in each jurisdiction to obtain estimates of time to completion of autopsy (and release of body) and completion of report.
Siassakos 2018			**Consensus-based recommendation 6.28:** A copy of the autopsy report (including the plain language summary, if available) of any stillbirth or neonatal death should be sent to the requesting healthcare professional and woman's general practitioner (GP).
Aladangady 2021 Cullen 2021 Cohen 2018	Holden 2019 Lewis 2019 Morris 2021 Yilmaz et al. 2017	**Low confidence** *Minor concerns of relevance, moderate concerns of methodological limitation and coherence. Major concerns of data adequacy.*	**Consensus-based recommendation 6.29**: Maternal and newborn services should ensure appropriate education on the local coronial process for perinatal deaths is provided for all healthcare professionals. Healthcare professionals should seek advice from the coroner if any doubt exists as to whether a death should be referred to the coroner.
Arthurs 2017 Shruthi 2018 Cassidy 2019 Cronin 2018 Das 2021a Das 2021b Fernandes 2019 Feroz 2019a Feroz 2019b Guruprasad 2021 Hailu 2020 Henderson 2017	Griffiths 2021 Grover 2017 Hyde 2020 Kang 2017 Kang 2020 McPherson 2017 Munguambe 2021 Ozdemir 2021a Ozdemir 2021b Patterson 2019 Rossi 2017 Shelmerdine 2020	**Moderate confidence** *No concerns of data adequacy, minor concerns of methodological limitation and relevance, moderate concerns of coherence.*	**Evidence-based recommendation 6.30:** Where a full autopsy is declined by the parents, alternative options of less or minimally invasive investigations should be offered and an explanation provided of the value in their circumstances following a multidisciplinary discussion including the obstetrician, and neonatologist/paediatrician pathologist, radiologist, and geneticist as required. In addition to all core investigations, the following should be offered to parents who decline a full autopsy: • limited autopsy or minimally invasive tissue sampling (where available) • external examination by the pathologist • full body X-ray imaging of the baby (also known as a 'babygram') • postmortem MRI (where available).

Hutchinson 2019 Leduc 2020 Lewis 2018 b Lewis 2019 a Lewis 2018a Lewis 2019d ACOG 2020 Nijkamp 2017 Shelmerdine 2020 Sonnemans 2018 Griffiths 2020	Shelmerdine 2021 Madhi 2019 Menendez 2017 Taweevisit 2019 Tsakiridis 2022 Ulm 2021 Sorop-Florea 2017 Tanko 2021 Tikmani 2021 Moeremans 2023		
Hyde 2020 Griffiths 2021 Kang 2021 Nijkamp 2017 Ozdemir 2021a Sonnemans 2017	Sonnemans 2018 Shruthi 2018 Shelmerdine 2020 Shelmerdine 2021 De Keersmaecker 2023 Moeremans 2023 Tijssen 2023	Low confidence *Minor concerns of relevance and coherence are noted, moderate concerns of methodological limitation and data adequacy are noted*.	Consensus-based recommendation 6.31: A postmortem MRI, where available, should be offered to parents as an adjunct to autopsy or in place of an autopsy where this is declined. • Ideally, MRI should be performed within 24 hours of stillbirth. • MRI has been shown to be helpful in identifying brain and spinal cord anomalies, particularly in macerated stillborn babies.

Table 4. Search strategies

Three search strategies were carried out for this report and are listed below.

Table 4a. Search strategy for stillbirth investigations

Database	Search strategy	
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]
	#2	"Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "medical termination"[Title/Abstract] OR "induced termination"[Title/Abstract] OR "pregnancy termination" OR "termination of pregnancy"
	#3	#1 OR #2
	#4	"Culturally Competent Care"[Mesh] OR "Patient Care"[Mesh] OR "Family Planning Services"[Mesh] OR "Postnatal Care"[Mesh]
	#5	"professional*"[All Fields] OR "nurs*"[All Fields] OR "doctor*"[All Fields] OR "physicians"[MeSH Terms] OR "physician*"[All Fields] OR "midwi*"[All Fields] OR "therapist*"[All Fields] OR "shared decision"[All Fields] OR "pregnancy planning"[All Fields] OR "future pregnanc*"[All Fields] OR "preconception plan*"[All Fields]
	#6	#4 OR #5
	#7	"Indigenous Peoples"[Mesh] OR "Transients and Migrants"[Mesh] OR "Refugees"[Mesh] OR "Health Disparity, Minority and Vulnerable Populations"[Mesh] OR "Vulnerable Populations"[Mesh]
	#8	parent* OR mother* OR father* OR patient* OR "women understand*" OR "women* percept*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR refugee OR ("indigene" OR "indigeneity" OR "indigeneous" OR "indigenes" OR "indigenization" OR "indigenous") OR "torres strait islander*" OR "ATSI" OR "aborigin*" OR "islander*" OR *migrant OR refugee* OR "asylum seeker*"
	#9	#8 OR #9
	#10	"Health Care Economics and Organizations"[Mesh]
	#11	cost*[Title/Abstract] OR econom*[Title/Abstract]
	#12	#10 OR #11
	#13	#6 OR #9 OR #12
	#14	Autops*[Title/Abstract] OR "post$mortem*"[Title/Abstract] OR postmortem*[Title/Abstract] OR forensic*[Title/Abstract] OR "histologic examin*"[Title/Abstract] OR histologic*[Title/Abstract] OR "Histologic investigat*"[Title/Abstract] OR "histological examin*"[Title/Abstract] OR audit[Title/Abstract] OR audits[Title/Abstract] OR "mortality review" [Title/Abstract] OR "death review"[Title/Abstract] OR "placenta histolog*"[Title/Abstract] OR "placental histolog*"[Title/Abstract]
	#15	Autopsy [Mesh] OR "Cause of Death"[Mesh] OR "Cytogenetic Analysis"[Mesh] OR "Karyotyping"[Mesh]
	#16	#14 OR #15
	#17	#3 AND #13 AND #16

Embase	1	exp stillbirth/ or exp fetus death/ or exp perinatal mortality/ or exp perinatal death/ or induced abortion/ or pregnancy termination/
	2	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mortalit*) OR ("medical termination" OR "induced termination" OR “pregnancy termination” OR “termination of pregnancy”) .ti,ab,kw.
	3	(((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal”) ADJ loss*) OR stillb*).ti,ab,kw.
	4	1 OR 2 OR 3
	5	exp transcultural care/ OR patient care/ OR exp family planning/ or exp health care planning/
	6	professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR "shared decision" OR "pregnancy planning" OR "future pregnanc*" OR "preconception plan*"
	7	6 OR 5
	8	exp indigenous health care/ or indigenous people/ or exp migrant/ or exp refugee/ or exp asylum seeker/ or vulnerable population/ or exp health disparity/
	9	parent* OR mother* OR father* OR patient* OR ((women or woman) ADJ3 (understand* OR percept* OR view* OR experience*)) OR migrant* OR immigrant* OR refugee* OR indigenous OR “torres strait islander*” OR ATSI OR aborigin* OR islander*
	10	8 OR 9
	11	exp health care cost/
	12	(cost* OR econom*).ti,ab,kw.
	13	11 OR 12
	14	10 OR 7 OR 13
	15	(autops* or "post mortem*" or postmortem* or forensic* or "histologic examin*" or histologic* or "Histologic investigat*" or "histological examin*" or audit or audits or "mortality review" or "death review" or "placenta histolog*" or "placental histolog*").ti,ab,kw.
	16	exp autopsy/ or exp “cause of death”/ or “fetus karyotyping”/ or karyotyping/ or “tissue microarray”/
	17	15 OR 16
	18	4 AND 14 AND 17

CINAHL	1.	(MM "Perinatal Death") OR (MM "Abortion, Induced")
	2.	AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) N2 (death* OR wast* OR demise* OR mortalit*)
	3.	AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal”) N1 loss*) OR stillb*) OR ("medical termination" OR "induced termination" OR “pregnancy termination” OR “termination of pregnancy”)
	4.	S1 OR S2 OR S3
	5.	(MM "Transcultural Care") OR (MM "Transcultural Nursing") OR (MH "Patient Care+") OR (MH "Family Planning+")
	6.	TX (professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR "shared decision" OR "pregnancy planning" OR "future pregnanc*" OR "preconception plan*")
	7.	S5 OR S6
	8.	(MM "Indigenous Peoples") OR (MM "Health Services, Indigenous") OR (MM "Indigenous Health") OR (MM "First Nations of Australia") OR (MM “special populations”) OR (MM "Refugees") OR (MM "Transients and Migrants") OR (MM "Healthcare Disparities")
	9.	TX (parent* OR mother* OR father* OR patient* OR ((women or woman) N3 (understand*OR percept*OR view* OR experience*)) OR migrant* OR immigrant* OR refugee* OR indigenous OR “torres strait islander*” OR ATSI OR aborigin* OR islander*)
	10.	S8 OR S9

11. (MH "Health Care Costs+")
12. AB (cost* OR econom*)
13. S11 OR S12
14. S7 OR S10 OR S13
15. (MM "Autopsy") OR (MM "Cause of Death") OR (MM "Postmortem Care") OR (MH "Cytogenetic Analysis") OR (MH "Tissue Array Analysis")
16. AB (autops* or "post mortem*" or postmortem* or forensic* or "histologic examin*" or histologic* or "Histologic investigat*" or "histological examin*" or audit or audits or "mortality review" or "death review" or "placenta histolog*" or "placental histolog*")
17. S15 OR S16
18. S4 AND S14 AND S17

Table 4b. Search strategy for perinatal autopsy (Part A)

Database	Search strategy	
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh]
	#2	"Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR “Neonatal loss*”[Title/Abstract] OR Neonatal mortalit*[Title/Abstract] OR Neonatal death*[Title/Abstract] OR “Neonatal Demise*”[Title/Abstract] OR Newborn death*[Title/Abstract] OR Newborn mortalit*[Title/Abstract]
	#3	#1 OR #2
	#4	((("Health Personnel"[Mesh]) OR ("Obstetrics"[Mesh] OR "Obstetrics and Gynecology Department, Hospital"[Mesh])) OR "Gynecology"[Mesh]) OR ("Infant, Newborn"[Mesh] OR "Intensive Care Units, Neonatal"[Mesh] OR "Intensive Care, Neonatal"[Mesh])
	#5	professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR “health care professional*” OR “health care person*” or obstetric* or gynecolog* OR neonatology* OR paediatric*
	#6	#4 OR #5
	#10	"Health Care Economics and Organizations"[Mesh]
	#11	cost*[Title/Abstract] OR econom*[Title/Abstract]
	#12	#10 OR #11
	#13	#6 OR #9 OR #12
	#14	"coroners and medical examiners"[MeSH Terms] OR "Forensic Pathology"[Mesh]
	#15	coroner*[Title/Abstract] or forensic[Title/Abstract] or "medico$legal"[Title/Abstract] or "medical legal"[Title/Abstract] or coronial[Title/Abstract]
	#16	#14 OR #15
	#17	#3 AND #13 AND #16

Embase	1	exp stillbirth/ or exp fetus death/ or exp perinatal mortality/ or exp perinatal death/ or exp newborn death/
	2	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn OR neonatal) ADJ2 (death* OR wast* OR demise* OR mortalit*).ti,ab,kw.
	3	(((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) ADJ loss*) OR stillb*).ti,ab,kw.
	4	1 OR 2 OR 3
	5	exp health care planning/ or exp health care personnel/ or exp obstetrics/ or gyneacology/ or exp neonatology/ or newborn intensive care/ or newborn/ or newborn period/
	6	professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR “health care professional*” OR “health care person*” or obstetric* or gynecolog*)
	7	6 OR 5
	8	exp health care cost/
	9	(cost* OR econom*).ti,ab,kw.
	10	11 OR 12
	11	10 OR 7 OR 13
	12	exp coroner/ or exp forensic science/
	13	(coroner* or forensic or "medico$legal" or "medical legal" or coronial).ti,kw,ab.
	14	15 OR 16
	15	4 AND 14 AND 17
CINAHL	S15	S4 AND S14
	S14	S12 OR S13
	S13	AB ("telehealth" OR "tele health" OR "SMS" OR (("mobile" OR "phone") N3 ("app" OR "application")) OR (("written" OR "audio" OR virtual) N5 "infORmation") OR "pamphlet*" OR (("visit*" OR "attend*" OR "allow*" OR "transfer" OR "accompany") N4 ("mortuary" OR "morgue" OR "body" OR "imaging" OR "radiology" OR "computeri$ed tomography" OR "magnetic resonance imaging" OR "MRI" OR "CT")) OR ("community" N3 "outreach") OR ("community" N1 "care") OR (("decision making" OR "decision aid*" OR "written" OR "electronic" OR "community" OR online) N3 "resources") OR "virtual consultation" OR "shared decision" OR "timeline*" OR "decision making" OR "decision-making" OR "shared-decision" OR counselling OR counselling)
	S12	(MM "Telehealth") OR (MM "Decision Making, Patient") OR (MH "Decision Making, Family") OR (MM "Decision Making, Shared")
	S11	(S5 OR S6 OR S7 OR S8 OR S9 OR S10)
	S10	AB (cost* OR econom*)
	S9	(MH "Health Care Costs+")
	S8	AB (parents OR mother* OR father* OR (patient* N2 (understan* OR need* OR resource* OR experience* OR view* OR "decision-making" OR "decision making" OR "shared decision")) OR "women understand*" OR "women* need*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR family OR families OR refugee* OR "indigenous" OR "torres strait islander*" OR ATSI OR "aborigin*" OR "islander*" OR remote* OR "linguistically diverse" OR "literacy" OR "low income" OR cultural OR elders)
	S7	(MH "Parents+")
	S6	(MM "Health Services, Indigenous") OR (MM "Rural Health Personnel") OR (MM "Rural Health Centers") OR (MM "Hospitals, Rural") OR (MM "Rural Health Services")

	S4	S1 OR S2 OR S3
	S3	AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal" OR neonatal) N1 loss*) OR stillb*)
	S2	AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*)
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
SCOPUS	((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) W/2 (death* OR wast* OR demise* OR mortalit* OR terminat*)) OR (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal") W/2 (loss* OR terminat*)) OR (stillb*) AND (professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR "health care professional*" OR "health care person*" or obstetric* or gynecolog* OR neonatology* OR paediatric* OR "indigenous health*" OR "health care cost*" OR "healthcare cost*" OR econom* OR cost*) AND (coroner* or forensic or "medico$legal" or "medical legal" or coronial)	
Australian Indigenous HealthInfoNet	Coroner and (stillbirth or (perinatal death) Coroner and (neonatal death) Coroner and (newborn death)	
Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees
	#2	MeSH descriptor: [Perinatal Death] explode all trees
	#3	MeSH descriptor: [Perinatal Mortality] explode all trees
	#4	MeSH descriptor: [Pregnancy Reduction, Multifetal] explode all trees
	#5	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mortalit*)
	#6	#1 OR #2 OR #3 OR #5
	#7	MeSH descriptor: [Health Services, Indigenous] explode all trees
	#8	MeSH descriptor: [Health Personnel] explode all trees
	#9	MeSH descriptor: [Gynecology] explode all trees
	#10	MeSH descriptor: [Obstetrics and Gynecology Department, Hospital] explode all trees
	#11	(professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR "health care professional*" OR "health care person*" or obstetric* or gynecolog* OR neonatology* OR paediatric*)
	#12	#7 OR #8 OR #9 OR #10
	#13	MeSH descriptor: [Coroners and Medical Examiners] explode all trees
	#14	MeSH descriptor: [Forensic Sciences] explode all trees
	#15	(coroner* or forensic or "medico$legal" or "medical legal" or coronial)

	#16	#13 OR #14 OR #15
	#17	#6 AND #12 AND #16
Informit Indigenous Collection	((“fetal death*” OR “foetal death*” OR “foetal demise*” OR “fetal wast*” OR “foetal wast*” OR “fetal mortalit*” OR “fetal demise*” OR “foetal mortalit*” OR “perinatal wast*” OR “perinatal mortalit*” OR “perinatal death*” OR “perinatal demise*” OR “prenatal death*” OR “prenatal mortalit*” OR “prenatal demise*” OR “antenatal mortalit*” OR “antenatal death*” OR “antenatal demise*” OR stillb* OR “fetal loss*” OR “foetal loss*” OR “perinatal loss*” OR “prenatal loss*” OR “peri natal loss*” OR “intrapartum mortalit*” OR “intrapartum death*”) OR (stillb*)) AND (coroner* or forensic or "medico$legal" or "medical legal" or coronial)	

Table 4c. Search strategy for perinatal autopsy (Part B)

Database	Search strategy		
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh]	Mesh
	#2	"Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR “Neonatal loss*” OR “Neonatal mortalit*”OR “Neonatal death*” OR “Neonatal Demise*” OR “Newborn death*” OR “Newborn mortalit*” OR “Sudden Unexpected death”	Title/abstract
	#3	#1 OR #2	
	#4	"Indigenous Peoples"[Mesh] OR "Transients and Migrants"[Mesh] OR "Refugees"[Mesh] OR "Health Disparity, Minority and Vulnerable Populations"[Mesh] OR "Vulnerable Populations"[Mesh] OR "Culturally Competent Care"[Mesh] OR "Rural Health Services"[Mesh] OR "Parents"[Mesh]	Mesh
	#5	parent* OR mother* OR father* OR patient* OR "women understand*" OR "women* percept*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR refugee* OR ("indigene" OR "indigeneity" OR "indigeneous" OR "indigenes" OR "indigenization" OR "indigenous") OR "torres strait islander*" OR "ATSI" OR "aborigin*" OR "islander*" OR “asylum seeker*” OR professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR “health care professional*” OR “health care person*” or obstetric* or gynecolog* OR neonatology* OR paediatric* OR consent* OR communicat* OR train* OR expertise OR barrier* OR timeframe* OR educat* OR standard* OR report* OR intervent* OR transfer OR relocate* OR “cause of death” OR remote* OR regional or require*	Title/ abstract
	#6	#4 AND #5	
	#7	"Health Care Economics and Organizations"[Mesh]	Mesh
	#8	cost* OR econom*	Title/ abstract
	#9	#7 OR #8	
	#10	#9 OR #6	
	#11	Autopsy [Mesh] OR "Cause of Death"[Mesh] OR "Cytogenetic Analysis"[Mesh] OR "Karyotyping"[Mesh]	Mesh
	#12	Autops* OR "post$mortem*" OR postmortem* OR forensic* OR “histologic examin*” OR histologic* OR “Histologic investigat*” OR “histological examin*” OR audit OR audits OR “mortality review” OR “death review” OR "placenta histolog*" OR "placental histolog*"	Title/ abstract

	#13	#11 OR #12
	#14	#3 AND #10 AND #13
Embase	1	exp stillbirth/ or exp fetus death/ or exp perinatal mortality/ or exp perinatal death/ or exp newborn death/ or induced abortion/ or pregnancy termination/
	2	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn OR neonatal) ADJ2 (death* OR wast* OR demise* OR mortalit*).ti,ab,kw.
	3	(((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal" OR neonatal) ADJ loss*) OR stillb* OR "Sudden Unexpected death").ti,ab,kw.
	4	1 OR 2 OR 3
	5	exp transcultural care/ or exp health care personnel/ or exp obstetrics/ or gyneacology/ or exp neonatology/ or newborn intensive care/ OR exp vulnerable population/ OR exp rural health care/ or exp indigenous health care/ or exp health disparity/ or indigenous people/
	6	parent* OR mother* OR father* OR patient* OR ((women or woman) ADJ3 (understand* OR percept* OR view* OR experience*)) OR migrant* OR immigrant* OR refugee* OR indigenous OR "torres strait islander*" OR ATSI OR aborigin* OR islander* OR "asylum seeker*" OR migrant OR immigrant OR professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR "health care professional*" OR "health care person*" or obstetric* or gynecolog* OR neonatology* OR paediatric* OR consent* OR communicat* OR train* OR expertise OR barrier* OR timeframe* OR educat* OR standard* OR report* OR intervent* OR transfer OR relocate* OR "cause of death" OR remote* OR regional or require* OR "shared decision"
	7	exp health care cost/
	8	(cost* OR econom*).ti,ab,kw.
	9	5 OR 6 OR 7 OR 8
	10	(autops* or "post mortem*" or postmortem* or forensic* or "histologic examin*" or histologic* or "Histologic investigat*" or "histological examin*" or audit or audits or "mortality review" or "death review" or "placenta histolog*" or "placental histolog*").ti,ab,kw.
	11	exp autopsy/ or exp "cause of death"/ or "fetus karyotyping"/ or karyotyping/ or "tissue microarray"/
	12	10 OR 11
	13	4 AND 9 AND 12
CINAHL	S15	S4 AND S14
	S14	S12 OR S13
	S13	AB (autops* or "post mortem*" or postmortem* or forensic* or "histologic examin*" or histologic* or "Histologic investigat*" or "histological examin*" or audit or audits or "mortality review" or "death review" or "placenta histolog*" or "placental histolog*")
	S12	(MM "Autopsy") OR (MM "Cause of Death") OR (MM "Postmortem Care") OR (MH "Cytogenetic Analysis") OR (MH "Tissue Array Analysis")
	S11	(S5 OR S6 OR S7 OR S8 OR S9 OR S10)
	S10	AB (cost* OR econom*)
	S9	(MH "Health Care Costs+")
	S8	AB parent* OR mother* OR father* OR patient* OR "women understand*" OR "women* percept*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR refugee* OR ("indigene" OR "indigeneity" OR "indigeneous" OR "indigenes" OR "indigenization" OR "indigenous") OR "torres strait islander*" OR "ATSI" OR "aborigin*" OR "islander*" OR "asylum seeker*" OR professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR "health care professional*" OR "health care person*" or obstetric* or gynecolog* OR neonatology* OR paediatric* OR consent* OR communicat* OR train* OR expertise OR barrier* OR timeframe* OR educat* OR standard* OR report* OR intervent* OR transfer OR relocate* OR "cause of death" OR remote* OR regional or require*

	S7	(MH "Parents+")
	S6	(MM "Health Services, Indigenous") OR (MH "Multidisciplinary Care Team+") OR (MH "Health Personnel+") OR (MM “Obstetrics”) OR (MM “Gynecology”)
	S5	(MM "Rural Health Personnel") OR (MM "Rural Health Centers") OR (MM "Hospitals, Rural") OR (MM "Rural Health Services")
	S4	S1 OR S2 OR S3
	S3	AB (((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) N1 loss*) OR stillb*)
	S2	AB (fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) N2 (death* OR wast* OR demise* OR mortalit*)
	S1	1. (MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
SCOPUS	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero OR newborn* OR neonatal) W/2 (death* OR wast* OR demise* OR mortalit*) (pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal") W/1 loss*) (stillb*) AND (parent* OR mother* OR father* OR patient* OR "women understand*" OR "women* percept*" OR "women* view*" OR "women* experience*" OR "woman* understand*" OR "woman experience*" OR migrant OR immigrant OR refugee* OR ("indigene" OR "indigeneity" OR "indigeneous" OR "indigenes" OR "indigenization" OR "indigenous") OR "torres strait islander*" OR "ATSI" OR "aborigin*" OR "islander*" OR “asylum seeker*” OR professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR “health care professional*” OR “health care person*” or obstetric* or gynecolog* OR neonatology* OR paediatric* OR consent* OR communicat* OR train* OR expertise OR barrier* OR timeframe* OR educat* OR standard* OR report* OR intervent* OR transfer OR relocate* OR “cause of death” OR remote* OR regional or require* OR cost* OR econom*) AND (autops* or "post mortem*" or postmortem* or forensic* or "histologic examin*" or histologic* or "Histologic investigat*" or "histological examin*" or audit or audits or "mortality review" or "death review" or "placenta histolog*" or "placental histolog*")	
Australian Indigenous HealthInfoNet	(Autopsy OR (sorry AND business))AND (stillborn or baby or newborn or infant)	
Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees
	#2	MeSH descriptor: [Perinatal Death] explode all trees
	#3	MeSH descriptor: [Perinatal Mortality] explode all trees
	#4	MeSH descriptor: [Abortion, Induced] explode all trees
	#5	MeSH descriptor: [Sudden Infant Death] explode all trees
	#6	(fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) ADJ2 (death* OR wast* OR demise* OR mortalit*)
	#7	#1 OR #2 OR #3 OR #4 OR #5 OR #6
	#8	MeSH descriptor: [Culturally Competent Care] explode all trees
	#9	MeSH descriptor: [Minority Health] explode all trees
	#10	MeSH descriptor: [Health Services, Indigenous] explode all trees
	#11	MeSH descriptor: [Vulnerable Populations] explode all trees

	#12	MeSH descriptor: [Parents] explode all trees
	#13	MeSH descriptor: [Parental Consent] explode all trees
	#14	MeSH descriptor: [Health Care Costs] explode all trees
	#15	MeSH descriptor: [Gynecology] explode all trees
	#16	MeSH descriptor: [Health Personnel] explode all trees
	#17	parent* OR mother* OR father* OR patient* OR ((women or woman) ADJ3 (understand* OR percept* OR view* OR experience*)) OR migrant* OR immigrant* OR refugee* OR indigenous OR "torres strait islander*" OR ATSI OR aborigin* OR islander* OR "asylum seeker*" OR migrant OR immigrant OR professional* OR nurs* OR doctor* OR physician* OR midwi* OR therapist* OR "health care professional*" OR "health care person*" or obstetric* or gynecolog* OR neonatology* OR paediatric* OR consent* OR communicat* OR train* OR expertise OR barrier* OR timeframe* OR educat* OR standard* OR report* OR intervent* OR transfer OR relocate* OR "cause of death" OR remote* OR regional or require* OR "shared decision"
	#18	#8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17
	#19	MeSH descriptor: [Autopsy] explode all trees
	#20	MeSH descriptor: [Cause of Death] explode all trees
	#21	MeSH descriptor: [Cytological Techniques] explode all trees
	#22	MeSH descriptor: [Genetic Testing] this term only
	#23	MeSH descriptor: [Histological Techniques] this term only
	#24	MeSH descriptor: [Tissue Array Analysis] this term only
	#25	(autops* or "post mortem*" or postmortem* or forensic* or "histologic examin*" or histologic* or "Histologic investigat*" or "histological examin*" or audit or audits or "mortality review" or "death review" or "placenta histolog*" or "placental histolog*")
	#26	#19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25
	#27	#26 AND #18 AND #7
Informit Indigenous Collection	"pregnancy terminat*" OR "Fetal death*" OR "Foetal death*" OR "Foetal Demise*" OR "fetal wast*" OR "foetal wast*" OR "Fetal mortalit*" OR "Fetal demise*" OR "Foetal mortalit*" OR "perinatal wast*" OR "perinatal mortalit*" OR "perinatal death*" OR "perinatal demise*" OR "Prenatal death*" OR "Prenatal mortalit*" OR "prenatal demise*" OR "Antenatal mortalit*" OR "Antenatal Death*" OR "Antenatal Demise*" OR Stillb* OR "fetal Loss*" OR "foetal Loss*" OR "perinatal Loss*" OR "Prenatal loss*" OR "peri natal loss*" OR "Intrapartum mortalit*" OR "Intrapartum Death*" OR "Neonatal loss*" OR "Neonatal mortalit*" OR "Neonatal death*" OR "Neonatal Demise*" OR "Newborn death*" OR "Newborn mortalit*" OR "Sudden Unexpected death"	

Figures 1. PRISMA flow diagrams of screening evidence

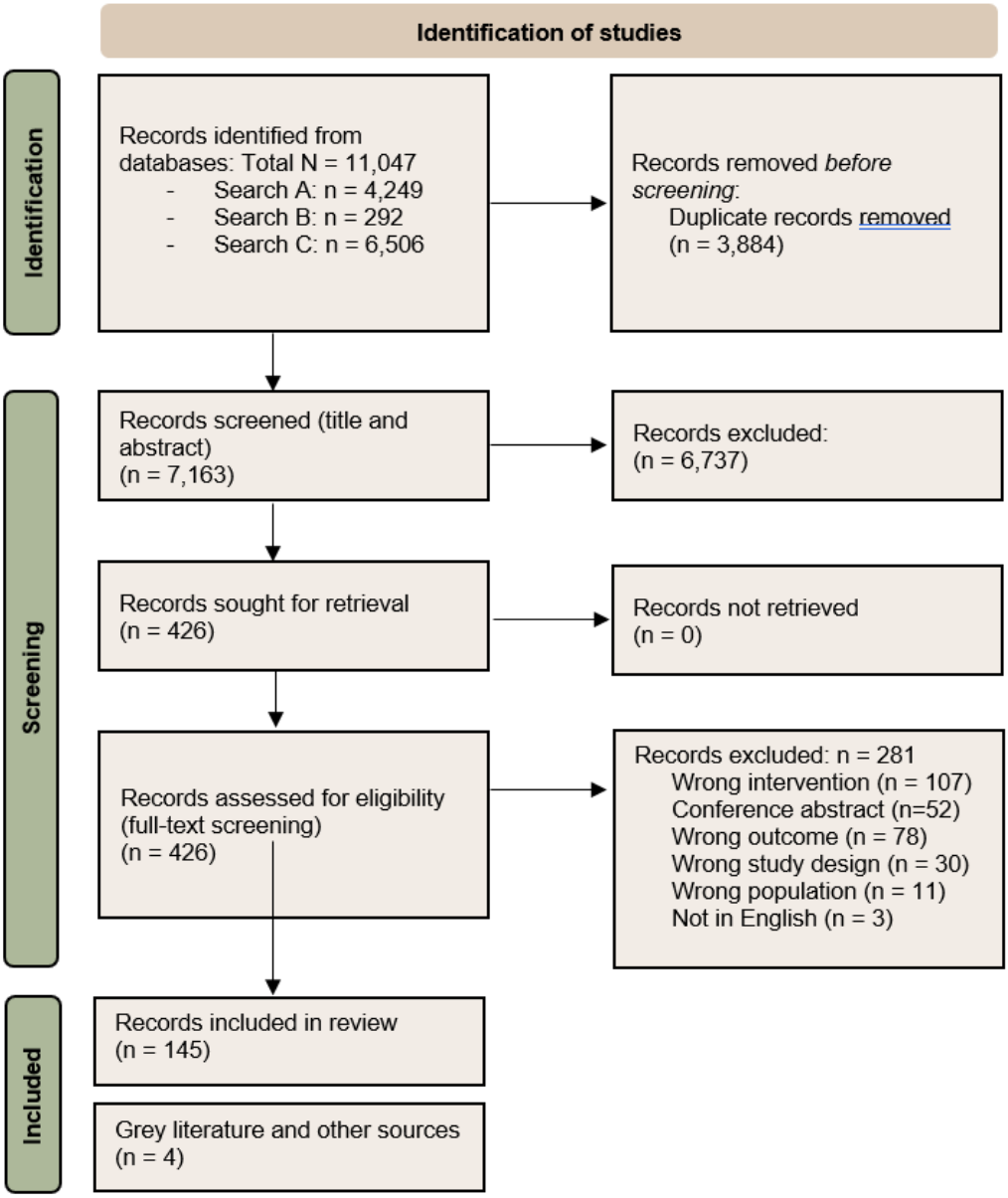


Table 5a. Study characteristics: Stillbirth investigations

Study	Country (period)	Locality (state/ national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool[a]
ACOG 2020	Multiple (not dated)	International literature	Review of the literature	NA	Qualitative	Narrative review	NA	NA	Stillbirth	Management, evaluation and strategies for prevention of stillbirth	None mentioned	Risk factors, potential causes and clinical considerations in the management of stillbirth	Checklist for text and opinion papers
Aiyelaagbe 2017	UK (2014–2015)	St Mary's Hospital, Manchester UK	Interviews	HIC	Qualitative	Pilot Thematic analysis	NA	58	Stillbirths (antepartum and intrapartum), early neonatal deaths	Parents experience of bereavement care	None	Parents of stillborn babies, or babies who died in the delivery unit	Checklist for qualitative research
Armes 2017	Australia (dates not reported)	Not stated	Fetal/ placental tissue, blood samples	HIC	Qualitative	Case series	NA	16	Stillbirth, NND	Whole genome sequencing technology in the Investigation of genetic causes of fetal, perinatal,	NA	Probands who had suffered a fetal, perinatal, or early infant death and had been subjected to a full	Checklist for case series studies

										and early infant death		diagnostic autopsy	
Arthurs 2017	UK (dates not reported)	National	Literature	HIC	Qualitative	Narrative review	NA	NA	Perinatal and paediatric deaths	Application of postmortem imaging to perinatal autopsy, and paediatric forensic deaths	NA	NA	
Avagliano 2022	Italy (dates not reported)	1 third level Italian university care centre	Online anonymous questionnaire	HIC	Quantitative	NA	Prospective cross sectional	34 clinicians	Stillbirth	Clinicians' knowledge about fetal autopsy	NA	Healthcare staff of the obstetrics unit	Checklist for cohort studies
Biswas 2018	Bangladesh	National	Review of literature	LMIC	Qualitative	Critical review	NA	NA	Neonatal death	Social autopsy	None	None	Checklist for qualitative research
Byrne 2023	Australia (no date reported)	Genomic Autopsy Study clinical network	Exome sequencing or genome sequencing records	HIC	Quantitative	NA	Cohort	n=200	Pregnancy loss and perinatal death	Evidence of severe atypical in utero presentations of known genetic disorders and identifies novel phenotypes and	NA	Pregnancy loss and perinatal death	Checklist for cohort studies

									disease genes				
Campbell 2018	Scotland (2011–2015)	South East Scotland	Hospital records (Pathology reports, demographic data, genetic test results, placental pathology)	HIC	Quantitative	NA	Diagnostic utility	129	Stillbirth, NND	Utility of genetic testing in contrast to placental pathology in explaining cause of death in the structurally normal stillborn population	Cases reported to the Procurator Fiscal (Scotland); cases with no consent for genetic testing included in autopsy authorisation; cases where anomalies were diagnosed antenatally or at postmortem	Structurally normal stillbirths defined as death at or after 24 weeks of gestation that occurred between Jan 2011–Dec 2015; Neonatal deaths within 2 h of birth	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Cassidy 2018	Spain (2013–2016)	National	Online self-completion questionnaire	HIC	Qualitative	Phenomenological	NA	796	Pregnancy loss stratified by GA (n=668 stillbirths ≥20 weeks GA)	Bereaved parents experience of care quality following intrauterine death	Respondents born outside of the Spanish national territory. Parents reporting neonatal deaths	Women who reported that their baby died within 60 months prior to survey completion.	Checklist for qualitative research

Cassidy 2019	USA (1994–2009)	University of California, San Francisco	Medical charts	HIC	Quantitative	NA	Comparative diagnostic accuracy	385	Pregnancy loss or termination for anomalies and other complications	Correlation between ultrasound and autopsy diagnosis	Babies who lived >6 hours, autopsies for reasons other than terminations or pregnancy, partial autopsy only, missing antenatal records, cases from elsewhere, no identified maternal or fetal indication for termination.	All autopsies performed at the University of California, San Francisco in cases of intrauterine fetal demise, termination for anomalies or fetuses delivered but not resuscitated.	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Cronin 2018	New Zealand (2012–2015)	20 New Zealand District Health Boards	Face-to-face interviews, and maternity and postmortem records	HIC	Quantitative	NA	Case Series	169	Stillbirth (n=169)	Exploration of factors influencing decision-making about postmortem examination.	Pregnancies with a known congenital abnormality at recruitment.	Women with singleton pregnancies that ended in late stillbirth (>=28 weeks GA) without	Checklist for case series studies

												known congenital abnormality.	
Cullen 2021	Ireland (2019–2020)	The National Maternity Hospital	Medical charts (maternal)	HIC	Qualitative	Case series	NA	25	Stillbirths (n=25)	Coroner's directives and cause of death following placental examination by the coroner	Terminations of pregnancy for fetal anomaly	Cases of stillbirth within the 9 months following the amendment to the coroner's act in Ireland.	Checklist for case series studies
Dalton 2023	USA (Mar 2006–Sept 2008)	59 hospitals in 5 geographic regions throughout the United States	Secondary analysis of the Stillbirth Collaborative Research Network study	HIC	Quantitative	NA	Retrospective cohort	393 stillbirths	Stillbirth	Relationship between abnormal copy number variants and fetal growth abnormalities in stillbirths	Maternal-offspring dyads were excluded if the parents did not consent to genetic analysis, if the chromosomal microarray failed, if the stillbirth occurred	Singleton stillbirth deliveries with chromosomal microarray analysis performed on the fetus or placenta to evaluate for associations with growth abnormali	Checklist for cohort studies

											<20 weeks gestational age, or if the birthweight was not recorded.	ty outcomes	
Dandona 2017	India (2014–2015)	Bihar	Verbal Autopsy interview questionnaires	LMIC	Mixed methods	Themes illustrated through case studies	Epidemiological study	1,103 stillbirths for quantitative component, n=200 narratives for qualitative component	Stillbirth	Factors associated with stillbirth in Bihar, India	None stated	Stillbirths defined as a foetal death with a gestation period of 28 weeks wherein the fetus did not show any sign of life	Checklist for qualitative research Checklist for studies reporting prevalence data
Darouich 2020	Tunisia (Jan–Dec 2013)	1 medical centre in Tunisia	Hospital autopsy registers	LMIC	Quantitative	NA	Retrospective cohort	147	Stillbirth	Contribution of the placental examination to the etiologic diagnosis of stillbirth	Multiple pregnancies, fetuses without placentas	Inclusion criteria included the occurrence of fetal death after 14 weeks of gestation, singleton pregnancy and placenta availability.	Checklist for cohort studies

Das 2020	India (Dec 2018–Jan 2019)	Tertiary care hospital in Delhi	Interviews	LMIC	Qualitative	Thematic analysis	NA	26	Stillbirth, NND, Child deaths	Perceptions of health care providers regarding acceptability and conduct of MITS	None mentioned	Doctors, nurses and support staff from paediatrics, neonatology, obstetrics and forensic medicine	Checklist for qualitative research
Das 2021	India (Sept 2018–April 2019)	Tertiary care hospital in Delhi	Observations and interviews	LMIC	Qualitative	Thematic content analysis	NA	13	Stillbirth (n=1), NND (n=7)	Process of counselling and obtaining consent for MITS	None specified	Parents and family members of deceased children and stillbirths, MITS research staff and healthcare providers	Checklist for qualitative research
Das 2021 (2)	India (2018–2019)	At and around a tertiary care hospital in Delhi	Observations, interviews and focus groups	LMIC	Qualitative	Thematic content analysis	NA	104	Stillbirth (n=44 parents of 22 stillbirths), NND (n=24 parents of 12 NND)	Perceptions of parents, community, and religious leaders on acceptability of MITS	Parents from outside Delhi were excluded	Parents of deceased children, neonates or stillbirths, community members and religious leaders	Checklist for qualitative research

DeKeersmaecker 2023	Belgium (2006–2016)	1 tertiary centre	Hospital database	HIC	Quantitative	NA	Diagnostic accuracy	68	TOPFA	Concordance of conventional autopsy (CA) and postmortem magnetic resonance (MR) after termination of pregnancy (TOP) in fetuses with prenatally detected central nervous system (CNS) anomalies.	Fetal genetic anomalies and cases without both postmortem MR and CA	All TOPs at the study institution between 2006 and 2016 with prenatally detected CNS involvement and having a postmortem MR and CA as postmortem examinations	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Fernandes 2019	Mozambique (Nov 2013–May 2015)	Quaternary hospital	CDA, MIA, clinical records	LIC	Quantitative	NA	Diagnostic accuracy	264	NND (n=41)	Diagnostic assessment of minimally invasive autopsy, CDA with and without clinical records.	Deaths of traumatic origin	Deaths of all ages (except for neonates) at the Maputo Central Hospital between Nov 2013 and March 2015 with following	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

												inclusion criteria: a CDA requested by the clinician as part of the medical evaluation; a verbal informed consent to perform the autopsy given by the relatives; no traumatic origin.	
Feroz 2019	Pakistan (2018)	National Institute of Child Health, Karachi, Pakistan	Focus groups and interviews	LMIC	Qualitative	Thematic analysis	NA	40 (32 for focus groups and 8 key informant interviews)	Stillbirth, NND	Health professionals' attitudes and perceptions related to MITS	None specified	Healthcare professionals including residents, consultants, staff nurses and trainees working at the National Institute of Child Health hospital	Checklist for qualitative research

												were included in focus groups. Interviews were conducted with public health experts, clinicians, and bioethics experts.	
Feroz 2019 (2)	Pakistan (Jul–Aug 2018)	National Institute of Child Health, Karachi, Pakistan	Focus groups and interviews	Lower middle income	Qualitative	Thematic analysis	NA	45 (40 for focus groups, 5 interviews)	Views and opinions of parents of newborns concerning MITS for stillbirth and neonatal death.	Parents' and religious leaders' perceptions related to MITS	Parents and/or families that experienced a recent neonatal death/still birth or who were in-patients	Parents of newborns who were visiting the OPD and well-baby clinics of NICH hospital for regular growth monitoring, postnatal check-ups and vaccinations were purposively sampled for focus group	Checklist for qualitative research

												discussions. Religious leaders, including Sunni Ulemas and Shia Muftis were purposively sampled for key informant interviews.	
Ganesan 2023	India (2015–2021)	Pathology Dept of one institute	Medical records	LMIC	Quantitative	NA	Diagnostic value	45 (n=34 TOPFA, n=4 IUFD, n=7 spontaneous abortions)	Stillbirth, TOPFA	Role of comprehensive autopsy examination in identifying Congenital Anomalies of the Kidney and Urinary Tract (CAKUT)	NA	All fetuses with renal malformations at the study institution during the study period (2015 to 2021).	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Goergen 2019	Not mentioned (Jan 2015–Jan 2017)	Three institutions	Radiology information systems of different institutions	HIC	Quantitative	NA	Diagnostic yield	13	TOPFA	Differences in diagnostic yield of foetal brain malformat	None specified	1. Tertiary prenatal ultrasound study suggesting a foetal brain	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

										ions for intra uterine foetal and post-mortem MRI, using autopsy as the reference standard		malformation (at ≥ 19 weeks gestation) 2. Subsequent iuMR showing a brain abnormality (not necessarily the same abnormality) 3. Termination of pregnancy for foetal brain abnormality by parental request 4. Perinatal PMMR	
Graham 2020	None specified	International	Review of literature	HIC	Qualitative	Critical review	NA	NA	Stillbirth	Role of placenta in explaining stillbirths	None specified	None	Checklist for qualitative research
Griffiths 2021	UK (2011–2014)	Fetal medicine units in the UK	Hospital presentations	HIC	Quantitative	NA	Prospective cohort study	62	TOPFA	Concordance between postmortem and in utero MRI	None specified	Pregnant women with a diagnosis of fetal brain	Checklist for cohort studies

										in detecting fetal brain abnormalities		abnormality as seen on ultrasound at 18 weeks GA or more, whose pregnancy ended in abortion	
Grover 2017	India (2004–2014)	One tertiary referral centre in Punjab	Hospital records	LMIC	Quantitative	NA	Diagnostic accuracy	100 perinatal autopsies	Stillbirth, NND, TOPFA	Comparison and correlation of antenatal ultrasound findings with perinatal autopsy	None stated	Fetuses referred to the study hospital for autopsy between years 2004 to 2014 in which a congenital anomaly was suspected on ultrasound or cause of death was unknown and parents consented for autopsy	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

Gupta 2022	None specified	Literature	MRI, Literature	Not stated	Qualitative	Literature review	NA	NA	Stillbirth	Review of normal postmortem MRI findings and factors which can influence interpretation of results	NA	Factors which can influence postmortem MRI interpretation	Checklist for text and opinion papers
Guruprasad 2021	India, Pakistan (Jul 2018–Feb 2020)	5 hospitals across 2 geographic regions in India and Pakistan	Secondary data from another study	LMIC	Quantitative	NA	Cross-sectional	453 fetal deaths, 352 NND	NND, Stillbirth	Usefulness of lung tissue and histological findings using MITS as part of a cause of death analysis for stillborn and preterm neonatal deaths	Where parents did not consent for MITS	Fetal deaths of all GAs greater or equal to 20 weeks and a postnatal age of less than or equal to 28 days	Checklist for studies reporting prevalence data
Hailu 2020	Ethiopia (Jul 2016–May 2018)	5 hospitals across 3 geographic regions	Hospital database	LIC	Quantitative	NA	Diagnostic usefulness	105	Stillbirth, NND	Validity of MITS compared to CDA	Any delivery which was a result of an induced abortion or for which the	Preterm infants admitted to any one of the study hospitals with a gestationa	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

											gestational age could not be reliably determined using study criteria was excluded	l age of less than 37 completed weeks and a postnatal age of <7 days	
Halim 2018	Bangladesh (2011–2012)	4 districts (Jamalpur, Moulvibazar, Narail, and Thakurgaon)	Verbal autopsy	LMIC	Quantitative	NA	Cross-sectional study	1327	Stillbirth (gestation age more than 28 weeks)	Causes and factors associated with stillbirth	Not mentioned	Stillbirths where verbal autopsies were performed	Checklist for analytical cross-sectional studies
Henderson 2017	UK (2013)	National	Postal survey	HIC	Mixed-methods	Thematic analysis	Cross-sectional descriptive study	477	Stillbirth	Experience of parents in relation to postmortem following stillbirth	None specified	Women who experienced a stillbirth in 2013	Checklist for qualitative research and Checklist for studies reporting prevalence data
Hutchinson 2019	UK (Jun 2011–Oct 2016)	1 tertiary referral centre	Medical database	HIC	Quantitative	NA	Case series	103	Stillbirth, NND, TOPFA	Minimally Invasive Autopsy with Laparoscopically assisted sampling in cases of	NA	Cases of fetal, neonatal or paediatric death that underwent Minimally	Checklist for case series studies

										fetal, neonatal and paediatric death		Invasive Autopsy with Laparoscopically assisted sampling	
Hyde 2020	UK (2012–2017)	Hospital (Sheffield Children's Hospital)	Mortuary electronic database	HIC	Quantitative	NA	Case series	105	Miscarriages (n=31), Stillbirth (n=48), Intrapartum deaths (n=1), Early NND (n=9), Late NND (n=2), TOPFA (n=14)	Minimally invasive postmortem as a viable alternative to traditional autopsy, when it is refused.	None mentioned	Families who suffered an intrauterine fetal death, TOP, or neonatal death up to 27 days of postnatal age and who sequentially refused a formal or limited traditional hospital postmortem	Checklist for case series studies
Kang 2017	UK (Oct 2012–Jul 2015)	One University hospital	Hospital database	HIC	Quantitative	NA	Diagnostic accuracy; Accuracy analysis	135	Miscarriage, Stillbirth, TOPFA	To compare diagnostic accuracy of fetal postmortem whole-	None mentioned	Parents suffering a fetal loss related to termination, stillbirth,	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

										body MRI at 3-T vs.1.5-T.		or miscarriage	
Kang 2020	Multiple	International literature	Published literature	NA	Qualitative	Critical review	NA	NA	Miscarriage, Stillbirth, TOPFA	Overview of possible fetal postmortem imaging techniques and recommendations	NA	Studies concerning the diagnostic accuracy of various postmortem procedures	Checklist for qualitative research
Lavezzi 2019	Italy (dates not reported)	Milan University, Italy	Guidelines developed by Lino Rossi-Research Center for the Study and Prevention of the Sudden Perinatal Death and SIDS; data collected as part of other publications by the group	HIC	Qualitative	Narrative paper	NA	NA	Stillbirth	Investigative post-mortem guidelines for cases of unexplained fetal deaths	None stated	NA	Checklist for text and opinion papers

Leduc 2020	Canada (Jun 2006–Sep 2018)	International, including Australia, Canada, United States	Previously published guidelines	HIC	not specified	Existing guideline/ Literature review	NA	not specified	Stillbirth	Guidelines for collecting family history, maternal history, review of maternal obstetric history, current pregnancy history, specific fetal conditions and placental or cord complications	Not specified	not specified	Checklist for text and opinion papers
Lewis 2017	UK (Dec 2015, Aug 2016)	International literature	Published literature	HIC	Qualitative	Systematic review	NA	34 papers	Stillbirth, NND, TOPFA, Child death	Factors affecting uptake of prenatal/ perinatal/ paediatric postmortem examination	(a) Included adult PM examination; focus on verbal, social or psychological PM; bereavement studies; (b) Non-English papers; (c)	Studies included: (a) Bereaved parents with experience of termination of pregnancy for fetal abnormality, stillbirth,	Checklist for systematic reviews and research syntheses

					Editorials, letters, abstracts or commentaries, non-research articles or case reports.	neonatal or childhood death (<16 years), or health professionals or general public; (b)where a diagnosis was known as well as where there was no confirmed diagnosis; (c) Factors affecting uptake or decline of perinatal/ paediatric PM examination; (d)Qualitative, quantitative or mixed methods; in English and peer-reviewed.

Lewis 2018	UK (Apr 2016–Jul 2017)	11 hospitals nationally	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	29 (25 health professionals, 4 coroners)	Stillbirth, NND, child death	Health professionals' and coroners' views on less invasive autopsy	None mentioned	Health professionals involved in discussions with parents about autopsy or those who conduct or interpret autopsy results, and coroners	Checklist for qualitative research
Lewis 2018 (2)	UK (Apr 2016–May 2017)	London, the Midlands, Leicester	Interviews and focus groups	HIC	Qualitative	Thematic analysis	NA	Interviews (n=19, 16 religious and faith-based authorities, 3 bereaved parents), focus groups (n=76, 60 Muslim participants, 16 Jewish participants)	Stillbirth, TOPFA, NND, child death	Religious permissibility and potential uptake of less invasive perinatal and paediatric autopsy in Muslim and Jewish communities	None specified	Religious leaders/ faith-based advocates, bereaved parents, members of Muslim and Jewish communities	Checklist for qualitative research

Lewis 2019	UK (2016–2017)	National	Cross-sectional survey, interviews, focus groups	HIC	Qualitative	Thematic analysis	NA	439 free-text responses, 20 parent interviews, 25 HCPs	Miscarriage, Stillbirth, NND, TOPFA, infant death	Parental decision making about postmortem	None specified	Bereaved parents-including pregnancy loss, neonatal or infant death, HCPs from a range of clinical backgrounds involved in discussing or conducting postmortem examinations with parents	Checklist for qualitative research
Lou 2020	Canada (Jan 2005–Apr 2017)	Hospital	Hospital autopsy files	HIC	Quantitative	NA	Non-experimental cross-sectional	123	Stillbirth (94 intrauterine fetal deaths, 29 intrapartum deaths)	Utility of different autopsy procedures in determining the cause of death in late gestation unexpected fetal deaths	multiple gestation, known severe maternal or fetal disease, or ultrasonographically identified major fetal malformations or survival	Unrestricted autopsies of singleton fetal deaths 34 weeks or greater	Checklist for analytical cross-sectional studies

											for more than 6 hours after birth		
Madhi 2019	South Africa (July 2015-Aug 2016)	Secondary /tertiary hospital in Soweto	Hospital records and admissions	LMIC	Quantitative	NA	Diagnostic accuracy	129	Stillbirth (n=129)	Utility of MITS, placental examination and clinical history to determine the cause of stillbirth	Not specified	Antepartum or intrapartum stillbirths (weighing ≥1000 g)	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Malusi 2019	South Africa (Jan 2011-Dec 2012)	1 tertiary referral hospital in Western Cape	Placental histology reports, lab database	UMIC	Quantitative	NA	Non-comparative study	822 (n=501 NND, n=321 stillbirths)	Stillbirth, NND	Value of placental histopathology in understanding adverse perinatal outcomes	Placentas from multiple pregnancies, of ≤23 weeks' gestation, or those submitted from hospitals or clinics other than the study institution	All singleton placentas of ≥24 weeks' gestation submitted to the Division of Anatomical Pathology at Tygerberg Hospital from deliveries at this institution between 1 Jan 2011 and 31 Dec 2012.	Checklist for case series studies

Marsden 2023	Australia (2013–2018)	National	Secondary data from Stillbirth Causes Study	HIC	Quantitative	NA	Prospective cohort/ Validation study	34	Stillbirth	Validation of a new tool (Stillbirth Investigation Utility Tool) to identify the clinical utility of stillbirth investigations	TOPFA	Stillbirths at ≥20 weeks gestation and/or ≥400 g birthweight	Checklist for cohort studies
Martinez-Portilla 2019	Multiple (2017–2018)	International	Literature (5 databases)	NA	Quantitative	NA	Meta-analysis	7 studies involving 903 stillbirths	Stillbirth	Added value of CMA over conventional karyotyping to assess the genetic causes in stillbirth	None stated	Case series published in English or Spanish of fetal loss ≥20 weeks of gestation, with normal or suspected normal karyotype, undergoing CMA and with at least five subjects analysed	Checklist for systematic reviews and research syntheses
Matsika 2019	Australia (2009–2018)	One study institute	Tissue samples obtained at autopsy	HIC	Quantitative	NA	Cross-sectional	176 fetuses, 44 neonates	Stillbirth, NND	Comparison of DNA quality from	NA	Fetuses (gestational ages 17–40	Checklist for analytical cross-

										various fetal organs and the placenta to determine the best source of DNA material for molecular testing in the perinatal autopsy setting of fetuses and neonates		weeks) and neonates (age range 0–28 days) at the study institution where tissue samples were extracted at autopsy	sectional studies
McPherson 2017	USA (1983-2017)	Wisconsin Stillbirth Service program (WiSSP, community-based program)	WiSSP program database	HIC	Quantitative	NA	Retrospective cohort study	3137	Stillbirth, NND	Alternatives to autopsy to identify cause of perinatal deaths	None mentioned	All cases of second trimester miscarriages, stillbirths and early NND	Checklist for cohort studies
Menendez 2020	Mozambique (2013–2015)	Tertiary level hospital	Hospital database	LIC	Quantitative	NA	Diagnostic accuracy of Verbal autopsy	316	Stillbirth (n=18), NND (n=41)	Validation of verbal autopsy model against CDA	Death of traumatic origin	Where a CDA was requested by the clinician and consent provided	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

												by the relatives. Only 2 CDA cases per day were included, with death reported before and closest to 8am	
Neşe & Bülbül 2018	Turkey (2000–2015)	Department of Pathology, Manisa Celal Bayar University Medical Faculty	Hospital records	UMIC	Quantitative	NA	Non-comparative study	486	Stillbirth, NND, TOPFA	Usefulness of autopsy in determining the cause of perinatal deaths	None mentioned	All perinatal autopsy cases in the study institution between 2000 and 2015, ranging in age from 15 weeks to 1-month after birth	Checklist for case series studies
Odendaal 2022	South Africa (Aug 2007-Jan 2015)	Tygerberg Academic Hospital, Cape Town	Secondary data from the Safe Passage Study	UMIC	Quantitative	NA	Diagnostic value	47	Stillbirth	Value of autopsy after placental histopatho	Stillbirths before 22 weeks, TOP, twin	Singleton fetal demise delivered at 22	Checklist for analytical cross-

										logy to identify a cause for stillbirth	pregnancies	weeks gestation or later, where clinical information, placental histology and autopsy results were available	sectional studies
Olaya-C 2018	Colombia (2013-2014)	San Ignacio University Hospital (HUSI—Hospital Universitario San Ignacio) in Bogota	Clinical records and pathology reports	UMIC	Quantitative	NA	Case series	412	NND	Umbilical cord features (insertion, vessels, entanglements, coiling, and knots) and their associations with clinical characteristics and neonatal prognosis.	Twin pregnancies	Singleton newborn placentas	Checklist for case series studies
Ozdemir 2021	Turkey (2001–2017)	Department of Obstetrics and Gynecology, Division	Hospital database	UMIC	Quantitative	NA	Retrospective descriptive	190	TOPFA	Comparison of prenatal ultrasound (USG) and postmorte	NA	Fetuses with USG-confirmed fetal CNS abnormalities of	Checklist for cohort studies

		of Maternal-Fetal Medicine, Istanbul University-Cerrahpasa, Cerrahpasa Medical Faculty								m examination findings of central nervous system (CNS) abnormalities in fetuses following termination of pregnancy		terminated pregnancies at the study institution between January 2001 and January 2017
Ozdemir 2021	Turkey (Jan 2001–Jan 2017)	Tertiary care clinic	Clinic database	UMIC	Quantitative	NA	Retrospective cohort study	82	TOPFA	Concurrence between prenatal ultrasound and fetal autopsy findings in terminations due to urogenital abnormalities	None mentioned	TOPFA before 24 weeks
Pacheco 2017	USA (Oct 2014)	26 teaching and nonteaching hospitals	Survey	HIC	Quantitative	NA	Prospective cross sectional	351 (fetal less than 20 weeks-31, perinatal-208 surveys, paediatric older than	Fetal, perinatal and paediatric deaths	Pathologist time required to complete fetal, perinatal, and	Surveys that appeared to contain aggregated institutional data were	Staff performing fetal, perinatal, and paediatric autopsies

								1 month-112 surveys)		paediatric autopsies	excluded, surveys that lacked the age or gestation of the patient were not included		
Page 2017	USA (2006-2008)	50 hospitals across 5 geographically diverse catchment areas	Secondary analysis of stillbirths enrolled in the Stillbirth Collaborative Research Network study	HIC	Quantitative	NA	Diagnostic utility	512	Stillbirth	Usefulness of different diagnostic tests to identify causes of stillbirth	Deliveries resulting from termination of a live fetus	Stillbirth defined as birth at or after 20 weeks of gestation with Apgar scores of 0 at 1 and 5 minutes and no signs of life on direct observation. Fetal deaths at an estimated gestational age of 18 or 19 weeks based on uncertain dating criteria	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

												were also enrolled. Only stillbirths/ feal deaths with complete fetal autopsy and placental histopatho logy were included in the current study.	
Page 2018	USA (2018)	NA	Literature	HIC	Qualitative	Narrative review	NA	NA	Stillbirth	Most useful tests for evaluation of potential causes of stillbirth	NA	NA	Checklist for text and opinion papers
Page 2020	USA (dates not reported)	NA	Literature	HIC	Qualitative	Review of literature and current practice	NA	NA	Stillbirth	Stillbirth evaluation and follow-up	None mentione d	NA	Checklist for text and opinion papers
Patterson 2019	Multiple (dates not reported)	NA	Literature	LICs and LMICs	Qualitative	Review	NA	NA	Stillbirth	Challenges in classificati on and assignmen t of causes	None mentione d	Stillbirths defined as birth weight of 500g or	Checklist for text and opinion papers

										of stillbirths in LICs and LMICs		GA of 22 weeks	
Pekkola 2020	Finland (2003-2015)	Helsinki University Hospital	Hospital database	HIC	Quantitative	NA	Cross-sectional study	214	Stillbirth (n=214)	Value of postmortem examination protocol and systematic re-evaluation of the cause of stillbirth	Multiple pregnancies, intrapartum stillbirths, stillbirths of unknown GA	Antepartum singleton stillbirths at or more than 22 weeks gestation or with a birth weight of 500g or more	Checklist for analytical cross-sectional studies
Ptacek 2014	Multiple (dates not reported)	International	Literature: 4 databases	HICs, MICs, LICs	Qualitative	Systematic review	NA	41 studies	Stillbirth	Placental pathology to identify cause of stillbirth	Case reports, narrative review articles and studies that failed to define diagnostic sub-groups	All studies that attempted to classify the cause of death for a population of stillbirths and/or perinatal deaths	
Quinlan-Jones 2019	UK (2015–2017)	West Midlands Regional Genetics Laboratory	Prospectively obtained fetal DNA at Autopsy	HIC	Quantitative	NA	Non-experimental cross-sectional	227 fetuses/ neonates	Stillbirth, TOP or neonatal death	Diagnostic yield of Exome sequencing compared to	None	Fetal DNA obtained at the West Midlands Regional	Checklist for analytical cross-sectional studies

										prenatal USS and autopsy findings		Genetics Laboratory	
RCOG 2010	UK (1980–2010)	National	Literature	HIC	Qualitative	Guidelines	NA	NA	Stillbirth	Guidelines for the management of late intrauterine fetal death and stillbirth	Multiple pregnancies with a surviving fetus, stillbirth following late fetocide, late delivery of fetus papyraceous or the management of specific medical conditions associated with increased risk of late IUFD.	Late intrauterine fetal death (IUFD: after 24 completed weeks of pregnancy) of a singleton fetus.	
Reid 2020	UK (Oct 2018–Apr 2019)	Great Ormond Street Hospital for Children	Hospital's radiology information system	HIC	Quantitative	NA	Retrospective cohort	238	Stillbirth	Significance of internal calcifications on perinatal postmortem skeletal	Forensic or coronial cases	All perinatal PMSS performed over a 6-month period (Oct 2018	Checklist for cohort studies

										surveys (PMSS)		to Apr 2019).	
Roberts 2023	USA (no dates reported)	National	Literature, Expert opinions	HIC	Qualitative	Narrative review	NA	NA	Stillbirth, TOPFA, NND	Placental triage criteria for obstetrical and neonatal providers	NA	NA	Checklist for text and opinion papers
Rossi 2017	Multiple (2016)	International	Literature: 4 databases	NA	Qualitative	Systematic review	NA	19 articles	Stillbirth, TOPFA	Correlation between fetal autopsy and ultrasound findings of fetal malformations	Personal communications, case reports and letters to editors, non-English language, data reported in graphs or percentage	Articles that examined the agreement between fetal autopsy and prenatal detection of fetal anomalies by ultrasound -Fetal autopsy performed after TOP or stillbirth, TOP for fetal anomalies, prenatal diagnosis of malformat	Checklist for systematic reviews and research syntheses

												ions, data reported as proportional rates	
Sauvegrain 2019	France (2014)	11 maternity hospitals in the district of Seine-Saint-Denis	Medical records and interviews	HIC	Mixed-methods design	Thematic analysis	Cohort study	151 women for audit data; 54 women participated in interviews	Stillbirth (n=156)	Autopsy acceptance rates and factors associated with declining an autopsy after stillbirth in a disadvantaged district with high migrant population	None mentioned	Women who experienced a stillbirth from 22 weeks of gestation or NND	Checklist for qualitative research Checklist for cohort studies
Sauvegrain 2020	France (2014)	11 maternity hospitals in Seine-Saint-Denis district	Medical records, maternal interviews, reviews of audit's expert panel, written narratives of midwife investigators	HIC	Mixed methods	Thematic analysis	Descriptive statistics	75 women, 3 midwife investigators	Stillbirth, NND	Benefits and challenges of including bereaved women in perinatal audit interviews	None mentioned	Women with stillbirth at or after 22 weeks gestation and NND up to 28th day of life, midwife investigators	Checklist for qualitative research

Scalise 2022	Italy (2014–2017)	"Magna Graecia" University of Catanzaro	Medical records	HIC	Quantitative	NA	Retrospective case series	11	Stillbirth	Contribution of the autopsy and placental examination in identifying the cause of stillbirths	Stillbirth cases where maternal clinical history, clinical data relating to the partner, external fetal examination and placental examination were not available	All cases of stillbirth with childbirth at 23rd week at the "Magna Graecia" University of Catanzaro from 2014 to 2017	Checklist for case series studies
Schirmann 2018	Australia and New Zealand (Dec 2015–Feb 2016)	National	Online survey	HIC	Qualitative	Framework analysis	NA	454	Stillbirth (n=454)	Mothers' decision-making needs for autopsy consent following stillbirth	Male respondents and mothers experiencing a loss earlier than 20 weeks	Mothers residing in Australia or Aotearoa New Zealand who reported a stillbirth after 20 weeks' gestation were included	Checklist for qualitative research

Schoner 2017	Germany (2004-2016)	Perinatal centres and a tertiary hospital in Marburg	Autopsy	HIC	Quantitative	NA	Non-comparative study	68	TOPFA	Fetal pathology of neural tube defects	None mentioned	Termination following diagnosis with NTD on perinatal ultrasound	Checklist for studies reporting prevalence data
Scott 2022 (2)	Australia (dates not reported)	1 metropolitan referral hospital	Hospital records	HIC	Quantitative	NA	Diagnostic utility	20	Stillbirth	Usefulness of simultaneous metagenomic and genomic analyses in identifying causes of congenital anomalies	None stated	Cases of fetal death between 13- and 40-weeks' gestation	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Sexton 2021	Australia (2013-2018)	18 hospitals nationally	Hospital database	HIC	Quantitative	NA	Prospective cohort study	697	Stillbirth (n=697)	Causes of stillbirth	TOPFA	Stillbirths at ≥20 weeks' gestation and/or ≥400 g birthweight	Checklist for cohort studies
Sharma 2018	India (2-year study period. Exact years not reported)	One tertiary care hospital	Ultrasound and autopsy findings	LMIC	Quantitative	NA	Prospective case series	252	TOPFA	Comparison of prenatal diagnosis of fetal anomaly with autopsy findings	None mentioned	TOPFA before 20 weeks gestation	Checklist for case series studies

Sharony 2018	Israel (2012–16)	University affiliated tertiary medical centre	Electronic hospital database and delivery room records	HIC	Quantitative	NA	Retrospective cohort study	181 women	TOPFA	Impact of third trimester genetic counselling on pregnancy management and its correlation with post-termination findings	Women who were lost to follow-up	Women who had genetic counselling at or beyond 28 weeks gestation, had a known pregnancy course and neonatal follow-up data	Checklist for cohort studies
Shelmerdine 2020	UK (June 2007-2013)	Great Ormond Street Hospital	Hospital medical records	HIC	Quantitative	NA	Diagnostic accuracy	81	TOPFA, Stillbirth, NND	Additional yield from autopsy following prenatal ultrasound and postmortem MRI	Cases were excluded where the prenatal imaging findings or autopsy reports were not available for re-review	Sequential cohort of fetuses and children referred to Great Ormond Street Hospital over a 6-year period where parents consented for traditional autopsy and PMRI	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

Shelmerdine 2020 (2)	Multiple (not dated)	International literature	Literature	NA	Qualitative	Critical review	NA	NA	Stillbirth, NND, TOPFA	Review of different imaging techniques and those in development	None mentioned	Imaging techniques currently in practice and those under development. Contribution of MRI biomarkers to diagnosis and image interpretation when autopsy data is unavailable.	Checklist for text and opinion papers
Shelmerdine 2020 (3)	UK (July 2017-Jan 2019)	Hospital	Hospital case presentations	HIC	Quantitative	NA	Prospective non-comparative study	30	TOPFA (n=9), Miscarriage (n=5), Stillbirths (n=16)	Feasibility of an incisionless perinatal needle biopsy procedure for perinatal autopsy	Forensic deaths or cases without parental consent	Parents who consented for a minimally invasive procedure	Checklist for case series studies
Shelmerdine 2021 (2)	UK (2016-2019)	Great Ormond Street Institute of Child Health	Hospital records	HIC	Quantitative	NA	Case series	268	Stillbirth, TOPFA	Postmortem microfocus computed tomography for	None stated	All fetuses referred for microfocus computed tomograp	Checklist for case series studies

										non-invasive autopsies		hy imaging at the study institution	
Shruthi 2018	India (June 2013–June 2015)	All India Institute of Medical Sciences, Delhi	Clinical records	LMIC	Quantitative	NA	Diagnostic accuracy	43	Stillbirth (n=34), TOPFA (n=9)	Comparison of virtual autopsy using postmortem MRI with conventional autopsy and its acceptability to parents	Cases of maternal and obstetric cause of death	Stillbirths and TOPFA at or after 20 weeks of gestation where parents consented to both conventional autopsy and postmortem MRI	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Soltanghoraee 2022	Iran (2012–2019)	Avicenna Research Institute	Medical records	LMIC	Quantitative	NA	Cross-sectional	42	Stillbirth	Most plausible cause of stillbirth by evaluating clinical records and autopsies	NA	Autopsy reports of all stillbirths (defined as the birth of a baby with 22 or more completed weeks of gestation who died before or during labour) at	Checklist for analytical cross-sectional studies

												the study institute from 2012 to 2019	
Sonnemans 2018	The Netherlands (Jan 2000-Jan 2016)	National, International literature	Literature (Medline, Embase)	HIC	Qualitative	Literature review	NA	19 articles (11 fetal-neonatal, 8 paediatric)	Stillbirth, NND	Guidelines for postmortem radiology in fetuses, neonates, and children	Case reports, forensic articles	Studies published in English and Dutch, comparing clinical postmortem radiology (i.e., CR, PMCT, PMMRI, and MIA) to autopsy in foetal, neonatal, and paediatric patients	Checklist for systematic reviews and research syntheses
Soropo-Florea 2017	Romania	Emergency County Hospital case series, international literature for literature review	Literature and hospital records for cases	HIC	Mixed methods	Literature review	Non-comparative study	NA for literature review, 3 for case series	Stillbirth, NND, TOPFA	Correlation between prenatal findings and autopsy results	None mentioned	Literature evaluating the agreement between fetal or neonatal autopsy and perinatal diagnosis of fetal anomalies. Parents	Checklist for systematic reviews and research syntheses and Checklist for case series studies

												who consented for postmortem morphological examinations for case series.	
Tanko 2021	Kazakhstan (Nov 2020-June 2021)	Pathological Bureau of the Akimat, city of Nur-Sultan	Clinical records, MTAS and CDA findings	UMIC	Quantitative	NA	Diagnostic value	24	Stillbirth (n=15), NND (n=9)	Reliability of MITS in identifying cause of perinatal death and comparison with CDA	Traumatic deaths, fire burns, drowning, severely macerated or autolysed bodies	Stillbirths from 22 weeks gestation age, NND and infant deaths up to 22 months where autopsy was requested	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Taweevisit 2019	Thailand (2003–2017)	King Chulalongkorn Memorial Hospital, Bangkok	Medical archives from the Pathology Dept	UMIC	Quantitative	NA	Case series	119 cases	Stillbirth, NND	Congenital heart defects in fetal and paediatric autopsies	fetuses younger than 20 weeks of gestation	Autopsy cases with congenital heart defects	Checklist for case series studies
Taweevisit 2022	Thailand (2001–2020)	Tertiary referral health facility in Bangkok	Retrospective autopsy reports	UMIC	Quantitative	NA	Cross-sectional	330	Stillbirths (126 antepartum, 204 intrapartum)	Classification of stillbirths using ICD classification	Cases lacking the placenta	All autopsy cases of stillbirth delivered at or after	Checklist for analytical cross-sectional studies

												22 weeks gestation	
Taweevisit 2022 (2)	Thailand (Jan 2004–Dec 2018)	Chulalongkorn University Hospital, Bangkok	Retrospective autopsy records	UMIC	Quantitative	NA	Non-experimental cross-sectional	208	Stillbirth (n=173), NND (n=35)	Role of placental pathology in determining the cause of perinatal deaths	Cases of lethal malformations/chromosomal aberrations, cases in which the placenta was not available and cases in which autopsy reports were incomplete or could not be retrieved	Singleton intrauterine deaths after 20 weeks, liveborn infants up to 1 week old for which placenta was available	Checklist for analytical cross-sectional studies
Tijssen 2023	The Netherlands (Jan 2015-Dec 2021)	Department of Radiology and Pathology at the study institution (1 rural university hospital)	Medical database/ records	HIC	Quantitative	NA	Diagnostic accuracy	80	Stillbirth, NND, TOPFA	Diagnostic value of post-mortem MRI versus autopsy regarding non-cardiac thoracic and abdominal abnormalities	PMMRI without subsequent autopsy, gestational age (GA) < 18weeks, and referral cases with PMMRI and/or autopsy	Fetuses at >18 weeks of gestation and preterm and term neonates who lived for <24 h for which PMMRI followed by autopsy	

											performed elsewhere	was conducted	
Tikmani 2021	India and Pakistan (dates not reported)	3 hospitals in South India, 2 public hospitals in Pakistan	Observations using a structured questionnaire	LMIC	Quantitative	NA	Cross-sectional study	1283	Stillbirth (n=219 India; n=470 Pakistan), NND (n=260 India; n=334 Pakistan)	Parental acceptance of MITS to understand the cause of death	None mentioned	Women who delivered a stillborn baby or had a preterm liveborn baby who later died	Checklist for analytical cross-sectional studies
Tsakiridis 2022	Multiple (dates not reported)	NA	International guidelines	NA	Qualitative	Descriptive review	NA	NA	Stillbirth	Synthesis and comparison of recommendations from influential guidelines on stillbirth investigation and management	None mentioned	Guidelines included from ACOG, the RCOG, the Perinatal Society of Australia and New Zealand and the Society of Obstetricians and Gynaecologists of Canada	Checklist for qualitative research
Tuchtan 2018	France (Jan-Dec 2014)	1 referral hospital	Hospital records	HIC	Quantitative	NA	Diagnostic accuracy	75	TOPFA, Stillbirth	Sensitivity and specificity of postmortem ultrasound	Parents' refusal of consent	Fetuses, coming from TOP and intrauterine fetal deaths at	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

										in the diagnosis of major congenital abnormalities of fetuses		the study institution, for which parents consented to undergo both autopsy and postmortem ultrasound	
Tumanova 2019	Russia (dates not reported)	Unclear	MRI and pathomorphological studies of autopsy materials	HIC	Quantitative	NA	Case-control	n=39 cases (20 stillbirths, 19NNDs), n=7 controls	Stillbirth, NND	Potentialities of postmortem MRI studies for the differentiation between stillborn and death of live newborns	None mentioned	Cases included 20 stillborn dead at 22-40 weeks of gestation (group 1) and 19 newborns that passed at the age of 2 h to 36 days (group 2). Control group was formed from 7 live newborns aged 1-7 days.	Checklist for case control studies

Tumanova 2020	Russia (dates not reported)	Unclear	Radiation and pathoanatomical study	HIC	Quantitative	NA	Case-control	36 stillbirths (n=31 those who died antenatally; n=5 those who died intranatally-control group)	Stillbirth	Postmortem MRI for assessing the degree of maceration and determining the duration of intrauterine fetal death	NA	Antenatal and intrapartum stillbirths between 22-40 weeks gestation	Checklist for case control studies
Ulm 2021	Austria (2012–2019)	Medical University Hospital of Vienna, Austria	Hospital database	HIC	Quantitative	NA	Diagnostic accuracy	222	Stillbirth, NND, TOPFA	Feasibility and diagnostic accuracy of 3T postmortem MRI in detection of fetal congenital heart disease compared to autopsy	Missing ultrasound reports, missing whole-body sequences in 3T pmMRI or unavailable autopsy reports	All babies who died between 12- and 41-weeks' gestation who had a prenatal ultrasound evaluation of the heart, 3T pmMRI, and conventional autopsy results available	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

Venkataswamy 2018	India (Jan 2009 –June 2016)	Tertiary Hospital	Autopsy and ultrasound	LMIC	Quantitative	NA	Objective 1 and 2 - Descriptive Objective 3 - Diagnostic accuracy	66	Fetal death during second trimester and TOPFA	Objective 1: To evaluate the reasons for second-trimester fetal autopsies Objective 2: to categorise the congenital malformations into various systems, syndromes, and complexes Objective 3: to compare autopsy findings with prenatal USG examination in cases of congenital malformations.	Fetuses with gestational age <14 weeks and >28 weeks	Objective 1 and 2: Fetuses with gestational age 14–28 weeks; consent for autopsy obtained from either parent. Objective 3: Fetuses with gestational age 14–28 weeks terminated due to prenatally diagnosed anomalies; consent for autopsy obtained from either parent.	Checklist for case series studies and Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

Vinutha 2020	India (dates not reported)	Dept Obstetrics and Gynecology at JSS Medical College and Hospital, Mysuru	Hospital database	LMIC	Quantitative	NA	Cross-sectional	50	Stillbirth	prevalence of congenital central nervous system anomalies among stillborn fetuses, the association between congenital anomalies and maternal factors, and the association between autopsy and ultrasound findings	Fetuses with gestational age less than 22 weeks and autolysed fetuses	Stillborn fetuses at or above 22 weeks and whose parents gave informed consent	Checklist for analytical cross-sectional studies
Wojcieszek 2018	Multiple (2017)	NA	Literature	NA	Qualitative	Systematic review	NA	NA	Stillbirth	Interventions for investigating and identifying the causes of stillbirth	Cross-over trials	RCTs, quasi RCTs and cluster RCTs including parents who had experienced a stillbirth of 20 weeks'	Checklist for systematic reviews and research syntheses

							gestation or greater. Trials assessing test, protocol or guideline for investigating the causes of stillbirth were included.

CDA: complete diagnostic autopsy; CMA: chromosomal microarray; HIC: high-income country; LIC: low-income country; MIA: minimally invasive autopsy; MITS: minimally invasive tissue sampling; MRI: magnetic resonance imaging; NND: neonatal death; RCT: randomised controlled trial; TOP: termination of pregnancy; TOPFA: Termination of Pregnancy due to Fetal Anomaly. **Quality appraisal tools[a]:** JBI Critical Appraisal Checklist for qualitative research; JBI Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies ; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data

Table 5b. Study characteristics: Perinatal autopsy

Study ID	Country (period)	Locality (state/national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Aiyelaagbe 2017	UK (2014–2015)	St Mary's Hospital, Manchester UK	Interviews	HIC	Qualitative	Pilot thematic analysis	NA	58	Stillbirths (antepartum and intrapartum), early neonatal deaths (n=NR)	Parents experience of bereavement care	None	Parents of stillborn babies, or babies that died in the delivery unit.	Checklist for qualitative research
Aladangady 2021	UK (2016-)	NA	Chief Coroner Guidelines	HIC	Qualitative	Commentary	NA	1 guideline	Neonatal death guideline	Review of the recent coroner's guideline	NA	NA	Checklist for text and opinion papers
Auger 2019	Canada (1989–2013)	All infant deaths in Quebec, Canada	Death registration certificates	HIC	Quantitative	NA	Cohort study	8214	NND, Infant deaths	Differences in neonatal autopsy among Francophones and Anglophones in Quebec, and factors that contribute to trends over time	Infants with foreign or Aboriginal home languages, bilingual French-English home languages and infants with unknown language	All Francophone and Anglophone infant deaths before 365 days of life	Checklist for cohort studies

											spoken at home, those missing data on maternal deprivation		
Auger 2018	South Africa (July–Dec 2012)	Tygerberg hospital, Cape Town, SA	Interviews and questionnaires	UMIC	Mixed-methods study	Content analysis	Demographic data (descriptive)	25	Stillbirth, miscarriage, ectopic pregnancy, Infant death	Mothers' attitudes towards obtaining autopsy	Women below 16 years of age	Women >16 years who experienced a stillbirth between 6 and 18 months before the interviews and offered autopsy	
Bezhenar 2021	Russia (not dated)	National	Main federal laws, orders of ministries and departments, orders, methodological letters and recommendations, and	HIC	Qualitative	Critical review	NA	NA	Stillbirth, NND, TOPFA	Legal aspects of perinatal loss	None mentioned	Fetal death starting from 22 weeks pregnancy in childbirth, as well as the death of a newborn in the first 7 days of life	Checklist for qualitative research

			materials on the Internet										
Bhale 2021	India (2017–2019)	1 tertiary institute, Aurangabad	Hospital records	LMIC	Quantitative	NA	Prospective non-comparative case series	33	Stillbirth (≥20 weeks' GA) (n=19) Miscarriage (≤19 weeks' GA) (n=14)	Cause of death determined after fetal autopsy	None	All fetuses dying in utero prior to birth.	Checklist for case series studies
Bond 2018	Australia (2006–2011)	Sydney Hospitals	Postal surveys	HIC	Mixed methods: qualitative and quantitative	Thematic analysis	Cross sectional retrospective study	36	Stillbirth	Experience of care during and after stillbirth	Pregnancy loss prior to 32 weeks GA. Non-English-speaking parents.	Women who experienced stillbirth after 23 weeks and delivered at one of the seven tertiary maternity centres in	Checklist for qualitative research and Checklist for analytical cross-sectional studies

												Sydney NSW.	
Booth 2021	UK (1996–2018)	Hospital/ Great Ormond St Hospital	Hospital paediatric autopsy database	HIC	Quantitative	NA	Retrospective study	3100	NND, Stillbirth, TOPFA	Machine learning to determine prediction of infant autopsy outcome	Not specified	Child deaths ≥2 years	Checklist for studies reporting prevalence data
Bryant 2018	UK (dates not reported)	National, International literature	Literature	HIC	Qualitative	Narrative paper	NA	NA	NND	Natural diseases causing sudden death in infancy and childhood	NA	NA	Checklist for text and opinion papers
Cassidy 2019	USA (1994–2009)	University of California, San Francisco	Medical charts	HIC	Quantitative	NA	Comparative diagnostic accuracy	385	Pregnancy loss or termination for anomalies and other complications	Correlation between ultrasound and autopsy diagnosis	Babies that lived >6 hours, autopsies for reasons other than terminations or pregnancy, partial autopsy only, missing antenatal records,	All autopsies performed at the University of California, San Francisco in cases of intrauterine fetal demise, termination for anomalies	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

											cases from elsewhere, no identified maternal or fetal indication for termination.	or fetuses delivered but not resuscitated.	
Cassidy 2018	Spain (2013–2016)	National	Online self-completion questionnaire	HIC	Qualitative	Phenomenological	NA	796	Pregnancy loss stratified by GA (n=668 stillbirths >=20 weeks GA)	Bereaved parents experience of care quality following intrauterine death	Respondents born outside of the Spanish national territory. Parents reporting neonatal deaths	Women who reported that their baby died within 60 months prior to survey completion.	Checklist for qualitative research
Cherian 2021	India (2012–2016)	Tertiary care hospital	Fetal lung specimens, medical records	LMIC	Quantitative	NA	Non-comparative study	108	Termination of pregnancy (n=108) Rate of pulmonary hypoplasia in fetuses with restrictive and non-restrictive congenital anomalies	Prevalence of pulmonary hypoplasia calculated by lung/body weight ratio and by radial alveolar count	Cases with Incomplete medical records	Terminated fetuses with congenital anomalies, with complete clinical information, received for autopsy in the Department of	Checklist for studies reporting prevalence data

												Pathology of our tertiary care hospital between 2012-2016.	
Cohen 2018	Multiple (not dated)	International literature	Literature	NA	Qualitative	Narrative review	NA	NA	Stillbirth, NND	Aspects of perinatal deaths important from a forensic pathologists' perspective	None mentioned	Estimation of fetal age, elapsed time between IUD and delivery, common causes of perinatal death	Checklist for qualitative research
Cronin 2018	New Zealand (2012–2015)	20 New Zealand District Health Boards	Face to face interviews, and maternity and postmortem records	HIC	Quantitative	NA	Case Series	169	Stillbirth (n=169)	Exploration of factors influencing decision-making about postmortem examination.	Pregnancies with a known congenital abnormality at recruitment.	Women with singleton pregnancies that ended in late stillbirth (>=28 weeks GA) without known congenital abnormality.	Checklist for case series studies

Cullen 2021	Ireland (2019–2020)	National Maternity Hospital	Medical charts (maternal).	HIC	Qualitative	Case series	NA	25	Stillbirths (n=25)	Coroners' directives and cause of death following placental examination by the coroner	Terminations of pregnancy for fetal anomaly	Cases of stillbirth within the 9 months following the amendment to the coroner's act in Ireland.	Checklist for case series studies
Das 2021	India (Sept 2018–April 2019)	Tertiary care hospital in Delhi	Observations and interviews	LMIC	Qualitative	Thematic content analysis	NA	13	Stillbirth (n=1), NND (n=7)	Process of counselling and obtaining consent for MITS	None specified	Parents and family members of deceased children and stillbirths, MITS research staff and healthcare providers	Checklist for qualitative research
DeKeersmaecker 2023	*Belgium/ 2006-2016*	1 tertiary centre	Hospital database	HIC	Quantitative	NA	Diagnostic accuracy	68	TOPFA	Concordance of conventional autopsy (CA) and postmortem magnetic resonance (MR) after termination of	Fetal genetic anomalies and cases without both postmortem MR and CA	All TOPs at the study institution between 2006 and 2016 with prenatally detected CNS involvement and having a postmorte	

										pregnancy (TOP) in fetuses with prenatally detected central nervous system (CNS) anomalies.		m MR and CA as postmortem examinations	
Evans 2020	UK (2013–2017)	National	Medical records	HIC	Quantitative	NA	Non-comparative study	25,316	Stillbirth, NND	Factors associated with the offer of and consent to perinatal PM	Cases of perinatal deaths with missing information on offer of postmortem and socioeconomic deprivation. Terminations of pregnancy	Cases of perinatal deaths of babies born between 2013-2017 with data collected by MBRRACE-UK	Checklist for case series studies
Fallet-Bianco 2018	Multiple (2010, 2011, 2017)	NA	Literature	NA	Qualitative	Systematised review	NA	NA	Fetal loss, stillbirth, NND	Fetal and perinatal autopsy following a prenatal diagnosis of non-chromoso	None stated	Systematic reviews, RCTs, controlled clinical trials, and observational studies.	Checklist for systematic reviews and research

						mal anomaly	Additional publications were identified from the bibliographies of these articles. Grey literature was identified through searching the websites of health technology assessment and health technology assessment-related agencies, clinical practice guideline collections, clinical trial registries, and national	syntheses

												and internatio nal medical specialty societies.	
Fernandes 2019	Mozambiq ue (Novembe r 2013– March 2015)	Quaternar y hospital	Clinical records	LIC	Quantitati ve	NA	Diagnostic accuracy	264	NND (n=41)	Diagnostic assessmen t of minimally invasive autopsy, complete diagnostic autopsy with and without clinical records.	Deaths of traumatic origin	Deaths of all ages (except for neonates) at the Maputo Central Hospital between Nov 2013 and March 2015 with following inclusion criteria: complete diagnostic autopsy requested by the clinician as part of the medical evaluation ; verbal informed consent to perform the autopsy given by	Quality Assess ment for Diagno stic Accura cy Studies (QUAD AS)

												the relatives; no traumatic origin.	
Feroz 2019 (2)	Pakistan (July–August 2018)	National Institute of Child Health (NICH), Karachi, Pakistan	Focus groups and interviews	LMIC	Qualitative	Thematic analysis	NA	45 (40 for focus groups, 5 interviews)	Views and opinions of parents of newborns concerning MITS for stillbirth and neonatal death.	Parents' and religious leaders' perceptions related to MITS	Parents and/or families that experienced a recent neonatal death/still birth or who were in-patients	Parents of newborns who were visiting the OPD and well-baby clinics of NICH hospital for regular growth monitoring, post-natal check-ups and vaccinations were purposively sampled for focus group discussions. Religious leaders, including Sunni Ulemas and Shia Muftis were	Checklist for qualitative research

												purposively sampled for key-informant interviews.	
Fitzgerald 2022	NA	NA	Literature	NA	Qualitative	Literature review	NA	NA	SUDI	Literature review of the risk factors and diagnosis of SUDI	none mentioned	Background, risk factors, diagnosis, bereavement care and future research directions	Checklist for text and opinion papers
Gordon 2021	Australia (2013–2018)	18 hospitals nationally	Purpose-built database for the Stillbirth Causes Study	HIC	Quantitative	NA	Economic evaluation	697	Stillbirth (n = 697)	Healthcare costs of investigations for stillbirths	TOPFA	Stillbirth (20 weeks gestation or 400 g birthweight) from 18 maternity hospitals in Australia	Checklist for economic evaluations
Helps 2020	Ireland (2005–2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	stillbirth, NND	Bereavement care provided to families following perinatal death/pregnancy loss as described in national inquiry reports	None stated	National inquiries into perinatal deaths/pregnancy loss services between 2005-2018.	Checklist for qualitative research

Henderson 2017	UK (2013)	National	Postal survey	HIC	Mixed-methods	Thematic analysis	Cross-sectional descriptive study	477	Stillbirth	Experience of parents in relation to postmortem following stillbirth	None specified	Women who experienced a stillbirth in 2013	Checklist for qualitative research and Checklist for studies reporting prevalence data
Holden 2019	UK	National	National guidelines and legislations	HIC	Qualitative	Narrative review/ Opinion piece	NA	NA	Stillbirth, NND, TOPFA	How perinatal postmortem are performed and interpreted	Not mentioned	Postmortem procedure and interpretation for stillbirth, NND and congenital anomalies	Checklist for text and opinion papers
Human 2017	South Africa (July–Dec 2012)	Tygerberg Hospital, Cape Town, SA	Interviews	UMIC	Qualitative	Content analysis	NA	25	Stillbirth (n=25)	Bereaved mothers' attitudes toward obtaining an autopsy on their stillborn baby	None mentioned	Bereaved women >16 years with a stillbirth between 6 and 18 months	Checklist for qualitative research

Hutain 2019	Sierra Leone (2014–2017)	Five urban slums in Freetown	Interviews	LIC	Mixed methods	Content analysis	Descriptive study	Total 215 deaths in <5yr olds, 79 being neonatal deaths	NND	Cause of death identified via verbal autopsy	Deaths not recorded in the vital events database; exclusions due to logistical considerations - travel time, weather conditions, ability to locate cases, time restrictions, availability of respondents.	Under 5yr old deaths identified by Volunteer Community Health Workers and entered into the vital events database; consent obtained from primary caregiver at the time of death	Checklist for qualitative research
Ibiebele 2017	Australia (July 2000–Dec 2011)	State (Queensland)	Queensland Perinatal Data Collection statewide registry on registered births.	HIC	Quantitative	NA	Cross-sectional study	3842	Stillbirth (n=3,842)	Predictors of autopsy following stillbirth	Stillbirths resulting from terminations of pregnancy for maternal psychosocial reasons	singleton stillbirths of at least 400 g birthweight or 20 weeks gestation	Checklist for analytical cross-sectional studies

Jones 2017	France (2005–2014)	Lower Normandy Regional Fetal-Infant Mortality Observatory	Fetal and placental autopsy, medical records	HIC	Quantitative	NA	Non-comparative	744	Stillbirth (n=744)	Rates of fetal and placental pathological examinations after stillbirth in the lower Normandy area; cause of stillbirth.	Termination of pregnancies	Stillbirths at over 22 weeks and/or fetal weight over 500g occurring in the Lower Normandy region in France between Jan 2005 and Dec 2014.	Checklist for case series studies
Kalanlar 2020	Turkey (NR)	49 hospitals across Ankara, Istanbul, and Izmir	Postal questionnaires	UMIC	Quantitative	NA	Cross-sectional study	29	Perinatal deaths, including stillbirth and neonatal death.	Managers, head physicians, head nurses, midwives, and specialist physicians caring for families following perinatal death	Dialysis, IVF, medical, physical therapy, and rehabilitation centres. Hospitals that were shut down, did not agree to take part, and did not have a maternity service	Purposive sampling to select provinces with the highest number of hospitals.	Checklist for analytical cross-sectional studies

											were filtered out		
Leduc 2020	Canada (June 2006–Sept 2018)	International (including US, Australia, Canada)	Previously published guidelines	HIC	Not specified	Existing guideline/ Literature review	NA	Not specified	Stillbirth	Guidelines for collecting family history, maternal history, review of maternal obstetric history, current pregnancy history, specific fetal conditions and placental or cord complications	Not specified	Not specified	Checklist for text and opinion papers
Lewis 2019	UK (2016–2017)	National	Cross-sectional survey, interviews, focus groups	HIC	Qualitative	Thematic analysis	NA	439 free-text responses, 20 parent interviews, 25 HCPs	Miscarriage, Stillbirth, NND, TOPFA, Infant death	Parental decision making about postmortem	None specified	Bereaved parents-including pregnancy loss, neonatal or infant death, healthcare profession	Checklist for qualitative research

												als from a range of clinical backgrounds involved in discussing or conducting post-mortem examinations with parents	
Lewis 2018	UK (Apr 2016–Jul 2017)	11 hospitals nationally	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	29 (25 healthcare professionals and 4 coroners)	Stillbirth, NND, child death	Healthcare professionals' and coroners' views on less invasive autopsy	None mentioned	Healthcare professionals involved in discussions with parents about autopsy or those who conduct or interpret autopsy results, and coroners	Checklist for qualitative research

Lewis 2018 (2)	UK (Apr 2016–May 2017)	London, the Midlands, Leicester	Interviews and focus groups	HIC	Qualitative	Thematic analysis	NA	Interviews (n=19, 16 religious and faith-based authorities, 3 bereaved parents), focus groups (n=76, 60 Muslim participants, 16 Jewish participants)	Stillbirth, TOPFA, NND, child death	Religious permissibility and potential uptake of less invasive perinatal and paediatric autopsy in Muslim and Jewish communities	None specified	Religious leaders/ faith-based advocates, bereaved parents, members of Muslim and Jewish communities	Checklist for qualitative research
Lewis 2019 (3)	UK (2016-2017)	7 hospitals in England, 4 parent support orgs	Surveys and phone interviews	HIC	Mixed methods	Thematic analysis	Cross-sectional survey	859 survey responses, 20 interviews (18 women)	Stillbirth, NND, TOPFA, miscarriage, infant death	Acceptability and uptake of less invasive autopsy methods by parents	None specified	Bereaved parents who had experienced pregnancy loss or a neonatal or infant death	Checklist for qualitative research and Checklist for studies reporting prevalence data
Lou 2020	Canada (Jan 2005–Apr 2017)	Hospital	Hospital autopsy files	HIC	Quantitative	NA	Nonexperimental cross sectional	123	Stillbirth (94 intrauterine fetal deaths, 29 intrapartum deaths)	Utility of different autopsy procedures in determining the cause of	multiple gestation, known severe maternal or fetal disease, or ultrasonog	Unrestricted autopsies of singleton fetal deaths 34	Checklist for analytical cross-sectional studies

										death in late gestation unexpected fetal deaths	raphically identified major fetal malformations or survival for more than 6 hours after birth	weeks or greater	
Manjee 2023	USA (Jan 2017–Oct 2019)	One study institute	Hospital Pathology database	HIC	Quantitative	NA	Retrospective cohort	122 (n=68 second trimester stillbirths, n=54 third trimester stillbirths)	Stillbirth	To compare autopsy pathology of second trimester and third trimester stillbirth	TOP, cases were excluded if the placenta was not included as part of the autopsy examination	Fetal autopsies performed at the study institute with complete placental examination	
Menendez 2020	Mozambique (2013–2015)	Tertiary level hospital	Hospital database	LIC	Quantitative	NA	Diagnostic accuracy of Verbal autopsy	316	Stillbirth (n=18), NND (n=41)	Validation of verbal autopsy model against complete diagnostic autopsy	Death of traumatic origin	Where a CDA was requested by the clinician and consent provided by the relatives. Only 2 CDA cases per day were included,	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

												with death reported before and closest to 8am	
Metz 2020	Multiple (not dated)	International literature	Review of the literature	NA	Qualitative	Narrative review	NA	NA	Stillbirth	Management, evaluation and strategies for prevention of stillbirth	None mentioned	Risk factors, potential causes and clinical considerations in the management of stillbirth	Checklist for text and opinion papers
Moeremans 2023	Belgium (Jun 2016–Feb 2022)	One institution	Medical database	HIC	Quantitative	NA	Diagnostic accuracy	50 (n=24 IUD, n=26 TOP)	Stillbirth, TOPFA	Value of combined prenatal US and post-mortem fetal MRI in addition to conventional autopsy in assessing non-neurologic fetal malformations	NA	Fetuses that had undergone PMMRI following intrauterine death or TOPFA, who also had prenatal ultrasound and CA done.	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

Morris 2021	Australia (Sep 2019–Oct 2019)	NSW	Online questionnaires	HIC	Quantitative	NA	Descriptive study	234	SUDI	Paediatricians experienced in conducting SUDI assessments in NSW	Survey 2: SUDI cases resulting from non-accidental injury or misadventure leading to external injury (e.g. accidental drowning)	Survey 1: Paediatricians practising in NSW and involved in the Australian Paediatric Surveillance Unit. Survey 2: Paediatricians practising in NSW and involved in the Australian Paediatric Surveillance Unit who have attended an infant with SUDI in the last 5 years.	Checklist for analytical cross-sectional studies
Mudda 2019	India (Jan 2016–Jan 2017)	One hospital in Karnataka	Hospital records	LMIC	Quantitative	NA	Retrospective study	217 fetal autopsy cases	TOPFA, Stillbirth, NND	Pattern and prevalence of congenital malformation	Gestational age <12 weeks and all neonates above 7	Dead fetus and neonates with gestational age 18 to 40 weeks	Checklist for studies reporting prevale

											days of age	of intra uterine life	nce data
Page 2020	USA (not dated)	NA	Literature	HIC	Qualitative	Review of literature and current practice	NA	NA	Stillbirth	Stillbirth evaluation and follow-up	None mentioned	NA	Checklist for text and opinion papers
Pekkola 2020	Finland (2003–2015)	Helsinki University Hospital	Hospital database	HIC	Quantitative	NA	Cross sectional study	214	Stillbirth (n=214)	Value of postmortem examination protocol and systematic re-evaluation of the cause of stillbirth	Multiple pregnancies, intrapartum stillbirths, stillbirths of unknown GA	Antepartum singleton stillbirths at or more than 22 weeks gestation or with a birth weight of 500gms or more	Checklist for analytical cross-sectional studies
Sauvegrain 2019	France (2014)	11 maternity hospitals in the district of Seine-Saint-Denis	Medical records and interviews	HIC	Mixed-methods	Thematic analysis	Cohort study	151 women for audit data; 54 women participated in interviews	Stillbirth (n=156)	Autopsy acceptance rates and factors associated with declining an autopsy after stillbirth in a disadvantaged	None mentioned	Women who experienced a stillbirth from 22 weeks of gestation or NND	Checklist for qualitative research and Checklist for cohort studies

									district with high migrant population			
Quinlan-Jones 2019	UK (2015–2017)	West Midlands Regional Genetics Laboratory	Prospectively obtained fetal DNA at Autopsy	HIC	Quantitative	NA	Non-experimental cross sectional	227 fetuses/ neonates	Stillbirth, TOP or neonatal death	Diagnostic yield of Exome sequencing compared to prenatal USS and autopsy findings	None	Fetal DNA obtained at the West Midlands Regional Genetics Laboratory	Checklist for analytical cross-sectional studies
Siassakos 2018	UK (2013)	Three maternity hospitals	Interviews, focus groups, service provision data	HIC	Qualitative	Thematic analysis	NA	Parents of 16 stillborn babies, 22 maternity staff	Stillbirth	Views of bereaved parents and maternity staff to improve bereavement care for families	Twin pregnancy and loss, intrapartum stillbirth	Parents with a stillborn baby (gestational age more than 23 weeks, 6 days)- singleton stillbirths with the fetal death diagnosed before the onset of labour, maternity staff	Checklist for qualitative research

Skaria 2019	NA	NA	Literature	NA	Qualitative	Literature review	NA	NA	TOPFA and perinatal death because of arthrogryposis multiplex congenita	Aetiology and classification of Arthrogryposis Multiplex Congenita (AMC), diagnosis of AMC through ultrasound and autopsy	NA	NA	Checklist for text and opinion papers
Spierson 2019	UK (May 2011–June 2012)	National (through British Association of Perinatal Medicine)	Online survey	HIC	Quantitative	NA	Cross-sectional study	98	NND	Healthcare professionals' practices and views on neonatal postmortem examination	Those who did not work with neonates and/or did not complete most of the survey	Neonatal healthcare providers in UK	Checklist for analytical cross-sectional studies
Sun 2021	Taiwan (Aug 2016–Jul 2018)	Medical centre in Taoyuan County	Interviews	HIC	Qualitative	Phenomenological	NA	20 couples (40 individuals)	Stillbirth	The meaning that parents attach to the care of the remains of their stillborn	Couples that did not provide consent	1) pregnant women aged ≥20 years; (2) married and whose spouse is also invited; (3) their child	Checklist for qualitative research

										babies in Taiwan		were diagnosed with foetal death and the couple accepted induction of labour for stillbirth; (4) participants must be able to communicate in Mandarin or Taiwanese.
Tijssen 2023	Netherlands (Jan 2015-Dec 2021)	Department of Radiology and Pathology at the study institution (1 rural university hospital)	Medical database/ records	HIC	Quantitative	NA	Diagnostic accuracy	80	Stillbirth, NND, TOPFA	Diagnostic value of post-mortem MRI versus autopsy regarding non-cardiac thoracic and abdominal abnormalities	PMMRI without subsequent autopsy, gestational age (GA) < 18weeks, and referral cases with PMMRI and/or autopsy performed elsewhere	Fetuses at >18 weeks of gestation and preterm and term neonates who lived for <24 h for which PMMRI followed by autopsy was conducted

Wojcik 2018	NA	NA	Literature	NA	Qualitative	Literature review	NA	NA	NND	Investigation and cause of NND and Infant death	NA	NA	Checklist for text and opinion papers
Yilmaz 2017	Turkey (2008–2009)	Council of Forensic Medicine	Autopsy reports and additional morphological analysis of alveoli	UMIC	Quantitative	NA	Diagnostic accuracy	44	Stillbirth, NND	The accuracy of three different methods to determine whether a deceased infant was stillborn or born alive.	Cases with missing data	Stillbirth and NND cases at the Council of Forensic Medicine between 2008 and 2009 with complete data.	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)

CDA: complete diagnostic autopsy; CMA: chromosome microarray; HIC: high-income country; IVF: in vitro fertilisation; LIC: low-income country; MIA: minimally invasive autopsy; MITS: minimally invasive tissue sampling; MRI: magnetic resonance imaging; NA: not applicable; NND: neonatal death; RCT: randomised controlled trial; SUDI: sudden unexpected death in infants; TOP: termination of pregnancy; TOPFA: Termination of Pregnancy due to Fetal Anomaly

Table 6a. Study quality assessment: Stillbirth investigations

Qualitative studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants ?	5. Did the case series have complete inclusion of participants ?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants ?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/ clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Relevance
Aiyelaagbe et al. 2017	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	I
Biswas et al. 2018	No	Yes	No	Yes	No	No	No	Unclear	No	No	Include	P
Cassidy 2018	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Dandona et al. 2017	Unclear	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	Include	P
Das 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Das 2021 (2)	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Das 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Feroz 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P

Feroz 2019 (2)	Unclear	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	No	Include	R
Graham 2020	Unclear	Yes	Yes	Yes	Yes	No	No	NA	NA	Yes	Include	R
Henderson 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Kang 2020	No	Yes	Unclear	Yes	Yes	No	No	NA	NA	Yes	Include	R
Lewis 2019	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Lewis 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Lewis 2018 (2)	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Sauvegrain 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Sauvegrain 2020	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Include	P
Schirmann 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Tsakiridis 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Unclear	NA	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5.Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Avagliano 2022	Yes	Yes	Unclear	Yes	Not applicable	Not applicable	Unclear	Yes	Include	R
Halim 2018	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Include	P
Lou 2020	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	P
Matsika 2019	Unclear	Yes	Yes	Yes	No	Unclear	Yes	Yes	Include	R
Pacheco 2017	Yes	Yes	Unclear	Yes	Not applicable	Not applicable	Unclear	Yes	Include	R
Pekkola 2020	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	P
Quinlan-Jones 2019	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	P
Soltanghoraee 2022	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	Include	R
Taweevisit 2022	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	U
Taweevisit 2022 (2)	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	P
Tikmani 2021	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Include	P
Vinutha 2020	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	Include	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/ clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Relevance
Armes 2017	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Yes	No	Not applicable	Include	R
Cronin 2018	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	No	Yes	Include	R
Cullen 2021	Yes	Yes	Yes	Unclear	Unclear	No	No	Yes	No	Yes	Include	U
Hutchinson 2019	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Hyde 2020	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	No	Yes	Include	P
Malusi 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Neşe & Bülbül 2018	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Include	P
Olaya-C 2018	Unclear	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Include	R
Scalise 2022	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	No	Yes	Include	R

Sharma 2018	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	No	Yes	Include	I
Shelmerdine 2020 (3)	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	Yes	Include	R
Shelmerdine 2021	Yes	Yes	Yes	Unclear	Yes	No	Yes	NA	No	Yes	Include	P
Sorop-Florea 2017	Unclear	Yes	Yes	No	No	Yes	Yes	Yes	No	NA	Include	P
Taweevisit 2019	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Unclear	Yes	Include	U
Venkataswamy 2018	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	NA	Include	R
Shelmerdine 2021 (2)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case-control studies

	1. Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?	2. Were cases and controls matched appropriately?	3. Were the same criteria used for identification of cases and controls?	4. Was exposure measured in a standard, valid and reliable way?	5. Was exposure measured in the same way for cases and controls?	6.Were confounding factors identified?	7. Were strategies to deal with confounding factors stated?	8. Were outcomes assessed in a standard, valid and reliable way for cases and controls?	9. Was the exposure period of interest long enough to be meaningful?	10. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Tumanova 2019	Unclear	Unclear	Yes	Yes	Yes	No	NA	Yes	Yes	Yes	Include	P
Tumanova 2020	NA	Unclear	Yes	Yes	Yes	No	NA	Yes	Yes	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Dandona 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Guruprasad 2021	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	NA	Include	R
Henderson 2017	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	P
Schoner 2017	Yes	Yes	Unclear	No	NA	Yes	Yes	NA	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/ sources logically defended?	Overall appraisal	Relevance
Arthurs 2017	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	R
Leduc 2020	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Gupta 2022	Yes	Unclear	Yes	Yes	Yes	NA	Include	R
Lavezzi 2019	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Metz 2020	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
Page 2018	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Page 2020	Yes	Yes	Yes	Unclear	Yes	NA	Include	I
Patterson 2019	Yes	Yes	Yes	Unclear	Yes	NA	Include	R
RCOG 2010	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Roberts 2023	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Shelmerdine 2020	Yes	Yes	Yes	Unclear	Yes	NA	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic reviews

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4.Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimise errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Lewis 2017	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	No	Yes	Yes	Include	R
Martinez-Portilla 2019	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Include	R
Ptacek 2014	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	No	Yes	Yes	Include	R
Rossi 2017	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	Include	U
Sonnemans 2018	Unclear	Yes	Unclear	Unclear	Yes	No	Yes	Yes	Unclear	Yes	NA	Include	R
Sorop-Florea 2017	Yes	Unclear	Yes	Yes	Unclear	Unclear	Unclear	Unclear	No	Yes	Yes	Include	P
Wojcieszek 2018	Yes	Yes	Yes	Yes	Yes	Yes	NA	NA	NA	NA	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4.Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Byrne 2023	Not applicable	Not applicable	Yes	Not applicable	Not applicable	Not applicable	Yes	Not applicable	Not applicable	Not applicable	Yes	Include	R
Dalton 2023	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	Include	R
Darouich 2020	Not applicable	Not applicable	Yes	No	Not applicable	Yes	Unclear	Yes	Yes	Not applicable	Yes	Include	R
Griffiths 2021	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	NA	Yes	Include	P
Marsden 2023	Not applicable	Not applicable	Yes	Not applicable	Not applicable	Yes	Yes	Not applicable	Yes	Not applicable	Yes	Include	R
McPherson 2017	Yes	Yes	Yes	NA	NA	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Miller 2016	Not applicable	Not applicable	Yes	No	No	Yes	Yes	Yes	Yes	Not applicable	Yes	Include	R
Ozdemir 2021	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	NA	Yes	Include	P
Sauvegrain 2019	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	NA	Yes	Include	P
Reid 2020	Yes	Yes	Yes	No	NA	Yes	Yes	NA	NA	NA	Yes	Include	U

Sexton 2021	Unclear	Unclear	Unclear	No	No	Yes	Yes	Yes	Yes	NA	Yes	Include	U
Sharony 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	No	No	Yes	Include	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Diagnostic accuracy studies

The QUADAS tool was used to assess the quality of the following studies.

- Odendaal et al. 2022
- Ganesan et al. 2023
- Ozdemir et al. 2021
- De Keersmaecker et al. 2023
- Tijssen et al. 2023
- Goergen et al. 2019
- Moeremans et al. 2023

Please contact the Stillbirth CRE for more information on quality assessment for these studies (e: stillbirthcre@mater.uq.edu.au).

Table 6b. Study quality assessment: Perinatal autopsy

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9.Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data?	Overall appraisal	Relevance
Aiyelaagbe 2017	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Auger 2018	Unclear	Yes	Yes	No	Unclear	No	No	Unclear	Yes	Yes	Include	P
Bezhenar 2021	Unclear	Yes	Yes	Unclear	Unclear	No	No	Not applicable	Yes	Yes	Include	U
Bond 2018	Yes	Unclear	Yes	Yes	Unclear	No	No	Unclear	Yes	Yes	Include	P
Cassidy 2018	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Cohen 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Not applicable	Not applicable	Yes	Include	I

Das 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Feroz 2019 (2)	Unclear	Unclear	Yes	Yes	Yes	No	No	Yes	Yes	No	Include	R
Helps 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Henderson 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	R
Hutain 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	U
Lewis 2019	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Lewis 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	U
Lewis 2018 (2)	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Include	R
Lewis 2019 (3)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Sauvegrain 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Include	P
Siassakos 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Include	R
Sun 2021	Yes	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Bond 2018	Yes	Unclear	Yes	Yes	No	No	Yes	Yes	Include	P
Ibiebele 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Include	P
Kalanlar 2020	No	No	No	No	No	No	No	Unclear	Include	I
Lou 2020	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	R
Morris 2021	Yes	Yes	NA	Yes	No	NA	Yes	NA	Include	R
Pekkola 2020	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	R
Quinlan-Jones 2019	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Include	P
Spierson 2019	Yes	Yes	Unclear	Yes	No	No	Yes	No	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Overall appraisal	Relevance
Booth 2021	Yes	Yes	Unclear	No	Yes	Yes	Yes	Yes	Not Applicable	Include	P
Cherian 2021	No	Yes	Unsure	No	No	Yes	yes	No	NA	Include	P
Henderson 2017	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Include	R
Lewis 2019 (3)	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Include	R
Mudda 2019	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/ sources logically defended?	Overall appraisal	Relevance
Aladangady 2021	Yes	Yes	Yes	No	Yes	Yes	Include	R
Bryant 2018	Yes	Unclear	Yes	Unclear	Yes	Not applicable	Include	R
Facchinette 2023	Yes	Yes	Yes	Unclear	Yes	Unclear	Include	R
Fitzgerald 2022	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	R
Holden 2019	Yes	Unclear	Yes	Yes	Yes	Not applicable	Include	I
Leduc 2020	Yes	Yes	Yes	Yes	Yes	Yes	Include	R
Metz 2020	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	P
Page 2020	Yes	Yes	Yes	Unclear	Yes	Not applicable	Include	I
Wojcik 2018	Yes	Yes	Yes	Yes	Yes	Not applicable	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimise errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Overall appraisal	Relevance
Fallet-Bianco 2018	Yes	Yes	Unclear	Yes	Yes	Unclear	Unclear	NA	NA	Yes	NA	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Overall appraisal	Relevance
Auger 2019	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Include	U
Sauvegrain 2019	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	NA	Yes	Include	P
Manjee 2023	Not applicable	Not applicable	Yes	Not applicable	Not applicable	Yes	Yes	Yes	Yes	Not applicable	Yes	Include	

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Overall appraisal	Comments (including reason for exclusion)
Bhale 2021	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	No	Yes	Include	R
Cronin 2018	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	No	Yes	Include	R
Cullen 2021	Yes	Yes	Yes	Unclear	Unclear	No	No	Yes	No	Yes	Include	R
Evans 2020	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Yes	Include	R
Jones 2017	Yes	Yes	Yes	Yes	Yes	No	Yes	Unclear	No	Yes	Include	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Economic evaluation

	1. Is there a well-defined question?	2. Is there comprehensive description of alternatives?	3. Are all important and relevant costs and outcomes for each alternative identified?	4. Has clinical effectiveness been established?	5. Are costs and outcomes measured accurately?	6. Are costs and outcomes valued credibly?	7. Are costs and outcomes adjusted for differential timing?	8. Is there an incremental analysis of costs and consequences?	9. Were sensitivity analyses conducted to investigate uncertainty in estimates of cost or consequences?	10. Do study results include all issues of concern to users?	11.Are the results generalizable to the setting of interest in the review?	Overall appraisal	Comments (including reason for exclusion)
Gordon 2021	Yes	Yes	Yes	Unclear	Unclear	Yes	Unclear	No	Unclear	No	Yes	Include	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Diagnostic accuracy studies

The QUADAS tool was used to assess the quality of the following studies.

- De Keersmaecker et al. 2023
- Tjissen et al. 2023
- Moeremans et al. 2023

Please contact the Stillbirth CRE for more information on quality assessment for these studies (e: stillbirthcre@mater.uq.edu.au).

Table 7. Detailed GRADE-CERQual assessment

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
6.5	Explain to parents that the placenta can be returned to them following examination by the pathologist. The pathology service should be notified of the parents' wishes when the placental examination is requested. Advice should be given to families/whānau about any relevant health and safety precautions when handling the placenta.						**Consensus based recommendation**
6.7	Provide parents with a clear timeline for receiving results of investigations and reports prior to discharge. The timeline should be made in conjunction with the multidisciplinary care team, including pathologists.	Five studies are included, four primary qualitative studies, and one mixed methods study.	Moderate concerns of methodological limitation are noted. Four of the included studies are deemed to have moderate concerns of methodological limitation, and one included study is deemed to have minor concerns of methodological limitation.	No concerns of relevance are noted. All included studies are deemed to be directly relevant to perinatal mortality investigations.	Minor concerns of coherence are noted.	Minor concerns of data adequacy are noted. All included studies source their evidence from high income country populations. Outcomes of interest include stillbirth (n=952) and composite perinatal mortality outcomes (n=25). The	**Moderate confidence** *No concerns of relevance, minor concerns of coherence and data adequacy. Moderate concerns of methodological limitation.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						view of mothers (two studies), parents (3 studies, n=477) and healthcare providers (two studies) are included from the evidence. The viewpoint of coroners and Aboriginal and Torres Strait Islander parents are also included within the evidence.	
6.8	The recommended core set of investigations, with further investigations based on the clinical circumstances, should be considered routine practice for all perinatal deaths. • In some circumstances it may not be appropriate to undertake all core investigations (e.g. where cause has been unequivocally determined antenatally). • Ideally, an individualised approach should be developed through multidisciplinary team discussion including the lead obstetrician, neonatologist/paediatrician, pathologist, radiologist, and	Nine studies are included: two qualitative primary research studies, four reviews, one cohort study, one guideline, and one assessment of a diagnostic tool.	Minor concerns of methodological limitation are noted through critical appraisal. Eight of the included studies are noted to have no or minor concerns of methodological limitation, and one qualitative study is noted to have moderate concerns due to tack of a statement of researcher's cultural position and fails to account for this through analysis. The	Minor concerns of relevance are noted. Eight of the included studies are deemed to be relevant to perinatal mortality investigations. One included literature review is deemed to be indirectly relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Eight of the included studies source their data from cohorts within high-income country populations. One study fails to report the data source.	**Moderate confidence** *No concerns of coherence, minor concerns of relevance and methodological limitation. Moderate concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
	geneticist, considering the clinical circumstances and parents' wishes. Refer to *Appendix 6A Stillbirth investigations flowchart* and *Appendix 6B: Neonatal death investigations flowchart*		outcomes are also not reported in a clear format.			Outcomes of interest include stillbirth (n=905, 7 studies), termination of pregnancy for fetal anomaly (one study) and composite perinatal mortality outcomes (n=11). The view of parents are in evidence from one study. Two studies included viewpoints of healthcare professionals. Moderate concerns of data adequacy are noted due to the small, combined sample size of cohorts, and	

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						the lack of parent and healthcare professional view.	
6.9	A comprehensive clinical summary should be completed for all perinatal deaths to inform the investigations required. This summary should be completed as soon as possible after the death and include the following: • medical, social, family, and pregnancy history • antenatal ultrasound results • antenatal testing • initial findings of maternal, infant, and placental examination • postmortem imaging using the tools provided in this guideline • parent's summary of the events surrounding the death.	Sixteen studies are included: six reviews, two cross-sectional studies, three cohort studies, one case series, one guideline, one primary qualitative study and two assessments of diagnostic tools.	Minor concerns of methodological limitation are noted. Thirteen of the included studies have no or minor concerns of methodological limitation through critical appraisal. Two studies are noted to have moderate concerns of methodological limitation.	Minor concerns of relevance are noted. Thirteen of the included studies are deemed to be relevant to perinatal mortality investigations. Two studies are deemed as partially relevant to perinatal mortality investigations and one study is of unclear relevance.	No concerns of coherence are noted.	Minor concerns of data adequacy are noted. Twelve of the included studies source their data from high income country populations, two from lower middle income country populations, and two studies did not report the source of the included data. Outcomes of interest include stillbirth (n=955), termination of pregnancy for	**High confidence** *No concerns of coherence, minor concerns of methodological limitation, relevance and data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						fetal anomaly (1 study), and composite perinatal mortality outcomes (n=3,137). The views of healthcare professionals are included in two studies and those of parents in one study. Minor concerns of data adequacy are noted.	
6.10	A formal antepartum fetal ultrasound for fetal abnormalities, biometry and amniotic fluid index should be performed by an appropriately trained healthcare professional and as soon as possible following diagnosis of fetal death.	NA	NA	NA	NA	NA	**Consensus based recommendation**
6.11	A Kleihauer–Betke test or flow cytometry to detect feto-maternal haemorrhage should be performed for stillbirths preferably prior to birth.	Nine studies are included. Five reviews including one systematic review, one cohort study, one primary qualitative study, one guideline and one assessment of a diagnostic tool.	Minor concerns of methodological limitation are demonstrated through critical appraisal. Eight of the included studies are deemed to have no or minor concerns of	Minor concerns of relevance are noted. Seven of the included studies are deemed to have directly relevant to perinatal morality investigations. Two of the	No concerns of coherence noted.	Minor concerns of data adequacy are noted. Seven of the included studies report	**High confidence** *No concerns of coherence, minor concerns of data adequacy, methodological*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
			methodological limitation. One included primary qualitative study is noted to have moderate concerns of methodological limitation.	included studies are deemed to be partially relevant.		sourcing their data from high-income country populations, and two included studies do not report their source. Outcomes of interest include stillbirths (n-512, 7 studies), terminations of pregnancy for fetal anomaly (1 study), and composite perinatal mortality outcomes (n=3,137). The views of HCPs are included in two studies and that of parents in one study. Minor concerns of	*limitation and relevance.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						data adequacy are noted.	
6.12	External examination of the baby should be undertaken by an appropriately trained clinician using Appendix 6E: Examination of baby checklist.	Six studies are included, three reviews, one case series, one guideline and one primary qualitative study.	Moderate concerns of methodological limitation are noted. Five included studies are deemed to have no or minor concerns of methodological limitation, and one included primary qualitative study is noted to have moderate concerns of methodological limitation.	No concerns of relevance are noted. All included studies are deemed relevant to perinatal mortality investigations.	No concerns of coherence are demonstrated.	Major concerns of data adequacy are noted. Five of the included studies report sourcing data from high-income country populations. One study does not report the data source. Outcomes of interest include stillbirth (n=11, 5 studies), and termination for fetal anomaly (one study). The view of HCPs and parents is included in evidence of	**Low confidence** *No concerns of relevance and coherence. Moderate concerns of methodological limitation and major concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						one included study. Major concerns of data adequacy are noted due to lack of an accurate sample size on which the evidence is based, and lack of viewpoints contained within the data.	
6.13	Clinical photographs, following consent from parents, should be taken for later review, particularly for births that occur in non-tertiary hospital settings. • These photos are additional to the bereavement photographs and should not be given to the parents. • They should be clearly labelled and filed in the medical record.	Three studies are included. One review of guidelines, one prevalence study and one primary qualitative study.	Moderate concerns of methodological limitation are noted. Two studies demonstrated no or minor concerns of methodological limitation through critical appraisal, and the other demonstrated moderate concerns.	Minor concerns of relevance are noted. Two included studies are deemed to be directly relevant to perinatal mortality investigations, and one study indirectly relevant.	No concerns of coherence are noted.	Major concerns of data adequacy are noted. Two studies report sourcing their cohorts from high-income country populations, and one does not report the source. Outcomes of interest	**Low confidence** *No concerns of coherence, minor concerns of relevance, moderate concerns of methodological limitation and major concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						include stillbirth (1 study) and TOPFA (n=68). No viewpoints are contained within the literature. Major concerns of data adequacy are noted.	
6.14	Examination of the placenta and cord at birth should be undertaken by the attending clinician at the time of birth following the *Indications for placental examination (Appendix 6N*); *Placental examination for healthcare professionals (Appendix 6D)*. • If offered locally, sample placenta for cytogenetic testing, including request to extract and store DNA for subsequent investigations. *Appendix 6D: Placental examination for healthcare professionals.*	Four studies are included. Three reviews, and one primary qualitative study.	Minor concerns of methodological limitation are noted. Three of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal, and one study is noted to have moderate concerns.	Minor concerns of relevance are noted, three studies are directly relevant to perinatal mortality investigations, and one study is deemed to be partially relevant.	No concerns of coherence are noted.	Major concerns of data adequacy are noted. Three of the included studies source their data from high income country populations, and one doesn't report the source. Outcomes of interest include stillbirth (two studies),	**Low confidence** *No concerns of coherence and minor concerns of relevance and methodological limitation. Major concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						termination of pregnancy for fetal anomaly (one study) and combined perinatal mortality outcomes (one study). The view of HCPs and parents is included in evidence of one included study. Major concerns of data adequacy are noted due to lack of accurate sample size reporting, and lack of viewpoints.	
6.15	Full body X-ray imaging of the baby (also known as a 'babygram') should be included in the routine investigations for perinatal deaths.	Eight studies are included. Three reviews (one systematic review), two primary qualitative research studies, one cohort study, one prevalence study and a case series study.	Moderate concerns of methodological limitation are noted through critical appraisal. Four included studies are noted to have no or minor	Minor concerns of relevance are noted. Six of the included studies are deemed to be directly relevant to perinatal mortality investigations. Two included	Minor concerns of coherence are noted.	Moderate concerns of data adequacy are noted through review.	Low confidence *Minor concerns of relevance and coherence. Moderate concerns of methodological*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
			concerns of methodological limitation. Four included studies are noted to have moderate concerns of methodological limitation, these include two qualitative studies, one case series, and one systematic review.	studies are deemed to be of partial relevance.		Five of the included studies source data from high income country populations. The remaining three studies do not disclose the source of their data. Outcomes of interest include stillbirth (n=506), termination of pregnancy for fetal anomaly (n=68) and composite perinatal mortality outcomes. No viewpoints are contained within the literature. Moderate concerns of data adequacy	*limitation and data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						are noted due to small, combined sample of outcomes, and lack of viewpoints.	
6.16	Histopathology of the placenta and umbilical cord should be undertaken for all perinatal deaths by a perinatal pathologist. Microbiological culture may be required as directed by pathologist.	25 studies are included. Three primary qualitative studies, seven reviews, four case series studies, three cross sectional studies, four cohort studies, one case-control study, one guideline and two assessments of diagnostic tools.	Minor concerns of methodological limitation are noted. Nineteen of the included studies are deemed to have no or minor concerns of methodological limitation. Six of the included studies are deemed to have moderate concerns of methodological limitation through critical appraisal. These include three case series, two primary qualitative studies and one cohort study.	No concerns of relevance are noted on review. All included studies are deemed to be relevant to perinatal mortality investigations.	No concerns of coherence are noted.	Minor concerns of data adequacy are noted. Eighteen of the included studies source their study cohort from high income country populations. Six source their population from lower and upper middle-income countries, and one study does not report the source of its evidence. Outcomes of interest include stillbirth	**High confidence.** *No concerns of coherence or relevance. Minor concerns of methodological limitation and data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						(n=2,252), termination of pregnancy for fetal anomaly (1 study) and composite perinatal mortality outcomes (n=433). The viewpoints of parents are included through evidence of 2 included studies and those of healthcare professionals through three studies. Minor concerns of data adequacy are noted due to the medium combined sample size, and lack of viewpoint of parents and community.	

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
6.17	Following a stillbirth or birth of a high-risk newborn, the placenta, membranes, and cord should be kept refrigerated and sent fresh and unfixed for macroscopic and histological examination by a perinatal pathologist as soon as possible (ideally within 48 hours of the birth).	Twelve studies are included. Two case-series studies, one cohort study, two cross sectional studies, one primary qualitative research study, three reviews, one guideline and two assessments of diagnostic tools.	Minor concerns of methodological limitation are noted. Nine of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. Three included studies are deemed to have moderate concerns of methodological limitation through critical appraisal. These include one primary qualitative study, one cross sectional study, and one case series study	Moderate concerns of relevance are noted. Seven of the included studies are deemed to be directly relevant to perinatal mortality investigations. Two included studies are deemed to be partially relevant, and three studies are deemed to be of unclear relevance to perinatal investigations.	Minor concerns of coherence are noted.	Minor concerns of data adequacy are noted. Nine of the included studies report that the source of their study cohort are high-income country populations. Three source their cohorts from lower and upper-middle-income countries. Outcomes of interest include stillbirth (n=1,172), termination of pregnancy for fetal anomalies (1 study), neonatal death (n=44, 1 study) and composite perinatal mortality	**Moderate confidence** *Minor concerns of methodological limitation, coherence and data adequacy. Moderate concerns of relevance.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						outcomes (n=3,959). The view of parents, HCPS, and coroners is contained in evidence from three included studies.	
6.18	Cytogenetic testing should be performed for all perinatal deaths by either conventional karyotyping or by chromosomal microarray. • Snap freezing a piece of chorionic plate or muscle (if baby is not very macerated) is worth considering for all cases should a genetic condition need to be investigated).	Twelve studies are included. Six reviews including one systematic review, two cohort studies, one qualitative primary research study, one guideline and two assessments of diagnostic tools.	Minor concerns of methodological limitation are noted. Eleven of the included studies are deemed to have no or minor concerns of methodological limitation through critical appraisal. One primary qualitative study is assessed to have moderate concerns of methodological limitation.	No concerns of relevance are noted. All of the included studies are deemed to be directly relevant to perinatal mortality investigations.	Minor concerns of coherence are noted.	Minor concerns of data adequacy are noted. Eight of the included studies source their cohorts from high-income country populations, one from upper-middle income country and three studies do not report the course of their evidence. Outcomes of interest include	**High confidence** *No concerns of relevance. Minor concerns of methodological limitation, coherence and data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						stillbirth (n=952, 10 studies), termination of pregnancy for fetal anomaly (one study), and composite perinatal mortality outcomes (n=3,137). The view of HCPs and parents is included from evidence of two included studies.	
6.19	In perinatal deaths where there may be a genetic cause, parents should be referred to a geneticist to discuss the option of genome-wide sequencing (i.e. whole exome sequencing or whole genome sequencing) where this option is available.	Seven studies are included, one review, a cross-sectional study, two cohort studies, one guideline, one case series and a primary qualitative research study.	Minor concerns of methodological limitation are noted. Five if the included studies are assessed to have no or minor concerns of methodological limitation, and two included studies are assessed to have moderate concerns through critical appraisal.	Minor concerns of relevance are noted. Four of the included studies are deemed to be directly relevant to perinatal mortality investigations, and one study is partially relevant.	No concerns of coherence are noted.	Major concerns of data adequacy are noted through review of the included studies. Five included study sourced their cohorts from high-income country populations.	**Low confidence** *No concerns of coherence, minor concerns of relevance, and methodological limitation. Major concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						Two included studies do not report the source of their evidence. Outcomes of interest include stillbirth (n=393, five studies), neonatal death (one study) and composite perinatal mortality outcomes (n=443, three studies). No viewpoints are contained within the data. Major concerns of data adequacy are noted due to the small, combined sample of outcomes, and lack of parents	

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						and HCPs viewpoints.	
6.20	Autopsy should be offered to all parents with an explanation of the likely value of the examination, including any limitations, in their specific circumstances.	Nineteen studies are included. Three case series studies are included, one cohort study, seven reviews including two systematic reviews, two guidelines, three assessments of diagnostic tools, one prevalence study and two primary qualitative studies.	Minor concerns of methodological limitation are noted. Fifteen of the included studies are assessed to have no or minor concerns of methodological limitation through critical appraisal. Four of the included studies (two diagnostic tool assessments, one primary qualitative study, and one systematic review) are deemed to have moderate concerns of methodological limitation through critical appraisal.	Minor concerns of relevance are noted. Sixteen of the included studies are deemed to be directly relevant to perinatal mortality investigations. Three of the included studies are deemed to be of partial relevance.	Minor concerns of coherence are noted.	Minor concerns of data adequacy. Twelve of the included studies source their data from high-income country populations. One sourced its data from a UMIC, three from lower middle-income countries and the remaining three studies do not report the data source. Outcomes of interest include stillbirth (n=1337), termination of pregnancy for fetal anomaly (n=60), and composite	**High confidence** *Minor concerns of methodological limitation, relevance, coherence, and data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						perinatal mortality outcomes (n=3,840). The view of parents and healthcare professionals is provided through evidence of two included studies. Minor concerns of data adequacy are noted.	
6.21	Consent for autopsy must clearly outline the extent of the investigations to be undertaken and should be recorded on an approved consent form, relevant to the jurisdiction.	Five studies are included. Two are primary qualitative research studies, one narrative review, and two mixed methods study.	Moderate concerns of methodological limitation are noted through critical appraisal of the included studies. Two of the included studies are assessed to have no or minor concerns of methodological limitation. Three of the included studies are noted to have moderate concerns of methodological limitation, studies are two primary qualitative studies, as well as a mixed methods	Minor concerns of relevance are noted. Two of the included studies are deemed directly relevance to perinatal mortality investigations, and three studies are deemed to be partially relevant.	Minor concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Three of the included studies report sourcing their data from high income country populations. One report sourcing data from a lower middle income	**Low confidence** *Minor concerns of relevance and coherence.* *Moderate concerns of methodological limitation and data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
			study. Qualitative components of all studies are noted to lack a statement of researcher cultural position, or to assess the impact on analysis and findings. Studies demonstrate varying degrees of poor congruity between intent, methods analysis, and philosophical perspective.			country population, and one study does not report the data source. Outcomes of interest include stillbirth (n=477), and composite perinatal mortality outcomes (n=919). The viewpoints contained within the evidence include parents (n=477), and HCPs (32 focus groups, and 8 focused interviews) Moderate concerns of data adequacy are noted due to the small, combined	

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						sample of outcomes.	
6.22	In perinatal deaths where there may be a genetic cause, parents should be referred to a geneticist to When consent is obtained for specific organ/s to be retained for further examination at autopsy, parents should be offered the option of either delaying the funeral until the organs can be returned to the body or specifying their preference for how their baby's retained organs are to be taken care of and their preferred method of organ disposal.	Two studies are included, one primary qualitative research study, and one mixed methods study.	Moderate concerns of methodological limitation are noted through critical appraisal of the included studies. One included study is noted to have minor concerns of methodological limitation, and the other noted to have moderate concerns of methodological limitation.	Moderate concerns of relevance are noted. Both included studies are deemed to have partially relevant to perinatal mortality investigations.	Minor concerns of coherence are noted due to the different focus of outcomes of the included studies.	Major concerns of data adequacy are noted. One study sourced its cohort from an HIC population and the other from an LMIC population. Outcomes of interest include perinatal mortality outcomes (n=919). Viewpoints of HCPs are contained in evidence of one study (n=40) Major concerns of data adequacy are noted due to the small,	**Low confidence** *Minor concerns of coherence, moderate concerns of methodological limitation and relevance. Major concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						combined sample size of outcomes and viewpoints, as well as the study settings.	
6.23	A comprehensive clinical summary should accompany the baby for autopsy and magnetic resonance imaging to guide the procedure including maternal, medical, social, family and pregnancy history, and results antenatal investigations and imaging. Ideally, the cord and placental should be sent with the baby for autopsy examination. Complete the following documents: • *Appendix 6D: Placental examination for healthcare professionals* • *Appendix 6E: Examination of baby checklist* • *Appendix 6G: Autopsy clinical summary form* • *Appendix 6M: Exemplar placental histopathology request form*	12 studies are included. Three reviews including cone systematic review, one cohort study, two cross sectional studies, three primary qualitative studies, two mixed methods studies, and one assessment of a diagnostic tool.	Moderate concerns of methodological limitation are noted. Eight of the included studies are assessed to have no or minor concerns of methodological limitation through critical appraisal. Three of the included studies are deemed to have moderate concerns of methodological limitation, and one included primary qualitative study is noted to have major concerns of all aspects of methodology.	Minor concerns of relevance are noted through review. Ten of the included studies are deemed to be directly relevant to perinatal mortality investigations. Two of the included studies are deemed to be partially relevant to perinatal mortality investigations.	No concerns of coherence are noted.	Minor concerns of data adequacy. Four of the included studies report sourcing their evidence from high-income country populations. Five included studies report sourcing data from lower and upper middle income country populations, and one study sources it's data from a low-income country population. Two included studies do not report the	**Moderate confidence** *No concerns of coherence, minor concerns of relevance and data adequacy. Moderate concerns of methodological limitation.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						course of their evidence. Outcomes of interest include stillbirth (n=1633), neonatal death (one study), termination of pregnancy for fetal anomaly (one study) and composite perinatal mortality outcomes (n=4,511). Viewpoints contained within the data include mothers (n=1,303), parents (3 studies) and healthcare professionals (n=78). Minor concerns of data adequacy	

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						are noted due to the income setting described of evidence included across the studies not adequately representing a high-income country population such as Australia or Aotearoa New Zealand.	
6.24	A perinatal/paediatric pathologist should perform or supervise all perinatal postmortem examinations.	Thirteen studies are included. One case series study, one cohort study, two cross-sectional studies, three narrative reviews, one systematic review three qualitative research studies, one guideline and one assessment of a diagnostic tool	Minor concerns of methodological limitation are noted through critical appraisal of the included studies. Ten of the included studies are assessed to have no or minor concerns of methodological limitations. Three of the included studies are deemed to have moderate concerns of methodological limitation.	No concerns of relevance are noted. All included studies are deemed to be directly relevant to perinatal mortality investigations.	No concerns of coherence are noted.	No concerns of data adequacy are noted. Eleven of the included studies report that the source of their cohorts is a high-income country population. Two studies did not report the income setting of the evidence source.	**High confidence** *No concerns of data adequacy, relevance or coherence, minor concerns of methodological limitation.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						Outcomes of interest include stillbirth (n= 26,321), neonatal death (n=98), termination of pregnancy for fetal anomaly (one study), and composite perinatal mortality outcomes (n=3345). The view of parents is contained across three studies (n=477) and the view of health care providers is included from evidence across five studies (n=610).	
6.25	If local autopsy is unavailable, transport for the baby to a centre with appropriate	Four studies are included. One cohort study, two case series,	Minor concerns of methodological limitation are noted.	Moderate concerns of relevance are noted.	Minor concerns of	Minor concerns of	**Moderate confidence**

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
	expertise should be arranged per local procedures.	and one assessment of a diagnostic tool.	All included studies are deemed to have no or minor concerns of methodological limitation through critical appraisal.	One included study is deemed to be directly relevant to perinatal mortality investigations. One study is partially relevant, and two studies are indirectly relevant to perinatal mortality investigation.	coherence are noted.	data adequacy are noted. Three of the included studies report sourcing their evidence from high-income country populations. One study sourced its evidence from an LIC population. Outcomes of interest include stillbirth (n=29,902) and neonatal death (n=264). No viewpoints are contained within the evidence. Minor concerns of data adequacy are noted due to the lack of	*Minor concerns of coherence, data adequacy and methodological limitation. Moderate concerns of relevance.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						parent and HCP viewpoint contained within the evidence.	
6.26	In remote settings, where autopsy is unavailable, communication with a multidisciplinary team (obstetrician and /or neonatologist/ paediatrician, perinatal pathologists, and geneticist) at tertiary centres should be established to ensure that any opportunities to gather information or investigations that can be performed locally are not missed.	One guideline review is included.	No concerns of methodological limitation are noted of the included study through critical appraisal.	The included study is deemed to be directly relevant to perinatal mortality investigations.	N/A	Major concerns of data adequacy are noted. One guideline review included.	**Consensus based recommendation**
6.27	Ideally the final autopsy report should be forwarded to the referring clinician within six weeks of the autopsy where the brain is not examined or 14 weeks if the brain is examined. (This is an aspirational target noting that reports may take longer to resource limitations).	Two primary qualitative research studies are included.	Moderate concerns of methodological limitation are noted through critical appraisal. One included study is noted to have minor concerns of methodological limitation, and the other is assessed to have moderate concerns.	Minor concerns of relevance are noted. One included study is deemed to be directly relevant to perinatal mortality investigations, and the other study is deemed to be partially relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Both included studies source their data from high-income country population settings. Outcomes of interest include stillbirth (n=16) and composite perinatal mortality	**Low confidence** *No concerns of coherence, minor concerns of relevance and moderate concerns of methodological limitation and data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						outcomes (n=484). The viewpoint of parent sis contained within both studies, and the view of HCPs is included in evidence from one study. Moderate concerns of data adequacy are noted due to the small, combined sample size of outcomes.	
6.28	A copy of the autopsy report (including the plain language summary, if available) of any stillbirth or neonatal death should be sent to the requesting clinician and mothers/birth parent's general practitioner (GP).	One primary qualitative study is included.	Minor concerns of methodological limitation are noted through critical appraisal of the included study.	The included study is deemed to be relevant to perinatal mortality investigations.	N/A	Major concerns of data adequacy are noted. The included study sources its data from the high-income country population, contains stillbirth as the main	**Consensus based recommendation**

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						outcomes (n=16) and contains the views of parents and HCPs.	
6.29	Maternal and newborn services should ensure appropriate education on the local coronial process for perinatal deaths is provided for all healthcare professionals. Healthcare professionals should seek advice from the coroner if any doubt exists as to whether a death should be referred to the coroner.	Seven studies are included. Two reviews, one case series, one cross-sectional, one diagnostic assessment, and two primary qualitative studies.	Moderate concerns of methodological limitation are noted through critical appraisal of the included studies. Three of the included studies are noted to have no or minor concerns of methodological limitation, and the remaining four studies included have moderate concerns of methodological limitation.	Minor concerns of relevance are noted. Six of the included studies are deemed to be directly relevant to perinatal mortality investigations. One included study is deemed to be of unclear relevance.	Moderate concerns of coherence are noted. Differences are noted and attributed to differences in coroner involvement in perinatal autopsy across jurisdictions included within the evidence.	Major concerns of data adequacy are noted. Five studies source their data from high income country populations, one from upper-middle income country and one did not report the income setting of their study cohorts. Outcomes of interest include stillbirth (n=25, three studies), neonatal death (four studies) and composite	**Low confidence** *Minor concerns of relevance, moderate concerns of methodological limitation and coherence. Major concerns of data adequacy.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						perinatal mortality outcomes (n=139). The viewpoints contained within the evidence include parents, HCPs (n=234), religious leaders, communities, and coroners. Major concerns of the data adequacy are noted due to the small, combined sample of outcomes.	
6.30	Where a full autopsy is declined by the parents, alternative options of less or minimally invasive investigations, should be offered and an explanation provided of the value in their circumstances following a multidisciplinary discussion including the obstetrician, and neonatologist/paediatrician pathologist, radiologist, and geneticist as required. In	45 studies are included. Six case series studies, three cohort studies, one cross-sectional study, 12 primary qualitative studies, four narrative reviews, and one guideline, one prevalence study, twelve assessments of	Minor concerns of methodological limitation are noted through critical appraisal. 24 of the included studies are deemed to have no or minor concerns of methodological	Minor concerns of relevance are noted on review. 33 of the included studies are deemed to be relevant to perinatal mortality investigations. 10 studies are deemed to be partially relevant;	Moderate concerns of evidence coherence are noted due to the differing indications for use of MRI, CT, and	No concerns of data adequacy are noted. 21 of the included studies source their data from HIC	**Moderate confidence** *No concerns of data adequacy, minor concerns of methodological limitation and relevance, moderate*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
	addition to all core investigations, the following should be offered to parents who decline a full autopsy: • limited autopsy or minimally invasive tissue sampling • external examination by the pathologist • full body X-ray imaging of the baby (also known as a 'babygram') • postmortem MRI.	diagnostic tools, two mixed methods studies and three systematic reviews.	limitation though critical appraisal. 20 studies are deemed to have moderate concerns of methodological limitation through critical appraisal.	two studies are of unclear relevance.	ultrasound throughout the evidence.	populations, 14 from low- and middle-income country populations, 4 from upper-middle income countries and 4 did not report the income setting of their study cohorts. Outcomes of interest include stillbirths (n=1,917), neonatal death (n=321), composite perinatal mortality outcomes (n=7,552), and termination of pregnancy for fetal anomaly (n=360). The view of parents is included across	*concerns of coherence.*

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						11 studies (n=545). HCPs view is included across 3 studies, and views of religious leaders and community are included through evidence of one included study. No concerns of data adequacy are noted.	
6.31	A postmortem MRI, where available, should be offered to parents as an adjunct to autopsy or in place of an autopsy where this is declined. • Ideally MRI should be performed within 24 hours after stillbirth. • MRI has been shown to be helpful in identifying brain and spinal cord abnormalities, particularly in macerated stillbirths.	Fourteen studies are included. Two cohort studies, two case series studies, one primary qualitative study, five assessments of diagnostic tools and four reviews including two systematic reviews.	Moderate concerns of methodological limitation are noted through critical appraisal of the included studies. Six of the included studies are assessed to have minor concerns of methodological limitation through critical appraisal, and Seven studies are noted to have moderate concerns.	Minor concerns of relevance are noted. Thirteen of the included studies are deemed to be directly relevant to perinatal mortality investigations. One study is partially relevant.	Minor concerns of coherence are noted.	Moderate concerns of data adequacy. Eight of the included studies report sourcing their data from HICs. Two reported sourcing their data from MICs, and three do not report the	**Low confidence** *Minor concerns of relevance and coherence are noted, moderate concerns of methodological limitation and data adequacy are noted*.

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						source of their evidence. Outcomes of interest include stillbirth (n=292), termination of pregnancy for fetal anomaly (n=346), neonatal death (one study), and composite perinatal mortality outcomes (n= 309). The viewpoint of mothers is included in one study. Moderate concerns of data adequacy are noted due to the small, combined sample size, and lack of parent and HCP view.	

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
6.25	A fetal MRI should be offered to parents prior to a planned termination of pregnancy where appropriate MRI services are available.	Three studies are included, one cohort study and two assessments of diagnostic tools.	Moderate concerns of methodological limitation are noted. The cohort study is assessed to have minor concerns of methodological limitation through critical appraisal, and the diagnostic tool studies are deemed to have moderate concerns.	Minor concerns of relevance are noted. One included study is deemed to be directly relevant to perinatal investigations and two are partially relevant.	No concerns of coherence are noted.	Major concerns of data adequacy are noted. All included studies source their evidence from high income country populations. Outcomes of interest include termination of pregnancy for fetal anomaly (n=75) and composite perinatal mortality outcomes (n=81). The view of mothers is included in one study. Major concerns of data adequacy are noted due to the small,	**Low confidence** *No concerns of coherence, minor concerns of relevance. Moderate concerns of methodological limitation and major concerns of data adequacy.*

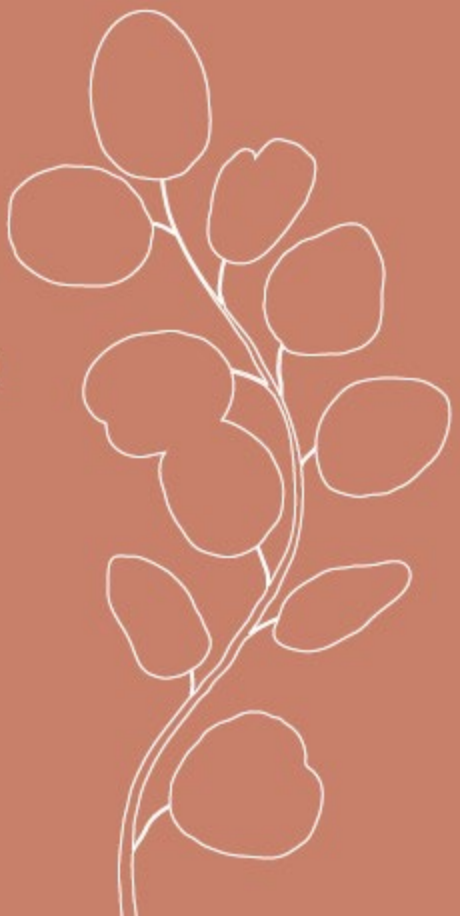
No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQUAL appraisal
						combined sample of both outcomes and viewpoints.	

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report



Section 7: Perinatal mortality audit and classification

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

Perinatal audit has been defined as "the systematic, critical analysis of the quality of perinatal care, including the procedures used for diagnosis and treatment, the use of resources and the resultant outcome and quality of life for women and their babies".[1] The critical analysis of each death in a no-blame, interdisciplinary setting has the potential to "tell a story about what could have been done differently to identify the solutions that should have been available for each woman and baby".[2] Perinatal audit can identify important areas for practice improvement to inform policy, change practice and improve health outcomes.[3] Findings of audit can help parents understand why their baby died and plan future pregnancies.[4] The World Health Organization recommends a systematic approach to clinical audit as an essential step to reducing perinatal death.[2]

National perinatal mortality audit programs are successfully run in the UK (MBRRACE),[5] New Zealand (PMMRC),[6] Netherlands (NAP),[7,8] and Ireland (NPEC).[9] Perinatal mortality audits across high-income country settings show that a high proportion of perinatal deaths are linked to substandard care factors: 20 to 30% overall and up to 60% for intrapartum stillbirths.[10,11] In the UK, rates of perinatal deaths have reduced by 20% between 2013–20.[5] Australia is yet to establish a national perinatal audit program; however, state and territory committees produce regular reports on rates and causes of perinatal mortality. Around a half of the states and territories undertake perinatal mortality audits at the jurisdictional level to identify possible contributing factors relating to care to inform practice improvements.[12] In 2017–18, 37% of perinatal deaths in Australia had results from these audits included in national reporting.[12] Contributory factors relating to the mother, family, and social situation, relating to access to care and the professional care received were identified in relation to 21% of those cases, with those factors likely to have significantly contributed to the outcomes in 8% of cases.

Methodology

The Guideline Development Committee developed research questions for perinatal mortality audit, including considerations for classification of stillbirth and neonatal death (Table 1). This report contains a synthesis of the evidence that addresses these research questions.

Table 1. Research questions

1	What are the different types of perinatal mortality reviews currently being done?
2	Do perinatal mortality audit programs reduce perinatal deaths?
3	What aspects of audit contribute most to reducing perinatal death?
4	Which findings from perinatal mortality audit meetings can be effectively implemented?
5	What needs to be sent to the jurisdictional perinatal mortality council or respective body?
6	What is the best mechanism of providing this information within other reporting requirements?
7	What would need to occur for a national online tool to be used, and to include jurisdictional requirements?
8	What are the essential requirements of perinatal mortality audit meetings, including meeting composition, to ensure optimal outcomes?
9	Which training programs for healthcare professionals result in improved care and outcomes after perinatal deaths?
10	Are there aspects of training programs that are particularly effective?

11	How is the value of locally approved service/unit-based training assessed and are they effective?
12	What strategies increase/optimise reporting?
13	What information is required to prepare and complete a perinatal mortality audit?
14	What is the minimal investigation required to accurately classify the causes of stillbirth and neonatal deaths?
15	Should a standard of relevant documentation be developed?
16	What are the most important strategies to ensure clear and accurate documentation in the medical record at the time of the perinatal death?
17	Should a proforma for verbal autopsy be developed?
18	When should a perinatal death be reviewed?
19	What should happen if there are delays?
20	What needs to be done to improve the quality of death certificate data on causes of death?
21	Who is the ideal person to complete the medical certificate?
22	Should the death certificate be routinely modified after investigations and audit have been complete?
23	Which approaches and processes for perinatal mortality audit improve parents' experience of care?
24	Does parent engagement in perinatal audit process for their baby's death result in improved outcomes for parents and high-quality audit?
25	What are the key aspects that are important in terms of supporting and communicating with families throughout the process?
26	Is there a role for a care coordinator within this process?
27	What are optimal approaches to, and timing of, providing parents with the results of investigations (and audit) and what needs to be presented and discussed?
28	What are parents' understanding and acceptance of the cause of death?
29	How should contributing factors be communicated to the family?
30	What is parents' understanding, acceptance and utility of the contributing factors provided?
31	What are the benefits of an open disclosure framework in discussions with parents following a perinatal death?
32	What are the considerations prior to undertaking open disclosure?
33	What are the risks and benefits of open disclosure?
34	What are the various approaches (benefit, risk of different approaches) to work out the best case-by-case individual process?
35	Should senior clinicians notify the general practitioner and other relevant healthcare professionals of the death as soon as possible? When is the ideal time for this to occur?
36	Following discharge hospitals after a perinatal death, what actions, and when, do clinicians need to provide to other health providers?

37	Should a comprehensive summary be provided to relevant healthcare professionals after the audit meeting, where appropriate and relevant? What should this contain?
38	Should a comprehensive clinical summary be provided by senior clinicians to the general practitioner and other relevant health care providers of outcomes of follow-up appointments and results as available, including subsequent pregnancy care plans?
39	What is the optimal classification system for identifying causes of perinatal deaths to inform policy and practice change and future research to reduce perinatal deaths?
40	Does a hierarchical system have benefits over a non-hierarchical system in terms of reliability and accuracy?
41	What distinguishes causes and associated factors?
42	How does the PSANZ system compare to ICD-PM in terms of cause of death outcomes? Including proportion of unexplained stillbirths. Can the PSANZ system be accurately mapped retrospectively to ICD-PM?
43	What is the optimal classification system for identifying contributing factors relating to care in perinatal deaths to inform policy and practice change and future research to reduce perinatal deaths?
44	How should perinatal death be defined to enhance practice change and research?
45	Which definition should be used, should there be conditional definitions e.g. termination of pregnancy for medical reasons, gestational cohorts?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the audit and classifications research questions for this report.

Table 2. PICO criteria

PICO	Inclusion criteria
Population	Defined in Australia and Aotearoa New Zealand as: • **Stillbirth:** birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[6,13] • **Neonatal death:** a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[6,13] The definition of stillbirths and neonatal deaths includes the death of a baby following a termination of pregnancy of 20 or more completed weeks of gestation or of 400 g or more birthweight.

Intervention	• Studies examining perinatal mortality audit practices or classification systems in maternal and newborn services
Comparator	• No clearly defined comparator. Studies with and without comparators were included.
Outcomes	• ***Audit:*** Outcomes, processes and experiences of parents, family members, healthcare professionals, maternal and newborn services around perinatal mortality audit practices including causes and contributing factors relating to care for stillbirths and neonatal deaths, and parent engagement in the review process. • ***Classifications:*** Outcomes, processes and experiences of healthcare professionals and services relating to the classification of stillbirths and neonatal deaths including optimal reporting, investigations, accurate classification, identification of causes and factors, and perinatal mortality classification systems.

Literature search

Searches were conducted between 9 September–21 November 2022. Search strategies incorporated all PICO criteria and were restricted to publications in English (Audit searches: Tables 4–8; Classifications searches: Table 9). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and the context of Australian or Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches strategies were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed
- Scopus.

In addition, the Technical Working Group conducted searches for grey literature, and committee members were encouraged to identify grey literature and articles of interest for this topic. Studies identified in database searches were imported into Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer. Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- wrong *language*: The study was not published in English.
- wrong *publication dates*: The study was published prior to 2017.
- wrong *evidence type*: The study was an abstract or protocol.

Figure 2 provides the PRISMA flowcharts of evidence from searches to appraisal for the audit and classifications sections of this report. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 10 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic accuracy studies, the QUADAS-2 tool was used. Table 11 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQua The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings? [15]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings? [16]
- Adequacy: The richness and quantity of data supporting the findings [17]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[18]

Each domain was assessed individually, and concerns were assessed as:

- no concerns or very minor concerns regarding domain
- minor concerns regarding domain
- moderate concerns regarding domain
- serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence supporting the synthesis findings was formulated following this review, and details of any concerns were identified and listed.[19] Table 14 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Section 1: Evidence synthesis for perinatal mortality audit

Question 1: What are the different types of perinatal mortality reviews currently being done?

Three levels of assessment of national perinatal deaths evident across high-income countries (HICs) are:

(i) collecting and reporting incidents and rates (done in many countries)

(ii) collecting and analysing incidents and rates; reviewing a large clinical audit dataset through regional or national perinatal audit, and making recommendations based on these

(iii) collecting and analysing incidents and rates; reviewing the deaths (either some or all) in detail, including examining the care provided and avoidable factors through confidential enquiry, and making recommendations based on these.[20]

While many countries collect and report incidents and rates of perinatal deaths, only four HICs have implemented nationwide audit policies and only three conduct in-depth analyses of substandard care factors through confidential enquiry.[21] By running structured local reviews and national audits, with in-depth examination of contributory factors alongside one another, local lessons can be learned as well as ensuring that national policy and clinical practice is informed on key findings from all perinatal mortality cases.[22]

Four countries that have national audit programs are the UK (MBRRACE), New Zealand (PMMRC), Netherlands (Perinatal Audit Netherlands [NAP]), and Ireland (National Perinatal Epidemiology Centre [NPEC]).[20,23] Although the methodology of the four audit programs differ, the programs are all state-funded, overseen by a single key stakeholder committee, use standardised electronic data collection forms, and produce annual reports with recommendations for raising public awareness of perinatal mortality risk factors, detecting fetal growth restriction, preventing preterm birth, and resources for data collection and review.[20] The UK, Netherlands and New Zealand also conduct in-depth reviews of a sample of defined cases through confidential enquiry by an expert panel.[20] For example, the Each Baby Counts program in the UK conducts a national review of the care of term babies stillborn of who died in the neonatal period or who have had a suspected brain injury because of intrapartum causes.[24] The documented local review of care is anonymised and assessed by senior clinicians to identify factors underlying the death or brain injury.[24]

Norway established a national perinatal audit program in 1984. However, the program has been terminated despite an observed decrease in perinatal mortality rates over the period of perinatal audit.[1]

The World Health Organization recommends perinatal audit through Maternal and Perinatal Death Surveillance and Response (MPDSR) to inform policy and improve practice in LICs.[25-27]

Questions 2–5: Do perinatal mortality audit programs reduce perinatal deaths? What aspects of audit contribute most to reducing perinatal death? Which findings from perinatal mortality audit meetings can be effectively implemented? What needs to be sent to the jurisdictional perinatal mortality council or respective body?

The key purposes of perinatal mortality audit are to enabling benchmarking and monitoring of causes of death to inform policy, practice, and research and to assist parents and care providers in decision-making in a subsequent pregnancy [28]. Ensuring good national coverage of quality and timely data from perinatal audits, ensures that there is the ability to obtain accurate mortality data, and assess the needs of health service interventions at a local level.[29,30]

Gutman et al.'s 2022 systematic review of perinatal mortality audits reinforced the importance of analysing cases of perinatal mortality to identify potentially reversible risk factors and to prevent the recurrence of critical mistakes at local and national system levels.[21] A study of perinatal audit in South Australia (reviewed by Gutman et al 2022) found that 11% of substandard care factors occurred due to deficiencies of professional care and differences in the quality of perinatal care across different hospitals, with regional primary care/midwifery-led hospitals having the most prevalent substandard care factors.[21] A perinatal audit project in the Netherlands (reviewed by Gutman et al. [21]) found that in cases of perinatal death with substandard care factors, failure to transfer to a tertiary care facility contributed to the death in 32% of cases, and substandard care factors related to night or late evening shifts occurred in 25% of cases.[21] While in another study in the Netherlands (reviewed by Gutman et al.[21]), the inability to follow guidelines, provision of care against normal practice, and inadequate communication between clinicians, were the most common sub-standard care factors.[21] In a nationwide in-depth review of late preterm deaths in the Netherlands between 2017–2019, fifty two substandard care factors were identified.[31] These care factors included inadequate fetal monitoring by cardiotocography during labour, factors related to care organisation, particularly around clarity in assigning of responsibilities and work procedures, and poor communication between involved healthcare professionals.[31]

In France, a perinatal audit study was undertaken to identify risk factors for perinatal death in a high-migrant district with mortality rates above the national average.[32] Risk factors included primiparity, multiple pregnancy, overweight and obesity, and pre-existing medical/obstetric conditions.[32] Problems accessing, communicating, and complying with care were identified. Suboptimal factors, including poor healthcare coordination and not adapting care to risk factors, were found in three-quarters of perinatal deaths.[32] Investigators judged one-third of deaths to be possibly or probably preventable. For women with gestational diabetes or hypertension, almost 45% of deaths were found to be preventable.[32]

In Queensland, a population-based study was undertaken to identify substandard care factors in a series of late gestation perinatal deaths (mainly stillbirth).[11] The central health department committee used the PSANZ Guideline tool to determine the presence of substandard care against best available guidelines/protocols. Of 56 perinatal deaths audited, substandard care factors were identified in 46 deaths, with substandard care factors possibly relating to the outcome in 20 cases and significantly likely to have contributed to the outcome in another 20 cases.[11] Areas for practice improvement identified mainly related to antenatal care for women with risk factors for stillbirth.[11]

In Italy, a pilot perinatal mortality surveillance system (SPItOSS) inspired by the UK MBRRACE program and the Italian Obstetric Surveillance System was efficient in analysing incidents and rates of perinatal death and identifying avoidable factors.[33] Another study in Italy found that a regional audit system for stillbirth improves identification of cause of death with the ReCoDe classification system and the identification of preventable factors.[34]

Combining perinatal mortality audit with neonatal near-miss audit and severe maternal morbidity audit may help identify risk factors and substandard care factors to inform on policy and clinical practice to improve care and reduce perinatal death.[35-37] Neonatal near-miss and severe maternal morbidity are often perceived as part of a continuum that includes stillbirth and neonatal death. In New Zealand, a cohort study (n=85) was undertaken to identify preventable factors in cases of severe maternal morbidity with adverse fetal and neonatal outcomes.[37] Investigators identified 47/85 cases as potentially avoidable. Avoidable contributing factors included healthcare provider lack of recognition of high risk, delay or failure to diagnose and delayed or inappropriate treatment.[37]

Audit combined with implementation of changes to address identified issues, can be effective in improving clinical practice and patient outcomes in HICs.[21] While the results from a randomised trial of perinatal audit and healthcare professional training in France were not clear-cut, perinatal morbidity related to suboptimal care may have decreased.[38] A review of the study emphasises the importance of ongoing healthcare professional training and mentorship to effective perinatal audit.[38] In the UK, an audit of stillbirths across 13 maternity units found variation in clinical practice, including inconsistencies in induction and management of labour and the frequency of investigation after stillbirth.[39] A formalised care pathway was developed from national guidelines to reduce variation, finding improvements in the care for women who had a stillbirth.[39]

HICs have translated findings from perinatal mortality audits into national perinatal death preventative campaigns. The UK Saving Babies' Lives Care Bundle and the Australia Safer Baby Bundle aim to promote public awareness of risk factors for perinatal death and improve clinical care provided in maternity services to address multiple issues concurrently.[20,40,41]

Resource-limited settings

As in HICs, audit in LMICs has been shown to be effective in identifying cause of death and substandard care factors contributing to perinatal deaths.[42-44] Avoidable factors were identified in 95% (56/59) of stillbirths and 74% (26/35) of neonatal deaths audited in two provinces of Papua New Guinea between 2017–2020.[43,44] An audit of neonatal deaths in North, Central, Metropolitan and South Brazil between 2008–2017, found that 70% of deaths were preventable.[3,45] Substandard care during pregnancy, labour and the postnatal period was the main cause of neonatal death.[3] In an audit of 250 perinatal deaths in two urban hospitals in Rwanda, delays in timely care-seeking occurred in more than three-quarters of deaths, and around half of perinatal deaths were mainly related to

modifiable maternal inadequate health seeking behaviours and suboptimal intrapartum care.[46] Women reported lack of money as a key problem that delayed their timely care-seeking.[46]

Perinatal audit combined with implementation of changes to address identified issues can improve clinical practice and perinatal outcomes in LMICs. In a systematic review of facility-based perinatal death audit in LMICs,[42] five studies found an improvement in the standard of care received by mothers and neonates, one study showed significant a reduction in the incidence of maternal obstetric complications (obstructed labour and antepartum haemorrhage), one study showed a 29% reduction in newborn mortality rate and another study found a 4.9% reduction in perinatal mortality rate after perinatal audit implementation.[42] In a private maternity hospital in Uganda, the introduction of perinatal death audit was associated with a significant decrease in early neonatal mortality rates, however there was no significant change in overall perinatal mortality rates or stillbirth rates.[47]

In India, interventions implemented to improve perinatal outcomes including clinical audits, training of staff, obstetric interventions and re-organisation, changes in staffing, and infrastructure development reduced the perinatal mortality rate and the rates of babies born with birth asphyxia requiring admissions to the Neonatal Intensive Care Unit.[48]

In Rwanda, a district-wide health system improvement program (All Babies Count) improving antenatal care, delivery management, and postnatal care through training and facility readiness support improved maternal and newborn care and reduce neonatal mortality by approximately 35% overall and 49% among high-risk preterm/low birth weight infants.[49] Improvements prenatal and neonatal quality of care and outcomes were maintained 12 months after the program was implemented.[50]

Question 6: What is the best mechanism of providing this information within other reporting requirements?

No studies

Question 7: What would need to occur for a national online tool to be used, and to include jurisdictional requirements?

No studies

Audit enablers

Question 8: What are the essential requirements of perinatal mortality audit meetings, including meeting composition, to ensure optimal outcomes?

"Establishment of multidisciplinary review committees, development of specific perinatal mortality review tools and/or guidelines will enable a more regulated, structured approach to the review/audit process".[22]

Multidisciplinary participation

Although the importance of healthcare professional attendance at perinatal mortality audits is well understood, multiple institutions report low attendance [51]. Barriers to attendance have been identified as high workload and inadequate staffing levels, lack of communication and education regarding perinatal mortality audit, failure to implement change, too many cases to review, and poor documentation.[42,51-53] Having permanent chairpersons and review committee members and scheduling regular audit meetings can help improve member attendance and the impact of audit outcomes in policy review and improvements.[22,42]

It is recommended that multidisciplinary teams should include clinical, support, managerial, emergency and intensive care unit teams.[27,54] Ensuring that all areas of the healthcare system, including emergency departments or intensive care units are involved serves to ensure that learning opportunities are maximised and findings can provide guidance across a range of specialities.[24] It is recommended that perinatal mortality review and classification with the PSANZ Classification System is undertaken by a multidisciplinary team including a perinatal pathologist to aid in interpretation of pathology reports.[55] The Perinatal Mortality Review Tool in the UK also recommends involving an external member as part of the review team, who may provide an unbiased opinion on the clinical care provided.[22] In Canada, reviews of neonatal deaths by two independent reviewers, internal physicians and external physicians, led to different positive and negative practice items and recommendations.[56] **Evidence supports that at a minimum, the lead consultant, obstetrician, neonatologist, midwives, nurses, pathologist and parent advocate should attend the perinatal mortality review meeting.[42,57]**

"No blame" principle

In a survey of healthcare professionals across maternity services in the Netherlands participating in a regional perinatal mortality audit program, valued aspects of the audit meetings included: the collective and non-judgmental search for substandard factors, the perception of safety, the motivation to reflect on one's own professional performance, and the inherent postgraduate education.[21] Another study, also in the Netherlands, found audit committee members felt secure discussing cases openly with other care providers within a supported framework of a national audit program.[21]

For perinatal mortality reviews to be effective, the system should not function as a blame process, but a process to learn from mistakes to prevent future perinatal deaths.[22,24,27,58,59] Confidentiality through the perinatal mortality audit review process encourages open participation and attempts to alleviate the blame culture of perinatal mortality audit processed. The chair of the perinatal mortality audit committee should have experience and training to facilitate the process.[57,59]

> **"The most difficult thing at the internal audit is the blaming issue, in audit by nature."[60]**

Tools

A systematic review of audit processes emphasises the importance of a structured standardised approach to perinatal audit.[21] In Australia, the PSANZ National Perinatal Death Clinical Audit Tool was shown to facilitate and streamline stillbirth investigation and audit helping to identify an underlying causes of stillbirth.[61] Following application of the tool, a cause of death was identified in more than half of the stillbirths in the study cohort, which initially considered to be 'unexplained'.[61] In another

Australian study, the PSANZ guidelines was found to enable a systematic approach to aid perinatal mortality audit implementation and reporting.[11] A review of stillbirths across New Zealand highlights the need for standardised reporting of placental pathology and clinician education on placental pathology to accurately identify placental causes of death using the PSANZ Classification System.[55] Accurate classification of causes of perinatal death should form part of a systematic approach to perinatal mortality audit wherever births occur,[28] and healthcare professionals involved in perinatal death audit need to understand the death classification being used in their facility.[62,63]

Education/training

Studies suggests that standardised training for healthcare professionals is needed to ensure high-quality perinatal audit.[21,27,64]

Questions 9–11: Which training programs for health care professionals result in improved care and outcomes after perinatal deaths? Are there aspects of training programs that are particularly effective? How is the value of locally approved service/unit-based training assessed and are they effective?

Two comprehensive systematic reviews exploring implementation barriers for perinatal mortality audits in MICs/HICs (20 studies, largely HIC including 3 from Australia)[21] and in LMICs (n=10, across 7 countries)[42] have identified inadequate training in the processes of auditing as an important factor, which impeded effective implementation. Evidence suggests that specific standardised staff training for healthcare professionals in perinatal audit is needed, particularly in the areas of investigation, classification of causes, identifying cases of substandard care, and implementing recommendations.[21,64] One paper (reviewed by Gutman et al 2022) recommended an elearning course for healthcare professionals on how to complete stillborn records and carry out diagnostic protocol.[21] Additionally, studies on parental engagement in the perinatal audit process,[57,58] suggests that healthcare professionals engaging parents in the audit process should be supported by receiving specific training in bereavement-care and communication.

In Australia and New Zealand, the IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) program is a key educational program available to support health professionals in maternity services to provide best practice care for women following a perinatal death according to the PSANZ/ Stillbirth CRE Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death.[65] The program covers topics including investigation, documentation, and reporting of perinatal deaths.[65] IMPROVE elearning resources (https://learn.stillbirthcre.org.au/) have been developed and made freely available by the Stillbirth CRE in partnership with PSANZ.[65] In 2020, the IMPROVE program had been completed by over 6,000 healthcare practitioners in Australia and has been well received.[65] The program has also been adapted and used internationally, including Norway, Canada, Fiji, Vietnam, Ireland, and Madrid.[65]

Resource-limited settings

Gondwe et al 2021 found that auditing even one death per week can be essential for identifying gaps in care in LMIC [21]. A study in Jordan found healthcare professional training and experience in perinatal audit and coding impacts audit compliance within hospitals.[66] Where there are negative attitudes

towards perinatal death classification systems and electronic coding databases, there is a negative impact on implementation of audit findings to improve care.[66,67]

In South Africa, engaging community health workers in the perinatal mortality audit process has been shown as a cost effective means of improving measurement of vital statistics in resource constrained settings and mobilising stakeholders to address causes of death in the community.[68]. Leading causes of death among children during the first month of life – especially those caused by infection – can be effectively addressed at the community level by community health care workers if they are properly trained with support.[69]

A case study in South Africa identified the following as potential important factors that may facilitate perinatal audit meetings[70]:

- Ensure careful preparation of the case before the meeting. Staff involved need to have time allocated for preparation before the meeting.
- Enable local ownership in the process. In all the case studies, a member of the clinical staff (normally doctors and/or the operational managers of the maternity ward) prepared the cases and presented the cases during the review meetings to ensure ownership.
- Remind participants about the purpose of the meeting at the start.
- A code of conduct or 'audit charter' is helpful for ensuring a blame free meeting.
- Steer the direction of the conversation to focus on the learning of the case.
- Demonstrate empathy. Facilitators who show empathy for those involved in the case and who humanise the patient by using terms, such as 'She was a fresh stillborn', remind the participants about the purpose of these meetings, to prevent future deaths and not to blame each other.
- Show humility. Facilitators help others learn when they can give examples of their own mistakes or experiences of an adverse outcome with what action was taken to correct it. Sharing your experience and ability to 'self-correct' or advocate for change encourages others.
- Promote inclusivity. Facilitators should speak to the whole room, making eye contact with everyone rather than one individual.
- Encourage and draw on the participation of external factors, such as the clinical specialist.
- Keep to time.[70]

Question 12: What strategies increase/optimise reporting?

Ensuring perinatal audit is conducted through multidisciplinary review committees with appropriate training, in a "no blame" environment, using structured perinatal mortality review tools can help optimise audit meetings outcomes and reporting (see questions 8–11). In addition to these strategies, studies have suggested that replacing paper-based systems with effective electronic systems may reduce clinician workload and improve reporting.[22,28] A study conducted across four major centres in Jordan[67] identified that causes of perinatal deaths are poorly documented and under-reported, which results in questionable statistics to inform practice. The study suggested that an electronic health information system and centralised database for compiling audit, registering births and deaths, and assigning causes of deaths should be developed and implemented. A study in Germany[71] trialled an algorithm to automatically identify cases of potentially avoidable neonatal death from electronic documentation of routine data using the Nordic-Baltic classification. This method was highly specific for selecting potentially avoidable neonatal deaths from routine data.[71] A study in India[72] trialled six

algorithms to automatically assign cause of death from an electronic verbal autopsy form (based on the WHO 2014 standard verbal autopsy instrument), in place of physician assignment. Verbal autopsy is an indirect method to determine cause of death, where non-medical field staff conduct interviews with caretakers or family members about signs, symptoms, and circumstances preceding death, and a physician then assigns cause of death based on the findings.[73] The study found the automated algorithms had a low sensitivity for cause of death.[72] It remains unanswered if automated algorithms can replace physician assignment of cause of death from verbal autopsy.

Investigations and documentation

Questions 13 and 14: What information is required to prepare and complete a perinatal mortality audit? What is the minimal investigation required to accurately classify the causes of stillbirth and neonatal deaths?

Perinatal mortality review should incorporate an evaluation of the medical notes, clinical investigations, input from the clinicians involved in the case, and feedback from parents on the care they received [74].

Identification of a known cause of death requires a concerted effort to complete a standard and uniform investigation in all perinatal death cases, including chromosome analysis as well as autopsy and placental investigations performed by a perinatal pathologist.[75] A comprehensive clinical history is considered a key investigation in accurate classification of the causes of perinatal deaths and may be the only source of information in low resources settings.[76]

Inadequate investigation of stillbirths may result in a high proportion of unexplained deaths; being the default for 'inappropriately investigated' [43]. Since 2017, the PSANZ Classification System has included subcategories under the 'unexplained' category for more comprehensive classification and to identify those that were not adequately investigated, which may explain the observed reduction in unexplained antepartum deaths reported in one series.[77] In Australia, low rates of autopsy and other key investigations is an impediment to accurate classification.[4,78,79] A Canadian study highlighted the value of autopsy in reducing the likelihood of stillbirths classified with an undetermined cause.[80] Similar findings were reported in the UK.[81]

Placental histopathology is one of the most important investigations for accurate classification of the causes of perinatal deaths.[78,82-88] A systematic review of causes of stillbirth globally, including 85 reports presenting causes of nearly half a million stillbirths from 50 countries highlighted the importance of placental conditions as a major contributor to stillbirths in all settings.[84] When detailed placental histology is undertaken, placental factors are reported as the major cause of perinatal deaths.[89] However, the contribution of placental pathology may be overestimated due to lack of definitions for placental causes of death. Many placental conditions are ill-defined and the causal links unclear (e.g., delayed villous maturation) and data quality is poor.[84] Over-interpretation of placental pathology could lead to erroneous classification of the truly unexplained.[55,84]

In the absence of complete diagnostic autopsy, MRI and minimally invasive tissue sampling can provide valuable findings for cause of death diagnosis.[86,90,91] In a retrospective cohort of 80 stillbirths, miscarriages and intrapartum deaths, MRI provided positive findings in over one-third of cases that

was not available from placental analysis.[86] Authors of another study found cause of death diagnosis through minimally invasive tissue sampling was consistent with diagnoses through complete diagnostic autopsy in 20 out of 24 perinatal deaths.[90]

In low resource settings, the lack of good quality information including clinical history and investigations is a major limiting factor to the classification of perinatal deaths.[43,76,92-95] Improvements in use of diagnostic protocols and guidelines is needed to obtain better data on cause of death, especially antepartum stillbirths.[96]

A study in Nepal[97] identified the need to improve quality of fetal heart sound monitoring and neonatal resuscitation to reduce misclassification of intrapartum stillbirth. It was estimated that 46% of intrapartum stillbirths were potentially misclassified.

Question 15: Should a standard of relevant documentation be developed?

Standardised perinatal audit tools are consistently recommended to improve the quality of cause of death reporting,[21,64] which may overcome issues of inaccurate, missing or incomplete reporting of clinical data and the sequence of events, and nonstandard audit methods,[21,42,98]

A systematic review of 20 studies of audit practices (three studies in Australia) showed issues affecting cause of death reporting included: insufficient information to classify the cause of death, inadequate uptake of investigations (one study reported 60% of perinatal deaths had postmortem examination completed), lack of specialised pathologist in perinatology and differences in reporting of placental histology (no standardisation), differences in classifications and criteria, and nonstandard methods for identifying substandard care factors; one study reported that half of substandard care factors were identified through explicit audit criteria and half were identified through implicit criteria agreed by audit panel.[21] The review highlights the need for a standardised tool to facilitate the process of reporting data.

In Australia, the National Perinatal Death Clinical Audit Tool developed by the Perinatal Society of Australia and New Zealand facilitates and streamlines stillbirth investigations and data collection for perinatal mortality audit. A centralised population-based perinatal mortality audit program undertaken by Queensland Health used the PSANZ guidelines tool in an audit of 56 perinatal deaths[11] findings contributing factors present in 46 deaths, factors possibly relating to the outcome in 20 cases and significantly likely to have contributed to the outcome in another 20 cases.[11] In another study, application of the tool resulted in the identification of characteristics that are known to be related to unexplained stillbirth such as parity, smoking, intra-uterine growth restriction and decreased fetal movements.[61]

Standardised data collection forms with clearly defined information requirements are used in national audit programs in the UK (MBRRACE), New Zealand (PMMRC), Netherlands (Perinatal Audit Netherlands [NAP]), and Ireland (National Perinatal Epidemiology Centre [NPEC]).[20] The MBRRACE Perinatal Mortality Review Tool has been used by local maternity services in the review of 88% of perinatal deaths since 2018.[21] Substandard care factors were identified in 90% of these cases.[21]

Question 16: What are the most important strategies to ensure clear and accurate documentation in the medical record at the time of the perinatal death?

In a cross-sectional study across Kenya and Uganda[99] data strengthening efforts were completed as part of the Preterm Birth Initiative (PTBi) trial to improve the accuracy and completeness of maternity registers. This included the provision of supplies (pregnancy wheels, tape measures, digital scales) with skill building sessions, monthly training and mentoring of labour and delivery staff on standard indicator definitions, and monthly feedback on the completeness of registers. These efforts resulted in increased completion of key neonatal clinical characteristics (birthweight, gestational age, APGAR), which highlighted the need for improved care of preterm and low birthweight infants and increased access to emergency obstetric care.[99]

Question 17: Should a proforma for verbal autopsy be developed?

Verbal autopsies with physician assignment of cause of death are commonly used in LICs for unattended deaths, where medical data are limited.[68,72,73,100] In Khayelitsha, South Africa, community health workers conducting verbal autopsies with structured questionnaires, found health system issues (poor quality of care, staff shortages) and socio-economic factors contributed to maternal and infant deaths they reviewed.[68] In 2016, the WHO verbal autopsy tool was revised to include stillbirths and perinatal deaths.[73] Studies using the tool have reported variable performance, when compared to standardised clinical data.[73] Russel et al. described the difficulties of using standard verbal autopsy tools in humanitarian settings, where tools have been perceived as "complex" and adaptations have been required.[100]

Audit timing

Question 18: When should a perinatal death be reviewed?

Understanding the causes and contributing factors is crucial to help parents understand why their baby died and plan future pregnancies.[4] Timely review of the death may also facilitate appropriate counselling and support for staff.[58] A recommendation that "the review meeting should take place within approximately 12 weeks from the baby's death" was identified during a consensus study of the perinatal mortality review process as 'critical' by most consensus-survey participants, however didn't meet threshold for inclusion in the final set of recommendations.[57] Holding the review meeting within 12 weeks after the perinatal death might not be feasible if investigations such as autopsy are not complete [57].

Question 19: What should happen if there are delays?

Bereaved parents in the UK expressed the view that they wanted to know when the perinatal mortality review process was taking place and that the process should be transparent.[101] Bakhbakhi et al.[57] recommend a dedicated bereavement midwife or nurse to provide a continual point of contact for bereaved families throughout the process, and who can inform parents of when the review meeting will take place.[74] Feedback should be provided to parents as soon as possible after the perinatal mortality review meeting (approximately 2 to 4 weeks) through a consultant follow-up meeting.[57]

Death certificates

Questions 20–22: What needs to be done to improve the quality of death certificate data on causes of death? Who is the ideal person to complete the medical certificate? Should the death certificate be routinely modified after investigations and audit have been complete?

For many parents the Medical Certificate of Stillbirth is the principal source of information regarding the cause of their baby's death.[64] High quality death certificate data are necessary for effective strategies to address preventable deaths.[102,103] However, information reported on death certificates are often inaccurate or incomplete.[64,67,98,103,104] In the UK, almost 80% of medical certificates of stillbirth contained errors, and 43.3% were officially registered as "unknown cause of death".[105]

The American College of Obstetricians and Gynecologists (ACOG) recommend that all obstetrician-gynaecologists familiarise themselves with local reporting requirements regarding medical death certificates and that prompt documentation of vital events are recorded.[106] In Russia, death certificates are completed by the doctor who provided medical care during childbirth, and in their absence, a paramedic or midwife.[107] If a baby is transferred to another hospital, and dies a few hours/days later, a medical certificate of perinatal death is issued by the medical organisation in which the child died.[107]

Higgins et al.[64] suggests that detailed review of case information available before completion of medical certificate of stillbirth could improve the usefulness of information, and calls for standardised training for all professionals completing Medical Certificates for Stillbirth. Education programs can improve the accuracy of adult medical certificates of death, so may aid in improving accuracy for perinatal deaths also.[64] In the USA, the National Center for Health Statistics online training for birth and fetal death data includes specific training on reporting fetal cause of death, with a focus on targeting reporting issues.[108] However, training alone may not be sufficient to improve accuracy of cause of death reported on death certificates, which are often issued before information from autopsy and placental histopathology are available.[64]

Autopsy and placental histopathology can provide additional information on stillbirth cause of death and information important to the management of the mothers future health and future pregnancies in up to 50% of cases.[64] A systematic review of audit data collection found that standardised investigation and audit tools were consistently recommended to improve the quality of cause of death reporting.[21] In Australia, perinatal audit using the PSANZ National Perinatal Death Clinical Audit Tool was shown to facilitate stillbirth investigation and audit and help to identify underlying causes of stillbirth.[61] Following perinatal audit, a cause of death was identified in more than half of the stillbirths in the study cohort, which were initially considered to be 'unexplained' after chart review alone.[61]

In Russia, it is recommended practice that medical certificates are initially issued as "preliminary". A new medical certificate is issued "instead of the preliminary one" once results from all investigations are available.[107]

Resource-limited settings

Perinatal death certificates are not reliably completed in LICs.[104,109] A study in Ghana found that when certificates for perinatal deaths were completed, the cause of death diagnosis was often inaccurate and should be interpreted with caution.[104] In LMICs, perinatal death data is often collected through national census and household data, which may be affected by memory recall and socio-cultural context.[109,110] A study using household surveys to collect stillbirth data in Afghanistan suggested that stillbirth misclassification may be reduced through education of mothers on ascertaining signs of life after birth, as culturally, signs may differ and lead to misreporting.[110]

Parental engagement

Question 23: Which approaches and processes for perinatal mortality audit improve parents' experience of care?

Parents' engagement in the perinatal mortality review process is limited and inconsistent worldwide.[111] In a multi-country survey of 854 healthcare professionals in six HICs, only a third of healthcare professionals whose facility held regular meetings reported some form of parent engagement.[111] When parental engagement did occur, it was primarily in the way of feedback provided from health professionals to parents following the review during a follow-up meeting. Australian survey respondents indicated that parental engagement in the perinatal mortality audit process in Australia is primarily through this one-way post-review feedback.[111] Higher levels of parent engagement were rarely reported; only 17% of all survey respondents described an explicit approach to engaging parents, where parents provided input, received feedback, and were represented at meetings.[111]

The PARENTS (Parents' Active Role and ENgagement in The review of their Stillbirth/perinatal death) portfolio of studies investigated the best way to enable parental engagement in the perinatal mortality audit process in the UK.[57,74,101,112,113] Bereaved parents, healthcare professionals, and other stakeholders in perinatal bereavement care consulted during these studies support the opportunity for parent engagement in the perinatal audit process.[74,101,112] Bereaved parents consulted during these studies felt that individualised approach to parent engagement should be taken to allow flexibility on when and how parents contribute to the perinatal mortality audit process.[101] Parents expressed the view that the process should be open and transparent and emphasised the need for an inclusive and positive approach to both medical and emotional aspects of care.[101]

Through Delphi consensus methods, the following 12 core principles for engaging parents in the perinatal audit process were identified[57]:

1. There should be a face-to-face explanation of the perinatal mortality review process, supported by a written information leaflet, prior to hospital discharge.
2. The form to obtain parental feedback should be completed in a face-to-face consultation at a private location of the parents' choice (if declined, option to receive feedback by telephone, e-mail or post should be offered).
3. The parents should be offered the opportunity to nominate a suitable advocate or bereavement-care midwife or nurse, who will complete the feedback form with the parents and attend the perinatal mortality review meeting.

4. All healthcare professionals involved in the case should be notified of the perinatal mortality review meeting in good time and attend where possible.
5. Staff involved in the case who cannot attend the perinatal mortality review meeting should, at the very least, submit their comments.
6. Responses to the parental feedback should be formally documented in the perinatal mortality review meeting.
7. If necessary, action plans should be made from the parental responses and monitored.
8. A plain English summary should be given to parents following the perinatal mortality review meeting.
9. The feedback from the perinatal mortality review meeting should be discussed at the consultant follow-up meeting, supported by the plain language summary.
10. The consultant follow-up meeting should take place as soon as possible after the perinatal mortality review meeting (approximately 2–4 weeks).
11. Parents should have the option to nominate a second member of staff (who could be the designated parents' advocate) to attend the follow-up meeting with the consultant.
12. If the parents decline to attend the consultant follow-up meeting, then the written plain language summary should be offered to be sent to the parents instead.[57]

Bakhbakhi et al. have a draft pathway for parent engagement in the perinatal mortality review process (covering weeks 1–16), based on the 12 core principles derived through consensus methods (Figure 1).

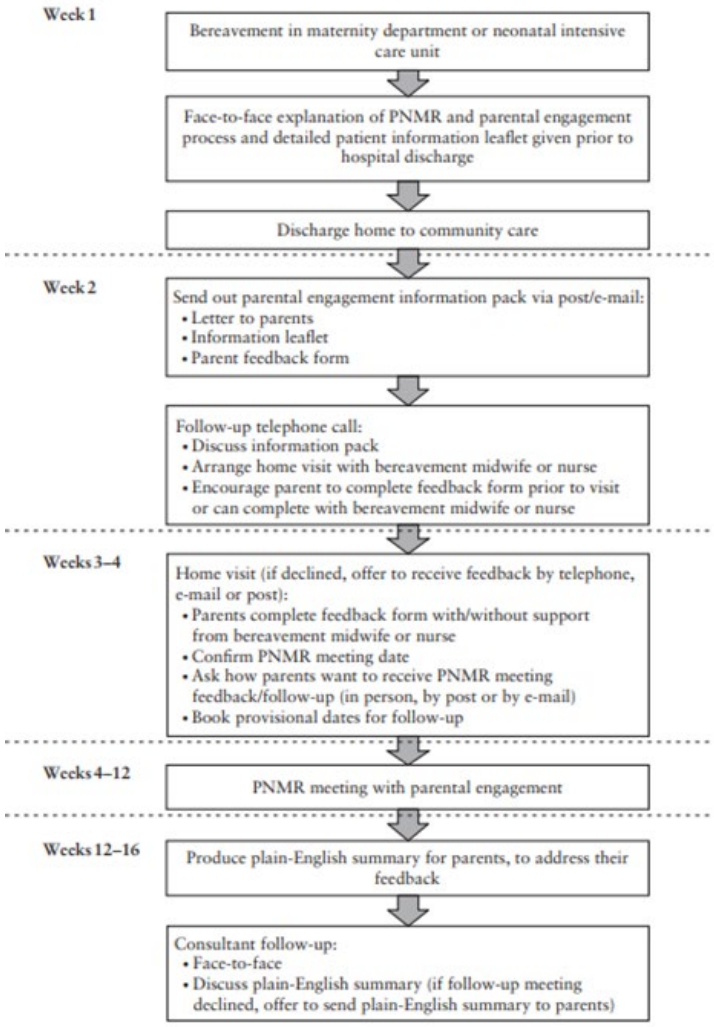


Figure 1. Draft pathway for parental engagement in perinatal mortality review process (Bakhbakhi et al. 2019)

Question 24: Does parent engagement in perinatal audit process for their baby's death result in improved outcomes for parents and high-quality audit?

Burden et al.[112] trialled Bakhbakhi et al.'s draft pathway for parent engagement in the perinatal mortality review process in a tertiary maternity unit in the UK. Bereaved parents participating in the study agreed that engagement in the perinatal mortality review process was invaluable and helped them in their grieving. Healthcare professionals participating in the study perceived that parent involvement improved the review process and lessons learned from the deaths; information to understand the impact of aspects of care on the baby's death were often only found in the parents' recollections.[112] However, healthcare professionals did have some negative perceptions of parent engagement; some healthcare professionals experienced distress on receipt of the parents' feedback, and experienced difficulties where there was conflict in the parents' perception of events compared

with documentation of events in the case records.[112] Additionally, healthcare professionals reported that parent feedback led to additional time and resources required to review each case within the meeting.[112]

Questions 25 and 26: What are the key aspects that are important in terms of supporting and communicating with families throughout the process? Is there a role for a care coordinator within this process?

Stakeholders consulted in Bakhbakhi et al.'s[57] consensus study thought that it is crucial that parents are informed about the review process and are offered the opportunity to share their perspectives of care as part of the PNMR, before they leave the hospital. Bakhbakhi et al.[57] suggest that parents are provided with an information leaflet describing the review process prior to discharge, and that they are advised that they would be sent a follow-up letter in the post with the timeline, the estimated date of the review meeting, information about the review process and the offer to be included in the process. Feedback should be provided to parents as soon as possible after the perinatal mortality review meeting (approximately 2-4 weeks), through a consultant follow-up meeting, supported by the plain language summary addressing parents questions.[57] See Figure 1.

Bakhbakhi et al.[57] suggest a "dedicated bereavement midwife or nurse to provide a continual point of contact for bereaved families, active participation in their care, bereavement support and personalised continuity of care so that parents 'do not have to repeat their story lots of times to health professionals'".

Question 27: What are optimal approaches to, and timing of, providing parents with the results of investigations (and audit) and what needs to be presented and discussed?

Bakhbakhi et al.'s 12 core principles and draft pathway for parent engagement recommends that feedback is provided to parents as soon as possible after the perinatal mortality review meeting (approximately 2–4 weeks). Findings should be provided through a consultant follow-up meeting and supported by the plain language summary.[57] See Figure 1.

Burden et al.[112] trialled Bakhbakhi et al.'s draft pathway for parent engagement in a tertiary maternity unit in the UK and received mixed feedback from bereaved parents regarding the plain language summary. The majority of parents who participated received the summary after their consultant follow-up meeting.[112] Some parents reported they would have wanted this before the follow-up meeting, so they have more time to assimilate the information.[112] Others felt having this information before the meeting would be detrimental, and it was acknowledged that this might vary on an individual basis.[112] Some parents commented that they would want the option to ask and have answered different questions after all the results of the review were fed back.[112]

Question 28: What are parents' understanding and acceptance of the cause of death?

No studies

Questions 29 and 30: How should contributing factors be communicated to the family? What is parents' understanding, acceptance and utility of the contributing factors provided?

In Bakhbakhi et al.'s qualitative study[101] of 11 bereaved parents, parents were largely unaware of the audit process in the UK and communicated varied levels of dissatisfaction – "*To me there is something fundamentally wrong, at no point did someone give us a piece of paper saying we're really sorry your child has died and this is how we investigate it.*" Parents wanted to know when the perinatal mortality review process was taking place and to have the lessons learned clearly communicated to them.[101] Parents wanted reassurance that the same thing would not happen again to other parents if a preventable cause was found.[101] They wanted to know what changes would be implemented following their loss and they wanted documented accountability in the process.[101]

Of the 25 healthcare professionals consulted in the UK consensus study[57]:

- 96% agreed that a face-to-face explanation of the perinatal mortality audit process was of critical importance
- 92% believed that responses to parents' comments should be formally documented
- 72% considered that parents should be offered the opportunity to nominate a suitable advocate to complete the feedback form with the parents and attend the perinatal mortality review meeting
- 96% indicated that it was vital for action plans to be translated into lessons learned and that this process should be monitored
- 100% of stakeholders voted that a **plain language summary addressing questions should be produced for the parents following the meeting**.

Workshop participants discussed the challenges of obtaining feedback and questions about their care from families with whom it may be more difficult to engage, such as non-English speaking parents, those in complex social situations or young people who prefer using technology to communicate.[57]

Questions 31–33: What are the benefits of an open disclosure framework in discussions with parents following a perinatal death? What are the considerations that need to be taken into account prior to undertaking open disclosure? What are the risks and benefits of open disclosure?

Fear of litigation is a potential challenge when engaging parents in the perinatal mortality audit process.[57] However, clear communication between hospital staff and parents as part of the audit process may reduce the number of complaints and litigation because poor communication between healthcare professionals and patients is a common reason that patients and their relatives file written complaints after an undesirable medical outcome.[57]

Question 34: What are the various approaches (benefit, risk of different approaches) in order to work out the best case-by-case individual process?

Most parents want the opportunity to provide input in the perinatal mortality review process.[74] In Bakhbakhi et al.'s qualitative study of 11 bereaved parents, parents felt that individualised approach to parent engagement should be taken to allow flexibility on when and how parents contribute to the perinatal mortality audit process.[101] In a qualitative study of healthcare professionals (n=27), participants recommended that a standard set of basic information about the purpose of the perinatal mortality review process should be given to parents; however, there should be the opportunity for personalisation according to the individual case.[74] Specific challenges of parental engagement were discussed by healthcare professionals in this study, including how to approach parents asking excessive, unexpected or unanswerable questions or demanding additional investigations that were not medically indicated; how or whether to involve both parents when there are relationship issues or breakdowns; and how to involve vulnerable parents.[74] A qualitative audit of parental preventable factors[32] noted that difficult or extreme situations including homelessness, family conflict and violence are noted in cases of perinatal death. Compliance and medical factors contributing to preventable deaths may prevent perinatal audit participation, and may affect the review process, but may be prevalent in populations at increased risk of stillbirth or neonatal death.[32] A key area for future research is how best to engage parents in the audit process.[22,28]

Handover to general practitioners and other healthcare professionals

Question 35: Should senior clinicians notify the general practitioner and other relevant health care providers of the death as soon as possible? When is the ideal time for this to occur?

Bakhbakhi et al. identified core principles for the perinatal audit process through Delphi consensus methods,[57] including when and how healthcare professionals who provided clinical care to the mother and baby should be involvement in the audit process. Bakhbakhi et al. suggest that "All healthcare professionals involved in the case should be notified of the perinatal mortality review meeting in good time and attend where possible" and that "Staff involved in the case who cannot attend the perinatal mortality review meeting should, at the very least, submit their comments".[57]

In the UK, participation in facility-based audits (e.g. death audits in health facilities based on significant event analysis), are an important part of revalidation for doctors.[114] The Royal College of General Practitioners recommends that "significant event analysis team discussions should be a routine part of your practice's quality improvement and clinical governance".[114] In South Africa, engaging community health workers in the perinatal mortality audit process has been shown as a cost effective means of improving measurement of vital statistics in resource constrained settings and mobilising stake-holders to address causes of death in the community.[68]

Question 36: Following discharge hospitals after a perinatal death, what actions, and when, do clinicians need to provide to other health providers?

No studies.

Question 37: Should a comprehensive summary be provided to relevant health care providers after the audit meeting, where appropriate and relevant? What should this contain?

Sharing perinatal mortality audit findings and recommendations with facility healthcare professionals, community-based healthcare professionals, and the community, facilitates the implementation of recommendations following perinatal death review and drives improvements in community healthcare services in LMICs.[115] Feedback of findings from referral to referring facilities in cases of sub-optimal care has led to improvements in the management of preterm babies in the Bungoma county of Kenya.[115] The review committees provide feedback to referring facilities before the perinatal mortality review has taken place when there is an urgent quality of care gap that requires immediate attention or after the perinatal death review when improvements to quality could be made in the future.[115]

Question 38: Should a comprehensive clinical summary be provided by senior clinicians to the General Practitioner and other relevant health care providers of outcomes of follow-up appointments and results as available, including subsequent pregnancy care plans?

No studies.

Classification and definitions

Question 39: What is the optimal classification system for identifying causes of perinatal deaths to inform policy and practice change and future research to reduce perinatal deaths?

More than 80 classification systems for causes of perinatal death have been reported globally,[116] and there is no agreement on a standardised international system.[28] Seventeen fundamental characteristics of a globally acceptable classification system have been identified through Delphi consensus.[28] The top five characteristics are:

1. easy to use and capable of producing data that are easily understood and valued by users
2. clear guidelines for use and definitions for all terms used; use rules to ensure valid assignment of cause of death categories
3. able to work with all levels of data (from both LICs and HICs), including minimal levels
4. cause of death categories relevant in all settings
5. producing data that can be used to inform strategies to prevent perinatal deaths.[28]

A global classification system should accommodate both stillbirths and neonatal deaths. A classification system should retain important information about the death, identify the underlying cause of death, and distinguish associated conditions from causes.[109] Given that placental pathology accounts for a significant proportion of perinatal deaths,[77] a classification system for perinatal deaths should include a placental category.[109] For a classification system to produce valid data, it must be reliable with high inter and intra-rater agreement.[109]

No classification system published between 2004–2016 meets all 17 characteristics of a quality global classification system.[117] The most aligned system was the Cause of Death & Associated Conditions

(CODAC) system (9/17 characteristics), followed by TULIP (7/17 characteristics), Perinatal Society of Australia and New Zealand Perinatal Death Classification (PSANZ Classification System) (6/17 characteristics), Child Health Epidemiology Reference Group (CHERG) (6/17 characteristics), Cole et al. (6/17 characteristics), Kotecha et al. (6/17 characteristics), and Ujwala et al (6/17 characteristics).[117]

More recently, a classification system to assign cause of death specifically in twin pregnancies (CoDiT) has been developed and tested using 265 perinatal deaths in the UK.[82] The system meets six of the 17 characteristics of a globally acceptable classification system: accommodates fetal death, stillbirths and NND; distinguishes between NND and stillbirth; has a small number of main categories shows strong inter and intra-rater agreement; allows associated factors such as placental descriptions to be recorded and distinguished from the cause of death; requires the single most important factor to be recorded. Further evaluation is required to determine whether the CODiT system meets other Delphi characteristics.

The Prenatal Alcohol in SIDS and Stillbirth (PASS) Network Classification System was published in 2017.[118] The system has five main categories, further subdivided into mechanism subcategories, to assign a cause of death and a status of sporadic versus recurrent cause. Authors have pilot tested the PASS system alongside existing INCODE and ReCoDe systems for 19 stillbirths and have found the PASS system to be comparable to existing systems. Further evaluation of the system is required.

The WHO ICD-Perinatal Mortality (ICD-PM) classification system is the only global system for classifying perinatal deaths. However due to inadequacies in the ICD-PM, HIC continue to use alternative systems.[109] A systematic review of 15 studies[119] that applied the ICD-PM system to identify causes of perinatal mortality found ICD-PM is used inconsistently. Challenges related to the use of the ICD-PM system include a high proportion of antepartum deaths of unspecified cause, the inability to determine the cause of death if the timing is unknown, and the challenge of assigning one cause of death when there are multiple contributing conditions.

Nine suggested amendments to overcome current challenges when using the ICD-PM system are:

1. Include a standardised definition of antepartum and intrapartum deaths in the ICD-PM system and develop a new category for causes of perinatal deaths of unknown timing.
2. Re-evaluate the “hypoxia” category and, if used, develop a clear explanation, and establish guidelines on what conditions should or should not be classified as “hypoxia”.
3. Elaborate recommendations on how to classify perinatal death causes and wherein the chain of events classification should be done.
4. Provide further guidance on when to classify something as a maternal condition, and how to distinguish between cause and contributing factor.
5. Highlight potential pitfalls of the ICD-PM in the new guidelines.
6. Add a diagnostic work-up checklist for after a perinatal death took place.
7. Consider ‘birth trauma’ as ‘subcategory’ instead of ‘main category’.
8. Create a link between the ICD-PM and the WHO ICD-MM and MNM tools.
9. Develop an additional category for modifiable causes.[119]

Note: refer to the summary of the grey literature for a summary of the International Stillbirth Alliance system that is currently under development.

Performance of classification systems

The rate of unexplained stillbirths is a commonly used as an indicator of the effectiveness of a classification system.[95] It is estimated that only 20% of stillbirths should fall into the unexplained category.[116,117] A systematic review of 31 classification systems published since the 1950s, found that unexplained perinatal deaths ranged from 0.39% using the Nordic-Baltic classification to 46.4% using the Keeling system.[92] Most of these systems were developed in HICs and require sources and types of information that may not be available in low-resource settings. The types of information required, the proportion of deaths for which a cause can be assigned, and ease of use of a system need to be considered when determining when and where a specific classification system should be used.

The PSANZ Classification System resulted in almost 50% of stillbirths at 34 weeks or more listed as unexplained stillbirth, in an Australian population with high rates of placental examination but low autopsy rates (37%).[11] This high unexplained stillbirth rate in late gestation has prompted changes to the system to better identify placental causes, which account for a high proportion of stillbirths.[77]

In a study in Ghana,[95] the PSANZ Classification System provided valuable insights into medical causes. However, given the low levels of investigations for stillbirth in Ghana (placental pathology and fetal autopsy were almost never performed), some adaptions to the system were suggested. For example, cultures of a pathogen from mother or placenta were rarely available in cases of stillbirth reviewed in this study. While the PSANZ system requires positive culture of a pathogen to classify a death due to perinatal infection, clinical evidence suggestive of infection affecting the fetus (e.g., foul-smelling amniotic fluid) was deemed sufficient to code a perinatal infection in the absence of evidence pointing toward other causes of death in this study. One-third of stillbirths were coded as unexplained following adaption of the PSANZ Classification System in this study.

The simplified CODAC classification system was developed for use in low-resource settings where there are limitations in investigative capacity. A study team in Timor-Leste used the simplified CODAC system to classify 138 perinatal deaths and found that while the system was easy to use, approximately 45% of stillbirths were classified as 'unknown'.[76]

The TULIP and Wigglesworth classifications systems were compared in a cohort of stillbirths in Portugal with a high rate of autopsy (conducted in 99/112 cases) and placental histopathological examination (112/112 cases).[120] Out of 112 stillbirths, 47 cases were "unexplained" when using the Wigglesworth system (42%) and 14 cases were "unexplained" when using the TULIP system. Of the additional 33 cases assigned a cause of death using the TULIP classification, 18 were assigned a placental cause. Findings suggest that important information in this cohort is not retained with the Wigglesworth classification system.

In 2018, Kunjachen Maducolil et al.[121] classified stillbirths in a Middle Eastern population with a low autopsy rate (9.1%) using the Wigglesworth, Aberdeen, TULIP, ReCoDe and ICD-PM classifications. The unexplained stillbirth rate was highest when using the Wigglesworth system (59.2%), which does not capture maternal risk factors, and the Aberdeen classification systems (46.6%), which does not capture placental pathology. The unexplained stillbirth rate was 16.6% using TULIP system, 11.6% using ReCoDe and 7% using ICD-PM. Based on proportion of unexplained stillbirth, ICD-PM was found to be the most appropriate classification system in this population.

The ICD-PM has been used in LICs, MICs, and HICs to classify perinatal deaths with varying degrees of success. In a large prospective cohort of stillbirths (n=1,267) in four low-income countries in Africa,

17.9–26% of stillbirths were unexplained when using ICD-PM.[96] A study in Turkey, found 212 out of 412 (51%) antepartum stillbirths were unexplained when using ICD-PM.[122] A retrospective study of perinatal deaths (n=119) in Hong Kong found that application of the ICD-PM reduced the proportion of unknown causes of perinatal death from 34.5% to 10.1%.[123]

A comparison of the ReCoDe classification, simplified CODAC classification and ICD-PM on a cohort of 443 stillbirths in Italy[83] found ICD-PM had the lowest rate of unexplained stillbirths in this population (9.3%). However, the authors attribute the low rate of unexplained stillbirths to the structure of the system (double coding with a maternal and neonatal cause of death) and a lack of recognition of a primary versus. associated condition, rather than it being a more accurate coding system. While an ideal classification system should result in a low rate of unexplained stillbirths, it must also be accurate, and distinguish associated conditions from causal factors.[109] The ReCoDe and ICD-PM systems were compared in a 2022 study in Italy.[124] The study found the percentage of unexplained/unspecified stillbirth cases when coding with ReCoDe (23.6%) and ICD-PM (20.9%) were comparable. However, inter-rater and intra-rater agreement were suboptimal for both systems owing to a lack of specific guidelines for using the systems. Another study in Italy[34] that used ReCoDe reported that regional perinatal audit for stillbirth was feasible with 14% classified unexplained. Compared to local audits, the regional group attributed different causes of death in 17% of cases. Stillbirths judged possibly/probably preventable with a different management (10.9%) occurred more frequently in non-Italian women and were mainly related to maternal disorders (OR 6.64, CI95% 2.61–17.02).

There are numerous studies evaluating the performance of a classification system or multiple systems within a specific setting.[76,95,120,124-130] In a systematic review of causes of stillbirth globally,[84] wide variation in use of systems made analysis and country comparisons problematic. From 85 reports presenting causes of nearly half a million stillbirths from 50 countries and all income settings, 15 major causal categories from nearly 900 causal terms were identified; eight categories were common to most reports. The information available from the reports was inconsistent and often of poor quality. It is difficult to compare the performance of classification systems across multiple studies, where study populations and the information used to classify perinatal deaths differ. Large supranational studies are needed to clarify which and when specific classification systems should be used.[124] The 2016 *Lancet* series called for the development of a single universal classification system.[28]

Question 40: Does a hierarchical system have benefits over a non-hierarchical system in terms of reliability and accuracy?

There are inherent challenges in ascertaining the cause of stillbirth because there is often an overlap between actual cause and associated conditions including risk factors.[84,130] A hierarchical approach has been proposed as a way of systematically classifying perinatal deaths where more than one condition is thought to be contributory. A hierarchical approach uses a structure where conditions placed higher up the list of conditions in a classification system take precedence over those appearing below. Of systems either developed or in use over the period 2009 to 2014 the majority do not use a hierarchical approach.[116] Hierarchy is more common among systems used only in LMICs.[116] This approach has been proposed to increase accuracy and ease of use and may be of value in low-resource settings with lack of skilled personnel. A retrospective cohort study across India, Pakistan, Guatemala, Democratic Republic of Congo, Zambia, and Kenya,[131] trialled an algorithm with a hierarchical approach to determine causes of stillbirths. The algorithm first determined whether a

stillbirth was associated with maternal or fetal trauma, then determined whether there is a visible congenital anomaly, followed by signs of maternal or fetal infection (such as fetal or vaginal odour), the presence of intrauterine asphyxia, and, finally, whether the death was a result of preterm birth. When using this system, asphyxia was the most common cause with nearly half associated with potentially preventable obstetric conditions.[131]

However, forced classification of less important factors listed higher up may result in rare or subtle causes of perinatal deaths being missed[73] and the value of the data from such systems may be diminished [28]. Earlier iterations of the PSANZ Classification System in Australia followed a hierarchical approach (e.g., if a congenital anomaly was present, it was classified as the cause of death) however now employs rules around common scenarios when multiple factors are involved (e.g. congenital anomaly is only classified if it is determined to be the cause of death). Changes in these rules may have impacted reported rates of preterm perinatal deaths due to congenital anomaly.[77] Consensus has not been reached on the use of a hierarchical approach to classifying perinatal deaths.[28]

Question 41: What distinguishes causes and associated factors?

There are inherent challenges in ascertaining the cause of stillbirth as there is always an overlap between actual cause and associated conditions including risk factors[84,130] and classification systems require detailed guidance to ensure consistency and accuracy[84] and classification through multidisciplinary discussion.

Some classification systems aim only to identify the relevant condition at the time of fetal death rather than differentiating underlying cause and associated conditions which may help to identify preventable deaths.[81,132] Simply including conditions that appear anywhere in the causal chain, rather than considering underlying condition alone, can markedly change the proportion of deaths attributed to various diagnoses.[133] and limits effective policies and further research to understand and effectively reduce these deaths.[133] As an example, fetal growth restriction (FGR) is accepted as an associated condition linked to other conditions leading to placental pathology; that is, FGR is on the causal pathway to perinatal death. Therefore, in recent updates to the PSANZ-PDC, the FGR category has been replaced with the causal category 'placental dysfunction or causative placental pathology' while allowing the presence of FGR to be captured as an associated condition.[77]

In an Australian study, close to 60% of stillbirths noted to have FGR had additional pathology identified as the underlying cause.[77] Women with high BMI had a much higher risk of FGR-associated stillbirth. While not underlying causes, identification of these conditions (high BMI, FGR) has important implications when developing strategies to reduce the risk of perinatal death. Further, comprehensive classification of all contributing conditions is also helpful in identifying specific medical conditions including chronic kidney disease and hypertensive disease that significantly increased the risk of severe maternal morbidity among women having a stillbirth.[134]

Question 42: How does the PSANZ system compare to ICD-PM in terms of cause of death outcomes? Including proportion of unexplained stillbirths. Can the PSANZ system be accurately mapped retrospectively to ICD-PM?

Alignment of 21 classification systems used across HICs with ICD-PM was examined in a systematic review.[84] Scoring (yes=1; partially=0.5; no=0) was undertaken against 1) whether the system

distinguished between antepartum and intrapartum stillbirth; 2) allows both fetal and maternal conditions to be recorded (yes=1; no=0); and (3) uses ICD codes (yes=1; no or unclear= 0). Of the 21 classification systems used, only one (CODAC) was fully aligned with the ICD-PM.[84] Four systems met two of the three criteria used to assess alignment, and 14 systems scored 0.5–1.5 out of a maximum of 3. The PSANZ Classification system scored of 1.5 out of 3. 9. In this systematic review, all causes of stillbirths reported globally could be accommodated within the ICD-PM. However, mapping of causes from good quality reports in high-income countries (including Australia and New Zealand) using clinical classification systems highlighted substantial variation in results. Meeting the needs of diverse settings is essential for global comparisons to identify important variation and inform programmatic change to reduce deaths.[84]

Question 43: What is the optimal classification system for identifying contributing factors relating to care in perinatal deaths to inform policy and practice change and future research to reduce perinatal deaths?

Existing national programs use different classification systems for causes of death making comparisons difficult.[1] In general, perinatal mortality audits consider the presence of contributing factors in three main areas: (i) the woman including her social situation; (ii) the setting in which the care was provided; and (iii) the clinical care provided.[1]

In Queensland, a central health department committee used the PSANZ Guideline tool to determine contributing factors relating to care.[11] A multidisciplinary team (including consumers) used case summaries and test results obtained for maternity services to determine the presence of substandard care against best available guidelines and protocols. The contributing factors were assigned to one of three categories: organisation/management (e.g., inadequate supervision of staff, lack of appropriate clinical management protocols, lack of communication between services), personnel (e.g., staff factors relating to professional care and service provision) and accessing/engaging with care (e.g., no, infrequent or late booking for antenatal care, women decline treatment/advice). The contribution of each identified factor in the death was then classified as: insignificant (suboptimal factors identified but unlikely to have contributed to the outcome), possible (suboptimal factors identified might have contributed to the outcome), significant (suboptimal factors identified were likely to have contributed to the outcome). Of 56 perinatal deaths audited, contributing factors were identified in 46 deaths, with contributing factors possibly relating to the outcome in 20 cases and significantly likely to have contributed to the outcome in another 20 cases.[11] Study investigators concluded that the PSANZ guidelines enable a systematic approach to aid perinatal mortality audit implementation and reporting.[11]

In Jordan, a “3 delay model” was used to determine modifiable factors contributing to perinatal deaths at three critical timepoints where healthcare provision can be delayed: a recognising the need for care and the decision to seek care, reaching care, and receiving care.[62] Of the 264 perinatal deaths reviewed, a delay in recognising the need for care and the decision to seek care contributed to almost 45% of deaths, a delay in reaching care contributed to 3% of deaths, and a delay in receiving care contributed to 30% deaths. The most common modifiable factors relating to poor antenatal care, the parents’ awareness of the problem or recognition of danger signs, parents’ financial concerns, insufficient clinician training and high workload.[62]

Questions 44 and 45: How should perinatal death be defined to enhance practice change and research? Which definition should be used, and should there be conditional definitions e.g., termination of pregnancy for medical reasons, gestational cohorts?

"There is probably no health outcome with a great number of conflicting, authoritative, legally mandated definitions" than that of fetal death in utero.[135] Across HICs, the lower limit of gestation for classifications of stillbirths varies from 20 to 28 weeks' gestation of pregnancy,[22,136] and the inclusion/exclusion of late terminations of pregnancies varies,[22] affecting national perinatal mortality rates.[22] In a global review of classification systems, poor data quality, insufficient detail in reports of stillbirth causes, and the inability to identify terminations of pregnancies in reporting of stillbirth causes was problematic.[84]The lack of standardised reporting criteria or clearly established definitions for perinatal death across HICs is a barrier to perinatal mortality audit and limits international comparisons.[4,21,22,136]

Canada's stillbirth definition (≥20 weeks' gestation of pregnancy or with a birth weight ≥500 g) and registration processes impede clinical care and public health [137]. Problems with the Canadian stillbirth definition and registration processes relate to the inconsistent viability criteria for reporting stillbirth (≥20 weeks' gestational age criterion is not congruent with ≥500 g, with the median birth weight at 20 weeks being 400 g. ≥20 weeks' gestational age criterion excludes fetuses born at <20 weeks, while the birth weight cut-off of ≥500 g means that some fetuses at 18 and 19 weeks' gestation may be registered), the inclusion of late terminations of pregnancies for congenital anomaly resulting in an artefactual increase in stillbirth rates and, the inclusion of fetal reductions (for multi-fetal pregnancy) as stillbirths [137]. The gestational age at fetal death and gestational age at stillbirth may be separated by hours, days, weeks, or months. The age at fetal death has greater etiologic and prognostic significance than the timing of the stillbirth, while both may be relevant from a maternal care standpoint [137]. Suggestions to overcome current issues include:

- All spontaneous fetal deaths at ≥20 weeks' gestation (or ≥400 g birth weight if gestational age is unknown) should be registered as vital events.
- That Canada's registration and surveillance processes focus on fetal death (i.e., death of the fetus at >20 weeks' gestation), rather than stillbirth (i.e., birth of an expired fetus ≥20 weeks' gestation). Both gestational age at fetal death and gestational age at stillbirth be documented for fetal deaths ≥20 weeks' gestation, and in cases where the gestational age at fetal death is unknown, the gestational age at stillbirth should be used as the gestational age at fetal death for documentation purposes.
- The distinction between a spontaneous fetal death at ≥20 weeks' gestation and a fetal death due to induced abortion at ≥20 weeks' gestation should be recognised.[137]

For international comparison of stillbirth rates, the WHO recommends 28 weeks' gestation as the lower limit for classification of stillbirths.[22] However, only including stillbirths from 28 weeks' gestation may underestimate the true burden of stillbirth.[138] A population-based study of 19 European countries reporting livebirths and stillbirths ≥ 22 weeks' gestation in 2015, found that one-third of stillbirths occur at 22 weeks to less than 28 weeks of gestation.[138] The study found consistent reporting of stillbirths at 24 weeks to less than 28 weeks across the 19 countries, suggesting that these deaths should be included in routinely reported stillbirth rates and international comparisons to inform clinical practice and policy.[138]

Resource-limited settings

In Pakistan, misclassification of stillbirth is a significant barrier to preventive strategies.[139]. About two-thirds of the Lady Health Workers (n=65) interviewed were unable to differentiate clearly between stillbirths and other adverse pregnancy outcomes and neonatal deaths.[139]

> *"It is very confusing to define stillbirth. I have asked the Lady Health Supervisor about the difference between a stillbirth and a neonatal death. She said, it's almost the same, so we can report it any way we want" – Lady Health Worker.*[139]

Study investigators recommend aligning the stillbirth reporting system in Pakistan with the WHO definition of stillbirth to avoid underreporting.[139]

Grey literature & other sources

In addition to the published academic literature, international and national government agency websites were searched for relevant information relating to perinatal mortality audit, including considerations around classification of stillbirth and neonatal death. A targeted Google search was also conducted. The findings of the grey literature are supported by both the current and previous editions of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*.

Audit

In 2016, the WHO launched the *Making every baby count: audit and review of stillbirths and neonatal deaths guideline* to assist healthcare professionals and managers establish a system for reviewing perinatal deaths at a healthcare facility level [2]. The guide recommends perinatal deaths are reviewed by interdisciplinary teams using a "no blame, no shame" approach through a six-step cycle: (1) identifying cases; (2) collecting information; (3) analysing information; (4) recommending solutions; (5) implementing solutions; and (6) evaluating the process and the outcomes and refining the process. The guide also provides information on expanding from an individual facility mortality audit system into a coordinated regional and/or national audit program. Such national perinatal mortality audit programs are successfully run in the UK through MBRRACE (Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries),[140] in New Zealand through PMMRC,[6] in the Netherlands through NAP[7,8] and in Ireland through NPEC.[141]

In 2018, MBRRACE established a national online Perinatal Mortality Review Tool to support standardised perinatal reviews cross NHS maternity and neonatal units in in the UK.[9] The tool includes materials to support NHS staff in engaging with parents during perinatal review. A flow chart for engaging with parents during perinatal review, a template information leaflet about perinatal review, template letter to parents, template parent feedback forms, and guidance for writing a plain English summary to parents following perinatal review are based on findings from the PARENTS studies (reviewed in Q23–34 of this technical report).

Australia is yet to establish a national perinatal audit program; however, state and territory committees produce regular reports on rates and causes of perinatal mortality. See Appendix 7F for an overview of the key aspects of state and territory reports.[142-149]

Classification

Perinatal mortality audit programs across high-income countries use different classification system for causes of stillbirths and neonatal deaths. In Australia and New Zealand, the PSANZ Classification System for Stillbirths and Neonatal deaths[150] is used to classify causes and associated conditions of perinatal deaths and the results are included in national reporting by the Australian Institute of Health and Welfare and the Perinatal and Maternal Mortality Review Committee.[6,151] In the UK, causes of perinatal death using the CODAC) classification system are reported to MBRRACE.[140] In the Netherlands, the Tulip system is used for national audit studies.[7,8] While the Canadian Perinatal Surveillance System (CPSS) uses a simple system to classify causes of stillbirths as one component of tracking the "fetal mortality rate".[152] Classification systems differ in their structure, rules, and definitions around cause of death and associated conditions, as outlined in the International Stillbirth Alliance Scientific Advisory Committee Background Report for a 2017 workshop on classification systems for data-rich settings.[153]

To enhance global comparison and overcome limitations of existing classification systems in use, the International Stillbirth Alliance are developing a classification system for causes of stillbirths and

neonatal deaths suitable for data-rich settings.[153] The system draws on existing classification systems used in high-income settings most align with the Delphi characteristics for an effective classification system and maps to the ICD-PM.[153] An evaluation of the ISA Classification System is scheduled to commence in 2023.[154]

References

This updated guideline comprises a systematic evidence review for studies published between 2017 and 2023. However, evidence not identified in the search but considered seminal by the Guideline Development Committee is also included in the summary of this report. This evidence includes methodology citations and grey literature and is indicated in the reference list by an asterisk (*)

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Table 3. Recommendations and summary of CERQual rating

Contributing studies		GRADE-CERQual Overall confidence Rating of evidence	Guideline recommendations
Lehner et al. 2019 Flenady et al. 2021 Knight et al. 2019 Helps et al. 2020 Sterpu et al. 2020 Gutman et al. 2022 Ebenezer et al 2019	Gondwe et al 2021 Kirabira et al 2020 Kinney et al 2020 Kinney et al 2022 Wilcox et al 2020 Vallely et al 2021a	Moderate confidence *No concerns of coherence. Minor concerns of methodological limitation and data adequacy. Moderate concerns of relevance.*	**Evidence-based recommendation 7.1:** All maternal and newborn services should implement a formal process for perinatal mortality audit, including identification of causes, associated conditions, and contributing factors relating to care
			Consensus-based recommendation 7.2: Smaller services, including those in rural and remote regions, are encouraged to participate in combined perinatal audit meetings with other experienced maternity and newborn services to ensure high-quality audit.
			Consensus-based recommendation 7.3: If a baby dies outside the hospital of birth, the audit should ideally be carried out by the hospital where the baby was born. Communication between hospitals that provided care is needed to ensure the perinatal mortality audit committee has access to all relevant details.
			Consensus-based recommendation 7.4: All maternal and newborn services should ensure that appropriate systems for undertaking perinatal mortality audit, reporting of findings, and implementation of recommendations are in place and that the perinatal mortality audit committee is adequately supported to ensure perinatal mortality audit is conducted effectively.
Bakhbakhi et al 2019 Bezhenar 2021		Low confidence	**Consensus-based recommendation 7.5:** The Perinatal Mortality Audit Committee should arrange for review of perinatal death to occur in a

Helps et al. 2020 Higgins et al 2018		*Minor concerns of methodological limitation, relevance, and coherence. Major concerns of data adequacy.*	timely manner, aiming to have the results in time for the initial follow-up visit with parents. • If test results are delayed, it may be necessary to re-review and arrange additional follow-up meetings with the parents to provide final results.
Bakhbakhi et al 2018 Bakhbakhi et al 2019 Burden et al 2021		Low confidence *No concerns of coherence, minor concerns of methodological limitation. Moderate concerns of relevance, and major concerns of data adequacy.*	**Consensus-based recommendation 7.6:** Discuss the audit process with parents including how parents may be involved, and when, and how the results of the audit will be provided. • This should be conducted by an experienced healthcare professional, ideally the lead healthcare professional involved in the parent's care or the known point of contact for each family/whānau (such as a bereavement midwife).
Bakhbakhi et al 2017 Bakhbakhi et al 2018 Flenady et al. 2017	Bakhbakhi et al 2019 Burden et al 2021 Helps et al 2020	Low confidence *No concerns of coherence, minor concerns of methodological limitation. Moderate concerns of relevance and data adequacy.*	**Consensus-based recommendation 7.7:** Offer parents the option of providing a summary of events for presentation at the audit meeting either through a written summary using the Australian Perinatal Mortality Audit Tool, or local equivalent, and/or a healthcare professional presenting information on their behalf.
Taweevisit et al 2022 Gulati et al 2020 Aminu et al 2017 Fabrizio et al 2022 Reinebrant et al 2018 Basu et al 2018 Kapurubandara et al 2017 Haruyama et al 2018	Hyde et al 2020 Jones et al 2017 Jayaratnam et al 2020 Vallely et al 2021 Housseine et al 2021 Vieira et al 2020 Kc et al 2020 Goldenberg 2019	High confidence *No concerns of coherence. Minor concerns of methodological limitation, relevance and data adequacy.*	**Evidence-based recommendation 7.8:** Perinatal mortality audit committees should ensure the classification of causes and associated factors for stillbirths and neonatal deaths use the best available information from a comprehensive history and appropriate investigation (see Section 6: Investigations for perinatal death)
			Consensus-based recommendation 7.9: The Australian Perinatal Mortality Audit Tool (or local equivalent) or the New Zealand Mother

			and Baby Rapid Reporting Forms for a Perinatal Death should be completed for each perinatal death in Australia and Aotearoa New Zealand, respectively, for purposes of committee review of the death and for relevant local and jurisdictional reporting requirements.
ACOG 2018 Bezhenar 2021 Higgins et al 2018		Low confidence *Moderate concerns of methodological limitation and data adequacy. Minor concerns of relevance, no concerns of coherence.*	**Consensus-based recommendation 7.10:** The Medical Certificate of Perinatal Death should be completed by (or supervised by) the lead/experienced healthcare professional responsible for care around the time of the death in accordance with local requirements.
Bakhbakhi et al. 2018 Bakhbakhi et al. 2019 Bartlett et al 2017 D'Aloja et al. 2021 Gulati et al 2020 Gutman et al 2022 Helps et al. 2020 Burke et al 2023	Gondwe et al. 2021 Kinney et al 2020 Mukinda et al 2021 Aguinara et al 2021 Knight et al 2019 Fabrizio et al 2022 Willcox et al 2023	Moderate confidence *Minor concerns of relevance, methodological limitation, data adequacy and coherence are noted.*	**Evidence-based recommendation 7.11:** The perinatal mortality audit process should be overseen by a multidisciplinary committee including medical staff (obstetric and neonatal), midwives, nurses, a perinatal pathologist (where possible), and parent advocate.
Helps et al 2020 Gutman et al 2022 Knight et al 2019	Gondwe et al 2021 Cetin et al 2022 Willcox 2023	Moderate confidence *Moderate concerns of data adequacy, minor concerns of methodological limitation, relevance and coherence.*	**Evidence-based recommendation 7.12:** The perinatal mortality committee chair must ensure audits are conducted in a no-blame environment.
Flenady et al 2021 Tindal et al 2022	Bartlett et al 2017 Angell et al 2019 Leisher 2016	High confidence *Minor concerns of methodological limitation, relevance and data adequacy. No concerns of coherence.*	**Evidence-based recommendation 7.13:** Perinatal mortality audit committees should use the PSANZ Classification system to assign the underlying cause of death and up to two associated conditions for every perinatal death after consideration of all relevant clinical information.

Bezhenar et al 2021 Higgins et al 2018 Lehner et al 2019	**Low confidence** *Major concerns of data adequacy. Moderate concerns of methodological limitation and relevance. Minor concerns of coherence.*	**Consensus-based recommendation 7.14:** Revise the death certificate based on the outcome of the perinatal mortality audit meeting and ensure a revised copy is sent to the parents.
		Consensus-based recommendation 7.15: The perinatal mortality audit committee should consider areas for practice improvement in relation to every perinatal death and develop recommendations and an accompanying implementation plan where relevant. This should also include any recommendations for care of the woman in a subsequent pregnancy.
Bakhbakhi et al 2018 Bakhbakhi et al 2019 Burden et al 2021	**Low confidence** *No or minor concerns of methodological limitation and coherence. Moderate concerns of relevance and data adequacy.*	**Consensus-based recommendation 7.16:** A follow-up meeting with the parents, ideally with the senior healthcare professional involved in the woman's care and the healthcare professional managing the perinatal mortality audit process (for example bereavement-care midwife), should be offered to discuss the outcome of the review by the perinatal mortality audit committee. There may be a need for more than one follow-up meeting depending on when the final results of investigations become available, and the audit committee finalises the review.
Bakhbakhi et al 2019 Burden et al 2021 Helps et al 2020	**Moderate confidence** *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*	**Evidence-based recommendation 7.17:** Parents should be offered a plain language summary of the outcome of the review of their baby's case by the perinatal mortality audit committee. Ideally, this should occur during a face-to-face follow-up meeting with the lead healthcare provider, the bereavement midwife, and other relevant members of the health care team.
		Consensus-based recommendation 7.18: A comprehensive clinical summary should be sent to the general practitioner and all care

			providers nominated to the parents after review by the perinatal mortality committee.
Best et al 2019 D'Aloja et al 2021 Flenady et al 2021 Helps et al 2020 Helps et al 2021a	Helps et al 2021b Knight et al 2019 Norris et al 2017	Moderate confidence *No or minor concerns of data adequacy, methodological limitation, and coherence. Moderate concerns of relevance.*	**Evidence-based recommendation 7.19:** Following the completion of the review by the perinatal mortality audit committee, the chair of the perinatal mortality audit committee or delegate should ensure a summary of the classification of causes and contributing factors relating to care is provided to the jurisdictional perinatal mortality committees for regional and national reporting.
Best et al 2019 D'Aloja et al 2021 Flenady et al 2021 Helps et al 2020 Helps et al 2021a	Helps et al 2021b Knight et al 2019 Norris et al 2017	Moderate confidence *No or low confidence of methodological limitation, coherence and data adequacy. Moderate concerns of relevance.*	**Evidence-based recommendation 7.20:** The assigned classifications for causes and contributing factors relating to care should be included in the routine perinatal data collections across jurisdictions for every perinatal death to enable comprehensive reporting of perinatal deaths.
Gutman et al 2022 Helps et al 2020 Joseph et al 2021 Reinebrant et al 2018		Low confidence *No or minor concerns of coherence and methodological limitation. Moderate concerns of relevance and data adequacy.*	**Consensus-based recommendation 7.21:** National definitions for statistical reporting of perinatal deaths should be used to ensure consistency and comparability in perinatal death data across Australia and Aotearoa New Zealand. Reports of perinatal deaths should present data with and without the inclusion of perinatal deaths resulting from termination of pregnancy.

Section 1: Audit

Note. For the 45 research questions identified for perinatal mortality audit and classification, six searches were conducted.

Table 4. Search strategy for Section 1 Search A: Staff training, documentation, and reporting

Database		Search strategy	
PubMed			
	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]	Mesh
	#2	("Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"[Title/Abstract] OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract])	Title/abstract
	#3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])	Title/abstract
	#4	("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "prenatal diagnosis") AND (terminat* or abortion or abort)	Title/abstract
	#5	#1 OR #2 OR #3 OR #4	
	#6	((((staff or ((healthcare or "health care") AND (professional or carer or team or personne* or workers)) or nurs* or midwi* or student* or doctor or obstetric* or practition* or specialist or "fetal medicine" or provider or facility* or institution* or registrar) AND (educat* or train or training or mentor* or simulation or pedagogy or "simulation-based")) AND (audit or review)))	Title/abstract
	#7	(documentation[Title/Abstract] OR documenting[Title/Abstract] OR document[Title/Abstract] OR "write up"[Title/Abstract] OR "medical note"[Title/Abstract] OR "medical note*"[Title/Abstract] OR "clinical summary"[Title/Abstract] OR reporting[Title/Abstract] OR "medical report*"[Title/Abstract] OR "clinical report*"[Title/Abstract] OR "required report*"[Title/Abstract] OR "reporting requirement*"[Title/Abstract] OR "discharge report*"[Title/Abstract] OR "discharge summar*"[Title/Abstract] OR referral[Title/Abstract]) AND ((strategies[Title/Abstract] OR strategy[Title/Abstract] OR standard[Title/Abstract] OR standards[Title/Abstract] OR requirement[Title/Abstract] OR requirements[Title/Abstract] OR clear[Title/Abstract] OR optimal[Title/Abstract] OR format[Title/Abstract] OR content[Title/Abstract]))	Title/abstract
	#8	"Education Department, Hospital"[Mesh] OR "Staff Development"[Mesh] OR "Medical Records"[Mesh]	Mesh
	#9	#6 OR #7 OR #8	
	#10	#5 AND #9	
Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees	
	#2	MeSH descriptor: [Perinatal Death] explode all trees	
	#3	MeSH descriptor: [Perinatal Mortality] explode all trees	

	#4 MeSH descriptor: [Abortion, Induced] explode all trees #5 ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) NEAR/2 (death* OR wast* OR demise* OR mortalit*)):ti,ab,kw #6 (((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) NEAR/1 loss*) OR stillb* OR (palliative NEAR/5 (pregnancy or newborn or neonate or fetus or feotus))))):ti,ab,kw #7 (((((“fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "life limiting" or "life limiting") NEAR/3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term"))))):ti,ab,kw #8 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 #9 ((((staff or ((healthcare or "health care") NEAR/2 (professional or carer or team or personne* or workers)) or nurs* or midwi* or student* or doctor or obstetric* or practition* or specialist or "fetal medicine" or provider or facility* or institution* or registrar) NEAR/5 (educat* or train or training or mentor* or simulation or pedagogy or "simulation-based")) AND (audit or review))):ti,ab,kw #10 ((documentation or documenting or document or "write up" or "medical note" or "medical notes" or "clinical summary" or reporting or ((medical or clinical or requir* or medical or discharge or referral) NEAR/1 (report or reports)))):ti,ab,kw #11 ((strategies or strategy or standard or standards or requirement or requirements or clear or optimal or format or content)):ti,ab,kw #12 #10 AND #11 #13 #9 OR #12 #14 MeSH descriptor: [Staff Development] explode all trees #15 MeSH descriptor: [Medical Records] this term only #16 MeSH descriptor: [Education, Nursing] explode all trees #17 #13 OR #14 OR #15 OR #16 #18 #17 AND #8
CINAHL	S16 S5 AND S13 S15 S5 AND S13 S14 S5 AND S13 S13 S6 OR S9 OR S10 OR S11 OR S12 S12 S7 AND S8 S11 (MM "Patient Record Systems") OR (MM "Medical Records") S10 (MM "Education") OR (MM "Education, Interdisciplinary") S9 (MM "Staff Development") S8 AB (strategies or strategy or standard or standards or requirement or requirements or clear or optimal or format or content)

	S7	AB (documentation or documenting or document or "write up" or "medical note" or "medical notes" or "clinical summary" or reporting or ((medical or clinical or requir* or medical or discharge or referral) N1 (report or reports)))
	S6	AB (((staff or ((healthcare or "health care") N2 (professional or carer or team or personne* or workers)) or nurs* or midwi* or student* or doctor or obstetric* or practition* or specialist or "fetal medicine" or provider or facility* or institution* or registrar) N5 (educat* or train or training or mentor* or simulation or pedagogy or "simulation-based")) AND (audit or review))
	S5	(S1 OR S2 OR S3 OR S4)
	S4	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
	S3	AB (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort))
	S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
Scopus		(((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)) OR (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "life limiting" or "life limiting") W/3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term" or "termination of pregnancy" or "pregnancy termination")) OR (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) W/1 loss*) or abortus* or stillb*)) AND (((staff or ((healthcare or "health care") W/2 (professional or carer or team or personne* or workers)) or nurs* or midwi* or student* or doctor or obstetric* or practition* or specialist or "fetal medicine" or provider or facility* or institution* or registrar) W/5 (educat* or train or training or mentor* or simulation or pedagogy or "simulation-based")) AND (audit or review)) OR ((documentation or documenting or document or "write up" or "medical note" or "medical notes" or "clinical summary" or reporting or ((medical or clinical or requir* or medical or discharge or referral) W/1 (report or reports))) AND (strategies or strategy or standard or standards or requirement or requirements or clear or optimal or format or content))
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/
	2	((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.

	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "life limiting" or "life limiting") adj3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term" or "termination of pregnancy" or "pregnancy termination")).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) adj1 loss*) or abortus* or stillb*).ti,ab.
	5	1 or 2 or 3 or 4
	6	(((staff or ((healthcare or "health care") adj2 (professional or carer or team or personne* or workers)) or nurs* or midwi* or student* or doctor or obstetric* or practition* or specialist or "fetal medicine" or provider or facility* or institution* or registrar) adj5 (educat* or train or training or mentor* or simulation or pedagogy or "simulation-based")) AND (audit or review)).ti,ab.
	7	(documentation or documenting or document or "write up" or "medical note" or "medical notes" or "clinical summary" or reporting or ((medical or clinical or requir* or medical or discharge or referral) adj1 (report or reports))).ti,ab.
	8	(strategies or strategy or standard or standards or requirement or requirements or clear or optimal or format or content).ti,ab.
	9	*training/ or *staff training/ or *education/ or *medical record/
	10	6 or (8 and 7) or 9
	11	5 AND 10
Australian Indigenous HealthInfoNet		"perinatal audit"
Informit Indigenous Collection		[All Fields: perinatal OR All Fields: stillbirth OR All Fields: 'neonatal death'] AND [All Fields: audit OR All Fields: review]

Table 5. Search strategy for Section 1 Search B: Parental engagement

Database		Search strategy
PubMed	11	#4 AND #7 AND #10
	10	#8 OR #9
	9	(("care coordinator"[Title/Abstract] OR "coordinator"[Title/Abstract] OR "point of contact"[Title/Abstract] OR manager[Title/Abstract] OR proces*[Title/Abstract] OR "open-disclosure"[Title/Abstract] OR "open disclosure"[Title/Abstract] OR communicat*[Title/Abstract]))
	8	((parent*[Title/Abstract] OR mother*[Title/Abstract] OR father*[Title/Abstract] OR family[Title/Abstract] OR "family's"[Title/Abstract] OR families[Title/Abstract] OR migrant[Title/Abstract] OR immigrant[Title/Abstract] OR refugee*[Title/Abstract] OR "indigenous"[Title/Abstract] OR "torres strait islander*"[Title/Abstract] OR ATSI[Title/Abstract] OR aborigin*[Title/Abstract] OR islander*[Title/Abstract] OR remote*[Title/Abstract] OR "linguistically diverse"[Title/Abstract] OR "literacy"[Title/Abstract] OR "low income"[Title/Abstract] OR "cultural care"[Title/Abstract] OR elder[Title/Abstract] OR maori[Title/Abstract] OR whanau[Title/Abstract] OR cost[Title/Abstract] OR economic*[Title/Abstract] OR sibling[Title/Abstract]))
	7	#5 OR #6
	6	"Medical Audit"[Mesh] OR "Management Audit"[Mesh]

	5	(((perinatal[Title/Abstract] OR mortality[Title/Abstract] OR death[Title/Abstract] OR "post-mortem"[Title/Abstract] OR "post mortem"[Title/Abstract] OR case[Title/Abstract] OR institutional[Title/Abstract] OR regional[Title/Abstract] OR organisatio*[Title/Abstract] OR organization*[Title/Abstract]) AND (audit[Title/Abstract] OR reporting[Title/Abstract])) OR "substandard care" OR "suboptimal care" OR "Contribute to")
	4	#1 OR #2 OR #3
	3	("fetal malformation"[Title/Abstract] OR "congenital abnormality"[Title/Abstract] OR "fetal anomaly"[Title/Abstract] OR "congenital anomaly"[Title/Abstract] OR "fetal anomalies"[Title/Abstract] OR "congenital anomalies"[Title/Abstract] OR "prenatal diagnosis"[Title/Abstract]) AND (terminat*[Title/Abstract] OR abortion[Title/Abstract] OR abort[Title/Abstract])
	2	("Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"[Title/Abstract] OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract])
	1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]
Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees
	#2	MeSH descriptor: [Perinatal Death] explode all trees
	#3	MeSH descriptor: [Perinatal Mortality] explode all trees
	#4	MeSH descriptor: [Abortion, Induced] explode all trees
	#5	((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) NEAR/2 (death* OR wast* OR demise* OR mortalit*)):ti,ab,kw
	#6	(((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal" OR neonatal) NEAR/1 loss*) OR stillb*))):ti,ab,kw
	#7	#1 OR #2 OR #3 OR #4 OR #5 OR #
	#8	(((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) NEAR/3 (care or audit or review or survey or reporting))):ti,ab,kw
	#9	MeSH descriptor: [Medical Audit] explode all trees
	#10	MeSH descriptor: [Clinical Audit] explode all trees
	#11	#8 OR #9 OR #10
	#12	((parent* or mother* or father* or family or "family's" or families or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elder or maori or whanau or cost or economic* or sibling)):ti,ab,kw
	#13	(("care coordinator" or "coordinator" or "point of contact" or manager or proces* or "open-disclosure" or "open disclosure" or communicat*)):ti,ab,kw
	#14	MeSH descriptor: [Parents] explode all trees
	#15	#12 OR #13 OR #14
CINAHL	S12	S9 AND S10 AND S11

	S11	S6 OR S7 OR S8
	S10	(S4 OR S5)
	S9	(S1 OR S2 OR S3)
	S8	(MM "Parents")
	S7	AB ("care coordinator" or "coordinator" or "point of contact" or manager or proces* or "open-disclosure" or "open disclosure" or communicat*)
	S6	AB (parent* or mother* or father* or family or "family's" or families or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elder or maori or whanau or cost or economic* or sibling)
	S5	(MM "Record Review") OR (MM "Nursing Audit") OR (MM "Audit")
	S4	AB ((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) N3 (care or audit or review or survey or reporting))
	S3	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
	S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
Scopus	((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)) OR ((((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) W/1 loss*) or abortus* or stillb*)) AND ((((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) W/3 (care or audit or review or survey or reporting)) OR "medical audit")) AND ((parent* or mother* or father* or family or "family's" or families or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elder or maori or whanau or cost or economic* or sibling)) OR ("care coordinator" or "coordinator" or "point of contact" or manager or proces* or "open-disclosure" or "open disclosure" or communicat*))	
Embase		
	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/
	2	((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.

	3	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) adj1 loss*) or abortus* or stillb*).ti,ab.
	4	1 or 2 or 3
	5	((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) adj3 (care or audit or review or survey or reporting)).ti,ab.
	6	*medical audit/
	7	5 or 6
	8	(parent* or mother* or father* or family or "family's" or families or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or remote* or "linguistically diverse" or "literacy" or "low income" or "cultural care" or elder or maori or whanau or cost or economic* or sibling).ti,ab.
	9	("care coordinator" or "coordinator" or "point of contact" or manager or proces* or "open-disclosure" or "open disclosure" or communicat*).ti,ab.
	10	*parent/
	11	8 or 9 or 10
	12	4 AND 7 AND 11
Australian Indigenous HealthInfoNet		"perinatal audit"
Informit Indigenous Collection		[All Fields: perinatal OR All Fields: stillbirth OR All Fields: 'neonatal death'] AND [All Fields: audit OR All Fields: review]

Table 6. Search strategy for Section 1 Search C: Personnel, processes, and death certificate requirements

Database	Search strategy	
PubMed	12	#3 AND #9
	11	#3 AND #9
	10	#3 AND #9
	9	#8 OR #7 OR #6 OR #5 OR #4
	8	"death certificat*"[Title/Abstract] OR "medical certificat*"[Title/Abstract]
	7	("jurisdictional need*"[Title/Abstract] OR "jurisdictional requir*"[Title/Abstract] OR "clinical requir*"[Title/Abstract] OR "council requir*"[Title/Abstract] OR composition[Title/Abstract] OR attendance[Title/Abstract] OR (findin*[Title/Abstract] AND (Implemen*[Title/Abstract] or "practice chang*"[Title/Abstract])))
	6	(((perinatal[Title/Abstract] OR mortality[Title/Abstract] OR death[Title/Abstract] OR "post-mortem"[Title/Abstract] OR "post mortem"[Title/Abstract] OR institutional[Title/Abstract] OR regional[Title/Abstract] OR organisatio*[Title/Abstract] OR organization*[Title/Abstract]) AND (audit[Title/Abstract])) OR "substandard care" OR "suboptimal care" OR "Contribute to")
	5	"Death Certificates"[Mesh]
	4	"Medical Audit"[Mesh] OR "Management Audit"[Mesh]
	3	#1 OR #2
	2	("Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"[Title/Abstract] OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract])
	1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]
Cochrane	ID	Search Hits
	#1	MeSH descriptor: [Fetal Death] explode all trees
	#2	MeSH descriptor: [Perinatal Death] explode all trees
	#3	MeSH descriptor: [Perinatal Mortality] explode all trees
	#4	MeSH descriptor: [Abortion, Induced] explode all trees
	#5	((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) NEAR/2 (death* OR wast* OR demise* OR mortalit*)):ti,ab,kw
	#6	(((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) NEAR/1 loss*) OR stillb*))):ti,ab,kw
	#7	#1 OR #2 OR #3 OR #4 OR #5 OR #6
	#8	MeSH descriptor: [Medical Audit] explode all trees
	#9	MeSH descriptor: [Clinical Audit] explode all trees

		#10 (((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) NEAR/3 (care or audit or audits or review or reviews or survey or surveys or surveillance or reporting) and (effect* or outcome or outcomes or evalua* or impact or "aspects of" or timing or delay or delays or needs or information or require or require* or fulfilment or online or "web-based" or "web based" or ((jurisdictional or council or govern*) NEAR/3 (needs or need or require* or require)) or composition or attendance or model or models or guide or guideline or mento* or coach* or coach or superviso* or (findin* and (implement* or "practice chang*")))):ti,ab,kw #11 MeSH descriptor: [Death Certificates] explode all trees #12 ((("death certificate*" or "medical certificate*") NEAR/9 (quality or compo* or information or completion or writ* or provis* or update or modif* or correc*))):ti,ab,kw #13 #8 OR #9 OR #10 OR #11 OR #12 #14 #7 AND #13
CINAHL	S12	S4 AND S9
	S11	S4 AND S9
	S10	S4 AND S9
	S9	S5 OR S6 OR S7 OR S8
	S8	AB (("death certificate*" or "medical certificate*") N9 (quality or compo* or information or completion or writ* or provis* or update or modif* or correc*))
	S7	(MM "Audit")
	S6	(MM "Death Certificates")
	S5	AB ((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) N3 (care or audit or audits or review or reviews or survey or surveys or surveillance or reporting) and (effect* or outcome or outcomes or evalua* or impact or "aspects of" or timing or delay or delays or needs or information or require or require* or fulfilment or online or "web-based" or "web based" or ((jurisdictional or council or govern*) N3 (needs or need or require* or require)) or composition or attendance or model or models or guide or guideline or mento* or coach* or coach or superviso* or (findin* and (implement* or "practice chang*"))))
	S4	(S1 OR S2 OR S3)
	S3	AB AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
	S2	AB AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")

Scopus	((TITLE-ABS-KEY(((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)))) OR (TITLE-ABS-KEY((((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) W/1 loss*) or abortus* or stillb*)))) AND ((TITLE-ABS-KEY(((perinatal or mortality or death or "post-mortem" or "post mortem" or medical or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) W/2 (audit or audits or review or reviews or survey or surveys or surveillance or reporting) and (effect* or evalua* or impact or "aspects of" or timing or delay or delays or needs or information or require or require* or fulfilment or online or "web-based" or "web based" or "substandard care" or "suboptimal care" or ((optim*) W/1 (care)) or ((jurisdictional or council or govern*) W/2 (require* or require)) or composition or attendance or models or guide or guideline or mento* or coach* or coach or superviso* or (findin* and (implement* or "practice chang*")))))) OR (TITLE-ABS-KEY((("death certificate*" or "medical certificate*") W/6 (quality or compo* or information or completion or writ* or provis* or update or modif* or correc*)))))
Embase	1 *stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/ 2 ((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab. 3 (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) adj1 loss*) or abortus* or stillb*).ti,ab. 4 1 or 2 or 3 5 ((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) adj3 (care or audit or audits or review or reviews or survey or surveys or surveillance or reporting) and (effect* or outcome or outcomes or evalua* or impact or "aspects of" or timing or delay or delays or needs or information or require or require* or fulfilment or online or "web-based" or "web based" or ((jurisdictional or council or govern*) adj3 (needs or need or require* or require)) or composition or attendance or model or models or guide or guideline or mento* or coach* or coach or superviso* or (findin* and (implement* or "practice chang*")))).ti,ab. 6 *medical audit/ or *death certificate/ 7 (("death certificate*" or "medical certificate*") adj9 (quality or compo* or information or completion or writ* or provis* or update or modif* or correc*)).ti,ab. 8 5 or 6 or 7 9 4 and 8
Australian Indigenous HealthInfoNet	“perinatal audit”
Informit Indigenous Collection	[All Fields: perinatal OR All Fields: stillbirth OR All Fields: 'neonatal death'] AND [All Fields: audit OR All Fields: review]

Table 7. Search strategy for Section 1 Search D: Handover to other healthcare professionals

Database	Search strategy		
Pubmed	14	#3 AND #12	
	13	#3 AND #12	
	12	#4 OR #7 OR #8 OR #9 OR #10 OR #11	
	11	(((perinatal[Title/Abstract] OR mortality[Title/Abstract] OR death[Title/Abstract] OR "post-mortem"[Title/Abstract] OR "post mortem"[Title/Abstract] OR institutional[Title/Abstract] OR regional[Title/Abstract] OR organisatio*[Title/Abstract] OR organization*[Title/Abstract]) AND (audit[Title/Abstract])) OR "substandard care" OR "suboptimal care" OR "Contribute to")	
	10	("jurisdictional need*"[Title/Abstract] OR "jurisdictional requir*"[Title/Abstract] OR "clinical requir*"[Title/Abstract] OR "council requir*"[Title/Abstract] OR composition[Title/Abstract] OR attendance[Title/Abstract] OR (findin*[Title/Abstract] AND Implemen*[Title/Abstract]))	
	9	((handover[Title/Abstract] OR "hand over"[Title/Abstract] OR "hand-over"[Title/Abstract] OR "summary"[Title/Abstract] OR "documentation"[Title/Abstract] OR "document"[Title/Abstract] OR "discharge"[Title/Abstract]) AND ("general practitioner"[Title/Abstract] OR GP[Title/Abstract] OR community[Title/Abstract] OR nurse[Title/Abstract] OR doctor[Title/Abstract]))	
	8	(("death certificate*"[Title/Abstract] OR "medical certificate*"[Title/Abstract]) AND (compo*[Title/Abstract] OR completion[Title/Abstract] OR writ*[Title/Abstract] OR provis*[Title/Abstract] OR modif*[Title/Abstract] OR correc*[Title/Abstract]))	
	7	"Death Certificates"[Mesh]	Most Recent
	4	"Medical Audit"[Mesh] OR "Management Audit"[Mesh]	
	3	#1 OR #2	
	2	("Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"[Title/Abstract] OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract])	
	1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]	
Cochrane	#1	MeSH descriptor: [Fetal Death] explode all trees	
	#2	MeSH descriptor: [Perinatal Death] explode all trees	
	#3	MeSH descriptor: [Perinatal Mortality] explode all trees	
	#4	MeSH descriptor: [Abortion, Induced] explode all trees	
	#5	((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) NEAR/2 (death* OR wast* OR demise* OR mortalit*)):ti,ab,kw	
	#6	(((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR “peri natal” OR neonatal) NEAR/1 loss*) OR stillb*))):ti,ab,kw	
	#7	#1 OR #2 OR #3 OR #4 OR #5 OR #6	

	#8	MeSH descriptor: [Medical Audit] explode all trees
	#9	MeSH descriptor: [Clinical Audit] explode all trees
	#10	(((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) NEAR/3 (care or audit or review or survey or reporting) NEAR/9 (effect* or outcome or evalua* or impact or "aspects of" or timing or delay or delays or needs or information or requirement or requirements or fulfilment or online or "web-based" or "web based" or ((jurisdictional or council or govern*) NEAR/3 (needs or need or require*)) or composition or attendance or model or models or guide or guideline or (findin* and implement*)))):ti,ab,kw
	#11	MeSH descriptor: [Death Certificates] explode all trees
	#12	((("death certificate*" or "medical certificate*") NEAR/9 (quality or compo* or information or completion or writ* or provis* or update or modif* or correc*))):ti,ab,kw
	#13	(((handover or "hand over" or "hand-over" or "summary" or "documentation" or "document" or "discharge") and ("general practitioner" or GP or community or nurse or doctor))):ti,ab,kw
	#14	#8 OR #9 OR #10 OR #11 OR #12 OR #13
	#15	#14 AND #7 with Cochrane Library publication date Between Jan 2017 and Oct 2022, in Trials
CINAHL	S11	S4 AND S10
	S10	S5 OR S6 OR S7 OR S8 OR S9
	S9	AB ((handover or "hand over" or "hand-over" or "summary" or "documentation" or "document" or "discharge") and ("general practitioner" or GP or community or nurse or doctor))
	S8	AB (("death certificate*" or "medical certificate*") N9 (quality or compo* or information or completion or writ* or provis* or update or modif* or correc*))
	S7	(MM "Death Certificates")
	S6	(MM "Audit")
	S5	AB ((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) N3 (care or audit or review or survey or reporting) N9 (effect* or outcome or evalua* or impact or "aspects of" or timing or delay or delays or needs or information or requirement or requirements or fulfilment or online or "web-based" or "web based" or ((jurisdictional or council or govern*) N3 (needs or need or require*)) or composition or attendance or model or models or guide or guideline or (findin* and implement*)))
	S4	(S1 OR S2 OR S3)
	S3	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
	S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")

Scopus	((TITLE-ABS-KEY((("death certificate*" or "medical certificate*") W/9 (quality or compo* or information or completion or writ* or provis* or update or modif* or correc*)))) OR (TITLE-ABS-KEY(((handover or "hand over" or "hand-over" or "summary" or "documentation" or "document" or "discharge") W/6 ("general practitioner" or GP or community or doctor)))) OR ((TITLE-ABS-KEY(((((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) W/2 (care or audit or review or survey or reporting)) OR "medical audit")))) AND (TITLE-ABS-KEY(((evalua* or "aspects of" or timing or delay or delays or information or requirement or requirements or fulfilment or online or "web-based" or "web based" or ((jurisdictional or council or govern*) W/2 (needs or need or require*)) or composition or attendance or guide or guideline or (findin* and implement*))))))) AND ((TITLE-ABS-KEY(((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)))) OR (TITLE-ABS-KEY(((((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) W/1 loss*) or abortus* or stillb*)))))
Embase	1 *stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/ 2 ((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab. 3 (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) adj1 loss*) or abortus* or stillb*).ti,ab. 4 ((perinatal or mortality or death or "post-mortem" or "post mortem" or case or institutional or regional or organisatio* or organization* or suboptimal or substandard or contribut*) adj3 (care or audit or review or survey or reporting) adj9 (effect* or outcome or evalua* or impact or "aspects of" or timing or delay or delays or needs or information or requirement or requirements or fulfilment or online or "web-based" or "web based" or ((jurisdictional or council or govern*) adj3 (needs or need or require*)) or composition or attendance or model or models or guide or guideline or (findin* and implement*))).ti,ab. 5 1 or 2 or 3 6 *medical audit/ or *death certificate/ 7 (("death certificate*" or "medical certificate*") adj9 (quality or compo* or information or completion or writ* or provis* or update or modif* or correc*)).ti,ab. 8 ((handover or "hand over" or "hand-over" or "summary" or "documentation" or "document" or "discharge") and ("general practitioner" or GP or community or nurse or doctor)).ti,ab. 9 4 or 6 or 7 or 8 10 5 and 9
Australian Indigenous HealthInfoNet	"perinatal audit"
Informit Indigenous Collection	[All Fields: perinatal OR All Fields: stillbirth OR All Fields: 'neonatal death'] AND [All Fields: audit OR All Fields: review]

Table 8. Search strategy for Section 1 Search E: Perinatal death classification

Database	Search strategy
Scopus	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)) OR (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)) OR (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*) AND ((death or "cause of death" or mortality or causes or cause or ((contributing or care or avoidable or preventable) W/2 (factor or risk or risks))) W/6 (classification or classifications or definition or definitions or classified)) OR (aberdeen or Bound OR Baird OR wigglesworth OR NICE OR PSANZ OR Tulip OR ReCoDe or CHAMPS or DeCoDe)
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Death] explode all trees #3 MeSH descriptor: [Perinatal Mortality] explode all trees #4 MeSH descriptor: [Abortion, Induced] explode all trees #5 ((fetal OR foetal OR fetus* OR perinatal OR prenatal OR antenatal OR "peri natal" OR intrapartum OR intrauterine OR "intra uterine" OR utero) NEAR/2 (death* OR wast* OR demise* OR mortalit*)):ti,ab,kw #6 (((((pregnancy OR foetal OR fetal OR fetus OR perinatal OR "peri natal" OR neonatal) NEAR/1 loss*) OR stillb* OR (palliative NEAR/5 (pregnancy or newborn or neonate or fetus or feotus))))):ti,ab,kw #7 (((((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "life limiting" or "life limiting") NEAR/3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term")))):ti,ab,kw #8 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 #9 (((death or "cause of death" or mortality or causes or cause or ((contributing or care or avoidable or preventable) NEAR/2 (factor or risk or risks))) NEAR/6 (classification or classifications or definition or definitions or classified))):ti,ab,kw #10 ((aberdeen or Bound OR Baird OR wigglesworth OR NICE OR PSANZ OR Tulip OR ReCoDe or CHAMPS or DeCoDe)):ti,ab,kw #11 MeSH descriptor: [Cause of Death] explode all trees #12 #9 OR #10 OR #11 #13 #8 AND #12
Australian Indigenous HealthInfoNet	“perinatal audit” “stillbirth audit”

Informit Indigenous Collection	[All Fields: perinatal OR All Fields: stillbirth OR All Fields: 'neonatal death'] AND [All Fields: audit OR All Fields: review]		
PubMed	#1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR "Abortion, Induced"[Mesh]	Mesh
	#2	("Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"[Title/Abstract] OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract])	Title/abstract
	#3	("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract])	Title/abstract
	#4	("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or “prenatal diagnosis”) AND (terminat* or abortion or abort)	Title/abstract
	#5	#1 OR #2 OR #3 OR #4	
	#6	(("cause of death" or mortality or causes or cause or ((contributing or care or avoidable or preventable) AND (factor or risk or risks))) AND (classification or classifications or definition or definitions or classified))	Title/abstract
	#7	((aberdeen or Bound OR Baird OR wigglesworth OR NICE OR PSANZ OR Tulip OR ReCoDe or CHAMPS or DeCoDe))	Title/abstract
	#8	"Cause of Death"[MeSH Terms]	Mesh
	#9	#6 OR #7 OR #8	
	#10	#5 AND #9	
CINAHL	S11	S5 AND S9	
	S10	S5 AND S9	
	S9	S6 OR S7 OR S8	
	S8	(MM "Cause of Death") OR (MM "Death Certificates")	
	S7	AB (aberdeen or Bound OR Baird OR wigglesworth OR NICE OR PSANZ OR Tulip OR ReCoDe or CHAMPS or DeCoDe)	
	S6	AB ((death or "cause of death" or mortality or causes or cause or ((contributing or care or avoidable or preventable) N2 (factor or risk or risks))) N6 (classification or classifications or definition or definitions or classified))	
	S5	S1 OR S2 OR S3 OR S4	

	S4	AB AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
	S3	AB AB (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") N3 (terminat* or abortion or abort))
	S2	AB AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/
	2	((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "life limiting" or "life limiting") adj3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term" or "termination of pregnancy" or "pregnancy termination")).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) adj1 loss*) or abortus* or stillb*).ti,ab.
	5	1 or 2 or 3 or 4
	6	((death or "cause of death" or mortality or causes or cause or ((contributing or care or avoidable or preventable) adj2 (factor or risk or risks))) adj6 (classification or classifications or definition or definitions or classified)).ti,ab.
	7	(aberdeen or Bound OR Baird OR wigglesworth OR NICE OR PSANZ OR Tulip OR ReCoDe or CHAMPS or DeCoDe).ti,ab.
	8	*"cause of death"/
	9	6 OR 7 OR 8
	10	5 AND 9

Table 9. Search strategy for Classification of Perinatal Deaths

Database	Search strategy
Scopus	((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) W/2 (death* or wast* or demise* or mortalit*)) OR (("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies") W/3 (terminat* or abortion or abort)) OR (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) W/1 loss*) or stillb*) AND ((death OR "cause of death" OR mortality OR causes OR cause OR ((contributing OR care OR avoidable OR preventable OR associate*) W/2 (factor OR risk OR risks))) W/3 (reported OR reporting OR classification OR classifications OR definition OR definitions OR classified)) OR (aberdeen OR Bound OR Baird OR wigglesworth OR NICE OR PSANZ OR Tulip OR ReCoDe OR CHAMPS OR DeCoDe OR INCODE OR PSANZ OR ICDPM OR "ICD PM" OR ICD?PM OR ICD-10 OR (ICD W/3 "perinatal mortality") OR "perinatal society of Australia and New Zealand")
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Mortality] explode all trees #3 MeSH descriptor: [Perinatal Death] explode all trees #4 MeSH descriptor: [Stillbirth] explode all trees #5 MeSH descriptor: [Abortion, Therapeutic] explode all trees #6 ((f?etal:ti,ab OR foetal:ti,ab OR fetus*:ti,ab OR antenatal:ti,ab OR intrapartum:ti,ab OR intrauterine:ti,ab OR "intra uterine":ti,ab OR utero:ti,ab) NEAR/2 (death*:ti,ab OR wast*:ti,ab OR demise*:ti,ab OR mortalit*:ti,ab)) #7 (((foetal:ti,ab OR fetal:ti,ab OR fetus:ti,ab OR perinatal:ti,ab OR "peri natal":ti,ab) NEAR/1 loss*:ti,ab) OR stillb*:ti,ab) #8 ((((("fetal malformation" or "congenital abnormality" or "fetal anomaly" or "congenital anomaly" or "fetal anomalies" or "congenital anomalies" or "life limiting" or "life limiting") NEAR/3 (condition or diagnosis or diagnoses or terminat* or abortion or abort or continue or continuing or "to term")))):ti,ab,kw #9 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 #10 ((death:ti,ab OR "cause of death":ti,ab OR mortality:ti,ab OR causes:ti,ab OR cause:ti,ab OR ((contributing:ti,ab OR care:ti,ab OR avoidable:ti,ab OR preventable:ti,ab OR associate*:ti,ab) NEAR/2 (factor:ti,ab OR risk:ti,ab OR risks:ti,ab))) NEAR/3 (reported:ti,ab OR reporting:ti,ab OR classification:ti,ab OR classifications:ti,ab OR definition:ti,ab OR definitions:ti,ab OR classified:ti,ab)) #11 (aberdeen:ti,ab OR Bound:ti,ab OR Baird:ti,ab OR wigglesworth:ti,ab OR NICE:ti,ab OR PSANZ:ti,ab OR Tulip:ti,ab OR ReCoDe:ti,ab OR CHAMPS:ti,ab OR DeCoDe:ti,ab OR INCODE:ti,ab OR PSANZ:ti,ab OR ICDPM:ti,ab OR "ICD PM":ti,ab OR ICD?PM:ti,ab OR ICD-10:ti,ab OR (ICD:ti,ab NEAR/3 "perinatal mortality":ti,ab) OR "perinatal society of Australia and New Zealand":ti,ab) #12 MeSH descriptor: [Cause of Death] this term only #13 #10 OR #11 OR #12 #14 #13 AND #9

Australian Indigenous HealthInfoNet	“perinatal audit” “stillbirth audit” “perinatal review” “stillbirth review”	
Informit Indigenous Collection	[All Fields: perinatal OR All Fields: stillbirth OR All Fields: 'neonatal death'] AND [All Fields: audit OR All Fields: review]	
PubMed	10	#9 AND #4
	9	#7 OR #8
	8	(aberdeen[tiab] OR Bound[tiab] OR Baird[tiab] OR wigglesworth[tiab] OR NICE[tiab] OR PSANZ[tiab] OR Tulip[tiab] OR ReCoDe[tiab] OR INCODE[tiab] OR CHAMPS[tiab] OR DeCoDe[tiab] OR PSANZ[tiab] OR ICDPM[tiab] OR "ICD PM"[tiab] OR "ICD-10"[tiab])
	7	#5 AND #6
	6	(classification[tiab] OR classifications[tiab] OR definition[tiab] OR definitions[tiab] OR classified[tiab])
	5	(("cause of death"[tiab] OR "cause of mortality"[tiab] OR "mortality classification"[tiab] OR "death classification"[tiab] OR ((contributing[tiab] OR care[tiab] OR avoidable[tiab] OR preventable[tiab] OR associate*[tiab]) AND (factor[tiab] OR risk[tiab] OR risks[tiab]))))
	4	#1 OR #2 OR #3
	3	("fetal malformation"[Title/Abstract] OR "congenital abnormality"[Title/Abstract] OR "fetal anomaly"[Title/Abstract] OR "congenital anomaly"[Title/Abstract] OR "fetal anomalies"[Title/Abstract] OR "congenital anomalies"[Title/Abstract] OR "prenatal diagnosis"[Title/Abstract]) AND (terminat*[Title/Abstract] OR abortion[Title/Abstract] OR abort[Title/Abstract])
	2	("Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"[Title/Abstract] OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract])
	1	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR "perinatal death"[Mesh] OR "Abortion, Induced"[Mesh]
CINAHL	S9	S5 AND S8
	S8	S5 OR S6 OR S7
	S7	(MM "Cause of Death") OR (MM "Death Certificates")
	S6	((TI aberdeen OR AB aberdeen) OR (TI Bound OR AB Bound) OR (TI Baird OR AB Baird) OR (TI wigglesworth OR AB wigglesworth) OR (TI NICE OR AB NICE) OR (TI PSANZ OR AB PSANZ) OR (TI Tulip OR AB Tulip) OR (TI ReCoDe OR AB ReCoDe) OR (TI CHAMPS OR AB CHAMPS) OR (TI DeCoDe OR AB DeCoDe) OR (TI INCODE OR AB INCODE) OR (TI PSANZ OR AB PSANZ) OR (TI ICDPM OR AB ICDPM) OR (TI "ICD PM" OR AB "ICD PM") OR (TI ICD?PM OR

		AB ICD?PM) OR (TI ICD-10 OR AB ICD-10) OR ((TI ICD OR AB ICD) N3 (TI "perinatal mortality" OR AB "perinatal mortality")) OR (TI "perinatal society of Australia and New Zealand" OR AB "perinatal society of Australia and New Zealand"))
	S5	(((TI death OR AB death) OR (TI "cause of death" OR AB "cause of death") OR (TI mortality OR AB mortality) OR (TI causes OR AB causes) OR (TI cause OR AB cause) OR (((TI contributing OR AB contributing) OR (TI care OR AB care) OR (TI avoidable OR AB avoidable) OR (TI preventable OR AB preventable) OR (TI associate* OR AB associate*)) N2 ((TI factor OR AB factor) OR (TI risk OR AB risk) OR (TI risks OR AB risks)))) N3 ((TI reported OR AB reported) OR (TI reporting OR AB reporting) OR (TI classification OR AB classification) OR (TI classifications OR AB classifications) OR (TI definition OR AB definition) OR (TI definitions OR AB definitions) OR (TI classified OR AB classified)))
	S4	S1 OR S2 OR S3
	S3	AB (((foetal or fetal or fetus or perinatal or "peri natal" or neonatal) N1 loss*) or stillb*)
	S2	AB ((fetal or foetal or fetus* or perinatal or antenatal or "peri natal" or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) N2 (death* or wast* or demise* or mortalit*))
	S1	(MM "Sudden Infant Death") OR (MM "Perinatal Death") OR (MM "Abortion, Induced")
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/
	2	((fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero or newborn or neonatal) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(((foetal or fetal or fetus or perinatal or "peri natal" or neonatal or newborn) adj1 loss*) or abortus* or stillb*).ti,ab.
	4	1 or 2 or 3
	5	((death or "cause of death" or mortality or causes or cause or ((contributing or care or avoidable or preventable or associate*) adj2 (factor or risk or risks))) adj3 (reported or reporting or classification or classifications or definition or definitions or classified)).ti,ab.
	6	(aberdeen or Bound or Baird or wigglesworth or NICE or PSANZ or Tulip or ReCoDe or CHAMPS or DeCoDe or INCODE or PSANZ or ICDPM or "ICD PM" or "ICD$PM" or ICD-10 or (ICD adj3 "perinatal mortality") or "perinatal society of Australia and New Zealand").ti,ab.
	7	*"cause of death"/
	8	5 OR 6 OR 7
	9	4 AND 8

Figure 2 PRISMA flow diagrams of screening evidence for perinatal mortality audits

Note. Six searches were conducted for the 45 research questions identified for perinatal mortality audit and classification. Results from the six searches are combined in the below PRISMA flow diagram.

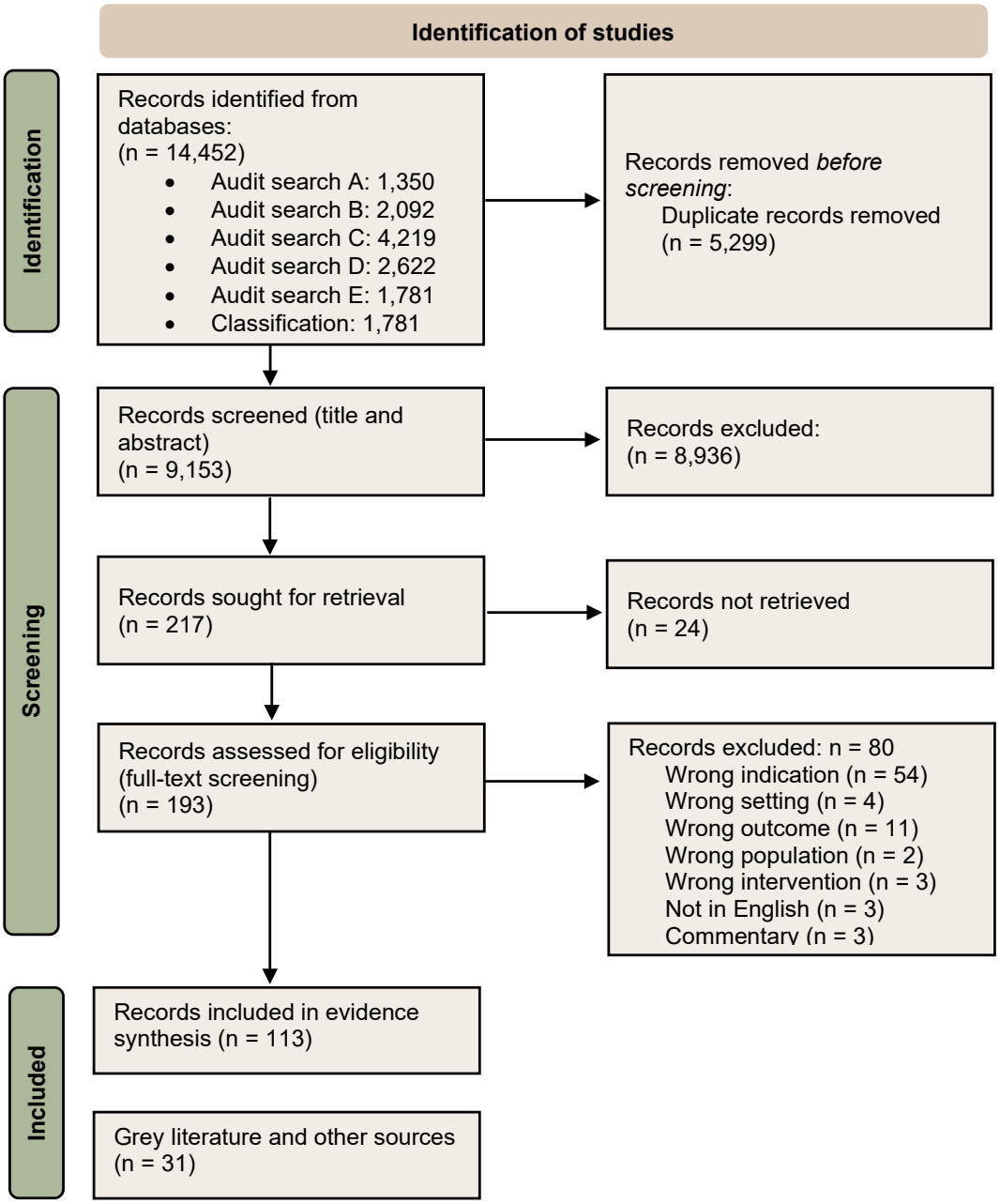


Table 10. Study characteristics for studies included in Section 1: Audit

Study	Country (period)	Locality (state/ national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality appraisal tool
ACOG 2018	USA (2018)	National	Opinion	HIC	Qualitative	Narrative	NA	NA	Fetal deaths	Importance of vital records and statistics for the obstetrician–gynaecologist	NA	NA	Checklist for text and opinion papers
Aguinaga 2021	Mexico (Jan 2016–Dec 2018)	The National Institute of Perinatal Health In Mexico City	Medical records (based on the ICD-PM and initial causes of fetal death (INCODE) classification systems)	UMI	Quantitative	NA	Prospective descriptive	N=297	Stillbirth, NND	Causal analysis of fetal death in high-risk pregnancies	None stated	All stillbirths between January 2016 and December 2018	Checklist for analytical cross-sectional studies

Alyahya 2019	Jordan (2018)	National	Focus groups, surveys	UMIC	Mixed methods	Thematic content analysis	cross-sectional survey	Quantitative study n=302; Qualitative part n=80	Stillbirth	Healthcare professional awareness, knowledge, use and perceived barriers to the ICD-10 for classifying perinatal deaths	Not specified	Qual: All healthcare professional who were paediatricians, obstetricians and gynaecologists, senior residents, registered nurses, and midwives. Quant: all physicians and registered nurses working in paediatric departments in the four hospitals.	Checklist for qualitative research Checklist for analytical cross-sectional studies
Aminu 2017	Multiple (1950–2015)	International /review	Previous publications with information on stillbirth cause of death classification	Unknown	Qualitative	Systematic review	NA	31 studies	Stillbirth	stillbirth classification systems	Excluded systems that were designed exclusively for neonatal, infant or general mortality	All published classification systems for stillbirth or perinatal death, published in English	Checklist for systematic reviews and research syntheses

Aminu 2019	Sub-Saharan Africa (Jan–Sept 2015)	International /hospitals in Kenya, Malawi, Sierra Leone, Zimbabwe	cause of death reported by hospitals for stillbirths (>28 weeks) classified using the ICD-PM	Mixed (LIC-LMIC)	Quantitative	NA	Prospective observational study	1,267/279 per country	Stillbirth	cause of death, assessed by expert panel and categorised to an ICD-PM code	Not specified	Stillbirths at or above 28 weeks gestation, or birth weight above 1000g.	Checklist for studies reporting prevalence data
Andrews 2020	Australia (no dates reported)	National	Literature, Opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth	Development and progress of the Safer Baby Bundle initiative in Australia	NA	NA	
Angell 2019	Ghana (8 June 2011-12 June 2012)	Hospital/ Komfo Anokye Teaching Hospital in Kumasi Ghana	Patient records	LMIC	Quantitative	NA	Retrospective review	465	Stillbirth	Cause of infant mortality, and reclassification according to the PSANZ PDC	Not specified	All stillbirths delivered at Komfo Anokye Teaching Hospital (at or after 28 weeks gestation)	Checklist for studies reporting prevalence data
Anwar 2018	Pakistan (June 2015–May 2016)	Tehsil Havelian (a sub-district) of the District of Abbottabad of Khyber Pakhtunkhwa province	Enhance Surveillance System	LMIC	Quantitative	NA	Cross-sectional	N=51690	Maternal and perinatal mortality	Comparison of mortality rates from Enhanced Surveillance System to the Routine Monitoring System	None stated	51,690 married women aged 18–49 years who were permanent residents of Tehsil Hevellian	Checklist for analytical cross-sectional studies

Assaad 2018	Canada (Aug 2014–Sept 2015)	Sainte-Justine Hospital, Montreal, Quebec	Hospital records, chart reviews	HIC	Quantitative	NA	Case series	n=55 NND (110 reviews)	NND	Internal and external reviewers to optimise neonatal mortality and morbidity conferences	Patients who died in the delivery room or during transport to the hospital	All consecutive neonatal deaths occurring in the NICU of the study hospital between Aug 2014 and Sept 2015	Checklist for case series studies
Auger 2018	Canada (1981–2015)	Quebec	Quebec registry data on death certificates	HIC	Quantitative	NA	Epidemiological	n=13,466 stillbirths, n=13,509 NND	Stillbirth, NND	Rates of fetal and infant autopsy over time	NA	All stillbirths weighing 500 g or more at delivery, and deaths in infants before 365 days of age registered in Quebec registry data	Checklist for studies reporting prevalence data
Bakhbakhi 2017	Multiple (dates not reported)	NA	Published research, guidelines, and best practice points	HIC	Qualitative	Descriptive review	NA	NA	Stillbirth	Best practice points in bereavement care research in high income countries	None mentioned	Published research, guidelines and best practice points in care following stillbirth in high income countries	Checklist for text and opinion papers

Bakhbakhi 2018	UK (May–June 2017)	Two geographically different maternity hospital sites in Bristol and Manchester	Focus groups	HIC	Qualitative	Thematic analysis	NA	22	Stillbirth, NND	Views of healthcare professionals and other key stakeholders on parental engagement in the perinatal mortality review	None mentioned	Clinical staff including midwives, obstetricians, neonatologists, nursing staff and chaplaincy services	Checklist for qualitative research
Bakhbakhi 2019	UK (2017)	National consensus meeting	Workshop, online questionnaire	HIC	NA	qualitative	Content analysis (Delphi study)	22 participants in consensus meeting (17 stakeholders and 5 members of research team); 25 respondents in subsequent online questionnaire	Stillbirth, NND	parental engagement in perinatal mortality review process	NA	NA	Checklist for qualitative research

Bandali 2019	Kenya (2014–2017)	Bungoma county	Retrieved perinatal data Kenya DHIS2 (quantitative) and Maternal and Perinatal Death Surveillance and Response (MPDSR) FGD questionnaires (qualitative)	LMI	Mixed methods	Thematic Analysis	Descriptive	n=1,042 (2014), n=949 (2015), n=984 (2016) and n=891 (2017) for quantitative portion. Focus group discussions were conducted with MPDSR committee members (approximately 12–15 participants per MPDSR committee) in three purposefully selected hospitals for qualitative portion.	Perinatal death	Maternal and Perinatal Death Surveillance and Response	None stated	Perinatal deaths in Bungoma county 2014–2017 (quantitative data). Maternal and Perinatal Death Surveillance and Response (MPDSR) team members, Health Records Information Officers, a maternity in charge and facility nursing officer-in charge (HRIOs) FGDs (qualitative data)	Checklist for qualitative research Checklist for analytical cross-sectional studies

Baptista 2021	Brazil (2008–2017)	Espirito Santo State	Neonatal mortality data from the Mortality Information System and from Live Birth Information System	UMIC	Quantitative	NA	Retrospective audit	Not reported	NND	Classification of neonatal death causes as preventable, deaths for ill-defined causes, other causes (not clearly preventable), and geographical analyses of preventability across regions	Not specified	Data were obtained from Mortality Information System and Live Birth Information System from the Public Health System Informatics Department	Checklist for studies reporting prevalence data
Bartlett 2017	Aotearoa New Zealand (2007–2013)	National	postmortem reports, placental pathology reports and clinical information of unexplained antepartum deaths at term from the Perinatal and Maternal Mortality Review Committee	HIC	Quantitative	NA	Prevalence reporting	257 unexplained antepartum deaths	Stillbirth	Determination of cause of death classification using placental pathology and the PSANZ-PDC10	Not specified	All unexplained antepartum deaths at term (≥37 weeks at birth) classified as PSANZ-PDC10 in Aotearoa New Zealand from 2007 to 2013 inclusive who had a postmortem examination and/or placental pathology	Checklist for studies reporting prevalence data

												were identified from the PMMRC database of perinatal-related death	
Basu 2018	Denmark (2010–2014)	Southern Denmark	Danish Medical Birth Registry, the National Patient Registry	HIC	Quantitative	NA	Retrospective cohort	95	Stillbirth, NND	Causes of death amongst full term stillbirths and early neonatal deaths in Southern Denmark	NA	Women in the Region of Southern Denmark, who gave birth at full term to a stillborn infant or a neonate who died within the first 7 days from 2010 through 2014	Checklist for cohort studies
Best 2019	UK (2014–2015)	England, Wales, Scotland, and the UK Crown Dependencies	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries	HIC	Quantitative	NA	Retrospective cohort	n=5651 stillbirths, n=2345 NND	Stillbirth, NND	Socioeconomic inequalities in cause-specific stillbirth and neonatal mortality	TOPFA, multiple births, Northern Ireland, NND<24 weeks	All singleton births between 1 January 2014 and 31 December 2015 at ≥24 weeks' gestation that resulted in stillbirths or NND	Checklist for cohort studies

Bezhenar 2021	Russia (dates not reported)	National	Main federal laws, orders of ministries and departments, orders, methodological letters and recommendations, and materials on the Internet	HIC	Qualitative	Critical review	NA	NA	Stillbirth, NND, TOPFA	Legal aspects of perinatal loss	None mentioned	Fetal death starting from 22 weeks pregnancy in childbirth, as well as the death of a newborn in the first 7 days of life	Checklist for qualitative research
Biswas 2018	Bangladesh	National	Review of literature	LMIC	Qualitative	Critical review	NA	NA	Neonatal death	Social Autopsy	None	None	Checklist for qualitative research
Blythe 2019	UK (2009–2015)	Sheffield children's Hospital NHS Foundation Trust	Hospital autopsy and placental records	HIC	Quantitative	NA	Case series	258	Stillbirth ≥24 weeks GA (n=258)	ReCoDe categories corresponding with perinatal mortality	Maternal conditions: prolonged rupture of membranes; diabetes; pre-eclampsia and related conditions such as HELLP, factor	Clinically unexplained stillbirths referred for postmortem to the Sheffield Children's hospital NHS foundation.	Checklist for case series studies

											V Leiden, anti-Ro, anti-C antibodies; retrovirus positivity; autoimmune conditions; substance/ alcohol misuse. Fetal conditions: hydrops; termination of pregnancy; any known malformation		
Boyd 2017	USA and South Africa (2007–2015)	International	Data from Safe Passage Study	HIC and UMIC	Quantitative	NA	Case series	19 stillbirths	Stillbirth	Stillbirth Classification System for the Safe Passage Study	maternal age less than 18 years, planned therapeutic abortion, HIV positive or refused testing, multiple fetuses, moving out of catchment area prior to estimated date of delivery, and clinical judgment	Stillbirths where fetal postmortem and placental examination were performed	Checklist for case series studies

Boyi Hounso 2021	Benin (2016–2018)	National	Online group discussions, MPDSR working groups report review, hospital databases	LMIC	Mixed methods	Thematic content analysis	Descriptive	n=42 for online discussions, 21 working group sessions	NND	Implementation of the Maternal and Perinatal Death Surveillance and Response (MPDSR) strategy in Benin	NA	Quantitative: all maternal and neonatal death notifications from the 34 health districts and 6 regional and 3 national tertiary hospital databases of the country Qualitative: Maternal and neonatal stakeholders for online discussions: 3 DMO; 3 Health district management team members, 3 Health district technical assistants, 1 Health regional officer, 2 Mother and child health regional officers, 1	Checklist for qualitative research Checklist for analytical cross-sectional studies

													MoH Representative, and Representative of MPDSR committees incl. National, hospital, and district-level managers, maternal and neonatal health providers, Health System Information managers for working group reports"	
Boyle 2021	Aotearoa New Zealand, Australia, Canada, Ireland, UK, and USA (Dec 2014–Feb 2015)	International	Online survey including open-ended questions	HIC	Mixed methods	Thematic content analysis	Cross sectional	1104 HCPs	Stillbirth	Parent engagement in perinatal mortality reviews	NA	Healthcare professionals, including obstetricians, gynaecologists, midwives, and nurses	Checklist for analytical cross-sectional studies Checklist for qualitative research

Breiman 2021	Multiple (Dec 2016–Nov 2020)	International	Verbal autopsy, clinical charts	LMICs and UMICs	Quantitative	NA	Epidemiological	n=1260 deaths under 5 with DeCoDe results; n=741 NND	NND	Using postmortem investigations to classify multiple causes of death	Stillbirths	Child deaths under 5 years of age in residents of the study catchment areas where MITS was done and results from DeCoDe were available	Checklist for studies reporting prevalence data
Burden 2021	UK (Nov 2018–May 2019)	One tertiary maternity unit in UK	Parent and HCP focus group and parent feedback on perinatal mortality review meeting through phone, face to face or post	HIC	Qualitative	Thematic analysis	NA	13 mothers for PNMR meetings, 11 parents (7 mothers, 4 fathers) and 7 HCPs for focus groups	Stillbirth (n=10), NND (n=3)	Feasibility of parents' engagement in perinatal mortality and associated barriers and facilitators	None mentioned	Women and their partners who experienced a perinatal death during the study timeframe and HCPs working in the Dept including midwives, obstetricians, neonatologists, neonatology nurses	Checklist for qualitative research

Burke 2023	Ireland (2017–2020)	1 large maternity hospital	Anonymous questionnaire including open-ended questions, sign in sheets of PM-MDT meetings	HIC	Mixed methods	Thematic analysis	Descriptive	78	Stillbirths, NND	Barriers to attendance at perinatal mortality meeting	NA	All staff who had direct clinical patient contact including medical staff, midwifery and nursing staff, healthcare assistants, and allied health professionals	Checklist for analytical cross-sectional studies and Checklist for qualitative research
Cetin 2022	Ethiopia (Feb–Mar 2020)	Obstetrics/ gynaecology departments and neonatal/paediatrics departments at government hospitals in urban cities	Semi-structured interviews	LIC	Qualitative	Narrative synthesis	NA	16 healthcare workers	Stillbirth, NND	Ethical and practical consequences clinicians experience concerning Maternal and Perinatal Death Surveillance and Response reporting practices in Ethiopia	NA	Healthcare workers incl. midwives, nurse, senior and junior doctors, intern working at the study locations	Checklist for qualitative research

Christiansen-Lindqust 2017	USA (2006–2008)	5 clinical sites in Georgia and Utah	Maternal interview, prenatal care medical chart abstraction, and biological specimens	HIC	Quantitative	NA	Case-control	n=334 cases where fetal death certificates were linked (n=126 in Georgia, 208 in Utah), n=48 cases with unlinked FDCs	Stillbirth	Fetal death certificate data quality	NA	Mothers who experienced stillbirths, were not incarcerated residents of DeKalb County, Georgia, or Salt Lake County, Utah, aged 13 years, with an identifiable fetal death certificate	Checklist for case control studies
Christou 2019	Afghanistan (Oct–Nov 2017)	one urban and two rural districts of Kabul province, Afghanistan	Interviews	LIC	Qualitative	Thematic analysis	NA	55 (mothers (21) and fathers (9) who had experienced a recent stillbirth, female community elders (3), local CHWs (5), various health service providers at tertiary-level facilities (11), and government	Stillbirth	how community and healthcare providers' perceptions and practices around stillbirth influence stillbirth data quality in Afghanistan	None mentioned	Women and men that recently experienced a stillbirth, female elders, community health workers, healthcare providers, and government officials in Kabul province, Afghanistan	Checklist for qualitative research

								health officials (2)					
D'Aloja 2021	Italy (July 2017–June 2019)	Lombardy (Northern Italy), Tuscany (Central Italy), and Sicily (Southern Italy)	Medical records, audits	HIC	Quantitative	NA	Epidemiological	138 maternity and neonatal units, accounting for 830 perinatal deaths	NND, Stillbirth	Perinatal mortality surveillance system to reduce perinatal deaths	NA	All maternity and neonatal units in the study regions	Checklist for studies reporting prevalence data
Dagdeviren 2022	Turkey (2015–2020)	University of Health Sciences' Ankara Etlik Zubeyde Hanım Women's Health Training and Research Hospital	Hospital records, patient files	UMIC	Quantitative	NA	Cross-sectional	475 stillbirths	Stillbirth	Application of ICD-PM system to stillbirths	None stated	All stillbirths at the study institution between 2015 and 2020	Checklist for analytical cross-sectional studies
Dase 2020	Nigeria (2010–2018)	1 major referral centre in northeast Nigeria	Maternal admission notes	LMIC	Quantitative	NA	Cross-sectional	760 stillbirths	Stillbirth	Application of WHO ICD-PM classification system to stillbirths	Case records not available	Stillbirths at the study institution between 2010-2018	Checklist for analytical cross-sectional studies

Dadzie 2021	Ghana (2014–2017)	20 hospitals across 4 regions of Ghana	Admission and discharge registers, newborn death certificate, clinician notes, audit reports	LMIC	Quantitative	NA	Epidemiological	1040 NND	NND	Completeness and accuracy of cause of death (COD) data for neonates in Ghana	Lots which had less than the minimum sample of 20 neonatal deaths	Health facilities across different regions of Ghana	Checklist for studies reporting prevalence data
de Graaff 2023	Multiple (Mar 2020–Jul 2021)	13 countries	Members of the Lancet Stillbirths in High-Income Countries Investigator Group, ISA working group members	HICs, UMICs	Quantitative	NA	Descriptive	Data from 13 countries	Stillbirth	Scorecard to track stillbirths in HICs and UMICs	NA	HICs and UMICs (members of the Lancet Stillbirths in High-Income Countries Investigator Group)	
Ebenezer 2019	India (2000–2018)	Labour and maternity unit of a tertiary centre in South India	Perinatal audits, chart reviews, hospital electronic database	LMIC	Quantitative	NA	Retrospective cross sectional	n=7946 births in 2000, n=14336 births in 2018	Stillbirth, NND	rates of perinatal mortality, birth asphyxia, and caesarean sections	NA	Number of deliveries, perinatal mortality rate, asphyxia admissions to the Neonatal Intensive Care Unit, and total and primary caesarean section rate over the years	Checklist for analytical cross-sectional studies

Fabrizio 2022	Italy (2014–2017)	Emilia–Romagna	Clinical records	HIC	Quantitative	NA	Prospective cohort	443 stillbirths	Stillbirth	Comparison of ReCoDe, Simplified CODAC and ICD-PM classification systems	NA	All cases of stillbirth that occurred in each hospital of the Emilia–Romagna Region, between January 2014 and December 2017	Checklist for cohort studies
Flenady 2017	Multiple (2017)	International	Literature	HICs and LMICs	Qualitative	Narrative review	NA	NA	Stillbirth, NND	Review of contemporary classification systems	NA	NA	Checklist for text and opinion papers
Flenady 2021	Australia (2018)	Queensland	Database/ Clinical records	HIC	Quantitative	NA	Retrospective cross sectional	N = 65 (56 stillbirths, 9 NND)	Stillbirth, NND	Perinatal deaths associated with contributing factors relating to care	Major congenital anomalies	All stillbirths ≥34 weeks' gestation, as well as neonatal deaths up to 28 days of age occurring from 1 January to 1	Checklist for analytical cross-sectional studies

												December 2018	
Goldenberg 2019	Multiple (2017)	International	Literature	LMICs	Qualitative	Narrative	NA	NA	Stillbirth, NND	Cause of death for stillbirths and neonatal deaths in low-resource settings	NA	NA	Checklist for text and opinion papers
Gondwe 2021	Multiple (2019)	International	Literature/ 6 databases	LMICs	Qualitative	Systematic review	NA	10 articles from 7 countries	Stillbirth, NND	Approaches, enablers, barriers and outcomes of facility stillbirth and neonatal death audit in low-income and middle-income countries	studies that only reported descriptive findings of audits, systematic reviews	(1) studies describing approaches, enablers, barriers or reporting outcomes of stillbirth and neonatal death audits at the facility level; (2) original research article reporting either quantitative,	Checklist for systematic reviews and research syntheses

												qualitative data or both (3) study done in LMIC(s) defined and identified according to World Bank list; (4) studies which implemented a full audit process; (5) published in English and (6) published between 1 January 2009 and 1 September 2019	
Gondwe 2022	Malawi (Jul–Dec 2020)	7 public hospitals from seven districts in the southern region of Malawi	Semi-structured interviews and FGDs	LIC	Qualitative	Thematic analysis	NA	n=38 for interviews, n= 49 for focus groups	Stillbirth, NND	Factors impacting stillbirth and NND audit in Malawi	NA	Audit committee members; clinicians and nurses working in nursery ward, labour ward, postnatal ward, nursery and paediatric wards, maternity	Checklist for qualitative research

												ward and antenatal and paediatric ward.	
Gordon 2020	Australia (no dates reported)	National	Literature, Opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth	Stillbirth Prevention Campaign to raise stillbirth awareness	NA	NA	
Gulati 2020	UK (Jan 2005–Dec 2016)	1 West Midlands tertiary unit	Postmortem reports	HIC	Quantitative	NA	Cross-sectional	265 stillbirths and NNDs from 144 twin pregnancies	Stillbirth, NND	New classification system designed to assign a cause of death in twin pregnancies (CoDiT)	NA	Twin pregnancies in the West Midlands affected by fetal or neonatal demise of one or both twins between 1 January 2005 and 31 December 2016 in which postmortem examination was undertaken	Checklist for analytical cross-sectional studies

Gurung 2019	Nepal (Jan–Jul 2017)	12 hospitals of Nepal	Demographic, obstetric and neonatal information via maternal interviews and patient case notes	LMIC	Quantitative	NA	Prospective cohort	n=119 antepartum stillbirths, n=29 misclassified antepartum stillbirths	Stillbirth	Misclassification of antepartum stillbirths in Nepal	Women whose fetal heart sound was not measured at the time of admission	women with pregnancy of 22 weeks or more who were admitted in the study hospitals and consented to participation	Checklist for cohort studies
Gutman 2022	Multipl (dates not reported)	International	Literature: 6 databases	MICs and HICs	Qualitative	Systematic review	NA	20 articles	Stillbirths	Perinatal mortality audits and reporting of perinatal deaths	Grey literature was not included nor manuscripts focusing primarily on maternal morbidity/ mortality audits or perinatal mortality audits in low-income countries or low resource settings	Peer-reviewed articles evaluating perinatal mortality audits or reporting, identifying risk or care factors of perinatal mortality through audits, evaluating perinatal mortality audit implementation and focused on middle and/ or high-income countries, with a publication	Checklist for systematic reviews and research syntheses

												date from 2000 and in English, Portuguese or Spanish	
Halim 2018	Bangladesh (2011–2012)	4 districts (Jamalpur, Moulvibazar, Narail and Thakurgaon)	Verbal autopsy	LMIC	Quantitative	NA	Cross-sectional study	N=1327	Stillbirth (gestation age more than 28 weeks)	Causes and factors associated with stillbirth	Not mentioned	Stillbirths where verbal autopsies were performed	Checklist for analytical cross-sectional studies
Harrist 2017	USA (2006–2013)	Wyoming	National Association for Public Health Statistics and Information System, Wyoming Department of Health Vital Statistics Service	HIC	Quantitative	NA	Descriptive cross sectional	n=263 fetal deaths	Stillbirth	Completeness, Data Quality, and Timeliness of Fetal Mortality Surveillance in Wyoming	Fetal deaths missing fetal weight information	All fetal deaths in Wyoming between 2006-2013	Checklist for studies reporting prevalence data

Haruyama 2018	Japan (2013–2014)	National	Japan Society of Obstetrics and Gynecology Perinatal Database	HIC	Quantitative	NA	Retrospective cross sectional	1075 stillbirths	Stillbirth	Causes and risk factors for singleton stillbirth in Japan	Multiple pregnancies, cases with gestational age missing, infants with any kind of congenital malformation, missing data on key variables of interest	Singleton stillbirths in Japan captured in Japan Society of Obstetrics and Gynecology Perinatal Database	Checklist for analytical cross-sectional studies
Helps 2020	Ireland (2005–2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	stillbirth, NND	Bereavement care provided to families following perinatal death/pregnancy loss as described in national inquiry reports	None stated	National inquiries into perinatal deaths/pregnancy loss services between 2005-2018.	Checklist for qualitative research
Helps 2021	Ireland (Oct–Dec 2018)	National	Irish enquiry reports	HIC	Qualitative	Thematic analysis	NA	n=10 inquiry reports	Stillbirth, NND	Effects of maternity services governance in Ireland on the management of perinatal deaths and bereavement services	NA	Health-service-commissioned enquiry reports relating to perinatal deaths and pregnancy loss services between 2005 and 2018	Checklist for qualitative research

Helps 2021 (2)	United Kingdom, Aotearoa New Zealand, Ireland, The Netherlands) (Oct 2020–May 2021)	International	Literature	HIC	Qualitative	Integrative review	NA	n=4 audits	Stillbirth, NND	National perinatal mortality audits' methodology in four countries	Audits from LMICs, national audits that have been discontinued, audits that were carried out at state/ province level	Ongoing national perinatal mortality audit in HICs, national initiatives and programmes addressing the audits' recommendations	Checklist for systematic reviews and research syntheses
Higgins 2018	UK (2015)	14 North West England obstetric units	Medical records	HIC	Quantitative	NA	Retrospective cross sectional	243 medical certificates (n=34 TOP)	Stillbirth, TOPFA	Inaccuracies in completion of medical certificates of stillbirth	Inadequate data, miscarriages	All Medical Certificates of Stillbirth (GA more than 24 weeks) issued from consultant-led obstetric units in the North West of England during 2015	Checklist for analytical cross-sectional studies
Housseine 2021	Tanzania (2017–2018)	Mnazi Mmoja Hospital, Zanzibar	Clinical records	LMIC	Quantitative	NA	Descriptive	661 (n=248 NND, n=413 stillbirths)	Stillbirth, NND	Feasibility of the application of International Classification of Diseases-10 to perinatal mortality (ICD-PM) in Tanzania	Perinatal deaths with a birth weight below 1000g; deaths with an unknown birthweight; Home deliveries, births before	Stillbirths and neonatal deaths with a birth weight above 1000 grams born between 16 October 2017 to 31 May 2018.	Checklist for case series studies

											arrival to the maternity unit and referred neonates		
Hoyert 2022	USA (2018–2020)	41 states and the District of Columbia	National Vital Statistics System, Fetal deaths	HIC	Quantitative	NA	Epidemiological	46,876 fetal deaths	Stillbirth	Fetal cause of death	NA	All 2018–2020 fetal deaths at 20 weeks of gestation or more in the study area	Checklist for studies reporting prevalence data
Hyde 2020	UK (2012–2017)	Hospital (Sheffield Children's Hospital)	Mortuary electronic database	HIC	Quantitative	NA	Case series	105	Miscarriages (n=31), Stillbirth (n=48), Intrapartum deaths (n=1), Early NND (n=9), Late NND (n=2), TOPFA (n=14)	Minimally invasive postmortem as a viable alternative to traditional autopsy when it is refused.	None mentioned	Families who suffered an intrauterine fetal death, termination of pregnancy (TOP), or neonatal death up to 27 days of postnatal age and who sequentially refused a formal or limited traditional hospital postmortem	Checklist for case series studies

Igumbor 2020	South Africa (2019)	Khayelitsha, Cape Town	Structured questionnaire, semi-structured interviews, FGDs	UMIC	Mixed methods	Thematic content analysis	Descriptive	N=5 stillbirths, n=8 NND, Qualitative component n=12 KIIs, 1 informal conversation, n=10 for FGDs	NND, Stillbirths	Engaging community health workers in maternal and infant death identification	NA	Stillbirths, maternal and infant deaths that occurred within Khayelitsha between January 2017 and July 2019; Community Health Workers who were recruited as fieldworkers for the social and verbal autopsy component of the study	Checklist for qualitative research and Checklist for analytical cross-sectional studies
Jayaratnam 2020	Timor-Leste (Jan–Jun 2016)	Hospital Nacional Guido Valadares	Hospital birth registry, maternal and neonatal records	LMIC	Quantitative	NA	Prospective Cross sectional	n=110 stillbirths, n=28 NND	Stillbirth, NND	Application of the simplified Causes Of Death and Associated Conditions (CODAC) classification to perinatal deaths in Timor-Leste	None stated	All perinatal deaths occurring at the study institution from 1 January 2016 to 30 June 2016	Checklist for analytical cross-sectional studies

Jha 2019	India (dates not reported)	117 villages in rural India in Gujarat and Punjab	Verbal autopsy interviews	LMIC	Quantitative	NA	RCT	n=4651 deaths physician assignment (standard group), n=4723 deaths automated group	NND	Automated versus physician assignment of cause of death for verbal autopsies	Stillborn deaths	All deaths in the study locations below 70 years of age	Checklist for randomised controlled trials
Jones 2017	France (2005–2014)	Lower Normandy Regional Fetal-Infant Mortality Observatory	Fetal and placental autopsy, medical records	HIC	Quantitative	NA	Non-comparative	744	Stillbirth (n = 744) Characteristics of	Rates of fetal and placental pathological examinations after stillbirth in the lower Normandy area; cause of stillbirth.	Termination of pregnancies	Stillbirths at over 22 w and/or fetal weight over 500g occurring in the Lower Normandy region in France between Jan 2005 - Dec 2014.	Checklist for case series studies
Joseph 2021	Canada (2020)	National	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth	Stillbirth definition and registration processes in Canada	NA	NA	Checklist for text and opinion papers

Kapuruban dara 2017	Australia (2005–2010)	1 Sydney tertiary referral hospital	Hospital obstetric database	HIC	Quantitative	NA	Retrospectiv e case series	215 stillbirths	Stillbirth	Incidence, causes and recent trends of singleton stillbirth at the study institution	Multiple pregnancies	All singleton stillbirths over a six-year period from 1 January 2005 to 31 December 2010 at the study institution	Checklist for case series studies
Kashif 2022	Pakistan (Jan 2015–Dec 2019)	Aga Khan University Hospital, Karachi	Medical record files	LMIC	Quantitative	NA	Retrospectiv e cross sectional	207	Stillbirth	Application of Relevant Condition at Death (ReCoDe) classification system in Pakistan	All women who delivered outside the study hospital or where the delivery or stillbirth information were missing	Women experiencing stillbirth after 24 completed weeks of pregnancy at the study hospital between 1 January 2015 and 31 December 2019	Checklist for analytical cross-sectional studies
Kc 2020	Nepal (Jan–Jul 2017)	12 public hospitals	Medical records	LMIC	Quantitative	NA	Prospective cohort	n=391 intrapartum stillbirths, n=180 potentially misclassified antepartum stillbirths	Stillbirth	Misclassificat ion of intrapartum stillbirth in Nepal	Women whose fetal heart sound was not measured at the time of admission, women whose FHS was absent at admission	women with pregnancy of 22 weeks or more who were admitted in the study hospitals and consented to participation	Checklist for cohort studies

Khader 2020	Jordan (Mar–May 2018)	4 major representative hospitals across different geographical areas in Jordan	Focus group discussions	UMIC	Qualitative	Content thematic analysis	NA	80 HCPs across 16 FGDs	Stillbirth, NND	Registration, documentation, and auditing of stillbirths and neonatal deaths in Jordan	NA	HCPs including paediatricians, obstetrics and gynaecologists, senior residents, registered nurses, and midwives	Checklist for qualitative research
Khader 2019	Jordan	4 hospitals in Jordan	Questionnaire using face to face structured interview	UMIC	Quantitative	NA	Cross sectional	n=84 physicians, n=218 nurses	Stillbirth, NND	Barriers to Implementation of Perinatal Death Audit in Maternity and Pediatric Hospitals in Jordan	NA	All physicians (paediatricians and obstetricians) and nurses working in the study hospitals	Checklist for studies reporting prevalence data
Kinney 2020	Nigeria, Rwanda, Tanzania, and Zimbabwe (Oct 2016–May 2017)	Sub-Saharan African region	Desk review, policy mapping, semi-structured interviews, observations	LMICs	Mixed methods	Thematic content analysis	Cross sectional	n=41 for stakeholder interviews, 55 health facilities	Stillbirth, NND	Maternal and perinatal death surveillance and response implementation in Nigeria, Rwanda, Tanzania, and Zimbabwe	NA	Subnational and facility managers and staff including four national stakeholders in Zimbabwe and Tanzania, and 37 regional and district government health officials supporting MPDSR in	Checklist for qualitative research and Checklist for analytical cross-sectional studies

												Zimbabwe, Tanzania, and Nigeria	
Kinney 2022	South Africa (Oct 2019–Mar 2020)	4 district hospitals in the Western Cape	Non-participant observations, key informant interviews	UMIC	Qualitative	Thematic analysis	NA	n=41 health providers and managers	Stillbirth, NND	Sustainability of Maternal and perinatal death surveillance and response in South Africa	NA	Key informants involved in the perinatal audit process at the district and subdistrict levels including medical manager, clinical manager, nursing manager, information manager or officer, manager of the maternity ward and front-line	Checklist for qualitative research

												health workers who were involved in the perinatal audit process, including doctors, midwives, nurses and PHC staff	
Kirabira 2020	Uganda (2008–2015)	1 tertiary hospital in Kampala	Clinic records	LIC	Quantitative	NA	Interrupted time series	526 perinatal deaths (259 NND, 267 stillbirths)	NND, Stillbirth	Effects of perinatal death (PND) audit on perinatal outcomes in Uganda	NA	All stillbirths (GA more than 28 weeks) and deaths within the first week of life	Checklist for quasi-experimental studies (non-randomised experimental studies)
Knight 2019	UK (no dates reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	NND	Confidential case reviews of maternal and newborn morbidity and mortality	NA	NA	Checklist for text and opinion papers
Kortekaas 2018	The Netherlands (2010–2012)	National	Perinatal Audit Registry of the Netherlands	HIC	Quantitative	NA	Descriptive cross sectional	705 term perinatal deaths	Stillbirth, NND	Causes of death and substandard care factors in term and post-term perinatal deaths	NA	All perinatal deaths of ≥37 weeks	Checklist for analytical cross-sectional studies

Kulkarni 2019	India (2017)	Christian Medical College, South India	Medical records	LMIC	Quantitative	NA	Retrospective cross sectional	247 stillbirths	Stillbirth	Application of ReCoDe Classification in assigning cause of stillbirths in India	NA	All cases of stillbirth at the study institution in 2017	Checklist for analytical cross-sectional studies
Kumar 2021	India (dates not reported)	2 districts of Karnataka	Hospital case records	LMIC	Quantitative	NA	Epidemiological	1070 perinatal deaths	Stillbirth, NND	Tools to Identify Preventable Perinatal Deaths	NA	Perinatal deaths in study hospitals	Checklist for studies reporting prevalence data
Kunjachen Maducolil 2018	Qatar (2015)	Hamad Women's Hospital Doha	Electronic medical records	HIC	Quantitative	NA	Retrospective cross sectional	120 stillbirths	Stillbirth	Risk factors and classification of stillbirth in a Middle Eastern population	NA	Stillbirths at the study institution with a gestational age >/ = 24 weeks in the year 2015	Checklist for analytical cross-sectional studies
Lavin 2018	South Africa (Nov 2017–Jan 2018)	National	National perinatal mortality audit system, the Perinatal Problem Identification Program	UMIC	Quantitative	NA	Epidemiological	n = 26 810 perinatal deaths (n=7466 NND)	Stillbirth, NND	Application of International Classification of Diseases-perinatal mortality (ICD-PM) coding to perinatal deaths in South Africa	NA	All perinatal deaths including stillbirths (of birth weight > 1000 g and after 28 weeks of gestation) or early neonatal deaths (age 0–7 days), that occurred between 1 October	Checklist for studies reporting prevalence data

												2013 and 31 December 2016.	
Lehner 2019	Australia (Jul 2004–Sept 2014)	1 Queensland Hospital	Hospital Information System, Perinatal Data Collection, medical records	HIC	Quantitative	NA	Retrospective cross sectional	170 stillbirths	Stillbirth	Causes of stillbirths and stillbirth care using the National Perinatal Death Clinical Audit Tool	TOP, stillbirths secondary to antenatally identified causes and fetal congenital anomalies	Unexplained stillbirths at the study hospital	Checklist for analytical cross-sectional studies
Leisher 2016	Multiple (dates not reported)	International	Literature	Multiple	Quantitative	NA	Systematic review	81 classification systems	Stillbirth, NND	Alignment of current classification systems with expert-identified characteristics for a globally effective classification system	NA	81 classification systems	Checklist for systematic reviews and research syntheses
Leisher 2017	Multiple (2014)	International	Literature: 5 databases	HIC; LMIC	Qualitative	Systematic review	NA	146	Stillbirth, NND	Review of classification systems for causes of stillbirth and neonatal death	Systems developed for specific populations (e.g., unexplained stillbirth at term, low birthweight babies) were excluded. Systems for which data on SB, NND,	Published and unpublished studies and national reports describing new classification systems or modifications of existing systems for causes of	

											and/or perinatal deaths could not be separated from data on deaths before or after the perinatal period (e.g., miscarriages, late infant deaths) were excluded. Papers describing use of only the ICD were also excluded.	perinatal death, or that used or tested such systems, between 2009 and 2014	
Lewkowitz 2019	USA (2005–2014)	Florida	Florida State Inpatient Database	HIC	Quantitative	NA	Retrospective cohort	n=9523 stillbirths, n=1,353,044 livebirths	Stillbirth	Association Between Stillbirth at 23 Weeks of Gestation or Greater and Severe Maternal Morbidity	Women whose index deliveries were coded as both liveborn singletons and stillborn fetuses at 23 weeks of gestation or more or as both singleton and multiple gestation. Females who	The first delivery of female Florida residents aged 13–54 years old from 2005 to 2014 was included	Checklist for cohort studies

											did not reside in Florida and patients listed as "male" were also excluded.		
Luk 2020	Hong Kong (May 2012–Apr 2019)	Kwong Wah Hospital	Case summaries	HIC	Quantitative	NA	Cross sectional	119 (n=92 stillbirths, 27 NND)	Stillbirth, NND	Application of International Classification of Diseases for Perinatal Mortality (ICD-PM) system to existing perinatal death data in Hong Kong	GA less than 24 weeks; TOPFA	Stillbirth cases diagnosed after 24 completed weeks gestation and Neonatal death cases within 28 days of birth at the study hospital	Checklist for analytical cross-sectional studies
Lupariello 2022	Italy (Jan 2015–Dec 2019)	Sant'Anna; referral hospital for high-risk pregnancies in Turin	Hospital records	HIC	Quantitative	NA	Retrospective cross sectional	191	Stillbirth	Comparison of ReCoDe and ICD-PM classification systems	NA	All cases of stillbirths characterised by gestational ages equal or higher than 22 weeks at the study hospital	Checklist for analytical cross-sectional studies

Magge 2020	Rwanda (2013–2015)	2 rural districts in Rwanda	Health facility registers, health management information system, chart reviews	LIC	Quantitative	NA	Pre-post intervention	476 women	NND	Impact of the All Babies Count initiative on neonatal care and outcomes in Rwanda	NA	Women attending antenatal care (ANC) and delivery services in all intervention facilities	Checklist for quasi-experimental studies (non-randomised experimental studies)
Mcclure 2018	India, Pakistan, Guatemala, Democratic Republic of Congo, Zambia, and Kenya (2014–2015)	International 7 sites in 6 LMICs	Global Network's Maternal and Newborn Health Registry	LMICs	Quantitative	NA	Epidemiological	n=2847 stillbirths	Stillbirth	Causes of stillbirth in LMICs	NA	Women who delivered at ≥20 weeks' gestation and experienced stillbirth	Checklist for studies reporting prevalence data
Mok 2021	China (2009–2018)	Tertiary university teaching hospital	Medical records	UMIC	Quantitative	NA	Retrospective cross sectional	135 stillbirths	Stillbirth	Application of ICD-PM in assigning cause of death to stillbirths in China	Women with potential dating problem	All women who suffered from antepartum or intrapartum stillbirth (GA at or more than 24 weeks) at the study hospital from 1 January 2009 to 31 December 2018	Checklist for analytical cross-sectional studies

Mukinda 2021	South Africa (May 2018–Sept 2019)	Rural South African health district in Mpumalanga Province	Observations of DSR practices and interviews	UMIC	Qualitative	Thematic analysis	NA	45 front line health managers and providers	NND	Death surveillance and response for maternal, newborn and child health in South Africa	NA	members of the enquiry or audit team or participants in one of the DSR meetings	Checklist for qualitative research
Musafili 2017	Rwanda (Jul 2012–May 2013)	2 urban hospitals at Kigali	Maternal interviews, clinical records	LIC	Quantitative	NA	Descriptive cross sectional	250 perinatal deaths (n=89 NND, 161 stillbirths)	Stillbirths, NND	Factors contributing to perinatal mortality and potentially avoidable deaths at Rwanda	Deaths that occurred among babies born outside the study sites	Stillbirths and early neonatal deaths occurring after 22 completed weeks of gestation or more, or weighing at least 500 g	Checklist for analytical cross-sectional studies
Nahimana 2021	Rwanda (2015–2016)	Kirehe and S. Kayonza districts in East Rwanda	FGDs, Interviews, Health Management Information System for Facility Data and community health worker, patient charts	LIC	Mixed methods	Thematic content analysis	Pre-post study	n=20 for interviews; 4 FGDs (n=8)	NND	Sustainability assessment of the All Babies Count Program in Rwanda	NA	Qualitative component: Focus group with nurses and midwives providing maternal or neonatal care at health centres and nurses providing maternal or	Checklist for qualitative research Checklist for quasi-experimental studies (non-randomised experimental studies)

													neonatal care at hospitals. Interviews with 2 ABC mentors, 4 MOH mentors, 1 program director, 6 nurses (3 from each district including 2 from health centres and 1 from hospitals), 4 directors of health centres, 1 district hospital director, 1 political leader, and 1 data manager	
Norris 2017	UK, Aotearoa New Zealand, The Netherlands (1998-2014)	International	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries; Perinatal and Maternal Mortality	HIC	Qualitative	Narrative	NA	NA	Stillbirth	Changes in the classification of the cause of death of stillbirths in high resource settings	NA	NA	Checklist for text and opinion papers

			Review Committee; Foundation Perinatal Audit in the Netherlands										
Panaitescu 2021	Romania (no dates reported)	National	Literature	HIC	Qualitative	Narrative	NA	NA	Stillbirth	Definitions and reporting systems for fetal death in utero	NA	NA	Checklist for text and opinion papers
Patterson 2019	Multiple (not dated)	NA	Literature	LICs, LMICs	Qualitative	Review	NA	NA	Stillbirth	Challenges in classification and assignment of causes of stillbirths in LICs and LMICs	None mentioned	Stillbirths defined as birth weight of 500g or GA of 22 weeks	Checklist for text and opinion papers
Po 2019	Italy (Jan 2014–Dec 2016)	29 hospitals in Emilia-Romagna region	Clinical records	HIC	Quantitative	NA	Epidemiological	332 stillbirths	Stillbirth	Implementation of a Regional Audit System for Stillbirth in Emilia-Romagna Region, Italy	NA	All cases of stillbirth in the study region between 2014-2016	Checklist for studies reporting prevalence data
Prüst 2020	Suriname (2017)	National	Medical files	UMIC	Quantitative	NA	Cross-sectional	113 stillbirths	Stillbirth	Application of the WHO ICD-PM tool to stillbirth cases in Suriname	NND	Stillbirths at or beyond 28 weeks of gestation or with a birth weight of ≥1000 grams	Checklist for analytical cross-sectional studies

Prüst 2022	Multiple (2021)	International	Literature: 4 databases	NA	Qualitative	Systematic review	NA	15 studies	Stillbirth, NND	Use of the International Classification of Diseases to Perinatal Mortality	Studies were excluded if 1) a classification system other than the ICD-PM was used to identify causes of death; 2) no original data was reported; 3) there was no full text available, or; 4) the ICDPM classification data could not be extracted from the presented text, tables, or additional files	Studies were included if they classified the causes of stillbirths and/or neonatal deaths according to the ICD-PM between January 1, 2016, and June 1, 2021	Checklist for systematic reviews and research syntheses
Reinebrant 2018	Multiple (2016)	International	Literature: 5 databases	LIC, MIC, HIC	Quantitative	NA	Meta-analysis	85 reports from 50 countries	Stillbirth	Globally reported causes of stillbirth, classification systems, and alignment with the ICD-PM	Reports were excluded if they: included non-consecutive or selected subgroups, e.g., preterm; aimed only	All published and unpublished cohort and cross-sectional reports from 1 January 2009 to 31 December 2016 that presented	Checklist for systematic reviews and research syntheses

											to identify risk factors or did not provide data on causes in an extractable format	causes of stillbirth	
Reis 2017	Portugal (Jan 2004–Dec 2013)	Maternidade Julio Dinis, a tertiary referral hospital in Oporto City	Clinical records	HIC	Quantitative	NA	Case series	112	Stillbirth	Comparison of Tulip and Wigglesworth classification systems	TOPFA, NND	All stillbirths (at or after 24 weeks of gestation) delivered at the study institution between 2004-2013	Checklist for case series studies
Rimmer 2022	UK (2019)	76 UK obstetric units	Birth registers, Medical certificate of stillbirth counterfoils and local perinatal mortality registers	HIC	Quantitative	NA	Cross sectional	1120 medical certificates	Stillbirth	Accuracy of Medical Certificate of Stillbirth	Where local data collectors were unable to verify eligibility for legal registration of birth (whether stillborn or live born) against maternal	Births during the study period of 1 January 2018 to 31 December 2018 where (i) Medical Certificate of Stillbirth was issued or (ii) where a Medical Certificate of	Checklist for analytical cross-sectional studies

											medical records or in late miscarriage/ neonatal death cases where no evidence of an MCS actually being issued was found.	Stillbirth should have been issued but was not included	
Russel 2022	Multiple (2019)	International	Interviews, document review, literature	Low resource settings	Qualitative	Thematic analysis	NA	55	Stillbirth, NND	Implementation of maternal and perinatal death surveillance and response system in humanitarian settings	NA	Individuals with (1) clinical, academic or programmatic experience in maternal and/or newborn health in humanitarian settings, and/or (2) programmatic or research experience in maternal and perinatal death surveillance and response system.	Checklist for qualitative research
Russell 2022	USA (2019)	New York city	Semi structured	HIC	Qualitative	Thematic analysis	NA	n=49 participants	Perinatal death	Implementation of the	NA	Interviews: individuals	

	interviews, expert consultation			for expert consultation; n=55 interviews	MPDSR process in humanitarian settings	meeting at least one of two criteria: (1) clinical, academic or programmatic experience in maternal and/or newborn health in humanitarian settings, and/or (2) programmatic or research experience in MPDSR. Expert consultation: participants from academia, government, UN agencies and non-governmental organizations

Sacks 2017	Multiple (dates not reported)	Global	Literature	LMICs mainly	Qualitative	Narrative review	NA	93 articles	NND	Effectiveness of community-based primary health care in improving neonatal care	Assessments were excluded if the primary project beneficiaries were more than 28 days of age, or if the assessment did not identify one of the following outcomes related to neonatal health: changes in knowledge about newborn illness, care seeking for newborn illness, use of postnatal care, nutritional status of neonates, neonatal morbidity, or neonatal mortality.	Health-related interventions carried out in the community outside of a health facility with a focus on neonates	Checklist for systematic reviews and research syntheses

Sandakabatu 2018	Solomon Islands (2017)	Paediatric department of the National Hospital in Honiara, Solomon Islands	Observations and patient medical records	LMIC	Quantitative	NA	Observational	n=66; 48 neonatal and 18 child deaths	NND	Process and outcomes of child death review in the Solomon Islands	NA	All cases of child/ neonatal deaths discussed in the hospital audit meetings over a period of 6 months	Checklist for analytical cross-sectional studies
Sander 2019	Germany (1973–1989)	East Berlin	Commission on the Reduction of Infant Mortality	HIC	Quantitative	NA	Retrospective cross sectional	1868 NND	NND	Single-case analysis of NND using Nordic-Baltic classification	NA	All cases of live births that died in the first 28 days of life between 1973 and 1989 in East Berlin	Checklist for analytical cross-sectional studies
Sauvegrain 2020	France (2014)	11 maternity hospitals in the district of Seine-Saint-Denis	Medical records and interviews	HIC	Mixed-methods study	Thematic analysis	Cohort study	151 women for audit data; 54 women participated in interviews	Stillbirth (n=156)	Autopsy acceptance rates and factors associated with declining an autopsy after stillbirth in a disadvantaged district with high migrant population	None mentioned	Women who experienced a stillbirth from 22 weeks of gestation or NND	Checklist for qualitative research

Sexton 2021	Australia (2013–2018)	18 hospitals nationally	Hospital database	HIC	Quantitative	NA	Prospective cohort study	697	Stillbirth (n=697)	Causes of stillbirth	TOPFA	Stillbirths at ≥20 weeks' gestation and/or ≥400 g birthweight	Checklist for cohort studies
Sharma 2021	India (Nov 2016–Oct 2017)	1 tertiary care centre of northern India	Case records, available investigations, interviews	LMIC	Quantitative	NA	Prospective observational	314 stillbirths	Stillbirth	ICD-PM classification system and CODAC to classify stillbirths in India	None stated	Stillbirths at the study institution between Nov 2016 and Oct 2017	Checklist for analytical cross-sectional studies
Soltanghoraee 2022	Iran (2012–2019)	Avicenna Research Institute	Maternal clinical records, autopsy findings	LMIC	Quantitative	NA	Retrospective cross-sectional	42 stillbirth autopsies	Stillbirth	Causes of stillbirth based on ReCoDe classification	NA	All stillbirth autopsies conducted at the study institute between Mar 2012-Feb 2019	Checklist for analytical cross-sectional studies
Singh 2021	India (Aug–Nov 2014)	10 districts of Odisha	Annual Health Survey, maternal interviews	LMIC	Quantitative	NA	Descriptive	4689 cases of stillbirth	Stillbirth	Factors causing stillbirth	NA	All stillbirths in the study locations between Aug-Nov 2014	Checklist for analytical cross-sectional studies

Smith 2018	Multiple (2004, 2010 and 2015)	19 European countries	Data from the Euro-Peristat project	HIC	Quantitative	NA	Epidemiological	n=9317 stillbirths from 19 countries	Stillbirth	Stillbirths before 28 weeks of completed gestational age in high-income countries	TOPFA, Countries without national data for stillbirths by gestational age, or where data available were not comparable between 2004 and 2015; countries with fewer than 10 000 births per year.	Aggregated data from the Euro-Peristat project for the numbers of livebirths and stillbirths by gestational age for the years 2004, 2010, and 2015 for countries with data from all three periods	Checklist for studies reporting prevalence data
Sterpu 2020	Sweden (2017)	6 labour wards in Stockholm	Medical chart reviews and audit meetings	HIC	Quantitative	NA	retrospective cohort	79 stillbirths; 78 women	stillbirth >= 22 weeks	if a regional multidisciplinary audit could help in identifying avoidable factors and delays associated with stillbirths	Registered stillbirths where the audit group assessed that the normal evolution of the pregnancy had stopped before 22 + 0 weeks of gestation	women with a stillbirth >= 22 weeks in Stockholm in 2017	Checklist for cohort studies

Tanko 2021	Kazakhstan (Nov 2020–June 2021)	Pathological Bureau of the Akimat, city of Nur-Sultan	Clinical records, MTAS and CDA findings	UMIC	Quantitative	NA	Diagnostic value	24	Stillbirth (n=15), NND (n=9)	Reliability of MITS in identifying cause of perinatal death and comparison with complete diagnostic autopsy	Traumatic deaths, fire burns, drowning, severely macerated or autolysed bodies	Stillbirths from 22 weeks gestation age, NND and infant deaths up to 22 months where autopsy was requested	Quality Assessment for Diagnostic Accuracy Studies (QUADAS)
Taweevisit 2022	Thailand (2001–2020)	Tertiary referral health facility in Bangkok	Retrospective autopsy reports	UMIC	Quantitative	NA	Cross-sectional	330	Stillbirths (126 antepartum, 204 intrapartum)	Classification of stillbirths using ICD classification	Cases lacking the placenta	All autopsy cases of stillbirth delivered at or after 22 weeks gestation	Checklist for analytical cross-sectional studies
Tayebwa 2020	Rwanda (Dec 2016–Jan 2017)	10 hospitals and 3 health centres from 11 districts	Desk reviews of strategic documents, facility observations and key informant interviews	LIC	Mixed methods	Descriptive	Descriptive cross sectional	13 health facilities	NND, stillbirths	Implementation of Maternal and Perinatal Death Surveillance and Response in Rwanda	NA	Health facilities with experience in conducting maternal and/or perinatal death reviews and/or implementing formal MPDSR processes or policies; health providers and facility managers	Checklist for qualitative research and Checklist for analytical cross-sectional studies

												involved in death audits	
Tindal 2022	Australia (2010–2018)	Victoria	Victorian Perinatal Data Collection	HIC	Quantitative	NA	Retrospective cohort	6849 (n=3906 stillbirths, n=1945 NND)	Stillbirths, NND	Causes of preterm stillbirth and neonatal death in Victoria, Australia	Terminations of pregnancy for maternal psychosocial indications	All perinatal deaths reported between 2010 and 2018 in Victoria.	Checklist for cohort studies
Tomlinson 2018	UK (2013–2016)	13 maternity units in North West of England	Clinical audit questionnaire	HIC	Mixed methods	NA (no qual data presented)	Descriptive case study	89 (29 stillbirths audited in 2014, 29 in 2015 and 31 in 2016)	Stillbirth	Evaluation of integrated care pathway program for stillbirth management	None mentioned	2 cases from each of 13 maternity units in North East England	
Vallely 2021	Papua New Guinea (Jul 2017–Jan 2020)	2 provinces in Papua New Guinea	Data from Women and Newborn Trial of Antenatal Interventions and Management trial	LMIC	Quantitative	NA	Retrospective cross sectional	59 stillbirths	Stillbirth	Perinatal death audit and classification of stillbirths in Papua New Guinea	NA	Women aged 16 years or over, less than 26 weeks pregnant (confirmed by obstetric ultrasound scan), and attending their first prenatal clinic visit	
Vallely 2021 (2)	Papua New Guinea (Jul 2017–Jan 2020)	2 provinces in Papua New Guinea	Data from Women and Newborn Trial of Antenatal Intervention	LMIC	Quantitative	NA	Retrospective cross sectional	n=2499 livebirths, 35 NND	NND	Causes of early neonatal death and the avoidable	NA	Women attending for their first antenatal clinic visit at any of the 10	Checklist for analytical cross-sectional studies

			s and Management trial							factors associated with these deaths		participating primary healthcare facilities, aged 16 years or over and less than 26 weeks pregnant (confirmed by obstetric ultrasound scan)	
Vieira 2020	Brazil (2011)	States of Rio de Janeiro and São Paulo	Mortality Information System; prenatal cards, medical records and Delivery Room Book records	UMIC	Quantitative	NA	Case series	98 perinatal deaths (65 fetal and 33 neonatal death)	Stillbirth, NND	Applicability of the Brazilian List of Avoidable Causes of Death (BAL) to perinatal mortality in Brazil	NA	Fetal deaths, at 22 weeks of pregnancy or more (and/or weight ≥500g) and early neonatal deaths between 0 to 6 complete days of life at the study hospitals	Checklist for case series studies
Waiswa 2020	Kenya, Uganda (Oct 2016–Mar 2018)	23 facilities (17 in Western Kenya, 6 in Eastern Uganda)	Maternity registers	LIC/LMIC	Quantitative	NA	Cross-sectional	46,531 live births, 1,834 late stillbirths, 244 early stillbirths, 653 NND	Stillbirth, NND	Facility-based pregnancy outcomes in Kenya and Uganda	births before arrival and births with no documented birth weight or gestational age	All live births, stillbirths and spontaneous abortions at the study sites	Checklist for analytical cross-sectional studies

Willcox 2020	Multiple (2019)	Global	Literature: 9 databases	HICs	Qualitative	Narrative synthesis	NA	(	Stillbirth, NND	Impact and cost-effectiveness of different types of death audits and reviews in reducing maternal, perinatal and child mortality	Excluded studies with only one intervention or control site for cluster randomised trials, cluster non-randomised trials and controlled before-and-after studies. For interrupted time series studies, excluded studies that did not have a clearly defined point in time when the intervention occurred and at least three data points before and three after the intervention	Cluster-randomised trials, cluster non-randomised trials, controlled before-and-after studies and interrupted time series studies of any form of death audit or review that involved reviewing individual cases of maternal, perinatal or child deaths, identifying avoidable factors, and making recommend ations	Checklist for systematic reviews and research syntheses

Willcox 2023	Multiple (2022)	International	Literature: 7 databases	LMIC	Qualitative	Systematic review	NA	59 studies	Perinatal death	Experiences and perceptions of people implementing maternal and/or perinatal death surveillance and response in low- and middle-income countries	None stated	Qualitative studies	Checklist for systematic reviews and research syntheses
Wojcik 2022	USA (Jan 2015–Jun 2017 and Jul 2017–Dec 2019)	1 level IV NICU	NICU death certificates	HIC	Quantitative	NA	Pre-post intervention	N=94 deaths (n=46 pre-intervention, n=48 post-intervention)	NND	Improving accuracy of death reporting in NICU	NA	Deaths occurring in the NICU at the study site pre and post intervention	Checklist for quasi-experimental studies (non-randomised experimental studies)
Zakar 2018	Pakistan (dates not reported)	4 districts of Pakistan from the two provinces of Sindh and Khyber Pakhtunkhawa	Interviews and focus group discussions	LMIC	Qualitative	Constant comparative method; inductive analysis	NA	14 focus group discussions (n=46 men, 42 women); n=285 for interviews	Stillbirth	Sociocultural practices and health system-related factors contributing to stillbirths and their underreporting	NA	Health professionals with more than 1 year of work experience, including District Health Coordinators, staff from the Health Facility in	Checklist for qualitative research

												Charge, Lady/ Community Health Workers and Traditional Birth Attendants, and parents who had experienced at least one stillbirth	
Zulfeen 2021	India (Jan–Dec 2018)	Tertiary teaching hospital in Karnataka state	Case records	LMIC	Qualitative	Descriptive	NA	89 (n=52 stillbirths, n=37 NND)	Stillbirth, NND	Application of ICD-PM and 3-delay classification to fetuses at risk in India	NA	All stillbirths and neonatal deaths at the study hospital	Checklist for qualitative research

GA: gestational age; HIC: high-income country; ICD-PM: International Statistical Classification of Disease and Related Health Problems-Perinatal Mortality; LIC: low-income country; LMIC: lower-middle-income country; MIA: minimally invasive autopsy; MITS: minimally invasive tissue sampling; MRI: magnetic resonance imaging; NA: not applicable; NICU: neonatal intensive care unit; NND: neonatal death; RCT: randomised controlled trial; TOP: termination of pregnancy; TOPFA: Termination of Pregnancy due to Fetal Anomaly; UMIC: upper-middle-income country **Quality appraisal tools[a]:** JBI Critical Appraisal Checklist for qualitative research; JBI Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data

Table 11. Study quality assessment for studies

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Relevance
Alyahya 2019	Unclear	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	R
Baauw 2023	Not applicable	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Not applicable	Yes	P
Bakhbakhi 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	I
Bakhbakhi 2019	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	Yes	Yes	P
Bandali 2019	Unclear	Yes	Yes	Yes	Unclear	No	No	Unclear	No	Yes	R
Bezhenar 2021	Unclear	Yes	Yes	Unclear	Unclear	No	No	Not applicable	Yes	Yes	P
Biswas 2018	No	Yes	No	Yes	No	No	No	Unclear	No	No	R

Boyi Hounso 2021	Unclear	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	U
Boyle 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Burden 2021	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Burke 2023	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Cetin 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	R
Christou 2019	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Crehan 2022	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	P
Gondwe 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Helps 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Helps 2021(b)	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	R
Igumbor 2020	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	P
Khader 2020	Unclear	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	U
Kinney 2020	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	I
Kinney 2022	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	P

Mukinda 2021	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	I
Nahimana 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	I
Russel 2022	Unclear	Yes	Yes	Unclear	Yes	Yes	Unclear	Unclear	Not applicable	Yes	I
Russell 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Not applicable	Yes	I
Sauvegrain 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	I
Tayebwa 2020	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	P
Zakar 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	U
Zulfeen 2021	Unclear	Yes	Yes	Unclear	Unclear	No	No	Not applicable	Yes	Yes	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Relevance
Aguinaga 2021	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	R
Alyahya 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P

Anwar 2018	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	U
Baauw 2023	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	P
Bandali 2019	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	R
Boyi Hounso 2021	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	U
Boyle 2021	Yes	Yes	Unclear	Yes	Not applicable	Not applicable	Unclear	Yes	R
Burke 2023	Yes	Yes	Unclear	Yes	Not applicable	Not applicable	Unclear	Yes	R
Cullen 2019	Yes	Unclear	Yes	Yes	No	No	Unclear	Yes	U
Dagdeviren 2022	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	P
Dase 2020	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	I
Ebenezer 2019	Yes	Unclear	Yes	Yes	Unclear	Unclear	Yes	Yes	U
Flenady 2021	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	R
Gulati 2020	Yes	Yes	Yes	Yes	No	Not applicable	Yes	Yes	P
Halim 2018	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	P
Haruyama 2018	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	P

Higgins 2018	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	R
Igumbor 2020	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	P
Jayaratnam 2020	Yes	Yes	Yes	Yes	No	No	Yes	Yes	R
Kashif 2022	Yes	Yes	Unclear	Yes	Not applicable	Not applicable	Yes	Yes	P
Khader 2019	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	P
Kinney 2020	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	I
Kortekaas 2018	Yes	Unclear	Unclear	Yes	No	No	Yes	Yes	P
Kulkarni 2019	Yes	Yes	Unclear	Yes	Not applicable	Not applicable	Yes	Yes	P
Kunjachen Maducolil 2018	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	P
Lehner 2019	Yes	Yes	Yes	Yes	No	No	Yes	Yes	I
Luk 2020	Yes	Unclear	Yes	Yes	Not applicable	Not applicable	Yes	Yes	P
Lupariello 2022	Yes	Unclear	Unclear	Yes	Not applicable	Not applicable	Yes	Yes	P
Mok 2021	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	I
Mungdagowa 2020	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	R

Musafili 2017	Yes	Yes	Yes	No	No	No	Yes	Yes	U
Prust 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Rimmer 2022	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	U
Sandakabatu 2018	Yes	Unclear	Unclear	Yes	No	No	Unclear	Yes	P
Sander 2019	Yes	Unclear	Unclear	Yes	No	No	Yes	Yes	I
Sharma 2021	Yes	Yes	Yes	Yes	No	No	Yes	Yes	R
Singh 2021	Yes	Yes	Unclear	Yes	Unclear	Unclear	Unclear	Yes	U
Soltanghoraee 2022	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	I
Taweevisit 2022	Yes	Yes	Yes	Yes	No	No	Yes	Yes	P
Tayebwa 2020	Yes	Unclear	Unclear	Yes	No	No	Unclear	Yes	P
Vallely 2021	Yes	Yes	Yes	Yes	No	No	Yes	Yes	U
Vallely 2021 (2)	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	U
Waiswa 2020	Yes	Yes	Unclear	Yes	Unclear	Unclear	Unclear	Yes	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimise errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Relevance
Aminu 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	yes	Yes	R
Gondwe 2021	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	No	Unclear	Unclear	R
Gutman 2022	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Not applicable	R
Helps 2020 (2)	Unclear	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	Not applicable	U
Helps 2021 (2)	Unclear	Yes	Yes	Unclear	Not applicable	Not applicable	Unclear	Yes	No	Yes	Not applicable	R
Hopkins Leisher 2017	Yes	Yes	Yes	Yes	Not applicable	Not applicable	Yes	Yes	No	Yes	Not applicable	R
Leisher 2016	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	R
Prust 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Not applicable	No	Yes	Not applicable	P
Reinebrant 2018	Yes	Yes	Unclear	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Not applicable	P
Sacks 2017	Unclear	Yes	Unclear	Unclear	Not applicable	Not applicable	Unclear	Yes	No	Yes	Yes	I

Willcox 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	R
Willcox 2023	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Relevance
Aminu 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not Applicable	R
Angell 2019	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Not Applicable	R
Auger 2018	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Not applicable	I
Baptista 2021	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Not applicable	I
Bartlett 2017	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Not applicable	P
Breiman 2021	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	U
D'Aloja 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	U
Dadzie 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	R

de Graaff 2023	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	Unclear	P
Harrist 2017	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Not applicable	P
Hoyert 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	P
Kumar 2021	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Unclear	P
Lavin 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	P
McClure 2018	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	Not applicable	I
Muin 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	I
Po 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	I
Smith 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not applicable	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/ sources logically defended?	Relevance
ACOG 2018	Yes	Yes	Yes	Unclear	Yes	Not applicable	P

Andrews 2020	Yes	Yes	Yes	Yes	Yes	Not applicable	I
Bakhbakhi 2017	Yes	Yes	Yes	Unclear	Yes	Not applicable	P
Flenady 2017	Yes	Yes	Yes	Yes	Yes	Not applicable	I
Flenady 2020	Yes	Yes	Yes	Yes	Yes	Not applicable	I
Goldenberg 2019	Yes	Yes	Yes	Unclear	Yes	Not applicable	R
Gordon 2020	Yes	Yes	Yes	Unclear	Yes	Not applicable	I
Joseph 2021	Yes	Yes	Unclear	Unclear	Yes	Not applicable	R
Knight 2019	Yes	Yes	Yes	Unclear	Yes	Not applicable	P
Norris 2017	Yes	Yes	Unclear	Yes	Yes	Not applicable	P
Panaitescu 2021	Yes	Yes	Yes	Yes	Yes	Yes	U
Patterson 2019	Yes	Yes	Yes	Unclear	Yes	Not applicable	U
RCPA 2004	Yes	Yes	Yes	Yes	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Quasi experimental studies

	1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?	Relevance
Kirabira 2020	Yes	Not applicable	Not applicable	No	Yes	Unclear	Not applicable	Unclear	Yes	U
Magge 2020	Yes	Not applicable	Not applicable	No	Yes	Unclear	Not applicable	Yes	Yes	U
Nahimana 2021	Yes	Not applicable	Not applicable	No	Yes	Unclear	Not applicable	Yes	Yes	I
Wojcik 2022	Yes	Yes	Yes	No	Not applicable	Not applicable	Yes	Unclear	Yes	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cohort studies

	1. Were the two groups similar and recruited from the same population?	2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	3. Was the exposure measured in a valid and reliable way?	4. Were confounding factors identified?	5. Were strategies to deal with confounding factors stated?	6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	7. Were the outcomes measured in a valid and reliable way?	8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	10. Were strategies to address incomplete follow up utilised?	11. Was appropriate statistical analysis used?	Relevance
Basu 2018	Not applicable	Unclear	Yes	No	Not applicable	Unclear	Yes	Yes	Yes	Not applicable	Yes	I
Best 2019	Yes	Yes	Yes	Yes	Yes	No	Yes	Not applicable	Not applicable	Not applicable	Yes	P
Fabrizio 2022	Not applicable	Not applicable	Yes	No	Not applicable	Unclear	Yes	Not applicable	Yes	Not applicable	Yes	P
Gurung 2019	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Not applicable	Not applicable	Not applicable	Yes	I
Kc 2020	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Not applicable	Not applicable	Not applicable	Yes	I
Sauvegrain 2020	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Not applicable	Yes	I
Sexton 2021	Unclear	Unclear	Unclear	No	No	Yes	Yes	Yes	Yes	Not applicable	Yes	I
Sterpu 2020	Not applicable	Yes	Yes	No	No	Yes	Unclear	Not applicable	Not applicable	Not applicable	Yes	U
Tindal 2022	Not applicable	Not applicable	Yes	No	No	Unclear	Yes	Not applicable	Not applicable	Not applicable	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case report studies

	1. Were patient's demographic characteristics clearly described?	2. Was the patient's history clearly described and presented as a timeline?	3. Was the current clinical condition of the patient on presentation clearly described?	4. Were diagnostic tests or assessment methods and the results clearly described?	5. Was the intervention(s) or treatment procedure(s) clearly described?	6. Was the post-intervention clinical condition clearly described?	7. Were adverse events (harms) or unanticipated events identified and described?	8. Does the case report provide takeaway lessons?	Relevance
Tomlinson 2018	No	No	Yes	Yes	No	Yes	No	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case series studies

	1. Were there clear criteria for inclusion in the case series?	2. Was the condition measured in a standard, reliable way for all participants included in the case series?	3. Were valid methods used for identification of the condition for all participants included in the case series?	4. Did the case series have consecutive inclusion of participants?	5. Did the case series have complete inclusion of participants?	6. Was there clear reporting of the demographics of the participants in the study?	7. Was there clear reporting of clinical information of the participants?	8. Were the outcomes or follow up results of cases clearly reported?	9. Was there clear reporting of the presenting site(s)/clinic(s) demographic information?	10. Was statistical analysis appropriate?	Relevance
Assaad 2018	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	I
Blythe 2019	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	I
Boyd 2017	Yes	Yes	Yes	Unclear	Unclear	No	Unclear	Yes	Unclear	Yes	I
Changede 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	U
Hayat 2021	Yes	Unclear	Unclear	Yes	Unclear	No	No	Yes	No	Unclear	R

Housseine 2021	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Hyde 2020	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	No	Yes	R
Jones 2017	Yes	Yes	Yes	Yes	Yes	No	Yes	Unclear	No	Yes	P
Kapurubandara 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Reis 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	R
Vieira 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Case-control studies

	1. Were the groups comparable other than the presence of disease in cases or the absence of disease in controls?	2. Were cases and controls matched appropriately?	3. Were the same criteria used for identification of cases and controls?	4. Was exposure measured in a standard, reliable and valid way?	5. Was exposure measured in the same way for cases and controls?	6. Were confounding factors identified?	7. Were strategies to deal with confounding factors stated?	8. Were outcomes assessed in a standard, valid and reliable way for cases and controls?	9. Was the exposure period of interest long enough to be meaningful?	10. Was appropriate statistical analysis used?	Relevance
Christiansen-Lindqust 2017	Yes	Unclear	Yes	Yes	Yes	No	Not applicable	Yes	Yes	Yes	P
Wijs 2017	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	U

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

RCTs

	1. Was true randomisation used for assignment of participants to treatment groups?	2. Was allocation to treatment groups concealed?	3. Were treatment groups similar at the baseline?	4. Were participants blind to treatment assignment?	5. Were those delivering treatment blind to treatment assignment?	6. Were outcomes assessors blind to treatment assignment?	7. Were treatment groups treated identically other than the intervention of interest?	8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	9. Were participants analysed in the groups to which they were randomised?	10. Were outcomes measured in the same way for treatment groups?	11. Were outcomes measured in a reliable way?	12. Was appropriate statistical analysis used?	13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?	Relevance
Jha 2019	Not applicable	Unclear	Yes	Unclear	Yes	Yes	Yes	Not applicable	Yes	Unclear	Unclear	Yes	Yes	I

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Diagnostic accuracy studies

The QUADAS-2 was used to assess the following diagnostic accuracy study:

- Tanko 2021

Please contact the Stillbirth CRE for more information on quality assessment for these studies (e: stillbirthcre@mater.uq.edu.au)

Table 12. GRADE-CERQual detailed assessment of studies for recommendations

No.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CER-Qual appraisal
7.1	All maternal and newborn services should implement a formal process for perinatal mortality audit, including identification of causes, associated conditions, and contributing factors relating to care	Thirteen studies are included. Three cross sectional studies, three primary qualitative studies, one cohort study, and four reviews (two systematic reviews, one review of contemporary classification systems, and one audit review). One mixed methods study is included, and one quasi-experimental study.	Minor concerns of methodological limitation are noted in the included studies through critical appraisal. Nine of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. Two included cross-sectional studies are noted to have moderate concerns due to a lack of confounder identification and adjustment through analysis. Two additionally were noted to have unclear validity in measurement tools of exposures. The included cohort study is noted to have moderate concerns of methodology due to lack of confounder identification and adjustment through analysis. The included mixed-methods study is noted to have moderate concerns of methodological limitation of its qualitative component through critical appraisal. Concerns of researcher's cultural position,	Moderate concerns of relevance are noted. Four of the included studies are deemed directly relevant to perinatal mortality classification and audit. Two studies are deemed partially relevant, and three studies are deemed indirectly relevant to classification and audit. Four included studies are deemed of unclear relevant to classifications and audit.	No issues of coherence were noted of the findings from the included studies, and the and review findings.	Minor concerns of data adequacy are noted. The included studies source their cohorts and data from high-, middle- and low-income country populations. Outcomes of interest included across studies are stillbirth (12 studies, reported n=575), neonatal deaths (9 studies, reported n=259). Viewpoints contained within the data include mothers (2 studies), healthcare professionals (including audit committee members, physicians, and nurses), and medical record reviews. Minor concerns of data adequacy are noted due to the small cohort of parents' viewpoint contained within the data.	**Moderate confidence** *No concerns of coherence. Minor concerns of methodological limitation and data adequacy. Moderate concerns of relevance.*

			and influence on the results and analysis were not accounted for. Appraisal also identified unclear congruity between the stated philosophical perspective, research methodology, methods used, representation of the data analysis, and interpretation of the findings.				
7.2	Smaller services, including those in rural and remote regions, are encouraged to participate in combined perinatal audit meetings with other experienced maternity and newborn services to ensure high-quality audit.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
7.3	If a baby dies outside the hospital of birth, the audit should ideally be carried out by the hospital where the baby was born. Communication between hospitals that provided care is needed to ensure the perinatal mortality audit committee has access to all relevant details.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
7.4	All maternal and newborn services should ensure that appropriate systems for undertaking perinatal mortality audit, reporting of findings, and implementation of recommendations are in place and that the perinatal mortality audit committee is adequately supported to ensure perinatal mortality audit is conducted effectively.	NA	NA	NA	NA	NA	**Consensus-based recommendation**

7.5	The Perinatal Mortality Audit Committee should arrange for review of perinatal death to occur in a timely manner, aiming to have the results in time for the initial follow-up visit with parents. • If test results are delayed, it may be necessary to re-review and arrange additional follow-up meetings with the parents to provide final results.	Four studies are included, three are primary qualitative research studies and one is a cross-sectional study.	Moderate concerns of methodological limitation are noted through critical appraisal. Two of the included studies are deemed to have no or minor concerns of methodological limitation. Two included studies are deemed to have moderate concerns of methodological limitation through critical appraisal. One qualitative study is noted to have concerns due to a lack of researcher cultural position statement, and lack of accounting for the researcher influence on the research and vice versa. One included cross-sectional study is deemed to have moderate concerns of methodological limitation due to lack of confounder identification or adjustment through analysis. Exposure measures are also deemed to be unclear.	Minor concerns of relevance are noted. Two of the included studies are deemed to be relevant to perinatal mortality audit and classification. The remaining two studies are deemed to be partially relevant to perinatal mortality audit and classification.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. All included studies source their data from high-income countries. Outcomes of interest included through the data are stillbirth (n=209), neonatal deaths and terminations of pregnancy for fetal anomaly (n=34). The viewpoints of stakeholder, (n=17), researchers (n=5) are included, as well as national inquiries (n=10) from one country. One study sourced their data from federal laws, agency regulations, orders of ministries and departments, methodological letters and recommendations, and materials on the Internet. Moderate concerns are noted due to small, combined cohort sizes across studies, and the narrow scope of viewpoints that did not contain the view of families, and few health care professionals.	**Low confidence** *Moderate concern of methodological limitation and data adequacy. Minor concerns of relevance and no concerns of coherence.*
7.6	Discuss the audit process with parents including how parents may be involved, and when, and how the results of the audit will be provided. • This should be conducted by an experienced healthcare professional, ideally the lead	Three studies are included, all are primary qualitative research studies.	Minor concerns of methodological limitation are noted. Two of the included studies are noted to have minor concerns of methodological limitations. One	Moderate concerns of relevance are noted. One included study is deemed to be relevant to perinatal mortality classification and audit.	Minor concerns of coherence are noted.	Moderate concerns of data adequacy are noted. All included studies source their data from high-income country settings.	**Low confidence** *Moderate concerns of relevance and data adequacy. Minor concerns of coherence*

	healthcare professional involved in the parent's care or the point of contact for each family (such as a bereavement midwife).		included study is deemed to have no concerns of methodological limitation through critical appraisal.	One is deemed to be partially relevant, and the final study is deemed to be indirectly relevant.		Outcomes of interest included across studies are stillbirth and neonatal deaths. The viewpoints of parents are included in one study (n=13), those of health care professionals in two studies (n=29) and those of stakeholders (n=17 and research team members (n=5) in another study. Moderate concerns are noted due to the small, combined sample of viewpoints contained within the evidence.	*and methodological limitation.*
7.7	Offer parents the option of providing a summary of events for presentation at the audit meeting either through a written summary using the Australian Perinatal Mortality Audit Tool, or local equivalent, and a healthcare professional presenting information on their behalf.	Six studies are included. Four of the included studies are primary qualitative research studies. The remaining two studies are reviews, one review of guidelines, and one review of contemporary classification systems.	Minor concerns are noted of methodological limitation. All the included studies were noted to have no or minor concerns of methodological limitation through critical appraisal.	Moderate concerns of relevance are noted of the included studies. Two of the included studies are deemed directly relevant to perinatal mortality audit and classification of death. Two studies are deemed partially relevant, and two studies are deemed to be indirectly relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. The included studies all source cohorts and data from high-income country populations, and one additionally sources its data from lower- and middle-income country populations. Outcomes of interest included across the study include stillbirths (6 studies) and neonatal deaths (5 studies). The viewpoints of parents are included through one study (n=13), and the view of health care professionals is also	**Low confidence** *No concerns of coherence, minor concerns of methodological limitation. Moderate concerns of relevance and data adequacy.*

						included (n=29). Additionally, stakeholders (n=17) and researchers (n=5) are also included through one study. One review of guidelines, one review of contemporary classification systems and one review of inquiries is also included. Moderate concerns are noted of the data adequacy due to small, combined cohort sizes across studies from primary sources incorporating the view of health care professionals and parents.	
7.8	Perinatal mortality audit committees should ensure the classification of causes and associated factors for stillbirths and neonatal deaths use the best available information from a comprehensive history and appropriate investigation (see Section 6: Investigations for perinatal death).	16 studies are included. Five case series, five cross-sectional studies, three cohort studies, two systematic reviews, and one narrative review.	Moderate concerns of methodological limitation are identified of the included studies. 12 of the included studies are deemed to have minor concerns of methodological limitation through critical appraisal. Four included studies are deemed to have moderate concerns of methodological limitation, two cross sectional studies are noted to lack confounder identification or adjustment through analysis. Two case series studies are noted to have concerns due to lack of demographics reporting of both	Moderate concerns of relevance are noted. Five of the included studies are deemed to be directly relevant to perinatal mortality audit and classification. Nine of the included studies are deemed to be partially relevant to perinatal mortality classification and audit. Two of the included studies are deemed to be indirectly relevant to perinatal mortality classification and audit.	No concerns of coherence are noted.	Minor concerns are noted of data adequacy. Seven of the included studies source their data from high income country populations, and seven from lower or upper-middle income country populations. One review sourced its included data from lower, middle- and high-income country populations. Outcomes of interest include stillbirths (n=3,919), neonatal deaths (n=330) and composite perinatal mortality outcomes (n=1,267).	**High confidence** *No concerns of coherence. Minor concerns of methodological limitation, relevance and data adequacy.*

			patients and medical sites, inclusion criteria are also unclear.			The views of mothers are included in two studies, the remainder of the primary research sourced their data from medical records, and registries. Minor concerns of data adequacy are noted due to the lack of health care professional view.	
7.9	The Australian Perinatal Mortality Audit Tool (or local equivalent) or the New Zealand Mother and Baby Rapid Reporting Forms for a Perinatal Death should be completed for each perinatal death in Australia and Aotearoa New Zealand, respectively, for purposes of committee review of the death and for relevant local and jurisdictional reporting requirements.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
7.10	The Medical Certificate of Perinatal Death should be completed by (or supervised by) the lead/experienced healthcare professional responsible for care around the time of the death in accordance with local requirements.	Four studies are included. One cross-sectional study, one primary qualitative research and two expert committee opinion pieces are included.	Moderate concerns of methodological limitation are noted through critical appraisal. Two included studies are deemed to have no or minor concerns of methodological limitation, and two studies (one cross sectional and one primary qualitative research) are deemed to have moderate concerns of methodological limitation. One cross-sectional study lacks confounder identification and	Minor concerns of relevance are noted. Three included studies are deemed to be directly relevant to perinatal mortality audit and classification. One study is deemed to be partially relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. All included studies source their cohorts and data from high income country populations. The outcomes include stillbirth (n=209), neonatal deaths, termination of pregnancy for fetal anomalies (n=34) and composite perinatal mortality outcomes.	**Low confidence** *Moderate concerns of methodological limitation and data adequacy. Minor concerns of relevance, no concerns of coherence.*

			adjustment through analysis, and the primary qualitative study fails to list the researcher cultural position, or the influence that this has on the results. This study was also noted to lack congruity between the philosophical perspective, methodology, representation of data and interpretation of result.			The source of data across studies are medical certificates, literature, expert opinions and views of hospital administrators and pathologists. One study sourced their data from federal laws, agency regulations, orders of ministries and departments, methodological letters and recommendations, and materials on the Internet. Moderate concerns of data adequacy are noted due to small, combined cohort size of primary research studies.	
7.11	The perinatal mortality audit process should be overseen by a multidisciplinary committee including medical staff (obstetric and neonatal), midwives, nurses, a perinatal pathologist (where possible), and parent advocate.	15 studies are included. Four are primary qualitative research, four are reviews (three systematic review, and one audit reviews), two are prevalence studies, two are cross-sectional studies, two mixed methods studies, and one cohort study.	Minor concerns of methodological limitation are noted. 12 of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. Three of the included studies are noted to have moderate concerns of methodological limitation. One mixed methods study is deemed to have moderate concerns of methodological limitations due to the qualitative component lacking a statement	Moderate concerns of relevance are noted. Five of the included studies are deemed to be directly relevant to perinatal audit and classification. Five of the included studies are deemed to be partially relevant to perinatal audit and classification. Four of the included studies are deemed to be indirectly relevant, and one of unclear relevance.	Minor concerns of coherence are noted.	Minor concerns of data adequacy are noted. Nine of the included studies source cohorts from high income country populations, four from lower middle income country populations, one form upper middle income country populations, and one includes a cohort from a mix of middle- and high-income country populations. Outcomes of interest include composite perinatal mortality outcomes (ten studies), stillbirths (3 studies, n=700),	**Moderate confidence** *Moderate concerns of relevance, minor concerns of methodological limitation, coherence and data adequacy.*

			of researcher cultural position, and also lack of accounting for the impact on analysis and findings. One systematic review is noted to have concerns of methodological limitation due to lack of independent critical appraisal, and methods to minimise errors. Furthermore, publication bias and recommendations from the evidence were not detailed in the methods or findings. A second mixed methods study was noted to have moderate concerns of methodological limitation due to lack of a statement of the researcher cultural position, and lack of accounting for the impact on analysis and findings. It was also noted that confounders weren't identified or accounted for through analysis.			and neonatal deaths (two studies). Viewpoints included across the primary research are that of health care professionals (4 studies), stakeholders (n=17), researchers (n=5) and facility managers and staff (n=41). The remaining primary research sources data from medical records and registries. There are minor concerns of data adequacy noted.	
7.12	The perinatal mortality committee chair must ensure audits are conducted in a no-blame environment.	Seven studies are included. Four primary qualitative studies, and three reviews (two systematic reviews and one audit review) are included.	Minor concerns of methodological limitation are noted. All included studies are noted to have no or minor concerns of methodological limitation.	Minor concerns of relevance are noted. Four of the included studies are deemed to be directly relevant to classification and audit of perinatal death. Two studies is deemed to be partially relevant, and the final study is deemed to	Minor concerns of coherence are noted.	Moderate concerns of data adequacy are noted. The included studies source their cohorts and data from high-, middle-, low-middle and low-income country populations. Outcomes of interest included across the study include	**Moderate confidence** *Moderate concerns of data adequacy, minor concerns of methodological limitation, relevance and coherence.*

				be indirectly relevant to classification and audit of perinatal death.		stillbirths (6 studies) and neonatal deaths (6 studies). The viewpoints of health care professionals are included across two studies (n=16), and those of stakeholders (n=17), researchers (n=5) and audit committee members are included through one study. Moderate concerns are noted of the data adequacy due to small, combined cohort sizes across studies and lack of parent views.	
7.13	Perinatal mortality audit committees should use the PSANZ Classification system to assign the underlying cause of death and up to two associated conditions for every perinatal death after consideration of all relevant clinical information.	Five studies are included. Two prevalence studies, one cohort study, one systematic review and one review of contemporary classification systems.	Minor concerns of methodological limitation are noted. All included studies are deemed to have no or minor concerns of methodological limitation through critical appraisal.	Minor concerns of relevance are noted. Three of the included studies are noted to be directly relevant to perinatal mortality classification and audit.	No concerns of coherence noted	Minor concerns of data adequacy are noted. Two of the included studies source data from high income country populations, one from lower middle income country populations, one from a mixture of high and low middle income country populations and one systematic review was inclusive of all income settings. Outcomes of interest include stillbirth (n=4,628), neonatal death (n=1,945) and composite perinatal mortality (n=5,851).	**High confidence** *Minor concerns of methodological limitation, relevance and data adequacy. No concerns of coherence.*

						The primary research includes data from medical records, and registry data. Minor concerns of data adequacy are noted.	
7.14	Revise the death certificate based on the outcome of the perinatal mortality audit meeting and ensure a revised copy is sent to the parents.	Three studies are included, two are cross-sectional studies and one is a primary qualitative research study.	Moderate concerns of methodological limitation are noted. All three included studies are deemed to have moderate concerns of methodological limitation. The included primary qualitative study due to lack of a statement of researcher cultural position, and lack of accounting for the influence of this through methods and findings. Unclear congruity between the philosophical perspective, methodology and representation and interpretation of the results was also noted. The two included cross-sectional studies both failed to identify confounders or to adjust for confounders through analysis. One was also noted to have unclear exposure measurements.	Moderate concerns of relevance are noted. One of the included studies is deemed to be directly relevant to perinatal mortality audit and classification, one study is deemed to be partially relevant, and the final study is deemed to be indirectly relevant.	Minor concerns of coherence are noted.	Major concerns of data adequacy are noted. All included studies source data from high-income country populations. Outcomes of interest include stillbirth (n=379), neonatal deaths and terminations of pregnancy for fetal anomaly (n=34). Data included is sourced from medical records or certificates, and federal laws, agency regulations, orders of ministries and departments, methodological letters and recommendations, and materials on the Internet. Major concerns of data adequacy are noted due to the lack of parent and health care professional view, and also due to the small, combined cohort included from evidence available.	**Low confidence** *Major concerns of data adequacy. Moderate concerns of methodological limitation and relevance. Minor concerns of coherence.*
7.15	The perinatal mortality audit committee should consider areas for practice improvement in						**Consensus-based recommendation**

	relation to every perinatal death and develop recommendations and an accompanying implementation plan where relevant. This should also include any recommendations for care of the woman in a subsequent pregnancy.						
7.16	A follow-up meeting with the parents, ideally with the lead healthcare professional involved in the woman's care and the healthcare professional managing the perinatal mortality audit process (for example bereavement midwife or nurse), should be offered to discuss the outcome of the review by the perinatal mortality audit committee. More than one follow-up meeting may be required, depending on when the final results of investigations become available, and the audit committee finalises the review.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
7.17	Parents should be offered a plain language summary of the outcome of the review of their baby's case by the perinatal mortality audit committee. Ideally, this should occur during a face-to-face follow-up meeting with the lead healthcare provider, the bereavement midwife, and other relevant members of the healthcare team.	Three studies are included, all are primary qualitative research studies.	Minor concerns of methodological limitation are noted. All three included studies are noted to have no or minor concerns of methodological limitation.	Minor concerns of relevance are noted. Two of the included studies are deemed relevant to perinatal mortality audit and classification. One study is deemed partially relevant to perinatal mortality audit and classification.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. All three of the included studies source their data from high income country populations. Outcomes of interest include stillbirths (three studies) and neonatal deaths (three studies).	**Moderate confidence** *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*

						Primary research included contains data from the view of parents, stakeholders, and researchers (2 studies), and one study contains data from national inquiries. Moderate concerns of data adequacy are noted due to the small, combined cohort size across the included evidence.	
7.18	A follow-up meeting with the parents, ideally with the senior healthcare professional involved in the woman's care and the healthcare professional managing the perinatal mortality audit process (e.g. bereavement-care midwife), should be offered to discuss the outcome of the review by the perinatal mortality audit committee. There may be a need for more than one follow-up meeting depending on when the final results of investigations become available, and the audit committee finalises the review.	Three studies are included, all are primary qualitative research studies.	Minor concerns of methodological limitation are noted. All three included studies are noted to have no or minor concerns of methodological limitation.	Moderate concerns of relevance are noted. One included study is deemed directly relevant to perinatal mortality audit and classification, one study is deemed partially relevant, and one study is deemed indirectly relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. All included studies source their data from high income country populations. Outcomes of interest include stillbirth and neonatal death within data of all three studies included. The viewpoint of parents is included in one study (n=13), and the view of health care professionals is included from two studies (n=29). One study additionally contains the view of stakeholders (n=17) and researchers (n=5). Moderate concerns are noted due to the small, combined sample of viewpoints contained within the evidence.	**Low confidence** *No or Minor concerns of methodological limitation and coherence. Moderate concerns of relevance and data adequacy.*

7.19	A comprehensive clinical summary should be sent to the woman's general practitioner and all care providers nominated to the parents after review by the perinatal mortality committee.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
7.19	Following the completion of the review by the perinatal mortality audit committee, the chair of the perinatal morality audit committee or a delegate should ensure a summary of the classification of causes and contributing factors relating to care is provided to the jurisdictional perinatal mortality committees for regional and national reporting.	Eight studies are included. Four reviews (one narrative, one systematic review, one review of contemporary classification systems, and one review of audits). Two primary qualitative studies are included, and one cohort and one prevalence study.	Minor concerns of methodological limitation are noted. Seven of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. The included systematic review in noted to have moderate concerns of methodological limitation through critical appraisal due to publication bias, an unclear review question, unclear sources and resources for searches, and unclear methods used to minimise errors in data extraction.	Moderate concerns of relevance are noted. Two of the included studies are deemed directly relevance to perinatal mortality classification and audit. Four of the included studies are deemed partially relevant, and one study is deemed indirectly relevant. The remaining prevalence study is deemed to have unclear relevance to perinatal mortality audit and classification.	Minor concerns of coherence are noted.	No concerns of data adequacy are noted. Seven of the included studies source their data from high-income country populations, the remaining study reports data sourced form high and lower-middle income country populations. Outcomes of interest include stillbirth (seven studies) and neonatal death (seven studies). One included study reports inclusion of the health care professionals view, and the remaining primary research studies include medical record and registry data as well as national inquiries. No concerns of data adequacy are noted.	**Moderate confidence** *No or minor concerns of data adequacy, methodological limitation, and coherence. Moderate concerns of relevance.*
7.20	The assigned classification for causes and contributing factors relating to care should be included in the routine perinatal data collections across jurisdictions for every perinatal death to enable	Eight studies are included. Four reviews (one narrative, one systematic review, one review of contemporary classification systems, and	Minor concerns of methodological limitation are noted. Seven of the included studies are noted to have no or minor	Moderate concerns of relevance are noted. Two of the included studies are deemed directly relevance to	Minor concerns of coherence are noted.	No concerns of data adequacy are noted. Seven of the included studies source their data from high-income country populations,	**Moderate confidence** *No or low confidence of methodological limitation, coherence and data adequacy.*

	comprehensive reporting of perinatal deaths.	one review of audits). Two primary qualitative studies are included, and one cohort and one prevalence study.	concerns of methodological limitation through critical appraisal. The included systematic review in noted to have moderate concerns of methodological limitation through critical appraisal due to publication bias, an unclear review question, unclear sources and resources for searches, and unclear methods used to minimise errors in data extraction.	perinatal mortality classification and audit. Four of the included studies are deemed partially relevant, and one study is deemed indirectly relevant. The remaining prevalence study is deemed to have unclear relevance to perinatal mortality audit and classification.		the remaining study reports data sourced form high and lower-middle income country populations. Outcomes of interest include stillbirth (seven studies) and neonatal death (seven studies). One included study reports inclusion of the health care professionals view, and the remaining primary research studies include medical record and registry data as well as national inquiries. No concerns of data adequacy are noted.	*Moderate concerns of relevance.*
7.21	National definitions should be used to ensure consistency and comparability in perinatal death data across Australia and Aotearoa New Zealand. Reports of perinatal deaths should present data with and without the inclusion of perinatal deaths resulting from termination of pregnancy.	Four reviews are included. Two systematic reviews, one integrative review, and one review of stillbirth reporting processes.	Minor concerns are noted of methodological limitation. Three of the included studies are noted to have minor concerns of methodological limitation through critical appraisal. One included systematic review is noted to have moderate concerns of methodological limitation due to unclear review question, sources, criteria for appraising studies, critical appraisal processes and analysis methods.	Moderate concerns of relevance are noted. One included study is deemed relevant to perinatal mortality audit and classification, one is deemed partially relevant, one is deemed indirectly relevant, and the remaining systematic review is deemed of unclear relevance.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Two of the included studies source data from high income country populations. The remaining two studies source their data from a variety of low-, middle- and high-income country populations. Outcomes of interest include stillbirth (3 studies) and composite perinatal mortality outcomes (1 study).	**Low confidence** *No or minor concerns of coherence and methodological limitation. Moderate concerns of relevance and data adequacy.*

					The data contains no viewpoints as no primary research is included. Moderate concerns of data adequacy are noted due to the lack of primary research findings and views. Furthermore, the data included from reviews spans across country income settings and may be of less relevance to a high-income country population setting such as Australia.

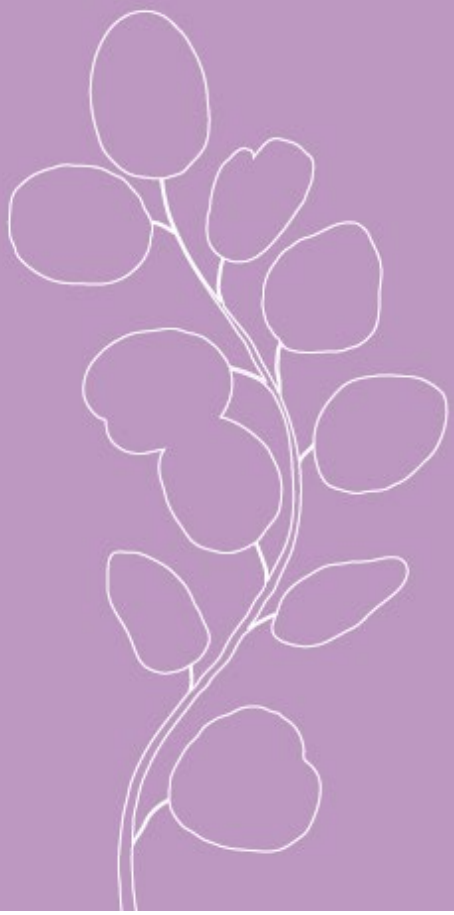
2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Technical report

Section 8: Organisational recommendations



The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Contents

Introduction

By establishing and following appropriate clinical standards, guidelines, and policies, maternal and newborn services can support staff to deliver best practice perinatal loss care. Lack of a robust clinical governance framework was implicated in a cluster of preventable perinatal deaths in Victoria in 2015.[1] The responsibilities of a maternal and newborn service towards parents and staff who experience stillbirth or neonatal death can impact the quality of perinatal loss care that parents experience. A parent's experience and satisfaction with care is inextricably linked to a services' approach to care.

Parents require maternal and newborn services to be flexible and responsive to their emotional, cultural, and spiritual needs. Structurally, maternal and newborn services should be designed to support perinatal loss care through designated built-for-purpose spaces to be with friends and family/whānau.[2,3] Maternal and newborn services should have systems in place for parents to be involved in providing feedback that can shape improvements to the service's care and service delivery.[4,5]

Providing perinatal loss care is challenging. Maternal and newborn services can support their staff by acknowledging and recognising the significant impact of their staff's exposure to traumatic incidents and the intensity of bereaved parents' grief and distress. This recognition should include giving staff access to formal and informal opportunities to debrief and receive counselling, as well as education, training, mentoring, and experiential learning.

Methodology

The Guideline Development Committee identified key research questions (Table 1) on which to focus the evidence synthesis on providing best practice from an organisational perspective.

Table 1. Research questions

1	What are the clinical standards for maternal and newborn services providing perinatal loss care including legal and reporting requirements?
2	How can parent experiences be incorporated into maternal and newborn service improvements?
3	What strategies and resources can services implement to support the emotional wellbeing of healthcare professionals and reduce adverse consequences such as compassion fatigue and burnout?
4	What are the training and education needs of healthcare professionals and what elements of training lead to improved outcomes for parents and families?

PICO criteria for determining study eligibility

PICO (population, intervention, comparator, outcome) criteria (Table 2) were formulated from the research questions for this report.

Table 2. PICO criteria

PICO	Inclusion criteria
Population	Defined in Australia and Aotearoa New Zealand as: • Stillbirth ○ birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight.

	It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term 'stillbirth' is used to describe the birth outcomes were accepted for inclusion.[6,7]
	• Neonatal death
	  ○ a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[6,7]
	• Inclusion of perinatal deaths following termination of pregnancy
	  ○ Stillbirths and neonatal deaths resulting from a termination of pregnancy (medical process of ending a pregnancy) are included).

Intervention	Studies exploring organisational enablers for provision of perinatal loss care following stillbirth or neonatal death in maternal or newborn services.
Comparator	Not applicable – no comparator within research questions
Outcomes	Outcomes, processes and experiences of parents, family members, healthcare professionals that relate to organisational resources and enablers for best practice perinatal loss care following termination of pregnancy, stillbirth, or neonatal loss. Outcomes specific to the following populations were specifically searched: • Aboriginal and/or Torres Strait Islander families • Linguistically diverse groups • Low-income groups • Low literacy groups • Māori families/whānau • Migrants, immigrants, and refugees • Religious groups • Rural or remotely living families

Literature search

Searches were conducted on 2 November 2022. Search strategies incorporated all PICO criteria and were restricted to publications in English (Table 4). Studies from low- and middle-income countries were included if their setting was applicable to the report topic and context of Australian and Aotearoa New Zealand maternal and newborn service settings (e.g., remote and very remote areas where services and resources are limited), or if their setting was applicable to cultural safety care considerations. Searches were constructed to identify evidence that included adequate representation of all populations and run in the following databases:

- Australian Indigenous HealthInfoNet
- CINAHL
- Cochrane
- Embase
- Informit Indigenous Collection
- PubMed

- Scopus

In addition, the Technical Working Group conducted searches for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for this topic.

Studies identified in database searches were imported to Covidence (https://www.covidence.org/) where duplicate citations were removed, and the remaining citations were screened by the review team.

Review of study eligibility and data extraction

At least two reviewers independently applied the PICO criteria to the title and abstract for each study. Disagreements were resolved by a third reviewer and senior member of the Technical Working Group with content expertise. All eligible papers were retrieved for full-text screening and independently reviewed by at least two reviewers, with disagreements resolved by the senior reviewer.

Inclusion was based on the following criteria:

- The study met the PICO criteria in Table 2.
- The study was published in a full text article, primary research, reviews (any), editorials, dissertations, and diagnostic evaluations.
- The study was published during or after 2017.

Exclusion was based on the following criteria:

- Wrong *population*: The study did not focus on termination of pregnancy for fetal anomaly, stillbirth or neonatal death as defined in Table 2.
- Wrong *intervention:* The study did not examine interventions outlined in the research questions in Table 1.
- Wrong *outcome*: The evidence did not examine outcomes relevant to the research questions listed in Table 1.
- Wrong *language*: The study was not published in English.
- Wrong *publication dates*: The study was published prior to 2017.
- Wrong *evidence type*: The study was an abstract or protocol.

Figure 1 provides the PRISMA flow chart of evidence from searches to appraisal. At least two reviewers independently extracted relevant characteristics and study data into a data extraction template. Table 5 provides detailed characteristics of each included study in this report.

Quality assessment of the evidence

Studies were assessed using critical appraisal checklist tools from the Joanna Briggs Institute. For diagnostic evaluation studies, the QUADAS-2 tool was used. Table 6 contains detailed quality assessment of individual studies. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Evidence to recommendation process

Recommendations (Table 3) were drafted by the Guideline Development Committee based on the evidence synthesis in this report and recommendations from the previous edition of the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Key research articles published prior to 2017 and international guidelines identified by the Guideline Development Committee also informed the development of recommendations for this report. Iterations of the evidence synthesis technical report and recommendations were circulated to the Guideline Development Committee

between September 2022 and October 2023 for feedback and consensus on recommendations included in this report. Public consultation was conducted in August and September 2023.

GRADE-CERQual assessment of the evidence-based recommendations

The evidence underpinning the recommendations was assessed using GRADE-CERQual.[8] The GRADE-CERQual approach is tailored to the assessment of qualitative evidence and includes a confidence rating of the strength of each recommendation. The GRADE-CERQual assessment methodology incorporated four key areas of appraisal:

- Methodological limitations: Are there concerns regarding the methodology used in the studies included to support the synthesis findings?[9]
- Coherence: How clear and cogent the fit is between the data from the evidence and synthesis findings?[10]
- Adequacy: The richness and quantity of data supporting the findings[11]
- Relevance: The extent to which the evidence from studies is applicable to the context specific in the guideline.[12]

Each domain was assessed individually, and concerns were assessed as:

- No concerns or very minor concerns regarding domain
- Minor concerns regarding domain
- Moderate concerns regarding domain
- Serious concerns regarding domain.

The Technical Working Group then reviewed the assessments of the four domains. An overall rating of the confidence in the evidence was formulated, and details of any concerns were identified and listed.[13] Table 7 lists the detailed GRADE-CERQual assessment for recommendations in this section.

Evidence synthesis

Question 1: What are the clinical standards for maternal and newborn services providing perinatal loss care including legal and reporting requirements?

Quality perinatal loss care can only occur consistently when planned for and enabled by maternal and newborn services. Ideally, a perinatal loss program would focus on parents and families, be flexible to meet different socio-cultural contexts, and comprise standard protocols of care and a team that has access to ongoing training and support.[14] Healthcare professionals perceive a lack of clinical guidelines, overburdening, lack of educational preparation and lack of support for the emotional impacts of providing this care. To address this, maternal and newborn services should prioritise:

- Establishing and maintain a multidisciplinary team[15]
- A bereavement professional figure (champion) in maternity wards[16]
- Continuity of care and carer[17-20]
- Continuum of care that continues after a parent has left the healthcare service to acknowledge to parents their baby and their parenthood[21]
- Data collection[22]
- Maintaining sufficient staffing for those providing direct patient care to bereaved families to work one-on-one[19]
- Access to easy-to-understand policies and guidelines[22]
- Reduced administrative responsibilities[19]
- Continuing education, training, and mentoring around perinatal loss care[23]
- Patient-centred care that acknowledges the death[24]
- Communication with patients that is non-medicalised and non-judgmental[14]
- Information resources for parents to support decision-making and understanding of the grieving process[25,26] and future pregnancy planning[27]
- Clear systems for investigation of perinatal deaths and follow-up[3,26,28]
- Having designated spaces that allow bereaved parents to be cared for away from parents with live babies and where support people may also attend[29,30]
- Resources and opportunities for parents to see and hold their baby and create memories[14,16,29,31,32]
- Systems and processes for parents to be involved, if they choose, in active learning and care improvement reviews with healthcare professionals[4]
- Providing parents with links to post-discharge support[21]
- Following well-developed bereavement outreach protocols.[28]

Multidisciplinary team

Perinatal loss care requires input from a range of team members including medical, nursing, midwifery, social work as well as volunteers and others such as religious community members and so on. Poor coordination of care and lack of healthcare professional knowledge or skill in managing care or in interactions with parents can exacerbate family's trauma and add to healthcare professional stress. Healthcare professionals value a collaborative approach to teamwork,[33] and parents value a standardised approach to follow-up, including opportunity to see 'their' multidisciplinary team.[3]

Continuity of care and carer

Parents should feel supported by a maternal and newborn services' approach to perinatal loss care. This approach should include a continuum of care from the death of their baby through to when they leave the hospital through to any planning for a subsequent pregnancy. Parents value continuity of carer because of the comfort from seeing a 'familiar face' and it removes the need for them to retell their story to another member of staff.[34] However, continuity of carer may be challenged by staff shortages and can lead to parents experiencing distress from fragmented care.[17,35] Managers of maternal and newborn services were perceived as needing to be facilitators of a continuity of care and carer approach.[17] The continuum of care should continue after a parent has left the maternal and newborn service.[21]

Purpose-built space and resources for perinatal loss care

Designated purpose-built rooms for perinatal care loss are integral to providing high-quality perinatal care. This space should provide privacy and separation from other parents and be as non-clinical as practicable.[2,3]

Shakespeare et al.[27,36] developed a global consensus set of evidence-based principles for bereavement care after stillbirth. Where organisational structure and processes are not in place to support bereavement care, healthcare professionals struggle to meet the expectations and needs of their patients.

Clinical standards for bereavement care, while often developed for specific jurisdictions and health systems, share commonalities and key principles. Ravaldi et al.[37] identified the following clinical care commonalities in international guidelines: (1) bereavement care, (2) pharmacological management and aftercare, (3) postmortem procedures and rituals, and (4) pattern of fetal movements.

Obtaining and conducting high-quality evidence in how to manage stillbirth is challenging. Research gaps have been identified for long term psychological and emotional impact of different mode and time intervals of delivery.[38]

Considerations for low-resourced settings

- In India, healthcare professionals who did not have defined protocols or standards in their place of work sought professional training.[39] Most healthcare professionals feel an urgent need for professional training to bridge the gap between the expectations of patients and the care provided.[39]
- Medical providers in Ghana and Ethiopia navigate structural and cultural challenges following the death of a newborn when communicating and supporting bereaved parents.[40]
- In Afghanistan, inadequate and insensitive communication and practices by healthcare providers, including avoiding or delaying disclosing the stillbirth were recurring concerns. There was a disconnect between parents' desires and healthcare professional's perceptions. The absence of shared decision-making on seeing and holding the baby and memory-making, manifested as profound regret. Healthcare professionals reported hospitals were not equipped to separate women who had a stillbirth and acknowledged that psychological support would be beneficial. However, the absence of trained personnel and resource constraints prevented provision of such support.[29]

Question 2: How can parent experiences be incorporated into maternal and newborn service improvements?

A parent's experience and satisfaction with care is inextricably linked to a service's approach to care. Studies exploring parental experience of perinatal loss care highlight areas where care provision could

be improved. However, input is rarely sought from bereaved parent inputs outside of a research context. Parents indicate a preference for continuity of care, sensitive and respectful communication, honest and clear information, to be listened to when experiencing health concerns, and involvement in investigations of the cause of their baby's death with timely follow-up communication. Parent perspectives often emphasise the need for care providers to acknowledge their parenthood and the psychosocial impact of their loss.[41] Interactions with care are often seen by parents as insensitive or excessively medically driven.[42] Parents seek a system that is individualised and tailored to their needs and circumstances. The system needs to be respectful, flexible, and realistic.[22]

Perinatal loss care is not one-size-fits-all and each family's unique situation, preferences and personalities predicate different needs. Cultural and religious variation around practices relating to both childbirth and death and dying mean that flexibility is required, and individualised approaches are needed. Regardless, there is a significant gap between established standards and parent's experience. Numerous studies of parents' experience highlight the same issues around poor communication, inadequate acknowledgement of death and its impact on parents. Greater appreciation of the psychosocial impacts is likely to have a positive effect on perceptions of care quality.[43]

There is a clear gap in the literature around how parent voices might be included in feedback about care and service improvement. The PARENTS[5] and PARENTS 2[4] studies provide a model for how parents may be involved in the process of investigating perinatal deaths and offer a promising way for parents to be involved ensuring high quality review and recommendations for future care improvement.

Response rates indicate mothers and partners are often willing to provide feedback when invited. In a study conducted in Ireland, 20 bereaved parents accepted an invitation to participate in semi-structured interviews about how they could be included in the maternity hospital perinatal death review. Thematic analysis of interviews identified parents want to be informed about the process, receive written and verbal information, have a key point of contact during and after their time in hospital, participate in a follow-up meeting, and be given opportunity to provide feedback to the hospital.[44]

In Helsinki, 57 mothers (47.9% response rate) and 46 partners (38.7% response rate) completed questionnaires about their experiences of care and support relating to stillbirth diagnosis, delivery, information provided about postmortem examinations, aftercare on the ward, and follow-up appointment. Most were satisfied with the manner that information was presented and communicated to them, as well as the care and support they received during and after delivery, including adequate time and opportunity to hold the baby. One area of dissatisfaction was support from the social worker/priest/psychologist/psychiatrist—many respondents reported they received sufficient written information from peer organisations. Follow-up visits evoked anxiety for 25.9% of mothers, and open feedback indicated some respondents wished for more support following their discharge from hospital.[45]

Question 3: What strategies and resources can maternal and newborn services implement to support the emotional wellbeing of healthcare professionals and reduce adverse consequences such as compassion fatigue and burnout?

Maternal and newborn services need resources, structures, and processes in place that support healthcare professionals, social workers, volunteers, and chaplains working in perinatal loss care. Identified support strategies include having continuity of care and a centralised point of contact,[17,18,26,34,35] providing staff education and training in bereavement care,[34,46-52] having a no-blame culture,[53] and minimising organisational barriers[54-56] such as inadequate staffing levels.[22] Maternal and newborn services can support staff providing perinatal loss care by establishing and maintaining systems and practical resources and ongoing training.[14] Elements found to be motivating for healthcare professionals to find the strength to engage with parents and family who have experienced perinatal loss include leader and peer support and guidance, professional and personal experiences, and conviction about care.[54] Support strategies should be documented in organisational policies and promoted to staff.[23] Policies and guidelines should be reviewed.[42]

Providing perinatal loss care is challenging for healthcare professionals. Many are not prepared for the work and are personally impacted by the exposure to grief and trauma of loss.[57] Adverse consequences for staff can include compassion fatigue,[58] burnout,[59] secondary traumatisation,[60] survivor syndrome,[61] and PTSD, depression, and psychosomatic disorders.[62] For nurses and midwives, greater involvement with the family exposed them to different sorts of stress including worry about saying the wrong thing or guilt.[4] Staff may use unhealthy coping strategies such as alcohol use[55] or becoming task focussed and providing dispassionate care.[55,60,63]

Literature largely focussed on the difficulties experienced by healthcare professionals when providing perinatal loss care with few examples of strategies to counter these difficulties. Many of the difficulties encountered by healthcare professionals are like those experienced by parents including the hidden or taboo nature of perinatal death meaning that healthcare professionals were also exposed to stigma and avoidance by others when caring for bereaved families, coupled with a lack of educational preparation for providing perinatal loss care.[23] Understanding which strategies support healthcare professionals is a priority for staff and patient wellbeing. Support strategies identified by healthcare professionals include a supportive organisational culture that minimises barriers where possible and provides access to debriefing and professional psychological support. Staff also feel supported by participating in training, education, and mentoring—*see Question 4 for further information.*

Voluntary organisations that support women who experience perinatal loss should also be offered education to remain up to date. Twenty-three support groups in Ireland were surveyed about their educational needs and identified 64 topics as potential learning needs. Topics were prioritised and a training program about the following topics was developed at an education day:

- Bereavement care for families who experienced a loss
- Bereavement support available to families following a loss
- Care of parents and baby with a diagnosis of a fatal fetal anomaly/life-limiting condition
- End-of-life care and transition to children's hospital or home/palliative care support
- Management of pregnancy
- Overview of pathology investigation
- Postnatal care and breastmilk donation
- Rights of women as patients in maternity hospitals

- Screening and prenatal diagnosis
- Supporting families through their subsequent pregnancies.

Attendees evaluated the program positively: 8.4/10 overall satisfaction with the program and 8.6/10 for perceived benefit of information delivered.[64]

Minimise organisational barriers

Maternal and newborn services can reduce staff burden by recognising and minimising organisational barriers. Effective service managers are essential for ensuring staff providing perinatal loss care are adequately supported through allocation of workloads and administrative support and through psychological support following these care episodes.[19] Staff who experience organisational barriers such as bureaucratic burden may switch to providing task focussed care to cope or experience compassion fatigue [54]. Staff want to feel supported by their place of work and to know that their wellbeing and health is a priority.[55] Workplaces can maintain or institute adequate staffing levels[22] and simplify paperwork to reduce organisational burden on staff.[56]

Finally, maternal and newborn services could consider using a validated measure such as the Traumatic Stress Scale for Midwives (TSSM) to gauge levels of traumatic stress among their staff.[65] Psychometric testing indicated that staff responses to items correlated with their levels of burnout and work engagement. The developers suggest that TSSM may be used to minimise turnover from traumatic stress.

Opportunity to debrief

Maternal and newborn services need to acknowledge the significant impact of their staff's exposure to traumatic incidents and the intensity of bereaved parents' grief and distress. Healthcare professionals value the opportunity to debrief but are not always provided this by their maternal and newborn service. Despite 80% of healthcare professional participants in one study seeking debriefing, only 11% reported that they were offered debriefing after being involved in an intrapartum death.[57] Debriefing should be formal, driven by staff needs and respect staff privacy.[17] Healthcare professionals, including midwives, may be left emotionally unsupported.[66] Staff require and value opportunity to debrief and to have their feelings acknowledged.[67] This may be through a psychologist within the team who can also assist parents in their bereavement[14] or through one-on-one counselling.[67] Staff may benefit from a dedicated space to discuss, analyse, and process grief or distress. This may be a physical space such as a quiet room for reflection,[67] through staff rotation to share the care of bereaved parents through a shift (Fenwick et al., 2007 in [59]) or an emotional space created by sharing experiences through peer support,[54,68,69] debriefing,[47] and team check-ins.[70,71] An organisational culture of teamwork and collegial support can assist healthcare professionals to give good care.[33] Staff who are isolated when providing perinatal loss care, or subject to blame or suspicion can withdraw and become cold or task focussed when dealing with families, which leads to negative experiences of care. Staff who may have made an unintentional error are particularly impacted and require support.[53]

Maternal and newborn services may be tempted to reason that staff can access their employee assistance program (EAP) if they require support. However, although EAPs can offer benefit, midwives providing care for women undergoing termination of pregnancy identified limitations of these programs. Limitations included the short session time in which midwives must establish a trusting rapport with the counsellor and a belief held by some midwives that outside counsellors may not understand or may be ethically opposed to their termination of pregnancy.[72] This suggests EAPs should be available as a support option but not the only support option offered.

Question 4: What are the training and education needs of healthcare professionals providing perinatal loss care and what elements of training lead to improved outcomes for parents and families?

Healthcare professionals want to provide good care and derive satisfaction from doing so; however, many have not received training in provision of perinatal loss care. Participating in educational programs can increase staff and student confidence to provide perinatal loss care.[73,74] Perinatal loss care knowledge and skills, improvement in clinical skills and psychological support for nurses and midwives are three core areas of education content.[49] Ratislavová et al.[75] systematically searched the literature and identified fourteen papers (published in English between 2002 and 2017) that evaluated perinatal bereavement education for midwives and neonatal nurses. Eight papers reported statistical improvements in attendee's knowledge, comfort in providing end-of-life care, or understanding of the emotional needs of families. Favoured teaching methods were simulation, discussion, and arts-based methods. All fourteen papers strongly supported perinatal palliative care education for healthcare professionals.

Healthcare professionals working with parents who experience stillbirth should have specific training to understand how parents wish to receive care. Parents value privacy at this time[76] and may wish to be told about options such as cool cots.[77] Perinatal care is complex because of ethical and moral challenges, so training should incorporate these elements so that healthcare professionals are prepared for the clinical reality.[78] Healthcare professionals may need training to understand local, national, and international guidelines. Introducing specific training programs about stillbirth management was seen as helpful for Italian midwives providing clinical and psychological management of perinatal loss.[37]

Educational programs about perinatal loss care may be delivered through attending a workshop[73,79,80] watching a medical procedure,[74] participating in patient simulation or role play exercises,[56,73,81] or another educational format. Programs should be evaluated for their usefulness in promoting outcomes that support staff. Knowledge, confidence, satisfaction and relevant psychological variables such as post-traumatic stress symptoms are frequently used to evaluate the success of education programs.[49] Healthcare professionals may seek education or training for a range of needs.

- Improve communication and counselling skills[2,4,25,51,59,74,79,82-86]
- Fill gaps in education, experience, and knowledge[48,62,87-89]
- Build confidence and feel more equipped to support patients[17,42,54,80,90-92]
- Build self-awareness of own needs[14,70]
- Understand guidelines[37]
- Promote healthy mourning[41]
- Experience learning opportunities where real-life learning opportunities are limited[35,93,94]
- Feel supported in their role[39,52,91]
- Learn about or update knowledge in a particular area of care[45,75,78]
- Better manage grief.[67]

Improved communication and counselling skills

Healthcare professionals require training communicating in a manner that evokes trust so that parents do not feel information is being withheld or that they are being misled about their baby's

condition or prognosis.[84] Parents value communication from healthcare professionals that is respectful, sympathetic, and informative.[86]

Healthcare professionals may become task focussed when they are unsure what to say[85] and fear 'saying the wrong thing'.[4] Receiving bad news is likely to remain a lasting memory for parents, so it is important this is done as sensitively as possible.[51,76] In Brazil, resident doctors in an obstetrics and paediatrics program participated in setting, perception, invitation, knowledge, emotion, and summary (SPIKES) training and video reviews to learn how to deliver bad news to perinatology patients. Residents found the training helpful and recommended its inclusion in their residency programs curricula.[82]

Communication about perinatal loss care needs to be culturally specific.[32,59,95] Patients may be more likely to consent to investigative procedures if they perceive the healthcare professionals is communicating in a culturally sensitive manner. The uptake of postmortem investigation among Aboriginal and Torres Strait Islander women who have experienced stillbirth or neonatal death is low, and reasons for not giving permission include that they were not asked in a sensitive manner and that they had inadequate time for decision making.[25]

Improved knowledge and confidence

Healthcare professionals report feeling underprepared to provide perinatal loss care[79] and may require support to address gaps in their knowledge, experience, or training. Some seek mentoring and exposure to real-life experiences with support from senior experienced healthcare professionals. Healthcare professionals who do not receive preparation during their undergraduate clinical training, for example because the topic is 'invisible' may struggle when faced with a real-life situation.[87]

A simulated educational approach can provide staff with experience that may be otherwise difficult to gain. Student paediatric nurses were given opportunity to participate in a neonatal simulated bereavement session that comprised teachings from expert neonatal nurses and a simulation facility.[81] For one simulation scenario, a staff member from the simulation facility acted as a mother of a baby in NICU that was not expected to live. An experienced neonatal nurse led a discussion with the 'mother' about moving her and the baby to the bereavement room. The student was invited to work with the neonatal nurse to prepare the mother and infant. Simulations also covered withdrawing ICU treatment, safely transferring the infant and its family to the bereavement suite and facilitating the perinatal loss process. Students completed Likert scales to evaluate the session. All 16 students agreed or strongly agreed they had learned from the session, and 87% reported increased confidence in providing perinatal loss care to babies and their families.

Delivering bad news was particularly stress inducing for obstetricians[96] and neonatologists highlighted end-of-life care discussions as challenging.[97] All staff would benefit from pre-registration and post-registration perinatal loss education that incorporates self-care and resilience strategies to manage adverse outcomes[57,98,99] and is offered within a supportive organisational culture.[71]

Increasing staff confidence is a key intended outcome of training programs in perinatal loss care. For example, healthcare professionals who watched an autopsy were more confident when explaining the procedure to parents.[74] Increasing staff confidence in perinatal loss care may also build staffing capacity because staff may be more willing to participate in providing the care.[56]

In Ireland, the TEARDROP workshops are aligned with the Irish National Bereavement Standards and are based on the SCORPIO model of participant-centred teaching.[79] Also in Ireland, a one-day interactive Educational Training Workshop in Bereavement Care was developed for final year and higher diploma student midwives. The workshop featured education sessions followed by a quiz,

training videos, role plays, demonstrations, journalling in a reflective diary, and a mindfulness exercise to promote self-care. Students were invited to provide feedback in a focus group. Thematic analysis indicated that students rated the workshop, especially the role plays, positively in increasing their confidence in providing perinatal loss care.[73,80]

Mentoring and feeling supported

Students and early career healthcare professionals value being mentored[80] and being exposed to new clinical experiences in a supported way.[94] Often students have little exposure to perinatal loss care during their training.[48] Having opportunity to learn from senior staff can build confidence in student midwives[80] whereas a negative encounter with death can evoke substantial mental and emotional distress.[48] Having opportunity to view an autopsy can improve the confidence of healthcare professionals in counselling patients. Knowing how to establish a rapport with patients and respond to emotional distress may overcome barriers to consent for postmortem investigations.[74] Participating in training can help healthcare professionals feel supported.

Through training, healthcare professionals should feel encouraged and supported to be attentive to their own feelings, fears, and reactions. Healthcare professionals who are self-aware may be more likely to support parents to practice self-care and recognise their own feelings.[70] Participating in structured training that involves the whole team may translate to real-life scenarios and minimise harm associated with unaddressed feelings.[14]

Maternal and newborn services always need to consider workforce retention. Providing staff with support and training opportunities to staff may contribute to retaining or increasing the bereavement care workforce because healthcare professionals who experience burnout may strongly consider leaving the profession.[59] Providing training in psychosocial support of patients[100] and offering interdisciplinary simulation in perinatal loss care[56] were seen as retention strategies.

Grey literature and other sources

Websites of international and national government agency and parent support organisations (Red Nose, Sands, Bears of Hope, Stillbirth Foundation Australia) were searched for relevant information relating to organisational recommendations for providing perinatal loss care. A targeted Google search was also conducted.

SA Health provides a *Stillbirth Investigations and Bereavement Care* online education program for Australian healthcare professionals working in maternity care.[101] The program contains best practice information about stillbirth rates and investigations, autopsy processes and documentation, cultural care, shared decision making, and resources to support discussions with parents and family. Bereavement care and self-care management are discussed. Activities are linked to the lived experiences of five families following stillbirth and subsequent pregnancy.

The *Stillbirth Clinical Care Standard* of the Australian Commission on Safety and Quality in Health Care[102] comprises 10 quality statements, indicators for monitoring and quality improvement, and resources for parents and families, healthcare professionals, and healthcare services. Relevant to this section are Quality Statement 9 (Bereavement care and support after perinatal loss) and Quality Statement 10 (Subsequent pregnancy care after perinatal loss):

- Quality Statement 9: parents experiencing perinatal loss should receive care that supports their physical, personal, cultural, and religious or spiritual needs and preferences. Healthcare

professionals should ask parents what their needs and preferences are and provide information in a manner that meets the parent's language and literacy requirements. Healthcare services should ensure policies, procedures and protocols are in place for providing best practice perinatal loss care.

- Quality Statement 10: parents who have experienced perinatal loss and are planning a subsequent pregnancy or are pregnancy again should receive care that is appropriate to their clinical, cultural, and psychosocial needs and preferences. Healthcare professionals should be aware of possible increased risk of adverse events for women in a subsequent pregnancy and work with parents to create an individualised plan for planning conception and care during and after a subsequent pregnancy. Healthcare services should ensure policies, procedures and protocols are in place for providing best practice care for women during or planning a subsequent pregnancy after perinatal loss.

Also in Australia are the *Australasian Health Facilities Guidelines,*[103] which contain recommendations for neonatal palliative care and family bereavement:

- A designated purpose-built room of 17 m^2 to accommodate dying infants receiving palliative care. The room should be in a quiet area of the unit that is easily accessed by family members, have comfortable and non-clinical furnishings, and be equipped with facilities for bathing and laying out the baby (recommendation 4.2.2)
- A purpose-built family bereavement room of 15 m^2 that is co-located with the palliative care room to enable parents to stay with their baby. The room should have comfortable and non-clinical furnishings, include access to an ensuite, accommodate family members, and be culturally and spiritually appropriate to families (recommendation 4.2.3).

The *Sands Australian Principles of Bereavement Care (Miscarriage, Stillbirth and Neonatal Death)*[104] cover 10 principles for providing high quality perinatal loss support. These principles encourage (A) individualised bereavement care; (B) Good communication with parents; (C) shared decision making between healthcare professionals and parents (D) recognition of parenthood; (E) acknowledgment of a partner's and family's grief; (F) acknowledgment that grief is individual; (G) awareness of burials, cremations, and funerals; (H) ongoing emotional and practical support; (I) healthcare professionals training in bereavement care; and (J) healthcare professionals with access to self-care. The American College of Obstetricians and Gynecologists included bereavement care principles adapted from Sands principles in its consensus document about stillbirth management.

The *Late Intrauterine Fetal Death and Stillbirth* guideline of the Royal College of Obstetricians and Gynaecologists was first published in 2010.[105] Organisational recommendations and guidance pertaining to bereavement care include appointing a bereavement officer to coordinate services and improving bereavement care training for staff and bereavement counsellors.

The *National Standards of Bereavement Care Following Pregnancy Loss and Perinatal Death*[106] used in Ireland contains standards relating to bereavement care. The standards apply across the care continuum of diagnosis, care in hospital, and care after discharge.

The *National Bereavement Care Pathway (NBCP)*[107] in the UK comprises five bereavement pathways to assist healthcare professionals provide the best perinatal loss care possible. The bereavement pathways are for miscarriage, ectopic pregnancy, and molar pregnancy; termination of pregnancy for fetal abnormality (ToPFA); stillbirth; neonatal death; and sudden unexpected death in infancy. The pathways are underpinned by nine bereavement care standards for each National Health Service Trust to aim for: (1) parent-led care plan, (2) bereavement care training for healthcare professionals; (3) assessment and referral of parents to emotional and mental health; (4) a bereavement lead

healthcare professional; (5) designated bereavement rooms; (6) informed choices; (7) parents are given opportunity to make memories; (8) system to signal perinatal loss; (9) healthcare professionals have access to resources to provide high quality care. Healthcare professionals can use the NBCP Resources Toolkit to embed the standards.

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Table 3. Recommendations and summary of GRADE-CERQual rating

Contributing studies	GRADE-CERQual overall confidence rating of evidence	Guideline recommendations
Aggarwal & Moatti (2022) Agwu Kalu et al. (2018) Berry et al. (2021) Dombrecht, Piette, et al. (2020) Ferreira Paris et al. (2021) Helps et al. (2020) Hendriks & Abraham (2022) Martínez-Serrano et al. (2018) Siassakos et al. (2018) Winters (2018)	Low confidence *No or minor concerns of relevance and coherence. Moderate concerns of methodological limitation, and major concerns of data adequacy.*	**Consensus-based recommendation 8.1:** Each maternal and newborn service should establish and support a multidisciplinary team approach across the continuum of care to meet the physical, social, and emotional, cultural, religious, and spiritual needs of bereaved parents and family/whānau. • Ensure processes are established for cultural support services including interpreters. • Use a recognisable marker that designates perinatal loss in all physical spaces where bereaved parents are cared for, to ensure all clinical and non-clinical staff are aware of loss.
		Consensus-based recommendation 8.2: Ensure a coordinated and informed approach to care across the continuum through a dedicated role within the service, ideally a bereavement midwife, to be a known point of contact (that is, contact details of a named healthcare professional) for bereaved parents and family/whānau. • This requires appropriate rostering of staff to provide high quality care.
		Consensus-based recommendation 8.3: Maternal and newborn services should have established protocols in place to access appropriate expertise where not

			available locally for all aspects of care around the time of a perinatal death and in subsequent pregnancies (such as team-to-team or telehealth consultations). • This is particularly important to ensure families/whānau who live in regional or remote areas have access to appropriate clinical, social, and emotional supports.
Austin et al. (2021) Boyle et al. (2022) Helps et al. (2020) Popoola et al. (2022) Watson et al. (2019)		Low confidence *No or minor concerns of relevance and coherence. Moderate concerns of data adequacy and methodological limitation.*	Consensus-based recommendation 8.4: Ensure culturally and linguistically appropriate information and resources are available in multiple formats (print, audio, digital) and languages for bereaved parents and family/whānau.
Actis Danna et al. (2023) Christou et al. (2021) Dombrecht, Piette et al. (2020) Due et al. (2018) Helps et al. (2020) Martínez-Serrano et al. 2018	Martínez-Serrano et al. 2019 Nuzum et al. (2017) Serafim et al. (2021) Siassakos et al. (2018) Sun et al. (2022) Watson et al. (2019)	Moderate confidence *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*	Evidence-based recommendation 8.5: Ensure a designated private and safe place is available for bereaved parents and family/whānau whose baby has died or is receiving palliative care. This includes capacity and resources to support: • parents to spend time with and create memories with their baby including mementos and other keepsakes • family members/whānau and other support people to gather • cultural, religious, and/or spiritual rituals or ceremonies.
			Consensus-based recommendation 8.6: Establish a local process for storing mementos for parents who initially choose not to take them, including how to store

			securely and label appropriately in medical records for future access.
Boyle et al. (2022) Catlin (2018) Paraíso Pueyo et al. (2021)		Moderate confidence *No or minor concerns of methodological limitation, relevance and coherence. Major concerns of data adequacy*	Evidence-based recommendation 8.7: Establish relationships and partnerships with parent support organisations to ensure appropriate commemorative rituals are available to parents, such as an annual remembrance service for parents whose babies have died.
			Consensus-based recommendation 8.8: All healthcare professionals should be aware of and familiar with the law, policy, practices, and clinical care standards related to reporting stillbirths and neonatal deaths.
Christou et al. (2021) Colwell (2017) Doherty, Coughlan et al. (2018) Doherty, Cullen et al. (2018) Kim & Kim (2022) Leitao et al. (2021) Qian et al (2021) Ravaldi et al. (2018)	Ravaldi, Mosconi et al (2022) Serafim et al. (2021) Setubal et al. (2017) Shakespeare et al. (2020) Sheehy & Baird (2022) Sorce & Chamberlain (2019) Spierson et al. (2019) Warland et al. (2020)	Moderate confidence *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*	Evidence-based recommendation 8.9: Maternal and newborn services should make available specific professional development opportunities in care around stillbirth and neonatal death to all staff. The Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) educational program has been well received by healthcare professionals across Australia.
		See Section 2: Technical report for cultural safety for evidence synthesis and GRADE-CERQual rating of this recommendation.	Consensus-based recommendation 8.10: Organisations must provide and maintain effective cultural education for all healthcare professionals particularly non-Indigenous health professionals. Education must include: • cultural awareness and understanding of diversity within and between cultural groups

			• understanding of implicit biases and ongoing racism for some population groups
			• impact of colonisation for some populations, particularly Aboriginal and Torres Strait Islander communities in Australia and Māori communities in Aotearoa New Zealand
			• awareness of history of trauma and loss, and previous negative experiences with health services particularly:
			  ○ intergenerational trauma among Aboriginal and Torres Strait Islander families
			  ○ complex trauma among women of refugee background
			• acknowledge the importance of each cultural group's vital support systems such as kinship and community care for Aboriginal and Torres Strait Islander families.

Dombrecht, Cohen et al. (2020) Fernández-Basanta et al. (2021) Laing et al. (2020) Lin et al. (2021) Margulies et al. (2020) Martínez-Serrano et al. (2018) McDaniel & Morris (2020)	McNamara et al. (2017) Mills et al. (2022) Nachinab et al. (2021) Ravaldi, Carelli et al (2022) Sheehy & Baird (2022) Shorey et al (2017) Verdon & deMontigny (2021) Winters (2018)	Low confidence *No or minor concerns of relevance and coherence. Moderate concerns of methodological limitation, and major concerns of data adequacy.*	Consensus-based recommendation 8.11: Maternal and newborn services should ensure that healthcare professionals who provide care around stillbirth and neonatal death have access to formal and peer support and are encouraged to prioritise their social and emotional wellbeing.
Bakhbakhi et al. (2017) Bakhbakhi et al. (2018) Cole et al. (2020)	Helps et al. (2021) Helps et al. (2023)	Low confidence *No or minor concerns of relevance and coherence.*	Consensus-based recommendation 8.12: All maternal and newborn services should implement a perinatal mortality audit program that is integrated into quality improvement activities to ensure practice improvement

		Moderate concerns of methodological limitation, and major concerns of data adequacy.	in the provision of care around stillbirth and neonatal death. The audit program should include parent experiences of care.
Agwu Kalu et al. (2018) Denney-Koelsch et al. (2018) Ferreira Paris et al. (2021) Helps et al. (2020)	Helps et al. (2023) Hendriks & Abraham (2022) Steen (2019)	Moderate confidence *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*	Evidence-based recommendation 2.2: To ensure continuity of carer, designate a lead contact person with training in perinatal loss care, ideally a bereavement midwife, to be a known point of contact for parents, family/whānau and other members of the care team (including hospital volunteers). This recommendation is in *Section 2: Approach to care*.

Table 4. Search strategy

Database	Search strategy	
Embase	1	*stillbirth/ or *fetus death/ or *perinatal mortality/ or *perinatal death/ or *pregnancy termination/
	2	((f?etal or foetal or fetus* or antenatal or intrapartum or intrauterine or "intra uterine" or utero) adj2 (death* or wast* or demise* or mortalit*)).ti,ab.
	3	(("f?etal malformation" or "congenital abnormality" or "f?etal anomaly" or "congenital anomaly" or "f?etal anomalies" or "congenital anomalies") adj3 (terminat* or abortion or abort)).ti,ab.
	4	(((foetal or fetal or fetus or perinatal or "peri natal") adj1 loss*) or stillb*).ti,ab.
	5	1 or 2 or 3 or 4
	6	("health care" or healthcare* or practition* or professional* or nurs* or doctor* or physician* or midwi* or obstetric* or gynecolog* or carer or "care management" or "counsel*" or provider or providers or "cultural care" or elders or maori or whanau or migrant or immigrant or refugee* or "indigenous" or "torres strait islander*" or ATSI or aborigin* or islander* or organisatio* or organizatio* or hospital or hospitals or institute or "birth center" or facility or "work environment" or interdisciplin* or cost? Or econom*).ti,ab.
	7	hospital/ or general hospital/ or hospital policy/ or hospital service/
	8	*organization/
	9	(Standard or standards or support or supports or resource or resources or train or trains or training or logisti* or educat* or care or workload or "work load" or management or manage or "care for" or "caring for").ti,ab.
	10	*organizational policy/ or *policy/
	11	*procedures/
	12	*education program/ or *interdisciplinary education/ or *graduate education/ or *medical education/ or *clinical education/ or *health education/ or *nursing education/ or *interprofessional education/ or *education/
	13	6 or 7 or 8
	14	9 or 10 or 11 or 12
	15	13 and 14
	16	(Burnout or "burn out" or "burn-out" or exhaust or exhaustion or anxiety or anxious or depres* or psychosocial or psychological or legal or requirement or requirements or "optimal care" or consequences or consequence or stress or stress* or guilt or "well being" or "well-being" or mindfulness or wellbeing or compassion or emotion* or psychology* or debrief or "de-brief" or "care provi*" or turnover or “turn-over”).ti,ab.
	17	exp burnout/
	18	*psychology/
	19	*outcome assessment/
	20	*physiological stress/
	21	16 or 17 or 18 or 19 or 20
	22	5 and 15 and 21
CINAHL	(MM stillbirth) OR (MM "fetus death") OR (MM "perinatal mortality") OR (MM "perinatal death") OR (MM "pregnancy termination") (((TI f#etal OR AB f#etal) OR (TI foetal OR AB foetal) OR (TI fetus* OR AB fetus*) OR (TI antenatal OR AB antenatal) OR (TI intrapartum OR AB intrapartum) OR (TI intrauterine OR AB intrauterine) OR (TI "intra uterine" OR AB "intra uterine") OR (TI utero OR AB utero)) N2 ((TI death* OR AB death*) OR (TI wast* OR AB wast*) OR (TI demise* OR AB demise*) OR (TI mortalit* OR AB mortalit*)))	

	(((TI "f#etal malformation" OR AB "f#etal malformation") OR (TI "congenital abnormality" OR AB "congenital abnormality") OR (TI "f#etal anomaly" OR AB "f#etal anomaly") OR (TI "congenital anomaly" OR AB "congenital anomaly") OR (TI "f#etal anomalies" OR AB "f#etal anomalies") OR (TI "congenital anomalies" OR AB "congenital anomalies")) N3 ((TI terminat* OR AB terminat*) OR (TI abortion OR AB abortion) OR (TI abort OR AB abort))) ((((TI foetal OR AB foetal) OR (TI fetal OR AB fetal) OR (TI fetus OR AB fetus) OR (TI perinatal OR AB perinatal) OR (TI "peri natal" OR AB "peri natal")) N1 (TI loss* OR AB loss*)) OR (TI stillb* OR AB stillb*)) S1 OR S2 OR S3 OR S4 ((TI "health care" OR AB "health care") OR (TI healthcare* OR AB healthcare*) OR (TI practition* OR AB practition*) OR (TI professional* OR AB professional*) OR (TI nurs* OR AB nurs*) OR (TI doctor* OR AB doctor*) OR (TI physician* OR AB physician*) OR (TI midwi* OR AB midwi*) OR (TI obstetric* OR AB obstetric*) OR (TI gynecolog* OR AB gynecolog*) OR (TI carer OR AB carer) OR (TI "care management" OR AB "care management") OR (TI counsel* OR AB counsel*) OR (TI provider OR AB provider) OR (TI providers OR AB providers) OR (TI "cultural care" OR AB "cultural care") OR (TI elders OR AB elders) OR (TI maori OR AB maori) OR (TI whanau OR AB whanau) OR (TI migrant OR AB migrant) OR (TI immigrant OR AB immigrant) OR (TI refugee* OR AB refugee*) OR (TI indigenous OR AB indigenous) OR (TI "torres strait islander*" OR AB "torres strait islander*") OR (TI ATSI OR AB ATSI) OR (TI aborigin* OR AB aborigin*) OR (TI islander* OR AB islander*) OR (TI organisatio* OR AB organisatio*) OR (TI organizatio* OR AB organizatio*) OR (TI hospital OR AB hospital) OR (TI hospitals OR AB hospitals) OR (TI institute OR AB institute) OR (TI "birth center" OR AB "birth center") OR (TI facility OR AB facility) OR (TI "work environment" OR AB "work environment") OR (TI interdisciplin* OR AB interdisciplin*) OR (TI cost# OR AB cost#) OR (TI econom* OR AB econom*)) (MH hospital) OR (MH "general hospital") OR (MH "hospital policy") OR (MH "hospital service") (MM organization) ((TI Standard OR AB Standard) OR (TI standards OR AB standards) OR (TI support OR AB support) OR (TI supports OR AB supports) OR (TI resource OR AB resource) OR (TI resources OR AB resources) OR (TI train OR AB train) OR (TI trains OR AB trains) OR (TI training OR AB training) OR (TI logisti* OR AB logisti*) OR (TI educat* OR AB educat*) OR (TI care OR AB care) OR (TI workload OR AB workload) OR (TI "work load" OR AB "work load") OR (TI management OR AB management) OR (TI manage OR AB manage) OR (TI "care for" OR AB "care for") OR (TI "caring for" OR AB "caring for")) (MH “1*organizational policy") OR (MM policy) (MM procedures) (MM "education program") OR (MM "interdisciplinary education") OR (MM "graduate education") OR (MM "medical education") OR (MM "clinical education") OR (MM "health education") OR (MM "nursing education") OR (MM "interprofessional education") OR (MM education) S6 OR S7 OR S8 S9 OR S10 OR S11 OR S12 S13 AND S14 ((TI Burnout OR AB Burnout) OR (TI "burn out" OR AB "burn out") OR (TI burn-out OR AB burn-out) OR (TI exhaust OR AB exhaust) OR (TI exhaustion OR AB exhaustion) OR (TI anxiety OR AB anxiety) OR (TI anxious OR AB anxious) OR (TI depres* OR AB depres*) OR (TI psychosocial OR AB psychosocial) OR (TI psychological OR AB psychological) OR (TI legal OR AB legal) OR (TI requirement OR AB requirement) OR (TI requirements OR AB requirements) OR (TI "optimal care" OR AB "optimal care") OR (TI consequences OR AB consequences) OR (TI consequence OR AB consequence) OR (TI stress OR AB stress) OR (TI stress* OR AB stress*) OR (TI guilt OR AB guilt) OR (TI "well being" OR AB "well being") OR (TI well-being OR AB well-being) OR (TI mindfulness OR AB mindfulness) OR (TI wellbeing OR AB wellbeing) OR (TI compassion OR AB compassion) OR (TI emotion* OR AB emotion*) OR (TI psychology* OR AB psychology*) OR (TI debrief OR AB debrief) OR (TI de-brief OR AB de-brief) OR (TI "care provi*" OR AB "care provi*") OR (TI turnover OR AB turnover) OR (TI turn-over OR AB turn-over)) (MH burnout+) (MM psychology)

	(MM "outcome assessment") (MM "physiological stress") S16 OR S17 OR S18 OR S19 OR S20 S5 AND S15 AND S21
Scopus	#1 (((f*etal OR foetal OR fetus* OR antenatal OR intrapartum OR intrauterine OR "intra uterine" OR utero) W/2 (death* OR wast* OR demise* OR mortalit*)) OR (("f*etal malformation" OR "congenital abnormality" OR "f*etal anomaly" OR "congenital anomaly" OR "f*etal anomalies" OR "congenital anomalies") W/3 (terminat* OR abortion OR abort)) OR (((foetal OR fetal OR fetus OR perinatal OR "peri natal") W/1 loss*) OR stillb*)) #2 (("health care" OR healthcare* OR practition* OR professional* OR nurs* OR doctor* OR physician* OR midwi* OR obstetric* OR gynecolog* OR carer OR "care management" OR counsel* OR provider OR providers OR "cultural care" OR elders OR maori OR whanau OR migrant OR immigrant OR refugee* OR indigenous OR "torres strait islander*" OR ATSI OR aborigin* OR islander* OR organisatio* OR organizatio* OR hospital OR hospitals OR institute OR "birth center" OR facility OR "work environment" OR interdisciplin* OR cost* OR econom*) AND (Standard OR standards OR support OR supports OR resource OR resources OR train OR trains OR training OR logisti* OR educat* OR care OR workload OR "work load" OR management OR manage OR "care for" OR "caring for" OR policy OR policies)) #3 (Burnout OR "burn out" OR burn-out OR exhaust OR exhaustion OR anxiety OR anxious OR depres* OR psychosocial OR psychological OR psychology OR legal OR requirement OR requirements OR "optimal care" OR consequences OR consequence OR stress OR stress* OR guilt OR "well being" OR well-being OR mindfulness OR wellbeing OR compassion OR emotion* OR psychology* OR debrief OR de-brief OR "care provi*" OR turnover OR turn-over) #1 AND #2 AND #3
Cochrane	#1 MeSH descriptor: [Fetal Death] explode all trees #2 MeSH descriptor: [Perinatal Mortality] explode all trees #3 MeSH descriptor: [Perinatal Death] explode all trees #4 MeSH descriptor: [Stillbirth] explode all trees #5 MeSH descriptor: [Abortion, Therapeutic] explode all trees #6 ((f?etal:ti,ab OR foetal:ti,ab OR fetus*:ti,ab OR antenatal:ti,ab OR intrapartum:ti,ab OR intrauterine:ti,ab OR "intra uterine":ti,ab OR utero:ti,ab) NEAR/2 (death*:ti,ab OR wast*:ti,ab OR demise*:ti,ab OR mortalit*:ti,ab)) #7 (((f?etal NEXT "malformation"):ti,ab OR "congenital abnormality":ti,ab OR (f?etal NEXT "anomaly"):ti,ab OR "congenital anomaly":ti,ab OR (f?etal NEXT "anomalies"):ti,ab OR "congenital anomalies":ti,ab) NEAR/3 (terminat*:ti,ab OR abortion:ti,ab OR abort:ti,ab)) #8 (((foetal:ti,ab OR fetal:ti,ab OR fetus:ti,ab OR perinatal:ti,ab OR "peri natal":ti,ab) NEAR/1 loss*:ti,ab) OR stillb*:ti,ab) #9 #1 OR #2 OR #3 Or #4 OR #5 OR #6 OR #7 OR #8 #10 ("health care":ti,ab OR healthcare*:ti,ab OR practition*:ti,ab OR professional*:ti,ab OR nurs*:ti,ab OR doctor*:ti,ab OR physician*:ti,ab OR midwi*:ti,ab OR obstetric*:ti,ab OR gynecolog*:ti,ab OR carer:ti,ab OR "care management":ti,ab OR counsel*:ti,ab OR provider:ti,ab OR providers:ti,ab OR "cultural care":ti,ab OR elders:ti,ab OR maori:ti,ab OR whanau:ti,ab OR migrant:ti,ab OR immigrant:ti,ab OR refugee*:ti,ab OR indigenous:ti,ab OR ("torres strait" NEXT islander*):ti,ab OR ATSI:ti,ab OR aborigin*:ti,ab OR islander*:ti,ab OR organisatio*:ti,ab OR organizatio*:ti,ab OR hospital:ti,ab OR hospitals:ti,ab OR institute:ti,ab OR "birth center":ti,ab OR facility:ti,ab OR "work environment":ti,ab OR interdisciplin*:ti,ab OR cost?:ti,ab OR econom*:ti,ab) #11 MeSH descriptor: [Hospitals] explode all trees #12 MeSH descriptor: [Hospitals, General] this term only

	#13 #10 OR #11 OR #12 #14 MeSH descriptor: [Policy] this term only #15 MeSH descriptor: [Economics, Hospital] this term only #16 MeSH descriptor: [Education, Nursing] explode all trees #17 MeSH descriptor: [Simulation Training] explode all trees #18 MeSH descriptor: [Psychology, Educational] this term only #19 (Standard:ti,ab OR standards:ti,ab OR support:ti,ab OR supports:ti,ab OR resource:ti,ab OR resources:ti,ab OR train:ti,ab OR trains:ti,ab OR training:ti,ab OR logisti*:ti,ab OR educat*:ti,ab OR care:ti,ab OR workload:ti,ab OR "work load":ti,ab OR management:ti,ab OR manage:ti,ab OR "care for":ti,ab OR "caring for":ti,ab) #20 #14 OR #15 OR #16 OR #17 OR #18 OR #19 #21 #20 AND #13 #22 (Burnout:ti,ab OR "burn out":ti,ab OR burn-out:ti,ab OR exhaust:ti,ab OR exhaustion:ti,ab OR anxiety:ti,ab OR anxious:ti,ab OR depres*:ti,ab OR psychosocial:ti,ab OR psychological:ti,ab OR legal:ti,ab OR requirement:ti,ab OR requirements:ti,ab OR "optimal care":ti,ab OR consequences:ti,ab OR consequence:ti,ab OR stress:ti,ab OR stress*:ti,ab OR guilt:ti,ab OR "well being":ti,ab OR well-being:ti,ab OR mindfulness:ti,ab OR wellbeing:ti,ab OR compassion:ti,ab OR emotion*:ti,ab OR psychology*:ti,ab OR debrief:ti,ab OR de-brief:ti,ab OR ("care" NEXT provi*):ti,ab OR turnover:ti,ab OR turn-over:ti,ab) #23 MeSH descriptor: [Burnout, Psychological] explode all trees #24 MeSH descriptor: [Stress, Psychological] this term only #25 #22 OR #23 OR #24
PubMed	"Stillbirth"[Mesh] OR "Fetal Death"[Mesh] OR "Perinatal Mortality"[Mesh] OR “perinatal death”[Mesh] OR "Abortion, Induced"[Mesh] 2. ("fetal anomal*"[Title/Abstract] OR "congenital anomal*"[Title/Abstract] OR "congenital malformation"[Title/Abstract]) AND ("termination of pregnancy"[Title/Abstract] OR abortion[Title/Abstract] OR "pregnancy termination"[Title/Abstract]) 3. (("fetal malformation"[Title/Abstract] OR "congenital abnormality"[Title/Abstract] OR "fetal anomaly"[Title/Abstract] OR "congenital anomaly"[Title/Abstract] OR "fetal anomalies"[Title/Abstract] OR "congenital anomalies"[Title/Abstract] OR "prenatal diagnosis"[Title/Abstract]) AND (terminat*[Title/Abstract] OR abortion[Title/Abstract] OR abort[Title/Abstract])) 4. "Fetal death*"[Title/Abstract] OR "Foetal death*"[Title/Abstract] OR "Foetal Demise*"[Title/Abstract] OR "fetal wast*"[Title/Abstract] OR "foetal wast*"[Title/Abstract] OR "Fetal mortalit*"[Title/Abstract] OR "Fetal demise*"[Title/Abstract] OR "Foetal mortalit*"[Title/Abstract] OR "perinatal wast*"[Title/Abstract] OR "perinatal mortalit*"[Title/Abstract] OR "perinatal death*"[Title/Abstract] OR "perinatal demise*"[Title/Abstract] OR "Prenatal death*"[Title/Abstract] OR "Prenatal mortalit*"[Title/Abstract] OR "prenatal demise*"[Title/Abstract] OR "Antenatal mortalit*"[Title/Abstract] OR "Antenatal Death*"[Title/Abstract] OR "Antenatal Demise*"[Title/Abstract] OR Stillb*[Title/Abstract] OR "fetal Loss*"[Title/Abstract] OR "foetal Loss*"[Title/Abstract] OR "perinatal Loss*"[Title/Abstract] OR "Prenatal loss*"[Title/Abstract] OR "peri natal loss*"[Title/Abstract] OR "Intrapartum mortalit*"[Title/Abstract] OR "Intrapartum Death*"[Title/Abstract] OR "Neonatal loss*"[Title/Abstract] OR "Neonatal mortalit*"OR "Neonatal death*"[Title/Abstract] OR "Neonatal Demise*"[Title/Abstract] OR "Newborn death*"[Title/Abstract] OR "Newborn mortalit*"[Title/Abstract] 5. #1 OR #2 OR #3 OR #4 6. ("health care"[tiab] OR healthcare*[tiab] OR practition*[tiab] OR professional*[tiab] OR nurs*[tiab] OR doctor*[tiab] OR physician*[tiab] OR midwi*[tiab] OR obstetric*[tiab] OR gynecolog*[tiab] OR carer[tiab] OR "care management"[tiab] OR counsel*[tiab] OR provider[tiab] OR providers[tiab] OR "cultural care"[tiab] OR elders[tiab] OR maori[tiab] OR whanau[tiab] OR migrant[tiab] OR immigrant[tiab] OR refugee*[tiab] OR indigenous[tiab] OR "torres strait islander*"[tiab] OR ATSI[tiab] OR aborigin*[tiab] OR islander*[tiab] OR organisatio*[tiab] OR organizatio*[tiab] OR hospital[tiab] OR hospitals[tiab] OR institute[tiab] OR "birth center"[tiab] OR facility[tiab]

	OR "work environment"[tiab] OR interdisciplin*[tiab] OR cost*[tiab] OR econom*[tiab]) 7. (("Hospitals"[Mesh]) OR "Hospital Costs"[Mesh]) OR "Organizations"[Mesh] 8. (Standard[tiab] OR standards[tiab] OR support[tiab] OR supports[tiab] OR resource[tiab] OR resources[tiab] OR train[tiab] OR trains[tiab] OR training[tiab] OR logisti*[tiab] OR educat*[tiab] OR care[tiab] OR workload[tiab] OR "work load"[tiab] OR management[tiab] OR manage[tiab] OR "care for"[tiab] OR "caring for"[tiab]) 9. ((((((("Policy"[Mesh]) OR "Education Department, Hospital"[Mesh]) OR "Education"[Mesh]) OR "Training Support"[Mesh]) OR "Simulation Training"[Mesh]) OR "Staff Development"[Mesh]) OR "Education, Nursing"[Mesh]))))))) 10. #6 OR #7 11. #9 OR #8 12. #10 AND #11 13. (Burnout[tiab] OR "burn out"[tiab] OR burn-out[tiab] OR exhaust[tiab] OR exhaustion[tiab] OR anxiety[tiab] OR anxious[tiab] OR depres*[tiab] OR psychosocial[tiab] OR psychological[tiab] OR legal[tiab] OR requirement[tiab] OR requirements[tiab] OR "optimal care"[tiab] OR consequences[tiab] OR consequence[tiab] OR stress[tiab] OR stress*[tiab] OR guilt[tiab] OR "well being"[tiab] OR well-being[tiab] OR mindfulness[tiab] OR wellbeing[tiab] OR compassion[tiab] OR emotion*[tiab] OR psychology*[tiab] OR debrief[tiab] OR de-brief[tiab] OR "care provi*"[tiab] OR turnover[tiab] OR turn-over[tiab]) 14. ("Burnout, Psychological"[Mesh] OR "Burnout, Professional"[Mesh]) OR ("Stress Disorders, Traumatic, Acute"[Mesh] OR "Stress Disorders, Traumatic"[Mesh] OR "Stress, Psychological"[Mesh] OR "Stress Disorders, Post-Traumatic"[Mesh] OR "Stress, Physiological"[Mesh]) 15. #13 OR #14 16. #5 AND #12 AND #15
Australian Indigenous HealthInfoNet	"Health education" OR stillbirth OR "neonatal death"
Informit Indigenous Collection	[[Abstract: neonat* OR Abstract: [] AND [Abstract: baby OR Abstract: fetal OR Abstract: pregnancy] AND [Abstract: die* OR Abstract: loss OR Abstract: death OR Abstract: 'pass away' OR Abstract: 'passed away' OR Abstract: 'sorry business' OR Abstract: dead OR Abstract: mortality] OR Abstract: stillb*]

Figure 1. PRISMA flow diagram of screening evidence

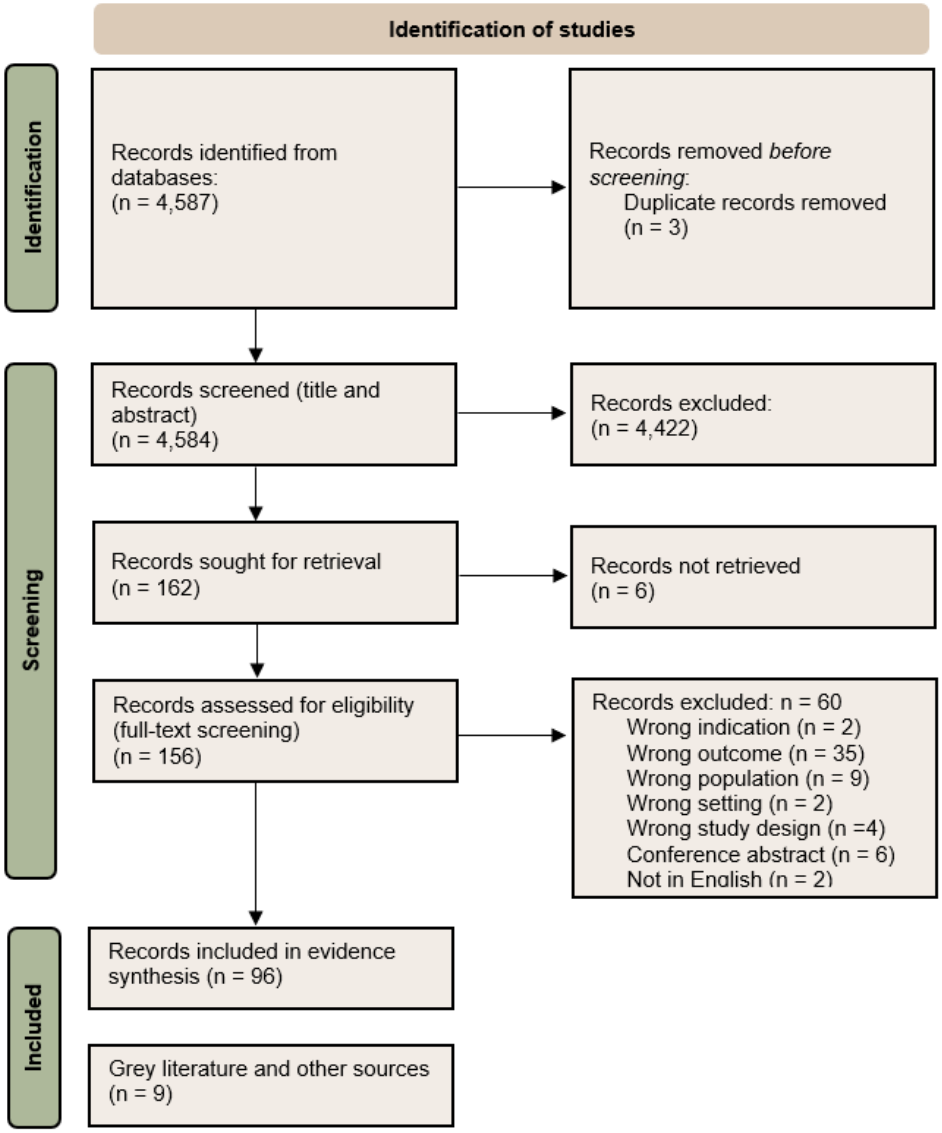

Table 5. Study characteristics

Study ID	Country (period)	Locality (state/ national/ hospital)	Data source	Income setting	Methodology	Study design (qualitative)	Study design (quantitative)	Cohort size	Outcomes of interest (stillbirth, NND, TOPFA)	Factors assessed	Exclusions	Inclusions	Quality assessment tool
Actis Danna et al. 2023	Malawi, Tanzania, and Zambia (dates not reported)	Women who had given birth at tertiary referral hospitals in Tanzania, Malawi, and Zambia	Semi-structured interviews	LIC	Qualitative	Grounded theory (symbolic interactionism)	NA	33 women	Stillbirth (within the preceding 12 months)	How and when women became aware of the death of their babies.	Women <18 years of age	Women who had experienced a stillbirth in the preceding 12 months and had capacity to consent.	Checklist for qualitative research
Aggarwal & Moatti 2022	India (2022)	NA	Literature	LMIC	Qualitative	Narrative review	NA	NA	NA	Bereavement care	NA	NA	Checklist for text and opinion papers
Agwu Kalu et al. 2018	Ireland (Aug 2013–Jul 2014)	Three large public maternity teaching hospitals in urban Ireland	Self-administered questionnaire, focus groups	HIC	Mixed methods	Content analysis	Cross-sectional study	277 for survey 11 for focus groups	Stillbirth, NND	Psychosocial factors that impact midwives' confidence to provide bereavement support to parents who have experienced a perinatal loss	Student midwives and agency midwives	Midwives and nurses registered with the Nursing and Midwifery Board of Ireland, employed by the hospitals to work in maternity services, and provided care to bereaved parents.	Checklist for qualitative research Checklist for analytical cross-sectional studies

Arach et al. 2022	Uganda (Aug 2019–Sept 2020)	Lira District, Northern Uganda	In-depth interviews	LMIC	Qualitative	Thematic analysis	NA	32 (18 women; 14 men)	Stillbirth, NND	Lived experiences of parents following perinatal loss	Participants were excluded if they had migrated to distant places beyond the reach of the study team or were not willing to talk about the perinatal deaths.	Participants were women and partners of women who had had either a stillbirth or an early neonatal death within the past 2 years. Those who lived in the study area (Aromo, Agweng and Ogura sub counties) from at least the third trimester (≥ 28 weeks of gestation) until 6 months after perinatal death were included in the study. Married women had to have their partner's permission to participate.	Checklist for qualitative research

Armour et al. 2021	Aotearoa New Zealand (dates not reported)	Two tertiary hospitals located in the North Island of Aotearoa New Zealand	Interviews	HIC	Qualitative	Thematic analysis	NA	8	TOPFA	Role of midwives in TOP care after 20 weeks, including the support they might need and the impacts caring for women who are having a TOP may have on them	NA	Midwives working on a regular basis with women having a TOP within the last 12 months.	Checklist for qualitative research
Asim et al. 2022	Pakistan (June 2018–May 2019)	Rural villages of district Thatta Sindh	Interviews	LMIC	Qualitative	Thematic analysis	NA	8 women	Stillbirth	Lived experience of multiple stillbirths	NA	Women experiencing multiple stillbirths, with last stillbirth occurring within the period of last 12 months from the date of interview	Checklist for qualitative research
Austin et al. 2021	England (2016–18)	54 National Health Service (NHS) Trusts from across the 4 regions of NHS England	Interview, patient leaflets	HIC	Qualitative	Thematic analysis	NA	86 (18 bereavement care providers; 15 funerary practitioners (mostly funeral	Miscarriage, stillbirth, TOPFA	Options offered for disposal of pregnancy remains and ways in which information	NA	Bereavement care providers; funerary practitioners; support people/ friends of	Checklist for qualitative research

								directors), 18 individuals who provide support for the bereaved, 35 people who had experienced miscarriage, TOPFA or stillbirth a minimum of 6 months before the interview)		around disposal are communicated		bereaved parents; bereaved parents	
Bakhbakhi et al. 2017	Multiple (dates not reported)	NA	Published research, guidelines and best practice points	HIC	Qualitative	Descriptive review	NA	NA	Stillbirth	Best practice in bereavement care research in HICs	NA	Published research, guidelines and best practice points in care following stillbirth in HICs	Checklist for text and opinion papers
Bakhbakhi et al. 2018	UK (May–June 2017)	Two geographically different maternity hospital sites in Bristol and Manchester	Focus groups	HIC	Qualitative	Thematic analysis	NA	22	Stillbirth, NND	Views of healthcare professionals and other key stakeholders on parental engagement in the perinatal	NA	Clinical staff including midwives, obstetricians, neonatologists, nursing staff and chaplaincy services	Checklist for qualitative research

										mortality review			
Barry et al. 2017	Ireland (Jan-March 2015)	Tertiary Hospital	Interviews	HIC	Qualitative	Thematic analysis	NA	6	Infant death	The influence of the Amulet artwork and exhibition on midwifery students' perspectives of caring for bereaved parents	NA	Postgraduate midwifery students (registered nurses) who attended the Amulet exhibition; consent obtained	Checklist for qualitative research
Berry et al. 2021	Multiple (2019–2020)	Western cultural countries (US, UK, Australia)	Literature	HIC	Qualitative	Systematic review	NA	5	Stillbirth, NND, TOPFA	Parents' experiences of perinatal loss in a Western cultural context	Articles were excluded if they were reports of studies conducted in non-Western cultures, of twin pregnancies, or of the perinatal loss experiences of others (e.g., healthcare professionals, siblings, surrogate parents, grandparents, etc.). We also excluded	Peer-reviewed articles published in English within the last 10 years, about qualitative research conducted in Western countries (e.g., US, UK, and Australia) that were focused on parents' experiences of perinatal loss (resulting from	Checklist for systematic reviews and research syntheses

											quantitative studies, scale validation studies, and grey literature.	miscarriage, stillbirth, neonatal death, or termination of pregnancy related to fetal anomalies).	
Borovich 2022	Israel (2017–2018)	Gynaecology department in a tertiary university affiliated hospital	Questionnaire	HIC	Quantitative	NA	Descriptive	51	Stillbirth, TOP	Impact and the post-traumatic potential of late TOP and stillbirth on medical staff	NA	Permanent personnel (attending physicians, nurses, and social workers) and rotating personnel (residents) working at the study hospital	Checklist for analytical cross-sectional studies
Boyle 2020	Australia (dates not reported)	National	Guideline, literature	HIC	Qualitative	Opinion piece	NA	NA	Stillbirth, NND	Perinatal bereavement care guidelines	NA	Components of best practice perinatal bereavement care	Checklist for text and opinion papers
Boyle et al. 2022	Australia (April 2020)	National	Online survey	HIC	Qualitative	Content analysis	NA	35	Stillbirth, NND, TOPFA	Healthcare professional's views of the impact of COVID-19 pandemic on provision of respectful care to	NA	Healthcare professionals who provided perinatal bereavement care in clinical settings or	Checklist for qualitative research

										parents and resulting practice changes		through support organisations in Australia	
Brierley-Jones et al. 2018	England (2014–2015)	Three hospitals in Northeast England	Focus groups, semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	60	Stillbirth	Views of health professionals and healthcare staff across three hospitals in the management of stillbirth	NA	Consultant obstetricians, trainees, midwives, midwife sonographers and chaplains	Checklist for qualitative research
Broderick et al. 2021	UK (2013)	NA	Book chapter	HIC	Qualitative	Narrative	NA	NA	Stillbirth	Caring for bereaved parents and their families	NA	NA	Checklist for text and opinion papers
Cassidy 2018	Spain (2013–2016)	National	Online self-completion questionnaire	HIC	Qualitative	Phenomenological	NA	796	Pregnancy loss stratified by GA (n=668 stillbirths ≥ 20 wks GA)	Bereaved parents experience of care quality following intrauterine death	Respondents born outside of the Spanish national territory. Parents reporting neonatal deaths	Women who reported that their baby died within 60 months prior to survey completion.	Checklist for qualitative research
Catlin 2018	USA (2016)	Texas	Interdisciplinary summit / Delphi study	HIC	Qualitative	Narrative	NA	32	Stillbirth	The needs of women who present with actual or potential pregnancy loss to the	NA	NA	Checklist for text and opinion papers

										emergency department			
Cetin et al. 2022	Ethiopia (Feb–Mar 2020)	Obstetrics/ gynaecology departments and neonatal/ paediatrics departments at government hospitals in urban cities	Semi-structured interviews	LIC	Qualitative	Narrative synthesis	NA	16 healthcare workers	Stillbirth, NND	Ethical and practical consequences clinicians experience concerning maternal and perinatal death surveillance and response reporting practices in Ethiopia	NA	Healthcare workers: midwives, nurse, senior and junior doctors, intern working at the study locations	Checklist for qualitative research
Cheer et al. 2021	Papua New Guinea (Feb 2017–Feb 2018)	Pacific Adventist University	Focus groups, interviews	LMIC	Qualitative	Grounded theory	NA	Focus groups n=9 participants, Interviews n=11	Stillbirth	Experiences of midwifery students at a faith-based university in caring for women following stillbirth	NA	Midwifery students identified as having been involved in a healthcare experience resulting in stillbirth	Checklist for qualitative research
Choummanivong et al. 2020	Lao PDR (Jun 2018)	Vientiane Province	Interviews	LMIC	Qualitative	Thematic analysis	NA	33 healthcare professionals	Stillbirth	Healthcare professionals' experiences of providing stillbirth care in the Lao People's Democratic Republic	NA	Doctors, nurses and midwives working at the study hospitals	Checklist for qualitative research

Christou et al. 2021	Afghanistan (Oct–Nov 2017)	3 high-volume referral maternity hospitals in Kabul and 2 lower-level health facilities and surrounding communities in 2 rural districts ~25–30 km west and north of Kabul city	Interviews	LIC	Qualitative	Deductive thematic analysis	NA	55 (21 mothers, 9 fathers, 3 female community elders, 20 healthcare professionals, 2 government officials)	Stillbirth	Parents' and healthcare professional's experiences of care after stillbirth	NA	Women and men experiencing stillbirth, community female elders, healthcare providers and key informants including government officials, hospital directors, chiefs of wards	Checklist for qualitative research
Cole et al. 2020	USA (dates not reported)	Hospital (Children's Hospital of Philadelphia)	Description of bereavement outreach program in a maternal-fetal care centre and words from patients from the perinatal palliative care and bereavement program including those who delivered in	HIC	Qualitative	Descriptive	NA	NA	Stillbirth, NND, TOPFA	Description of bereavement outreach program in a maternal-fetal care centre	NA	NA	Checklist for qualitative research

			the Special Delivery Unit										
Colwell 2017	UK (dates not reported)	Northwest of England	4 discussion sessions, and 2 simulation scenarios	HIC	Qualitative	Simulation	NA	NA	Neonatal death care training, building confidence in care during infant bereavement.	The influence of simulation built into training programs.	NA	NA	Checklist for qualitative research
Denney-Koelsch et al. 2018	USA (dates not reported)	Rochester	Interviews	HIC	Qualitative	Phenomenological	NA	16 women; 14 partners	Health-care interactions during termination of pregnancy for fetal anomaly	Feeling cared for; experiencing added burden	NA	Women >18 years who chose to continue their pregnancy following a lethal fetal diagnosis	Checklist for qualitative research
Doherty, Cullen et al. 2018	Ireland (2017)	Hospital	Pre-post questionnaires	HIC	Quantitative	NA	Pre-post	38 students	Stillbirth, NND	Evaluation of a bereavement care education program for midwifery students	Participants who had recently suffered bereavement, participants who were unavailable or who did not wish to participate	Fourth year Bachelor of Science Midwifery Degree and Higher Diploma Midwifery students	Checklist for quasi-experimental studies
Doherty, Coughlan et al. 2018	Ireland (dates not reported)	Clinical site	Focus groups	HIC	Qualitative	Thematic analysis	NA	12 students	Stillbirth, NND	Student midwives' experience of attending	NA	Fourth year Bachelor of Science and Higher	Checklist for qualitative research

										a bereavement education workshop		Diploma Midwifery students	
Dombrecht, Piette et al. 2020	Belgium (Dec 2017–Jul 2018)	Four tertiary hospital NICUs (university hospitals of Ghent, Brussels, and Leuven, and general hospital Sint-Jan Bruges)	Interviews and questionnaires	HIC	Qualitative	Thematic analysis	NA	30	NND	Barriers to and facilitators of end-of-life decision making by neonatologists and neonatal nurses in neonates	NA	Neonatologists working as resident physicians at one of four Flemish NICUs between Dec 2017 and Jul 2018 who had been the attending/ treating physician to at least one child who had died at the NICU where an end-of-life decisions was made in the past year, and nurses who had been the most involved.	Checklist for qualitative research
Dombrecht, Cohen et al. 2020	Belgium (May 2017)	8 NICUs in Flanders	Survey	HIC	Quantitative	NA	Population - based study	272 (n=52 neonatologists, n=250 neonatal nurses)	NND	Attitudes of neonatologists and nurses towards perinatal	NA	All neonatologists and neonatal	Checklist for studies reporting

										end of life decisions		nurses in all 8 NICUs	prevalence data
Due et al. 2018	Australia (2013)	South Australia	Interviews	HIC	Qualitative	Thematic analysis	NA	15	Stillbirth	Women's experiences with the healthcare system following pregnancy loss in South Australia	NA	Women aged >18 years, fluent in English, resident in South Australia at the time of their loss and have experienced at least one pregnancy loss at any stage between conception and birth. Women who had experienced multiple losses were eligible for inclusion.	Checklist for qualitative research
Kim & Kim 2022	Korea (Sept 2019)	7 hospitals in Seoul and Gyeonggi Province	Questionnaires	HIC	Quantitative	NA	Descriptive	136 nurses	Stillbirth, NND	Nurses' attitudes and stress related to perinatal bereavement care in Korea	Nurses with less than 1 year of experience	Nurses working at the seven general hospitals located in Seoul and Gyeonggi Province,	Checklist for analytical cross-sectional studies

												Korea, in departments that deal with perinatal death, i.e., labour and delivery, maternity unit, newborn nursery, and NICUs, who had at least 1 year of experience and experienced at least one case of perinatal death	
Farrales et al. 2020	USA (dates not reported)	Unclear	Focus groups	HIC	Qualitative	Thematic analysis	NA	27	Stillbirth	Experiences of grieving parents during their interaction with health care providers during/after the stillbirth of a baby	NA	Participants were recruited from a cohort of bereaved parents who participated in a two-day workshop on the topic of grief after stillbirth. 19 years of age	Checklist for qualitative research

												or older. Consent obtained.	
Fernández-Basanta et al. 2020	Multiple (Aug 2019)	International /5 countries	Literature/ 5 databases	HIC	Qualitative	Meta-ethnography	NA	10 studies	Stillbirth	Nurses' and midwives' experiences of caring for parents following an involuntary pregnancy loss	Papers not in English, Portuguese, or Spanish	Qualitative or mixed method studies in which the sample comprised nursing staff and in which the type of loss was miscarriages and stillbirths	
Fernández-Basanta et al. 2022	Spain (2020)	NA (review)	PubMed and 4 other databases	Global	Qualitative	Mata-synthesis	NA	11 studies	Stillbirth	Emotional experiences of midwives and nurses when caring for parents who have suffered an involuntary pregnancy loss	NA	Original qualitative or mixed articles considered adequate for the research objective, whose sample comprised nurses and midwives and whose type of loss was miscarriages and stillbirths,	Checklist for systematic reviews and research syntheses

												were included.	
Fernández-Basanta 2021	Spain (Feb–April 2019)	10 primary healthcare centres in northern Spain	Interviews	HIC	Qualitative	Phenomenological hermeneutic approach	NA	11	Stillbirth	The experiences of primary healthcare midwives who care for parents who have suffered an involuntary pregnancy loss	NA	Primary healthcare midwife and having experience in providing care to parents who have suffered an involuntary pregnancy loss.	Checklist for qualitative research
Ferreira Paris et al. 2021	Brazil, Canada (dates not reported)	Maringa in Southern Brazil; Gatineau in Canada	Semi-structured interviews	UMIC; HIC	Qualitative	Thematic analysis	NA	44 (26 Brazilian women, 18 Canadians)	Stillbirth	Professional care for maternal grief following stillbirth	NA	Mothers whose address was in Maringa after authorisation by the municipal health department of deaths investigated by the mortality committee, and mothers who participated in the grief support group at	Checklist for qualitative research

												CERIF in Gatineau	
Gandino et al. 2019	Italy (dates not reported)	16 Italian hospitals	Questionnaire including open-ended questions	HIC	Qualitative	Linguistic analysis	NA	485 healthcare professionals	Stillbirth, NND	Impact of perinatal loss	NA	Physicians, nurses, midwives, ward assistants	Checklist for qualitative research
Helps et al. 2020	Ireland (2005–2018)	National	Inquiry reports	HIC	Qualitative	Thematic analysis	NA	10	Stillbirth, NND	Bereavement care provided to families following perinatal death/pregnancy loss as described in national inquiry reports	NA	National inquiries into perinatal deaths/pregnancy loss services between 2005-2018.	Checklist for qualitative research
Helps et al. 2021	Ireland (Oct–Dec 2018)	National	Irish enquiry reports	HIC	Qualitative	Thematic analysis	NA	10 enquiry reports	Stillbirth, NND	Effects of maternity services governance in Ireland on the management of perinatal deaths and bereavement services	NA	Health-service-commissioned enquiry reports relating to perinatal deaths and pregnancy loss services between 2005 and 2018	Checklist for qualitative research
Helps et al. 2023	Ireland (Nov 2020–Mar 2021)	National	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	20 (16 mothers, 4 fathers)	Stillbirth, NND	Bereaved parents' involvement in maternity hospital	NA	Parents who were over 18 years of age, spoke fluent English, were	Checklist for qualitative research

										perinatal death review processes		at least 6 months post perinatal bereavement (stillbirth or neonatal death) and had no more than 6 years since completion of their child's death review	
Hendriks & Abraham 2022	Switzerland (dates not reported)	Tertiary perinatal centre of a Swiss University Hospital	Participatory observations in the perinatal centre; interviews	HIC	Qualitative	Content analysis	NA	10	TOPFA	Communication with healthcare professionals, end-of-life decisions and parents' wishes and preferences during late termination of pregnancy	NA	Parents who had a TOPFA ≥20 weeks gestation at a tertiary perinatal centre of a Swiss University Hospital one or more year before the onset of the study. Perinatal healthcare professionals working in a discipline relevant to perinatal end-of-life decision	Checklist for qualitative research

												making (midwife, nurse, obstetrician, neonatologist, clinical director) at the tertiary perinatal centre of a Swiss University Hospital	
Kalu 2020	Ireland (dates not reported)	3 maternity hospitals in Ireland	Literature, cognitive interviews, questionnaire	HIC	Quantitative	NA	Cross-sectional	n=10 midwives for cognitive interviews, n=6 midwifery experts for face and content validation, n=26 for test-retest reliability n=277 midwives for construct validation	Stillbirth, NND	Development of Perinatal Bereavement Care Confidence Scale for midwives	NA	Expert panel for content validation included two directors of midwifery, two midwifery academics, one perinatal bereavement specialist midwife, and one practising midwife who had more than ten years of clinical experience. For cognitive interviewing	Checklist for analytical cross-sectional studies

												and test-retest reliability, midwives from one hospital in Ireland participated. For construct validity, midwives, and nurses from three maternity hospitals in Ireland participated.	
Kesbiç & Boz 2022	Turkey (May 2019–Mar 2020)	2 university hospitals	Interviews	UMIC	Qualitative	Thematic analysis	NA	16 nurses	Stillbirth, NND	Perinatal nurses' experiences, thoughts, and feelings on compassion satisfaction and compassion fatigue	Nurses working in practice areas such as outpatient clinics where individual patient care was not provided and previously diagnosed with burnout, secondary traumatic syndrome, and	Nurses in the field of perinatology and working in the perinatology for more than 6 months.	Checklist for qualitative research

											compassion fatigue.		
Kilcullen et al. 2020	Australia (2005–2015	Townsville Hospital	Semi-structured interviews with women	HIC	Qualitative	Thematic analysis	NA	5	Stillbirth	Aboriginal and Torres Strait Islander women's decisions to consent for autopsy after stillbirth	Women with active mental health difficulties	Aboriginal and Torres Strait Islander women who experienced stillbirth between 2005–2015	Checklist for qualitative research
Köktürk Dalcalı et al. 2022	Turkey (dates not reported)	City hospital in Turkey	Semi-structured interviews	UMIC	Qualitative	Thematic content analysis	NA	7 nurses	NND	Emotional Responses of Neonatal Intensive Care Nurses to Neonatal Death	NA	Nurses working at the neonatal intensive care unit of a city hospital in Turkey	Checklist for qualitative research
Kubota & Horiuchi 2023	Japan (Jul 2016–Nov 2016)	National	Self-administered questionnaire	HIC	Quantitative	NA	Cross-sectional	511 midwives	Stillbirth, NND	Traumatic stress experienced by midwives	Midwives who may be amid a traumatic experience; midwives who were assessed by their superiors as not suited to participate in this study	Midwives employed in hospitals, clinics, and midwifery centres throughout Japan	Checklist for analytical cross-sectional studies

Laing et al. 2020	Australia (2012–2014)	National	Personal Inventory Questionnaire, group blog activity, focus groups, email interviews	HIC	Qualitative	Thematic analysis	NA	17 midwives	NND	Midwives' experiences of caring through, and learning from, perinatal death	NA	Current registration with the Australian Health Practitioner Regulation Agency (AHPRA) as a Registered Midwife or Midwifery Student; experience in caring for a minimum of one mother whose baby died during the perinatal period; and access to a computer with internet and a telephone to be able to take part in data collection.	Checklist for qualitative research
Lappeman & Swartz 2022	South Africa (2018–2019)	One hospital located in an impoverished area	Interviews	LMIC	Qualitative	Thematic analysis	NA	10	Stillbirth	Women's experience of hospital care following stillbirth	Women aged <18; who drank medication or self-harmed to	Mothers experiencing stillbirth at the hospital between	Checklist for qualitative research

											terminate a pregnancy; abused substances; had families working in the labour ward of the hospital	January and August 2018	
Leitao et al. 2021	Ireland (2019–2020)	National for pilot workshop; 3 maternity units for second workshop	Paper feedback questionnaires completed after the two program workshops	HIC	Quantitative	NA	Descriptive	36 for first workshop; 47 for second workshop	Stillbirth, NND, TOPFA	Evaluation of a perinatal bereavement care training program for healthcare professionals	NA	Healthcare professionals participating in the training workshops	Checklist for studies reporting prevalence data
Lin et al. 2021	Taiwan (dates not reported)	One regional teaching hospital in northern Taiwan	Reflective group sessions	HIC	Qualitative	Thematic analysis	NA	10 nurses participating in 8 group sessions	Stillbirth	Nurses' experiences of labour of a stillborn baby	NA	Nurses with direct stillbirth nursing care experience in one hospital in Taiwan	Checklist for qualitative research
Listermar et al. 2020	Sweden (2014–2016)	40 maternity clinics in Sweden	Open-ended response on questionnaire	HIC	Qualitative	Content analysis	NA	110	Stillbirth	Midwives' experience of using cold cots	NA	Midwives using cooling cot (Cubitus baby) while caring for parents of a stillborn child	Checklist for qualitative research
Margulies et al. 2020	USA (2016)	George Washington University Hospital	Anonymous questionnaire	HIC	Quantitative	NA	Prospective observational	105	Stillbirth, NND	Impact of adverse events on providers	NA	Physicians (obstetrics, gynaecology, and	Checklist for analytical cross-

										and maternity staff		anaesthesia), residents, midwives, social workers, nurse practitioners, and hospital employees in foodservice and housekeeping working at the study hospital	sectional studies
Martínez-Serrano et al. 2018	Spain (Feb 2012–March 2014)	10 public hospitals; 1 primary health centre	Three focus groups	HIC	Qualitative	Hermeneutic phenomenological analysis	NA	18 midwives	Stillbirth	Experiences of midwives regarding attention given during labour in late fetal death	Any midwives who had undergone a similar event either personally, or within their immediate family, were excluded	Midwives having experience in attending cases of late fetal death	Checklist for qualitative research
Martínez-Serrano et al. 2019	Spain (2012–2017)	1 hospital and local pregnancy loss support organisation	Interviews	HIC	Qualitative	Thematic analysis	NA	11 parents (7 mothers, 4 fathers)	Stillbirth	Mothers' and fathers' experience of care received during delivery in cases of stillbirth	Those with psychological functional impairment and not fluent in Spanish	Women and men >18 years; monitored low obstetric and neonatal risk pregnancy; attended for	Checklist for qualitative research

												labour after stillbirth through a vaginal birth.	
McDaniel & Morris 2020	USA (dates not reported)	NA	Literature	HIC	Qualitative	Narrative, case vignette	NA	NA	Stillbirth, NND	Second victim phenomenon in midwives	NA	NA	Checklist for text and opinion papers
McNamara et al. 2017	Ireland (2010–2015)	1 tertiary maternity hospital	Questionnaire including open-ended questions	HIC	Mixed methods	Thematic analysis	Cross-sectional	n=89	Stillbirth	Experiences of healthcare professionals following exposure to intrapartum death	NA	Consultant obstetrician/ gynaecologists, non-consultant hospital doctors training in obstetrics and gynaecology, and labour ward midwives working at the study hospital	Checklist for qualitative research Checklist for analytical cross-sectional studies
McNamara et al. 2018	Ireland (Nov 2015–Dec 2016)	1 tertiary university maternity unit	Semi-structured interviews	HIC	Qualitative	IPA	NA	10 obstetricians	Stillbirth	Attitudes and responses of obstetricians following direct involvement with an intrapartum fetal death	NA	All obstetricians at the study location with direct involvement with an intrapartum fetal death	Checklist for qualitative research

Mills et al. 2021	Kenya and Uganda (July 2017–May 2019)	5 facilities in Nairobi and Western Kenya, Kampala, and Central Uganda	Interviews	LIC, LMIC	Qualitative	Thematic analysis	NA	75 women, 59 men	Stillbirth	Parents' experience of care and support after stillbirth	NA	Women and men aged >18 years who had experienced the stillbirth of their baby (≤1 year previously) and received care in the included facilities.	Checklist for qualitative research
Mills et al. 2022	Kenya, Uganda (dates not reported)	5 facilities in Kenya and Uganda	Interviews	LIC and LMIC	Qualitative	Thematic analysis	NA	61 healthcare professionals (nurse midwives (n = 37), midwives (n = 12) and doctors (N = 10), 1 hospital social worker, 1 reproductive health counsellor)	Stillbirth	Lived experiences of healthcare professionals (midwives, doctors, and others), caring for women after stillbirth in Kenya and Uganda	NA	Healthcare professionals regularly providing care for women and families after the death of a baby in included study facilities	Checklist for qualitative research
Muin et al. 2021	Austria (2020)	National	Online survey with one open ended question	HIC	Mixed methods	Content analysis	Cross-sectional study	369 for quantitative component, 74 responded to open-ended question	Stillbirth	Facilitators and strategies used by obstetricians when communicating	NA	Austrian obstetricians and gynaecologists registered with the Austrian Society of	Checklist for qualitative research Checklist for analytical cross-

										intrauterine fetal death to parents		Obstetrics and Gynaecology	sectional studies
Nachinab et al. 2021	Ghana (dates not reported)	1 district in Northern Ghana	Interviews	LMIC	Qualitative	Thematic content analysis	NA	15 midwives	Stillbirth	Experiences of midwives upon conducting stillbirth deliveries in Northern Ghana	NA	All practicing midwives living in the study location who had conducted labour which was a stillbirth delivery	Checklist for qualitative research
Nuzum et al. 2017	Ireland (2008–2013)	1 tertiary maternity hospital	Interviews	HIC	Qualitative	IPA	NA	17 parents (12 mothers, 5 fathers)	Stillbirth	Communication of bad news to parents following a diagnosis of stillbirth	NA	Parents of babies who had received a diagnosis of stillbirth were purposively sampled from 2008, 2010 and 2013.	Checklist for qualitative research
Paraíso Pueyo et al. 2021	Multiple (2018–2019)	International literature	Literature (4 databases)	HIC	Qualitative	Scoping review	NA	9 papers	NND	Nursing interventions to help parents of neonates admitted to neonatal intensive care units cope with perinatal loss	Studies relating to stillbirth, TOP for non-medical reasons, miscarriage	Studies published between 2000–2019 that included mothers and/or fathers and/or the immediate family who	Checklist for systematic reviews and research syntheses

												have experienced the death of an infant in the perinatal period in a NICU. Papers written in Spanish whose title and abstract had also been written in English.	
Pekkola et al. 2022	Finland (2016–2020)	Hospital/ Helsinki University Hospital	Postal questionnaires	HIC	Quantitative	NA	Cross-sectional	57 mothers, 46 partners	Stillbirth	Stillbirth diagnosis, delivery, information on postmortem examinations, aftercare at the ward, follow-up appointments, all assessed using researcher created statements with a 5-point Likert scale for response (agree-disagree)	NA	Antepartum singleton stillbirth at or after 22 weeks, language of communication was Finnish or Swedish	Checklist for studies reporting prevalence data

Popoola et al. 2022	Nigeria (2017)	Saki	Semi-structured interviews	LMIC	Qualitative	Thematic analysis	NA	20	Stillbirth	Nigerian women's experiences of grief after stillbirth	Women who were pregnant at the time of recruitment	To be eligible for study participation, the participant must be a Yoruba living in Saki, and at least 6 months must have passed since stillbirth to minimise causing distress	Checklist for qualitative research
Qian et al. 2021	Multiple (Dec 2020)	International	Literature/ 8 databases	HICs mainly	Qualitative	Scoping review	NA	18 studies	Stillbirth, NND	Perinatal bereavement care education programmes for nurses and midwives	1) duplicated publications; 2) conference abstracts, reviews, news or study protocols and 3) studies published in a language other than English.	1) studies conducted in participants, including but not limited to nurses and midwives or nursing and midwifery students; 2) original studies focusing on the evaluation of the effectiveness of any education program or	Checklist for systematic reviews and research syntheses

												support for facilitating the provision of perinatal bereavement care; 3) studies focusing on experiences of participation in perinatal bereavement care education programs; 4) both quantitative or qualitative studies were included	
Qian & Wang et al. 2022	China (Mar–May 2021)	Tertiary maternity hospital, Zhejiang University	Semi-structured interviews	UMIC	Qualitative	Thematic analysis	NA	6 nurses, 13 midwives, 7 women	Stillbirth, TOPFA	How women who have experienced pregnancy loss and obstetric nursing staff perceive their interactions, what influencing factors impacted their experiences	Women who had a multifetal pregnancy reduction were not included	Nurses and midwives qualified to participate if they worked in the obstetric ward or delivery room and had experiences caring for women who had experienced	Checklist for qualitative research

												pregnancy loss. Women were included if they (1) were pregnant for more than 14 weeks; and (2) had already completed termination of pregnancy due to miscarriage, stillbirth, or fatal fetal anomaly.	
Qian & Cai et al. 2022	China (2021)	11 hospitals in Zhejiang Province	Online survey	UMIC	Quantitative	NA	Cross-sectional	571 nurses and midwives	Stillbirth, NND	Influencing factors of perinatal bereavement care confidence among nurses and midwives in China	NA	Clinical nurses or midwives who worked in maternity wards or delivery rooms with experience providing perinatal bereavement care	Checklist for analytical cross-sectional studies
Ratislavová et al. 2019	Czech Republic (dates not reported)	International	Literature	HIC	Qualitative	Integrative review	NA	14 studies	Perinatal palliative care	Teaching healthcare professionals in perinatal	Papers not in English	Evaluation of teaching on care for grieving	Checklist for systematic reviews and research syntheses

										palliative care		parents after perinatal loss	
Ravaldi et al. 2018	Italy (2009–2015)	National (11 hospitals)	Hardcopy survey questionnaire	HIC	Quantitative	NA	Cross-sectional study	674	Stillbirth	Current practices of health care providers caring for women experiencing a stillbirth and to explore their training needs	NA	Practising midwives, obstetricians, nurses, and psychologists of the obstetrics and gynaecology wards in 11 Italian hospitals	Checklist for analytical cross-sectional studies
Ravaldi, Mosconi et al. 2022	Italy (dates not reported)	National	Online survey	HIC	Quantitative	NA	Cross-sectional	445 midwives	Stillbirth, NND	Italian midwives' knowledge of stillbirth clinical management, bereavement care and prevention of recurrences	NA	Midwives working either in the hospital or in different settings	Checklist for analytical cross-sectional studies
Ravaldi, Carelli et al. 2022	Italy (dates not reported)	National	Online survey	HIC	Quantitative	NA	Cross-sectional	445 midwives	Stillbirth, NND	Burnout after perinatal loss in midwifery	NA	Participants were considered eligible to complete the survey if working as midwives, whether in the hospital or in other	Checklist for analytical cross-sectional studies

												settings, such as community-based care, maternity clinics, or private practice	
Rent et al. 2023	Ethiopia and Ghana (2018)	3 hospitals in Addis Ababa, Ethiopia, and Kumasi, Ghana	Interviews	LIC, LMIC	Qualitative	Grounded theory	NA	40 healthcare professionals	NND	Provider perceptions on bereavement following newborn death	NA	Nurses, midwives, medical trainees, and senior physicians with at least 1 month experience in caring for newborn infants in their hospital	Checklist for qualitative research
Salenius 2019	UK (dates not reported)	UK	Literature review	HIC	Qualitative	NA	NA	NA	Stillbirth	Using psychological and sociological theories to examine grief following a stillbirth and how these findings relate to midwifery practice.	NA	NA	Checklist for text and opinion papers

Serafim et al. 2021	São Paulo countryside, Brazil (dates not reported)	Hospitals; family health unit	Interviews	LMIC	Qualitative	Thematic content analysis	NA	11 healthcare professionals	Stillbirth	Experiences of health professionals dealing with fetal death	Professionals who were away or on vacation during data collection	Healthcare professionals who worked directly in women's health care and obstetric care (physicians, nurses, obstetric nurse, midwife, technicians and nursing assistants and psychologist) with at least one year experience	Checklist for qualitative research
Setubal et al. 2017	Brazil (June 2014–Feb 2015)	One medical school in São Paulo, Brazil	Open ended question data collected as part of an RCT	UMIC	Qualitative	Framework analysis	NA	20	Stillbirth, NND	To analyse the perception of residents regarding a training program in communicating bad news in perinatology	NA	Volunteer residents from the 1st to the 4th year from the obstetrics and paediatrics programs at a medical school in São Paulo, Brazil	Checklist for qualitative research
Shakespeare et al. 2019	Multiple (2017)	International	Literature (6 databases)	LMIC	Mixed methods	Narrative synthesis	Meta-analysis	34 studies across 17 countries	Stillbirth	Parents' and healthcare professionals	Studies explicitly addressing	Qualitative, quantitative, and mixed	Checklist for systematic reviews and

										' experiences of care after stillbirth in LMIC	miscarriage, fetal anomaly, and neonatal death alone were excluded. Review articles, opinion pieces, and books were excluded.	method studies that addressed parents' or healthcare professionals ' experience of care after stillbirth in LMIC	research syntheses
Shakespeare et al. 2020	Global (Sept 2017–Oct 2018)	26 countries	Systematic reviews, meetings & online surveys	NA	Mixed methods (policy-Delphi methodology)	Thematic analysis	Descriptive (Likert scale)	Round 1 n=23 Round 2 n=19 Round 3 n=236 Round 4 n=30 Round 5 n=143	Bereavement care after stillbirth	Global consensus on a set of feasible and evidence-based core principles for best practice bereavement care after stillbirth	NA	International clinical and academic experts and healthcare workers with experience in providing bereavement care	Checklist for qualitative research Checklist for analytical cross-sectional studies
Sharma et al. 2022	India (2020)	National	Online survey	LMIC	Quantitative	NA	Descriptive cross-sectional	281	Stillbirth	Experience, views, and practices of healthcare professionals while managing women with stillbirths	NA	Healthcare providers including medical officers, physicians, nursing officers and obstetricians & gynaecologists	Checklist for studies reporting prevalence data

Sheehy & Baird 2022	Sydney, Australia (June 2021)	NSW	In-depth interviews	HIC	qualitative	Thematic analysis	NA	15 midwives	Perinatal loss	Early career midwives' experiences of clinical encounters of perinatal grief, loss, and trauma	NA	Midwives who had undertaken their pre-registration education and had commenced working as a registered midwife in Australia and were within their first 5 years of practice, were eligible to participate.	Checklist for qualitative research
Shorey et al. 2017	Multiple (2016)	International	Literature (12 databases)	NA	Qualitative	Scoping review	NA	30 papers	Stillbirth, NND	Impact of perinatal death on the perspectives of healthcare professionals working in maternity units	Neonatal death beyond one month of the baby's age and studies examining the experiences of neonatal intensive care units' staff (doctors, nurses, and midwives) without specifying	The inclusion criteria for the articles were: 1) exploring the experiences and needs of healthcare professionals (either nurses, doctors, and midwives separately or all in one study); 2) perinatal death	Checklist for systematic reviews and research syntheses

											the age of neonate death, which could include up to a year after baby is born, were excluded from this review.	including fetal death from week 20 onwards or neonatal death within a month after the birth of the baby; and 3) maternity units, including obstetrics and gynaecological settings.	
Sorce & Chamberlain 2019	US (dates not reported)	One hospital	Pre–post questionnaires	HIC	Quantitative	NA	Pre-test-post-test evaluation	54	Stillbirth, NND	Evaluation of an education session for perinatal nurses using standardised patients and role play during perinatal bereavement	NA	Nurses in the study institution	Checklist for quasi-experimental studies
Spierson et al. 2019	UK (May 2011–June 2012)	National (through British Association of Perinatal Medicine)	Online survey	HIC	Quantitative	NA	Cross-sectional study	98	NND	Healthcare professionals' practices and views on neonatal postmortem	Those who did not work with neonates and/or did not complete	Neonatal healthcare providers in UK	Checklist for analytical cross-sectional studies

											most of the survey		
Steen 2019	USA (dates not reported)	One hospital in Minneapolis, Minnesota	Feedback from staff and parent evaluations	HIC	Qualitative	Thematic analysis and narrative review	NA	NA	Stillbirth, NND	Description of a perinatal bereavement program	NA	Different components of a perinatal bereavement program at one hospital	Checklist for qualitative research
Sun et al. 2021	Taiwan (Aug 2016–Jul 2018)	Medical centre in Taoyuan County	Interviews	HIC	Qualitative	Phenomenological	NA	20 couples (40 individuals)	Stillbirth	The meaning that parents in Taiwan attach to the care of the remains of their stillborn babies	Couples that did not provide consent	1) pregnant women aged ≥20 years; (2) married and whose spouse is also invited; (3) their child was diagnosed with fetal death and the couple accepted induction of labour for stillbirth; (4) able to communicate in Mandarin or Taiwanese.	Checklist for qualitative research
Verdon & deMontigny 2021	Canada (dates not reported)	Four regions of Quebec, Canada	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	25 nurses	Stillbirth	Experience of nurses who support parents during	NA	Registered nurses across different settings such	Checklist for qualitative research

										perinatal death		as, hospital-based maternity units, emergency departments, birth centres, and community-based follow-up care who worked with parents who experienced perinatal death	
Warland & Glover 2019	Australia (dates not reported)	National	Online survey	HIC	Quantitative	NA	Descriptive	10	Stillbirth	Content of stillbirth education in undergraduate midwifery curricula in Australia	NA	Midwifery program leaders from each of the Australian Universities that deliver undergraduate midwifery education	Checklist for analytical cross-sectional studies
Warland 2020	Australia (dates not reported)	Tasmania	Pre–post questionnaires	HIC	Quantitative	NA	Pre–post intervention study	30 maternity care providers	Stillbirth	Effectiveness of an educational stillbirth awareness workshop for maternity care providers	NA	Maternity care providers working in the north and northwest regions of Tasmania who	Checklist for quasi-experimental studies

												participated in one of two half day stillbirth education workshops	
Watson et al. 2019	Canada (2017)	Ontario, Canada	Online survey including one open-ended question	HIC	Mixed methods	Thematic analysis	Descriptive cross-sectional	596 for quantitative survey, 269 for qualitative component	Stillbirth, NND, TOPFA	How families access existing care and supports around the time of their loss and their experiences of receiving such care	Families not living in Ontario at the time of their loss	People who lived in Ontario and had a pregnancy loss at any gestation of pregnancy (i.e. the person who carried the pregnancy or their intimate partner/s), or who had experienced the death of an infant	Checklist for qualitative research Checklist for studies reporting prevalence data
Willis 2019	USA (Sept–Nov 2014)	2 acute care hospitals in Southeastern Massachusetts	Interviews	HIC	Qualitative	Thematic analysis	NA	9	Stillbirth, NND	Nurses' perspective on caring for women experiencing perinatal loss	NA	Registered nurses employed at one of the sites, regularly assigned to labour and delivery, had experience caring for a woman who	Checklist for qualitative research

												had a perinatal loss, and were willing to share their experience	
Winters 2018	USA (2018)	NA	Literature	HIC	Qualitative	Narrative	NA	NA	NND	Secondary traumatic stress and compassion fatigue in childbirth professionals in cases of NND	NA	NA	Checklist for text and opinion papers
Wool 2019	USA (dates not reported)	NA	Literature, opinion	HIC	Qualitative	Narrative	NA	NA	Stillbirth, NND, miscarriage	Integrated system of care for perinatal bereavemen t	NA	NA	Checklist for text and opinion papers
Zhong et al. 2022	China (2019)	40 hospitals in 5 provinces of China	Surveys	UMIC	Quantitative	NA	Cross-sectional	550	NND; palliative care	Barriers and facilitators of neonatal nurses' attitudes to palliative care for neonates	NA	Nurses in neonatal intensive care units in mainland China regardless of experience in the field	Checklist for analytical cross-sectional studies
Zwerling et al. 2021	USA (dates not reported)	1 academic tertiary care research hospital with a level three NICU in	Semi-structured interviews	HIC	Qualitative	Thematic analysis	NA	15 nurses	Stillbirth, TOPFA	Nurses' experience caring for patients undergoing labour	NA	Nurses from the labour and delivery unit at the study hospital	Checklist for qualitative research

	Southern California		induction for fetal anomalies or fetal demise

HIC: high-income country; LIC: low-income country; LMIC: lower-middle-income country; NA: not applicable; GA: gestational age; NICU: neonatal intensive care unit; NND: neonatal death; TOP: termination of pregnancy; TOPFA: termination of pregnancy due to fetal anomaly; RCT: randomised controlled trial; UMIC: upper middle-income country. **Quality appraisal tools**[a] JBI Critical Appraisal Checklist for qualitative research; JBI: Critical Appraisal Checklist for text and opinion papers; JBI Critical Appraisal Checklist for analytical cross-sectional studies; JBI Critical Appraisal Checklist for systematic reviews and research syntheses; Checklist for quasi-experimental studies; JBI Critical Appraisal Checklist for studies reporting prevalence data.

Table 6. Study quality assessment

Qualitative studies

	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice- versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Relevance
Actis Danna et al. 2023	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	P
Agwu Kalu et al. 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Arach et al. 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	I
Armour et al. 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Asim et al. 2022	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	I
Austin et al. 2021	Unclear	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	P
Bakhbakhi et al. 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Barry et al. 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R

Boyle et al. 2022	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Brierley-Jones et al. 2018	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Cassidy 2018	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Cetin et al. 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	I
Cheer et al. 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Choummanivong et al. 2020	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Christou et al. 2021	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	P
Cole et al. 2020	NA	Yes	Yes	Unclear	Unclear	No	No	Unclear	Yes	Yes	R
Colwell 2017	No	No	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	R
Denney-Koelsch et al. 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	R
Doherty, Coughlan et al. 2018	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Dombrecht, Piette et al. 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	R
Due et al. 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	R

Farrales et al. 2020	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	R
Fernández-Basanta 2021	Yes	Yes	Yes	No	Yes	Yes	No	Unclear	Yes	Unclear	R
Feroz 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	Unclear	I
Ferreira Paris et al. 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Gandino et al. 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Helps et al. 2020	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Helps et al. 2021	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	P
Helps et al. 2023	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Hendriks & Abraham 2022	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Kesbiç & Boz 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Kilcullen et al. 2020	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P
Köktürk Dalcalı et al. 2022	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	P
Laing et al. 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R

Lappeman & Swartz 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	P
Lin et al. 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	R
Listermar et al. 2020	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	I
Martínez-Serrano et al. 2018	Yes	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Unclear	R
Martínez-Serrano et al. 2019	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	R
McNamara et al. 2017	Unclear	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	Yes	R
McNamara et al. 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	I
Mills et al. 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Mills et al. 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	P
Muin et al. 2021	Unclear	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Yes	R
Nachinab et al. 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Unclear	Yes	P
Nuzum et al. 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	P
Popoola et al. 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	R

Qian & Wang et al. 2022	Unclear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	R
Rent et al. 2023	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	P
Serafim et al. 2021	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Setubal et al. 2017	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	R
Shakespeare et al. 2020	Yes	Yes	Yes	Yes	Yes	No	NA	No	Yes	Yes	P
Sheehy & Baird 2022	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	R
Steen 2019	Unclear	Yes	Yes	Unclear	Unclear	No	No	Unclear	No	Yes	R
Sun et al. 2021	Yes	Yes	Yes	Unclear	Yes	No	No	Unclear	Yes	Yes	R
Verdon & deMontigny 2021	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Watson et al. 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Willis 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	R
Zwerling et al. 2021	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Cross-sectional studies

	1. Were the criteria for inclusion in the sample clearly defined?	2. Were the study subjects and the setting described in detail?	3. Was the exposure measured in a valid and reliable way?	4. Were objective, standard criteria used for measurement of the condition?	5. Were confounding factors identified?	6. Were strategies to deal with confounding factors stated?	7. Were the outcomes measured in a valid and reliable way?	8. Was appropriate statistical analysis used?	Relevance
Agwu Kalu et al. 2018	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	R
Borovich 2022	Yes	Yes	Unclear	Yes	Unclear	Unclear	Yes	Yes	R
Kim & Kim 2022	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	R
Kalu 2020	Yes	Yes	Yes	Yes	NA	NA	Unclear	Yes	R
Kubota & Horiuchi 2023	Yes	Yes	Yes	Yes	No	No	Yes	Yes	P
Margulies et al. 2020	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	R
McNamara et al. 2017	Yes	Yes	Yes	Yes	No	No	Unclear	Yes	R
Muin et al. 2021	Yes	Yes	Unclear	No	No	NA	Yes	Yes	R
Qian & Cai et al. 2022	Yes	Yes	Yes	Yes	No	No	Yes	Yes	R
Ravaldi et al. 2018	Yes	Yes	Yes	Yes	No	NA	Yes	Yes	R
Ravaldi, Mosconi et al 2022	Yes	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes	R

Ravaldi, Carelli et al. 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	R
Shakespeare et al. 2020	Yes	No	Unclear	No	NA	NA	Yes	Yes	P
Spierson et al. 2019	Yes	Yes	Unclear	Yes	No	No	Yes	No	R
Warland & Glover 2019	Yes	No	Unclear	Yes	NA	NA	Unclear	Yes	R
Zhong et al. 2022	Yes	Yes	Unclear	Yes	No	NA	Unclear	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Prevalence studies

	1. Was the sample frame appropriate to address the target population?	2. Were study participants sampled in an appropriate way?	3. Was the sample size adequate?	4. Were the study subjects and the setting described in detail?	5. Was the data analysis conducted with sufficient coverage of the identified sample?	6. Were valid methods used for the identification of the condition?	7. Was the condition measured in a standard, reliable way for all participants?	8. Was there appropriate statistical analysis?	9. Was the response rate adequate, and if not, was the low response rate managed appropriately?	Relevance
Dombrecht, Cohen et al. 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	R
Leitao et al. 2021	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	R
Pekkola et al. 2022	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Unclear	P
Sharma et al. 2022	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	R

Watson et al. 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Text/narrative/opinion piece

	1. Is the source of the opinion clearly identified?	2. Does the source of opinion have standing in the field of expertise?	3. Are the interests of the relevant population the central focus of the opinion?	4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed?	5. Is there reference to the extant literature?	6. Is any incongruence with the literature/sources logically defended?	Relevance
Aggarwal & Moatti 2022	Yes	Yes	Yes	Yes	Yes	No	R
Bakhbakhi et al. 2017	Yes	Yes	Yes	Unclear	Yes	NA	R
Boyle 2020	Yes	Yes	Yes	Yes	Yes	NA	R
Broderick et al. 2021	Yes	Yes	Yes	Unclear	No	NA	P
Catlin 2018	Yes	Yes	Yes	Yes	Yes	Yes	R
McDaniel & Morris 2020	Yes	Yes	Unclear	Unclear	Yes	NA	R
Salenius 2019	Yes	Yes	Yes	Yes	Yes	Yes	R
Winters 2018	Yes	Yes	Unclear	Unclear	Yes	NA	R
Wool 2019	Yes	Unclear	Yes	Unclear	Yes	NA	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Systematic review and research synthesis studies

	1. Is the review question clearly and explicitly stated?	2. Were the inclusion criteria appropriate for the review question?	3. Was the search strategy appropriate?	4. Were the sources and resources used to search for studies adequate?	5. Were the criteria for appraising studies appropriate?	6. Was critical appraisal conducted by two or more reviewers independently?	7. Were there methods to minimise errors in data extraction?	8. Were the methods used to combine studies appropriate?	9. Was the likelihood of publication bias assessed?	10. Were recommendations for policy and/or practice supported by the reported data?	11. Were the specific directives for new research appropriate?	Relevance
Berry et al. 2021	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	NA	Yes	Yes	P
Fernández-Basanta et al. 2020	Yes	Yes	Unclear	Yes	Yes	Unclear	Unclear	Yes	No	Yes	Yes	R
Fernández-Basanta et al. 2022	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	P
Paraíso Pueyo et al. 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	R
Qian et al. 2021	Yes	Yes	Yes	Yes	NA	NA	Yes	Yes	No	Yes	Yes	R
Ratislavová et al. 2019	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	NA	R
Shakespeare et al. 2019	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	R
Shorey et al. 2017	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Unclear	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Quasi-experimental studies

	1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	2. Were the participants included in any comparisons similar?	3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	4. Was there a control group?	5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	7. Were the outcomes of participants included in any comparisons measured in the same way?	8. Were outcomes measured in a reliable way?	9. Was appropriate statistical analysis used?	Relevance
Doherty, Cullen et al. 2018	Yes	NA	NA	No	Yes	Yes	NA	Yes	Yes	R
Sorce & Chamberlain 2019	Yes	NA	NA	NA	Yes	No	NA	Yes	Yes	R
Warland 2020	Yes	NA	NA	No	Yes	Yes	NA	Unclear	Yes	R

GRADE-CERQual relevance component: I, indirect relevance; P, partial relevance; R, relevant; U, uncertain relevance

Table 7. GRADE-CERQual detailed assessment

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
8.1.	Each maternal and newborn service should establish and support a multidisciplinary team approach across the continuum of care to meet the physical, social, and emotional, cultural, religious, and spiritual needs of bereaved parents and family/whānau. • Ensure processes are established for cultural support services including interpreters. • Use a recognisable marker that designates perinatal loss in all physical spaces where parents are cared for to ensure all clinical and non-clinical staff are aware of loss.	10 studies are included. 6 studies are primary qualitative studies, one is a systematic review, one is a narrative review, and one is an author opinion. One mixed method study incorporates qualitative and cross-sectional methodology.	Moderate concerns of methodological limitation are noted. Six of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. The remaining four studies (three primary qualitative research, and one systematic review) were noted to have moderate concerns of methodological limitation. Critical appraisal identified concerns for a lack of researcher cultural position statement, and lack of assessment of the researchers' cultural position on the findings and analysis. One qualitative study additionally failed to provide a statement of ethics approval. The included systematic review with moderate	Minor concerns of relevance are noted. Nine of the included studies are deemed relevant to organisational responsiveness to care around stillbirth and neonatal death. One study is deemed to be partially relevant.	No concerns of coherence are noted.	Moderate concerns of data adequacy are noted. Of the included studies, 9 sourced their cohorts from high-income country populations. One study also included participants from upper-middle income countries in addition to high-income countries, and another is a narrative review from a lower-middle income country. Outcomes of interest include stillbirths (n=78), termination of pregnancy for fetal anomaly (n=10) and composite perinatal mortality outcomes (n=293). The viewpoints contained within the data included are from mothers (n=44), parents (n=15), healthcare professionals (n=358) and from national inquiries (n=10). Moderate concerns of data adequacy are noted due to	Low confidence *No or minor concerns of relevance and coherence. Moderate concerns of data adequacy and methodological limitation.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			concerns of methodological limitation demonstrates an unclear search strategy, unclear literature sources, and further failed to conduct appraisal by two independent reviewers.			inadequate combined cohort size and inadequate outcomes included.	
8.2.	Ensure a coordinated and informed approach to care across the continuum through a dedicated role within the service, ideally a bereavement midwife, to be a known point of contact (that is, contact details of a named healthcare professional) for bereaved parents and family/whānau. • This requires appropriate rostering of staff to provide high quality care.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
8.3.	Maternal and newborn services should have established protocols in place to access appropriate expertise where not available locally for all aspects of care around the time of a perinatal death and in subsequent pregnancies (such as team-to-team or telehealth consultations). • This is particularly important to ensure families/whānau who live in regional or remote areas	NA	NA	NA	NA	NA	**Consensus-based recommendation**

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	have access to appropriate clinical, social, and emotional supports.						
8.4	Ensure culturally and linguistically appropriate information and resources are available in multiple formats (print, audio, digital) and languages for bereaved parents and family/whānau.	Five studies are included. Four are primary qualitative studies, and one is a mixed methods study.	Moderate concerns of methodological limitation are noted. Two studies are noted to have no or minor concerns of methodological limitation. Three studies are noted to have moderate concerns of methodological limitation, two qualitative studies and one prevalence study. The qualitative studies are noted to lack a statement of researcher cultural position, and also to account for the influence of the researcher on findings and analysis. Two also lack congruity between the stated philosophical perspective, methods and analysis. The included mixed methods study was found to have minor concerns of quantitative methodology, but moderate concerns of the qualitative body of work due to the same	Minor concerns of relevance are noted. Four of the included studies are deemed relevant to organisational responsiveness to care around stillbirth and neonatal death, and one study is deemed partially relevant.	Moderate concerns of coherence are noted as one of the two included studies focuses findings on organisational responsiveness during the COVID-19 pandemic.	Moderate concerns of data adequacy are reported. Four included studies sourced their cohorts from high-income country populations, and one from lower middle-income country populations. Outcomes of interest include stillbirths (n=20) and composite perinatal mortality outcomes (n=996). The viewpoints contained within the data included are from mothers (n=20), healthcare professionals and national inquiries (n=10). Moderate concerns of data adequacy are noted due to small, combined sample of viewpoints included and inadequate outcomes.	Low confidence *Moderate concerns of methodological limitation, coherence and data adequacy. Minor concerns of relevance.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			reasons for the above studies.				
8.5	Ensure a designated private and safe place is available for bereaved parents and family/whānau whose baby has died or is receiving palliative care. This includes capacity and resources to support: • parents to spend time with and create memories with their baby including mementos, and other keepsakes • family members/whānau and other support people to gather • cultural, religious, and/or spiritual rituals or ceremonies	Twelve studies are included. Of these, 11 are primary qualitative studies and one is a mixed-methods study.	Moderate concerns of methodological limitation through critical appraisal are noted. Seven of the included studies are note dot have no or minor concerns of methodological limitation. Five of the included studies are noted to have moderate concerns of methodological limitation through critical appraisal. Four are qualitative primary studies noted to lack a statement of researcher cultural position, and account for the influencer of the researcher on findings and analysis. Three furthermore are noted to lack congruity between the stated philosophical perspective and methods. The included mixed methods study was found to have minor concerns of quantitative methodology, but moderate concerns of the qualitative body of	Minor concerns of relevance are noted. Nine of the included studies are deemed relevant to organisational responsiveness to care around stillbirth and neonatal death, and three studies are deemed partially relevant.	Minor concerns of coherence are noted.	Minor concerns of data adequacy are noted. Nine studies sourced their cohorts from high-income country populations, two from low-income countries and one from lower middle-income country. Outcomes of interest include stillbirths (n=218), neonatal death (n=30) and composite perinatal mortality outcomes (n=885). The viewpoints contained within the data included are from mothers (n=48), parents (n=161), and healthcare professionals (n=51). Minor concerns of data adequacy are noted due to inadequate combined cohort size.	**Moderate confidence** *Moderate concerns of methodological limitation, minor concerns of relevance, coherence and data adequacy.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			work due to the same reasons for the above studies.				
8.6.	Establish a local process for storing mementos for parents who initially choose not to take them including how to store securely and label appropriately in medical records for future access.	NA	NA	NA	NA	NA	Consensus-based recommendation
8.7	Establish relationships and partnerships with parent support organisations to ensure appropriate commemorative rituals are available to parents such as an annual remembrance service for parents whose babies have died.	Three studies are included. One scoping review, one qualitative study and one narrative review is included.	Minor concerns of methodological limitation are notes. Two of the included reviews are deemed through critical appraisal to have no or minor concerns of methodological limitation. The included qualitative primary research is deemed to have moderate concerns of methodological limitation. Critical appraisal assessment noted a lack of statement around the researcher cultural influence on findings and analysis. Lack of congruity between methods and intent was also noted.	No concerns of relevance are noted. All included studies are deemed relevant to organisational responsiveness to care around stillbirth and neonatal death.	Minor concerns of coherence are noted as an included primary qualitative research study focuses findings on organisational responsiveness during the COVID-19 pandemic.	Moderate concerns of data adequacy are noted. All included studies sourced their cohorts from high-income country populations. Outcomes of interest across the data include stillbirth, neonatal death and termination of pregnancy for fetal anomaly, however the sample sizes for these outcomes were not specified. The viewpoints of healthcare professionals were included in one study (n=35), another included composite viewpoints of healthcare professionals and parents (n=32) and the scoping review included viewpoints of parents (n=641).	Moderate confidence *No or minor concerns of methodological limitation, relevance and coherence. Moderate concerns of data adequacy.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
						Moderate concerns of data adequacy are noted due to small, combined sample of viewpoints included and lack of information about the sample sizes for the outcomes of interest.	
8.8	All healthcare professionals should be aware of and familiar with the law, policy, practices, and clinical care standards related to reporting stillbirths and neonatal deaths.	NA	NA	NA	NA	NA	**Consensus-based recommendation**
8.9	Maternal and newborn services should make available specific professional development opportunities in care around stillbirth and neonatal death to all staff. The Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) educational program has been well received by health care professionals across Australia.	15 studies are included. Of the included studies, six are primary qualitative research studies, four are cross-sectional studies, two are quasi-experimental studies, one is a prevalence study, and one is a systematic review. One mixed methods study incorporating qualitative and cross-sectional methodology is also included.	Moderate concerns of methodological limitation are noted. 10 of the included studies are deemed to have no or minor concerns of methodological limitation. Five included studies are deemed to have moderate concerns of methodological limitation. Two qualitative studies due to lack of a statement of researcher cultural position, and the influence of the researcher on analysis and findings. The studies further lacked congruity between	Minor concerns of relevance are noted. Thirteen of the included studies are deemed relevant to organisational responsiveness to care around stillbirth and neonatal death. Two studies are deemed to be partially relevant.	Minor concerns of coherence are noted.	Minor concerns of data adequacy are noted. Eleven of the included studies source their cohorts from high-income country populations, one from low-income country, one from lower middle-income country, and one from upper middle-income country. One study did not specify the income levels of their study cohorts. Outcomes of interest across the data include stillbirth (n=1,191), neonatal death (n=98) and composite perinatal	**Moderate confidence** *Moderate concerns of methodological limitation, minor concerns of relevance, coherence and data adequacy.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			philosophical perspective, methods, analysis and results presented. Three cross-sectional studies also were noted to lack confounder identification or confounder adjustment through analysis. One also was noted to include unclear exposure measures.			mortality outcomes (n=803). The viewpoints of healthcare professionals (n=163) were included in seven studies, and those of parents (n=55) in one study. Minor concerns of data adequacy are noted due to small, combined sample sizes of viewpoints included.	
8.10	Organisations must provide and maintain effective cultural education for all healthcare professionals particularly non-Indigenous health professionals. Education must include: • cultural awareness and understanding of diversity within and between cultural groups • understanding of implicit biases and ongoing racism for some population groups • impact of colonisation for some populations, particularly Aboriginal and Torres Strait Islander communities in Australia						See *Section 2: Technical report for cultural safety* for evidence appraisal.

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
	and Māori communities in Aotearoa New Zealand • awareness of history of trauma and loss, and previous negative experiences with health services particularly: o intergenerational trauma among Aboriginal and Torres Strait Islander families o complex trauma among women of refugee background acknowledge the importance of each cultural group's vital support systems such as kinship and community care for Aboriginal and Torres Strait Islander families.						
8.11	Maternal and newborn services should ensure that healthcare professionals who provide care around stillbirth and neonatal death have access to formal and peer support and are encouraged to prioritise their social and emotional wellbeing.	Fourteen studies are included. Of these, nine are primary qualitative studies, two are cross-sectional studies, one is a systematic review, and one is an opinion paper. One mixed-method study incorporating qualitative and cross-sectional design is also included.	Moderate concerns of methodological limitation are noted through critical appraisal. Ten of the included studies are noted to have no or minor concerns of methodological limitation. Four primary qualitative studies have moderate concerns of methodological limitation,	Minor concerns of relevance are noted. 12 of the included studies are deemed to be relevant to organisational responsiveness to care around stillbirth and neonatal death, and two studies are deemed to be partially relevant.	No concerns of coherence.	Moderate concerns of data adequacy are noted. Of the included studies, eleven sourced their cohorts from high income country populations, one from low- and lower-middle income countries and another from lower-middle-income countries. One systematic review did not specify the income	**Low confidence** *No or minor concerns of relevance and coherence. Moderate concerns of methodological limitation, and major concerns of data adequacy.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			all due to lack of a statement of researcher cultural position, and failure to account for the influence on findings and analysis. All four also lack congruity between the philosophical perspective and methodology. One furthermore fails to demonstrate clear ethical approval statements.			levels of the study cohorts included in their data. Outcomes of interest across data include stillbirths (n=229), neonatal deaths (n=47) and composite perinatal mortality outcomes (n=565). Viewpoints included across the data include that of healthcare professionals (n=104). Moderate concerns of data adequacy are noted due to small sample size of viewpoints included and inadequate outcomes.	
8.12	All maternal and newborn services should implement a perinatal mortality audit program that is integrated into quality improvement activities to ensure practice improvement in the provision of care around stillbirth and neonatal death. The audit program should include parent experiences of care.	Five studies are included. Four are primary qualitative research studies, and one is a narrative review.	Moderate concerns of methodological limitation and noted. Three of the included studies are noted to have no or minor concerns of methodological limitation through critical appraisal. Two of the included primary qualitative research studies are noted to have moderate concerns of	Minor concerns of relevance are noted. Four of the included studies are deemed relevant to organisational responsiveness to care around stillbirth and neonatal death. One study is deemed to be partially relevant.	No concerns of coherence noted.	Moderate concerns of data adequacy are noted. All included studies sourced their cohorts from high-income country populations. Outcomes of interest include stillbirth and composite perinatal mortality outcomes (n=52).	**Low confidence** *Moderate concerns of methodological limitation and data adequacy. Minor concerns of relevance, and no concerns of coherence.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			methodological limitation due to lack of statements of researcher cultural position, and influence of the researcher on analysis and findings. There also lacked congruity between the philosophical perspective, stated methodology and actual methods.			The viewpoints of healthcare professionals were included in one study (n=22). Moderate concerns of data adequacy are noted due to inadequate, combined cohort size, and lack of parent and community viewpoint.	
2.2	To ensure continuity of carer, designate a lead contact person with training in perinatal loss care, ideally a bereavement midwife, to be a known point of contact for parents, family/whānau and other members of the care team (including hospital volunteers).	Seven studies are included. Six primary qualitative studies, and one mixed methods study incorporating qualitative and cross-sectional methodology.	Moderate concerns of methodological limitation are noted. Two of the included study are deemed to have no or minor concerns of methodological limitation through critical appraisal. Four of the included studies are deemed to have moderate concerns of methodological limitation, and one is noted to have severe concerns of all aspects of methodology assessed through critical appraisal. Four primary qualitative studies are all noted to have moderate concerns due to a lack of a statement of the	No concerns of relevance are noted. All included studies are deemed relevant to organisational responsiveness to care around stillbirth and neonatal death.	Minor concerns of coherence are noted.	Minor concerns of data adequacy are noted. All included studies sourced their cohorts from high-income country populations. One study also sourced their cohorts from upper-middle income country populations in addition to high-income country. Outcomes of interest across the data include stillbirth (n=44), termination of pregnancy for fetal anomaly (n=10) and composite perinatal mortality outcomes (n=348). The viewpoints of mothers (n=44), parents (n=40), healthcare professionals	**Moderate confidence** *Moderate concerns of methodological limitation, minor concerns of data adequacy and coherence, and no concerns of relevance.*

Rec.	Recommendation	Studies contributing	Methodological limitations	Relevance	Coherence	Adequacy of data	GRADE-CERQual appraisal
			researcher cultural position and this influence on analysis and findings. One was also noted to have unclear ethical approvals in place, and another was noted to have unclear congruity between the stated philosophical perspective and methods.			(n=288) and data from national inquiries (n=10) was included. Minor concerns of data adequacy are noted due to small, combined cohort size.	