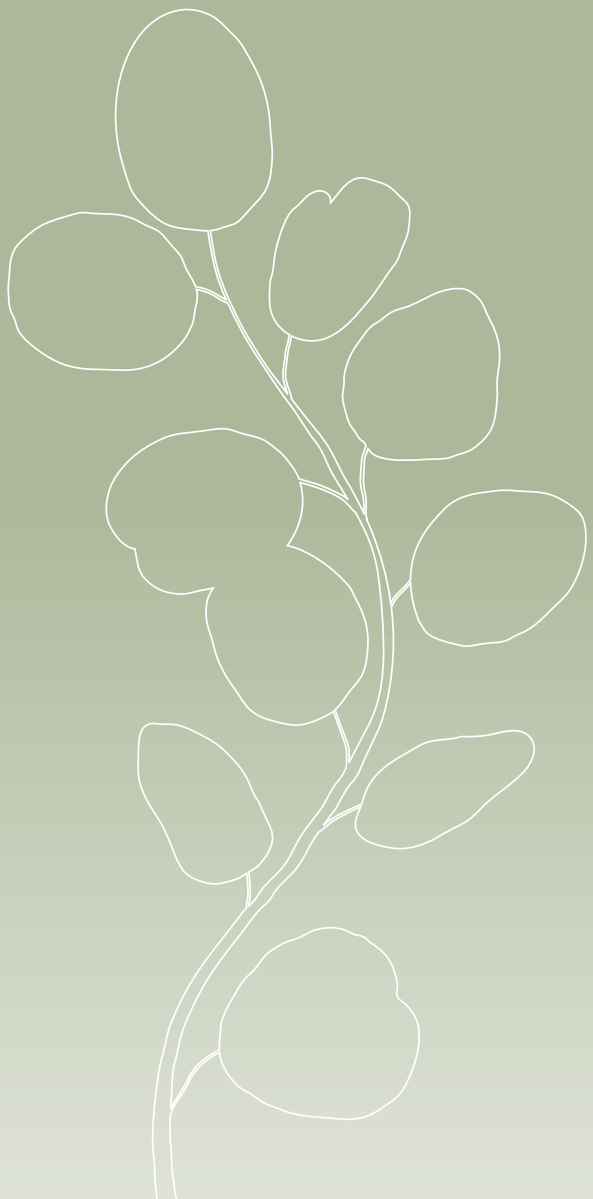
2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline



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

Authorship

This guideline was developed by the National Health and Medical Research Council (NHMRC) Centre of Research Excellence in Stillbirth (Stillbirth CRE) in partnership with the Perinatal Society of Australia and New Zealand (PSANZ).

Date of publication

This edition of the guideline was published in 2024 and updates and expands on previous editions.[1]

Copyright statement

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The Stillbirth CRE acknowledges the funding provided by the Australian Government Department of Health and Aged Care for the development of this guideline edition.

Expiry of the guideline

The Stillbirth CRE will monitor new publications and reports that may be relevant to the guideline. In addition, evidence will be reviewed three years after publication to evaluate whether all or part of the guideline should be updated. Due to the number of topics in this guideline, a selective updating approach (based on a living guideline process) may be taken by the Guideline Development Committee to ensure incorporation of new evidence, rapid update of some recommendations, and identification of additional topics for future consideration.

Scan the QR code to access the digital version of the guideline and supporting documents including the Executive Summary and List of Recommendations.

Publication Approval

Australian Government
National Health and Medical Research Council

The guideline recommendations on pages 6 to 23 in the Executive Summary were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 8 December 2023 under section 14A of the *National Health and Medical Research Council Act 1992*. In approving the guideline recommendations, NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of five years.

NHMRC is satisfied that the guideline recommendations are systematically derived, based on the identification and synthesis of the best available scientific evidence, and developed for health professionals practising in an Australian health care setting.

This publication reflects the views of the authors and not necessarily the views of the Australian Government.

"Protection"

We acknowledge the Traditional Owners of this land and their ongoing custodianship. We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country. We acknowledge the diversity across Aboriginal and Torres Strait Islander cultures, language, and practices and that it is vital that all health care services respectfully manage protocol and provide a culturally positive healthcare experience for Aboriginal and Torres Strait Islander people when going through Sorry Business.

We acknowledge and recognise ngā iwi Māori as the Tangata Whenua of Aotearoa New Zealand. We acknowledge language, customary practices, and whānau inclusivity. Providing a culturally acceptable environment by acknowledging all these things by action and deed.

FOREWORD

We know Indigenous people and migrant and refugee families/whānau have a higher risk of stillbirth in Australia and Aotearoa New Zealand. We also know that these population groups are resilient, caring, and proud. To reduce the risk of preventable stillbirth and to provide appropriate care to families/whānau when this devastating event does occur, it is imperative that all healthcare professionals are respectful and responsive to the cultural needs of these families/whānau. For healthcare professionals caring for families following the death of a baby, this provides an opportunity to strive for better outcomes and be reflective on their own practice. This is turn can mean families/whānau feel more satisfied with their care, building up trust and safety – a crucial element to all aspects of a families/whānau health and wellbeing.

While this is a high quality evidence-based guideline for maternal and newborn services and the families/whānau in their care, we can also look at it as a story of how to work together in hope, safety, togetherness, and trust. A commitment to culturally responsive care can help shape this.

When we know better, we do better.

Skye Stewart (Wergaia and Wamba Wamba research midwife)
On behalf of the Guideline Cultural Considerations Expert Working Group

Forewords

STILLBIRTH CRE AND PSANZ

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) and Perinatal Society of Australia and New Zealand (PSANZ) are pleased to publish the 2024 update of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*. This guideline represents our shared vision to improve care for parents and families/whānau who experience the tragedy of stillbirth or neonatal death.

The first edition of the guideline was released in 2008 and has been updated four times. As in previous editions, this edition incorporates the latest evidence for perinatal loss bereavement care, investigations to understand why a baby died, and audit and classification processes to inform prevention and improve future care for bereaved families/whānau.

In this edition, a greater focus has been placed on culturally responsive and safe care practices and the role of organisations in enabling the provision of best practice care. We also incorporate two new sections focused on perinatal palliative care and care in subsequent pregnancies.

While early pregnancy loss (before 20 weeks' gestation) was not included in the scope of the guideline, it is important to acknowledge that respectful supportive care for families/whānau should be the same after any pregnancy loss and that this care should extend into a subsequent pregnancy. We hope to expand the guideline in the next update to specifically address the needs of families/whānau experiencing early pregnancy loss.

We acknowledge the enduring loss experienced by parents and families/whānau when the anticipated joy of bringing a baby home turns to tragedy through pregnancy loss at any gestation.

We acknowledge and thank the Guideline Development Committee and Expert Working Groups for their time, and dedication, particularly the Technical Working Group who prepared this edition.

Prof Vicki Flenady
Prof Adrienne Gordon
Co-Chairs Guideline Development Committee
Stillbirth CRE and PSANZ

STILLBIRTH FOUNDATION AUSTRALIA

Stillbirth Foundation Australia endorses the 2024 update of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline*. The death of any baby is a tragedy and Stillbirth Foundation Australia acknowledges the lasting impact on parents and their families/whānau.

Healthcare professionals have a crucial role in providing care and support for bereaved families/whānau around the time of a baby's death and before and during any future pregnancy. This guideline contains high-quality information and recommendations based on the best available scientific evidence that will reduce stillbirth and lessen its impact on families/whānau. We strongly encourage healthcare professionals to read the guideline and implement its recommendations into their clinical practice. In addition to previous editions, the current guideline has an increased focus on providing culturally responsive care and the role of organisations in enabling best practice care and supporting healthcare professional wellbeing. We welcome the addition of two new and important sections on perinatal palliative care and care in subsequent pregnancies following perinatal loss.

Stillbirth Foundation Australia is a proud partner of the Centre of Research Excellence in Stillbirth. We fund researchers to generate new knowledge about stillbirth causes and prevention and translation of research findings into practice. We also support the community and healthcare professionals through education to change behaviours that will help reduce the incidence of stillbirth and support bereaved families, and extend the reach and impact of the stillbirth community by advocating on behalf of bereaved families. Stillbirth Foundation Australia provides an opportunity for parents to share their stories about their beloved babies who were stillborn.

Stillbirth Foundation Australia, in partnership with the Centre of Research Excellence in Stillbirth, developed the *Guiding Conversations* booklet that is included in this guideline (Section 1.4). We hope that healthcare professionals will use this parent version of the guideline to support parents and families/whānau during this devastating time.

Our thoughts are with all families/whānau who are missing their beloved babies - they are forever loved and in our hearts. We also acknowledge and thank all healthcare professionals who care for and support bereaved families/whānau during and after stillbirth.

A/Prof Sean Seeho
Chair, Stillbirth Foundation Australia

PINK ELEPHANTS SUPPORT NETWORK

The Pink Elephants Support Network is Australia's leading early pregnancy loss support charity, providing up-to-date resources such as information for bereaved parents, their families and friends, and their workplaces, and a range of peer support options for anyone impacted by the emotional, physical, and mental health effects of early pregnancy loss.

Early pregnancy loss, or miscarriage, is often fraught with unknowns, silence, shame and stigma. Pink Elephants welcomes this guideline, which we believe will improve care for all women and families following pregnancy loss, regardless of gestation. As an organisation that provides early intervention support to bereaved parents who lose a baby during the first 20 weeks of pregnancy, we know how important it is that all losses are met with the same validation, empathy, and referral for support. We welcome the plans to extend this guideline to address the specific needs of women and families who experience early pregnancy loss.

Sam Payne
CEO, Pink Elephants Support Network

RED NOSE AUSTRALIA

The death of a baby is a devastating experience for parents, their families and support people. Healthcare professionals play such an important role in caring and supporting bereaved families in the immediate days, weeks and months following the death of a baby.

Red Nose is a proud partner of the Centre of Research Excellence in Stillbirth. We welcome this edition of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline* and its expanded focus on culturally responsive care, perinatal palliative care, and care in subsequent pregnancies.

We will continue to support implementation across Australia to ensure all families receive high quality support throughout the continuum of care.

Red Nose have supported grieving families in Australia for more than 40 years. We have worked together with healthcare professionals and hospitals to provide bereavement resources and supports across the grief journey including providing 24/7 bereavement support, professional counselling, the Hospital to Home program, a full range of peer support programs and our Treasured Babies Program. All programs aim to support families as they navigate the complex loss experience following the death of a baby, including in subsequent pregnancies.

We extend our warmest condolences to all families who are missing their little ones. We also acknowledge and support all healthcare professionals who care for bereaved families during this devastating time.

Keren Ludski
Red Nose

MIRACLE BABIES FOUNDATION

Having a premature or critically ill baby that requires specialised medical care in a neonatal unit can be a traumatic and emotional experience. Heartbreakingly, sometimes babies will pass away despite the highest level of intensive care. For these bereaved families, the journey is life long and can be life changing. It is extremely beneficial for bereaved parents to connect with other parents with a shared experience of their baby passing away in the neonatal unit. This can help reduce the isolation and loneliness whilst building supportive communities and connections.

Miracle Babies Foundation is Australia's leading not for profit supporting premature and sick babies and their families, including bereaved families. For almost twenty years, Miracle Babies has developed and delivered peer support services and resources through all parts of the neonatal journey, the transition to home and beyond.

Making memories and being involved in their baby's clinical and palliative care is very important for parents. We thank all health care professionals caring for these miracle babies and their families at this time.

Our sincere thoughts are with each family at the passing of their baby and through the years ahead.

Kylie Pussell
Miracle Babies Foundation

ENDORSING ORGANISATIONS

The 2024 edition of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline* is endorsed by the following organisations.

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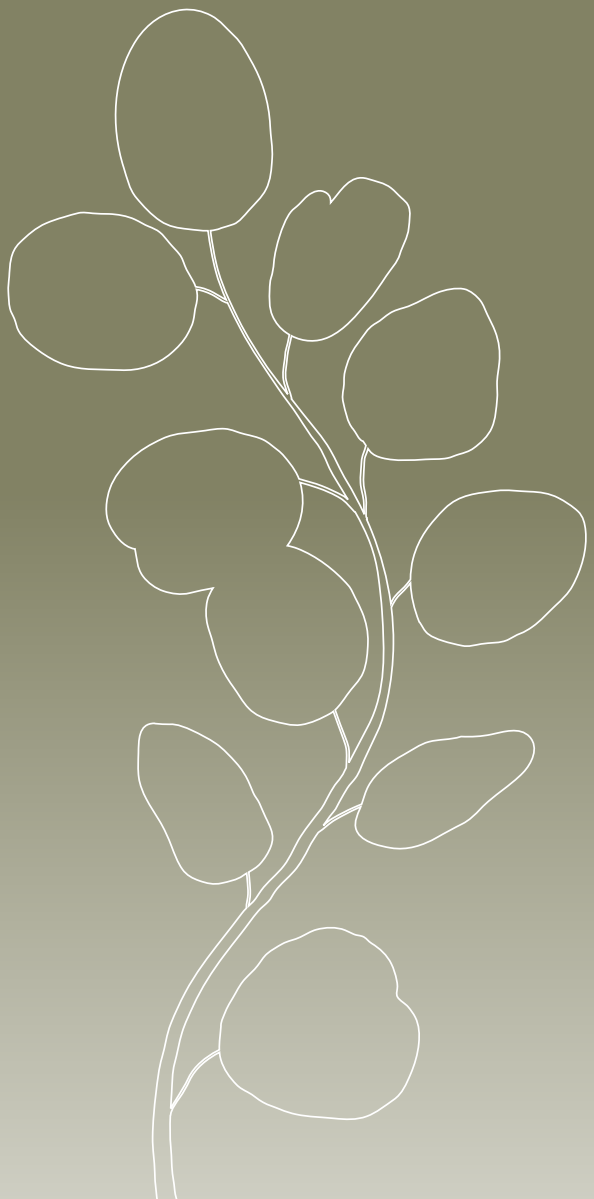


Section 1: Introduction

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

Section 1: Introduction

The death of a baby during pregnancy or soon after birth has long-lasting social and emotional consequences.[3] There are also ongoing impacts on healthcare professionals who care for parents around the time of loss,[4] and economic impacts on health systems and society.[5-7] The quality of care that parents and family/whānau receive around the time their baby dies, including care following diagnosis of a life-limiting condition and termination of pregnancy, is a major contributor to immediate and long-term wellbeing, including into subsequent pregnancies.[3,4]

Globally, more than 4 million babies die during the perinatal period each year.[8] Stillbirths represent the majority of these deaths and have been identified as an unaddressed global public health problem due to little or no improvement in the rates of these deaths and inadequate perinatal loss care for those who experience this loss.[9,10] While the global burden of perinatal death lies in low and middle-income countries, high-income countries have substantial room for improvement.[11] The Lancet stillbirth series in 2016 set out a comprehensive call to action to address stillbirth[12] including priorities for high-income countries. [11]

In Australia and Aotearoa New Zealand late gestation stillbirth rates (28 weeks or more) are approximately 26% and 37% higher respectively than other high-income countries with the lowest rates.[13] Further, First Nations peoples, some migrant and refugee communities[14] and those living in rural and remote regions and other areas of disadvantage[15-17] experience up to double the rates.

In 2021 the perinatal mortality rate in Australia was 9.9 perinatal deaths for every 1,000 births representing 2,272 stillbirths and 642 neonatal deaths[18] and in 2020 the rate in Aotearoa New Zealand was 10.8 per 1,000 births representing 489 stillbirths and 153 neonatal deaths.[19]

Identifying the causes of stillbirth and neonatal (perinatal) death through appropriate diagnostic investigations is an essential component of quality care for parents and families/whānau. Parents need the best possible information to help them understand why their baby died and to guide care in subsequent pregnancies.[20,21] Accurate information on the cause of death is also necessary to inform effective prevention strategies.[11] Congenital anomalies account for around one-third of perinatal deaths in Australia and Aotearoa New Zealand,[18,19] often following termination of pregnancy. With low autopsy rates in many jurisdictions, many stillbirths are not adequately investigated, and valuable information may be lost. Contributing factors relating to care (also called sub-optimal, avoidable, or preventable factors) have been reported in 30 to 50% of perinatal deaths with lack of appropriate care for women with risk factors a common finding.[22-25] **The Safer Baby Bundle** has been implemented across Australia to address this gap.

The first edition of the guideline was released in 2008 and updated four times. In this edition, a greater focus has been placed on culturally appropriate care, perinatal palliative care and care for families/whānau experiencing a perinatal death following a termination of pregnancy. Care for families/whānau who experience an early pregnancy loss was beyond the scope of this guideline and we plan to include this in future updates. However, we acknowledge the burden on families/whānau of all pregnancy loss no matter when it occurs and hope that this guideline will assist in better care and outcomes for families/whānau after early loss across maternity care settings.

The IMPROVE (IMproving Perinatal mortality Review and Outcomes Via Education) program first developed in 2008 was designed to implement the guideline into everyday care. The program includes a new e-learning module[26] including the *Guiding Conversations* booklet for parents and families and the *Jiba Pepeny* booklet for Aboriginal and Torres Strait Islander parents.

The National Stillbirth Action and Implementation Plan (The Plan) in Australia[27] has identified improving care after stillbirth, with specific focus on the needs of priority populations, as a priority. The first report of the Ending Preventable Stillbirths (EPS) and Bereavement Care Scorecard for High- and Upper Middle-Income Countries (released in 2023) highlighted the progress in Australia associated with the establishment of the Stillbirth CRE and The Plan. However, substantial room for improvement was identified, particularly in addressing the persistent disparity in care and outcomes for First Nations peoples and other disadvantaged communities, including in Australia and Aotearoa New Zealand.[28]

This guideline has been updated as part of the national plan to provide individual healthcare professionals and the maternal and newborn services in which they work with best practice recommendations to enable optimal care for parents who experience the loss of a baby in the perinatal period, no matter where they live or their cultural and religious background.

Application of this guideline

The purpose of this guideline is to promote best practice across Australia and Aotearoa New Zealand around the time a baby dies. Maternal and newborn care settings are the primary focus, as well as interfaces between hospital-based services and the community, and the longer-term support needs of parents and families/whānau.[29]

Scope

This clinical practice guideline provides guidance to frontline healthcare professionals in maternal and newborn services in Australia and Aotearoa New Zealand, including primary care, obstetric and midwifery practice, and public and private hospitals, who provide care to parents and families/whānau around the time of perinatal death.

For this guideline, perinatal death is defined as follows.

- **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.[19,30]
- **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.[19,30]

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.

The guideline does not specifically address or provide best practice recommendations for the care of parents who experience early pregnancy loss/miscarriage (including ectopic or molar pregnancy). In Australia, **Miscarriage Australia** and **Pink Elephants Support Network** provide tailored information and support. In Aotearoa New Zealand, **Miscarriage Support** and **Miscarriage Matters** provides online resources and best practice recommendations.

Target audience

Primary audience: This guideline is for all healthcare professionals who care for parents and families/whānau in maternal and newborn care services in Australia and Aotearoa New Zealand. This may include doctors, midwives, nurses, social workers, psychologists, Aboriginal and Torres Strait Islander health workers and practitioners as well as Aboriginal liaison officers, and community-based healthcare professionals including community first responder organisations (e.g. ambulance services). This guideline is also for healthcare professionals who care for families/whānau in the transition from hospital to community and provide longer-term ongoing support. Other healthcare professionals such as sonographers, pathologists, and radiologists may also find this guideline helpful in identifying the cause of a baby's death. Healthcare professionals will apply this guideline according to their knowledge, skills, and role, as well as the geographical and cultural setting in which they provide care. Strong multidisciplinary partnerships are essential to ensure optimal care for parents and families/whānau.

Secondary audience: The guideline may also be used by policy makers, health system administrators, and others involved in implementation of maternal, newborn and child health programs. In addition, the guideline may be useful for parents, families/whānau and their support people, including those who have been affected by stillbirth or neonatal death and/or are involved in advocacy related to maternal and newborn health.

A note about terminology

This guideline uses parent-centred language that is intended to be inclusive of all affected by loss. We use the term 'woman' throughout the guideline to refer to the person who is pregnant and gives birth.[31] We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth identify as a woman. The term 'parent' is used to refer to expectant and bereaved mothers, fathers, and partners. It is important to recognise individuals who identify themselves as parents. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents.[32]

This guideline uses 'baby' when referring to stillbirth, neonatal death because these terms are preferred by many bereaved parents. Terms such as 'fetus' may add to parents' distress because this language denies personhood[33] and is inconsistent with recognition of parenthood that is crucial to providing respectful and supportive care.

This guideline uses 'healthcare professional' to denote all those working with bereaved parents and family/whānau (see Glossary).

A note about the evidence

Care of parents and babies after perinatal death is an area of practice that is complex, multifaceted, not well defined, and largely informed by observational and qualitative evidence.

Four Cochrane reviews that have addressed aspects of care after perinatal death found limited trial evidence to support clinical practice.[20,34-36] The review assessing the effectiveness of interventions intended to provide psychological support or counselling to mothers, fathers or families/whānau after perinatal loss, found no eligible randomised controlled trials (RCTs).[34] The review on approaches to investigations for stillbirth also found no RCTs.[20] The reviews on subsequent pregnancy care[36] and autopsy consent found very limited evidence from RCTs.[35] The review authors acknowledge the challenge of conducting experimental study designs in this area and the need to rely on non-randomised and observational studies to guide practice.

There is a growing body of qualitative and non-randomised evidence with consistent findings, which helps to inform best practice care around stillbirth and neonatal death. We have drawn on this body of research evidence and the insights from an experienced multidisciplinary team as part of the Development Committee and its specialised subcommittees in developing the recommendations in this guideline. Further, when cross referencing our findings against all relevant international guidelines we found consistency in interpretation of the evidence and recommendations.

Many recommendations are consensus-based drawing on the available literature and expert knowledge and experience of the committee members and the wider audience through public consultation. For many of the evidence based recommendations the evidence was rated as low to moderate quality. The recommendations have been developed so that maternal and newborn services can strive to meet best practice care to improve outcomes for families around the time of stillbirth or neonatal death.

Acknowledgements

This edition of the clinical practice guideline was produced by a multidisciplinary working group led by the Centre of Research Excellence in Stillbirth (Stillbirth CRE) based at Mater Research Institute–The University of Queensland, Brisbane, Australia in partnership with the Perinatal Society of Australia and New Zealand (PSANZ). Support for guideline development was received from the Australian Government Department of Health and Aged Care. See *Appendix 1A* for membership of the Guideline Development Committee and Expert Working Groups.

How to use the guideline

The guideline is presented in eight sections:
Section 1: Introduction
Section 2: Approach to care
Section 3: Perinatal loss care
Section 4: Perinatal palliative care
Section 5: Care in subsequent pregnancies
Section 6: Investigations for perinatal death
Section 7: Perinatal mortality audit and classification
Section 8: Organisational recommendations

Resources are provided to assist healthcare professionals implement the recommendations including resources for parents and families/whānau.

Implementation and review

Refer to *Implementation and dissemination plan*. The guideline and all supporting documents and resources will be available as a web-based tool and as a printable text document (PDF) from the Stillbirth CRE website (**https://stillbirthcre.org.au/**) so that they are accessible to healthcare professionals and the broader community.

NHMRC approval of recommendations is valid for five years. However, evidence will be reviewed three years after publication to evaluate whether all or part of the guideline should be updated. In Australia, the National Stillbirth Action and Implementation Plan[27] highlights the need for all families/whānau who experience stillbirth to receive personalised, respectful, supportive and holistic clinical and community care.

A co-designed national care pathway is currently under development by the Stillbirth CRE to ensure best practice care around stillbirth and neonatal death is provided across the continuum of care and different settings. In Aotearoa New Zealand, a national perinatal bereavement pathway is under development with key stakeholders including governmental and non-governmental organisations to ensure high-quality, appropriate, and equitable care for all.

The Australian Commission on Safety and Quality in Health Care (the Commission) released the Stillbirth Clinical Care Standard (the Standard) in November 2022. The Standard aims to reduce variation in the prevention and investigation of stillbirth, and to support best practice in bereavement care after any perinatal loss. This Standard provides maternal and newborn services with a robust tool to help with implementation of the guideline.

Resource implications associated with implementation of the recommendations

This clinical practice guideline was produced to support the delivery of appropriate care after stillbirth or neonatal death, based on the best evidence available at the time of development. Healthcare professionals are advised to use clinical discretion and consider the circumstances of the individual patient and their family when applying recommendations from the guideline. In some settings, resources to support best practice care may not be as readily available as in others. In these situations we hope this guideline may be used as an advocacy tool for services to use in planning care provision for families who experience stillbirth or neonatal deaths. By acknowledging and addressing resource implications we aim to contribute to the sustainable and equitable implementation of clinical recommendations to improve care for families.

In a survey of maternity services, we identified variation in implementation of recommendations of the previous guidelines[37] in Australia. Services in rural and remote regions and non-tertiary centres were less likely to report optimal care practices. As many of the recommendations in this update are similar in terms of respectful supportive care with a strengthening of the focus on culturally appropriate care, education of healthcare professionals and continuity of care there is likely to be variation in resource requirements for implementing or upscaling based on type and place of service. See also the *Implementation and Dissemination Plan*.

Recommendations

This edition of the guideline contains two types of recommendations — evidence-based and consensus-based. Both provide best practice, respectful and culturally responsive care to parents and families/whānau around stillbirth and neonatal death. The methodology and recommendation process are detailed in the technical reports for each section.

Evidence-based recommendations (EBR) were developed by the Guideline Development Committee and Expert Working Groups (see *Appendix 1A* for member details) and were based on systematic reviews of the available evidence published between 2017 and 2023 and seminal evidence identified by the Committee.

Where available, evidence was graded using CER-Qual[38] and assigned a confidence rating. The GRADE-CERQual (Confidence in Evidence from Reviews of Qualitative research) approach has been developed by the GRADE (Grading of Recommendations Assessment, Development and Evaluation) Working Group. The approach has been developed to support the use of findings from qualitative evidence syntheses in decision making, including guideline development and policy formulation. Confidence ratings are as follows:

- **High confidence:** It is highly likely that the evidence is a reasonable representation of the recommendation
- **Moderate confidence:** It is likely that the evidence is a reasonable representation of the recommendation
- **Low/Very low confidence:** It is possible that the evidence is a reasonable representation of the recommendation. Where there is low confidence in the evidence, recommendations are listed as Consensus-based recommendations (see below).

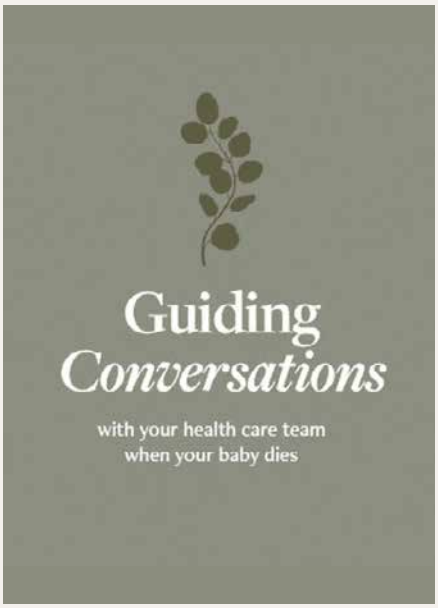
Consensus-based recommendations (CBR) were formulated by the Guideline Development Committee and Expert Working Groups where there was low confidence in the evidence or evidence was limited or lacking. These recommendations are based on expert opinion and consensus for best practice.

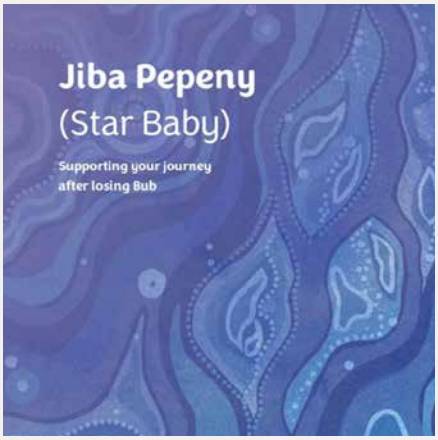
See *Executive summary* for summary of recommendations.

Parent versions of the guideline

Guiding Conversations

Guiding Conversations is a companion resource to this guideline and is designed to support parents and assist healthcare professionals as they navigate difficult conversations and decisions around the time of a baby's death. This parent version of the guideline gives parents access to evidence-based information about care around stillbirth and neonatal death in an appropriate and sensitive way. *Guiding Conversations* is based on extensive consultation with parents and healthcare professionals and follows established processes for developing parent-centred information, such as discussion prompts to enhance parent-centred decision making.





Jiba Pepeny (Star Baby) for Aboriginal people

Jiba Pepeny is a resource made by Aboriginal people for Aboriginal people. As Aboriginal people, we sadly have higher rates of bubs born sleeping than our non-Indigenous friends.

We know as Aboriginal people, we do best when we are together. Whether that is in celebration and joy, or hard times and grief. We know supporting and being there for each other, with our Aboriginal ways of knowing, being and doing is what gets us through our grief and pain, and what supports us healing.

This resource is to help Aboriginal people through the Sorry Business of losing their bub.

Scan here to access the parent versions of the guideline:

Glossary and abbreviations

Aboriginal and Torres Strait Islander peoples	A person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which they live. We acknowledge that some groups prefer the term 'First Nations' or 'First Australians' people to acknowledge Aboriginal and Torres Strait Islander people as the traditional custodians of this land.[39]
ACOG	American College of Obstetricians and Gynecologists
antenatal	Before birth; pregnancy; prenatal.
anticipatory grief	Anticipatory grief, also referred to as anticipatory loss or preparatory grief, is the distress a person may feel in the days, months or even years before the death of a loved one or other impending loss.
anxiety	Excessive worry and feelings of apprehension.
anxiety disorder	Anxiety disorders are a cluster of mental disorders characterised by significant and uncontrollable feelings of anxiety and feelings such that a person's social, occupational, and personal function are significantly impaired.
case-control study	Case-control studies are used to evaluate multiple risk factors associated with a particular disease or outcome. They are particularly useful when the condition is rare.
chromosome microarray (CMA)	A chromosome microarray (also known as a molecular karyotype) is a diagnostic tool that is used to identify genetic causes of illness and developmental problems. It is used to quantify the number of copies of thousands of segments of DNA simultaneously.
confidence intervals (95% CI)	A range of values about which there is a 95% chance that it includes the true value. For example, if the stillbirth rate is 5.4 per 1,000 total births and the 95% confidence interval is 5.3 to 5.5 per 1,000 total births, there is a 95% chance that the actual stillbirth rate lies between 5.3 and 5.5 per 1,000 total births.
congenital anomaly	A physical malformation, chromosomal disorder or metabolic abnormality that is present at birth.
continuum of care	A coordinated and integrated approach to care that tracks an individual during and after the time they are under the care of a maternal and newborn service. For perinatal loss care, this may start at preconception.
cultural, religious and/or spiritual considerations	Cultural beliefs, practices, and customs that healthcare professionals should consider when providing individualised care including, supporting shared decision making and the social and emotional wellbeing of parents and families/whānau. This includes religious and spiritual beliefs, practices, and customs.
cultural safety	The concept of cultural safety originated in response to the harmful effects of colonisation and the ongoing legacy of colonisation on the health and healthcare of Māori people – in particular in mainstream healthcare services. In Australia, for the purpose of developing a monitoring framework for Aboriginal and Torres Strait Islander health, cultural safety is defined with reference to the experience of the Indigenous healthcare consumer, of the care they are given, their ability to access services and to raise concerns.

	Essential features of cultural safety include an understanding of one's culture; an acknowledgment of difference; and a requirement that caregivers are actively mindful and respectful of this difference; and the ability to recognise, address and prevent racism. The presence or absence of cultural safety is determined by the experience of the care recipient and is not defined by the caregiver.
depression	Persistent feelings of sadness, hopelessness, and worthlessness, as well as loss of interest in previously pleasurable activities.
designated healthcare professional	A dedicated role within a maternal and newborn service with responsibility for ensuring a coordinated approach to care. This could be a social worker, counsellor, Aboriginal health practitioner, or midwife.
disenfranchised grief	Grief that society (or some element of it) limits, does not expect, or may not allow a person to express. Disenfranchised grief may isolate the bereaved individual from others and thus impede recovery.[40]
evidence	Data collected from research studies that helps answer a research question. Evidence may be synthesised from a body of work about a research question.
evidence-based recommendation (EBR)	A recommendation formulated after a systematic review of the evidence, with a clear linkage from the evidence base to the recommendation using GRADE methods.
family	Family refers to anyone who is identified by the parents as family, including siblings and grandparents.
fetal	In this guideline, the term fetal refers to an unborn baby of any gestation.
fetal death	Death of a baby before birth. The term is often used synonymously with stillbirth
fetal growth restriction (FGR)	FGR is often used interchangeably with 'small for gestational age' (SGA). SGA is defined as a baby with antenatal ultrasound biometry assessment less than the 10th centile for gestational age according to population-based birthweight centiles. FGR strictly refers to babies who have not reached their growth potential during pregnancy. They are frequently but not always SGA.
flow cytometry	A widely used, laser-based technique for analysing the expression of cell surface and intracellular molecules.
genome sequencing	A scientific test that can help identify the cause of health and developmental problems. In many cases, clinical exome sequencing or whole genome sequencing is used to seek answers where other testing has failed to find a cause.
GRADE	Grading of Recommendations Assessment, Development and Evaluation
guideline	Guidance documents containing recommendations based on the best available evidence, developed by a multidisciplinary team, and informed by experts, consumers, and other individuals with an interest in the guideline.
healthcare professional	All those who provide health care and related medical services to bereaved parents and family/whānau, including doctors, nurses, Aboriginal health workers and allied health professionals.
Indigenous	Refers to Aboriginal and Torres Strait Islander people and Māori people.

institutional racism	Embedding of practices, policies or processes within systems or institutions that maintain and reproduce avoidable and unfair inequalities.
intrauterine fetal death (IUFD)	Death of a baby in utero after 20 weeks' gestation or weighing at least 400g at birth. See stillbirth.
Kleihauer–Betke	A blood test performed on the mother's blood to identify whether substantial bleeding has occurred from the unborn baby into the mother's circulation.
life-limiting condition	An incurable illness that is likely to cause death.
low- and middle-income country settings	The World Bank classifies economies for analytical purposes into four income groups: low, lower-middle, upper-middle, and high income. Definitions for the 2024 fiscal year, calculated using the World Bank Atlas method, based on gross national income (GNI) per capita in 2022, are: • low-income economies: GNI of US$1,135 or less • lower middle-income economies: GNI between US$1,136 and US$4,465 • upper middle-income economies: GNI between US$4,466 and US$13,845 • high-income economies: GNI of US$13,846 or more.[41]
Māori	We refer to Māori as the Indigenous people of Aotearoa New Zealand. We acknowledge language, customary practices, and whānau inclusivity.[42]
maternal and newborn services	For the purposes of this guideline, we use maternal and newborn services to refer to primary care, obstetric and midwifery practice, and public and private hospitals. This includes interfaces between hospital-based services and the community and the longer-term support needs of parents and families/whānau.
mental health	A state of mental wellbeing that enables people to cope with the stresses of life, realise their abilities, learn well and work well, and contribute to their community.[43]
microaggression	Commonplace verbal, behavioural or environmental slights, whether intentional or unintentional, that communicate hostile, derogatory, or negative attitudes toward stigmatised or culturally marginalised groups.
minimally invasive tissue sampling (MITS)	A postmortem procedure for obtaining samples from key organs and body fluids, using biopsy needles. Samples are subsequently analysed using histopathological and microbiological methods. MITS may be used where autopsy is not available or unacceptable to parents as part of a less invasive investigation protocol in low- and middle-income country settings.
multidisciplinary team	Teams that bring together relevant professionals and practitioners with expertise across care disciplines, which can be an effective means to encourage better coordination of their work.
National Stillbirth Action and Implementation Plan (The Plan)	The first national plan to strategically address the issue of stillbirth in Australia (referred to in this guideline as The Plan). The Plan is funded by the Australian Government Department of Health and Aged Care and published in December 2020. The primary goal is to reduce stillbirth rates in Australia by 20% or more within the five years from publication of the Plan.

neonatal death	The death of a live born baby in the first 28 days of life. For statistical purposes, neonatal death is defined as 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.
NHMRC	National Health and Medical Research Council
perinatal full autopsy	A specialist medical examination undertaken following stillbirth or neonatal death, including external examination, examination of all the internal organs (usually via two or more incisions), examining small samples of tissue under a microscope, medical photographs, and other tests such as genetic investigations. Tests may also be done for infection and other possible teratogens, causes of death or complications. The placenta will usually also be examined.
perinatal limited autopsy	A limited autopsy involves only the examination of those organs specified on the autopsy consent and includes where tissue may be obtained from the baby for examination for suspected abnormalities.
perinatal loss	A term that encompasses all pregnancy loss including early pregnancy loss/ miscarriage (including ectopic or molar pregnancy) before 20 weeks' gestation, stillbirth, and neonatal deaths. This guideline uses this term to specify care of bereaved parents and families in maternal and newborn care settings.
perinatal mortality audit	A process to document the medical causes of each death and contributing systemic failures to identify solutions and actions. It is not a solution. It is a systematic way of improving quality of care through collecting and analysing data, linking solutions, and ensuring accountability for changes in care.
perinatal palliative care	Perinatal palliative care is a holistic multidisciplinary model of care for both baby and family in the event of a perinatal diagnosis of a life-limiting condition. It aims to provide optimal symptom control and end-of-life care to the baby as well as specialised support to families from diagnosis through to birth, death, and bereavement.[44]
perinatal pathologist	Pathologist with specialist professional training in examining tissues of pregnancy (placenta, embryo, fetal tissue) to identify cause of death during the perinatal period. Perinatal pathologists are also trained in performing autopsies to investigate causes of neonate death.
postmortem	Occurring after death. While often used synonymously with autopsy, postmortem examination/investigation may or may not include an autopsy.
post-traumatic stress disorder (PTSD)	PTSD is a treatable anxiety disorder. It happens when fear, anxiety and memories of a traumatic event do not go away. The feelings last for a long time and interfere with how people cope with everyday life.
pre-eclampsia	Pre-eclampsia is one of the more common complications of pregnancy and can happen at any time during the second half of pregnancy or the first few days after the birth. The signs of pre-eclampsia are high blood pressure, protein in urine and sudden excessive swelling of the face, hands, and feet. Sudden blurred vision is also a symptom. It is also possible to have preeclampsia without having any symptoms at all.
PSANZ	Perinatal Society of Australia and New Zealand

RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCOG	Royal College of Obstetricians and Gynaecologists (United Kingdom)
small for gestational age (SGA)	A baby with a birthweight lower than the 10th centile using population-based birthweight centiles.
Sorry Business	In Australia, Aboriginal and Torres Strait Islander peoples refer to grief, loss, and the healing process as Sorry Business. Stillbirth is referred to as ‘a Sorry Business baby’.
stillbirth	Birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400g or more birthweight.
Stillbirth CRE	NHMRC Centre of Research Excellence in Stillbirth
sudden unexpected death in infancy (SUDI)	Sudden and unexpected death of a live born baby, where a cause of death cannot be identified.
systematic review	A systematic review collates all empirical evidence that fits pre-specified eligibility criteria to answer a specific research question. The process entails explicit, systematic methods that are selected with a view to minimising bias, to provide more reliable findings from which conclusions can be drawn and decisions made.
teratogens	A chemical that increases the occurrence of structural or functional abnormalities in neonates if administered to either parent before conception, to the mother during pregnancy, or directly to the developing baby.
termination of pregnancy for medical reasons	When a pregnancy is terminated due to a chromosomal, genetic, or structural anomaly in the baby, or where continuing the pregnancy would risk the health or life of the mother.
whānau	Refers to Māori extended family or family group and is the primary economic unit of traditional Māori society. In the modern context the term is sometimes used to include friends who may not have kinship ties to other members.[42]

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Membership of the Guideline Development Committee and Expert Working Groups

Membership of the Care Around Stillbirth and Neonatal Death Clinical Practice Guideline Development Committee (2021–2023)

We gratefully acknowledge the contribution of all members of our committees and expert working groups (EWG). We also acknowledge the authors of previous editions of this guideline.

The group was comprised of multidisciplinary healthcare professionals from across Australia and Aotearoa New Zealand including professional colleges and organisations, and parent representatives from parent support organisations. Members of the guideline committee and working groups have also been supported by their host institutions to enable participation.

Name	Discipline/role	Representation	Jurisdiction, Country	Role
Professor Vicki Flenady	Perinatal epidemiology	Stillbirth CRE	QLD, Australia	Guideline Development Committee co-chair Chair of Expert Working Groups
Professor Adrienne Gordon	Neonatologist	University of Sydney Royal Prince Alfred Hospital	NSW, Australia	Guideline Development Committee co-chair Reviewer of guideline, technical reports, and recommendations Member of Perinatal Palliative Care Expert Working Group
Dr Anneka Bowman	Researcher: Stillbirth risk and Aboriginal and Torres Strait Islander family health	Aboriginal Communities and Families Health Research Alliance (ACRA) South Australian Health and Medical Research Institute (SAHMRI) Perinatal Society of Australia and New Zealand (PSANZ)	SA, Australia	Lead methodologist Including contribution to: literature search and screening; data extraction; appraisal of literature; synthesis of evidence and GRADE of recommendations; drafting recommendations and guideline content.
Associate Professor Fran Boyle	Social scientist and bereaved parent	Institute for Social Science Research, University of Queensland	QLD, Australia	Reviewer of guideline, technical reports, and recommendations

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Dr Siobhan Loughnan	Researcher: Perinatal psychology	Stillbirth CRE Perinatal Society of Australia and New Zealand (PSANZ)	QLD, Australia	Co-lead of the Technical Working Group; Lead writer; Co-Chair of Expert Working Groups
Keren Ludski	Parent representative, CEO Red Nose	Red Nose	VIC, Australia	Reviewer of guideline, technical reports, and recommendations
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Kelsey Sutton (March 2022 - July 2023)	Policy	Department of Health and Aged Care	National, Australia	Reviewer of guideline, technical reports, and recommendations
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Technical Working Group membership

This group was coordinated by the Centre of Research Excellence in Stillbirth (Stillbirth CRE) and consisted of a multidisciplinary team with expertise in systematic review and evidence synthesis. Special thanks to Dr Michelle Carty, Natasha Cocker, Dr Rupesh Gautam, Dr Sarah Henry, Lina Jalloub, Ann Lancaster, Dr Harriet Lawford, Dr Jessica Sexton, Megan Weller, and Dr Aleena Wojcieszek for their contribution and support of the Technical Working Group in preparation of this edition.

Special acknowledgement and thanks to Christie Brewster for graphic design and to Jenny Ramson for technical editing of this edition.

Name	Discipline/role	Representation	Primary role
Dr Siobhan Loughnan	Researcher: Perinatal psychology	Stillbirth CRE, QLD, Australia Perinatal Society of Australia and New Zealand (PSANZ)	Co-lead; Lead writer Including contribution to: literature screening; data extraction; appraisal of literature; synthesis of evidence and recommendations; writing guideline content.
Professor Vicki Flenady	Researcher: Perinatal epidemiology	Stillbirth CRE, QLD, Australia	Co-lead Including contribution to: literature screening; data extraction; appraisal of literature; synthesis of evidence and recommendations; writing guideline content.
Dr Anneka Bowman	Researcher: Stillbirth risk and Aboriginal and Torres Strait Islander family health	Aboriginal Communities and Families Health Research Alliance (ACRA), SA, Australia	Lead methodologist Including contribution to: literature search and screening; data extraction; appraisal of literature; synthesis of evidence and

		South Australian Health and Medical Research Institute (SAHMRI) Perinatal Society of Australia and New Zealand (PSANZ)	GRADE of recommendations; drafting recommendations and guideline content.
Professor Philippa Middleton	Researcher: Implementation science	Stillbirth CRE, SA, Australia South Australian Health and Medical Research Institute (SAHMRI) Perinatal Society of Australia and New Zealand (PSANZ) Aboriginal Communities and Families Health Research Alliance (ACRA)	Methodology support Including contribution to: literature screening; data extraction; appraisal of literature and GRADE of recommendations; synthesis of evidence; drafting recommendations and guideline content.
Dr Chrissie Astell	Researcher: Perinatal science	Stillbirth CRE, QLD, Australia	Including contribution to: literature screening; appraisal of literature; synthesis of evidence; drafting recommendations and guideline content for audit and classification.
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Aditi Lohan	Bereaved parent and Researcher: Perinatal care	Stillbirth CRE Institute for Social Science Research, University of Queensland, QLD, Australia	Including contribution to: literature screening; appraisal of literature and GRADE of recommendations; synthesis of evidence; drafting recommendations and guideline content.
Shannon Loughnan	Physiotherapist and Researcher: Women's Health	Bathurst Physiotherapy and Sports Injuries Clinic; Bathurst Private Hospital, NSW, Australia	Including contribution to: literature screening; appraisal of literature.

Dr Tania Marsden	Researcher: Stillbirth investigations; Pathology	Stillbirth CRE Eastern Health, VIC, Australia	Including contribution to: synthesis of evidence; drafting recommendations and guideline content for investigations for perinatal death.
Grace McBride	Researcher: Lactation pharmacology	South Australian Health and Medical Research Institute (SAHMRI), SA, Australia	Including contribution to: literature screening; appraisal of literature.
Elahe Nikoohard Salehi	Researcher: Social science	Stillbirth CRE, QLD, Australia Institute for Social Science Research, The University of Queensland, QLD, Australia	Including contribution to: literature screening; appraisal of literature; grey literature
Laura Singline	Researcher: Social science	Stillbirth CRE, QLD, Australia	Including contribution to: literature screening; appraisal of literature; synthesis of evidence; drafting recommendations and guideline content.
Jacinda Wilson	Researcher: Behavioural science	Stillbirth CRE, QLD, Australia	Including contribution to: literature screening; appraisal of literature; synthesis of evidence; drafting recommendations and guideline content; technical editing.

Expert Working Group Membership

Name	Discipline/ role	Representation	Jurisdiction, Country	Role
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Kassia Beetham	Bereaved parent Exercise physiology and pregnancy researcher	Australian Catholic University	QLD, Australia	Consulted to review guideline and draft recommendations
Renee Castelluccio	Bereaved parent, Research Nurse	NA	VIC, Australia	Consulted to review guideline and recommendations

Dr Adrian Charles	Pathologist	Health Department Western Australia	WA, Australia	Consulted to review stillbirth investigations technical report and draft recommendations
Robin Cronin	Midwifery	The University of Auckland	Aotearoa, New Zealand	Consulted to review and contribute to the guideline and recommendations
Professor Fabricio Da Silva Costa	Obstetrics and gynaecology	Gold Coast University Hospital Griffith University	QLD, Australia	Consulted to review care in subsequent pregnancies and draft recommendations
Professor Jane Dahlstrom	Pathologist	Canberra Clinical School, Australian National University	ACT, Australia	Consulted to review stillbirth investigations technical report and draft recommendations
Dr Lilian Downie	Geneticist	Mercy Hospital for Women Murdoch Children's Research Institute	VIC, Australia	Consulted to review stillbirth investigations technical report and draft recommendations
Dr Fatima El-Assaad	Bereaved parent Medical researcher	University of New South Wales	NSW, Australia	Consulted to review guideline
Associate Professor Carolyn Elloway	Geneticist	University of Sydney	NSW, Australia	Consulted to review stillbirth investigations technical report and draft recommendations
Associate Prof Lisa Hui	Maternal fetal medicine specialist	Mercy Hospital for Women Murdoch Children's Research Institute	VIC, Australia	Consulted to review stillbirth investigations technical report and draft recommendations
Professor Alison Kent	Neonatologist	The Newborn & paediatric Emergency Transport Service (NETS NSW) Women's Healthcare and Children's Healthcare Australasia	SA, Australia	Consulted to review Neonatal investigations and Palliative Care technical report and draft recommendations
Professor Yee Khong	Pathologist	University of Adelaide	SA, Australia	Consulted to review stillbirth investigations technical report and

		SA Pathology		draft recommendations
Dr Christoph Lehner	Maternal fetal medicine specialist	Royal Australian and New Zealand College of Obstetrics and Gynaecologists Royal Brisbane Women's Hospital, Brisbane	QLD, Australia	Consulted to review stillbirth investigations technical report and draft recommendations
Professor Helen Liley	Neonatologist	Mater Mothers' Hospital	QLD, Australia	Consulted to review Neonatal investigations technical report and draft recommendations
Dr Admire Matsika	Anatomical pathologist	Mater Hospital	QLD, Australia	Consulted to review stillbirth investigations technical report and draft recommendations
Dr Elizabeth McCarthy	Maternal fetal medicine specialist	Mercy Hospital for Women	VIC, Australia	Consulted to review care in subsequent pregnancies and draft recommendations
Dr Scott Petersen	Maternal fetal medicine specialist	Mater Mothers' Hospital	QLD, Australia	Consulted to review stillbirth investigations technical report and draft recommendations
Emma Porter	Perinatal loss - Clinical midwifery consultant	Mater Mothers' Hospital	QLD, Australia	Consulted to review perinatal loss care, perinatal palliative care and draft recommendations
Dr Anand Vasudevan	Geneticist	Royal Women's Hospital	VIC, Australia	Consulted to review stillbirth investigations technical report and draft recommendations

Future directions

In summarising the evidence for the guideline gaps were identified and are summarised here as potential research questions. Future research directions identified in published studies are cited accordingly.

Monitoring progress and evaluation of the guideline

National implementation of the guideline across public and private health services is needed to reduce variation in care received by parents and families/whānau. Monitoring implementation, customising and adapting services, and evaluating outcomes and benefits is crucial.

- What are the barriers and enablers to dissemination and implementation of the guideline in Australia and Aotearoa New Zealand?
- How can a national approach to implementation and monitoring be achieved to ensure the guideline is meeting its objectives and for outcomes to inform future updates?

Perinatal loss care

- How can support from healthcare professionals be routinely offered to parents and their families/whānau when their baby has died or is likely to die?
- What is the effectiveness of bereavement counselling or other interventions for bereaved parents and families/whānau?
- What is the prevalence of adverse mental health outcomes among parents and how can intimate partner relationships be supported and maintained?
- How can relationships among family/whānau (such as siblings and grandparents of a stillborn or deceased baby) be supported and maintained?
- What are the specific considerations of perinatal loss care for termination of pregnancy for medical reasons?
- What are the specific care and support needs of parents who experience early pregnancy loss (before 20 weeks gestation age)?

Birth planning after stillbirth or diagnosis of a life limiting condition

- How can a shared decision-making approach be used to support decisions around method and time to birth following diagnosis of stillbirth?
- Is a water birth an option after the diagnosis of stillbirth or a life-limiting condition?
- What are the most effective (and safe) interventions (for example misoprostol) for induction of labour for stillbirth?
- What are the safest labour and birthing regimens following diagnosis of stillbirth for women with uterine scars?
- What are the most effective methods of intrapartum pain relief for women birthing a stillborn baby?
- What are the optimal pharmacological and non-pharmacological approaches to suppress lactation after stillbirth?

Cultural diversity

- What is the benefit of integrated trauma-informed care for bereaved parents and families/whānau particularly women from refugee backgrounds?
- How do Aboriginal and Torres Strait Islander and Māori parents and family/whānau want to be supported when they suffer the loss of a baby?
- How can Aboriginal and Torres Strait Islander and Māori frameworks of health and wellbeing be used to improve healthcare services for bereaved indigenous parents and family/whānau?
- What are the barriers to care experienced by parents from migrant and/or refugee backgrounds? How can language and information barriers be addressed? How can an interpreter's role in the care team be improved?

Social and emotional support for perinatal grief

- What are the long-term effects of perinatal loss on parent and family/whānau?
- What factors facilitate posttraumatic growth in bereaved parents and family members following a perinatal death?
- What are the intergenerational impacts of perinatal loss?
- What types of support bring meaning and healing to bereaved families/whānau?
- What types of support are not effective and for whom?
- What is the best national approach to ensure parents are connected with community-based supports following hospital discharge?
- What perinatal grief education is included in multidisciplinary professional education programs and training opportunities?

Perinatal palliative care

- How can better access to and engagement with perinatal palliative care be provided?
- Are there terms preferred by parents and families/whānau for palliative care (for example 'perinatal hospice' or 'comfort care')?
- How can cultural beliefs and values be properly integrated in decision making throughout perinatal palliative care?

Care in subsequent pregnancies

- Following perinatal death, is a pre-conception consultation effective in understanding subsequent pregnancy risks and informing subsequent pregnancy care?
- How can coordinated care in subsequent pregnancies be strengthened across all sectors of health and community services?
- How can healthcare professionals support women and families to manage mixed emotions including anxiety, hope, and grief?[1]
- How can healthcare professionals develop rapport and effective communication with parents in pregnancies after perinatal death?
- Is a specialised pregnancy loss clinic more effective than regular antenatal care?
- What is the optimal frequency of ultrasound assessment of fetal growth in pregnancy after late stillbirth?

- What is the role of aspirin to reduce adverse outcomes for women in a subsequent pregnancy?
- What are the risks of stillbirth recurrence in relation to gestational age?[2]

Understanding through investigations and audit why a baby died

Understanding causal pathways

- What are the potential causal mechanisms of maternal BMI and fetal death?
- Can induction of labour in gestational week 39 for women with obesity reduce both caesarean section and stillbirth? [3]
- What effective screening strategies can identify women at risk for fetal death?
- What interventions are effective in preventing fetal death (for example screening for gestational diabetes mellitus in particular populations)?
- What effective antenatal strategies are there for recognising fetal growth restriction and preventing fetal death?
- What is the association between maternal microbiome and pregnancy loss?
- What is the best validation and clinical evaluation of risk prediction models for stillbirth?
- Why do some babies with a genetic disorder die in utero, while other babies with the same genetic disorder are born alive?
- Why are there more stillbirths among women with low socio-economic status, and what are the underlying pathways causing stillbirth?
- What are the causes of perinatal death for Aboriginal and Torres Strait Islander families?

Investigations for perinatal death

- How informative is meconium sampling for detecting maternal drug use?
- What is the role of gestational diabetes mellitus screening after intrauterine fetal death?
- What are the most valuable components of investigations for determining causes of perinatal deaths according to different clinical characteristics?
- What is the role of minimally invasive autopsy options using MRI according to different clinical characteristics?
- How can interpretation of the impact of placental lesions be understood and improved, including consensus on definitions of placental lesions?
- Which preventative and/or intervention strategies are there for placental lesions such as villitis?
- Under which circumstances should postmortem MRI be used?
- Does a sequential approach to investigations using less invasive investigations such as clinical information, placental pathology, cytogenetics, and MRI prior to decision for autopsy reduce the need for autopsy while maintaining diagnostic accuracy?
- Does provision of a comprehensive placental reporting form assist in accurate assignment of cause of death?
- What should a plain language summary of a perinatal autopsy contain?
- What is the appropriate timeframe for perinatal autopsy results to be made available?

- What format should be used to summarise the findings of the perinatal mortality committee review of the death for parents?
- *Rural and remote considerations:* How can health services and systems facilitate communication between healthcare professionals in rural and remote facilities and pathologists and geneticists at tertiary centres? How can transport to healthcare facilities be facilitated/improved?

Genomics

- How do changes in fetal and parental DNA impact stillbirth and perinatal death?
- Which difficult-to-diagnose fetal or maternal infections contribute to stillbirth?
- What is the role of genetics in perinatal death?
- How can exome sequencing be used or optimised to increase diagnostic value?
- How can ultra-rapid genomic testing of critically ill babies deliver higher diagnostic rates?

Perinatal mortality audit

- What are optimal ways to engage and support parents and families/whānau in the perinatal mortality audit process?
- What are effective ways to support healthcare professionals in engaging in perinatal mortality reviews to improve clinical care?
- How can data collection systems for perinatal mortality reporting be improved?
- How can a national perinatal mortality audit program be implemented in Australia and Aotearoa New Zealand?

Classification systems

- How can consensus be reached on using one perinatal classification system in high-income countries?
- Which perinatal classification systems perform best?

Organisational enablers and quality improvement processes

- What are the core perinatal loss care training and education requirements for healthcare professionals and services in Australia and Aotearoa New Zealand?
- What are the core elements of education programs for care around stillbirth and neonatal death training programs in Australia and Aotearoa New Zealand? What are the mandatory elements for cultural safety and trauma-informed care training?
- What is the best approach to ensure that parents' experiences of care drive quality improvement?
- What is the prevalence of secondary traumatic stress (compassion fatigue) and burnout in healthcare professionals caring for bereaved parents and families/whānau? Does this differ between professions and services?
- How can health services provide optimal support to healthcare professionals caring for families/whānau who experience perinatal death? What is the role of professional and peer support? What is the role of communities of practice in this field?
- What levels of perinatal loss training are provided to medical, nursing, midwifery, and allied health undergraduates? What is the role of peer facilitated bereavement training?

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Plain language brief summary

Brief summary

The death of a baby in pregnancy or soon after birth is highly distressing for parents and families/whānau. It is vital that parents receive the best possible care. This 2024 update of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline* for Australia and Aotearoa New Zealand helps healthcare professionals provide that care. The guideline is for healthcare professionals in maternal and newborn services, including hospitals and community services. It contains the latest evidence about the best possible care for parents and families/whānau around stillbirth, newborn death, and termination of pregnancy when there is a life-limiting condition for baby or mother.

Care begins at diagnosis, continues through pregnancy to birth, postnatal care and longer-term support including next pregnancies. Six core goals for respectful and supportive care of bereaved parents and families/whānau underpin the guideline. These are:

- good communication defined by empathy and compassion
- recognition of parenthood and care practices that respect and honour the baby and affirm identity as a parent
- cultural safety where healthcare professionals respond to the diverse needs, beliefs, and practices that are important to parents and families/whānau
- effective support in the immediate and longer-term that includes physical, emotional, and social aspects
- parent-centred decision making where parents receive support and information to be involved in decisions and to explore different options
- organisational enablers where organisations support healthcare professionals to provide the best possible care.

The guideline sets out clear recommendations for:

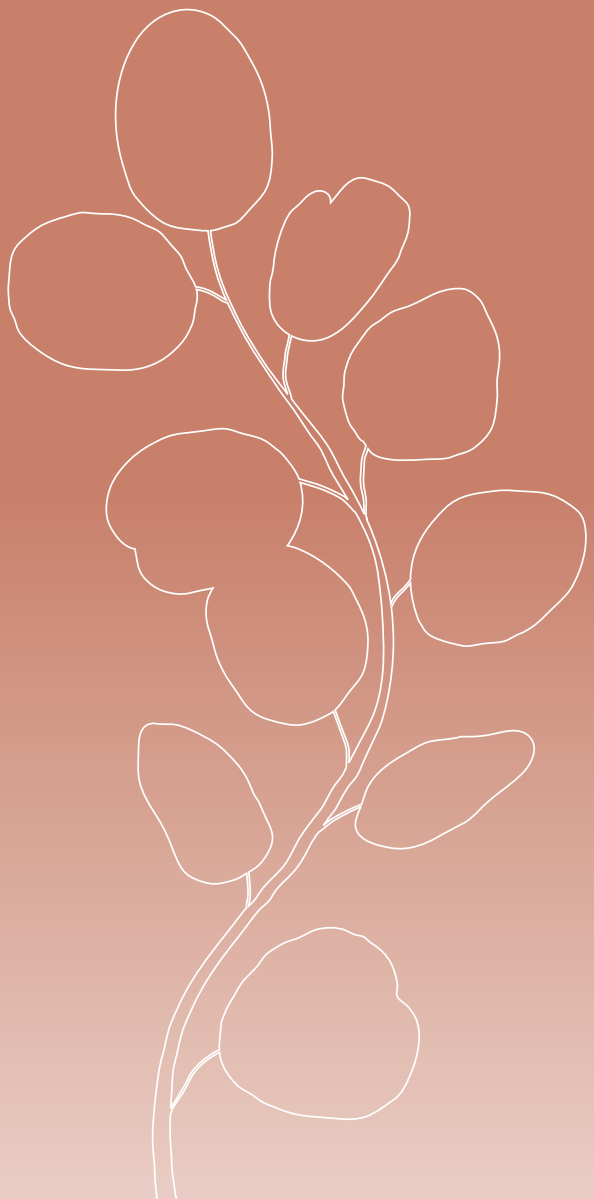
- perinatal loss care that responds to the individual needs of parents and families/whānau and supports their decision-making
- perinatal palliative care that supports the needs of parents whose baby has a life-limiting condition
- investigations for perinatal death to help parents understand why their baby died, including supporting parents to make decisions about the type of investigation that is right for them and their baby
- perinatal mortality audit including classifications to provide information for prevention and future care in maternal and newborn services
- care in subsequent pregnancies that recognises the concerns many parents may have
- organisational responsibilities to support a service-wide approach to best practice care that includes training and support for all staff.

Resources for putting the recommendations in place include a parent version of the guideline, guidance for audit and research activities, and information to support decisions about investigations. The Centre of Research Excellence in Stillbirth and Perinatal Society of Australia and New Zealand developed the guideline with extensive input from bereaved parents, healthcare professionals, researchers, and policy makers.

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline



Section 2: Approach to care

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

Stillbirth CENTRE OF RESEARCH EXCELLENCE

PERINATAL SOCIETY of Australia & New Zealand PSANZ

Background

The death of a baby during pregnancy or soon after birth has long-lasting social and emotional consequences for parents and families/whānau, and wide-ranging economic impacts on health systems and society both globally and in Australia and Aotearoa New Zealand.[1,2] The quality of care that parents and family/whānau receive around the time that their baby dies is a major contributor to immediate and long-term wellbeing, including into subsequent pregnancies.[3,4]

This section of the guideline outlines an optimal approach to care around stillbirth and neonatal death. This includes an organisational framework that sets out six core goals of care, which are interrelated and relevant to bereaved parents and family/whānau. Comprehensive care in the context of perinatal loss is multifaceted and interdisciplinary.[5,6] This framework contributes to the overall goals and experience of care.[8]

> **"When my baby died, I had no idea what I needed to know, or what was possible. It was such an overwhelming time. What I really needed was to know the options I had so that we could make decisions that were right for us."**
>
> Parent quote from the *Guiding Conversations* booklet.

Objective

This section aims to assist frontline healthcare professionals to provide high quality and comprehensive care and support to parents and family/whānau following the death of a baby before or soon after birth.

The evidence synthesis of this section includes care of parents who have experienced stillbirth or neonatal death, including stillbirths and neonatal deaths following termination of pregnancy.

This guideline acknowledges all parents and family/whānau who have experienced the death of a baby during pregnancy or soon after birth including early pregnancy loss. Implementation of these recommendations will ensure high quality consistent care for all parents and family/whānau who are cared for in maternal or newborn settings, regardless of when or where their baby dies.

A note about terminology

This guideline uses parent-centred language that is intended to be inclusive of all affected by loss. We use the term 'woman' throughout the guideline to refer to the person who is pregnant and gives birth.[9] We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth identify as a woman. The term 'parent' is used to refer to expectant and bereaved mothers, fathers, and partners. It is important to recognise individuals who identify themselves as parents. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents.[10]

This guideline uses 'baby' when referring to stillbirth, neonatal death because these terms are preferred by many bereaved parents. Terms such as 'fetus' may add to parents' distress because this language denies personhood[11] and is inconsistent with recognition of parenthood that is crucial to providing respectful and supportive care.

This guideline uses 'healthcare professional' to denote all those working with bereaved parents and family/whānau (see Glossary).

Framework for care around stillbirth and neonatal death

This framework (Figure 1) sets out the core goals of best practice care following the death of a baby in maternal and newborn care settings. Each goal of care is associated with specific practices and actions that are reflected in the guideline recommendations.

Good communication involves finding the right words and approaches, and paying attention to what is said and how it is said, when caring for bereaved parents and families/whānau. Good communication involves empathic and compassionate responses, appropriate non-verbal communication, and respect for privacy. Quiet and private physical spaces and surroundings are essential.

Parent-centred decision making recognises that decisions faced by parents around the time of perinatal loss are highly sensitive to personal preferences and values and that there is rarely one 'right' decision.[8] Providing parents with the support and information needed to enable them to be involved in decisions to the extent they choose, and to explore different options is essential. Active partnership between parents and healthcare professionals is vital to keep parents' preferences and values at the centre of care.

Recognition of parenthood encompasses many actions and words that affirm for parents their identity as parents of their baby. This begins by acknowledging the baby, the relationship that parents may already have established with the baby, and the enormity of the loss that has occurred. Caring for the baby with respect, and supporting parents to engage in caregiving activities and memory making are central aspects of recognition of parenthood. Care practices that honour their baby and recognise parenthood are central to the care of parents.[21,27,73]

Effective support addresses the immediate and longer-term physical, emotional, social and practical needs of parents and families/whānau who have experienced the birth and death of a baby.[1] Parents require immediate support as they face the initial stage of their grief and then pathways to support in their community once they have left hospital.[1]

Organisational enablers are the conditions and structures needed to support and enable healthcare professionals to provide high quality care to parents and families/whānau.[1] Provision of care is a responsibility shared between the organisation and individual healthcare professionals.

Cultural safety requires healthcare professionals to acknowledge and address beliefs and practices important to parents and families/whānau. Cultural safety is particularly significant for Aboriginal and Torres Strait Islander and Māori peoples but is relevant to all parents to enable them to feel safe in their interactions with the health system. Care practices must be responsive to the diverse needs of parents including those from migrant and refugee groups, spiritual and faith groups, the LGBTQIA+ community and people with disabilities.[20,71]

Approach to care

The quality of care that parents and family/whānau receive can have immediate and long-lasting consequences and extend into subsequent pregnancies and beyond.[3,4] Respectful, supportive and culturally responsive care should be provided to all parents and family/whānau who experience perinatal loss, regardless of whether the loss occurs during pregnancy or after birth. Optimal perinatal loss care is based on the needs of parents rather than the type of loss.[12]

Healthcare professionals play a central role across the continuum of care from the moment of bad news, through birth and postpartum, and into future pregnancies.[6]

Best practice care around stillbirth and neonatal death should encompass a continuum of care and incorporate planning and parent-centred decision making. Where possible, parents should be cared for by a multidisciplinary team of healthcare professionals.[13] This may vary across the continuum of care, depending on the purpose, and can include a bereavement midwife, lead maternity carer (community-based midwife), lead healthcare professional, general practitioner, cultural, religious or spiritual advisors, bereavement counsellor,[14] as well as sonographers, radiologists,[15] and other healthcare professionals.

An individualised parent-centred approach to care planning validates the experiences of parents and family/whānau. This facilitates a seamless transition across the continuum of care, from diagnosis through to discharge and follow-up and any subsequent pregnancy.[3] Care is individualised and supportive when it responds to the needs, preferences, circumstances, and cultural context of bereaved parents and family/whānau.[16,17]

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 (for example 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.

Consensus-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).

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.

Evidence-based recommendation 2.4
Evidence quality: Moderate confidence
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.

Evidence-based recommendation 2.5
Evidence quality: Moderate confidence
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.

Caring for parents around termination of pregnancy for medical reasons

In this guideline, termination of pregnancy for medical reasons specifically refers to the experience of parents who have made the decision to have a termination of pregnancy (from 20 weeks gestational age) because of a diagnosis of an anomaly in the baby following scan findings or other antenatal test results or due to a life-threatening condition for the woman.[18] Care up to this point (including investigations, diagnosis, and the decision to terminate the pregnancy) is outside the scope of this guideline; however, we would expect that parents have received respectful high quality care and access to accurate and balanced information and support as needed to make their decision.[18]

It is important that healthcare professionals recognise the profound emotional impact and intense shock and grief experienced by parents when an anomaly in the baby is detected, with the need to then provide parents with clear and comprehensive information on anomalies, prognosis and future care plans.[19]

While the decisions faced by parents will vary according to the baby's diagnosis, all parents will require information and non-judgmental support.[20] Expressing understanding, and normalising and validating parents' decisions is critical.[19,21]

Disenfranchised grief, societal stigma, and feelings of shame and guilt are commonly reported by parents following perinatal loss and these may be even more pronounced for parents who have made the decision to terminate a pregnancy for medical reasons.[22,23] This can greatly affect parents' coping and decision making around care planning. Some parents may decide not to tell family/whānau and/or friends due to personal, cultural, religious, and/or spiritual reasons and/or fear of being judged for their decision. The emotional complexity around termination of pregnancy for medical reasons, labour and birth, and memory making requires individualised care that is nonjudgmental, empathetic, and supportive.

"When making the decision to end my baby's life the biggest judgment I felt was not loving my baby enough when in fact the decision to suffer and carry this burden myself was to save and love my baby."
Bereaved mother, Australia, 2023

Through the Unexpected is an Australian charity providing information and social and emotional resources to expectant parents and families faced with an antenatal diagnosis of an anomaly in their baby.

It is crucial that all discussions are carefully documented to ensure parents' views are acknowledged, and that sensitive decisions and discussions are not conducted repeatedly and/or unnecessarily. Healthcare professionals need to be aware of parents' wishes for confidentiality if they have chosen not to disclose their decision or details of their loss to others (such as support person, family/whānau members).

See Section 3: Perinatal loss care for best practice recommendations for parent-centred care planning around birthing in grief, including postnatal care, lactation after loss, leaving hospital and ongoing support in the community. It is essential that parents are given the choice and supported to create memories (including mementos such as photographs) with their baby. This recognises their role as parents. It is appropriate to use the word 'baby' if this is acceptable to the parents. Parents should also be asked if they have named their baby and, if so, permission should be sought to use the name. However, it is also important to be aware that some parents may not identify as parents and may choose not to create memories with their baby. In these situations, the lead from parents regarding the preferred language for their baby should be taken. For example, they may prefer the word 'fetus' over 'baby'.[11]

For parents and family/whānau who choose a perinatal palliative care approach, providing support services as early as possible maximises the time available for them to consider options and make choices including opportunities for memory making and a birth plan that is consistent with their preferences and hopes. See *Section 4: Perinatal palliative care* for best practice recommendations.

Healthcare professionals should discuss options for possible investigations (for example perinatal autopsy) with parents. See *Section 6: Investigations for perinatal death* for best practice recommendations. See the RANZCOG's *Clinical Guideline for Abortion Care: An evidence-based guideline on abortion care in Australia and Aotearoa New Zealand.*

It is important for healthcare professionals to acknowledge the difficulties faced by parents who are planning a termination for a wanted baby.[19]

"It's about being respectful of that baby in death and that family in birth. Because they're happening at the same time, in the same space. That space of these moments that you only get once."

Midwife, Aotearoa New Zealand [23]

Consensus-based recommendation 2.6
Acknowledge the specific care and support needs of parents who experience a termination of pregnancy and ensure perinatal loss care planning is across the continuum of care.

Social and emotional support for perinatal grief

Grief is an expected and normal response following the death of a baby. High levels of distress and multifaceted emotional responses are also a normal part of the grieving process for many parents and family/whānau members.[4] Many bereaved individuals will have support from their existing social networks; and some parents will find benefit in engaging with peer support or professional counselling support options.[24,25]

Perinatal loss can be associated with:

- stigma and misperceptions[2,21,26]
- self-blame for their baby's death
- feelings of failure, shame, guilt, anger, and/or isolation[2,27]
- lack of acknowledgement of their baby, the extent of their loss, and their identity as bereaved parents leading to disenfranchised grief,[28] where parents feel their grief is not legitimate or socially acceptable to others.[4,21,29]

Parents grieve the loss of their baby, as well as hopes and dreams for the future.[6]

It is essential to consider all those affected by each perinatal loss. Feelings of loss and grief are experienced by fathers/partners who also need validation and support.[30] Studies have shown men experience significant and persistent grief across all types of loss.[31,32] All fathers/partners need to be offered support immediately after the loss, and in the following months.[33] It is also important to acknowledge and validate differences in grieving between partners, which can greatly affect communication and relationships.[34]

"From the start my partner and I handled our baby's death completely differently. I thought he should be upset, but he looked like he was okay.

One of the most helpful things I read was that the biggest strain on relationships isn't that you've lost a child, but that you aren't able to accept each other's ways of grieving. Then I just thought to myself 'All right, we are not going to grieve the same way."

Parent quote from the Guiding Conversations booklet.

It is also critical to recognise and validate the impact of perinatal loss on other family/whānau members such as other children and grandparents.[35,36] Grandparents have reported experiences of a 'double grief', as they often play a significant role in supporting their children through perinatal loss, while also experiencing grief for the loss of their grandchild. Grandmothers described their experiences of pregnancy loss as an ambiguous and compounded loss, with disenfranchisement.

The quality of care and support that bereaved parents and families/whānau receive across the continuum of care directly affects their immediate and long-term wellbeing.[24,25,37] All parents and families/whānau should be offered support that is individualised and sensitive to their needs, culture, and circumstances.

It is important to avoid making assumptions about how parents will grieve or what supports they will need.[21] Providing details of sources of support at the earliest possible stage is beneficial to families/whānau who may feel a sense of isolation, especially in the early days following diagnosis.

Support and anticipatory guidance on what to expect should be offered at the time of breaking bad news and continue throughout the continuum of care.[10,38] See *Section 3: Perinatal loss care* for more information and best practice recommendations for breaking bad news.

Social support that is perceived as helpful is a significant predictor of positive bereavement outcomes.[39] Individual and group peer support has been reported as highly valued by bereaved parents and family/whānau members. Peer support can foster a sense of community and support, comfort and hope.[40,41] Bereavement support programs may also benefit family/whānau members, including grandparents and siblings.[42] There is also some evidence that family/whānau support programs can help prevent posttraumatic stress symptoms for women who experience termination of pregnancy for medical reasons.[35,36]

Support services for parents and families/whānau can often be limited or unavailable in rural regions, with long waitlists. Online and internet-based supports suit many, being readily accessible and usually providing anonymity and privacy.[43] The *Living with Loss Program (LWL)* developed by the Stillbirth CRE[44] is an evidence-based self-guided online program for parents in Australia who have experienced perinatal loss. LWL consists of flexible modules focused on normalising and validating the individual experience of grief and coping processes and is grounded in cognitive and behavioural approaches to bereavement, including mindfulness and compassion focused therapy. In a randomised controlled trial, bereaved mothers who accessed the LWL program experienced significantly lower symptoms of psychological distress at the end of the 8-week study period, compared to those in usual care.[45]

The public health model for bereavement support proposes three tiers of support according to level of need: (1) universal support, primarily provided by existing social supports (such as family/whānau, friends); (2) formal support options from the wider community for people with moderate needs; and (3) specialist support from mental health services for those identified as having complex needs.[37,46] While evidence on effective bereavement interventions is limited,[39] support should be targeted, accessible, and available across the continuum of care from the moment of bad news, through birth and postpartum, and through to any subsequent pregnancies and parenthood.

"The other thing about being supported by someone who had been through baby loss before, it showed that somehow life goes on and people can still develop and grow and maybe have other children afterwards as well. It is not like the end."[7]

"When you feel hopeless and have no idea what to do with such a devastating experience, it was good to know I have this."

Bereaved mother, LWL participant, Australia 2022.

Consensus-based recommendation 2.7
Normalise and validate parents' 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 members express grief.

Consensus-based recommendation 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.

Consensus-based recommendation 2.9
Acknowledge the grief and loss of other family/whānau members, especially grandparents and other children (siblings), and offer appropriate support options.

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.

Consensus-based recommendation 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.

Mental health considerations

The death of a baby has a profound impact on short- and long-term psychological, social, and emotional outcomes for bereaved parents.[47] Grief is an expected and normal response to the death of a baby, however the wellbeing of bereaved parents and family/whānau depends greatly on how their individual grief process is supported.

Following the death of a baby, parents are at increased risk of high levels of anxiety, depression, severe symptoms of post-traumatic stress, and prolonged grief years later,[48,49] which can extend into subsequent pregnancies and parenthood.[47,50] Risk factors for adverse mental health outcomes such as major depressive disorder, generalised anxiety disorder, and post-traumatic stress disorder (PTSD) include a history of a previous mental health diagnosis,24,25,51 limited social support, relationship difficulties and breakdown, societal stigma, and blame and isolation.[29,52-57]

Grief and depression share similar features and may be experienced simultaneously. This can complicate standard mental health screening and assessments for bereaved parents and family/whānau members.[51] It is important to be aware whether bereaved parents or family/whānau members appear to be struggling with co-occurring mental health difficulties that require referral to professional support. While each family will need individual consideration depending on their circumstances, discussion with parents may be considered appropriate around more prolonged and severe symptoms of distress, substance use, and thoughts around suicide.[58]

Grief, and sometimes depressive symptoms, are a common experience following the death of a child and should be viewed as normal.[47]

Social and emotional interventions have been found to be effective in reducing depression and anxiety among parents after perinatal loss.[59] Offers of psychological support may be valued by some parents as they imply recognition of loss, particularly to those parents at risk of disenfranchised grief.[60] In an Australian study examining the impact of bereavement services on the progression to complicated grief, 75% had a perinatal PTSD score that indicated the need for support from mental health services, with 43% meeting the criteria for complicated grief.[61] Women whose PTSD scores were in the highest quartile were most likely to access services. This requires grief training of hospital staff, and for referral to bereavement services to be offered after hospital discharge.[61] Perinatal loss also increases a woman's risk for major depressive disorder with 60–70% of women meeting diagnostic criteria for grief-related depression up to one year after their baby's death, and a further half of those women experiencing depression for at least four years post loss.[2,62] The role of family/whānau support following stillbirth can also be helpful in mediating maternal anxiety and depression,[63] with social support also often mediating to help reduce PTSD symptoms following perinatal loss.[64,65]

While not all bereaved parents will require or access formal psychological support, they all need information about the range of support options available, including professional services (such as counsellors, psychologists) with expertise in perinatal loss. It is also important to consider geographic limitations and availability and accessibility to support services for each family/whānau.[66]

> **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 (for example post-traumatic stress), particularly parents who have pre-existing mental health conditions.

Other considerations

Many circumstances can add to the complexity of parents' grief experiences and heighten the need for sensitivity and understanding from healthcare professionals.

- *Multiple births:* Parents of twins or higher order births may experience conflicting emotions when one or more of their babies die and one or more survive. This can be compounded by the surviving twin being unwell and being in neonatal intensive care. Common emotions may include guilt relating to the amount of time spent with a deceased baby, feeling torn between spending time with their living and deceased babies. Acknowledging such conflicting feelings is important, to validate both the baby who has died and the parents' grief for that child, particularly when the response of others may be to focus on the surviving baby (see *Guiding Conversations* booklet).
- *Maternal illness:* If a woman is unwell following the birth, every effort must be made to ensure appropriate and timely communication to ensure she is kept informed and involved in decision making.[67] Opportunities for the woman to have access to her baby and to delay decisions where possible need to be considered and discussed with the woman, her partner/support person and other family/whānau members as appropriate.
- *Maternal death:* While maternal death is rare in countries such as Australia and Aotearoa New Zealand, [68,69] it has an overwhelming impact on families/whānau. There is an increased incidence of previous experience of maternal death in refugee and some immigrant populations, affecting their care requirements. In the case of both maternal death and perinatal death, the impact on the remaining parent is devastating and requires expert individualised care.
- *Previous loss experiences:* Parents' responses to the death of a baby may be intensified by previous experiences of loss, including miscarriage, perinatal or child death, and difficulties conceiving.[70] Some parents may have clear ideas regarding the way in which they choose to manage the death of their baby due to previous experience. It is important for healthcare professionals to respect parents' wishes, provide appropriate support and information, and be guided by the parent's response.

- Red Nose provides specialised grief and loss support services in Australia, including support for healthcare professionals. The **Red Nose *Hospital to Home Program*** is a peer support program that provides emotional and practical support to parents for up to three months following the death of a baby.[7] Red Nose together with **SMS4Dads** provide a text-based messaging service to support bereaved fathers.
- **Bears of Hope** also provide a range of support options including professional grief counselling and peer support such as parent workshops and father-specific support weekends.
- **Miracle Babies Foundation** also have a 24/7 peer support helpline *Nurture*Line for bereaved parents following newborn loss.
- The **Pink Elephants Support Network** provides peer support programs (including Peer Support Live Chat), emotional support resources for parents following early pregnancy loss, including workplace programs to better support parents returning to work.
- The **Perinatal Loss Centre** maintains a therapist register to enhance access to counselling support across Australia.
- The **Centre for Perinatal Psychology** provides a national directory of psychologists with expertise in counselling and support around perinatal loss.
- The **Centre of Perinatal Excellence** has an online directory that can be filtered by location to show perinatal mental health services in Australia.
- **PANDA** and **Gidget Foundation** offer a range of mental health and wellbeing support options for parents in Australia.

In Aotearoa New Zealand, parents and families/whānau who experience perinatal loss can receive support from a range of support groups, organisations, and resources.

- **Whetūrangitia** is an online resource for parent information.
- **Sands New Zealand** is a nationwide parent-run network for bereaved parents that offers face-to-face support (group meetings and one-on-one) and online and print resources, as well as providing memory making services in most hospitals.
- **Baby Loss NZ** also provides memory making services.
- **Miscarriage Support** and **Miscarriage Matters** provides online resources and best practice recommendations.
- **PADA – Perinatal Anxiety and Depression Aotearoa** is an advocacy and awareness charity.
- See the **Baby Loss Directory** for more support options.

Provision of culturally responsive care

Australia and Aotearoa New Zealand have socioculturally diverse populations, and care around stillbirth and neonatal death must be culturally responsive. Some groups will have experienced extensive trauma and loss and a trauma-informed approach is essential. Healthcare professionals need awareness and understanding of different cultural, religious, and spiritual belief systems and approaches to life, birth, and death. It is also necessary for healthcare professionals to be aware of the continued negative impacts of colonisation for Indigenous peoples, in this case Aboriginal and Torres Strait Islander peoples and Māori, which result in many forms of trauma. Provision of culturally responsive and trauma-informed care can help families/whānau feel safer to express their religious, cultural, and spiritual needs, traditions, and rituals.

It is essential that care is always provided within a cultural context, acknowledging the potential cumulative experience of complex trauma (including intergenerational trauma) and existing mental health disorders, particularly complex psychological trauma.[71-73] There is limited evidence on how to provide culturally sensitive care to meet the needs of parents and family/whānau members from culturally diverse backgrounds.[71,74] However, these communities, including Aboriginal and Torres Strait Islander women, Māori women, and families from migrant and refugee backgrounds, are at greatest risk of perinatal loss.[71,75-77]

"When I was first told about Bub, everything stopped. Like time just stopped and I didn't know what they meant when they said Bub had no heartbeat."

Parent quote from the Jiba Pepeny (Star Baby) booklet.

In Australia, the *National Strategic Framework for Aboriginal and Torres Strait Islander People's Mental Health and Social and Emotional Wellbeing 2017–2023*[78] provides culturally appropriate guidance for clients, consumers, service providers, policy makers, advocates, and researchers. The nine guiding principles of the framework reflect the holistic and whole-of-life definition of health held by Aboriginal and Torres Strait Islander peoples.

In Aotearoa New Zealand there are several health and wellbeing frameworks grounded in te reo Māori (the Māori language) can provide guidance to healthcare professionals. The interpretation and application of such frameworks should be approached carefully in collaboration with Māori to avoid misinterpretation, and tokenistic application.

The *National Stillbirth Action and Implementation Plan*[79] contains two actions specific to reducing rates of stillbirth among Aboriginal and Torres Strait Islander women and among some groups of migrant and refugee women:

- ensuring culturally safe stillbirth prevention and care for Aboriginal and Torres Strait Islander women
- ensuring culturally and linguistically appropriate models for stillbirth prevention and care for migrant and refugee women.

In Aotearoa New Zealand, the Perinatal and Maternal Mortality Review Committee (PMMRC) has been working to bring attention to the inequities within the health care system that disproportionately affect Māori women. One of the four priority recommendations included in the 2022 report[69] of the PMMRC concerns the establishment of regulatory bodies to mandate cultural safety education for all individuals working across all areas of the maternity and neonatal workforce. Another recommendation asks government agencies to address the impact of structural racism.

Communication and decision making

Good communication is essential for the provision of culturally responsive and trauma-informed care. It is important to be aware of terminology and language and acknowledge that some words such as 'stillbirth' do not translate in other languages.[80] For example, in Australia, Aboriginal families refer to grief, loss, and the healing process as Sorry Business and may refer to a stillbirth as 'a Sorry Business baby'. Being cognisant of language and terminology that is important to parents and family/whānau is an essential aspect of providing respectful and responsive care around perinatal loss.

Asking parents and family/whānau to be responsible, solely, for decisions involving the life and death of their unborn or newborn baby may not be acceptable for some cultural groups.[81] In some cultures, it is not common for the woman to be the decision maker.[81-83] Information should be provided to both parents and their family/whānau because decisions may be shared. For example, in Māori culture, the baby is a recognised part of the wider whānau, who are often part of decision-making processes.

Some cultural groups may have taboos against talking about death and expressing grief in public, particularly relating to stillbirth.[84]

Aboriginal and Torres Strait Islander families may need space to perform ceremonies such as a smoking ceremony and other 'Sorry Business' rituals. Māori whānau may need space and time for karakia and the observation of tikanga related to caring for the baby, woman and whānau. The diversity across Aboriginal and Torres Strait Islander cultures highlights the need for healthcare professionals to understand the significance of birthing and passing away on Country.[85]

Across cultures, and within migrant and refugee populations, parents and family/whānau may discuss varying beliefs and understanding of the reason for stillbirth or neonatal death. It is important that healthcare professionals do not make cultural generalisations, make assumptions, or dismiss religious, cultural, and/or spiritual beliefs held by parents and family/whānau. What is critical at every step is that healthcare professionals ask parents about their needs, seek guidance from them, and facilitate the support they need.

Within maternal and newborn services, cultural support is usually accessible in person or through various other recommended resources,[71] which should be culturally and linguistically appropriate and available in a range of formats such as print, audio, and digital.[71,80,85-87]

Bereavement support and resources should be given to "Elders and senior health workers in communities to enable easy [care provision and handover]"

Indigenous healthcare provider, Australia.[87]

It is important to acknowledge the status of Elders, religious/spiritual advisors and other important community members and their roles in ceremonies and supporting each family/whānau. Religious advisors/supporters may be involved in the care and support of bereaved parents and family/whānau.[88] Support from cultural advisors and Elders from the first point of contact with the maternal and newborn service, until discharge to community care should be considered across all aspects of care.[87] For Indigenous cultures, bonds of kinship are of profound importance, extending beyond the 'nuclear' family, including grandparents and other family and community members. In Māori culture, tribal identity also holds great importance for many families/whānau and the distinctive customs and traditions that may be upheld and retained.

Trauma-informed care considerations

For some parents and families/whānau, the hospital environment is associated with an environment of trauma, particularly for Aboriginal, Torres Strait Islander and Māori families/whānau. Culturally responsive care aims to promote cultural safety and avoid cultural power imbalances of places, people, and policies within maternal and newborn services and other healthcare settings.[89]

"coming into a hospital and having [the stillbirth of a baby] happen can be really [traumatic]…fear about the hospital environment is deeply ingrained"

Metro Indigenous healthcare provider, Australia.[85]

Maternal and newborn services have a responsibility to ensure all healthcare professionals have appropriate training and education in culturally responsive care. This includes awareness and understanding of institutional racism, which may still occur in health settings and lead to further exclusion for Aboriginal and Torres Strait Islanders, immigrants, and refugees.[90] The WellMob website contains resources developed by Aboriginal and Torres Strait Islander People to help healthcare professionals understand cultural identity, grief and Sorry Business, appropriate language use, the impact of trauma and intergenerational trauma, and other social and emotional wellbeing issues.

Rural and remote care considerations

Parents and families/whānau living in rural and remote regions of Australia and Aotearoa New Zealand face barriers to accessing high quality care and support. While telehealth is widely used for antenatal care, evidence is limited for care around stillbirth and neonatal death. Although provision of homebased paediatric telehealth palliative care is feasible, there are challenges.[91] A scoping review of telehealth use by Indigenous populations in Aotearoa New Zealand, Australia, Canada, and the United States acknowledged the range of available telehealth modalities but noted that co-design is critical to acceptance of telehealth among Indigenous communities.[92]

Evidence-based recommendation 2.13

Evidence quality: Moderate confidence

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.

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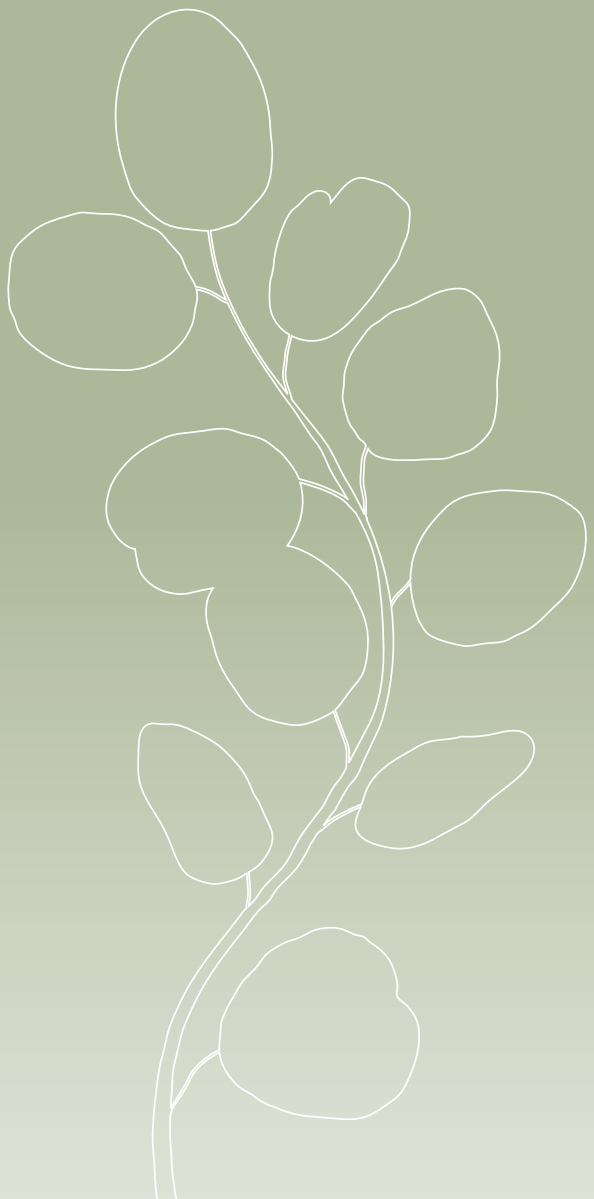
2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline



Section 3:
Perinatal loss care

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

Background

The death of a baby is a devastating pregnancy outcome with long-lasting social and emotional consequences for parents and families, and wide-ranging economic impacts on health systems and society.[1,2] The quality of care that parents and family/whānau receive around the time their baby dies is a major contributor to immediate and long-term wellbeing, including into subsequent pregnancies.[3,4]

Healthcare professionals can support parents by offering opportunities to connect with their baby. Recognising parenthood is a core goal of care and requires actions by healthcare professionals that validate a baby's existence and support the creation of lasting memories.[4-6] These actions are highly valued by many parents and enable them to get to know their baby, to engage in parenting activities, and to collect tangible mementos of their baby.

Objective

The overarching objective of this section is to assist frontline healthcare professionals to provide the best possible care for parents and family/whānau faced with the death of a baby before or soon after birth. Specifically, this section aims to help healthcare professionals:

- provide parents and family/whānau with care and support to meet their individual needs
- support parent-centred decision making and care planning
- strengthen coordinated care and referral pathways across all sectors of health and community services.

The evidence synthesis of this section includes care of parents who have experienced stillbirth or neonatal death including stillbirths and neonatal deaths following termination of pregnancy.

This guideline acknowledges all parents and family/whānau who have experienced the death of a baby during pregnancy or soon after birth including early pregnancy loss. Implementation of these recommendations for perinatal loss care will ensure high quality consistent care for all parents and family/whānau who are cared for in maternal or newborn settings, regardless of when (during pregnancy or soon after birth) or where (location of maternal or newborn health service) their baby dies.

A note about terminology

This guideline uses parent-centred language that is intended to be inclusive of all affected by loss. We use the term 'woman' throughout the guideline to refer to the person who is pregnant and gives birth.[7] We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth identify as a woman. The term 'parent' is used to refer to expectant and bereaved mothers, fathers, and partners. It is important to recognise individuals who identify themselves as parents. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents.[8] This guideline uses 'baby' when referring to stillbirth, neonatal death because these terms are preferred by many bereaved parents. Terms such as 'fetus' may add to parents' distress because this language denies personhood[9] and is inconsistent with recognition of parenthood that is crucial to providing respectful and supportive care. This guideline uses 'healthcare professional' to denote all those working with bereaved parents and family/whānau (see Glossary).

Breaking bad news

A baby's condition, diagnosis and prognosis is often complex and uncertain.[10] How news is communicated to parents has immediate and lasting effects on parents' experiences of care and wellbeing.[11-15] Communication when confirming the baby's death or life-limiting prognosis, and during labour and birth care, should always be respectful, honest, and free from distractions.

The attitudes and communication skills of healthcare professionals, the timing of the communication, and the physical surroundings in which the news is delivered are all important.[10,16,17] A coordinated multidisciplinary approach may be the most effective way to ensure parents receive accurate and consistent information, with diagnosis shared as soon as confirmed.[18,19] 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.[12,20,21] The Parent-centred communication in obstetric ultrasound guideline developed by the Australasian Society for Ultrasound in Medicine (ASUM) provides recommendations and support to sonographers to improve care of expectant parents.

There are many ways of breaking bad news. No way is good, but some are better.[18]

For breaking news about the death of an unborn baby, guidelines on perinatal loss care recommend using sensitive language, selecting appropriate and understandable messages, and ensuring enough time is given for parents to absorb that information.

No parent is prepared for the news of the death, or possible death, of their baby and intense shock and grief are to be expected.[25]

When breaking news about a life-limiting diagnosis for an unborn baby, the timing, amount, and quality of information provided to parents has implications for their wellbeing and understanding of the situation. Balanced and accurate information about all available options should be presented to parents. Parents may face much uncertainty, and ultimately must decide whether to continue the pregnancy. Parents who choose to continue the pregnancy should have immediate access to perinatal palliative care (see *Section 4: Perinatal palliative care*).

Through the Unexpected is an Australian charity providing information and social and emotional resources to expectant parents and families faced with an antenatal diagnosis of an anomaly in their baby.

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 empathic 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.

Consensus-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 (for example 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.

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.

Care planning and decision making

Parents face many difficult and emotionally charged decisions when their unborn baby is diagnosed with a life-limiting condition or has died. Decisions will often need to be made about the mode and timing of the baby's birth along with decisions about end-of-life care.

All care planning should be conducted within a parent-centred decision-making approach, which recognises that decisions faced by parents around the time of perinatal loss are highly sensitive to personal values and preferences and that there is rarely one 'right' decision.[22,23] This allows parents to be supported and involved in decisions to the extent they choose. Active partnership between parents and healthcare professionals is essential to keep parents' values and preferences at the centre of care and ensure that they are provided with the best available evidence about benefits, risks and uncertainties of care and are able to reach the most appropriate and informed decision.[24,25,26]

Supporting parents in decision making requires more than a one-off conversation.[25]

Care planning is a process, not just a written document.[8]

Members of the multidisciplinary team should be empowered to support families/whānau throughout the pregnancy as they process the diagnosis and/or prognosis and begin to plan care. It is important to communicate openly with parents and families/whānau including providing anticipatory guidance, where possible, and advising on the need for flexibility as care plans may change.[27] It is also important to explore with parents their decision-making style, values, and preferences to promote the tailoring of information and approaches to suit their individual needs.[23]

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 *Guiding Conversations* booklet and *Jiba Pepeny (Star Baby)* booklet for Aboriginal and Torres Strait Islander families.

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 (for example 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.

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 (for example mode of birth, how the baby's condition may change, time to autopsy).

Evidence-based recommendation 3.9
Evidence quality: Moderate confidence
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 the multidisciplinary team.

"After finding out that our baby had died in utero, we were devastated. The two days of planning before our baby was born, allowed us to make wonderful memories that otherwise would have been memories that we would want to forget."

Bereaved father[23]

Labour and birth

The optimal mode of birth following the death of an unborn baby or when a baby is expected to be born with a life-limiting condition is one that combines medical considerations and parent values, preferences and wishes. However, achieving an approach that balances parent-directed choice and professional care in the highly stressful, emotive, and time-pressured circumstances can be challenging.[28] If the baby has died or if a life-limiting condition is known before labour has started, parents' involvement in decision making around the timing, mode and place of birth can help to increase their sense of empowerment and control and will allow for practical, social, and emotional planning.

It is important to provide parents with options and information at all stages, including what might happen when giving birth to a baby who is going to be stillborn. Ensure that information is applicable to each parent's situation.[29] Information around labour and birth, including pain relief options, should be given in a range of formats bearing in mind that parents often report impaired clarity of thought in stressful and emotive situations. Parents should be given as much time as they need to make decisions about options offered.[30]

When a baby is not expected to survive for long after birth, a driving factor for mode of birth may be the parents' wish to have time together with their baby while alive. This may also be an important consideration for religious or cultural ceremonies. There is wide agreement that, in such instances, caesarean birth should be provided as an option, together with appropriate discussion to ensure the parents are aware of the risks associated with this option.

Decisions about the length of time between diagnosis of the death of an unborn baby and the induction of labour and birth may need to be made. The timing of birth depends on a variety of factors and management should be individualised.[31] Allowing sufficient time for discussion and decision making is important.[10,32,33] Some parents may prefer that the birth occurs straight away and others may wish to go home before the birth to allow time to consider their birthing options, to share the news with family and to gather support.[33]

The mode of birth may be dependent on the baby's gestational age and maternal clinical history and should be individualised with consideration for parents' preferences. In Australia and elsewhere, guidelines for management of the birth of a baby who has died generally recommend vaginal birth, with caesarean birth reserved for special circumstances such as an increased risk of uterine rupture.[34,35] In the USA, women whose baby has died usually give birth vaginally regardless of whether labour was spontaneous or induced or whether they had a prior caesarean birth. However, 15% of women underwent caesarean birth, often without a documented obstetric indication.[36] The RCOG Guideline[34] recommends vaginal birth for most women with intent to optimise future pregnancy outcomes, but caesarean birth will need to be considered for some. Vaginal birth carries the potential advantages of both quicker physical recovery and return to home, but with the risks of vaginal/perineal trauma and the need for forceps/ventouse or an emergency caesarean birth.[31]

"I think having choice helped us feel in control and helped us also to feel like parents, that we weren't just suddenly the rejects if you like and having things done to us, we still had a say in how our daughter was born."

Bereaved parent, Australia.[29]

Options for birth after diagnosis of late stillbirth include spontaneous vaginal birth, immediate induction, delayed induction, caesarean birth or expectant management. Methods of induction include misoprostol (with or without mifepristone), syntocinon infusion, and mechanical methods. Refer to RCOG Guideline[34] for summary of induction of labour methods.

The full range of pharmacological and non-pharmacological pain relief options (including labour and birth in water) should be discussed with parents including advantages and disadvantages of each pain relief option.[1,13] Parents should be advised of the potential for sedation to lead to later regrets about lost opportunities for interacting and spending time with the baby.[37]

Recognition of parenthood involves caring for parents in the same way as any other parents who are preparing for their baby's birth. This includes providing reassurance that pain relief and physical and emotional support will be available during labour and birth.[31] Parents want healthcare professionals to facilitate their choices, their sense of control, their autonomy, and their agency.[30] Ensuring that all staff are aware of parents' wishes and preferences is vital to supporting parents' experiences of labour, birth and first moments with their baby.

"Birth is your Bub's first ceremony. You are still the parent of a beautiful Traditional Owner of the lands you are from."

Parent quote from the *Jiba Pepeny (Star Baby)* booklet.

Evidence-based recommendation 3.10
Evidence quality: Moderate confidence
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.

Special considerations about maternal illness

Provisions should be made if the woman is unwell around the time of or following the birth. Careful consideration and sensitive discussion with parents to inform their decision about and preferences for care planning is required, as maternal medical complications associated with late stillbirth are high, including implications of caesarean birth for future pregnancies.[38,39] When a woman is admitted to an intensive care unit or transferred to another hospital following birth, every effort must be made to ensure appropriate and timely communication so that she is kept informed and involved in decision making and care planning, particularly regarding memory making opportunities and considerations around perinatal death investigations.[22] Opportunities for her to have access to her baby and to delay decisions where possible need to be considered and discussed with the woman, her partner and other family/whānau members as appropriate.

Memory making and spending time with baby

For many parents and families/whānau, creating lasting and meaningful memories is an important way of honouring their baby. Having a continuing bond with their baby may allow parents to maintain an enduring connection with their child who is integrated in their everyday lives and social relationships. Continuing bonds are associated with more positive bereavement adaptation.[40]

The time parents will have to spend with their baby is limited so every contact with their baby is precious.[3]

Healthcare professionals can support parents by offering opportunities for parents to spend time with their baby and engage in acts of caregiving and parenting, such as bathing and dressing, and reading and singing to their baby.[22,41] Spending time and engaging with their baby can help parents to create a social identity for the baby, and for themselves as parents, while simultaneously providing an opportunity to say goodbye.[41] Parents may also value opportunities to take their baby out of the clinical environment and into natural settings.[22]

Healthcare professionals need to ensure that parents feel guided, supported, and prepared to meet their baby and engage in memory making that is meaningful to them, and to the extent that they wish.[22,41] Parents may initially feel emotionally unprepared, hesitant, or fearful of seeing their baby, including how to approach, touch, and hold him or her. Parents report being grateful to healthcare professionals who actively support them to engage in memory making.[42,43] It is important to take time to explore with parents their concerns and preferences, and areas of uncertainty or apprehension regarding parenting activities. It is also essential for healthcare professionals to be aware of and facilitate important cultural, religious, and spiritual practices. For example, Māori families (including extended family/whānau members) will often gather and say prayers with the bereaved and baby at certain times of the day or night.

"At first, I was really afraid when I thought about spending time with our baby. I talked with my midwife who was able to tell me what other parents have found helpful and to make suggestions."

Parent quote from the *Guiding Conversations* booklet.

Parents of twins, triplets, or multiple babies

Parents of twins, triplets or other multiples may experience conflicting emotions when one or more babies has died and one or more survive. It can be difficult for parents to think about and plan to spend time with a baby who has died while also caring for and spending time with the surviving baby or babies. Healthcare professionals can support parents in their decision making by validating the loss of their baby and not solely focusing on the surviving baby or babies. It is important that parents are cared for by healthcare professionals who have training in supporting parents who experience a loss from a multiple pregnancy. The *Guiding Conversations* booklet has information for parents around loss of multiple babies. Healthcare professionals should be aware of their local legislation requirements around registration of birth pending different scenarios in multiple pregnancy (see CBR 8.8).

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 (for example by name)
- providing parents information about their baby (for example 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.

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.

Evidence-based recommendation 3.14
Evidence quality: Moderate confidence
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.

Consensus-based recommendation 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
- 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.

"At our service we have coolamons ready for babies to rest in. The families bring in a blanket and we put that down first. Bub is placed in gently and the whole room gets quiet and it feels so special. Families say they feel like their Bub's spirit is connected to Country when they are laying in the coolamon, made from the trees, holding them peacefully."

Healthcare professional quote from the *Jiba Pepeny (Star Baby)* booklet.

Collection and creation of mementos

Supporting parents in creating memories through collecting mementos is highly meaningful for bereaved parents and family/whānau who often have a strong desire to maintain a lifelong connection with their baby. Mementos often include photographs, hand and footprints, casts/moulds of hands and feet, baby identification bracelets, and special clothing.[13,44-46] Memory boxes are also highly valued and can contain a range of tangible items.[47]

In Australia, **Red Nose's Treasured Babies Program** and **Angel Gowns Australia** provide bereaved families with gifts of handmade clothing and Angel boxes for their baby. **Miracle Babies Foundation** also provides memory boxes for newborn loss. **Bears of Hope**, **Possum Portraits**, and **Huggable Hearts** also support bereaved families with mementos and keepsakes for lasting memories. In Aotearoa New Zealand, **Baby Loss NZ**, **Sands New Zealand**, and **A Star is Born** provide memory making services.

Mementos provide evidence to affirm the life of the baby and the role of the parent.[51]

High quality photographs and video recordings provide lasting and valuable memories for many bereaved parents and families/whānau. Photographs and videos can be an essential means of:

- validating their baby's existence, their parenthood, and their baby's place in the family unit[38,48,49,44,50,51,44,52,53]
- providing opportunities to share their baby with others and facilitate difficult conversations (for example to help siblings understand the loss)[51]
- supporting creation of a family legacy and a continuing bond[64]
- creating a permanent and tangible record that can provide parents with comfort and reassurance and relieve fears of forgetting their baby over time.[64]

"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 recognised and celebrated in the pictures."
Bereaved mother.[44]

If a professional photographer is not available, healthcare professionals can support parents in taking photographs and videos. Parents appreciate natural and candid photos that capture irreplaceable moments and activities associated with parenting, and the small details about their baby's appearance.[50,51] See **tips for healthcare professionals on taking bereavement photos** by Heartfelt.

For parents who may be unsure or apprehensive about seeing their baby, photographs can be used by healthcare professionals as a way of preparing parents to see and spend time with their baby.[9] The experience of taking photographs can also create positive memories by providing parents with special moments to hold their baby, spend time together as a family, and, for some, foster a sense of normalcy.[64]

In Australia and Aotearoa New Zealand, **Heartfelt** is a volunteer organisation of professional photographers who provide photographic memories free of charge for families/whānau who experience perinatal loss.

"Because parents left the hospital without a child, the photographs took on an increased importance, often becoming their most valuable and irreplaceable possessions."
Healthcare professional.[44]

All aspects of memory making should be parent led. It is crucial that healthcare professionals do not initiate collection or gathering of mementos without parents' involvement or permission (for example cutting a lock of hair or dressing the baby). Some parents' preferences, values, and wishes for memory making may be tied to long-established cultural customs and tradition. For example, the baby not being left alone at any time,[54] ways of handling their baby's body and placement of limbs, and items important for burial (such as clothing).[55-59]

It is important to acknowledge and support parents who choose not to engage in parenting activities or memory creation. Discussion of memory making and spending time with the baby should be carefully approached with the parents and family/whānau by a trusted healthcare professional.[60-62] Parents' decisions must be respected. In addition, it is essential that healthcare professionals are aware of processes for storing mementos (for example baby identification bracelets) for parents who may wish to collect them later when/if they are ready.

Consensus-based recommendation 3.16
Offer and facilitate opportunities to gather tangible mementos of the baby (for example 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.

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.

"I just didn't feel able to spend time with my baby. But a midwife told me how she cared for him and how he looked. She described how she carefully wrapped our son and placed him in a cot, and the details of his face and hands. I am so grateful to the midwife for allowing me to see my baby through her eyes."

Parent quote from the *Guiding Conversations* booklet.

Commemorative rituals

Healthcare professionals have an important role in supporting parents and family/whānau to make decisions about and arrange bereavement rituals that meet their cultural, religious, and spiritual needs. These rituals may include blessings, naming services or baptism, and burial or cremation. For example, the placenta holds great significance and importance in Indigenous cultures. Many Aboriginal families have ceremony for the placenta, mostly burying it on the bub's Country. In Māori culture, it is customary for families/whānau to return to the earth the umbilical cord (pito) and afterbirth (whenua) by burying them at home (turangawaewae).

Evidence-based recommendation 3.19
Evidence quality: Moderate confidence
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/whānau in their decision making
- contact details for relevant services
- information about available financial support.

"On the day of Bub's funeral, Uncle made the fire out on the grass in the backyard. He made it big and I held my Bub in my arms and we passed over the smoke, again and again and again until it felt right to stop. I felt like it helped Bub's spirit go over, you know? That process of cleansing. It felt like it helped me too. We were all there together, cleansing so we could send my son off peacefully."

Parent quote from the *Jiba Pepeny (Star Baby)* booklet.

Postnatal care and physical recovery

Best practice care for parents and family/whānau includes immediate and ongoing physical, social, emotional and practical support that recognises the birth and death of a baby.[1] The woman should be informed of the physical effects and changes that will occur following the birth of the baby. This includes the body's preparation for lactation, physical recovery process such as after-birth pains and discomfort, bleeding, and bowel movements and potential complications. Recovery from a caesarean birth should also be discussed with the woman (for example wound care) and appropriate support provided.

It is common for a woman who has experienced loss to have also experienced a complicated pregnancy and be more likely to experience postnatal complications, which can compound the grief response. It is important that women are provided with support and information to help prepare them for what to expect, particularly in the six weeks following birth, including when to seek medical advice and professional support.[9,47,63] Physical changes and medical treatment for postnatal complications should be addressed by healthcare professionals as early as possible and before parents leave the hospital.[64]

Lactation after loss

Discussion and management of lactation in the context of perinatal loss is an important aspect of best practice care. Information and support around lactation management is often reported by parents as inadequate.[63] Many women will experience breast changes including discomfort, engorgement, and milk leakage,[65] which, if not managed effectively, can lead to infection and mastitis. Without anticipatory guidance, the experience of lactation can be a significant source of distress for a woman.

Just as grief is an individual process, every woman's experience of lactation will be different. Not all women will choose the same option.[69]

Women should be provided with sensitive and timely anticipatory guidance on lactation and their full range of options for management. It should not be assumed that mothers will want to suppress breastmilk immediately. As well as immediate suppression of lactation using medication, options include gradual suppression through expressing; the use of breastmilk to craft a memento such as jewellery; and ongoing lactation and donation of breastmilk to a milk bank or through a community-based sharing network (where available; this may be dependent on screening eligibility requirements).[66-68] Women who choose to express their breastmilk should be assisted with information about hiring or buying a breast pump.

More information is available via **The Australian Breastfeeding Association**. Women can access free telephone counselling support within Australia from the **National Breastfeeding Helpline**.

It is important to acknowledge lactation, physical changes, and parent's emotional responses and meaning that may be attached to this experience.[65] It is also be important for bereavement lactation management to be inclusive of family members, incremental and responsive to changing needs and circumstances, and for information to be provided in a range of formats.[69]

Ensure medical follow-up (with general practitioner [GP] or obstetrician) and community-based supports are activated through appropriate handover and referrals. GPs play a vital role in supporting the physical, social, and emotional health of parents and families, including into subsequent pregnancies. It is also important to share information with parents about how to engage other healthcare professionals for physical health, such as women's health physiotherapists, exercise physiologists, and dietitians and nutritionists. Other activities, including yoga[70] and engaging with nature,[37] may also have benefits for women following perinatal loss.

"I wasn't expecting to feel so emotional about all the changes in my body after the birth. Having an appointment with my GP helped to reassure me."

Parent quote from the *Guiding Conversations* booklet.

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.

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.

Leaving hospital and ongoing support

Parents require immediate support in the initial stage of their grief, and pathways to ongoing support in their community once they have left hospital. However, parents often report that the support they received is inadequate.[71] The Lancet *Ending Preventable Stillbirth* series highlighted the unmet needs of bereaved parents following hospital discharge, with 31% of women describing their post-hospital care after stillbirth as poor.[72] Lack of care and follow-up support is likely to compound parents' griefand contribute to feelings of isolation and loneliness.[73,74,75]

Appropriate discharge planning is essential to ensure that bereaved parents are supported in their transition from hospital to home. It is important that healthcare professionals are sensitive to parents' needs at hospital discharge and ensure that parents are not left feeling abandoned or uncared for. Leaving hospital without their baby is highly distressing for parents. Every effort should be made to ensure that parents are emotionally supported as they leave hospital. It is important that parents are not faced with potentially confronting interactions, delays, or chance meetings or environments that may be a source of distress (for example walking past nursery, being in a lift with expectant parents).

Communication between hospital- and community-based healthcare professionals is an important part of continuity of care, and this needs to occur in a streamlined and standardised way. Follow-up with bereaved parents provides healthcare professionals an opportunity to connect them with additional support services and community resources if needed.[76]

In Australia, the Red Nose Hospital to Home Program is available to bereaved parents and family/whānau members for up to three months following the death of a baby. This program is designed to provide emotional and practical support for bereaved parents as they make the transition from hospital to home in the early phases of their grief. Support may include assistance with hospital discharge, accompanying parents to medical appointments, helping parents lodge paperwork such as birth and death registrations, and re-integrating parents with their employment or other general activities. Evaluation shows that the Program has made a meaningful difference to bereaved parents as demonstrated by high levels of satisfaction with the support received and significant improvements in domains of wellbeing that are known to be adversely affected following the death of a baby when parents are at most risk of isolation and psychological distress.[77]

Leaving hospital can be a time of mixed emotions for parents. Some parents want to leave as soon as possible, while others may feel they are leaving a place that holds many precious memories of their baby.

Guiding Conversations booklet.

No one is expecting you to go back to your old self, before the loss of Bub. No one is expecting you to get over it and move on quickly. Jiba

Jiba Pepeny (Star Baby) booklet.

In Australia, parents and their partners may be entitled to **compassionate leave**, **parents or carer's leave**, **bereavement leave** or **parental leave and unpaid special maternity leave**.[78]

Returning to work after the loss of a baby can be a daunting prospect for parents because of concern about colleagues' reactions, being exposed to triggers of grief, or general feelings of tiredness and reduced concentration.[78] Workplace leaders may struggle to understand the sensitivities around perinatal loss or to know how to provide support. The **Pink Elephants Support Network** provides training and support for workplace leaders to support employees who experience perinatal loss.[79] It is essential that parents and family/whānau members, including grandparents, are provided with a range of support options.

- Red Nose provides specialised grief and loss support services in Australia, including support for healthcare professionals. The **Red Nose *Hospital to Home Program*** is a peer support program that provides emotional and practical support to parents for up to three months following the death of a baby.[75]
- **SMS4Dads** is a text-based messaging service to support bereaved fathers.
- **Bears of Hope** also provide a range of support options including professional grief counselling and peer support such as parent workshops and father-specific support weekends.
- **Miracle Babies Foundation** also have a 24/7 peer support helpline *Nurture*Line for bereaved parents following newborn loss.
- The **Pink Elephants Support Network** provides peer support programs (including Peer Support Live Chat), emotional support resources for parents following early pregnancy loss, including workplace programs to better support parents returning to work.
- The **Perinatal Loss Centre** maintains a therapist register to enhance access to counselling support across Australia.
- The **Centre for Perinatal Psychology** provides a national directory of psychologists with expertise in counselling and support around perinatal loss.
- The **Centre of Perinatal Excellence** has an online directory that can be filtered by location to show perinatal mental health services in Australia.
- **PANDA** and **Gidget Foundation** offer a range of mental health and wellbeing support options for parents in Australia.

In Aotearoa New Zealand, parents and families/whānau who experience perinatal loss can receive support from a range of support groups, organisations, and resources.

- **Whetūrangitia** is an online resource for parent information.
- **Sands New Zealand** is a nationwide parent-run network for bereaved parents that offers face-to-face support (group meetings and one-on-one) and online and print resources, as well as providing memory making services in most hospitals.
- **Baby Loss NZ** also provides memory making services.
- **Miscarriage Support** and **Miscarriage Matters** provides online resources and best practice recommendations.
- See the **Baby Loss Directory** for more support options.
- **PADA – Perinatal Anxiety and Depression Aotearoa** is an advocacy and awareness charity.

Consensus-based recommendation 3.23
Discuss with parents prior to hospital discharge, their preferences for advising relevant healthcare professionals involved in their care (for example 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.

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.

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.

Evidence-based recommendation 3.27
Evidence quality: Moderate confidence
Ensure parents receive follow-up calls or visits, as required, from an appropriately skilled healthcare professional.

Evidence-based recommendation 3.28
Evidence quality: Moderate confidence
Ask parents about their social and emotional wellbeing at all postnatal care appointments and appropriately refer to support services where needed.

- 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*

Communication with parents about findings of investigations

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.[77] Refer to *Section 6: Investigations for perinatal death* for more information about communication and follow-up with parents.

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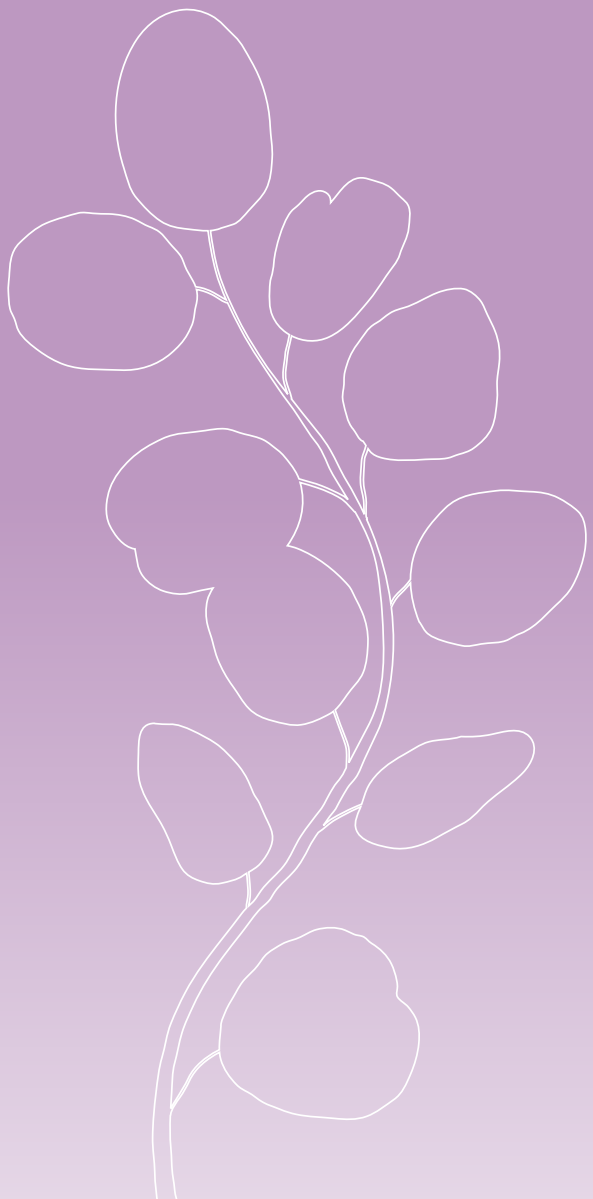
2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline



Section 4: Perinatal palliative care

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

Stillbirth CENTRE OF RESEARCH EXCELLENCE

PERINATAL SOCIETY of Australia & New Zealand PSANZ

Background

Perinatal palliative care is a holistic multidisciplinary model of care for both baby and family/whānau in the event of a perinatal diagnosis of a life-limiting condition. It aims to provide optimal symptom control and end-of-life care to the baby as well as specialised support to families/whānau. The aim is to provide a coordinated continuum of care and support to parents and family/whānau during pregnancy, birth and the newborn period.[2] 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.[3]

Perinatal palliative care is a right for all babies with a lifethreatening or life-limiting illness – and their families.[4]

Objective

This section provides frontline healthcare professionals with guidance about how best to support parents and family/whānau whose baby has been recognised as having a life-limiting or life-threatening condition, when a palliative care approach has been agreed/chosen. This guidance includes assisting healthcare professionals to:

- support communication, decision making and care planning with parents
- strengthen coordinated care across all sectors of health and community agencies
- support parents in their bereavement.

This section of the Guideline is accompanied by best practice recommendations outlined in *Section 2: Approach to care* and *Section 3: Perinatal loss care*. Many of the recommendations contained in those sections also apply to perinatal palliative care. This section focuses on additional aspects of care when a baby is known to have a life-limiting condition and is expected to die at or soon after birth. The Paediatric Palliative Care National Action Plan (2022) is a roadmap for a national approach to prioritise and work towards common goals and objectives for paediatric palliative care including care of babies.

A note about terminology

This guideline uses parent-centred language that is inclusive of all individuals. Throughout this guideline, we use the term ‘woman’ to refer to the person who is pregnant and gives birth. We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth will identify as a woman. The term ‘parent’ is used to refer to expectant and bereaved mothers, fathers, and partners. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents. This guideline uses ‘baby’ when referring to stillbirth, neonatal death, or termination of pregnancy for medical reasons, because this is preferred by many bereaved parents and validates the magnitude of the loss experienced. This guideline uses ‘healthcare professional’ to denote all those working with bereaved parents and family/whānau.

Resources

- **Appendix 4A**: Example of a perinatal palliative care plan

Approach to care

Palliative and end-of-life care for newborns and their family/whānau is an integral component of perinatal care.[2,5] Generally, perinatal palliative care should be considered in the following circumstances:

- fetal anomalies or life-limiting conditions diagnosed before birth
- a pre-viable preterm baby where birth is imminent
- a newborn with a postnatally diagnosed life-limiting condition.[2]

It is important for all involved in care to present a united front for families.[11]

Perinatal palliative care is a right for all babies with a life threatening or life-limiting illness and their parents and families/whānau.[6-8] However, the timing and approach to perinatal palliative care planning can be challenging because information about a baby's diagnosis and prognosis is often complex and uncertain.[9] Timing of referral to perinatal palliative care depends on diagnosis and decision making of parents and healthcare professionals. The decision to take a palliative approach to perinatal care needs to be jointly made by the parents, any chosen support people (for example family/whānau), and the multidisciplinary team of healthcare professionals supporting the parents and the baby.[3,10]

How things evolve for the family is going to impact them for the rest of their lives.[10]

Palliative care providers need to partner with parents and families/whānau to develop individualised, seamless, and compassionate care plans that address the physical, emotional, and cultural needs of the baby, parents, and family/whānau. Continuity of care and a central coordinating contact is important.[11] Bereaved parents report benefit in having a perinatal palliative care coordinator (often a midwife or nurse) who is able to coordinate care between family/whānau and healthcare professionals and team members.[12] All team members and family/whānau members should be able to contact the care coordinator who serves as a single key point of contact to ensure care is seamless.[2,13] Team members who are able to respond to the family's social and emotional needs (for example social workers; psychologists; cultural, religious, and spiritual advisors) should be integrated in the palliative care team to support and provide continuity of services throughout the perinatal period,[14] including offering information and support for practical considerations (such as accommodation, parking, family/whānau leave benefits). Parents and family/whānau should be offered options for and access to community-based resources, including opportunities to talk with other parents who may have had similar experiences.[2]

Care may be planned and started before birth or may be initiated for newborns after birth. Perinatal palliative care programs generally include the following:[15-17]

- formal antenatal consultation
- development of a coordinated care plan including access to other neonatal and paediatric specialties, as needed
- support and care during pregnancy, birth, and postpartum periods including perinatal loss counselling
- emotional and social support and cultural, religious, and spiritual support for parents and family/whānau (including siblings) and staff.

"Avoid having families need to tell their story over and over; consolidate and provide continuity."[11]

Parent-centred communication and decision making

Discussions with parents and family/whānau about palliative care for their baby are often challenging for healthcare professionals.[18] All communication should be clear, sensitive, honest and timely.[1] Medical terms should be explained in lay language and care should be taken with choice of words, and terms such as 'withdrawal of treatment' or 'withdrawal of care' should be avoided ('palliative' or 'comfort care' are better alternatives).

Good communication involves finding the right words and the right approach with attention to what is said and how.

Above all, parents need to be assured that they and their baby have the support of the care team and that all will be done to ensure their baby's comfort and care.[2] Vitally important is that parents are encouraged to express their values, goals, wishes, and fears, and that these are incorporated in care planning.[19] This includes the ability to reflect on their choices along the care pathway and change their mind if necessary.

Effective and compassionate communication respects individual needs and values and promotes a parent-centred decision-making framework. Healthcare professionals can provide individualised care by acknowledging parents as the primary carers and as equal partners in decision making with the multidisciplinary team.[1,13] It is important to acknowledge the complexity of decisions being faced by parents at a highly emotional time. Uncertainty of prognosis, ethical and legal aspects may add to this complexity. It is important that parents and family/whānau members are provided with sensitive parent-centred information and that they are given time to process that information and opportunities to discuss with other family or support persons and to ask follow-up questions of their care team. Different decision-making styles need to be acknowledged. Conflicts between parents and between parents and the healthcare team members may arise and parents should be prepared for this possibility. Discussion should occur ahead of time about procedures for managing any such differences. A senior and appropriately experienced member of the team should lead these discussions.[2]

Creating a culturally responsive environment requires understanding that communication and consultation is crucial in empowering families to voice their cultural, religious, and spiritual needs.[16,20,21] A carefully developed perinatal palliative care plan can help to highlight the religious, cultural and spiritual needs of parents and family/whānau during the birth.[22] Healthcare professionals should invite parents and family/whānau to involve their cultural advisors or spiritual Elders across the continuum of perinatal palliative care to ensure appropriate rituals andtraditions are available to them and their baby. A qualified interpreter should be made available if needed.

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.

Care planning

The need for palliative care may be recognised during pregnancy (for example at the 20-week antenatal scan), or may not become apparent until after a baby is born.[1] Healthcare professionals should discuss the option of palliative care with parents and begin care planning as soon as possible if a palliative care approach is chosen. A palliative care approach may continue for many months.

Care planning starts when you make the decision to take a palliative care approach.

Perinatal palliative care planning includes a birth care plan, palliative care plan, and perinatal loss care plan to support parents and family/whānau based on their values, preferences, and wishes and their cultural, religious, and spiritual needs.[22,23] Parallel planning is a process of developing multiple plans for ongoing care alongside planning for end-of-life care.[1] Parallel planning takes into account the often unpredictable course of conditions and potential outcomes and can help prepare parents and families/whānau for what may happen during pregnancy, birth and after birth.

Members of the multidisciplinary team should support family/whānau as they process the diagnosis and care plan throughout the pregnancy.[24] Team members need to embrace flexibility when the care plan is changing and communicate this openly to parents.[25] Perinatal palliative care planning can help parents gain a sense of control over their pregnancy and define a relationship with their baby, while also serving as a communication tool for healthcare professionals.[13,19]

The decision-making process of developing and implementing a care plan can help parents regain some control over their baby's future.[16]

Perinatal palliative care planning should be available across the continuum of care regardless of where parents are in their pregnancy (Figure 1). The Western Australia Department of Health Perinatal Palliative Care Model of Care[2] provides pathways for the referral and entry of the baby and their family/whānau into a palliative care approach. Healthcare professionals and the wider community of service providers can use the model when planning and providing perinatal palliative care. **Palliative Care Australia provides a practical guide to palliative care in paediatrics** to empower healthcare professionals to care for babies and children at home or as close to home as possible. In Aotearoa New Zealand, the '*Comfort as a Model of Care*' document co-developed by the Neonatal Nurses College Aotearoa and the New Zealand Nurses Organisation outlines a set of principles to assist neonatal nurses in providing palliative care to babies in partnership with families/whānau.[3] The *Paediatric Palliative Care Clinical Guidelines* developed by the New Zealand Paediatric Palliative Care Clinical Network provides clinical guidelines for end-of-life care of babies, children, and young people in Aotearoa New Zealand.[26] See *Appendix 4A* for an example of a perinatal palliative care plan.

Stages of care

Pre-diagnosis → **Learning diagnosis** → **Living with diagnosis** → **Birth & death** → **Post death**

Core principles

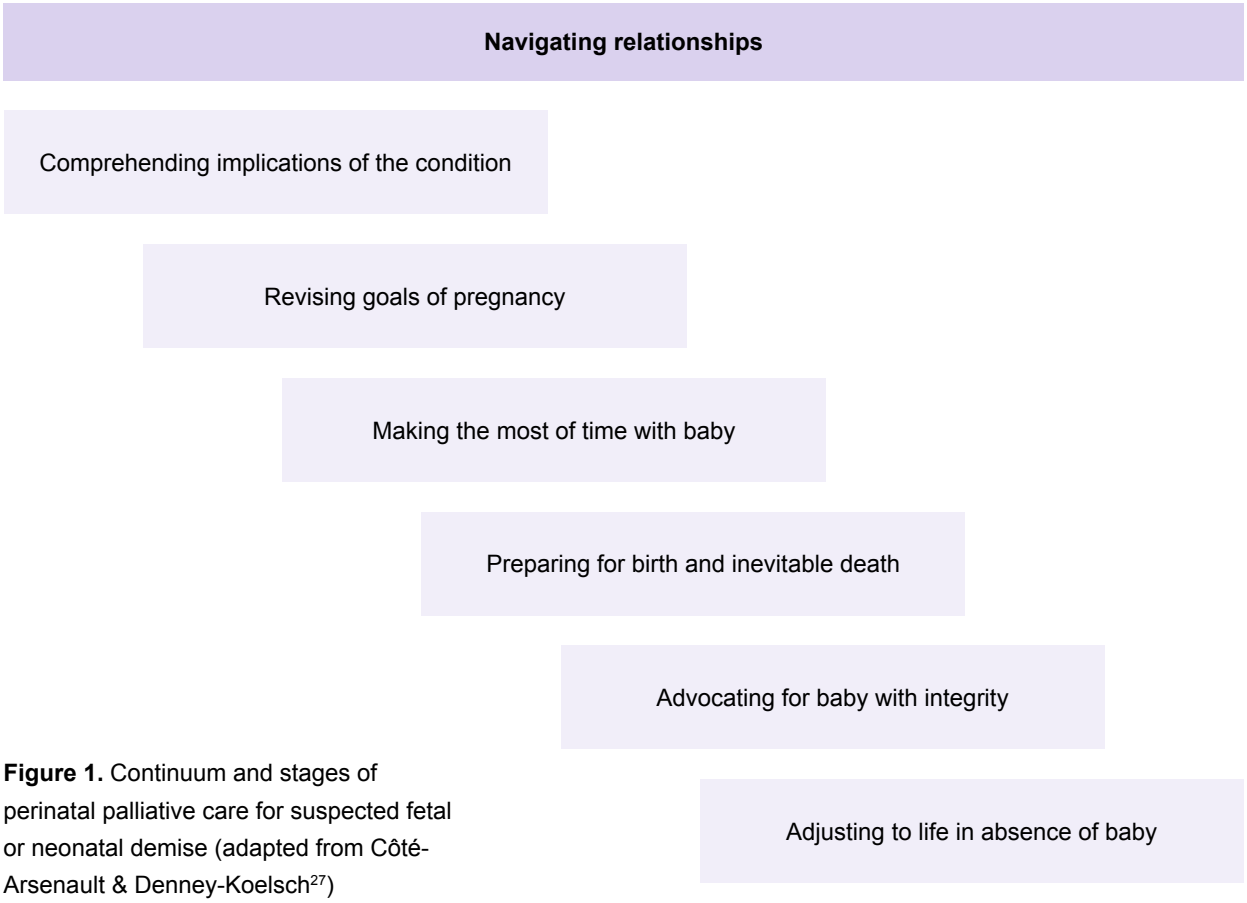


Figure 1. Continuum and stages of perinatal palliative care for suspected fetal or neonatal demise (adapted from Côté-Arsenault & Denney-Koelsch[27])

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.

Evidence-based recommendation 4.3
Evidence quality: Moderate confidence
Provide perinatal palliative care within a parent-centred decision-making framework involving parents and family/whānau and the multidisciplinary care team.

Before the baby's birth

For parents who have entered perinatal palliative care during pregnancy, memories made during the pregnancy often become very important. These memories provide a record and documentation of the pregnancy and may represent a time when the baby was still 'safe' and are a way of honouring their baby. Parents and family/whānau should be encouraged to gather mementos and engage in experiences as they may have planned before their prenatal diagnosis. For example, an audio recording of baby's heartbeat may be an important memento for families.[28]

Parents face numerous decisions at a time of shock and grief and sometimes in the face of prognostic uncertainty. All these decisions are difficult, and some have significant ethical components. For example, 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 comfort measures for their baby such as oxygen, medications, and pain relief.[17]

Feelings of uncertainty, responsibility, and guilt about decisions made may have long-term implications for parents. It is important that parents and family/whānau are assured that decisions and plans can be revised.

Decisions about giving birth will be similar to those in *Section 3: Perinatal loss care*. It is important for healthcare professionals to consider specialised childbirth classes for parents who plan to have a vaginal birth.[18] A driving factor for mode of birth may be the wish to have time together with a live born baby. This may also be an important consideration for religious or cultural ceremonies.

After the baby's birth

Some babies who are born alive may live for only a short time and remain with the parents while others may live for days, weeks or longer. The setting for care and the environment in which parents meet and spend time with their baby will differ. Regardless of the care setting, healthcare professionals play a vital role in supporting parents and encouraging their engagement in care giving activities before, during and after the baby's death.[29,30]

It is important for healthcare professionals to understand that parents may experience difficult feelings knowing that the time with their baby will be limited. As for most aspects of perinatal grief, a wide variety of responses are to be expected. Some parents may choose not to create memories with their baby, and this should be respected.

Most parents value the opportunity to see, touch, and hold their newborn during end-of-life care.[31] Refer to *Section 3: Perinatal loss care* for information and best practice recommendations for memory making and spending time with the baby, and ongoing support in the community.

For babies who are transferred to a neonatal intensive care unit (NICU), the unfamiliar and potentially alienating atmosphere may evoke fear and anxiety and parents may be fearful of touching or holding their baby. It is important to ensure that parents have the opportunity for time with their baby unrestricted by monitoring and other medical devices and for photos in a non-clinical environment without medical equipment. All parents should be supported to take their baby outside of the clinical environment and into a natural setting.[18,29,32] Where possible, provisions should be made for the baby to die unattached to technology, being held, and out of pain.[12] Maintaining privacy for end-of-life care is essential. This may involve moving babies to more private corners or sections of rooms[12] or making available an appropriate space that is free from distractions or potentially upsetting items. Witnessing or becoming aware of the death of another baby in NICU greatly affects parents.

Parents more often perceive suffering in their baby compared with healthcare professionals. Concerns about pain and suffering of the baby and symptoms such as respiratory distress, agitation, and skin breakdown may be highly distressing to parents, and it is important to prepare parents and provide explanations about these responses. Anxiety about how and when the baby will die is likely to be high, and it is important to prepare parents about what to expect at the time of the baby's death. It is essential that parents and family/whānau, including grandparents and other children, are provided with a range of support options.

The time parents have with their baby can be very short and therefore very precious – if it is missed it is gone forever.

One key aim of perinatal palliative care is to enable families to have no regrets about how they spend this time.[1]

In Australia, **Red Nose/Sands** provide specialised emotional and practical support services such as live chat with a peer supporter and a 24/7 bereavement support line. **Bears of Hope** also provides a range of support options including professional grief counselling and peer support, such as parent workshops and father-specific support weekends. **Miracle Babies Foundation** also has a 24/7 peer support helpline *Nurture*Line for bereaved parents following newborn loss.

In Aotearoa New Zealand, parents and families/whānau who experience perinatal loss can receive support from a range of support groups, organisations, and resources (see the **Baby Loss Directory**). **Sands New Zealand** is a nationwide parent-run network for bereaved parents that offers face-to-face support (group meetings and one-on-one) and online and print resources, as well as providing memory-making services in most hospitals.

The Australian Centre for Grief and Bereavement has developed a parents resource following the death of a baby or child titled 'After the loss of a child'.

Evidence-based recommendation 4.4
Evidence quality: Moderate confidence
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.

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Example of a perinatal palliative care plan

Information for the care team

- Names of parents, baby, other significant family/whānau members such as siblings and grandparents
- Summary of pregnancy journey and value-driven goals of care
- Names and contact information for key care team members and family/whānau/social supports
- Use of a universal identifier (symbol) to indicate that a baby has died or has a life-limiting condition

Care of the mother (Continuum: pregnancy, birth, postpartum care plan)

- Antenatal planning including:
  - individualised childbirth classes
  - antenatal care schedule: what, where, when, who
  - timing and mode of birth
  - parent-centred hopes for the experience of birth (people to be present, creation of desired environment, plans for pain management, cutting of the umbilical cord, photographs, cultural needs, etc.)
  - parental wishes for fetal heart rate assessment during labour, including agreed upon approach to fetal distress
  - resuscitation extent (or not)

- Postpartum planning including:
  - immediate postpartum care: where, what, time
  - newborn-parental bonding: parenting; holding, seeing, and touching newborn; skin-to-skin (or swaddling) contact
  - maternal self-care after delivery
  - family/whānau care

Care of the newborn (Palliative care plan)

- Care for the baby, specifying a focus on
  - comfort care (agreed goals, warmth, hydration, feeding, pain/distress) versus
  - medical stabilisation/actions (e.g. desire for oxygen to be used, effort, pain/distress as ordered)
  - describe any limitations to the degree of intervention and/or identify indications for redirecting care goals

- Description of parent and family/whānau plans for the first moments of life (additional visitors, introduction to significant family/whānau members, special prayer/blessing/ritual, use of special mementos, etc.)
  - Feeding plan (and any limitations due to condition)
  - Role of lactation consultant in breastfeeding/breastmilk goals, if requested

- Plans for additional diagnostic testing (cord blood for genetics, echocardiogram, X-ray, etc.)
- Symptom management if comfort-focused newborn care with anticipated end-of-life signs discussed
- If medical evaluation is planned, location of ongoing newborn care and recommended communication with team members discussed

Care of the family/whānau (Bereavement care plan)

- Anticipated opportunities for memory-making (photography; handprints, footprints, or moulds; heartbeat recording, etc.)
- Social and emotional support and referral to local services and parental support organisations
- Cultural, religious, and spiritual rituals needs or requests
- Inclusion and support of other significant family/whānau members as appropriate
- Consideration of continuing care in community/home

Details of care coordination

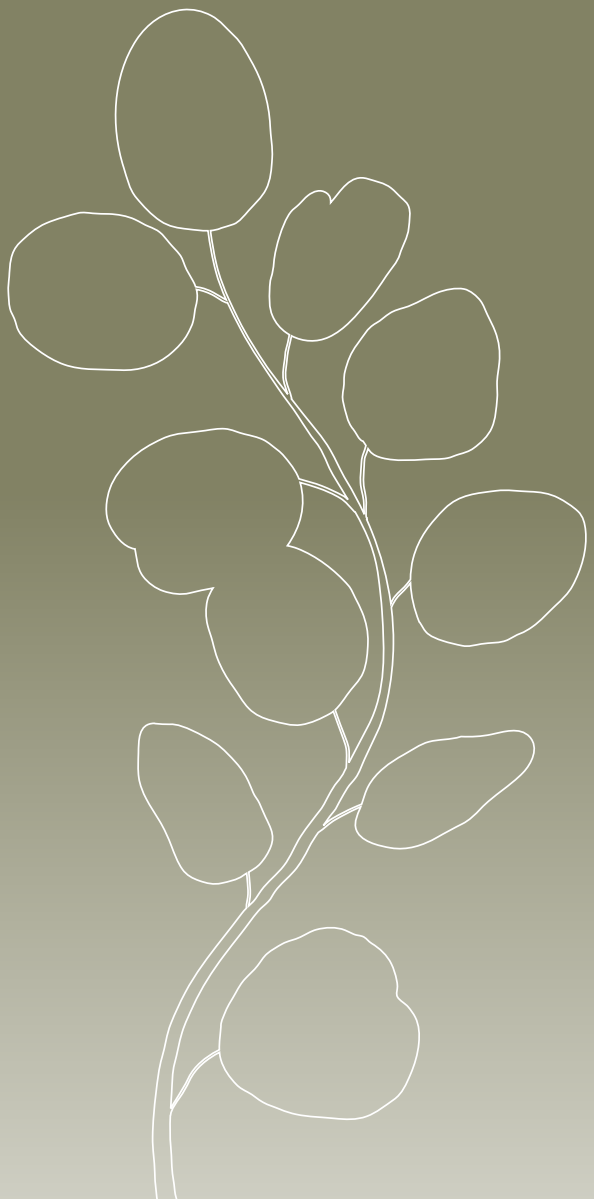
- Plans for continuing care by multidisciplinary care regarding any ongoing needs or planned evaluations
- Plans for ongoing care if baby remains alive (details for admitting to home-based care or inpatient hospice, anticipated home care needs planned and documented with appropriate referrals to other providers, etc)
- Plans for care of baby's body after death, including documentation of discussions regarding postmortem investigations, organ donation (if available and desired), cremation or burial, identified funeral home)

This plan is adapted from Table 2 of Humphrey & Schlegal (2022).

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline



Section 5: Care in subsequent pregnancies

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

Stillbirth CENTRE OF RESEARCH EXCELLENCE

PERINATAL SOCIETY of Australia & New Zealand PSANZ

Background

Parents with a history of stillbirth or neonatal death may be at increased risk of stillbirth and other complications in subsequent pregnancies, including preterm birth, low birth weight, placental abruption, pre-eclampsia, and gestational diabetes.[1,2] In this context, parents face social and emotional challenges, including increased risk of distress, anxiety and depression, and delayed attachment.[3,4] There may be mixed emotions and conflict between the desire for another baby and fear of adverse outcomes.[4-6]

Parents need continued respectful and supportive perinatal loss care from the time a baby dies through to a subsequent pregnancy.[4,7,8] Many parents will become pregnant within 12 months of the death of their baby.[9,10]

The grief associated with the death of a baby is enduring.[124]

Objective

Providing best practice care for parents and families/whānau in pregnancies following stillbirth or neonatal death includes:

- meeting parents' medical, social, and emotional needs, and providing pathways to specialised care
- parent-centred decision making and care planning, including preconception counselling, pregnancy management, and consideration of timing of birth
- coordinated care across health and community services
- culturally safe and responsive care
- supporting wellbeing of parents, including referral to support.

A note about terminology

This guideline uses parent-centred language that is inclusive of all individuals. Throughout this guideline, we use the term 'woman' to refer to the person who is pregnant and gives birth. We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth will identify as a woman. The term 'parent' is used to refer to expectant and bereaved mothers, fathers, and partners. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents. This guideline uses 'baby' when referring to stillbirth, neonatal death, or termination of pregnancy for medical reasons, because this is preferred by many bereaved parents and validates the magnitude of the loss experienced. This guideline uses 'healthcare professional' to denote all those working with bereaved parents and family/whānau.

Approach to care

Informed, sensitive, and specialised care benefits parents and optimises their short-term and longer-term health and social and emotional wellbeing.[4,11] Care should start with a postpartum/preconception consultation following the death of a baby to discuss future pregnancy planning.[8] This includes addressing modifiable risk factors (for example, smoking, obesity, and diabetes).[11,13-15] Review of parents' health and obstetric history allows healthcare professionals to anticipate and provide necessary care such as targeted support, referrals (such as to genetic counsellors)[11] and further investigation into cause of death, if required or appropriate. Parents should be assured that their expectations and concerns can be revisited at future appointments, as these may change over the course of the pregnancy. Healthcare professionals and parents can work together to develop and follow an appropriate flexible plan that considers individual risk, parent preferences, and available resources.

Addressing management of future pregnancies is an important component of postpartum care following a stillbirth or newborn death.

It is important to acknowledge and consider the specific care and support needs of parents who are planning a pregnancy following termination of a wanted pregnancy for medical reasons. In these circumstances, parents often experience disenfranchised grief, societal stigma, and feelings of shame and guilt, which extend into subsequent pregnancies. Subsequent pregnancies may be characterised by high levels of anxiety and depression, particularly in the first trimester.[16] It is crucial that all parents receive compassionate, trauma-informed care and nonjudgmental support that considers their previous loss, history of positive screening test results, and risk of recurrence of fetal anomaly and termination.[16,17] Expressing understanding, and normalising and validating parents' fears, concerns and worries is critical.[18]

Evidence-based recommendation 5.1
Evidence quality: Moderate confidence
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.

The optimal interpregnancy interval for a pregnancy following stillbirth or neonatal death is unclear. Interpregnancy interval is defined as the time between the end of a pregnancy and the conception of a subsequent pregnancy.[19-21] In a large international cohort study, parents who conceived within 12 months did not have increased risk of adverse outcomes (for example subsequent stillbirth, preterm birth, or small-for-gestational-age [SGA] birth) compared with parents who conceived within two to five years.[19] Interpregnancy interval and subsequent birth outcome appear to be unrelated to gestational length of the previous pregnancy resulting in stillbirth.[19] However, in an earlier systematic review an interpregnancy interval of less than 12 months was associated with increased risk of stillbirth, early neonatal death, preterm birth, and low birthweight,[20] and a 2006 meta-analysis found interpregnancy intervals shorter than 18 months and longer than 59 months were associated with increased risk of preterm birth, low birth weight, and SGA.[21]

Parents often face challenges in planning and deciding on pregnancy after loss, including their desire for parenthood, fear and readiness[6] and impact on the partner relationship. Understanding, through postmortem investigations, why their baby died is crucial for many parents and may inform the timing of a subsequent pregnancy.[6]

Evidence-based recommendation 5.2
Evidence quality: Moderate confidence
Support parents to plan the timing of a subsequent pregnancy, taking into consideration physical and emotional recovery and the circumstances of the previous birth.

Multidisciplinary models of continuity of care are associated with improved clinical outcomes for parents in a pregnancy following loss, particularly a reduction in risk of preterm birth and improved experience for the woman.[7] Several specialist clinics dedicated to pregnancy after loss have been established in Australia and internationally to provide care from specialist obstetricians and midwives. For example, the Rainbow Clinic in the United Kingdom (UK) ensures each woman has a structured care plan to meet their clinical and counselling needs, and partners and extended family can also receive support.[22] In 2018, a social return on investment analysis was conducted on the Rainbow Clinic to evaluate the effectiveness of this model of care in terms of social impact and health, wellbeing and social changes. For every pound invested in the Rainbow Clinic, £6.1 of value was derived for parents and staff.[23]

Parents value acknowledgement of the unique challenges of pregnancy and parenting after previous loss.[10]

In Australia, the Pregnancy After Loss Clinic (PALC) at the Mater Mothers' Hospital in Brisbane[24] and the STAR (Stillbirth and Reproductive Loss) Clinic at the Mercy Hospital in Melbourne[25] are examples of specialised clinics providing care to parents and families/whānau experiencing pregnancy following stillbirth or neonatal death. These clinics provide emotional and clinical care to parents and families within a multidisciplinary continuity of care model involving midwives, registrar, sonographer, counsellor, and consultant obstetricians. Care includes pre-pregnancy advice, investigation, and extra support through obstetric care, midwifery care, point-of-care ultrasound, and perinatal care. Individualised care plans include the availability of increased and flexible appointments, opportunity to contact healthcare professionals between appointments (for example telephone contact), individualised preparation for birth, and education and postnatal support that can benefit parents in a pregnancy following perinatal loss.[11]

Cultural considerations

Parents and families/whānau need to feel safe to express their cultural needs, traditions, and rituals. Culturally responsive care for parents and families/whānau in a pregnancy following loss can be achieved by:

- avoiding cultural stereotypes and culture-based assumptions
- asking all parents whether they have any cultural, religious, or spiritual

needs and related preferences for care (for example ethnicity or gender of interpreters)
- offering to contact appropriate cultural support services on behalf of the parent
- using language that is in line with health literacy and language needs
- being aware that vulnerable groups may have a history of trauma and loss.[26]

Ask parents how you can better meet their cultural and spiritual needs and offer resources to enable these needs to be met.[26]

Parents living in rural and remote regions of Australia and Aotearoa New Zealand face unique barriers to accessing care and support during pregnancy. Telehealth is widely used for pregnancy care, although evidence of its effectiveness is limited. Preliminary evidence for use of telehealth applications in high-risk pregnancies indicates similar maternal and neonatal outcomes between telehealth and routine care.[27]

Pregnancy after a stillbirth or neonatal loss may be a time of intense anxiety for parents and families/whānau.[12] Healthcare professionals can assist discussions about the needs and expectations of parents and their family/whānau so that cultural respect for a deceased baby can be maintained in a subsequent pregnancy.

Multidisciplinary specialist care and cultural, religious, and spiritual care for parents and family/whānau should be discussed with the parents/family/whānau and previous pregnancies reviewed.[1,5,28] For some populations within Australia and Aotearoa New Zealand, consanguineous unions are common,[29] and cultural respect regarding this should be maintained.[28]

Evidence-based recommendation 5.3
Evidence quality: Moderate confidence
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.

Evidence-based recommendation 5.4
Evidence quality: Moderate confidence
Acknowledge parents' previous loss, including if and how they would like healthcare professionals to refer to their previous baby (for example by name).

Evidence-based recommendation 5.5
Evidence quality: Moderate confidence
Ensure effective referral pathways and appropriate handover and documentation processes are in place, with previous loss identifiable in medical records.

Management of a subsequent pregnancy

Parents with a history of stillbirth are at an increased risk of stillbirth and other complications in subsequent pregnancies, including pre-eclampsia, SGA, fetal growth restriction (FGR), placental abruption, fetal distress, chorioamnionitis, preterm birth, and neonatal morbidity and death.[10,11] Strategies for reducing the risk of adverse outcomes in a subsequent pregnancy include addressing modifiable risk factors, monitoring the pregnancy (for example using ultrasound), and considering timing/mode of birth for the current pregnancy.

Getting the results of postmortem investigations was of paramount importance for couples whose babies had agenetic or congenital anomaly.

"…having a reason of course is huge. It was a 4% chance of it happening again."

Bereaved parents, daughter stillborn.[5]

Modifiable risk factors

Modifiable risk factors for stillbirth include overweight (body mass index 25 to 29.9 kg/m^2) and obesity (body mass index ≥30 kg/m^2), smoking, FGR, hypertension, and diabetes.[7,11,30] Risk mitigation strategies should begin from the postpartum/preconception counselling visit and continue through subsequent pregnancies.

Evidence-based recommendation 5.6
Evidence quality: Moderate confidence
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.

Evidence-based recommendation 5.7
Evidence quality: High confidence
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.

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.

Antenatal monitoring and targeted interventions

Fetal monitoring frequency and schedules should be based on obstetric history, screening findings, and parental preferences.[2,11] Women with a history of stillbirth with or without SGA/FGR may be at risk for FGR in the subsequent pregnancy and may benefit from serial growth ultrasound. Recommended monitoring and management of these pregnancies includes consideration of fetal growth ultrasound every 4 weeks from 24 weeks' gestation, with additional ultrasounds as clinically indicated and standardised serial symphyseal fundal height (SFH) measurements at each antenatal visit from 24 weeks' gestation. Serial fetal biometry measurements are recommended for detecting SGA/FGR.[31,32] Additional ultrasound investigations such as uterine artery Doppler, middle cerebral artery Doppler, cerebroplacental ratio and ductus venosus Doppler may be used to assist in the investigation and management of established FGR.[7]

Parents may benefit from additional support or scans at significant milestones in the pregnancy (such as at the gestational age at which their previous baby died). However, some parents may prefer not to have a scan unless it is clinically indicated[9,31,33] because increased monitoring and scans may provide only temporary reassurance and increase anxiety and fear.[2,11,31]

Maternal perception of decreased fetal movement often precedes stillbirth.[34-36] All pregnant women should be routinely provided with verbal and written information about fetal movement, including what is considered normal, and what to do if fetal movements stop, decrease[11,37-39] or change. All women who report a concern about fetal movements to their healthcare professionals should be invited to the health service for assessment without delay.[37,40,41] The benefit of remote home monitoring is yet to be established in high-risk pregnancy populations and for women in pregnancies following loss.[42]

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.

It is recognised that low-dose aspirin (LDA) is frequently used in clinical practice and there is no strong evidence of harm associated with its use. While LDA to prevent preterm pre-eclampsia is well established,[32,43,44] its routine use is not indicated for women with a history of stillbirth without other risk factors for preterm pre-eclampsia. There is no high-level evidence to support the use of LDA to prevent FGR and therefore there is practice variation.[45] In Aotearoa New Zealand, the **Small for Gestational Age and Fetal Growth Restriction Clinical Practice Guideline**[46] does recommend LDA to reduce the risk of developing FGR.

Consensus-based recommendation 5.10
Consider the use of low dose aspirin (LDA) prophylaxis in a pregnancy following loss if preterm preeclampsia, 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.

Low-molecular-weight heparin (LMWH) may be prescribed with the primary aim of preventing fetal complications among women with a history of stillbirth, although currently there is no high-level evidence for this use.[47] However, LMWH should be considered for women at high risk of maternal venous-thromboembolism due to antiphospholipid syndrome.[47] Further, unfractionated heparin (UFH) or LMWH given in combination with aspirin during pregnancy may increase live birth rates among women who have persistent antiphospholipid antibodies. However, this finding is from one study and the comparator was aspirin treatment alone.[45]

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.

Timing and mode of birth

Healthcare professionals and parents should engage in open discussions and parent-centred decision making about the timing and mode of birth in subsequent pregnancies.[11] Currently, giving birth at 39 weeks' gestation or beyond is recommended unless earlier birth is medically indicated.[15] Emotional support is crucial for parents who have previously experienced stillbirth, and early birth may be required. For some parents, early term birth may be an opportunity for reducing risk of stillbirth, but this must be balanced with the risks of adverse outcomes for the newborn.[11,15]

There is no evidence about the role of caesarean birth for nonmedical reasons in reducing perinatal death or morbidity for women with a history of stillbirth.[1] The option of a planned caesarean birth should form part of the parent-centred decisionmaking process.[31] Women who have experienced a previous intrapartum stillbirth may be more likely to choose a planned caesarean birth.[1]

It is important for parents to receive care from consistent caregivers familiar with their prior experiences, plans, and birthing decisions to reduce distress and improve feelings of security.[24]

Evidence-based recommendation 5.12
Evidence quality: Moderate confidence
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.

Evidence indicates that specialist antenatal classes for bereaved parents are rarely provided, despite the benefits of group-based/peer antenatal support and education programs for parents who have experienced loss.[9]

Evidence-based recommendation 5.13
Evidence quality: Moderate confidence
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.

Social and emotional support

The experience of pregnancies after perinatal loss can be stressful and cause anxiety. Many parents will experience mixed emotions and conflict between their desire for another baby and fear of potential adverse outcomes.[4,6,48]

Parents who have previously experienced the death of a baby are at increased risk for anxiety, depression, and posttraumatic stress in subsequent pregnancies and into the postpartum period.[6,49,50] Grief, anxiety, fear, vulnerability, stress, guilt, and worry are common and may be heightened at certain points in pregnancy and as the birth approaches.[5,9,11,33,51] Parents may continue to experience disenfranchised grief, societal stigma, and feelings of shame and guilt in their subsequent pregnancies.[52,53] This can greatly affect parents' coping and decision making around care planning.

It is important to avoid making assumptions about how parents will grieve or the support they will need in a subsequent pregnancy.

It is important to acknowledge and manage parents' anxiety in subsequent pregnancies. For example, parents may have a strong desire to monitor their baby's movements at home using heart rate monitoring equipment or may seek reassurance through increased interactions with healthcare professionals and services.[4,7,11,54] However, resulting feelings of relief and reassurance may be short lived.[5,11] For other parents, avoiding interactions with healthcare professionals following sub-optimal care in their previous pregnancy may need to be addressed. The need for reassurance may increase at certain points in pregnancy such as at the gestational age when the previous baby died. It is essential that health care professionals discuss and anticipate these points in pregnancy and after birth, so that appropriate support and referrals can be offered.[51,55] Specialised antenatal education classes for pregnancy after loss may provide parents with a safe space to discuss concerns and worries and provide access to further support and appropriate referrals.[11] As subsequent pregnancies can be filled with fear and anxiety, pregnancy may not be enjoyable or celebrated. Connecting with others through peer support can be particularly helpful in countering social isolation.[11,31]Journaling (for example through diaries)[56] and relaxation strategies may also be beneficial for coping with pregnancy-related anxiety and fear.[56]

These emotional reactions seemed to carry over into the subsequent pregnancy with partners having "difficulty trusting that things would be all right" and feeling "stressed and hypervigilant."[24]

It is essential to consider all those affected by each perinatal loss. Feelings of loss and grief are experienced by fathers/partners, who also need validation and support. It may be beneficial to take a family-centred approach by including partners, siblings, and grandparents in appointments, teaching sessions, and discussions about fears and concerns including opportunities for questions. [24,52]

Some parents may refrain from or have difficulty forming a bond and attachment with the baby during pregnancy due to fear of further loss.[54] This may present as parents not giving their baby a name, not preparing practically for their baby, and/or not attending medical appointments.[48,51,57,58] Healthcare professionals should ask parents about their preparations for the baby and acknowledge the unique challenges of pregnancy and parenting after previous loss.[11] Parents may also benefit from open discussions with health care professionals about the possible stresses that may be experienced postpartum, including delayed parent attachment with their baby, and breastfeeding and parenting challenges.[4,54]

Women with a history of stillbirth are at increased risk for adverse pregnancy and mental health outcomes including longer-term parenting difficulties.[59] Psychological distress increases the risk of poor pregnancy outcomes and longer-term parenting difficulties.[59] However, access to support during subsequent pregnancies is generally offered less than other types of care such as additional antenatal appointments.[9,10] It is important to identify parents experiencing complex or intense grief responses who may benefit from professional follow-up and support after perinatal loss.[60] However, there is little evidence to support the use of mental health screening tools in pregnancies following loss. It is important that all parents receive information and referral to professional support services (such as counsellors, psychologists) with expertise in perinatal mental health.

All parents should be provided with information on local support groups and a list of resources specific to subsequent pregnancies.[51,59,61] Peer support is valued by many families and may counteract social isolation and normalise certain experiences in subsequent pregnancies.[11]

Red Nose and **Bears of Hope** provide a range of support options, including professional grief counselling and peer support. The **Pink Elephants Support Network** provides peer support programs (including Peer Support Live Chat), emotional support resources for parents following early pregnancy loss, including workplace programs to better support parents returning to work. In Aotearoa New Zealand, parents and families/whānau who experience perinatal loss can receive support from a range of support groups, organisations, and resources (see **Baby Loss Directory**).

National perinatal emotional support and mental health is available through PANDA, **ForWhen**, and **Gidget Foundation Australia**. The **Centre of Perinatal Excellence** has an online directory that can be filtered by location to show perinatal mental health services in Australia. The **Centre for Perinatal Psychology** provides a national directory of psychologists with expertise in counselling and support around perinatal loss. The **Perinatal Loss Centre** also maintains a therapist register to enhance access to counselling support across Australia.

Evidence-based recommendation 5.14
Evidence quality: Moderate confidence
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.

Evidence-based recommendation 5.15
Evidence quality: Moderate confidence
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.

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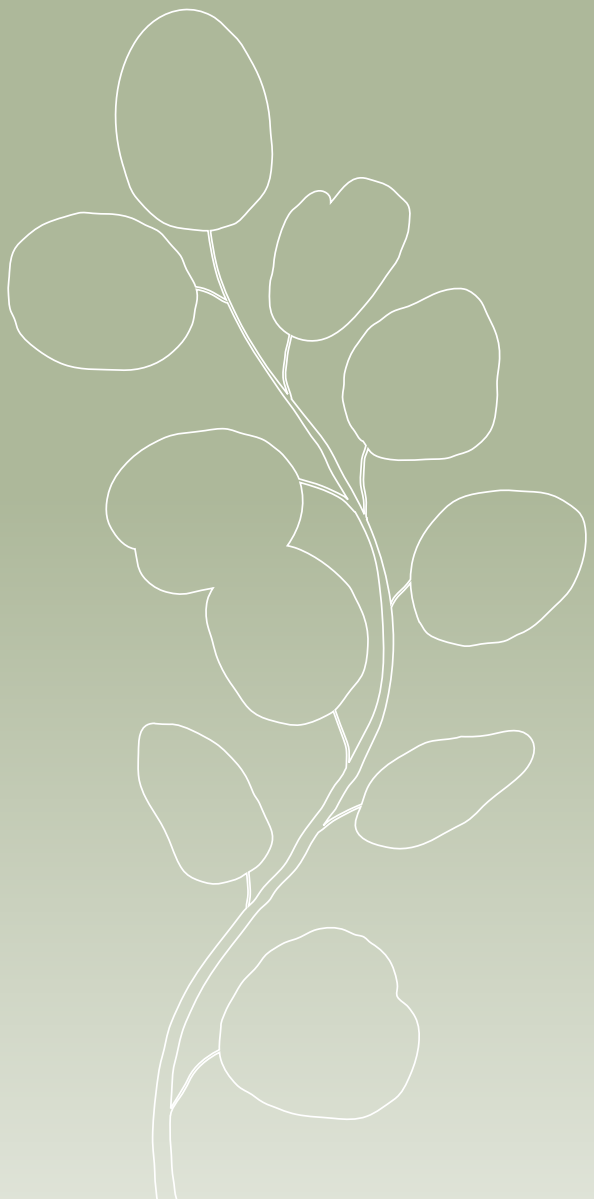
2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline



Section 6: Investigations for perinatal death

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

Background

Identifying the causes of stillbirth and neonatal (perinatal) death through appropriate diagnostic investigations is an essential component of quality care for parents and families/whānau. Parents need the best possible information to help them understand why their baby died and to guide care in subsequent pregnancies.[1,2] Accurate information on the cause of death is also necessary to inform effective prevention strategies.[3]

The quality of information and counselling parents receive about their options can have a significant impact on their decision making around investigations, grieving process, and longterm social and emotional wellbeing.[4,5] However, most stillbirths are not appropriately investigated, many remain unexplained,[2] and parents often report inadequate counselling.

A wide variety of tests and investigations are potentially available. These differ in the level of expertise required, how invasive they are, and their economic costs.[1] While robust evidence to inform the optimal approach is lacking, autopsy combined with genetic testing, placental pathology along with a comprehensive history, and other testing depending on the clinical scenario or initial findings is considered optimal.[6] Congenital anomalies account for around one third of perinatal deaths in Australia and Aotearoa New Zealand,[7,8] underscoring the importance of appropriate investigation to determine cause and risk of recurrence.

Perinatal autopsy rates for Australia and Aotearoa New Zealand are 41%[7] and 34%[9] for stillbirths and 27%[7] and 24% for neonatal deaths,[9] respectively. However, variation in perinatal autopsy rates across Australia indicates higher rates may be possible. In 2020, the highest rates were in Western Australia (57%)[10] and South Australia (56%),[11] compared to 38% in Queensland[12] and Tasmania.[13]

Alternative less invasive options to a full autopsy include a limited autopsy and magnetic resonance imaging (MRI) where available. However, these approaches may limit the information used to establish the specific cause of death or factors that may have contributed to the death.

Whether to have an autopsy is one of the most difficult decisions a parent must make following the death of their baby.[1,14] Discussing postmortem investigations and seeking consent for autopsy can potentially be a very challenging conversation for healthcare professionals, however these discussions are crucial in supporting parents' decision making to understand why their baby died.

Objective

The objective of this section is to provide guidance for frontline healthcare professionals who care for parents and families/whānau in maternal and newborn care services in Australia and Aotearoa New Zealand. This may include doctors, midwives, nurses, social workers, psychologists, Aboriginal and Torres Strait Islander health workers and practitioners as well as Aboriginal liaison officers, and community-based healthcare professionals including community first responder organisations (e.g. ambulance services). This guideline is also for healthcare professionals who care for families/whānau in the transition from hospital to community and provide longer-term ongoing support. Other healthcare professionals such as sonographers, pathologists, and radiologists may also find this guideline helpful in identifying the cause of a baby's death. Healthcare professionals will apply this guideline according to their knowledge, skills, and role, as well as the geographical and cultural setting in which they provide care.

Strong multidisciplinary partnerships are essential to ensure optimal care for parents in identifying the cause of their baby's death.

A note about terminology

This guideline uses parent-centred language that is intended to be inclusive of all affected by loss. We use the term 'woman' throughout the guideline to refer to the person who is pregnant and gives birth.[9] We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth identify as a woman. The term 'parent' is used to refer to expectant and bereaved mothers, fathers, and partners. It is important to recognise individuals who identify themselves as parents. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents.[10] This guideline uses 'baby' when referring to stillbirth, neonatal death because these terms are preferred by many bereaved parents. Terms such as 'fetus' may add to parents' distress because this language denies personhood[11] and is inconsistent with recognition of parenthood that is crucial to providing respectful and supportive care. This guideline uses 'healthcare professional' to denote all those working with bereaved parents and family/whānau (see Glossary).

There was an obligation as parents to find out what had gone wrong and to obtain factual information for themselves, for their baby, and for future children. Emotionally, the desire to protect their baby from further harm was strong, as was the desire "*to be a good mother*".

For some mothers this meant leaving their baby's body intact "*…complete, innocent and perfect as he was*"; for others this meant proceeding with autopsy as "*we owed it to our little man.*"

Bereaved parents, Australia.[16]

Resources

- **Appendix 6A** Stillbirth investigations flowchart
- **Appendix 6B** Neonatal death investigations flowchart
- **Appendix 6C** Estimation of severity of feto-maternal haemorrhage
- **Appendix 6D** Placental examination for healthcare professionals
- **Appendix 6E** Clinical examination of baby checklist
- **Appendix 6F** Instructions on taking clinical photographs
- **Appendix 6G** Autopsy clinical summary form
- **Appendix 6H** Birthweight centiles
- **Appendix 6I** Information for parents and healthcare professionals about perinatal death investigations
- **Appendix 6J** Information for healthcare professionals seeking parental consent for postmortem investigations of a baby
- **Appendix 6K** Exemplar placental histopathology request form
- **Appendix 6L** Indications for placental examination by the pathologist

Communication and decision making

Frontline healthcare professionals providing perinatal loss care play a critical role in helping parents to understand why their baby died and to make a decision about investigations that is right for them. A parent-centred approach to counselling should be taken by a healthcare professional with appropriate training and skills, supported by the multidisciplinary care team.[15]

A wide variety of tests and investigations are potentially available. Autopsy combined with genetic testing, placental pathology along with a comprehensive history, and other testing depending on the clinical scenario or initial findings is considered optimal for most perinatal deaths.[6]

Consenting to autopsy for their baby is one of the most difficult and confronting decisions that parents will make. Some parents may feel strongly for or against an autopsy, and some will feel somewhere in between.[16] All perinatal autopsies require parental consent, except for a small number of deaths where a coronial autopsy is required.

A diverse range of factors influences parents' final decision about autopsy, including personal values; views of extended family/whānau; societal norms; cultural, religious and spiritual beliefs and practices; parents' relationship/s with their healthcare team; parents' degree of emotional distress; and legal issues.[14] The emotional benefits of understanding why their baby died may be important for parents.[4,17-20] Congenital anomalies account for around one-third of perinatal deaths in Australia and Aotearoa New Zealand,[7,8] often following a termination of pregnancy. For some parents who experience a termination of pregnancy for fetal anomaly, autopsy can provide reassurance and validation for their decision.

The way in which healthcare professionals discuss and convey information about investigations such as autopsy has an important influence on parents' decision-making. If healthcare professionals are reluctant to discuss autopsy or believe and convey (even through subtle cues via tone, timing, and content) that an autopsy will add little to no value to understanding why a baby died, parents may be more likely to decline. However, research has shown that parents may later regret not consenting to an autopsy.[16] It is important for healthcare professionals to provide parents with appropriate counselling regarding their options for investigations, including autopsy, to help them make the decision that is right for them and their baby.

"I wanted the doctor to tell me only the most important information because there was too much to take in, but my partner wanted much more detail and to find out everything. We both needed time to think about things."

Parent quote from the *Guiding Conversations* booklet.

Even when the cause of death remains unexplained after completion of all investigations, parents have reported consolation in having explored and excluded known causes to make sense of their baby's death and alleviate feelings of guilt and self-blame. [4,19-23]

"The post-mortem was inconclusive – no cause found – and I felt better because it was nothing I'd done."

Bereaved parent, Aotearoa New Zealand.[20]

Ensuring that parents feel fully informed and adequately involved in the decision-making process may help to minimise regret, regardless of the decision made. Box 1 summarises steps that healthcare professionals can take to create a supportive and parent-centred approach to the autopsy consent process.

To create a supportive decision-making environment, healthcare professionals should:

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 minimise 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.

Box 1: Core attributes of parent-centred practice on counselling on options for stillbirth investigations[16]

Parents may have many questions and concerns about autopsy and other investigations, and these may not always be anticipated by healthcare professionals. Some parents may find it hard to voice their questions and concerns. Concerns may include needing to know[16,24]:
- that their baby is cared for and protected

- where their baby will be taken for investigations
- whether they will be able to see their baby again, and how their baby may look after autopsy
- if there may be delays for funeral arrangements or other important rituals or ceremonies
- the amount of time they will be able to spend with their baby, and whether they can take their baby home if they wish.

Written or digital resources should be used to support decision making by allowing parents to review information in their own time and reflect on what is most important to them. The impact of grief and loss on parents' ability to process information and to make decisions that are best for them can be acknowledged by providing appropriate resources and decision-support tools. Refer to *Appendix 6I* for parent resources to support decision making around investigations, including the *Guiding Conversations* booklet (pages 47–59). In Aotearoa New Zealand, *Pānui/information for whānau/families about post-mortem examination (brochure)* is available in English, te reo Māori, Samoan, Hindi or Chinese.

"We made some decisions on our own, but there were times when it helped to ask questions and talk to others. It was exhausting and overwhelming, but in the end we feel comfortable with our decision. We felt reassured to know that our baby would always be treated with care and respect."

Guiding Conversations booklet.

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.

Evidence-based recommendation 6.3
Evidence quality: High confidence
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.
- how their baby will look after the autopsy
- any costs to them related to investigations.

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.

Cultural considerations

Providing care in a culturally diverse population requires healthcare professionals to acknowledge and address a wide range of beliefs and practices that may be important to parents and families/whānau around the time of a baby's death. Parents from minority populations, and those with fewer educational opportunities are significantly less likely to be offered postmortem investigations such as autopsy.[25,26]

Perceptions about cultural, religious, and spiritual concerns should not be reasons to avoid discussions about investigations.[25] Discussions around cultural, religious, and spiritual needs associated with investigations should be had with parents in the presence of (if required) cultural Elders and interpreters. Open questions help to explore with families/whānau their needs and preferences and to identify appropriate actions, which may include contacting appropriate cultural, religious, or spiritual support services or engaging an accredited interpreter. For example, for Māori whānau the decision-making process may be related to investigations being perceived as a procedure that may disrupt Māori tikanga and cultural protocols around grief, rather than the knowledge that may be gained. Healthcare professionals should avoid assuming that viewpoints are similar within groups. Uptake of investigations may increase if turnaround times can be minimised and awareness raised among community members and healthcare professionals.[27,28]

Physical handling and positioning of baby and placenta may hold cultural, religious, and spiritual significance and meaning for each family/whānau. This may be different within and between cultures. For example, one item in the Arab Muslims' Perceptions of Perinatal Loss Care scale developed in the USA is "I would want my baby turned on his/her right side (towards Mecca) while in the hospital".[29]

Burying the placenta is a common tradition in many First Nations cultures. For Aboriginal and Torres Strait Islander peoples, the placenta is considered the baby's soul map, which must be buried for them to receive Ancestor guidance when they are older.[30]

"I knew I needed Bub's placenta back in the ground on our Country. To me, it means that Bub is connected to her place, even when she was gone. It helps our family to be strong because a part of her is still here."

Parent quote from the *Jiba Pepeny (Star Baby)* booklet.

"[Some non-Aboriginal care providers] have no idea that the placenta is a sacred part of this birth"

Metro Indigenous health worker, Australia

Evidence-based recommendation 6.6
Evidence quality: Moderate confidence
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

Follow-up and communication with parents about results of investigations

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. Finding out the results of investigations can be a difficult time for parents and families/whānau. Uncertainty around timeframes and lengthy waiting times for results are a commonly reported source of distress for many parents.[16,25,31] It is important that parents are assured that they will receive results as soon as they are available.

Healthcare professionals and parents report long delays between hospital discharge and follow-up consultations including information on autopsy results. The delays are characterised by a lack of information and support.[15] A national survey in the UK reported that fewer than half of parents had the results of their baby's autopsy within eight weeks.[15,32] A clear timeline for results and reports of investigations should be made in conjunction with the entire care team, including pathologists, to allow for better structure and predetermined expectations prior to discharge.[15,33] The Royal College of Pathologists of Australasia (RCPA) have developed best practice guidelines for perinatal pathologists.[34]

Evidence-based recommendation 6.7
Evidence quality: Moderate confidence
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.

Bereaved parents often place high value on information about the causes of and contributors to their baby's death to inform quality improvement processes.[35,36] This includes parents being involved in perinatal mortality audit review processes to the extent that they wish. Parent engagement in the review process is strongly advocated by bereaved parents, parent support organisations and many healthcare professionals.[36] It should be explained that the hospital has a clinical meeting where all the results of the investigations are reviewed by a team of experienced healthcare professionals and that the findings of that meeting will be discussed with parents at a follow-up visit.[31,37] See *Section 7: Perinatal mortality audit and classification* for more information and recommendations on perinatal mortality review and classification, including parent engagement.

"I also wanted the possibility that any information learned from her autopsy might prevent loss for someone else sometime in the future. I wanted her to have a 'purpose'."
Bereaved parent, Australia.[16]

Approach to investigations for perinatal deaths

The approach to investigations into perinatal deaths should take into account the most common causes and risk factors within the particular setting of these deaths,[38] the value of investigations, the specific clinical circumstances including timing of the death (intrapartum or antepartum stillbirth or neonatal death), and parent preferences. Congenital anomaly is the most frequent classified cause of perinatal deaths in Australia and Aotearoa New Zealand.[7,8] Spontaneous preterm birth, often associated with ascending infection, also makes an important contribution to perinatal deaths and is the major cause of neonatal deaths.[7,8] Placental insufficiency (with fetal growth restriction) is another important contributor to perinatal deaths.[7,8,39] Factors that increase the risk of stillbirth include preexisting diabetes and hypertension, maternal overweight or obesity, smoking during pregnancy, advanced maternal age, and previous stillbirth.[39,40]

The goal of investigation is to ensure that the most valuable information is obtained from an objective and cost-effective range of tests. Value can be measured according to whether the test identified a new diagnosis, or excluded or confirmed suspected causes.[41]

Although a cause of death may not be found, a negative result may still be valuable to inform future pregnancy planning and parents' coping with the loss of their baby.

While evidence is limited to inform the optimal investigation protocol for stillbirths, there is growing consensus across guidelines internationally.[6] A review of existing national guidelines for stillbirth[6] from the UK,[42] USA,[43] Canada,[44] and Australia and Aotearoa New Zealand[45] showed agreement on a core set of investigations, with additional investigations undertaken depending on initial findings and clinical scenario. For example, thrombophilia testing is now usually recommended in the presence of placental complications, such as fetal growth restriction.[6] The use of a rapid placental examination[46] and imaging prior to a decision for autopsy[47] has been proposed. However, further evaluation of these approaches is needed.

Neonatal deaths can result from disorders of the newborn, the placenta, or the woman. While there are limited studies to guide specific investigation protocols for neonatal deaths,[48] many core investigations for stillbirth may also apply to neonatal deaths. However, due to the presence of a wide range of aetiological, clinical, and geographic circumstances across the spectrum of neonatal deaths, the nature of investigations undertaken may vary widely. For example, the investigation of the collapse and death of a newborn receiving standard hospital postnatal care will require a very different investigative approach to that of a baby born at 24 weeks gestation who eventually succumbs to the complications of prematurity after a lengthy course of neonatal intensive care.

Approaches for alternative less invasive investigations (including imaging), where autopsy is declined by parents, are becoming more standardised.[47,49] However, access to high quality imaging services in Australia and Aotearoa New Zealand is a limitation.

Depending on the circumstances of a perinatal death (for example family/whānau wishes, access to services), it may not be feasible for some investigations to be carried out. Situations will exist where the cause of death is already known (for example an unequivocal diagnosis from prenatal testing). However, as selective investigative approaches may result in important diagnoses being missed, a non-selective approach using the core investigations should be the standard initial approach for all perinatal deaths.

Strong multidisciplinary partnerships are essential to ensure optimal investigation of perinatal deaths. The relative merits of the available investigations should be considered on an individual case basis involving consultation between the healthcare team (including the pathologist, obstetrician and/or neonatologist, radiologist, and geneticist) and the parents. Good communication between neonatal and maternity care teams is important to ensure appropriate investigation of neonatal death – for example in the case of suspected neonatal congenital infection.

Clinical reference guides for healthcare professionals on the recommended core and additional investigations for stillbirth and neonatal deaths are provided. Please see *Appendix 6A: Stillbirth investigations flowchart* and *Appendix 6B: Neonatal death investigations flowchart.*

Further details on additional investigations are also provided under *Additional investigations in specific clinical scenarios.*

Evidence-based recommendation 6.8
Evidence quality: Moderate confidence
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).
- 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.*

Core investigations

A comprehensive history

A comprehensive maternal (medical, social, family/whānau) and pregnancy history is a fundamental component of the investigation protocol[6] that can inform the approach to investigations and may contribute to identifying the cause of death in one-third of perinatal deaths.[50] Identification of risk factors for perinatal death through history taking is an important component of the approach to investigation which may help to inform future pregnancy planning. Further, a systematic approach to gaining parents' summary of events surrounding the death is now recognised as an important part of the history.[51]

Evidence-based recommendation 6.9
Evidence quality: High confidence
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.

Postmortem antepartum fetal ultrasound

A formal fetal ultrasound following diagnosis of a fetal death may provide valuable information, particularly where parents decline an autopsy. This may detect fetal anomalies and allows fetal growth assessment.

Consensus-based recommendation 6.10
A formal ultrasound for fetal anomalies, biometry and amniotic fluid index may be considered. 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.

Testing for feto-maternal haemorrhage

Feto-maternal haemorrhage (FMH) has been identified as an important factor in 1% to 13% of stillbirths. In a US prospective stillbirth cohort, 43.6% of women were tested for FMH, and 4.6% had a positive test.[41] Given the narrow window for testing and relative utility, testing for FMH is recommended for all stillbirths. A Kleihauer–Betke test to detect FMH (with follow-up flow cytometry for quantification if any FMH is detected) should be performed following the diagnosis of the death of any unborn baby, preferably prior to birth but this may also be useful after the birth.[38]

Refer to *Appendix 6C: Estimation of severity of feto-maternal haemorrhage*.

Evidence-based recommendation 6.11
Evidence quality: High confidence
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.

A detailed external examination of the baby by the attending healthcare professional

General examination of a stillborn baby needs to be done promptly, noting any dysmorphic features and obtaining measurements of weight, length, and head circumference.[44] A detailed external examination of the baby is an essential component of the investigation of a perinatal death and is recommended in all current international guidelines.[6] This initial external examination performed at birth by the attending healthcare professional may provide important information to guide further investigations, such as autopsy and magnetic resonance imaging. A proforma is provided to assist the midwife/doctor in carrying out the examination.

Refer to A*ppendix 6E: Clinical examination of baby checklist.*

Consensus-based recommendation 6.12
External examination of the baby should be undertaken by an appropriately trained healthcare professional using *Appendix 6E: Clinical examination of baby checklist.*

Clinical photographs of the baby

Clinical photographs are commonly recommended as part of the investigation of perinatal deaths,[6,52] as these can help to identify a cause of death by guiding further investigation and can also assist in genetic counselling.[53]

The Wisconsin Stillbirth Service Program (WiSSP) indicated that 28% of all stillborn babies had anomalies identifiable on photographs and that photographs were critical in establishing a diagnosis in approximately 5% of cases.[54] Consent from the parents for clinical photographs should be sought and documented in the medical record. While clinical photographs are usually taken as part of the autopsy examination, they should be taken by the health care professional as soon as possible after the death if autopsy is declined or if the parent's decision about autopsy may be delayed.

Refer to *Appendix 6F: Instructions on taking clinical photographs.*

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.

Examination of the placenta and cord by the healthcare professional at time of birth

A detailed macroscopic examination of the placenta and cord by the healthcare professional at time of birth, with documentation of the normal and abnormal findings in the medical record, may help to guide further investigation including autopsy and placental examination by the pathologist.[38,45] Healthcare professionals should document possible cord complications at the time of birth such as 'cord around the neck' or cord entanglement with the baby's body or limbs and take clinical photos to assist in establishing the contribution of such pathologies to the death.

At this time, with the parents' consent, the healthcare professional may take a sample of placental tissue for chromosomal analysis if the placenta is not being sent to the pathology service. If a prenatal karyotype has already been performed, these samples should still be taken for DNA extraction and storage.[55]

Refer to *Appendix 6L: Indications for placental examination by the pathologist; Appendix 6D: Placental examination for healthcare professionals.*

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 6L); 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.*

Full body X-ray imaging of the baby (babygram)

A babygram, comprising antero-posterior and lateral whole-body images to depict the axial skeleton and extremities, is usually carried out at the time of autopsy. It may be undertaken without autopsy and is particularly helpful where skeletal anomalies are suspected[47] to guide further testing and genetic counselling[53] and to estimate gestational age when pregnancy dating is uncertain.

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.

Examination of the placenta and cord by a pathologist

Examination of the placenta and cord by a perinatal pathologist is one of the most cost-effective tests for stillbirth investigation, reducing the likelihood of an unexplained stillbirth and potentially influencing care in subsequent pregnancies.[56] Pathological placental changes have been reported in 23% to 96% of stillbirths.[38,57,58,44]

The value of placental pathological examination extends beyond identifying placental abnormalities, such as those found in pre-eclampsia and intrauterine or intrapartum infection, which can have a causal role in perinatal mortality. Placental pathological examination can also provide prognostic information for the woman and baby[59-61] and support practice improvement.[61] Ideally, all placentas should be retained for a few days after birth to allow for subsequent retrieval should a baby deteriorate, which may occur with sepsis or metabolic disorder.[62]

For a priority list of indications for placental examination by the pathologist, refer to *Appendix 6L: Indications for placental examination.*

Evidence-based recommendation 6.16
Evidence quality: High confidence
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.

Evidence-based recommendation 6.17
Evidence quality: Moderate confidence
Following a stillbirth or birth of a high-risk newborn, the placenta, membranes, and cord should be kept refrigerated and sent fresh to the laboratory and unfixed for macroscopic and histological examination by a perinatal pathologist as soon as possible (ideally within 48 hours of the birth).

Genetic testing

A genetic diagnosis in stillbirth may provide an explanation for the cause of death and influence counselling regarding the risk of recurrence and future pregnancy outcomes.[63] Genetic anomalies are identified as relevant in 6% to 17% of stillbirths.[38] Genetic disease can be the result of chromosomal anomalies, monogenic disease (de novo or inherited) or mitochondrial conditions.

Cytogenetics

Cytogenetics looks for changes in chromosomes including aneuploidy, deletions and duplications, and translocations. The chromosome microarray (CMA) is the most recommended test for the investigation of stillbirth, due to its higher success rate and higher genomic resolution compared to conventional G-banded karyotyping.[63] CMAs that use single nucleotide polymorphism technology have the additional advantage of detecting long continuous stretches of homozygosity in the babies of consanguineous couples who are at increased risk of autosomal recessive conditions, and some cases of uniparental disomy. CMA can be performed on placenta, cord or cord blood, fetal tissue, or saliva.

Evidence-based recommendation 6.18
Evidence quality: High confidence
Cytogenetic testing should be performed for all perinatal deaths by either conventional karyotyping or by chromosome 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 at some point.

Genomic sequencing

Diseases caused by a variant in a single gene are detectable through genomic sequencing (GS). These tests include whole exome sequencing (WES), which identifies variants in the exons (protein coding region of the genes) and whole genome sequencing (WGS), which includes non-coding regions as well. WES is used more frequently in a clinical setting because it is more cost-effective and most single gene disorders are due to variants in exons. WGS has the advantage of detecting variants in other parts of the genome that may affect expression of the gene and cause disease. WGS can also detect deletions or duplications more accurately.[64]

GS is increasingly used in the perinatal setting to understand the cause of fetal anomalies detected on ultrasound when cytogenetic testing has not been informative.[65] Due to the high cost, its application has been limited to situations where a single gene aetiology is considered likely. With appropriate case selection, the pooled diagnostic yield of WES for babies with structural anomalies has been reported as 31% when CMA has been non-diagnostic.[66] The incremental diagnostic yield of WES differs significantly by phenotype, with the highest yields reported for skeletal anomalies (53%), neuromuscular anomalies/ fetal akinesia deformation sequence (37%), and multisystem malformations (29%). Other phenotypes with relatively high yields on WES include isolated nonimmune hydrops (25%)[67] and central nervous system malformations (25%).[68] Australian research[69] on the use of WES to investigate stillbirths has shown that a genomic diagnosis can aid future reproductive planning for some families/ whānau, including the provision of preimplantation genetic testing. GS used as an adjunct to perinatal autopsy can provide a likely diagnosis in approximately 50% of cases when microarray or panel testing did not. The majority of pathogenic or likely pathogenic variants occur de novo. Stillbirths with no associated congenital anomalies have the lowest diagnostic yield (8%).[69]

GS is most informative when performed as a trio analysis with both biological parents.[70] This allows a more accurate interpretation of the impact of a variant in the individual. Genomic testing can provide unexpected information about risk of unrelated disease, family/whānau relationships and reproductive implications and therefore should be offered in conjunction with genetic counselling by an appropriately qualified professional.

Funding models for genomic pathology vary by state/territory and health service. Equitable access to GS[71] and increasing demands on the Australian genetic workforce are major challenges in the implementation of GS.[72] In Victoria, there is public funding to support genomic sequencing for babies who die before or during birth if a multidisciplinary case review deems that a single gene cause is likely and management would be aided if a genetic cause was identified.

Consensus-based recommendation 6.19
In perinatal deaths where there may be a genetic cause, parents should be referred to a multidisciplinary team with expertise in clinical genetics to discuss the option of genomic sequencing where this option is available.

Perinatal autopsy

A full perinatal autopsy is one of the most useful diagnostic tests to determine causes of perinatal death.[6,44,73] Autopsy has been shown to be important in identification of a cause of death in 16%[58] to 42%[41] of stillbirths and 27% of neonatal deaths.[74] While data are limited, the value of autopsy may vary according to clinical scenario.[41]

However, some studies have shown less favourable results for autopsy.[38] For example, one large study showed that investigation of stillbirths and neonatal deaths using a comprehensive protocol (including targeted imaging) without autopsy, had a similar overall rate of diagnosis as those with a full autopsy (56% versus 58%).[50] Variation in findings for studies examining the value of autopsy may be due to different populations, different investigation protocols, and classification systems used.[38]

Perinatal autopsies should be undertaken by pathologists with appropriate expertise and training.[59] Local access to perinatal pathologists may improve consent rates and the quality of autopsy due to removal of transfer needs, and time constraints.[76] In one study, cause of death was confirmed in up to 42% of previously unexplained stillbirths[44] when performed by a perinatal pathologist in consultation with a geneticist. Due to a shortage of trained perinatal pathologists some countries, including Australia and Aotearoa New Zealand, have considerable wait times for autopsy results.[76]

Appropriate clinical information is an essential part of a good quality autopsy. The history of the pregnancy, results of antenatal investigations and circumstances of perinatal loss are vital in determining the relevant questions to be addressed by the autopsy and to inform appropriate ancillary investigations.[1,6,43,50,52]

The value of a negative result from autopsy cannot be underestimated; this may still provide useful information that can help plan and manage future pregnancies and provide reassurance for parents.[52]

A wider importance of autopsy is its value for quality control for antenatal diagnosis, teaching, and research.[75]

Evidence-based recommendation 6.20
Evidence quality: High confidence
Autopsy should be offered to all parents with an explanation of the likely value of the examination, including any limitations, in their specific circumstances.

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.

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 retained organs are to be taken care of and their preferred method of organ disposal.

Evidence-based recommendation 6.23
Evidence quality: Moderate confidence
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: Clinical examination of baby checklist*
- *Appendix 6G: Autopsy clinical summary form*
- *Appendix 6K: Exemplar placental histopathology request form*.

Evidence-based recommendation 6.24
Evidence quality: High confidence
A perinatal/paediatric pathologist should perform or supervise all perinatal autopsy examinations.

Considerations for perinatal autopsy in rural and remote settings

In settings where a perinatal pathologist may not be available, the Genetics Committee of the Society of Obstetricians and Gynaecologists of Canada recommend that gestational age and biometry be documented, photographs and X-rays be taken, and tissue sampling (either from placenta, umbilical cord, or skin) be performed. Communication with a medical genetics service (on-call service available in tertiary care centres) can facilitate these investigations and help coordinate further evaluations when clinically indicated.[33] Transportation of the baby to a centre with appropriate perinatal pathology expertise may be warranted where this expertise does not exist in the birth facility[38,77] In Australia and Aotearoa New Zealand transportation to a tertiary centre with appropriate expertise in perinatal pathology can generally be achieved in a timely manner but this may involve some delay in release of the body for cremation or burial, and parents should be made aware of the expected timelines.

Evidence-based recommendation 6.25
Evidence quality: Moderate confidence
If local autopsy is unavailable, transport for the baby to a centre with appropriate expertise should be arranged as per local procedures.

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.

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.

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).

Coronial autopsy

Healthcare professionals should know consent requirements for perinatal autopsies, which may differ between jurisdictions. Although the coronial process is independent from the hospital, the bereaved parents need explanations regarding what a coronial autopsy involves and the length of time it can take. The purpose of a coroner's autopsy is to determine the cause of death, specifically whether it was natural or unnatural. Each jurisdiction has reasons for notification, so it is important to reference the Coroner's Act for your state or territory. Some examples are:

- babies dead on arrival at hospital
- unattended stillbirths
- deaths after an operation, anaesthetic, or invasive procedure
- deaths because of accident
- unnatural, criminal, or suspicious deaths — for example from neglect, abuse, poisoning
- deaths caused by drugs, prescribed or otherwise
- deaths because of medical mishap
- unexpected death on the ward.[78,79]

If there is any doubt as to whether a death should be referred to the coroner, discussion with an experienced coronial officer or with the coroner is advised. Prior to contacting a coroner's office, maternal and newborn services in rural and remote regions may wish to seek advice from their local tertiary service. Refer to *Section 8: Organisational recommendations* and Consensus-based recommendation 8.3 for more information on establishing protocols to access appropriate expertise when not available locally.

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.

Options for less invasive postmortem investigations

While a full autopsy remains the diagnostic method of choice for most perinatal deaths,[42-44,47,49] noninvasive or minimally invasive approaches should be offered to parents who decline a full autopsy. Offering alternatives to full autopsy reduced the proportion of Māori women in Aotearoa New Zealand who had no investigations for their babies.[20]

Less invasive autopsy options include a limited autopsy (where only specific organs are examined) and minimally invasive tissue sampling.[50] Non-invasive options include imaging (babygram, ultrasound, magnetic resonance imaging [MRI] and computed tomography [CT]) and external examination by a pathologist.[47,49,80,81]

In a review of imaging in investigating perinatal deaths,[47] MRI performed better than ultrasound irrespective of the state of maceration, except for the abdomen, for which there was no significant difference between imaging techniques when the baby was macerated. Microfocus computed tomography (micro-CT) is a promising approach for imaging babies. The authors proposed a stepwise diagnostic approach for fetal examination, where imaging is undertaken prior to a decision about autopsy, which may reduce the need for autopsy.[47] However, further research is needed to test this application in routine practice.[47] Imaging decision trees have been proposed to guide the use of imaging and autopsy for perinatal death[49,82,83] and may prove helpful.

The systematic review from the Dutch postmortem imaging guideline group included a practice-based flowchart for radiology in non-forensic fetal and neonatal deaths.[49] The authors concluded that MRI is the imaging modality of choice for perinatal deaths. Postmortem MRI can provide valuable diagnostic information for perinatal deaths particularly for brain and spinal cord anomalies with advantages over conventional autopsy in the presence of maceration.[47,49,83] MRI should be undertaken within three days of the death and optimally within 24 hours where practicable.[83] When termination of pregnancy because a suspected brain malformation is planned, a fetal MRI may provide more information than postmortem MRI alone.[84]

Postmortem imaging techniques cannot replace the value of histology results in all cases. Tissue sampling (with parental consent) may be required in addition to imaging and is best achieved by image-guided laparoscopic tissue sampling; however, this may be difficult for small babies. Image guided needle tissue biopsy can overcome this limitation,[85] where appropriate services are available. In selected cases, when combined with imaging and other core investigations, the addition of targeted tissue sampling may provide similar results to full autopsy.[27,50]

Due to the complex nature of many perinatal deaths, the optimal approach to alternative investigations should ideally be developed by a multidisciplinary team.[47,85]

Evidence-based recommendation 6.30
Evidence quality: Moderate confidence
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).

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.

Additional investigations in specific clinical scenarios

Some of the main clinical scenarios for perinatal deaths where additional investigations may be required are briefly summarised here. Further, additional investigations for high-risk newborns may provide valuable information particularly in the event of neonatal death where consent for autopsy is not obtained. These suggested recommendations are based on consensus of the Guideline Development Committee and Investigations Advisory Group drawing on international guidelines.[42-44] Refer to *Appendix 6A: Stillbirth investigations flowchart* and *Appendix 6B: Neonatal death investigations flowchart.*

Suspected congenital infection

Routine testing for infection is no longer recommended.[6,38] Targeted investigation should be undertaken if infection is suspected based on maternal history, autopsy and/or placental findings and/or a small-for-gestational age (SGA) baby. To assign infection as the cause of death, refer to PSANZ Classification System (v4: *Appendix 7D and 7E*; v5: *Appendix 7F and 7G*).

Cytomegalovirus (CMV) is the most frequent infectious cause of neurodevelopmental anomalies.[86] Congenital CMV infection is also a recognised cause of fetal anomalies and stillbirth, usually in association with other prenatal or postnatal findings, including fetal brain anomalies, microcephaly, nonimmune hydrops fetalis, severe fetal growth restriction (FGR, petechiae or placental villitis. Placental and autopsy investigations for CMV should be considered where there is a clinical suspicion of congenital infection.

Congenital toxoplasmosis can cause miscarriage, stillbirth, neurological disability, and visual impairment but most babies infected will not have sequelae. As toxoplasmosis is not a common cause of stillbirth,[87] routine testing in the absence of other indications in not recommended.

Parvovirus (B19) can cause severe fetal anaemia, nonimmune hydrops, and fetal death.[88] The peak incidence of B19V-associated hydrops fetalis is at 21 to 24 weeks gestation during the fetal hepatic stage of haematopoiesis.[89] However, the overall contribution of parvovirus infection to fetal loss is low (0.1% to 0.8% during epidemics).[90] Testing for parvovirus is only recommended as part of the investigation of stillbirth if severe anaemia or non-immune hydrops is present.[91,92]

Rubella is associated with a wide variety of adverse fetal outcomes, including stillbirth.[93,94] However, with universal vaccination, congenital rubella infection in developed countries is rare.[95] Most pregnant women are immune and if they have not been tested during the initial routine antenatal blood testing, testing for rubella should be done only if indicated based on core investigations.

Syphilis can cause infection in the placenta and unborn baby and may cause fetal death through placental inflammation and insufficiency, or through fetal anaemia and hydrops.[96] If untreated, syphilis can result in fetal death in approximately 40% of cases.[97] Congenital syphilis may also result in neonatal death, prematurity, and major long-term sequelae in surviving children. Antenatal screening for syphilis for all women is currently recommended to facilitate treatment early in pregnancy. However, congenital syphilis has been increasing in recent years, particularly in some Aboriginal and Torres Strait Islander communities, and additional vigilance for this cause of stillbirth is recommended.[98] Maternal serology and/or postmortem tissue testing should be performed if there is any clinical suspicion based on fetal/baby symptoms including hydrops fetalis, hepatosplenomegaly, thrombocytopenia, and anaemia.

Fetal macrosomia and suspected growth restriction

The increased risk of perinatal morbidity and death with maternal diabetes is well known.[99,100] The possibility of undiagnosed maternal diabetes should be considered in the case of fetal macrosomia (or large for gestational age [LGA]) or suspected FGR including small for gestational age (SGA). HbA1c (glycated haemoglobin) monitors glycaemia over the previous three months by reflecting the average glucose concentration over the life of the red cells. Therefore, it may provide information regarding the contribution of maternal diabetes to a fetal death. Routine HbA1c testing following stillbirth without other indication is not currently justified.[38,42-44] Although most women in Australia and Aotearoa New Zealand undergo screening for diabetes in pregnancy, further testing with HbA1c may still be indicated if there is a clinical indication or a high index of suspicion based on risk factors for gestational diabetes.

It is recommended that HbA1c testing be carried out where LGA, FGR or SGA is detected. If there is no clear maternal diabetic history, other causes of macrosomia in the newborn should be considered such as Beckwith–Wiedemann syndrome with close examination for syndromic features and placental changes. Refer to the Australasian Diabetes in Pregnancy Society (ADIPS) 2020 guideline[99] or the New Zealand Screening, Diagnosis and Management of Gestational Diabetes Mellitus Guideline for further information.[100]

Thrombophilia

Routine testing for inherited thrombophilias following perinatal death is no longer recommended. Testing for APS (anticardiolipin, lupus anticoagulant, and anti-B2 glycoprotein-1 antibodies) is recommended selectively when stillbirth occurs in the presence of one or more of the following: family history of thrombosis; personal history of venous thrombosis; fetal growth restriction; placental abruption; or placental infarction.[38,42-44]

Severe cardiorespiratory depression

Investigations for neonatal deaths from otherwise unexplained severe cardiorespiratory depression at birth should focus on identification of infection, genetic metabolic disorder, and chromosomal anomaly.

Birth trauma

While birth trauma involving the baby has declined in high-income countries over recent decades, perinatal deaths still occur due to birth trauma, particularly associated with instrumental and assisted births. Careful autopsy, particularly of the neck and paravertebral tissues, spinal cord, brainstem, and nerve roots is important when trauma is suspected. These neonatal deaths usually necessitate escalated enquiry such as root cause analysis and/or coronial investigation.

Suspected genetic metabolic disorders

To ensure a precise diagnosis, perimortem evaluation of babies is required when a genetic metabolic disorder is suspected. Healthcare professionals need to counsel parents sensitively about the importance of an accurate diagnosis for future genetic risks. Metabolic disease may cause a baby to be both weak and floppy. Babies with respiratory failure at birth or shortly afterwards should be investigated for peroxisomal disorders, non-ketotic hyperglycinaemia, lipid and storage disorders and mitochondrial disease. Due to the complexity and number of different possible diseases, it is strongly recommended that healthcare professionals discuss each individual case with the clinical geneticist to identify the optimum tests to request. Consultation with a clinical metabolic specialist or paediatric neurologist may be advisable for suspected neurometabolic disease.

The predominant clinical or biochemical presentations of genetic metabolic disorders are as follows: acute encephalopathy; hypoglycaemia, hyperammonaemia, ketosis, disorders of acid base balance; seizures as an early predominant feature; acute hepatocellular disease; sudden death; severe hypotonia; non-immune hydrops fetalis; and facial dysmorphism, with or without congenital malformations.

Obstetric cholestasis

Abnormalities in maternal liver function tests are markers for viral hepatitis, acute fatty liver of pregnancy, HELLP (haemolysis, elevated liver enzymes, low platelet count) syndrome and obstetric cholestasis (OC).[101,102] OC is a pregnancy-specific liver disease, characterised by maternal pruritus and raised serum bile acids. Risk factors for OC include ethnicity, history of previous liver and/or gallbladder disease including hepatitis B and C, prior OC, and multiple pregnancy. A large prospective study[103] confirmed the association between severe OC and adverse perinatal outcomes. The study confirmed that the association previously reported for fasting bile acid testing remains when postprandial samples were used. Liver function and (non-fasting) bile acid testing is therefore recommended following the diagnosis of fetal death if there is a maternal history of pruritus.

Other conditions and investigations

A maternal blood group and antibody screen is recommended as a routine antenatal test at booking and again in the third trimester of pregnancy. If a blood group and antibody screen has not been performed antenatally, it should be performed selectively to exclude haemolytic disease of the newborn due to maternal sensitisation to red cell antigens[104] where the baby is anaemic, jaundiced and/or hydropic.

The RCOG guideline[45] 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). Specifically, RCOG 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.

Illicit drug use including amphetamine, methamphetamine, cocaine, pethidine, meperidine, hydrocodone, and tetrahydrocannabinolic acid may contribute to a range of adverse pregnancy outcomes, and use of these substances has been associated with a 2–3 fold increased risk of stillbirth.[105] While screening for illicit substance use is not recommended as a routine investigation following stillbirth, testing should be considered where indicated based on maternal history.

Additional postmortem investigations for perinatal death following termination of pregnancy for medical reasons need to be considered on a case-by-case basis.

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Stillbirth investigations flowchart

This flowchart provides guidance to healthcare professionals on appropriate investigations to identify the cause of stillbirth. See Appendix 6B for Neonatal death investigations flowchart.

Core investigations	Clinical presentations	Key selective investigations*
Mother • Comprehensive history • Examination • Kleihauer-Betke or Flow cytometry	Diagnosis is unequivocal (including antenatal diagnosis and termination of pregnancy)	Consider whether further investigations are needed
	Personal or family history of vascular thrombosis; previous pregnancy complications (e.g. recurrent early pregnancy loss)	Antiphospholipid antibody test[a] (repeat at ~6–12 wks postpartum if positive)
	Suspected cholestasis	Bile acids; LFTs
	Suspected systemic infection	Blood cultures, midstream urine, vaginal swabs
	No recent scan or no mid-trimester scan	Consider antepartum fetal ultrasound
	Women who have not had a diabetes screen in current pregnancy; women with pre-pregnancy diabetes	HbA1c
	Other conditions e.g. pre-eclampsia; drug use	Consider if further investigations required
Baby • Examination • Clinical photographs • Full autopsy • Full body X-ray (Babygram) If full autopsy declined ⬇ • Limited autopsy • Minimally invasive tissue sampling • External examination by the pathologist • Full body X-ray (Babygram) • Postmortem MRI	Macerated or suspected brain anomalies	Consider postmortem MRI where services are available
	Large for gestational age; macrosomia; polyhydramnios with no identified anatomical cause	HbA1c
	Hydrops	Maternal anti-red cell antibody serology; Maternal anti-Ro and anti-La antibodies; Infections (parvovirus B19; toxoplasmosis; CMV; syphilis; coxsackie)
	Small for gestational age; fetal growth restriction	HbA1c, Infections (CMV; syphilis) Consider antiphospholipid antibody test[a] if growth restriction (repeat at 6–12 wks postpartum if positive)
Placenta • Macroscopic examination • Histopathology studies • Placental microbiology • Cytogenetics	Suspected or confirmed fetal anomalies	Further testing as directed by pathologist, which may include testing for infections; consider clinical genetics review
	Placental abruption or infarction	Antiphospholipid antibody test[a] (repeat at ~6–12 wks postpartum if positive)

[a]Antiphospholipid antibody test includes anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1 antibodies; CMV: Cytomegalovirus; LFTs: liver function tests; HbA1c: Haemoglobin A1c; MRI: magnetic resonance imaging

Neonatal death investigations flowchart

This flowchart provides guidance to healthcare professionals on appropriate investigations to identify cause of neonatal death. See Appendix 6A for Stillbirth investigations flowchart.

Core investigations	Clinical presentations	Key indicated selective investigations*
Mother • Comprehensive history • Examination	Extreme prematurity	• Vaginal swab
	Severe cardio-respiratory depression at birth; overwhelming sepsis	• Vaginal swab • Blood culture
	Congenital infection	• Vaginal swab • CMV, toxoplasmosis, parvovirus B19, syphilis, rubella serology (if not already done in pregnancy)[a]
	Severe fetal growth restriction; hydrops; pallor/suspected severe anaemia; lethal congenital anomalies	CMV, toxoplasmosis, parvovirus B19, syphilis, rubella serology (if not already done in pregnancy)
Neonate • Examination • Clinical photographs • Full autopsy • Full body X-ray (Babygram)	Extreme prematurity	• FBC, CRP • Blood culture
	Severe cardio-respiratory depression at birth; overwhelming sepsis	• FBC, NRBC, CRP • Blood culture • BGL, ABG, LFTs
If full autopsy declined ↓ • Limited autopsy • Minimally invasive tissue sampling • External examination by the pathologist • Full body X-ray (Babygram) • Postmortem MRI	Congenital infection; severe fetal growth restriction; hydrops; pallor/suspected severe anaemia	• FBC, NRBC, CRP
	Macrosomic infant	• FBC • BGL
	Suspected genetic metabolic disorders	• FBC • BGL, ammonia, ketones, ABG, LFTs, urine metabolic • Microarray/karyotype/DNA for storage or further testing[b]
Placenta • Macroscopic examination • Histopathology studies • Placental microbiology • Cytogenetics	Suspected or confirmed fetal anomalies	Further testing as directed by pathologist, which may include testing for infections; consider clinical genetics review
	Severe cardio-respiratory depression at birth; overwhelming sepsis	• Placental swab aerobic, anaerobic culture and fungal culture • Placental biopsy for PCR/viral culture
	Congenital infection	Vaginal swab; CMV, toxoplasmosis, parvovirus B19, syphilis, rubella serology (if not already done in pregnancy)[a]; Consider further tests as directed.

[a]Palasanthiran, P., Starr, M., Jones, C., & Giles, M. (eds). (2022). Management of perinatal infections. Australasian Society for Infectious Diseases; [b]blood sample/cord/tissue; ABG: arterial blood gas; BGL: blood glucose level; CMV: cytomegalovirus; CRP: C-reactive protein; FBC; full blood count; LFTs: liver function tests; MI: minimally invasive; MRI: magnetic resonance imaging; NRBC: nucleated red blood cells; PCR: polymerase chain reaction.

Estimation of severity of feto-maternal haemorrhage

To determine if a positive test for FMH should be considered as the likely cause of fetal death, the *percent of total fetal blood volume lost* should be calculated. Such a calculation uses the following correction factors: fetal red cells are 122% the size of adult red blood cells; 92% of fetal red cells are detected by the Kleihauer-Betke test on average; maternal red cell volume near term averages about 1800 ml; average fetal hematocrit is about 50%; fetal blood volume is about 150 ml per kilogram of body weight. Combining all of these then means that:

$$\text{Percent Fetal Blood} = \frac{\text{Fetal Cells} \times 1800 \times 1.22 \times 100}{\text{Volume Lost Maternal Cells } 92 \times 2 \times 100 \\ 150 \times \text{Fetal Weight (kg)}}$$

or, to simplify,

$$\text{Percent Fetal Blood} = \frac{\text{Fetal Cells} \times 3200}{\text{Fetal wt}}$$

Volume Lost Maternal Cells (kg)

So, for example, if the Kleihauer-Betke shows that *200 of 5000* cells counted are fetal and the fetus weighs *2.0 kg,* then the estimate of percent blood volume loss would be *200/4800 x 3200 ÷ 2.0,* or *66%.*

Probably less than 20% volume loss is enough to cause death if it happens all at once. On the other hand, much larger volumes can be lost over a long period and the fetus can compensate. Unfortunately there is no straightforward way to know whether one is dealing with acute or chronic haemorrhage. This makes determination of whether a haemorrhage is or is not causal more problematic.

Taken from
Fetal-Maternal Hemorrhage and Stillbirth, Richard M. Pauli, M.D., Ph.D.

Placental examination for healthcare professionals

Please complete details as required

☐ Singleton ☐ Multiple

Baby Number ☐ (e.g. Twin 1)

Maternal sticker

Inc Name, DOB, UR, Address, Telephone number

Step 1

Accoucheur examination of the placenta, membranes and cord using sterile gloves

Cord insertion (Circle)		Eccentric / Central / Marginal / Velamentous / Other:			
Cord appearance (Circle)		Thin / Thick / Meconium Stained / Other:			
No. of cord vessels		**Total cord length**	cm	Cord knots (Circle)	Yes / No
Placental dimensions	cm	**Placental weight**	g	**Placental odour**	
Maternal surface (Circle all that apply)		Intact / Incomplete / Gritty / Infarcts / Retroplacental Clot / Succenturiate / Circumvallate / Bipartite			

Step 2

Tissue sampling for chromosomal analysis

Prior to sending the placenta to pathology, a sample of umbilical cord should be collected using aseptic technique as outlined below. If there are any clinical indications of placental mosaicism, then a placental sample may be required as well.

- Collect a 1cm3 sample from cut end of umbilical cord using sterile surgical knife and dissection forceps
- Place in either a designated cytogenetics bottle or a sterile container, with either sterile saline solution or cell culture transport medium. Then seal the bottle and label with maternal name, UR number, date and time of collection and multiple number if appropriate

Step 3

Send placenta

Send placenta, membrane and cord to the Pathology fresh and unfixed for histopathological examination

Clinical examination of baby checklist

Maternal sticker
(Inc Name, DOB, UR, Address, Telephone number)

◯ Singleton ◯ Multiple Baby #: _____
e.g. Twin 1

1. Baby Measurements

a. **Crown - heel (stretched)** _____ cm
b. **Head Circumference:** _____ cm
c. **Weight:** _____ g

If stillbirth:

a. **Estimated date of IUFD:** / /
b. **Maceration degree:**

- ☐ Fresh *(no skin peeling)*
- ☐ Slight *(focal minimal skin slipping)*
- ☐ Mild *(some skin sloughing, moderate skin slippage)*
- ☐ Moderate *(much skin sloughing, no secondary comprehensive changes or decomposition)*
- ☐ Marked *(advanced)*

2. Head and Face

a. **Head:**
- ☐ Relatively normal ☐ Anencephalic
- ☐ Collapsed ☐ Hydrocephalic
- ☐ Abnormal shape *(please describe below)*

b. **Eyes:**
- ☐ Normal ☐ Prominent
- ☐ Close Together ☐ Far Apart
- ☐ Sunken ☐ Straight
- ☐ Upslanting ☐ Downslanting
- ☐ Globes Normal ☐ Absent
- ☐ Eyes very small ☐ Eyes very large
- ☐ Lens opacity ☐ Corneal opacity
- ☐ Eyelids fused
- ☐ Other *(please describe)*

c. **Nose:**
- ☐ Normal ☐ Asymmetric
- ☐ Abnormally small ☐ Abnormally large

d. **Nostrils:**
- ☐ Apparently patent ☐ Obstructed
- ☐ Single Nostril
- ☐ Other *(please describe)*

e. **Mouth**
- ☐ Normal Size ☐ Large ☐ Small

f. **Upper Lip**
- ☐ Intact
- ☐ Cleft
  - ☐ Left ☐ Right
  - ☐ Bilateral ☐ Midline

g. **Palate**
- ☐ Intact ☐ Cleft

h. **Mandible**
- ☐ Normal Size ☐ Large ☐ Small
- ☐ Other *(please describe)*

i. **Ears**
- ☐ Normal ☐ Preauricular tags
- ☐ Lowset ☐ Preauricular pits
- ☐ Preauricular rotated
- ☐ Other *(please describe)*

3. Torso

a. **Neck**
- ☐ Normal ☐ Mass

b. **Chest**
- ☐ Normal ☐ Long & Narrow
- ☐ Short & Broad ☐ Long & Narrow
- ☐ Other *(please describe)*
- ☐ Spina Bifida *(please describe)*

c. **Abdomen**
- ☐ Normal ☐ Flattened
- ☐ Distended ☐ Hemia
- ☐ Omphalocele ☐ Gastroschisis

d. **Back**
- ☐ Normal ☐ Scoliosis
- ☐ Kyphosis
- ☐ Spina Bifida *(please describe)*
- ☐ Other *(please describe)*

4. Genitalia

a. **Anus**
- ☐ Normal ☐ Imperforate
- ☐ Other *(please describe)*

b. **Gender**
- ☐ Male
  - i. **Penis**
    - ☐ Normal ☐ Very Small
    - ☐ Hypospadias ☐ Chordee
    - *(please describe level of opening)*
  - ii. **Scrotum**
    - ☐ Normal ☐ Abnormal *(please describe)*
  - iii. **Testes**
    - ☐ Descended ☐ Undescended
    - ☐ Other *(please describe)*
- ☐ Female
  - i. **Urethral opening**
    - ☐ Present ☐ Absent/unidentifiable
  - i. **Vaginal introitus**
    - ☐ Present ☐ Absent/unidentifiable
  - iii. **Clitoris**
    - ☐ Present ☐ Unidentifiable
    - ☐ Enlarged
    - ☐ Other *(please describe)*
- ☐ Ambiguous sex *(please describe)*

5. Limbs

a. **Length**
- ☐ Normal ☐ Long
- ☐ Short *(please describe which segments)*

b. **Form**
- ☐ Normal ☐ Asymmetric ☐ Missing Parts
- ☐ Other *(please describe)*

5. Hands

a. **Length**
- ☐ Normal ☐ Long
- ☐ Short *(please describe which segments)*

b. **Fingers**
- i. **Number present:** _____
  (if not 4+4, please describe)
- ☐ Unusual form of fingers
- ☐ Unusual position of fingers
- ☐ Abnormal webbing or syndactyly
  (If abnormal, please describe)

b. **Thumbs**
- i. **Number present:** _____
  (if not 1+1, please describe)
- ☐ Unusual position ☐ Looks like a finger
  (If abnormal, please describe)

c. **Finger nails**
- ☐ All Present ☐ Other *(please describe)*

5. Feet

a. **Appearance**
- ☐ Normal ☐ Abnormal *(please describe)*

b. **Toes**
- i. **Number present:** _____
  (if not 5+5, please describe)
- ii. **Spacing**
  - ☐ Normal ☐ Abnormal *(please describe)*

c. **Toe Nails**
- ☐ All Present ☐ Other *(please describe)*

Examined by:

Date

Revised gestational age:

Based on:

Summary of key findings:

Instructions on taking clinical photographs

Clinical photographs should be taken by an expert trained in perinatal pathology or medical imaging, at the time of postmortem. Occasionally situations may arise where by clinical staff (doctor, midwife, nurse) are required to take clinical photographs. Photographs may be critical to making a diagnosis in a non-examined baby. Reasons for staff taking these photographs may include: family not wanting to be separated from the baby, immediate burial is required thus precluding postmortem examination, or prior to deterioration if there is a delay in postmortem being conducted.

Purpose

High quality medical photographs are necessary as part of the clinical investigation pathway, and ideally digital photographs should be taken. These are most often taken in Perinatal Pathology by trained staff, and/or Medical Imaging may be the appropriate unit in some organisations. There must be a secure process for storage of these images (see local unit policy).

These photographs are in addition to bereavement/social photographs, which are commonly taken by midwives in attendance in the labour and birth suite. There are a number of volunteer organisations who will provide professional bereavement photographs to bereaved parents, often at no charge, and all institutions should be aware of local availability of such a service. There must be a process in place for providing these photographs to parents (see local unit policy).

There are a number of volunteer organisations who will provide professional bereavement photographs to bereaved parents

Consent

Parental consent is necessary prior to taking clinical photographs (see local unit policy on ‘Consent for Taking Clinical Photographs’ or similar). If there is no consent policy or consent proforma, ensure that the consent process is documented in the maternal medical record. A generic ‘consent’ form may be considered if there is no specific consent form available. Documentation should include: information provided on benefit/need for clinical photographs, who will be using the photographs, how photographs are stored, and the purposes for which the photographs can be used, options include for visual examination, for presentation, for publication etc. Bereavement photographs may require verbal agreement that they are taken and provided (see local unit policy).

Identification

The baby must be identified in the photographs. Write the baby’s medical record number, if available, depending on status at birth, place of birth and local unit policy. If there is no individual medical record number, write the maternal medical record number with the baby's date and time of birth. This identifying information should be written on the paper tape measure for identification, some local policies will allow a baby leg/arm band to be used as identification.

Stillborn babies often do not have a medical record number, then use the mother’s medical record number and the baby’s date and time of birth to identify the body.

If photographs are being used for publication or presentation, it is important that no identifying features are seen.

Instructions on taking clinical photographs

Setting

Photographs should be taken in a private area away from the parents, with sensitivity. However, some parents may request the photographs be taken in their presence.

The setting should comply with occupations safety and health regulations, such as infection control guidelines, work place design, etc.

Scale

Place a paper tape measure next to the baby (a plastic ruler will create glare) for scale. Ensure zero is aligned at the base of the foot or crown of the head and extend lengthways. You can use sticky tape to ensure the tape is straight (rigid) and measure should be on the bottom of the frame or the left.

Technique

A hard surface with a blue background is best when taking clinical photos.

The photographs should be taken from directly above the baby. Consequently, it is best to place the baby on a low bench, in order to get sufficient height above the baby.

Magnification

Use a digital camera to take the photographs, do not use the zoom to get a close up; however, do make sure you move the camera closer to the body. This will produce better quality photographs that may be enlarged for presentation.

Baby

The baby should be naked for all the photographs.

Position

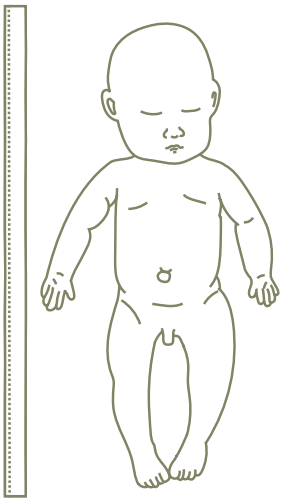
- Anterior Posterior (AP) view – whole body frontal including limbs
- Posterior Anterior (PA) view – whole body back including limbs
- Lateral view of the body
- Lateral views of the face
- Frontal view of the face
- Photographs of any abnormalities.

General comments

Additionally, staff should

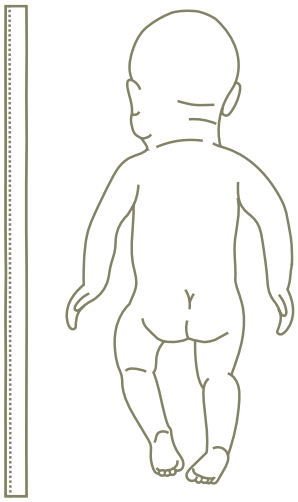
- Refer to local unit policy/guidelines
- Document processes and actions
- Ensure a documentation trail for storage.

Instructions on taking clinical photographs



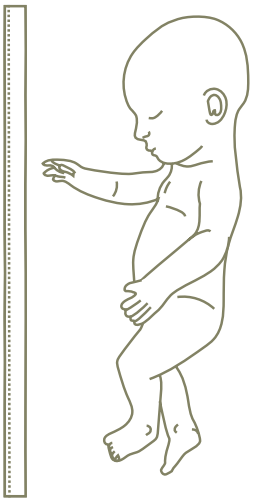
AP View - Whole body frontal including limbs

- Tape measure to the left
- Palms facing up



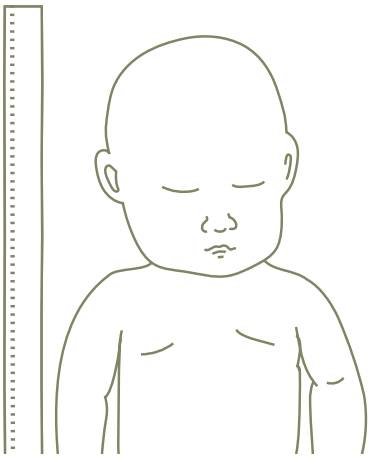
PA View - Whole body back front including limbs

- Keep baby in this position for the minimum time possible
- Tape measure to the left
- Palms facing down



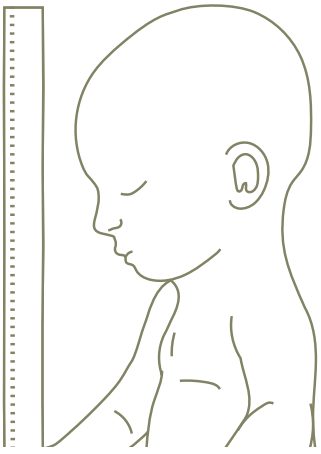
Lateral view of the body

- Pull underneath arm forwards
- Legs in ‘running position'
- Top arm and leg will fall forward which will aid stability
- Tape measure to the left



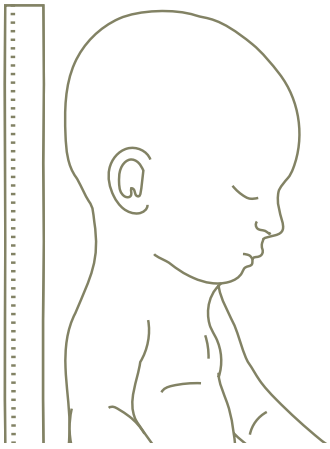
Frontal view of the face

- Ensure tape measure is in the frame



Right lateral views of the face

- Tape measure to the left of the frame to aid easy identification of the side being viewed



Left lateral views of the face

- Tape measure to the left of the frame to aid easy identification of the side being viewed

Autopsy clinical summary form

Please attach the following:

- *copy of the death certificate*
- *copies of all antenatal ultrasound reports, and*
- *copy of amniocentesis report if available*

Maternal sticker
(Inc Name, DOB, UR, Address, Telephone number)

◯ **Singleton** ◯ **Multiple** **Baby #:** e.g. Twin 1

Baby Details

a. **UR Number:**

b. **Sex**
◯ Male ◯ Female ◯ Undetermined

c. **Gestational age:** weeks / days

d. **Birthweight:** g

e. **Date & Time of Birth:** / / :

f. **Place of Birth:**

g. **Type of Death:**
◯ Fetal
a. **Antepartum death**
◯ Unknown ◯ No
◯ Yes, estimated date of death: / /
◯ Neonatal (NND)
a. NND Date & Time of Death: / / :

h. **Death Certificate Completed**
◯ Yes ◯ No

Autopsy Hazard

a. **Treatment or condition likely to cause hazard at autopsy:**
◯ Hepatitis B Pos ◯ Tuberculosis
◯ HIV (AIDS Virus)
◯ Other ***(please describe)***

Clinical Summary *(including details to be clarified at autopsy)*

Provisional Clinical Diagnosis *(to be completed by physician requesting autopsy)*

1.
2.
3.
4.

Please list doctors to receive report

Name	Address
1.	
2.	

Consultant:

Clinical Contact:

Signature: (person completing this form)

Print Name:

Telephone:

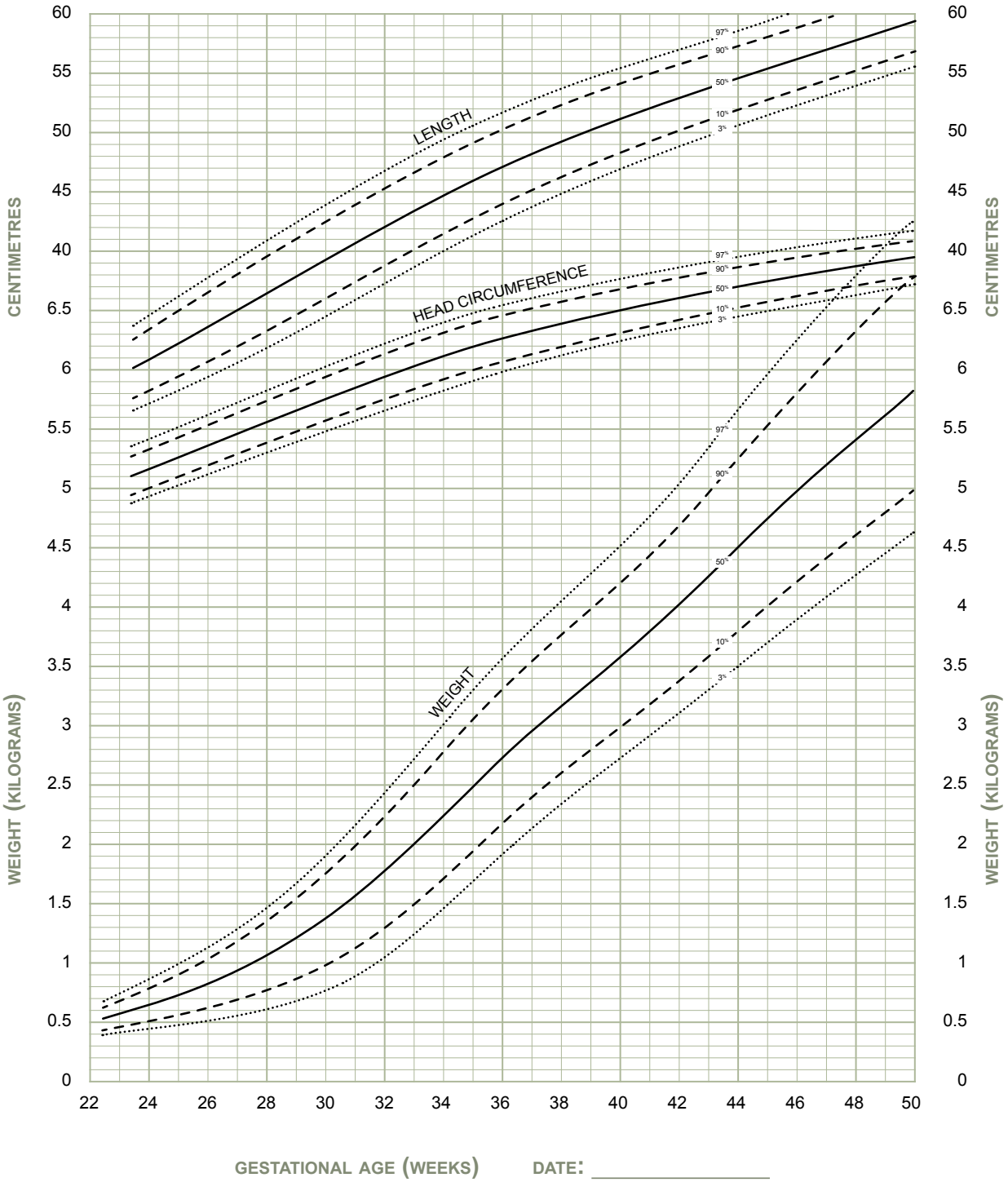
Pager:

Date: / /

Birthweight centiles

AUSTRALIAN BIRTHWEIGHT CENTILES FOR BOYS

FENTON PRETERM GROWTH CHART - BOYS



GESTATIONAL AGE (WEEKS) DATE: _____

Curves equal the WHO Growth Standard at 50 weeks.

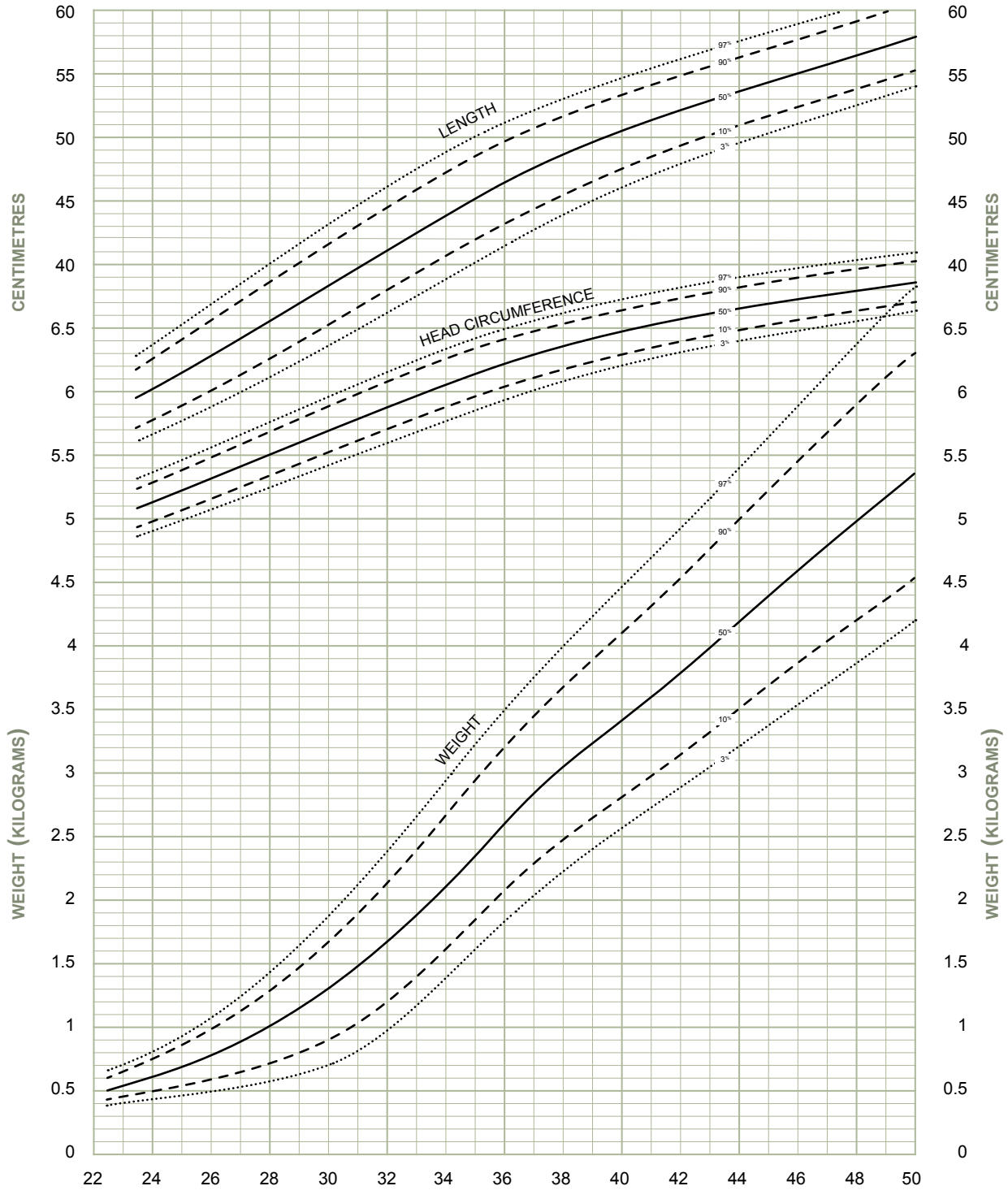
From: Fenton TR, Kim JH. A systematic review and meta-analysis to revise the Fenton growth chart for preterm infants. BMC Pediatrics 2013; 13(1): 39

Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death, Third Edition, March 2018

Birthweight centiles

AUSTRALIAN BIRTHWEIGHT CENTILES FOR GIRLS

FENTON PRETERM GROWTH CHART - GIRLS



Curves equal the WHO Growth Standard at 50 weeks.

From: Fenton TR, Kim JH. A systematic review and meta-analysis to revise the Fenton growth chart for preterm infants. BMC Pediatrics 2013; 13(1): 39

Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death, Third Edition, March 2018

Information for parents and healthcare professionals about perinatal death investigations

Resources for parents

The Stillbirth CRE together with the Stillbirth Foundation Australia and Red Nose have developed a range of parent-facing resources to support decision making around perinatal death investigations.

Please scan the QR code to access these resources for printing. Note, most resources listed are designed to be printed and provided to parents as a hard-copy resource. Most are not currently available to parents in digital format (e.g. to view on an app or tablet).

If you would like to receive a kit of printed resources, please contact the Stillbirth CRE via email: stillbirthcre@mater.uq.edu.au

- *Guiding Conversations (parent version of the guideline)*. This booklet is a companion resource to the CASaND Guideline and specifically developed for parents. It is designed to support parents and assist healthcare professionals as they navigate difficult conversations and decisions around the time of a baby's death.
- *Jiba Pepeny (Star Baby) (parent version of the guideline)*. This booklet is a companion resource to the CASaND Guideline and developed by Aboriginal people for Aboriginal people. This resource is to help Aboriginal people through the Sorry Business of losing their bub.
- *Trying to find answers when your baby has died*. This two-page brochure describes the types and process of an autopsy to help parents understand their options and some of the decisions to be made.

- *Understanding what happened to your baby.* This brochure is intended to help parents understand their options and some of the decisions to be made.
- *Translated resources.* Booklets and videos about autopsy and investigation in Arabic, Chinese (simplified and traditional), Spanish, Vietnamese, Dari, Dinka, Hindi, and Karen.
- *Understanding what happened to your bub.* This brochure is codesigned with First Nations people and is intended to help Indigenous and Torres Strait Islander peoples understand their options and some of the decisions to be made.
- *Parents of loss*. This brief video (4.37 min) has been created by bereaved parents to help share common thoughts and feelings around stillbirth investigation and autopsy.

Resource for healthcare professionals

Discussing postmortem investigations with parents. This brochure outlines the importance of discussing postmortem investigations with parents, including descriptions of autopsy and alternatives to autopsy, barriers to autopsy consent, and information to have available when holding discussions. Available in CASaND Guideline: Appendix 6J

Information for healthcare professionals seeking parental consent for postmortem investigations of a baby

Discussing postmortem investigations with parents

The death of a baby is devastating for parents and their family. Often the death is unexpected, and the parents are confronted with the shock of losing their baby, as well as the overwhelming emotions that follow. Sensitivity and compassion are critically important when providing information to parents around the death of a baby. This resource aims to provide guidance to healthcare professionals when approaching bereaved parents to discuss postmortem investigations. Each hospital should have its own policy and procedures regarding parental consent for autopsy and other investigations. This policy should initially be consulted.

Why is it important to offer bereaved parents postmortem examinations?

Provision of information on why postmortem investigations are performed will help parents make the right decision for their baby. The primary reason for postmortem investigations is to understand why the baby has died. The investigations may confirm suspected reasons for the death or uncover new information, which may help parents to understand what happened and may be useful in planning care for future pregnancies. Information from investigations after a perinatal death can also help healthcare services and researchers understand why babies sometimes die. A full investigation does not always provide an answer as to why a baby died, but it does offer the best opportunity to get this information, and may rule out some possible causes.

Parents should be given time to consider the information before making their decision

What are the options?

Explain to the parents that a full work-up following stillbirth or neonatal death and a full autopsy provides the highest likelihood of finding a cause of death along with placental examination.

As soon as possible after diagnosis of a fetal death in utero, a **fetal postmortem ultrasound** should be performed by a skilled healthcare professional; this may help to identify selected abnormalities.

Placental examination is one of the most important investigations. Parents should be offered the option of taking the placenta home after examination.

Full autopsy is where a perinatal pathologist makes surgical incisions and examines the baby's internal organs. Samples may be taken for examination under a microscope and medical photographs and X-rays may be taken. Examination of the placenta is included.

Less invasive options may be offered if parents decline a full autopsy. It is helpful to discuss these options with a perinatal pathologist to ensure the most appropriate investigation is undertaken. Less invasive options include **limited autopsy** which includes targeted examination of organs or tissues (also known as minimally invasive tissue sampling) by the pathologists based on clinical suspicion of case (e.g. the chest organs only, if a cardiac anomaly is suspected).

Noninvasive options include **external examination** of the baby by a specialist doctor or pathologist without surgical incisions. **Medical photographs** may help to identify possible causes of death and enable consultation with specialist expertise. **Full body Xray** imaging of the baby (also known as a 'babygram'), helpful where skeletal abnormalities may be suspected.

A postmortem MRI, where appropriate MRI services are available, can be helpful as an adjunct or, where parents decline an autopsy, in place of autopsy. Consultation between the obstetric and /or neonatal team, perinatal pathologist, and radiologists will help to inform specific situations where postmortem MRI is likely to be most helpful.

Barriers to autopsy

The most common reason for parents to decline a full autopsy is concern about the invasiveness of the procedure. In addition, there are common misunderstandings around autopsy that may lead parents to decline. For example, parents may have concerns that they will not get to see their baby following the examination or that organs will not be returned. Sometimes autopsy is at odds with religious or cultural practices around death. It is important to acknowledge parents' protective instincts towards their baby, address any unfounded concerns, and respond honestly to questions. Other important barriers are belief that the cause is already known. A lack of understanding by healthcare professionals about the value of autopsy can also be a barrier.

When is the best time to discuss options?

The best time to discuss postmortem investigations varies. When a baby dies in utero, the parents should be given time to begin processing the information that their baby has died before discussing postmortem investigations. Discussing postmortem investigations prior to birth may be appropriate, particularly if parents are asking for information about why baby has died. However, some parents can't comprehend that their unborn baby has really died until the baby is born, so mentioning postmortem investigations prior to the birth can be difficult in this circumstance. In addition, many parents are too distressed immediately following the birth to discuss autopsy and require time before initiating this conversation. Each situation is different. The decision to have a postmortem investigation is time-sensitive in that it is ideally performed within 72 hours of birth. However, the timing for initiating the discussion needs to be as sensitive as possible.

Who should ask?

Due to the sensitive nature of the issue, the person most appropriate to initiate a discussion about postmortem investigations is the consultant obstetrician or paediatrician, or the healthcare professional, such as lead midwife or specialist bereavement care midwife, who has an established relationship with the parents. In all cases, the healthcare professional must be familiar with the process of discussing postmortem investigation options with parents' and be competent in answering questions relating to the procedures and processes in a sensitive and informative manner. The IMPROVE course is recommended for all healthcare professionals providing care for families around the time of a perinatal death. **https://stillbirthcre.org.au/researchers-clinicians/education-and-workshops/**.

Where should the discussion be held?

The most appropriate environment is a quiet, private room away from other patients, relatives, and hospital staff. It is not appropriate to have this discussion in a corridor, shared room, or public waiting room. Some parents may prefer that discussions about postmortem investigations not take place in the presence of their baby.

How do I discuss postmortem investigations with parents?

The healthcare professional should approach the discussion with honesty, integrity, and respect. They should explain all the investigation options, their clinical indications, and why they recommend certain options.

Generally, terms such as fetus, products of conception or termination, should be avoided. Although healthcare professionals should take their cues from the parents in terms of preferred language. If the baby has been given a name, refer to them using their name because this helps to validate the importance of the baby to the parents, as well as the significance of their loss.

Parents should be given time to consider the information before making their decision, and encouraged to discuss with others in their decision-making circle. It is important to understand that parents are likely to have questions and/or concerns about the autopsy process. Parents should be encouraged to express these concerns openly.

Some parents may require information several times as shock and grief may limit the ability to take in and process new and unfamiliar information. Parents should be offered written and/or audiovisual information to refer to following the discussion. However, some may prefer not to have detailed autopsy information, so check before presenting this.

Ask all parents about any cultural, spiritual or religious needs around death and dying that are relevant to the discussion of autopsy. It is important not to make

assumptions about religious or cultural practices based on the parent stated or apparent religion or ethnicity. Cultural and religious requests should be accommodated where possible.

Information you need to have

- Types of postmortem investigations available and the advantages and disadvantages of these.
- Where the baby will go for the autopsy, when it is likely to occur, and when the baby will be returned to the parents.
- Information regarding the presentation of the baby after autopsy, for example, where the incisions will be made, and that they will be delicately repaired and covered with a dressing. Baby will be carefully redressed and wrapped afterwards.
- Confirmation that the baby will be returned to the parents for burial or cremation according to their wishes.
- Confirmation that they will be able to see and hold their baby after the autopsy.
- If any organ, including the placenta, is to be retained for longer, the parents can either delay the funeral, or have a separate burial or cremation of the organs later.
- Process for communicating the results, including contact details of who will arrange an appointment to discuss the results.
- Any associated costs for the autopsy or investigations.

Reporting results

Explain to parents that the final report may not be available for several weeks or months. Although, provisional results are likely to be available sooner. Advise parents of how the results will be communicated to them (e.g. never by text message or by phone with no preparation). This will help to reduce anxiety in the parents as they wait for the final report. Ensure parents understand that sometimes no explanation is found for the cause of death.

Important things to keep in mind when counselling parents

- Treat parents with respect.
- Always be honest.
- Use the baby's name if this is the parents' preference.
- Use a quiet, private place to conduct discussions.
- Introduce details at the individual's pace and use language that parents understand.
- Give parents time to make their decision.
- Offer written and audiovisual material.
- Make a note of what you say and what the parents say.
- Avoid terms such as 'fetus', 'products of conception', and 'termination' to refer to the baby unless parents use these terms first.
- Be prepared for strong emotions. Do not get defensive. Parents may be looking to blame healthcare professionals and may be feeling hostile and angry. These are real emotions that may help bereaved parents maintain a sense of control in an uncontrollable situation. These emotions must be acknowledged by you in an understanding and supportive manner.

Avoid terms such as 'fetus', 'products of conception,' and 'termination' to refer to the baby unless parents use these terms first

"The healthcare professional should approach the discussion with honesty, integrity, and respect."

Stillbirth Foundation Australia
Research, education and advocacy to reduce the incidence and impact of stillbirth.
(02) 9557 9070
stillbirthfoundation.org.au

Stillbirth Centre of Research Excellence
Research, resources and information to reduce the number of stillborn babies and provide best possible support for parents and families when a baby dies.
stillbirthcre.org.au

Red Nose
Supporting families whose babies have died through peer support and professional counselling services.
1300 308 307 (Available 24 hours)
rednose.org.au

Bears of Hope
Leading support and exceptional care for families who experience the loss of a baby.
1300 11 HOPE
bearsofhope.org.au

Still Aware
Supporting a safer pregnancy through education and awareness programs nation-wide.
stillaware.org

Pink Elephants Support Network
Providing the latest resources, information, and peer support for anyone impacted by early pregnancy loss.
pinkelephants.org.au

Exemplar placental histopathology request form

This placenta is a:

- ☐ singleton
- ☐ twin (monochorionic/dichorionic)
- ☐ twin (monoamniotic/diamniotic)

with the following features:

PLACENTAL MATURITY:

This is a:

- ☐ mature placenta
- ☐ premature placenta
- ☐ immature placenta

In keeping with ☐ **weeks gestation.**

Is there placental dysmaturity?

☐ Yes ☐ No

PLACENTAL WEIGHT:

☐ **grams**

☐ **centile**

Fetoplacental weight ratio:

☐

Placental cord diameter:

☐

PLACENTAL HYPOPLASIA:

(weight <10th centile for gestation and/or cord diameter <10th centile for gestation or <8 mm diameter at term):

☐ Present ☐ Not identified

PLACENTOMEGALY:

(weight >90th centile for gestation):

☐ Present ☐ Not identified

PLACENTAL VASCULAR PROCESSES:

Maternal stromal-vascular lesions:

☐ Present ☐ Not identified

Developmental changes: Superficial implantation:

☐ Present ☐ Not identified

Changes of maternal malperfusion:

☐ Present ☐ Not identified

GLOBAL CHANGES:

Early (distal villous hypoplasia):

☐ Present ☐ Not identified

☐ **Focal (lower 2/3rds placental disc/ >30% of slide/1 slide/ Not Identified)**

☐ **Diffuse (lower 2/3rds placental disc/>30% of slide/>2 slides/Not Identified)**

Late (accelerated villous maturation):

☐ Present ☐ Not identified

Increased syncytial knots (>30% villi):

☐ Present ☐ Not identified

SEGMENTAL CHANGES:

Villous infarct(s): ☐ Present ☐ Not identified

Number: ☐ **Site:** ☐

Size: ☐ **Age:** ☐

Recent Established Variable: ☐

Placental involvement: ☐ **%**

DECIDUAL ARTERIOPATHY:

☐ Present ☐ Not identified

Site:
☐ **Placental bed**
☐ **Parietal membranes**
☐ **Not Identified**

Acute atherosis: ☐ **Present** ☐ **Not identified**

Fibrinoid necrosis: ☐ **Present** ☐ **Not identified**

Spiral artery remodelling:
☐ **Present** ☐ **Not identified**

Parietal mural hypertrophy:
☐ **Present** ☐ **Not identified**

Intramural trophoblast: **third trimester:**
☐ **Present** ☐ **Not identified**

Chronic perivasculitis:
☐ **Present** ☐ **Not identified**

Increased immature extravillous trophoblast:
☐ **Present** ☐ **Not identified**

LOSS OF MATERNAL VASCULAR INTEGRITY:

Abruptio placenta (arterial):
☐ **Present: (Acute/Chronic)** ☐ **Not identified**

Retroplacental haemorrhage:
☐ **Present** ☐ **Not identified**

Indentation: ☐ **Present** ☐ **Not identified**

Size:

Weight of separate blood clot: **g**

Compression of overlying placenta:
☐ **Present** ☐ **Not identified**

Villous congestion/haemorrhage:
☐ **Present** ☐ **Not identified**

Marginal abruption (venous):
☐ **Present: (Acute/Chronic)** ☐ **Not identified**

Fetal stromal-vascular lesions:

DEVELOPMENTAL:

Villous capillary lesions:
☐ **Present** ☐ **Not identified**

Chorangioma:
☐ **Present** ☐ **Not identified**

Delayed villous maturation (maturation defect; >34 weeks gestation, monotonous villous population, >10 villi >30% 1 slide):

☐ **Present**
☐ **Not Identified**
☐ **Not Applicable (gestational age <34 weeks)**

☐ **Grade: Focal (1 slide)/Diffuse (>/= 2 slides)**
☐ **Diabetes related**
☐ **Idiopathic**

Dysmorphic villi: ☐ **Present** ☐ **Not identified**
Villous oedema: ☐ **Present** ☐ **Not identified**

CHANGES OF FETAL MALPERFUSION:

Global/partial:

Obstructive lesions of umbilical cord:
☐ **Present** ☐ **Not identified**

Recent intramural fibrin in large fetoplacental vessels:
☐ **Present (site: arterial/venous)**
☐ **Not identified**

Small foci of avascular or karyorhectic villi:
☐ **Present** ☐ **Not identified**

Segmental/complete:

Chorionic plate or stem villous thrombi:
☐ **Present** ☐ **Not identified**

Large foci of avascular or karyorhectic villi:
☐ **Present** ☐ **Not identified**

Loss of vascular integrity:

Large vessel rupture (fetal haemorrhage):
☐ **Present** ☐ **Not identified**

Small vessel rupture (fetomaternal haemorrhage):
☐ **Present** ☐ **Not identified**

PLACENTAL INFLAMMATORY-IMMUNE PROCESSES:

Acute maternal inflammatory response:

☐ **Present** ☐ **Not identified**

- ☐ **Stage 1: Subchorionitis/chorionitis (6-12 hours)**
- ☐ **Stage 2: Chorioamnionitis (12-36 hours)**
- ☐ **Stage 3: Necrotising chorioamnionitis (>36 hours)**
- ☐ **Grade: Severe/Not Severe**

Subacute/chronic maternal:

☐ **Present** ☐ **Not identified**

- ☐ **Mixed neutrophilic - histiocytic chroioamnionitis (weeks)**

Acute fetal inflammatory response:

☐ **Present** ☐ **Not identified**

- ☐ **Stage 1: Chorionic vasculitis/umbilical phlebitis (variable time)**
- ☐ **Stage 2: Umbilical arteritis (variable time) Stage 3**
- ☐ **Necrotising funistis (days)**
- ☐ **Grade: Severe/Not Severe**

Subacute/chronic fetal response:

☐ **Present** ☐ **Not identified**

- ☐ **Subnecrotising or necrotising funistis/prevasculitis (weeks)**

Chronic maternal/fetal inflammatory response:

Villitis:

☐ **Present** ☐ **Not identified**

Infectious lesions:

☐ **Present** ☐ **Not identified**

Viral inclusions:

☐ **Present** ☐ **Not identified**

Other organisms:

☐ **Present** ☐ **Not identified**

Immune/idiopathic inflammatory lesions:

☐ **Present** ☐ **Not identified**

Chronic maternal/fetal inflammatory response (continued):

Villitis of unknown etiology:

☐ **Present** ☐ **Not identified**

Location:

- **Basal:** ☐ **Yes** ☐ **No**
- **Parabasal:** ☐ **Yes** ☐ **No**
- **Paraseptal:** ☐ **Yes** ☐ **No**
- **Random parenchyma:** ☐ **Yes** ☐ **No**
- **Subchorionic:** ☐ **Yes** ☐ **No**

Type:

- ☐ **Lymphocytic villiti**
- ☐ **Lymphoplasmacytic villiti**
- ☐ **Lymphohisticyitic villitis**

Giant cells: ☐ **Present** ☐ **Not identified**

Grade:

- ☐ **Focal low grade (<10 contiguous villi any one focus, on a single slide)**
- ☐ **Multi-focal low grade (<10 contiguous villi any one focus, on multiple slides)**
- ☐ **Patchy high grade (at least one focus <10 contiguous villi on multiple slides)**
- ☐ **Diffuse high grade (at least one focus >10 contiguous villi, 30% terminal villi involved).**
- ☐ **Ungradable, possible low grade, villitis (one focus < 10 contiguous villi).**
- ☐ **Ungradable, possible high grade, villitis (one focus >10 contiguous villi)**

Obliterative fetal vascular changes:

☐ **Present** ☐ **Not identified**

Chronic chorioamnionitis:

☐ **Present** ☐ **Not identified**

Lymphoplasmacytic deciduitis:

☐ **Present** ☐ **Not identified**

Eosinophil T-cell fetal vasculitis:

☐ **Present** ☐ **Not identified**

Intervillositis:

Chronic histiocytic intervillositis:

☐ **Present** ☐ **Not identified**

Acute intervillositis: ☐ **Present** ☐ **Not identified**

Fibrin deposition: ☐ **Present** ☐ **Not identified**

OTHER PLACENTAL PATHOLOGY:

Massive perivillous fibrinoid deposition (maternal floor infarction)
☐ **Present** ☐ **Not identified**

Abnormal placental shape or umbilical insertion site:
☐ **Present** ☐ **Not identified**

Morbidly adherent placentas (accrete):
☐ **Present** ☐ **Not identified**

Meconium-associated changes:
☐ **Present** ☐ **Not identified**

Increased circulating nucleated red blood cells:
☐ **Present** ☐ **Not identified**

Changes of fetal death in utero:
☐ **Present** ☐ **Not identified**

Changes suggestive of aneuploidy:
☐ **Present** ☐ **Not identified**

Changes suggestive of polyploidy:
☐ **Present** ☐ **Not identified**

COMMENTS:

CONCLUSION:

Indications for placental examination

Maternal indications include:

- Systemic disorders such as an active autoimmune disease, uncontrolled diabetes, or other significant maternal disease that has affected the pregnancy
- Moderate or severe pre-eclampsia
- Intrapartum fever or infection
- Suspected chorioamnionitis
- Unexplained bleeding in the third trimester
- Excessive bleeding (more than 500ml)
- Placental abruption
- Severe maternal trauma
- Amniotic Fluid Index (AFI) abnormalities.

Fetal and neonatal indications include:

- Admission to neonatal intensive care
- Failure to respond to resuscitation
- Spontaneous or iatrogenic preterm birth
- Fetal compromise including growth restriction
- Severe cardiorespiratory depression at birth
- Signs consistent with congenital infection
- Severe growth restriction
- Diagnosis of hydrops fetalis
- Suspected severe anaemia
- Suspected or known major congenital abnormalities
- Death.

Placental indications include:

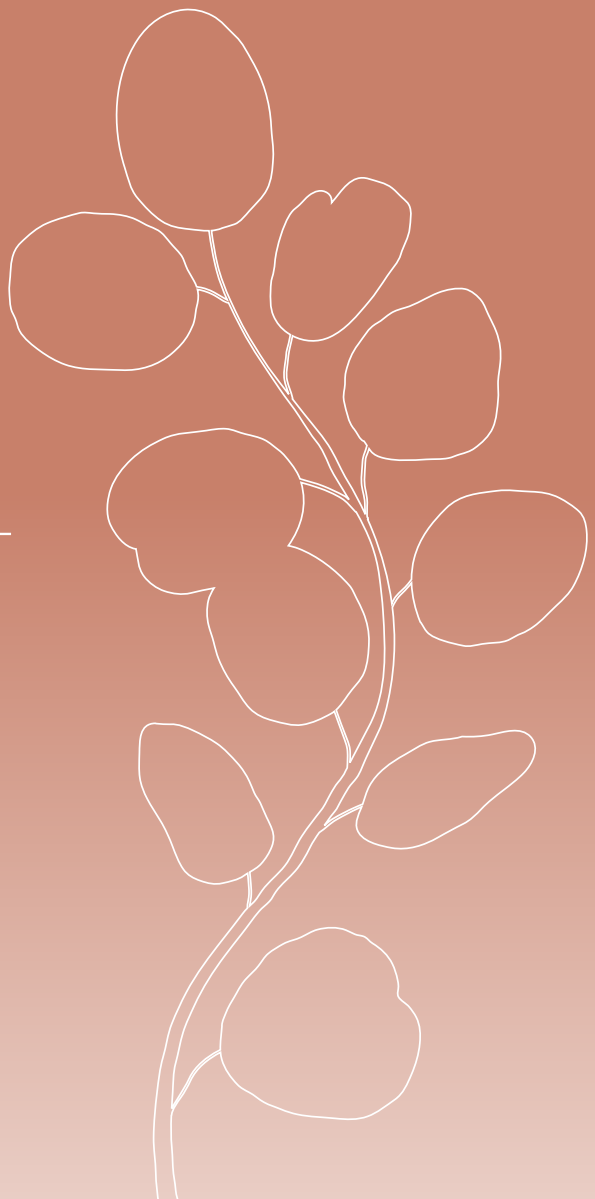
- Physical abnormality
- Abnormal placental size or weight for gestational age (small or large)
- Suspected vasa praevia
- Umbilical cord lesions
- Abnormal cord length.

NSW Health. Maternity - Indications for Placental Histological Examination. 2014. **https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2014_006.pdf**

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline



Section 7: Perinatal mortality audit and classification

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

Background

Understanding the causes of and factors contributing to perinatal deaths (stillbirths and neonatal deaths) is essential to prevent these deaths from occurring in the future and to help parents understand why their baby died and plan future pregnancies.[2]

Perinatal mortality audit captures information on the causes of deaths and analyses quality of care, in a no-blame interdisciplinary setting.[3] Local perinatal mortality audit carried out within the hospital setting can improve care of women and their babies.[4] Perinatal mortality audit programs including in-depth analyses of contributory factors (substandard care factors), can identify important areas for practice improvement to inform policy and clinical practice.[5-14]

National perinatal mortality audit programs have been implemented in Aotearoa New Zealand[15], the UK[16], the Netherlands,[17] and Ireland.[18] Contributory factors relating to access to care, the professional care received, and organizational/management factors were identified in 25% of perinatal deaths (excluding termination of pregnancies) in Aotearoa New Zealand during 2018.[19] Approximately 13% of perinatal deaths were likely avoidable.[19] Of the contributing factors identified, 'barriers to access and/or engagement with care' was the most common factor cited and was more frequent among Māori and Pacific mothers.[19]

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.[20-27] Around half the states and territories also conduct indepth analyses of contributory factors at the jurisdictional level to inform practice improvements.[28] Results from perinatal mortality classification and audit are included in national reporting by the Australian Institute of Health and Welfare.

In 2017–18, 37% of perinatal deaths in Australia had results from jurisdictional audits of contributory factors included in national reporting.[28] Contributory factors relating to the woman, family/whānau, and social situation, relating to access to care and the professional care received, were identified in 21% of cases. Those factors were likely to have significantly contributed to the outcomes in 8% of cases. The proportion of perinatal deaths with contributing factors was much higher in an audit of deaths ≥34 gestational weeks in Queensland in 2018.[9] Contributing factors were identified in 71% of deaths and likely to have significantly contributed to the outcome in 30% of deaths.

Objective

This section provides guidance for frontline healthcare professionals and maternity services on optimal perinatal mortality audit, including classification of causes, associated conditions, and contributing factors relating to care.

A note about terminology

This guideline uses parent-centred language that is intended to be inclusive of all affected by loss. We use the term 'woman' throughout the guideline to refer to the person who is pregnant and gives birth.[29] We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth identify as a woman. The term 'parent' is used to refer to expectant and bereaved mothers, fathers, and partners. It is important to recognise individuals who identify themselves as parents. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents.[30]

This guideline uses 'baby' when referring to stillbirth, neonatal death because these terms are preferred by many bereaved parents.Terms such as 'fetus' may add to parents' distress because this language denies personhood[31] and is inconsistent with recognition of parenthood that is crucial to providing respectful and supportive care. This guideline uses 'healthcare professional' to denote all those working with bereaved parents and family/whānau. Many healthcare professionals may be familiar with the term 'audit' when applied to perinatal deaths and mortality, while others are more familiar with the term 'review'. This Guideline uses both terms interchangeably.[3] (see Glossary).

Resources

- **Appendix 7A:** Australian Perinatal Mortality Audit Tool
- **Appendix 7B:** New Zealand Baby and Mother Rapid Reporting Forms for a Perinatal Death
- **Appendix 7C:** Sample mortality audit meeting code of practice declaration
- **Appendix 7D:** PSANZ Classification System for Stillbirths and Neonatal Deaths (version 4)
- **Appendix 7E:** PSANZ Classification quick reference sheet (version 4)
- **Appendix 7F:** PSANZ Classification System for Stillbirths and Neonatal Deaths (version 5)
- **Appendix 7G:** PSANZ Classification quick reference sheet (version 5)
- **Appendix 7H:** Definitions of Australian state and territory and Aotearoa New Zealand reports on rates and causes of stillbirths and neonatal deaths.

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.[36]

Part A: Audit framework

The *WHO Making every baby count: audit and review of stillbirths and neonatal deaths guideline* recommends that following a perinatal death, a systematic review of the causes and circumstances leading up to and surrounding that death take place within the hospital service.[3] The six-step cycle from the WHO guideline[3] with an additional two steps to engage with and provide feedback to parents[32-34] is suggested (Figure 1). An audit framework (Part A) underpins the eight steps of the audit cycle (Part B) and must be established before the audit cycle can be implemented.

Steps in the perinatal mortality audit cycle

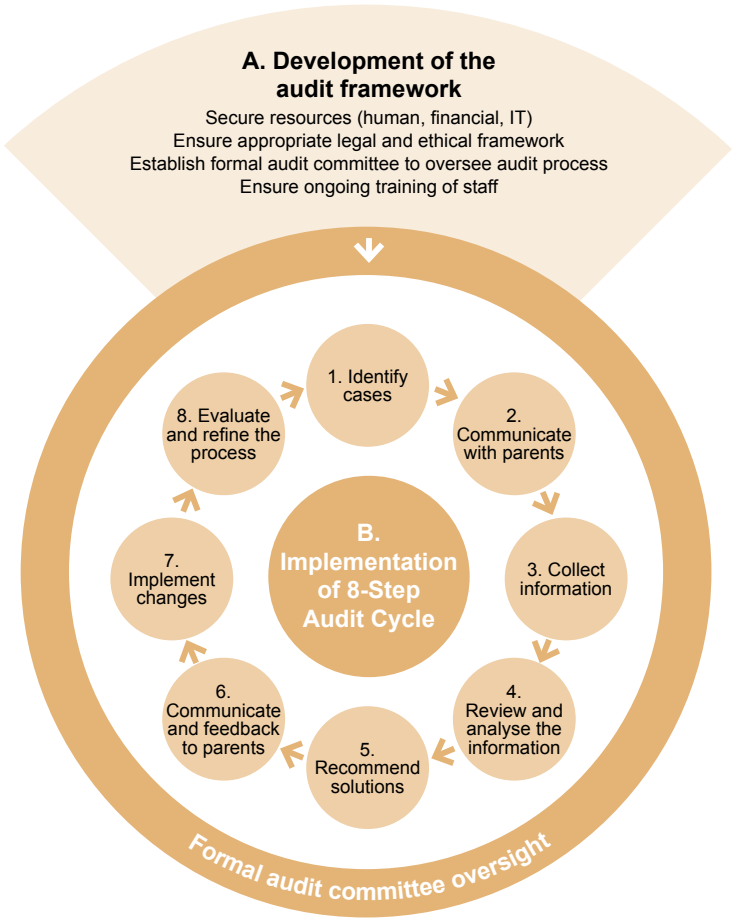


Figure 1. Audit framework (A) and eight steps (B) of the perinatal mortality audit cycle based on the *WHO Making every baby count: audit and review of stillbirths and neonatal deaths guideline*[3] and two steps to engage with and provide feedback to parents.[32-34]

Evidence-based recommendation 7.1
Evidence quality: Moderate confidence
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 maternal 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.

Hospital leadership and support

Healthcare professionals may be reluctant to participate in perinatal audit meetings because of high workload, lack of communication and education regarding perinatal mortality audit meetings, fear of blame, fear of litigation, and failure to implement change.[4,5,35] A standing multidisciplinary perinatal mortality audit committee and a permanent chairperson role to oversee each perinatal mortality audit meeting can increase attendance and improve the impact of audit outcomes in policy review and improvements.[4,36] Ideally, the perinatal mortality audit committee should include key stakeholders who reflect all areas of the healthcare system caring for women, babies, and their families/whānau to drive improvements across a range of specialties.[37,38] Members may be representatives from neonatology/paediatrics, obstetrics, midwifery/nursing, pathology, clinical genetics, pharmacy, epidemiology/statistics, social work, general practice, and administration.[3,39] Studies consistently recommend standardised training for healthcare professionals to ensure high quality data on causes of and factors contributing to perinatal deaths[5,40] and to support communication with parents during the audit process.[34,41]

The hospital administration should establish a standing multidisciplinary perinatal mortality audit committee and should support the committee through:

- adequate training on perinatal mortality audit through training programs such as IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) (see *Section 8: Organisational recommendations* for further information)
- ensuring appropriate scheduling of meetings so the maximum number of key clinical staff can attend, and cases are reviewed within an acceptable time frame
- ensuring adequate staffing and resources are available for organisation and administration of meetings, and for data collection, analysis and reporting to the jurisdictional level
- establishing systems for clear reporting of de-identified audit findings to the hospital service board's quality (clinical governance) committee or lead
- ensuring systems for authorisation, implementation, and evaluation of audit recommendations into hospital policy and practice are in place
- ensuring systems for reporting processes where serious system failures or misconduct are identified are in place
- ensuring that committee members and their deliberations are appropriately indemnified if required while undertaking this kind of audit on their behalf.[42]

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.

Part B: 8-step audit cycle

Step 1: Identify cases

A perinatal death audit should be undertaken as soon as results are available from initial investigations, so that it occurs within recent memory of those involved and enables information from the audit to be discussed with the parents, ideally at their routine hospital follow-up visit. Timely audit of the death may also facilitate appropriate counselling and support for staff.[41] If subsequent investigations change the findings of the initial investigations, further review of the death by the mortality committee may be required.

Parents whose baby have died have the greatest stake in understanding why their baby died and what contributed to their baby's death.[1]

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 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.

Step 2: Engage and communicate with parents

When a baby is stillborn or dies soon after birth, parents generally place a high value on information about the causes of and contributors to their baby's death.[1]

Often, parents are not actively involved in the audit process,[43] despite many parents indicating that they are willing to provide feedback on their care and want to know the audit cycle is taking place. In the UK, the PARENTS studies provide a model for how parents may be involved in the process.[32-34]

"It really focussed the meeting on discussing what was important to the parents, which is not always what the healthcare professional would perceive is important to discuss."
Healthcare professional.[1]

The PARENTS studies recommend that parents are provided with a face-to-face explanation of the audit process, supported by a written information leaflet, prior to hospital discharge.[34] In the UK, this meeting is led by the senior healthcare professional responsible for care (such as an obstetrician, midwife or paediatrician) and/or a contact person such as a bereavement midwife/nurse who supports them through the audit process.[44]

Following hospital discharge, the PARENTS studies suggest that parents are contacted via post/email with information on how they can provide feedback.[34] This can be followed up with a phone call to discuss the feedback process and a home visit to go through their feedback.[34] If a home visit is declined, the option to receive feedback by telephone, email or post can be offered.[34] In the UK, this process is coordinated by the bereavement midwife/nurse[44] who will complete the feedback form with the parents.[44] Parents may opt to have the bereavement midwife or nurse represent them at the audit meeting.[34,44]

Taking an individualised approach enables parents to contribute to the audit process if and as much as they wish.[32,34]

> **"I think having the support is crucial, but also having a voice to give your feedback on a process that you have been through is also really powerful, and it feels like you've been listened to…**
>
> **Nothing can change the situation, but at least you think you might be able to help improve things in the future for other people, and that's important"**
>
> *Bereaved parent.*[1]

The Australian Open Disclosure Framework can support open communication between healthcare professionals and parents during perinatal audit.[45] Additional codesigned parent engagement materials to support healthcare professionals during this step of the audit cycle are currently under development. For further information, the Stillbirth CRE can be contacted via email: **stillbirthcre@mater.uq.edu.au**.

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 parents' care or the known point of contact for each family/whānau (such as a bereavement midwife).

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.

Step 3: Collect information

Perinatal mortality audit should incorporate an evaluation of the medical notes,[46,47] clinical investigations,[13,48-58] input from the healthcare professionals involved in the case, and thorough history from the woman (and their partner) on the care they received and events leading to the death.[32-34] Healthcare professionals should ensure that all relevant clinical details are documented clearly and accurately in the medical record at the time of the event.[12] Notes should be obtained from private healthcare professionals, if applicable.

Transportation of the baby to a centre with appropriate perinatal pathology expertise may be warranted where this expertise does not exist in the birth facility, which may be the case in rural and remote settings.[59,60] Communication with a multidisciplinary team at tertiary centres should be established to ensure that any opportunities to gather information or investigations that can be performed locally are not missed. Refer to Section 6 for guidance on the appropriate investigations and parent-centred decision-making and communication around their options for investigations.

Standardised perinatal audit tools are recommended to facilitate the data collection process[5,36,40,55] and may overcome issues of inaccurate or incomplete reporting of clinical data and nonstandard audit methods.[4,5,61] The Australian Perinatal Mortality Audit Tool (APMAT) (Appendix 7A[12]) and the New Zealand Mother and Baby Rapid Reporting Forms for a Perinatal Death (Appendix 7B) have been designed to capture a standardised dataset to facilitate the identification of causes of and factors contributing to perinatal deaths in Australia and Aotearoa New Zealand, respectively. Feedback from parents and healthcare professionals involved in the case should be recorded in the case summary sections of the APMAT and Rapid Reporting forms.

Evidence-based recommendation 7.8
Evidence quality: High confidence
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.

Death certificates

The Royal College of Pathologists of Australasia recommends that death certificates are issued or supervised by the lead healthcare professional responsible for care.[62] A recent study in Russia recommends that a medical practitioner responsible for care around the time of death should complete the death certificate, and in their absence, a midwife or paramedic should complete the death certificate.[63] Healthcare professionals should familiarise themselves with local reporting requirements for death certificates.[64]

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.

Step 4. Review and analyse the information

Generally, perinatal mortality audit meetings should review all perinatal deaths occurring in that hospital. Maternity and newborn services (particularly smaller hospitals) may choose to combine audit meetings with another hospital committee or a regional mortality review committee.

Multidisciplinary participation

Perinatal mortality committee members (see Part A Development of an Audit Framework) attend and oversee each Perinatal Mortality Audit meeting where individual perinatal deaths are reviewed in detail. In addition, healthcare professionals familiar with the circumstances of a particular perinatal death should be notified promptly of the perinatal mortality review meeting and invited to attend the case review.[34] At a minimum, the lead consultant, obstetrician, neonatologist, midwives, nurses, pathologist, and parent advocate should attend the perinatal mortality review meeting.[4,34]

Evidence-based recommendation 7.11
Evidence quality: Moderate confidence
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.

"No blame" principle

For perinatal mortality reviews to be effective, the system should function as a process to learn from mistakes to prevent future perinatal deaths rather than as a blame attribution process.[36,65,66] The chairperson should be skilled in chairing meetings of a highly sensitive nature.[34] While an experienced medical practitioner usually fulfils the role of chairperson, it is also important to involve nurses and midwives in this role.[3]

Having participants agree to a code of practice[3] that ensures confidentiality[65] can help ensure a blame-free environment (see *Appendix 7C: Sample mortality audit meeting code of practice declaration*).

Evidence-based recommendation 7.12
Evidence quality: Moderate confidence
The perinatal mortality committee chair must ensure audits are conducted in a no-blame environment.

Classification system

More than 80 classification systems for causes of perinatal death have been reported globally,[67] none of which is clearly superior (see *Section 7: Technical report for perinatal mortality audit and classification* for further information). The WHO recommend the use of the WHO–ICD for perinatal mortality (ICD-PM),[3] which uses ICD rules and classifies a single underlying cause of perinatal death based only on death certificate data. While the ICD-PM holds promise for consistent global reporting of causes of perinatal death, the system has limitations,[50,68,69] particularly for well-resourced settings where more information is available to allow more specific classification of causes.[67]

The PSANZ Classification System for Stillbirths and Neonatal Deaths (Appendix 7D to 7G) is currently used across Australia and Aotearoa New Zealand to classify causes of perinatal death.[20-28] The PSANZ Classification System was first released in 2003, and subsequently revised in 2004, 2009, and 2018. The current version for use is version 4. Version 5 has been finalised and is intended for use across Australia and Aotearoa New Zealand for perinatal deaths occurring for births from 1 January 2025. The PSANZ Classification System performs well against other systems[70] and until further enhancements are made to the ICD system, the PSANZ Classification System remains the recommended system for causes of perinatal deaths in Australia and Aotearoa New Zealand.

The key principles of the PSANZ Classification System are:

- to identify an underlying cause of death for stillbirths and neonatal deaths
- to identify up to two associated conditions for stillbirths and neonatal deaths.

Evidence-based recommendation 7.13
Evidence quality: High confidence
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.

Determining the cause of death and presence of contributing factors relating to care

A standardised approach to data collection, using tools such as the Australian Perinatal Mortality Audit Tool (APMAT) (Appendix 7A) and the New Zealand Mother and Baby Rapid Reporting Forms (Appendix 7B), may facilitate the identification of causes and contributing factors for perinatal deaths during audit meetings.[5,9,40] The APMAT also contains a “Contributory Factors Relating to Care” component to systematically classify the types of contributing factors present and their relation to the death. Use of the APMAT in Queensland has found that the tool is helpful in identifying the underlying causes of stillbirths[12] and identifying contributing factors relating to care (substandard care factors).[9] Contributory factors were found to have significantly likely contributed to 35% of perinatal deaths audited using the APMAT in one of the study cohorts (n=56).[9] The review of contributing factors should consider recommendations of a facility-based root cause analysis, if one was conducted.[71,72]

*Refer to **Consensus-based recommendation 7.9**.*

Revision of perinatal death certificates

Perinatal death certificates are often issued prior to the results of investigations becoming available,[40] which may result in significant error in cause-of-death data. In a recent cross-sectional audit in the UK, almost 80% of medical certificates of stillbirth contained errors and 43% were registered as "unknown cause of death".[73] Review of autopsy and placental histopathology during perinatal audit can provide additional information on the cause of death.[48-54,56,57,74] This guideline recommends that death certificates are reviewed during perinatal mortality audit meetings and revised if required.[63] As the process of revising death certificates varies across Australia and Aotearoa New Zealand, each Perinatal Mortality Committee should become familiar with the process within their region and implement a process that ensures that a revised death certificate is submitted if required, and that parents are advised of this.

Consensus-based recommendation 7.14
The maternity service (ideally through a designated bereavement service) should ensure the death certificate is revised, when necessary, based on the outcome of the perinatal mortality audit meeting and ensure a revised copy is sent to the parents.

- Parents should be informed by the lead carer (ideally a bereavement midwife) that they will receive a revised death certificate including the reasons for the revision.

Step 5: Recommend solutions to improve quality of care

The development of recommendations linked to action plans with clear targets is an important step of the audit cycle that is often missed.[4,5,36] The *WHO Making every baby count: Audit and review of stillbirths and neonatal deaths* guideline recommends the development of SMART solutions (specific, measurable, action-orientated, realistic, and time-bound) to help ensure the proposed actions are achievable.[75]

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.

Step 6: Communicate and feedback to parents

The PARENTS studies recommend that parents are given a plain language summary of the outcome of the review conducted by the perinatal mortality audit committee.[34] This feedback should be provided during a face-to-face follow-up meeting with the lead healthcare professional involved in the woman's care (such as an obstetrician, midwife, paediatrician) and, where applicable, the specialised bereavement midwife/nurse who supported the family/whānau during the audit process.[34] Early feedback to the woman's general practitioner and other relevant healthcare professionals may also be important.[42] Other key considerations in communication with parents at the face-to-face follow-up meeting include the following.

- Where possible, someone with specific expertise in interpreting the results of perinatal death investigations and providing feedback on the outcome of the audit review should also attend the meeting with parents.
- Schedule the meetings after all relevant test results are available and following perinatal mortality audit meeting review.
- Inform parents if the results of key investigations (such as autopsy) will not be available at the time of the scheduled meeting and offer them an additional or alternative time to receive those results.

For cases of a congenital anomaly, it may be appropriate to discuss the need for genetic counselling with a geneticist prior to the follow-up appointment with the lead healthcare professional who provided the woman's care. The geneticist can either attend the follow-up consultation or offer a genetic counselling consultation. Depending on the results of the initial investigation, it may also be necessary to arrange further tests. See *Section 6: Investigations for perinatal deaths*.

"I remember feeling that I couldn't follow everything the doctor was saying about the possible reasons our baby died. I was able to ask her to explain it again in a way that made sense. And it was good to have the short summary that didn't use all the complicated medical words"

Parent quote from the *Guiding Conversations* Booklet.

Consensus-based recommendation 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.

Evidence-based recommendation 7.17
Evidence quality: Moderate confidence
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 woman's general practitioner and all care providers nominated to the parents after review by the perinatal mortality committee.

Step 7: Implement changes into clinical practice

Systematic reviews report failure to implement change as a common reason for healthcare professionals' reluctance to participate in the audit process, and a major challenge to effective perinatal audit.[4,5,66] The perinatal mortality audit cycle needs to be completed by implementing and re-evaluating recommended changes to reduce perinatal deaths.[36]

A process of feedback to healthcare professionals should be established, to ensure recommendations from perinatal audit inform clinical practice and hospital policy.[5,37] Educational meetings, in addition to the perinatal mortality audit meetings, which engage a wider group of healthcare professionals across the hospital service may be helpful in translating findings from the audit into practice. The Australian Commission on Safety and Quality in Health Care recommends using the plan-do-study-act (PDSA) cycle to improve clinical practice.[76]

Step 8: Evaluate and refine the process

The *WHO Making every baby count: Audit and review of stillbirths and neonatal deaths guideline*[3] recommends a final step in the audit cycle to evaluate the success of the audit processes undertaken. An electronic data system can enable easy access to aggregate data to assess time trends in rates and causes of perinatal deaths and contributing factors.[44] The WHO guideline[3] has questions to help users assess and reflect on progress (Table 1).

Table 1. Questions for reflection on the implementation and maintenance of the audit system

- How can review meetings be improved and used more effectively?
- How often and to whom is feedback given?
- What are the gaps in the feedback procedures?
- How can the feedback to service providers and senior management in the facility be improved?
- How can engagement in the audit process, the use of the findings and the application of recommendations be improved?
- How can feedback outside the facility be improved, e.g. district or provincial levels, and community?
- How can involvement from each of these levels be improved?
- Who is responsible for keeping the audit system together, e.g. one person, a team, formally or informally designated?
- Who is leading the audit? Who takes responsibility when the leader(s) is/are not there?
- What kind of succession plan do we have?
- How do staffing issues such as rotations and turnovers influence the audit activities?
- If lacking, how can staff stability be improved?
- What is the facility's responsibility in reaching out to another facility or facilities to introduce and establish an audit program?

National and international reporting considerations

Hospital-based perinatal audit programs should be supported by, and feed into, regional and national audit programs to inform high-level changes in national policy and clinical practice.[36,77] In Aotearoa New Zealand, the Perinatal and Maternal Mortality Review Committee has produced annual reports with national recommendations for raising public awareness of perinatal mortality risk factors, detecting fetal growth restriction, preventing preterm birth, and resources for data collection and review.[15] The Perinatal and Maternal Mortality Review Committee has also conducted in-depth reviews of the investigation and management of cases of neonatal encephalopathy. From 1 July 2023, the National Mortality Review Committee will be responsible for reviewing and reporting on perinatal mortality in Aotearoa New Zealand. In Australia, a national audit program is yet to be established; however, state and territory committees report on rates and causes of perinatal mortality. Some state and territory committees also conduct in-depth reviews of a sample of defined cases to identify possible contributing factors relating to care to inform practice improvements.[20-28]

Evidence-based recommendation 7.19
Evidence quality: Moderate confidence
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.

Evidence-based recommendation 7.20
Evidence quality: Moderate confidence
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.

Definitions

Differences in definitions impede comparable national and international reporting of perinatal deaths.[5,52,78-80] The WHO defines stillbirth as a baby born with no signs of life at ≥22 weeks of pregnancy but recommends 28 weeks' gestation as the lower limit for international comparison of stillbirth rates.[81] However, only including stillbirths from 28 weeks' gestation may underestimate the true burden of stillbirth,[82] and countries continue to use their own definitions.[36,80] Differences in the lower limit of gestation for classification of stillbirth and the inclusion/exclusion of late termination of pregnancies, affects national perinatal mortality rates.[36,80] In Australia, gestational age and birth weight cut offs, and the inclusion/exclusion of terminations in reported rates of perinatal mortality is inconsistent across states and territories;[20-27] some jurisdictions report fetal deaths of at least 20 weeks gestational age or at least 400 g birthweight, other jurisdictions report fetal deaths of at least 20 weeks' gestation, or if gestational age is unknown, at least 400 g birthweight. Inclusion of perinatal deaths resulting from termination of pregnancy in perinatal mortality statistics is also variable. Please refer to Appendix 7H for regional definitions reported across Australia and Aotearoa New Zealand. To ensure consistency and comparability within Australia and Aotearoa New Zealand, these guidelines recommend that reporting

of stillbirths and neonatal deaths adhere to the recommended definitions from the Australian Institute of Health and Welfare[83] and the Perinatal and Maternal Mortality Review Committee.[15]

It should be noted that the definitions for the registration of perinatal deaths across the different perinatal data collections in Australia may differ from that recommended for statistical purposes. Healthcare professionals should be aware of the definitions for registration of perinatal deaths and of their requirements for reporting a perinatal death in their jurisdiction.

> **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.

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Australian Perinatal Mortality Audit Tool

Type of perinatal death

☐ **STILLBIRTH (Fetal death):**

Death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 g or more birthweight where gestation is not known. The death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.

Please select type:

☐Antepartum fetal death

☐Intrapartum fetal death

☐Termination of pregnancy

☐Unknown

☐ **NEONATAL DEATH**

Death of a liveborn infant occurring before 28 completed days after birth.

Please select type:

☐Non-admitted neonatal death

☐Neonatal death in hospital

☐Unknown

Please follow the instructions and answer all questions as directed. You may not know the answer to some of the questions, but please provide as much detail as possible. Personally identifiable information collected on this form will be kept confidential. Information included in reports will be grouped and non-identifiable.

SECTION 1: CLINICAL DATA RELEVANT TO PERINATAL DEATH

PLEASE COMPLETE THIS SECTION WITHIN 48 HOURS OF THE STILLBIRTH OR NEONATAL DEATH

BABY DETAILS

1) Case number_____

2) Was this a multiple pregnancy?

☐Yes ☐No ***(go to Q3)*** ☐Unknown ***(go to Q3)***

a) Plurality of pregnancy

☐Twin ☐Triplet ☐Quadruplet
☐Quintuplet ☐Sextuplet ☐Unknown
☐Other *(please specify):* _____

b) Birth order

☐First ☐Second ☐Third
☐Other *(please specify):* _____

c) Chorionicity

☐Dichorionic Diamniotic (DCDA) ☐Monochorionic diamniotic (MCDA) ☐Monamniotic (MA)
☐Unknown ☐Other *(please specify):* _____

3) Baby's URN_____

4) Type of death

☐Undetermined
☐Stillbirth (fetal death)
If yes, please specify the timing of the fetal death:
☐Antepartum fetal death
☐Intrapartum fetal death
☐Unknown
☐Neonatal death
If yes, please specify the hospital episode for neonatal death
☐Hospital other
☐Hospital of birth
☐Home
☐Unknown
☐Post-neonatal death
If yes, please specify the hospital episode for post-neonatal death
☐Hospital other
☐Hospital of birth
☐Home
☐Unknown

5) Was this perinatal death a result of a termination of pregnancy?

☐Yes ☐No ***(go to Q6)*** ☐Unknown ***(go to Q6)***

a) What was the reason for termination of the pregnancy?

☐Congenital abnormality ☐Psychosocial reason: maternal mental health

☐Medical/pregnancy condition ☐Psychosocial reason: maternal circumstantial indication
☐Unknown

b) If medical/pregnancy conditions, what was the pregnancy or medical condition requiring termination of pregnancy?

☐Fetal growth restriction ☐Pre-eclampsia ☐Preterm PROM
☐Other:

_____

6) Date of baby's birth_____(DD/MM/YYYY)

7) Time of baby's birth_____

8) Gender

☐Male ☐Female ☐Intersex or indeterminate
☐Unknown

9) Indigenous status

☐ Aboriginal but not Torres Strait Islander origin ☐ Torres Strait Islander but not Aboriginal origin ☐ Both Aboriginal and Torres Strait Islander origin
☐ Neither Aboriginal nor Torres Strait Islander origin ☐ Not stated/unknown

10) Calculated gestation of pregnancy at birth_____

11) Birthweight _____g

12) Did this baby have a major congenital abnormality?

☐Yes ☐No ☐Unknown

13) Was this death unexpected?

☐Yes ☐No ☐Unknown
☐Cannot be determined

MOTHER'S DETAILS

14) Mother

Surname: _____

Given name(s): _____

Other(s): _____

15) Mother's URN: _____

16) Mother's date of birth: _____(DD/MM/YYYY)

17) Usual residential address of mother at time of birth

Country: _____

Town/City/Locality: _____

State: _____

Postcode: _____

18) Indigenous status

☐ Aboriginal but not Torres Strait Islander origin
☐ Torres Strait Islander but not Aboriginal origin
☐ Both Aboriginal and Torres Strait Islander origin
☐ Neither Aboriginal nor Torres Strait Islander origin
☐Not stated/Unknown

19) Mother's understanding of spoken English

☐Very well
☐ Well (requires help with medical terminology)
☐ Not well (requires help with everyday English)
☐Not at all
☐Unknown

PREVIOUS PREGNANCIES

20) Number of mother's previous pregnancies: _____ ☐Unknown

21) Mother's parity (do not include current pregnancy): _____ ☐Unknown

	Date of birth	**Place of birth *(options below)***	**Gestation *(weeks)***	**Pregnancy outcome *(codes below)***	**Type of birth *(codes below)***	**Birthweight *(g)***	**Complications (*codes below*)**
1							
2							
3							
4							
5							
6							
7							
8							

Place of birth: Home, Birth centre, Public hospital, Private hospital, Unattended / Free birth, Born before arrival (in transit), Other, Unknown.

Pregnancy outcome: LB = live birth; **SM** = spontaneous miscarriage; **TOP** = termination of pregnancy; **E** = ectopic pregnancy; **SB** = stillbirth; **NNDE** = early neonatal death (<7 days age); **NNDL** = late neonatal death (7 days – 28 days); **INFD** = infant death (28 days – 1 year); **U** = unknown.

Type of birth: NVB = normal vaginal birth; **OVD** = operative vaginal delivery; **VB** = vaginal breech; **CS** = caesarean section; **U** = unknown.

Complications: NIL = no complications; **HE** = hyperemesis; **APH** = ante partum haemorrhage/abruption; **CxS** = cervical stitch; **FGR** = fetal growth restriction; **GDM** = gestational diabetes mellitus; **GH** = gestational hypertension; **U** = unknown; **Other** = please comment in summary section.

CURRENT PREGNANCIES

(This section is not required for terminations of pregnancy for maternal mental health or maternal circumstantial reasons)

22) Mother's height: _____cm

23) Mother's weight:
Current (around time of birth): _____kg
At booking (antenatal visit): _____kg

24) Artificial reproductive technology in this pregnancy?
☐Yes ☐No ***(go to Q25)*** ☐Unknown ***(go to Q25)***

If yes, please specify fertility treatment
☐Ovulation induction agents
☐Donor insemination
☐Embryo transfer to uterus (GIFT)
☐Embryo transfer to fallopian tubes (TEST) (ZIFT)
☐In vitro fertilisation other/unspecified
☐Intracytoplasmic sperm injection (ICSI)
☐Other_____

25) What was the mother's smoking status and history during pregnancy?
☐ Smoking during pregnancy
☐ Never smoked
☐ Stopped before this pregnancy
☐ Stopped smoking during the first 20 weeks of pregnancy
☐ Stopped smoking after the first 20 weeks of pregnancy
☐ Unknown

26) Did the mother drink alcohol during this pregnancy?
☐Yes ☐No ***(go to Q27)*** ☐Unknown ***(go to Q27)***

If yes, specify the average number of standard alcoholic drinks per week
First trimester: _____ standard drinks per week *or* ☐Unknown
Month prior to birth: _____ standard drinks per week *or* ☐Unknown

27) Did the mother use illicit drugs during this pregnancy?
☐Yes ☐No ***(go to Q28)*** ☐Unknown ***(go to Q28)***

If yes, please specify:

	During first trimester	Month prior to birth
Heroin	☐	☐
Cannabis	☐	☐
Amphetamines	☐	☐
Ecstasy	☐	☐
Hallucinogens	☐	☐
Cocaine	☐	☐
Chroming/Petrol/Paint	☐	☐
Methadone	☐	☐
Herbal Highs	☐	☐
Unknown	☐	☐
Other: _____	☐	☐

28) Has the mother suffered family violence during this pregnancy?
☐Yes ☐No ☐Not asked ☐Unknown

29) Place of birth
Please select from both columns

	Intended place of birth before labour	Actual place of birth
Hospital, excluding birth centre	☐	☐
Birth centre, attached to hospital	☐	☐

Birth centre, free standing	☐	☐
Home (other)	☐	☐
Home - private midwife care	☐	☐
Home - public homebirth program	☐	☐
In transit	☐	☐
Unknown	☐	☐
Other	☐ _____	☐_____

30) Model of antenatal maternity care

	Booking	At birth
Private obstetrician (specialist care)	☐	☐
Private midwifery care	☐	☐
General Practitioner obstetrician care	☐	☐
Shared care	☐	☐
Combined care	☐	☐
Public hospital maternity care	☐	☐
Public hospital high risk maternity care	☐	☐
Team midwifery care	☐	☐
Midwifery group practice caseload care	☐	☐
Remote area maternity care	☐	☐
Private obstetrician and privately practicing midwife joint care	☐	☐
No antenatal care provider	☐	☐
If other, please specify	☐ _____	☐ _____

31) Maternal outcome

☐Alive and generally well ☐Alive but serious morbidity ☐Died

MOTHER'S MEDICAL HISTORY

32) Does the mother have any pre-existing medical conditions?

☐Yes ☐No ***(go to Q33)*** ☐Unknown ***(go to Q33)***

If yes, please specify:

		Yes	No	Unknown
a)	Asthma	☐	☐	☐
b)	Diabetes pre-pregnancy (type 1 or 2)	☐	☐	☐
	i) If yes, is the diabetes well controlled?	☐	☐	☐
	ii) How is the diabetes managed?			
	☐ Insulin			
	☐ Oral hypoglycaemic			
	☐ Diet and exercise			
	☐ Unknown			
	☐ Other *(please specify)* _____			
c)	Epilepsy	☐	☐	☐

d)	Heart condition (congenital or acquired)	☐	☐	☐
e)	Hypertension	☐	☐	☐
f)	Thyroid abnormality	☐	☐	☐
	i) *If yes, please specify* ☐ Hyperthyroidism ☐ Hypothyroidism ☒ Unknown			
g)	Inflammatory bowel disease	☐	☐	☐
h)	Systemic lupus erythematosus	☐	☐	☐
i)	Other autoimmune disorder	☐	☐	☐
j)	Mental health disorder	☐	☐	☐
	i) If yes, please specify			
	☐Depression	☐	☐	☐
	☐Psychotic disorder	☐	☐	☐
	☐Other *(please specify)* _____			
k)	Renal disease	☐	☐	☐
l)	Venous thromboembolism	☐	☐	☐
m)	Haematological disorders	☐	☐	☐
	i) *If yes, please specify*			
	☐Anaemia	☐	☐	☐
	☐Thalassaemia trait	☐	☐	☐
	☐Thrombophilia	☐	☐	☐
	☐Other *(please specify)* _____			
n)	Cervical surgery	☐	☐	☐
o)	Uterine surgery	☐	☐	☐
p)	Urinary tract infection	☐	☐	☐
q)	Uterine abnormality	☐	☐	☐
r)	Other: _____	☐	☐	☐

Further medical conditions:

_____

_____

33) Family history of thrombosis?

☐Yes ☐No ☐Unknown

OBSTETRIC CONDITIONS

34) Obstetric complications during this pregnancy and obstetric consultation

Indicate all conditions known to be present during this pregnancy

a) Hypertension ☐Yes ☐No ☐Unknown

i) *If yes, please specify type of hypertension*

- ☐ Eclampsia
- ☐ Preeclampsia
- ☐ Gestational hypertension
- ☐ Chronic hypertension
- ☐ Unknown

ii) *Was there consultation with an obstetrician for hypertension?*

- ☐ Yes
- ☐ No

☐ Already under obstetric care
☐ Unknown

b) HELLP Syndrome ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for HELLP syndrome?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

c) Preterm labour ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for preterm labour?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

d) Pre-labour rupture of membranes ☐Yes ☐No ☐Unknown

i) *If yes, please specify the gestation of the membrane rupture* ☐Unknown
_____ *or*

ii) *Was there consultation with an obstetrician for pre-labour rupture of membranes?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

e) Obstetric cholestasis ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for obstetric cholestasis?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

f) Vaginal bleeding ☐Yes ☐No ☐Unknown

i) *If yes, at what gestation did vaginal bleeding occur?*
☐ Before 20 weeks
☐ At or after 20 weeks
☐Unknown

ii) *Reasons for vaginal bleeding*
☐ Abruption
☐ Placenta praevia
☐ Vasa praevia
☐ Uterine rupture
☐ Cervical cause
☐ Unknown
☐ Other *(please specify):* _____

iii) *Was there consultation with an obstetrician for vaginal bleeding?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

g) Placental praevia without haemorrhage ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for placental praevia without haemorrhage?*
☐ Yes

☐ No
☐ Already under obstetric care
☐ Unknown

h) Gestational diabetes ☐Yes ☐No ☐Unknown

i) *If yes, please indicate*
First HbA1C measure during pregnancy: _____
Last HbA1C measured during pregnancy: _____

ii) *How was the diabetes managed?*
☐ Insulin
☐ Oral hypoglycaemic
☐ Diet and exercise
☐ Unknown
☐ Other *(please specify):*
_____

iii) *Was there consultation with an obstetrician for gestational diabetes?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

i) Multiple pregnancy ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for multiple pregnancy?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

j) Prolonged pregnancy (<41 weeks) ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for prolonged pregnancy?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

k) Breech presentation ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for breech presentation?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

l) Unstable lie ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for unstable lie?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

m) Size of fetus ☐Yes ☐No ☐Unknown

i) *If yes, please specify the size of the fetus*
☐ Large
☐ Small
☐Unknown

ii) *Was there consultation with an obstetrician for size of fetus?*

☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

n) Decreased fetal movements ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for decreased fetal movements?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

o) Polyhydramnios ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for polyhydramnios?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

p) Oligohydramnios ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for oligohydramnios?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

q) Non-reassuring CTG ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for non-reassuring CTG?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

r) Fetal abnormality ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for fetal abnormality?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

s) Other obstetric conditions ☐Yes ☐No ☐Unknown
Please specify: _____

i) *If yes, was there consultation with an obstetrician for other obstetric conditions?*
☐ Yes
☐ No
☐ Already under obstetric care
☐ Unknown

35) Were there any medical complications during this pregnancy?
☐Yes ☐No ***(go to Q36)*** ☐Unknown ***(go to Q36)***

If yes, indicate all medical complications known to be present during this pregnancy:

a) Confirmed maternal infection ☐Yes ☐No ☐Unknown

i) *If yes, what type of infection?*
☐ Pyelonephritis
☐ Lower urinary tract infection
☐ Unknown

☒ Other (please specify):
_____

ii) *Was there consultation with an obstetrician for confirmed maternal infection?*
- ☐ Yes
- ☐ No
- ☐ Already under obstetric care
- ☐ Unknown

b) Trauma ☐Yes ☐No ☐Unknown

i) *If yes, what type of trauma*
- ☐ Vehicular
- ☐ Fall
- ☐ Violent personal injury
- ☐ Unknown
- ☐ Other *(please specify):*

_____

ii) *Was there consultation with an obstetrician for trauma?*
- ☐ Yes
- ☐ No
- ☐ Already under obstetric care
- ☐ Unknown

c) Renal ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for renal complications?*
- ☐ Yes
- ☐ No
- ☐ Already under obstetric care
- ☐ Unknown

d) Cardiac ☐Yes ☐No ☐Unknown

i) *If yes, was there consultation with an obstetrician for cardiac complications?*
- ☐ Yes
- ☐ No
- ☐ Already under obstetric care
- ☐ Unknown

36) Were there other reasons for obstetric consultations?

☐Yes ☐No ***(go to Q37)*** ☐Unknown ***(go to Q37)***

If yes, what was/were the reason(s) for the obstetric consultation? Please select all that are applicable:

- ☐ Mother's request
- ☐ Previous perinatal death
- ☐ Recurrent miscarriage
- ☐ Previous intrauterine growth restriction
- ☐ Previous pre-term birth
- ☐ Previous caesarean section
- ☐ Other poor obstetric history
- ☐ Mother's age ≥35 years
- ☐Raised BMI
- ☐Surgery
- ☐Unknown
- ☐Other:

_____
_____

37) Was the mother referred to another healthcare service during pregnancy?

☐Yes ☐No ***(go to Q38)*** ☐Unknown ***(go to Q38)***

If yes, what healthcare service was the mother referred to? Please select all that applicable:

☐ Medical service (*please specify reason for referral to medical services*): _____
_____
_

☐ Mental health ☐ Social worker ☐Unknown
☐ Drug and alcohol ☐ Surgery
☐Other: _____

ANTENATAL PROCEDURES

38) Antenatal visits? ☐Yes ☐No ***(go to Q39)*** ☐Unknown ***(go to Q39)***

If yes, please indicate:

a) Total number of visits recorded: _____

b) Gestation at first antenatal visit: _____ weeks _____ days or ☐Unknown

39) Antenatal procedures

Please indicate all procedures undertaken in pregnancy excluding those after fetal death in utero

a) First trimester screening ultrasound scan ☐Yes ☐No ☐Unknown

b) Morphology/anomaly ultrasound scan at 18–20 weeks' gestation ☐Yes ☐No ☐Unknown

c) Total number of antenatal ultrasound scans (exclude those performed after fetal death) Number of ultrasounds _____ ☐Unknown

d) Chorion villus (CV) sampling ☐Yes ☐No ☐Unknown

If yes, what were the CV results?

☐ Normal
☐ Abnormal
☐ Uncertain
☐ Unknown

What were the chromosomal microarray results?

☐ Not performed
☐ Normal
☐ Abnormal
☐ Uncertain
☐ Unknown

e) Cervical suture (vaginal or transabdominal) ☐Yes ☐No ☐Unknown

If yes, what was the date of cervical suture: _____ ☐Unknown

or

f) Amniocentesis ☐Yes ☐No ☐Unknown

If yes, what were the amniocentesis results?

☐ Normal
☐ Abnormal
☐Uncertain
☐Unknown

What were the chromosomal microarray results?

☐ Not performed
☐ Normal
☐ Abnormal
☐ Uncertain
☐ Unknown

g) Doppler studies ☐Yes ☐No ☐Unknown

If yes, what were the studies performed?

	☐ Umbilical artery doppler	☐ Normal	☐ Abnormal	☐Unknown
	☐ Uterine artery doppler	☐ Normal	☐ Abnormal	☐Unknown
	☐Middle-cerebral artery doppler	☐ Normal	☐ Abnormal	☐Unknown
	☐ Other: _____ ☐Unknown	☐ Normal	☐ Abnormal	☐Unknown
h)	External cephalic version	☐Yes	☐No	☐Unknown
	If yes, what was the date this was performed: _____ or			☐Unknown
i)	Fetocide	☐Yes	☐No	☐Unknown
j)	Amnioreduction	☐Yes	☐No	☐Unknown
k)	Laser treatment	☐Yes	☐No	☐Unknown
l)	Intrauterine fetal blood transfusion	☐Yes	☐No	☐Unknown
m)	Ligation of vessels for twin-to-twin transfusion	☐Yes	☐No	☐Unknown
n)	Other: _____	☐Yes	☐No	☐Unknown

40) Were maternal corticosteroids given in pregnancy?

☐Yes ☐No ***(go to Q41)*** ☐Unknown ***(go to Q41)***

If yes, please indicate:

a)	Course of corticosteroids started at what gestation? _____ weeks _____ days			☐Unknown
b)	Was course of corticosteroids completed?	☐Yes	☐No	☐Unknown

MOTHER'S MEDICATIONS

41) Were medications or supplements taken in this pregnancy?

Please indicate all over the counter and supplements taken in the pregnancy

☐Yes ☐No ***(go to Q42)*** ☐Unknown ***(go to Q42)***

If yes, please select medications:

☐ACE inhibitor	☐Antihypertensives	☐Magnesium sulphate
☐Glyceryl trinitrate	☐Nifedepine	☒Salbutamol
☐Ritodrine	☐Other tocolytic	☐Steroids other than fetal lung maturation
☐Valproate	☐Anticonvulsant/other	☐Infertility treatment
☐Antiemetics	☐Antibiotics	☐Antidepressants
☐Sedatives or anxiolytics	☐Indomethacin	☐NSAID/other
☐Aspirin	☐Clexane	☐Heparin
☐Warfarin	☐Narcotics	☐Non-narcotic analgesia

☐Other *Please indicate:* _____

42) Was folic acid taken pre pregnancy?

☐Yes ☐No ☐Unknown

43) Was folic acid taken during the first trimester?

☐Yes ☐No ☐Unknown

LABOUR AND BIRTH

(This section is not required for terminations of pregnancy for maternal mental health or maternal circumstantial reasons)

44) Date of admission to hospital for birth episode

Date: _____(DD/MM/YYYY) ☐Unknown

Time: _____ ☐Unknown

45) Primary caregiver at onset of labour

☐Obstetrician ☐Midwife ☐General Practitioner

☐No intrapartum care provider ☐Unknown

☐Other: _____

46) Onset of labour

☐ Spontaneous ***(go to Q47)*** ☐Induced ☐No labour (***go to Q50)*** ☐Unknown (***go to Q47)***

If induced, please provide the following information:

a) Date of induction of labour: _____(DD/MM/YYYY) ☐Unknown

b) Time of induction of labour: _____ ☐Unknown

c) Specify methods used to induce labour

☐Oxytocin ☐Prostaglandins ☐Artificial rupture of membranes (ARM)

☐Balloon ☐Unknown

☐Other: _____

d) Main indication for induction

☐Prolonged pregnancy ☐Prelabour rupture of membranes ☐Diabetes

☐Hypertensive disorders ☐Multiple pregnancy ☐Chorioamnionitis (includes suspected)

☐Cholestasis of pregnancy ☐Antepartum haemorrhage ☐Maternal age

☐Body Mass Index (BMI) ☐Maternal mental health indication ☐Previous adverse perinatal outcome

☐Other maternal obstetric or medical indication ☐Fetal compromise (includes suspected) ☐Fetal growth restriction (includes suspected)

☐Fetal macrosomia (includes suspected) ☐Fetal death ☐Fetal congenital anomaly

☐Administrative or geographical indication ☐Maternal choice in the absence of any obstetric, medical, fetal, administrative, or geographical indication ☐Unknown

☐Other: _____

47) Labour augmentation ☐Yes ☐No ***(go to Q48)*** ☐Unknown ***(go to Q48)***

If yes, please select method used to augment labour

☐Oxytocin ☐Prostaglandins

☐Artificial rupture of membranes (ARM) Date of ARM: _____(DD/MM/YYYY)

☐Unknown ☐Other: _____

48) Analgesia during labour ☐Yes ☐No ***(go to Q49)*** ☐Unknown ***(go to Q49)***

If yes, please indicate type of analgesia administered

☐Nitrous oxide ☐Systemic opioids ☐Epidural or caudal

☐Spinal ☐Combined spinal/epidural ☐Unknown

☐Other: _____

49) Did part of labour occur in bath/pool? ☐Yes ☐No ***(go to Q50)*** ☐Unknown ***(go to Q50)***

If yes, was the baby born in the bath/pool? ☐Yes ☐No ☐Unknown

50) Was there fetal monitoring during the labour? ☐Yes ☐No ***(go to Q51)*** ☐Unknown ***(go to Q51)***

If yes, what was the method of fetal monitoring?

☐Intermittent auscultation ☐Admission cardiotocography ☐ Intermittent cardiotocography
☐Continuous external cardiotocography ☐Internal cardiotocography (scalp electrode) ☐Fetal blood sampling
☐Unknown ☐Other: _____

51) What was the method of birth of this baby?

☐ Vaginal - non-instrumental ***(go to Q52)***
☐ Vaginal - forceps ***(go to Q51a)***
☐ Vaginal - vacuum extraction ***(go to Q51a)***
☐ Vaginal – forceps and vacuum extraction ***(go to Q51a)***
☐ Planned caesarean - no labour ***(go to Q51b)***
☐ Planned caesarean - labour ***(go to Q51b)***
☐ Unplanned caesarean - labour ***(go to Q51b)***
☐ Unplanned caesarean - no labour ***(go to Q51b)***
☐ Unknown ***(go to Q52)***

a) Were anaesthetics administered? ☐Yes ☐No ☐Unknown

If yes, please select which method

☐Local anaesthetic to perineum ☐Pudendal block ☐Epidural or caudal block
☐Spinal block ☐General anaesthesia ☐Combined spinal-epidural block
☐Unknown ☐Other: _____

b) What was the main indication for caesarean?

☐Fetal compromise ☐Suspected fetal macrosomia
☐Malpresentation ☐Lack of progress; less than or equal to 3cm cervical dilatation
☐Lack of progress in the first stage; greater than 3cm to less than 10cm cervical dilatation ☐Lack of progress in the second stage
☐Placenta praevia ☐Placental abruption
☐Vasa praevia ☐Antepartum/intrapartum haemorrhage
☐Multiple pregnancy ☐Unsuccessful attempt at assisted delivery
☐Cord prolapse ☐Previous adverse perinatal outcome
☐Previous caesarean section ☐Previous severe perineal trauma
☐Previous shoulder dystocia ☐Maternal choice in the absence of any obstetric, medical, surgical, psychological indications
☐Other: _____

i) Were forceps or vacuum tried first?

☐Forceps ☐Vacuum ☐Forceps and vacuum
☐No instrumental attempted before caesarean ☐Unknown

ii) Were anaesthetics administered? ☐Yes ☐No ☐Unknown

If yes, please select which method

☐Local anaesthetic to perineum ☐Pudendal block ☐Epidural or caudal block
☐Spinal block ☐General anaesthesia ☐Combined spinal-epidural block
☐Unknown ☐Other: _____

52) What was the birth presentation?

☐Vertex ☐Breech ☐Face

☐Brow ☐Unknown ☐Other: _____

53) Complications in labour/birth ☐Yes ☐No ***(go to Q54)*** ☐Unknown ***(go to Q54)***

If yes, please indicate relevant option:

☐APH ☐Cord entanglement/prolapse ☐Meconium-stained liquor
☐Shoulder dystocia ☐Fetal bradycardia ☐Failure to progress/dystocia
☐Non-reassuring CTG ☐Unknown ☐Other: _____

54) Labour and membrane rupture duration

a) First stage of labour duration: _____ hours _____ minutes ☐Unknown

b) Second stage of labour duration: _____ hours _____ minutes ☐Unknown

c) Duration of membrane rupture prior to birth: _____ days _____ hours _____ minutes ☐Unknown

55) Were antibiotics given in labour? ☐Yes ☐No ***(go to Q56)*** ☐Unknown ***(go to Q56)***

a) If yes, what was the indication?

☐Group B streptococcus ☐Prolonged rupture of membranes ☐Clinical chorioamnionitis
☐Suspected or confirmed infection ☐Unknown ☐Other _____

b) Date antibiotics given: _____(DD/MM/YYYY) ☐Unknown

BABY RESUSCITATION AT BIRTH

(This section is not required for terminations of pregnancy for maternal mental health or maternal circumstantial reasons)

56) Apgar scores

Please indicate a score between 1–10 with no decimals

a) 1 min: _____ ☐Unknown
b) 5 min: _____ ☐Unknown
c) 10 min: _____ ☐Unknown
d) 15 min: _____ ☐Unknown

57) Did the baby receive any resuscitation at birth? ☐Yes ☐No ***(go to Q58)*** ☐Unknown ***(go to Q58)***

a) If yes, what was the outcome of the resuscitation?

☐Baby resuscitated and stayed with mother ☐Baby resuscitated and transferred to neonatal special or intensive care nursing ☐Baby was not able to be resuscitated ☐Unknown

b) What was the method of resuscitation at birth?

☐Continuous positive airway pressure with air ☐CPAP with oxygen ☐Endotracheal intubation and IPPR with oxygen
☐Endotracheal intubation and IPPR with air ☐External cardiac massage and ventilation ☐Intermittent positive pressure respiration bag and mask with air
☐Intermittent positive pressure respiration bag and mask with oxygen ☐Oxygen therapy ☐Suction
☐Unknown ☐Other: _____

☐Medications
Which medications?
☐Adrenalin
☐Narcotic antagonist
☐Sodium bicarbonate
☐Volume expander
☐Unknown
☐Other: _____

c) What was the professional category of the most senior staff member at the resuscitation?

☐Paediatric registrar ☐Obstetric registrar ☐Obstetric consultant
☐Consultant paediatrician ☐Neonatal consultant ☐Unknown

58) Were cord gases taken at birth? ☐Yes ☐No ***(go to Q59)*** ☐Unknown ***(go to Q59)***

If yes, please indicate:

a) pH - arterial: _____ ☐Unknown
b) Base deficit- arterial: _____ ☐Unknown
c) Lactate- arterial: _____ ☐Unknown
d) CO2- arterial: _____ ☐Unknown
e) pH- venous: _____ ☐Unknown
f) Base deficit- venous: _____ ☐Unknown
g) Lactate- venous: _____ ☐Unknown
h) CO2- venous: _____ ☐Unknown

NEONATAL/POSTNEONATAL CARE

59) Was the baby transferred from place of birth (e.g. via NETS) prior to death to a higher level of care? ☐Yes ☐No ***(go to Q60)*** ☐Unknown ***(go to Q60)***

a) If yes, what was the main reason for the transfer?
☐Prematurity
If yes, please specify
☐Less than 28 weeks gestation
☐28–31 weeks gestation
☐32–36 weeks
☐Unknown
☐Respiratory
If yes, please specify
☐Hyaline membrane disease (respiratory distress syndrome)
☐Meconium aspiration
☐PPHN
☐Pneumothorax
☐Congenital adenomatoid lesion of the lung
☐Tracheoesophageal fistula
☐Other: _____
☐Unknown
☐Cardiac
If yes, please specify
☐Coarctation of the aorta
☐Transposition of the great arteries
☐Tetralogy of Fallot
☐Hypoplastic left heart

☐Atrioventricular septal defect
☐Other: _____
☐Unknown

☐Gastrointestinal
If yes, please specify
☐Necrotising enterocolitis
☐Pyloric stenosis
☐Other: _____
☐Unknown

☐Neurological
If yes, please specify
☐HIE
☐Seizures
☐Intraventricular haemorrhage
☐Other intracranial haemorrhage
☐Neuromuscular disorder
☐Other: _____
☐Unknown

☐Musculoskeletal
If yes, please specify
☐Congenital diaphragmatic hernia
☐Gastroschisis
☐Omphalocele
☐Other: _____
☐Unknown

☐Sepsis
If yes, please specify
☐GBS
☐E. Coli
☐Other: _____
☐Unknown

☐Metabolic
If yes, please specify
☐Hypoglycaemia
☐Hyponatraemia
☐Other: _____
☐Unknown

☐Haematology
If yes, please specify
☐Rh isoimmunisation
☐ABO isoimmunisation
☐Alloimmune thrombocytopenia
☐Unknown
☐Other: _____

☐Other: _____
☐Unknown

b) Date baby was transferred: _____(DD/MM/YYYY) ☐Unknown

60) Neonatal diagnosis (select all applicable)

☐Prematurity
If yes, please specify
☐Less than 28 weeks gestation
☐28–31 weeks gestation
☐32–36 weeks
☐Unknown

☐Respiratory
If yes, please specify
☐Hyaline membrane disease (respiratory distress syndrome)
☐Meconium aspiration
☐PPHN
☐Pneumothorax
☐Congenital adenomatoid lesion of the lung
☐Tracheoesophageal fistula
☐Other: _____
☐Unknown

☐Cardiac
If yes, please specify
☐Coarctation of the aorta
☐Transposition of the great arteries
☐Tetralogy of Fallot
☐Hypoplastic left heart
☐Atrioventricular septal defect
☐Other: _____
☐Unknown

☐Gastrointestinal
If yes, please specify
☐Necrotising enterocolitis
☐Pyloric stenosis
☐Other: _____
☐Unknown

☐Neurological
If yes, please specify
☐HIE
☐Seizures
☐Intraventricular haemorrhage
☐Other intracranial haemorrhage
☐Neuromuscular disorder
☐Other: _____
☐Unknown

☐Musculoskeletal
If yes, please specify
☐Congenital diaphragmatic hernia
☐Gastroschisis
☐Omphalocele
☐Other: _____
☐Unknown

☐Sepsis
If yes, please specify
☐GBS
☐E. Coli
☐Other: _____
☐Unknown

☐Metabolic
If yes, please specify
☐Hypoglycaemia
☐Hyponatraemia
☐Other: _____
☐Unknown

☐Haematology
If yes, please specify

☐Rh isoimmunisation
☐ABO isoimmunisation
☐Alloimmune thrombocytopenia
☐Other: _____
☐Unknown

☐Other: _____
☐Unknown

61) Did the baby receive any neonatal treatment? ☐Yes ☐No ***(go to Q62)*** ☐Unknown ***(go to Q62)***

If yes, please specify

☐IV therapy ☐Antibiotics ☐Nitric oxide
☐Inotropes ☐Mechanical ventilation ☐Phototherapy
☐Extracorporeal membrane oxygenation ☐Therapeutic hypothermia ☐Unknown
☐Other: _____

62) Were active life supporting measures withdrawn? ☐Yes ☐No ***(go to Q63)*** ☐Unknown ***(go to Q63)***

a) If yes, on what date were the measures withdrawn: _____(DD/MM/YYYY) ☐Unknown

b) At what time were the measures withdrawn: _____ ☐Unknown

63) Please provide a summary of significant neonatal events

_____
_____
_____
_____
_____
_____

64) Place of neonatal/post neonatal death

☐Home ☐Emergency department ☐NICU
☐PICU ☐SCN ☐Paediatric ward
☐Unknown ☐Other: _____

MATERNAL INVESTIGATIONS AFTER STILLBIRTH OR NEONATAL DEATH

(This section is not required for terminations of pregnancy for maternal mental health or maternal circumstantial reasons)

65) Maternal blood tests

a) Was a full blood count performed? ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) Hb: _____g/L
ii) WCC: _____×10^9 ☐Unknown
iii) Platelets: _____×10^9 ☐Unknown

b) Was a blood group and antibody screen performed? ☐Yes ☐No ☐Unknown

i) If yes, what was the blood group?

☐A positive ☐A negative ☐AB positive
☐AB negative ☐B positive ☐B negative

☐O positive ☐O negative ☐Unknown

ii) What was the antibody screen?

☐Positive ☐Negative ☐Unknown

Please specify antibody:

☐D RHESUS
☐C (LITTLE C) RHESUS
☐K- KELL
☐C (BIG C) REHSUS
☐E (LITTLE E) RHESUS
☐E (BIG E) RHESUS
☐JKA- KDD
☐JKB- KDD
☐FYA- DUFFY
☐FYB- DUFFY
☐Other:

_____

Please note, Question **c)** is a core test for all stillbirths

c) Was testing for maternal fetal haemorrhage performed? ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) Date tests performed: _____(DD/MM/YYYY) ☐Unknown

ii) What was the result of testing for maternal fetal haemorrhage? ☐Positive ☐Negative ☐Unknown

iii) Please state which test was performed to detect maternal fetal haemorrhage:

☐Kleihauer–Betke ☐Flow cytometry ☐Unknown

☐Other: _____

iv) Was the estimated fetal to maternal transfusion volume more than 1 ml? ☐Yes ☐No ☐Unknown

If yes, what was the estimated volume of maternal transfusion? _____

d) Renal function tests? ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) Creatinine: _____ umol/L ☐Unknown

ii) Uric acid (Urate)_____mmol/L ☐Unknown

iii) Urea: _____mmol/L ☐Unknown

e) Liver function test? ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) AST: _____ umol/L ☐Unknown

ii) ALT: _____ U/L ☐Unknown

iii) Bilirubin Total: _____ umol/L ☐Unknown

f) HBA1c? ☐Yes ☐No ☐Unknown

If yes, what was the result: _____mmol/mol *or* % *or* ☐Unknown

g) Thyroid function test? ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) TSH: _____ mU/L ☐Unknown

ii) Free T4: _____ pmol/L ☐Unknown

h) Bile acids? ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) Results: _____ umol/L ☐Unknown

ii) Type of test ☐Fasting ☐Non-fasting ☐Unknown

i) CMV ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) CMV-IgM result ☐Reactive ☐Non-reactive ☐Unknown

ii) CMV-IgG result ☐Reactive ☐Non-reactive ☐Unknown

iii) CMV avidity testing ☐Yes ☐No ☐Unknown

If yes, result? _____

j) Toxoplasma ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) Toxoplasma- IgM result ☐Reactive ☐Non-reactive ☐Unknown

ii) Toxoplasma- IgG result ☐Reactive ☐Non-reactive ☐Unknown

iii) Toxoplasma avidity testing ☐Yes ☐No ☐Unknown

If yes, result? _____

k) Parvovirus B19 ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) Parvovirus B19- IgM result ☐Reactive ☐Non-reactive ☐Unknown

ii) Parvovirus B19-IgG result ☐Reactive ☐Non-reactive ☐Unknown

iii) Parvovirus B19 avidity testing ☐Yes ☐No ☐Unknown

If yes, result? _____

l) Rubella

Performed at routine antenatal screen? ☐Yes ☐No ☐Unknown

If yes or performed at routine antenatal screen, please indicate result:

☐ Immune ☐Not immune ☐Indeterminate ☐Unknown

m) Syphilis serology

Performed at routine antenatal screen? ☐Yes ☐No ☐Unknown

If yes or performed at routine antenatal screen, please indicate result:

☐Positive ☐Negative ☐Unknown

n) Thrombophilia tests at time of birth ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) ☐ Anticardiolipin antibodies ☐Positive ☐Negative ☐Unknown

ii) ☐ Lupus anticoagulant ☐Positive ☐Negative ☐Unknown

iii) ☐ APC resistance ☐Positive ☐Negative ☐Unknown

If positive, Factor V Leiden? ☐Yes

Result? ☐Positive ☐Negative ☐Unknown

☐No

☐Unknown

iv) ☐ Anti B2 glycoprotein-1 antibodies ☐Positive ☐Negative ☐Unknown

If yes, results? _____

66) Was thrombophilia testing undertaken around the time of the follow-up visit? ☐Yes ☐No ***(go to Q67)*** ☐Unknown ***(go to Q67)***

If yes, please indicate:

a) Anticardiolipin antibodies ☐Yes ☐No ☐Unknown

If yes, please indicate:

i) Date: ☐Unknown

_____

ii) Results: ☐Positive ☐Negative ☐Unknown

iii) Anti B2 glycoprotein-1 antibodies ☐Yes ☐No ☐Unknown

If yes, please indicate:

(1) Date: _____ ☐Unknown

(2) Results ☐Positive ☐Negative ☐Unknown

67) Were there any other maternal investigations performed to investigate the cause of death? ☐Yes ☐No ***(go to Q68)*** ☐Unknown ***(go to Q68)***

a) If yes, please specify other investigations:
_____

b) If yes, please specify the results:
_____

EXTERNAL EXAMINATION OF THE BABY, CORD, PLACENTA, AND MEMBRANES BY CLINICIAN

(Core tests required for all stillbirths)

68) Was an external examination of the baby performed? ☐Yes ☐No ☐Unknown

If yes, please indicate:

a) Were any external abnormalities identified on external examination of the baby? ☐Yes ☐No ☐Unknown
If yes, please specify:
_____

b) Length: _____cm ☐Unknown

c) Head circumference: _____cm ☐Unknown

69) Was an examination of the placenta, cord, and membrane performed? ☐Yes ☐No ☐Unknown

If yes, please indicate:

a) Placenta weight: _____g ☐Unknown

b) Cord length: _____cm ☐Unknown

c) Were any placental abnormalities noted on external examination ☐Yes ☐No ☐Unknown
If yes, please specify

☐Incomplete ☐Retroplacental clot ☐Gritty/Calcified
☐Ragged membranes ☐Offensive odour ☐Vasa praevia
☐Succenturiate lobe/bi-lobed ☐Circumvallate ☐Bipartite
☐Unknown ☐Other: _____

d) Were any features apparent in the umbilical cord? ☐Yes ☐No ☐Unknown
If yes, please specify

☐Hyper-coiled appearance ☐Hypo-coiled appearance ☐Marginal cord insertion
☐Velamentous cord insertion ☐Abnormal cord length- short ☐Abnormal cord length- long
☐Unusual cord thickness- thin ☐Unusual cord thickness- thick ☐Meconium stained
☐Two vessels in the cord ☐True knot- loose ☐True knot- tight
☐Unknown ☐Other: _____

e) Was the cord wrapped around the neck or other structure?

☐No ☐Nuchal cord ☐Unknown ☐Other: _____

If yes to nuchal cord, how many times was the cord wrapped around the neck? _____ *or*
☐Unknown

f) Were there any membrane abnormalities identified? ☐Yes ☐No ☐Unknown

If yes, please specify

☐Abnormal colour- green ☐Malodour ☐Retro-membranous blood- fresh
☐Retro-membranous blood- old ☐Spotty (e.g. Amnion nodosum) ☐Unknown
☐Other: _____

70) External examination of the baby by expert in addition to clinician at birth? ☐Yes ☐No ☐Unknown

If yes, please indicate

a) External examination performed by

☐Perinatal/Paediatric pathologist ☐Pathologist other ☐Pathologist unspecified
☐Clinical geneticist ☐Paediatrician ☐Neonatologist
☐Unknown ☐Other: _____

b) Were abnormalities identified? ☐Yes ☐No ☐Unknown

If yes, please specify: _____

PLACENTAL HISTOPATHOLOGY AND AUTOPSY

(This section is not required for terminations of pregnancy for maternal mental health or maternal circumstantial reasons) (Core tests required for all stillbirths)

71) Placental and cord histopathology

a) Placental histopathology

☐Not performed ☐Normal ☐Abnormal
☐Uncertain ☐Unknown

If abnormal, please specify:

☐Funisitis ☐Chorioamnionitis ☐Acute villitis
☐Placental abscesses ☐Infarct- single ☐Infarct- multiple
☐Massive perivillous fibrin ☐Histiocytic intervillositis ☐Maternal floor infarction
☐Villitis of unknown aetiology ☐Fetal thrombotic vasculopathy ☐Retroplacental haemorrhage
☐Chorioangioma ☐Metastatic tumour ☐Haemosiderin laden macrophages
☐Unknown ☐Other: _____

b) Placental swab for culture

☐Uncertain ☐Unknown

☐Group B Streptococcus ☐Group A Streptococcus ☐Other Streptococcus
☐E coli ☐Trichomonas Vaginalis ☐Gardbnerella Vaginalis
☐Chlamydia Trachomatis ☐Ureaplasma Urealyticum ☐Mycoplasma Hominis
☐Candida ☐Neisseria Gonorrhoea ☐Herpes
☐Pseudomonas ☐Klebsiella ☐Clostridium
☐Proteus ☐Bacteroids ☐Enterococcus
☐Fusobacterium ☐Enterobacterium ☐Hep A
☐Hep B ☐Hep C ☐HIV
☐Syphilis- Treponema Pallidum ☐Rubella ☐CMV
☐Toxoplasma Gondii ☐Parvovirus ☐Listeria
☐Varicella ☐Malaria ☐Echovirus
☐Chlamydia Psittaci ☐Haemophilus ☐Unknown

☐Other: _____

c) Other site culture taken by pathologist? ☐Yes ☐No ☐Unknown

If yes, please specify

i) Site of other culture taken: _____

ii) Results of other culture taken ☐ No pathogen ☐ Pathogen ☐ Uncertain ☐ Unknown

If pathogen found, please specify:

☐Group B Streptococcus	☐Group A Streptococcus	☐Other Streptococcus
☐E coli	☐Trichomonas Vaginalis	☐Gardbnerella Vaginalis
☐Chlamydia Trachomatis	☐Ureaplasma Urealyticum	☐Mycoplasma Hominis
☐Candida	☐Neisseria Gonorrhoea	☐Herpes
☐Pseudomonas	☐Klebsiella	☐Clostridium
☐Proteus	☐Bacteroids	☐Enterococcus
☐Fusobacterium	☐Enterobacterium	☐Hep A
☐Hep B	☐Hep C	☐HIV
☐Syphilis- Treponema Pallidum	☐Rubella	☐CMV
☐Toxoplasma Gondii	☐Parvovirus	☐Listeria
☐Varicella	☐Malaria	☐Echovirus
☐Chlamydia Psittaci	☐Haemophilus	☐Unknown

☐Other: _____

d) Genetic testing ☐Yes ☐No ☐Unknown

If yes, please specify the following

i) Culture karyotype

☐Not performed ☐Normal ☐Abnormal ☐Uncertain ☐Unknown

Please specify abnormal or uncertain results: _____

ii) Chromosomal microarray

☐Not performed ☐Normal ☐Abnormal ☐Uncertain ☐Unknown

Please specify abnormal or uncertain results: _____

iii)

☐Not performed ☐Normal ☐Abnormal ☐Uncertain ☐Unknown

Please specify abnormal or uncertain results: _____

72) Autopsy

i) Parental consent for an autopsy examination?
☐Yes- full (go to Q1)
☐Yes- limited (*please describe autopsy limitations)* (go to Q1 and Q3)
_____
☐No (go to Q2 and Q3)
☐Unknown (go to Q74b)

(1) If yes-full or yes-limited, please specify the following:

What were the autopsy results?
☐No abnormality ☐Abnormal ☐Inconclusive ☐Unknown
If abnormal or inconclusive, please describe: _____

What was the autopsy examination and clinical diagnosis?

☐Confirms clinical diagnosis (no change in counselling for future pregnancies from postmortem information)	☐Changes clinical diagnosis (diagnosis changed enough to alter counselling for future pregnancies)	☐Additional information (clinical diagnosis not altered but additional clinical findings e.g. abnormalities)	☐Unknown

(2) If no, please specify the following:

What was the most relevant reason why the parents did not consent to an autopsy examination?

☐Inexperience of staff in counselling about autopsy	☐Lack of rapport with the parents	☐ Lack of diagnostic value in this case	☐Staff workload	☐Parent emotional distress
☐Religious or cultural beliefs	☐Time to receive results	☐Negative perceptions in general about autopsy	☐Multiple pregnanc y fetocide	☐Unknown

☐Other: _____

(3) If yes-limited or no, please provide comments on the barriers to approach and consent for autopsy in this case:
_____
_____

ii) Who sought consent for autopsy?
☐Junior medical staff ☐Midwife ☐Nurse ☐Obstetric specialist
☐Obstetric registrar ☐GP ☐Paediatrician ☐Unknown
☐Other: _____

If yes-limited or no, please provide comments on the barriers to approach and consent for autopsy in this case :
_____
_____

iii) Please indicate the most relevant reason from the clinical staff perspective why the option of an autopsy was not offered in this case

☐Inexperience of staff in counselling about autopsy	☐Lack of rapport with the parents	☐ Lack of diagnostic value in this case	☐Staff workload	☐Parent emotional distress
☐Religious or cultural beliefs	☐Time to receive results	☐Negative perceptions in general about autopsy	☐Multiple pregnan cy fetocide	☐Unknown

☐Other: _____

iv) Please provide comments on the barriers to approach and consent for autopsy in this case: _____

b) Was a Babygram (skeletal survey) performed?

☐Not performed
☐Yes- No abnormality
☐Yes- Abnormal
☐Yes- Inconclusive
☐Unknown

If yes-abnormal or yes-inconclusive, please specify results: _____

BABY PATHOLOGY AND IMAGING

(This section is not required for terminations of pregnancy for maternal mental health or maternal circumstantial reasons)

Please note, Question **73** is a core test for all stillbirths

73) What were the clinical photographs?

☐Not taken ☐Normal ☐Abnormal ☐Unknown

If abnormal, please specify: _____

74) Swabs of ear and throat taken for culture?

☐No (go to Q77) ☐Yes, no pathogens (go to Q77) ☐Yes, pathogen isolated
☐Uncertain (go to Q77) ☐Unknown (go to Q77)

If yes, pathogens isolated, please specify:

☐Group B Streptococcus	☐Group A Streptococcus	☐Other Streptococcus
☐E coli	☐Trichomonas Vaginalis	☐Gardbnerella Vaginalis
☐Chlamydia Trachomatis	☐Ureaplasma Urealyticum	☐Mycoplasma Hominis
☐Candida	☐Neisseria Gonorrhoea	☐Herpes
☐Pseudomonas	☐Klebsiella	☐Clostridium
☐Proteus	☐Bacteroids	☐Enterococcus
☐Fusobacterium	☐Enterobacterium	☐Hep A
☐Hep B	☐Hep C	☐HIV
☐Syphilis- Treponema Pallidum	☐Rubella	☐CMV
☐Toxoplasma Gondii	☐Parvovirus	☐Listeria
☐Varicella	☐Malaria	☐Echovirus
☐Chlamydia Psittaci	☐Haemophilus	☐Unknown

☐Other: _____

75) Magnetic resonance imaging?

☐Not performed (go to Q78) ☐Normal (go to Q78) ☐Abnormal
☐Inconclusive ☐Unknown (go to Q78)

If abnormal or inconclusive, please specify: _____

76) Were cord and cardiac blood samples taken?

☐Yes, cord ☐Yes, cardiac ☐No ☐Unknown

If cord or cardiac blood samples were taken, was a full blood count with smear done (nucleated red count)?

☐Yes ☐No ☐Unknown

If yes, please specify:

a) Hb: _____g/L ☐Unknown

b) WCC: _____×10^9 ☐Unknown

c) Platelets: _____×10^9 ☐Unknown

77) Genetic testing of the baby- tissue or blood?

☐Yes ☐No (go to Q80) ☐Unknown (go to Q80)

If yes, please specify:

a) Specimen from the baby for the genetic testing

☐Cord ☐Blood ☐Skin

☐Cartilage ☐Unknown ☐Other: _____

b) Type of genetic testing

☐Karyotype ☐Chromosomal microarray ☐Unknown ☐Other: _____

What were the results of the testing?

☐Normal ☐Abnormal ☐Uncertain ☐Unknown

If abnormal or uncertain, please describe:

_____

78) Were any other investigations performed?

☐Yes ☐No (go to Q81) ☐Unknown (go to Q81)

If yes, please specify investigations and results:

_____
_____
_____
_____
_____

CASE DOCUMENTS

79) Please attach an autopsy, placental pathology and other relevant pathology results

CASE SUMMARY

80) Please provide a brief summary of key clinical events including factors that you consider may have contributed to the death. Please also provide any information you think relevant that was not covered in the previous questions, which you consider may have contributed to the outcome.

_____
_____
_____
_____
_____
_____
_____
_____
_____

81) Please include any feedback parents have provided or questions they would like addressed during the review meeting. This may include comments on and questions about the antenatal care, intrapartum care, and/or postpartum care the parents and their baby received.

_____
_____
_____
_____
_____
_____
_____
_____
_____

HOSPITAL REVIEW DETAILS

82) Was this case referred to the coroner?

☐Yes ☐No ***(go to Q84)*** ☐Unknown ***(go to Q84)***

If yes, was this the coroner's case?

☐Yes ☐No ☐Unknown

Please provide details:

_____

83) Sentinel event report

☐Yes ☐No ***(go to Q85)*** ☐Unknown ***(go to Q85)***

84) Root cause analysis report

☐Yes ☐No ***(go to Q86)*** ☐Unknown ***(go to Q86)***

If yes, please provide details:

_____
_____
_____

85) Date scheduled for hospital committee review: ☐Unknown

_____(DD/MM/YYYY)

86) Responsibility for the completion of the data

a) Name: _____

b) Designation: _____

c) Date completed: _____(DD/MM/YYYY)

Section 2: MATERNITY SERVICE REPORT

COMPLETE THIS SECTION AT PERINATAL MORTALITY COMMITTEE REVIEW

Mother's surname:	
If multiple birth, indicate birth number of this baby	
Date of perinatal death	
Gestation	
Facility reporting	

Death certificate details:

1) Main disease or condition in fetus or infant: _____

_____

2) Other diseases or conditions in fetus or infant: _____

_____

3) Main maternal disease or condition affecting fetus or infant: _____

_____

4) Other maternal diseases or conditions affecting fetus or infant: _____

_____

5) Other relevant circumstances: _____

_____

CLASSIFICATION OF CAUSE OF DEATH

6) PSANZ Perinatal Death Classification – Primary condition. Presumed at time of death (PSANZ-PDC)

Category classification

Please insert full numerical code _____

Please insert full text_____

NB. If stillbirth, go to question 8.

7) PSANZ Neonatal Death Classification – Primary condition. Presumed at time of death (PSANZ-NDC)

Category classification

Please insert full numerical code _____

Please insert full text _____

_____

8) Level of understanding of the diagnosis at time of death (rated by clinician completing the death certificate)

☐ Well understood ☐Poorly understood ☐Not understood

☐ Not recorded ☐Unknown

9) PSANZ Perinatal Death Classification – Primary condition. (PSANZ-PDC)

Category classification

Please insert full numerical code _____

Please insert full text _____

_____

10) Were any associated conditions present according to PSANZ-PDC that contributed to the death?

☐ Nil ☐One ☐Two
☐ Not recorded ☐ Unknown

a) PSANZ Perinatal Death Classification (PSANZ-PDC) – Associated condition 1

Category classification

Please insert full numerical code _____

Please insert full text _____

_____

b) PSANZ Perinatal Death Classification (PSANZ-PDC) – Associated condition 2

Category classification

Please insert full numerical code _____

Please insert full text _____

_____

NB. If stillbirth, go to question 12.

11) Were any associated conditions present according to PSANZ-NDC which contributed to the death?

☐ Nil ☐One ☐Two
☐Not Recorded ☐Unknown

a) PSANZ Neonatal Death Classification (PSANZ-NDC) – Associated condition 1

Category classification

Please insert full numerical code _____

Please insert full text _____

_____

b) PSANZ Neonatal Death Classification (PSANZ-NDC) – Associated condition 2

Category classification

Please insert full numerical code _____

Please insert full text _____

_____

12) Was the perinatal death referred to the coroner?

☐ Yes ☐No ☐Unknown

FACTORS RELATED TO CARE

1) Were factors relating to organisational and/or management identified? (e.g. inadequate supervision of staff, lack of appropriate clinical management protocols, lack of communication between services)

☐Yes ☐No ☐Unknown

If yes, please specify each question based on the following rates:

1- Insignificant. Sub-optimal factors identified but unlikely to have contributed to the outcome
2- Possible- Sub-optimal factors identified might have contributed to the outcome
3- Significant. Sub-optimal factors identified were likely to have contributed to the outcome
4- Undetermined. Insufficient information available
5- Unknown

	Please rate	Please state the specific factors and include any relevant comments
☐Poor organisational arrangements of staff		_____ _____ _____
☐Inadequate education and training		_____ _____ _____
☐Lack of policies, protocols, or guidelines		_____ _____ _____
☐Inadequate number of staff		_____ _____ _____
☐Poor access to senior clinical staff		_____ _____ _____
☐Failure or delay in emergency response		_____ _____ _____
☐Delay in procedure (e.g. Caesarean section)		_____ _____ _____
☐Inadequate systems/process for sharing of clinical information between services		_____ _____ _____
☐Equipment (e.g. faulty equipment, inadequate maintenance, or lack of equipment)		_____ _____ _____

☐Building and design functionality (e.g. space, privacy, ease of access, lighting, noise, power failure, operating theatre in distant location)		_____ _____ _____
☐Other: _____ _____ _____ ___		_____ _____ _____
☐Unknown		

2) Were factors relating to personnel identified? (staff factors relating to professional care and service provision)

☐Yes ☐No ☐Unknown

	Please rate	Please state the specific factors and include any relevant comments
☐Knowledge and skills of staff were lacking		_____ _____ _____
☐Delayed emergency response by staff		_____ _____ _____
☐Failure to maintain competence		_____ _____ _____
☐Communication between staff was inadequate		_____ _____ _____
☐Failure to seek help/supervision		_____ _____ _____
☐Failure to follow recommended best practise		_____ _____ _____
☐Lack of recognition of complexity or seriousness of condition by care giver		_____ _____ _____
☐Other: _____ _____ _____ _____		_____ _____ _____

☐Unknown		_____ _____ _____

3) Were barriers to accessing/engaging with care identified? (e.g. no, infrequent or late booking for antenatal care, women decline treatment/advice)

☐Yes ☐No ☐Unknown

	Please rate	Please state the specific factors and include any relevant comments
☐No antenatal care		_____ _____ _____
☐Infrequent or late booking		_____ _____ _____
☐Declined treatment or advice		_____ _____ _____
☐Obesity impacted on delivery of optimal care (e.g. USS)		_____ _____ _____
☐Substance use		_____ _____ _____
☐Family violence		_____ _____ _____
☐Lack of recognition by the woman or family of the complexity or seriousness of the condition		_____ _____ _____
☐Maternal mental illness		_____ _____ _____

☐Cultural barriers		_____ _____ _____
☐Language barriers		_____ _____ _____
☐Not eligible to access free care		_____ _____ _____
☐Environmental (e.g. isolated, long transfer, weather prevented transport)		_____ _____ _____
☐Other: _____ _____ _____ _____		_____ _____ _____

RECOMMENDATIONS FOR IMPROVEMENT

4) How many recommendations resulted from the review meeting?

5) Please list the recommendation/s and the action/s required

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

6) Has the action/s been completed?

☐Yes ☐No ☐Unknown

If yes, please specify the action taken and the date the action was taken:

_____
_____
_____

_____
_____

If no, why has this action not been completed:

_____
_____
_____
_____
_____
_____

FURTHER COMMENT

7) Please provide any further comments on factors that you consider may have contributed to the death:

_____
_____
_____
_____
_____
_____
_____
_____

PERINATAL MORTALITY REVIEW ADMINISTRATION DETAILS

8) Location of perinatal mortality review: _____

9) Date of review: _____(DD/MM/YYYY)

10) Have the patients been provided with an update on results as required?

☐Yes ☐No ☐Unknown

11) Has the GP and other relevant care providers been sent a case summary?

☐Yes ☐No ☐Unknown

12) Responsibility for complete of data

Name: _____

Designation: _____

Date completed: _____(DD/MM/YYYY)

National Mortality Review Committee | Perinatal and Maternal Mortality Review

Rapid reporting form for a perinatal death – mother

Please use the *Guidelines for the completion of the mother and baby forms following a perinatal death March 2016 Version 10* to help you complete this form. You can obtain these guidelines from www.otago.ac.nz/pmmrc. Please contact your local coordinator for assistance with logging in.

Both the mother and the baby National Mortality Review Committee forms need to be completed by the lead maternity carer or other clinician for any baby who dies from 20 weeks gestation (ie, ≥20^{0}, or **if gestation is unknown** a birth weight ≥400 g), including all terminations, to before 28 completed days of life (ie, up to midnight on the 27th day).

This mother form can be submitted electronically before you submit the baby form. If you are submitting written forms, please courier this and the mother form to the address at the end of the form. We understand that you may not know the answer to some questions, but please answer as many as possible. Compulsory entries are marked with two asterisks (**).

Please complete within 48 hours of the baby's death if possible.

Personally identifiable information (of the mother, baby or lead maternity carer) collected on this form will be kept confidential. The information included in reports by the National Mortality Review Committee is grouped and non-identifiable.

Place patient label here if available

**How many perinatal losses are linked to this pregnancy: .....

**Mother's NHI: ..... Date of birth: _____ /_____ /_____
DD MM YYYY

First name: ..... Surname: .....

Mother's other name(s): .....

Usual residential address at time of delivery

Property/house name .....

Flat/unit number .....

Street number/rapid number (rural) .....

Street name .....

Suburb/locality .....

Town/city .....

Country (if not New Zealand) .....

Postcode .....

Ethnicity (select all that apply)

- ☐ New Zealand European
- ☐ Māori
- ☐ Samoan
- ☐ Cook Island Māori
- ☐ Tongan
- ☐ Niuean
- ☐ Chinese
- ☐ Indian
- ☐ Other (please state).....

What is the country of birth?

- ☐ New Zealand
- ☐ Australia
- ☐ England
- ☐ China
- ☐ India
- ☐ South Africa
- ☐ Samoa
- ☐ Cook Islands
- ☐ Other (please state) .....

Source of ethnicity information (select all that apply)

- ☐ Woman
- ☐ Family/whānau
- ☐ DHB patient registration form
- ☐ LMC notes
- ☐ Clinical notes
- ☐ NHI details
- ☐ Other (please state) .....
  .....

Maternal height: ____ cm

(If not available, please measure height and weight.)

Maternal weight ____ kg (earliest measured in pregnancy)

Obstetric history

Previous pregnancies (Do not include index pregnancy in parity. Multiple births are counted as one.)

Gravidity ____ Parity: ____ ☐ Unknown

Please complete for each pregnancy. See footnotes for codes for each section.

Date of delivery	Place of birth	Gestation (weeks)	Pregnancy outcome[1]	Delivery method[2]	Birth weight	SGA <10th centile	Complications[3]

[1]Pregnancy outcome: LB, live born; SM, spontaneous miscarriage; TOP, termination of pregnancy; E, ectopic pregnancy; SB, stillbirth; END, early neonatal death (<7 days age); LND, late neonatal death (7–27 days); CYD, Child and Youth Death (28 days–24 years); U, unknown.

[2]Delivery method: NVD, normal vaginal delivery; OV, operative vaginal delivery; VB, vaginal breech; CS, Caesarean section; U, unknown.

[3]Complications: NIL, no complications; HE, hyperemesis; APH, ante partum haemorrhage/abruption; CxS, cervical stitch; GDM, gestational diabetes; PET, pre-eclampsia; Other, please comment in summary section; U, unknown.

All the following questions relate to this pregnancy

Has the mother experienced family violence during this pregnancy?

☐ No

☐ Not asked

☐ Unknown

☐ Yes

If yes, was she offered referral to relevant support services?

☐ Yes ☐ Yes, but declined ☐ No ☐ Unknown

Does the mother have a history of infertility for >12 months before this pregnancy?

☐ Yes ☐ No ☐ Unknown

Fertility treatment for this pregnancy (select all that apply)

☐ Artificial insemination – donor

☐ Artificial insemination – husband/partner

☐ Clomiphene citrate

☐ Follicle-stimulating hormone

☐ Intra-cytoplasmic sperm injection

☐ In vitro fertilisation (number of embryos transferred: _____)

☐ Surgery to increase fertility

☐ Insulin sensitisers, eg, metformin

☐ Letrozole

☐ Other (please state).....

Was treatment in New Zealand?

☐ Yes ☐ No ☐ Unknown

If overseas, where: .....

Intended place of birth

☐ Home

☐ Birthing unit

☐ Hospital level 1

☐ Hospital level 2

☐ Hospital level 3

☐ Other

☐ Unknown

☐ Not registered

☐ Name of place/unit/hospital.....

.....

Actual place of birth

☐ Home

☐ Birthing unit

☐ Hospital level 1

☐ Hospital level 2

☐ Hospital level 3

☐ Other

☐ Unknown

☐ Fetus still in utero

☐ Name of unit/hospital.....

.....

If the intended place of birth was different to the actual place of birth, when was the mother transferred to the actual place of birth?

☐ Before labour ☐ In labour ☐ Unknown

Lead maternity carer

Please select the mother's lead maternity carer (LMC) at time of first registration and at birth (select one in each column)[1]

	LMC at booking	LMC at birth
Not registered	☐	☐
Self-employed midwife	☐	☐
DHB care	☐	☐
General practitioner	☐	☐
Obstetrician (private)	☐	☐
Unknown	☐	☐

Please indicate who was clinically responsible for the woman's care at the time of the birth (select one)

☐ No care

☐ Self-employed midwife

☐ DHB care

☐ General practitioner

☐ Obstetrician (private)

☐ Unknown

If clinical responsibility is different to 'LMC at booking, when did this transfer of clinical responsibility occur?

☐ Antenatal ☐ Intrapartum

Antenatal procedures **(select all that apply)**

☐ Scan at 22 weeks gestation (how many scans: _____)

☐ 1st trimester screening (MSS1)

☐ 2nd trimester screening (MSS2)

☐ Anatomy scan: gestation of first anatomy scan: ____ weeks ____days

gestation of second anatomy scan: ____ weeks ____ days

☐ Chorionic villus sampling

☐ Cervical suture

☐ Amniocentesis

☐ Doppler studies

☐ Growth scan

☐ External cephalic version *(list continues over page)*

[1] For 'LMC at booking' to be different to 'LMC at birth', a new registration must have been completed.

☐ Fetocide

☐ Amnioreduction

☐ Fetoscopic laser treatment

☐ Traditional massage

☐ Other (please state).....

☐ No antenatal procedures

☐ Unknown

Smoking

Smoking at first registration with an LMC (cigarettes)

☐ Yes ☐ No ☐ Unknown

Smoking status at birth (cigarettes)

☐ Never smoked

☐ Current non-smoker

☐ Stopped before this pregnancy

☐ Stopped <16 weeks gestation

☐ Stopped ≥16 weeks gestation

☐ Previous status unknown

☐ Current smoker

How many cigarettes per day: ____ ☐ Unknown

☐ Smoking status unknown

Smoking cessation support

☐ No

☐ Yes – by LMC/clinician only

☐ Yes – referred to external agent

☐ Offered but declined

☐ Unknown

Maternal use of alcohol and other drugs

☐ Yes (please complete the section below) ☐ No ☐ Unknown

	During first trimester	Month before birth	Describe *(list continues over page)*
Alcohol	☐	☐	.....
Amphetamine/P	☐	☐	.....
Cocaine	☐	☐	.....
Ecstasy	☐	☐	.....
Hallucinogens	☐	☐	.....
Herbal highs	☐	☐	.....
Synthetic cannabis	☐	☐	.....

Marijuana	☐	☐	.....
Opiates	☐	☐	.....
Methadone	☐	☐	.....
Petrol/paint/glue	☐	☐	.....

Other (please state) .....

Antenatal visits before fetal death/or delivery

Total number of visits from antenatal record: ____ ☐ Unknown

Gestation at first antenatal visit with LMC: ____ weeks ☐ Unknown

Gestation at first antenatal visit with any health provider: ____ weeks ☐ Unknown

Mother's clinical history (including any diagnoses made in this pregnancy; please answer all questions; list continues over page)

Asthma	☐ Yes	☐ No	☐ Unknown
Diabetes	☐ Yes	☐ No	☐ Unknown
	☐ Type 1 diabetes		
	☐ Type 2 diabetes		
	☐ Impaired glucose tolerance		
Epilepsy	☐ Yes	☐ No	☐ Unknown
Heart condition	☐ Yes	☐ No	☐ Unknown
	☐ Congenital heart condition		
	☐ Rheumatic heart disease		
	☐ Coronary artery disease		
	☐ Other cardiac condition (please state)		
Thyroid abnormality	☐ Yes	☐ No	☐ Unknown
	☐ Hypothyroidism		
	☐ Hyperthyroidism		
	☐ Other (please state).....		
Inflammatory bowel disease	☐ Yes	☐ No	☐ Unknown
Systemic lupus erythematosus	☐ Yes	☐ No	☐ Unknown
Other autoimmune disorder	☐ Yes	☐ No	☐ Unknown
Mental health disorder	☐ Yes	☐ No	☐ Unknown
	☐ Depression		
	☐ Psychotic disorder		
	☐ Other (please state).....		
Renal disease	☐ Yes	☐ No	☐ Unknown
Venous thromboembolism	☐ Yes	☐ No	☐ Unknown

Blood disorder ☐ Yes ☐ No ☐ Unknown

☐ Anaemia

☐ Thalassaemia trait

☐ Thrombophilia

☐ Other (please state).....

Hypertension ☐ Yes ☐ No ☐ Unknown

☐ Chronic/essential hypertension

☐ Secondary hypertension

Cervical surgery ☐ Yes ☐ No ☐ Unknown

Urinary tract infection ☐ Yes ☐ No ☐ Unknown

Uterine abnormality ☐ Yes ☐ No ☐ Unknown

Uterine surgery ☐ Yes ☐ No ☐ Unknown

Other (please state).....

Diabetes in pregnancy

Was the mother screened for diabetes in pregnancy ☐ Yes ☐ No ☐ Unknown ☐ Declined

Gestational diabetes confirmed ☐ Yes ☐ No ☐ Unknown

Laboratory results

HbA1c at booking _____ mmol/mol Date ___/___/____

HbA1c at ≥20 weeks (record highest result) _____ mmol/mol Date ___/___/____

Polycose (record highest result) ____ . ____ mmol/L Date ___/___/____

Glucose tolerance test (record highest result)

Fasting ___ . ___ mmol/L 2 hr ___ . ___ mmol/L Date ___/___/____

Was this a multiple pregnancy?

☐ Yes ☐ No ☐ Unknown

Number of fetuses/babies at first ultrasound in pregnancy: _____

Total number of babies born in this delivery, including stillbirths: _____

Was a fetal reduction performed?

☐ Yes (please describe):.....

☐ No

☐ Unknown

Select the type of multiple:

☐ Dichorionic diamniotic

☐ Monochorionic diamniotic

☐ Monoamniotic

☐ Other multiple – please describe chorionicity

☐ Unknown

Please write the NHI of all fetuses/babies

☐ First NHI .....

☐ Second NHI.....

☐ More than two (please add all NHI):.....

.....

Was there any vaginal bleeding related to this pregnancy? (Please complete both)

Before 20 weeks	☐ Yes	☐ No	☐ Unknown
After 20 weeks	☐ Yes	☐ No	☐ Unknown

Did the mother have any of these obstetric conditions in this pregnancy? (Select all that apply)

Hypertension	☐ Yes	☐ No	☐ Unknown
	☐ Gestational hypertension		
	☐ Pre-eclampsia		
	☐ Pre-eclampsia with chronic hypertension		
	☐ Eclampsia		
	☐ Chronic hypertension		
	☐ Unspecified		
Preterm labour	☐ Yes	☐ No	☐ Unknown
Prolonged rupture of membranes	☐ Yes	☐ No	☐ Unknown
	☐ Preterm rupture <37 weeks gestation		
	☐ Term rupture ≥37 weeks gestation		
Cholestasis of pregnancy	☐ Yes	☐ No	☐ Unknown
Confirmed maternal infection	☐ Yes	☐ No	☐ Unknown
	☐ Pyelonephritis		
	☐ Lower urinary tract infection		
	☐ Other infection:.....		
Trauma	☐ Yes	☐ No	☐ Unknown
	☐ Vehicular		
	☐ Violent personal injury or assault		
	☐ Other, eg, falls:		

Other obstetric condition
☐ Yes (please state) .....
☐ No
☐ Unknown

Surgery in pregnancy
☐ Yes (state type of surgery): .....
☐ No
☐ Unknown

Was fetal growth restriction suspected before fetal demise?

☐ No ☐ Yes, but no scan performed

☐ Yes, and confirmed by scan ☐ Yes, but normal growth on scan

☐ Unknown

Was a customised growth chart generated for this woman antenatally?

☐ Yes ☐ No ☐ Unknown

Was folic acid taken:

Pre-pregnancy? ☐ Yes ☐ No ☐ Unknown

In the first trimester? ☐ Yes ☐ No ☐ Unknown

Was there consultation with an obstetrician during pregnancy?

☐ Obstetrician was lead maternity carer ☐ No ☐ Unknown

☐ Yes (choose reasons for obstetrician consultation below)

- ☐ Prolonged pregnancy (41 weeks)
- ☐ Age of mother
- ☐ Breech
- ☐ Recurrent miscarriage
- ☐ Mother's request
- ☐ Stillbirth (this pregnancy)
- ☐ Previous stillbirth
- ☐ Suspected size of fetus ☐ large fetus ☐ small fetus
- ☐ Previous intrauterine growth restriction
- ☐ Previous Caesarean section
- ☐ Renal
- ☐ Cardiac
- ☐ Hypertension
- ☐ Prolonged rupture of membranes
- ☐ Cholestasis
- ☐ Other medical (please state) .....
- ☐ Surgery in pregnancy
- ☐ Significant infection
- ☐ Multiple pregnancy
- ☐ Antepartum haemorrhage
- ☐ Diabetes
- ☐ Unstable lie
- ☐ Fetal abnormality
- ☐ Raised BMI
- ☐ Other reason (please state) .....

Was the mother referred to any other healthcare services (apart from midwifery and obstetrics) during pregnancy?

☐ Yes ☐ No ☐ Unknown

- ☐ Medical (including MFM, non-obstetric specialists)
- ☐ Mental health
- ☐ Drug and alcohol
- ☐ Social
- ☐ Other service (please state) .....

Induction

☐ Yes ☐ No ☐ Unknown

Medication/method used

- ☐ Balloon
- ☐ Cervidil
- ☐ Misoprostol (dose: ____ mcg)
- ☐ Mifegyne
- ☐ PG gel 1 mg
- ☐ PG gel 2 mg
- ☐ PGE2 tablets
- ☐ Oxytocin
- ☐ Artificial rupture of membranes (time: : 24-hr clock; date: ___/___/___)
- ☐ Other (please state) .....

Reason for induction

- ☐ Post dates
- ☐ Pre-eclampsia
- ☐ APH
- ☐ Diabetes
- ☐ Maternal request
- ☐ Intrauterine fetal death
- ☐ Intrauterine growth restriction
- ☐ Fetal abnormality
- ☐ Prolonged rupture of membranes
- ☐ Other (please state).....

Augmentation

☐ Yes ☐ No ☐ Unknown

Medication/method

- ☐ Artificial rupture of membranes (time: : 24-hr clock; date: ___/___/___)
- ☐ Oxytocin
- ☐ Other (please state).....

Analgesia in labour

☐ Yes ☐ No ☐ Unknown

- ☐ Opiate
- ☐ Nitrous oxide
- ☐ Epidural
- ☐ TENS (transcutaneous electrical nerve stimulation)
- ☐ Unknown
- ☐ Other (please state) .....

Bath or pool during labour

Did part of labour occur in bath/pool?	☐ Yes	☐ No	☐ Unknown
Was the baby born in bath/pool?	☐ Yes	☐ No	☐ Unknown

Mode of birth (select one for each baby/fetus this pregnancy)

	First baby/ fetus	Second baby/ fetus
Normal vaginal delivery	☐	☐
Vaginal breech (also answer 'a')	☐	☐
Operative vaginal delivery (also answer 'b')	☐	☐
Caesarean section (also answer 'c')	☐	☐
Unknown/not stated	☐	☐

Were there more than two babies/fetuses? ☐ Yes ☐ No ☐ Unknown

[a]Breech

When was breech diagnosed? ☐ Before labour ☐ During labour

Mode of delivery: ☐ Assisted ☐ Extraction ☐ Spontaneous

Was an anaesthetic administered?

☐ Yes ☐ No ☐ Unknown

- ☐ General
- ☐ Spinal
- ☐ Epidural
- ☐ Local
- ☐ Other (please state) .....

[b]Operative vaginal delivery

Mode of delivery

☐ Forceps low	☐ Ventouse low
☐ Forceps mid-cavity	☐ Ventouse mid
☐ Forceps mid-cavity with rotation	☐ Ventouse mid-rotation

Was an anaesthetic administered?

☐ Yes ☐ No ☐ Unknown

- ☐ General
- ☐ Spinal
- ☐ Epidural
- ☐ Local
- ☐ Other (please state) .....

[c]Caesarean

Were forceps tried first?

☐ Forceps/ventouse attempted before Caesarean

☐ Forceps/ventouse not attempted before Caesarean

Type of Caesarean section

☐ **Planned** – no labour ☐ **Unplanned** – during labour

☐ **Planned** – during labour ☐ **Unplanned** – no labour

Was an anaesthetic administered?

☐ Yes ☐ No ☐ Unknown

☐ General

☐ Spinal

☐ Epidural

☐ Local

☐ Other (please state) .....

Maternal outcome

☐ Alive and generally well

☐ Alive but with serious morbidity, eg, admitted to ICU, hysterectomy or stroke

☐ Dead (Please add further details if morbidity or mortality has occurred)

.....

.....

.....

.....

.....

Placenta

Placenta weight: ___ gm ☐ Placenta not weighed ☐ Unknown

Placental examination

☐ Not examined

☐ Normal

☐ Some abnormalities (select all that apply)

☐ Retroplacental clot

☐ Gritty/calcified

☐ Circumvallate placenta

☐ Other (please state) .....

Umbilical cord examined?

☐ Yes ☐ No ☐ Unknown

Any problems with cord? (Select all that apply)

☐ True knot: ☐ tight knot ☐ loose knot

☐ Cord round neck: ☐ tight around ☐ loose around

☐ Cord round limbs or body: ☐ tight around ☐ loose around

☐ Torsion/spring-like cord (eg, hypercoiled)

☐ Marginal/velamentous insertion

☐ Abnormal cord thickness ☐ thin cord ☐ thick cord

☐ Meconium stained

☐ Tear in cord

☐ Two vessels

☐ Other abnormality (please state) .....

Summary

Please provide any other information you consider relevant or may have contributed to the outcome but that was not covered in these questions.

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.....

Form completed by

Name: .....

Designation: .....

Phone .....

Email .....

Date .....

LMC name and address if different to clinician completing the form

Name: .....

Phone .....

Email .....

Date .....

Please courier the completed form to:

National Coordinator Perinatal and Maternal Mortality Review

Level 9, Accuro House, 17–21 Whitmore St, Wellington 6011

If you have questions, please contact your local Perinatal and Maternal Mortality Review coordinator

National Mortality Review Committee | Perinatal and Maternal Mortality Review

Rapid reporting form for a perinatal death – baby

Please use the *Guidelines for the completion of the mother and baby forms following a perinatal death March 2016 Version 10* to help you complete this form. You can obtain these guidelines from www.otago.ac.nz/pmmrc. Please contact your local coordinator for assistance with logging in.

Both the mother and the baby National Mortality Review Committee forms need to be completed by the lead maternity carer or other clinician for any baby who dies from 20 weeks gestation (ie, ≥20^0, or **if gestation is unknown** a birth weight ≥400 g), including all terminations, to before 28 completed days of life (ie, up to midnight on the 27th day).

This baby form can be submitted electronically **after** you have submitted the mother form. If you are submitting written forms, please courier this and the mother form to the address at the end of the form.

Please complete within 48 hours of the baby's death if possible

Personally identifiable information (of the mother, baby or lead maternity carer) collected on this form will be kept confidential. The information included in reports by the National Mortality Review Committee is grouped and non-identifiable.

Place patient label here if available

Mother's NHI: ..... Baby's NHI: .....

Mother's first name: ..... Surname:.....

Mother's other name(s):.....

Baby's first name: ..... Surname:.....

Baby's other name(s):.....

Baby's sex: ☐ Male ☐ Female ☐ Indeterminate ☐ Unknown

Baby's ethnicity (select all that apply)

☐ New Zealand European ☐ Māori

☐ Samoan ☐ Cook Island Māori

☐ Tongan ☐ Niuean

☐ Chinese ☐ Indian

☐ Other (please state).....

Source of ethnicity information (select all that apply)

☐ Parents ☐ LMC notes

☐ Family/whānau ☐ Clinical notes

☐ DHB patient registration form ☐ NHI details

☐ Other (please state) .....

Live or stillbirth (select one) ☐ Stillbirth ☐ Live birth ☐ Unknown

Was this birth the result of a termination of pregnancy?

☐ Yes ☐ No ☐ Unknown

Date of birth: _____ /_____ /_____ Time of birth __:__ hrs (use 24-hour clock)
DD MM YYYY

Gestation at birth: ____ weeks ____ days ☐ Unknown

Best estimate of gestational age based on:

☐ Ultrasound in first trimester ☐ Ultrasound 20 weeks gestation

☐ Ultrasound >20 weeks gestation ☐ Last menstrual period

☐ Clinical examination at birth

Baby's birthweight: _____ g ☐ Unknown

If this was a multiple pregnancy, what was the birth order of the deceased fetus/baby?

☐ First ☐ Second

☐ Other (please state) .....

When did death occur?

☐ Antepartum ☐ Intrapartum – first stage

☐ Neonatal ☐ Intrapartum – second stage

☐ Unknown ☐ Intrapartum – unknown

If stillbirth, estimated gestational age at time of fetal death: __ weeks __ days ☐ Unknown

Place of death for live-born babies:

☐ Home ☐ Hospital (please also answer the next question)

☐ Other (please state).....

Area of hospital where baby died

☐ Delivery suite ☐ Postnatal ward ☐ Neonatal unit

☐ Children's ward ☐ Operating theatre ☐ Antenatal ward

☐ Emergency department ☐ SCBU

☐ Other (please state).....

Baby examination

Were any external abnormalities noted on external examination of the baby?

☐ No

☐ Yes (please state).....

.....

Post-mortem examination

Was a post-mortem examination discussed or offered to parents/whānau

☐ Yes ☐ No ☐ Unknown

If not, why not?.....

.....

.....

Was the pānui/information for whānau/families about post-mortem examination provided to the whānau (Note: it is available in te reo Māori, Samoan, Hindi and Chinese at www.hqsc.govt.nz/resources/resource-library/panuiinformation-for-whanaufamilies-about-post-mortem-examination-brochure)

☐ Yes ☐ No ☐ Unknown

Who discussed or offered the post-mortem? (Select all that apply)

☐ Fetal medicine specialist ☐ Paediatric/neonatal SMO

☐ Perinatal pathologist ☐ Paediatric registrar

☐ Obstetric SMO ☐ Paediatric SHO

☐ Obstetric registrar ☐ Midwife LMC

☐ Obstetric SHO ☐ Midwife core

☐ Other (please state).....

If a post-mortem was discussed or offered, was consent given?

☐ Unknown

☐ Yes: What type of post-mortem examination was consented to?

☐ Full post-mortem ☐ Limited post-mortem ☐ External post-mortem

☐ No (describe the reasons why not) .....

.....

Was the death referred to the coroner?

☐ Yes ☐ No ☐ Unknown

Did the coroner take jurisdiction?

☐ Yes ☐ No ☐ Unknown

If neonatal death, what was the date and time of death:

Date: _____ /_____ /_____ Time: __:__ hrs (use 24-hour clock)
DD MM YYYY

Apgar scores

1 minute .....

5 minutes..... (If the score for 5 minutes is <9, complete the next three)

10 minutes.....

15 minutes.....

20 minutes.....

Cord gases

☐ Not taken		Arterial	Venous
pH		__ . __ __	__ . __ __
Base deficit	/	__ __ . __	__ __ . __
CO_2		__ __ . __	__ __ . __
Lactate		__ __ . __	__ __ . __

Was the baby resuscitated at birth?

☐ Yes – resuscitated and transferred to another clinical area

☐ Yes – baby unable to be resuscitated

☐ No

☐ Unknown

Were maternal corticosteroids given antenatally?

☐ Yes, course started at gestation: __ weeks __ days

☐ No ☐ Unknown

Was the course of corticosteroids completed?

☐ Yes ☐ No ☐ Unknown

Was the baby transferred from their place of birth before their death?

☐ Unknown

☐ Yes, the baby was transferred to:

- ☐ Neonatal intensive care unit (NICU)/special care unit (SCU)
- ☐ Special care baby unit (SCBU)
- ☐ Postnatal ward
- ☐ Home
- ☐ Died in transfer
- ☐ Tertiary services
- ☐ Other (please state) .....

.....

☐ No, the baby was not transferred because:

- ☐ Died at place of birth
- ☐ Died in birthing unit/theatre
- ☐ Other (please state) .....

.....

Summary

Please provide any other information you consider relevant or that may have contributed to the outcome but was not covered in these questions.

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.....

.....

.....

Form completed by

Name: .....

Designation: .....

Phone: .....

Email: .....

Date .....

Please courier the completed form to:

National Coordinator Perinatal and Maternal Mortality Review

Level 9, Accuro House, 17–21 Whitmore St, Wellington 6011

If you have questions, please contact your local Perinatal and Maternal Mortality Review coordinator.

Sample mortality audit meeting code of practice declaration

In order to foster an environment of collaboration rather than blame, a written and agreed to code of practice may be be helpful to establish by the Perinatal Mortality Audit Steering Committee, in discussion with facility staff and management. Having wording specific to each team is encouraged, but here is suggested short text that can be signed by each individual before each review meeting.

An attendance sheet could also be signed at the end of the meeting, to credit those who stayed and participate throughout the meeting.

To show respect for the babies and families we are responsible to look after, we, the staff of _____ (name of facility), agree to respect the rules of good conduct during meetings reviewing death cases in our facility. We understand and appreciate that the results of these meetings will not result in punitive measures.

The rules of our mortality audit meetings include:

- Participate actively in discussions
- Respect everyone's ideas and ways of expressing these
- Accept discussion and disagreement without verbal violence
- Respect the confidentiality of the discussions in the group
- Agree not to hide useful information or falsify information which could allow the understanding of the case under review
- Try (as much as possible as it is not easy) to accept that your own actions can be questioned
- Arrive on time to the audit meeting

Signed: _____ Date: _____

Signed: _____ Date: _____

Signed: _____ Date: _____

Signed: _____ Date: _____

Signed: _____ Date: _____

Signed: _____ Date: _____

This appendix has been adapted from the World Health Organization (WHO) *Sample mortality audit meeting code of practice declaration* (Annex 6). https://www.who.int/docs/default-source/mca-documents/maternal-nb/making-every-baby-count.pdf

PSANZ CLASSIFICATION SYSTEM FOR STILLBIRTHS AND NEONATAL DEATHS

Version 4.0, 2020

Preface

The purpose of the PSANZ Perinatal Death Classification System is to ensure comprehensive and consistent data on causes and associated conditions for stillbirths and neonatal deaths across Australia and Aotearoa New Zealand. Consistent data will enable benchmarking and monitoring of causes of death to inform policy, practice, and research, help parents understand why the death occurred and to assist in future pregnancy planning.

The PSANZ Classification System for Stillbirths and Neonatal Deaths was first released in 2003, and subsequently revised in 2004, 2009 and 2018. The current version for use is version 4 (this version). Version 5 has been finalised and is intended for use across Australia and New Zealand for perinatal deaths occurring for births from 1 January 2025.

Principles, structure and performance indicators

Principles

The key principles of the PSANZ system are:

- To identify an underlying cause of death for stillbirths and neonatal deaths
- To identify up to two associated conditions for stillbirths and neonatal deaths
- To enable reporting by ICD-PM through identifying timing of death and mapping of categories to ICD-PM.

Including the assigned PSANZ system category codes as part of routinely collected individual birth record data across ANZ jurisdictions will enable reporting by timing of death (antepartum, intrapartum, early and late neonatal deaths or timing of death unknown) and also allows more detailed analyses by demographic and clinical factors to aid identify where attention is most needed.

Structure

The PSANZ System for stillbirths and neonatal deaths consists of two main sets of conditions (categories) and one set of associated conditions (contributory).

The two main category grouping are: 1) The Perinatal Death Classification (PDC) which includes maternal/fetal causes of stillbirths and neonatal deaths; and 2) The Neonatal Death Classification (NDC) including neonatal causes of death.

The PSANZ Associated Conditions list includes both the PDC and NDC categories plus other associated factors e.g. maternal risk factors and placental pathologies.

General rules for applying the PSANZ PDC System

Classification of underlying cause and associated conditions

In accordance with ICD-PM, the PSANZ Classification System identifies a single underlying cause of death for stillbirths and neonatal deaths as well as the presence of associated conditions. For all stillbirths and neonatal deaths, a maternal/fetal condition according to the PDC is assigned and, in addition for neonatal deaths, the underlying neonatal condition which caused the death is assigned according to the NDC. Therefore, for neonatal deaths the PSANZ system at least two conditions are assigned; the neonatal condition which resulted in the death and a maternal/fetal condition (according to the PDC). If no maternal/fetal condition is identified the classification category of "no obstetric antecedent" is applied.

Definitions

Underlying cause of death: According to ICD

> "the disease or injury which initiated the train of morbid events leading directly to a person's death or the circumstances of the accident or violence which produced the fatal injury, as represented by a code[10]"

Associated conditions are defined as conditions which were considered to have contributed to the death but are not considered to be the main underlying cause. Conditions which were present but not considered to be contributory are not classified as associated conditions.

Please refer to the PSANZ Associated Conditions list (see page 33).

Classification of terminations of pregnancy

All terminations of pregnancy are identified by the inclusion of an "009" for two-digit codes and a "09" for the three-digit codes and "9" for four-digit codes i.e. 1.1 becomes 1.1009; 1.83 becomes 1.8309; 6.111 becomes 6.1119. This includes induction of labour without expectation of fetal survival e.g. in the case of severe pre-eclampsia at pre-viable gestations, or prolonged premature rupture of membranes with severe infection.

Classification numbering approach

As far as possible, the subcategory .8 has been used for 'Other conditions' and .9 for 'Unspecified conditions' within its category, as has been the case in the ICD classification.

If data are entered with a decimal point, a subcategory such as 'Structural anomaly' (Category 1, *Congenital Anomaly*) would be 1.1, but as a 4-digit numeric would be 0110. Similarly, subcategory 'Group B Streptococcus' (Category 2, *Perinatal Infection*) would be 2.11 or 0211.

Inclusion in routine perinatal data collections at the individual case record level

It is recommended that PSANZ classification codes are included within routine perinatal data collections in each region for every perinatal death to enable disaggregation to better identify areas to focus prevention e.g. by Indigenous and socioeconomic status and other risk factors, and timing of death. The ability to analyse causes of perinatal deaths by timing of death (i.e. antepartum, intrapartum, neonatal, or unknown) is consistent with ICD-PM rules.

Reporting according to ICD-PM

Reporting by ICD-PM system enables international comparisons and should be based on the causes of perinatal deaths following thorough investigation and perinatal mortality committee review. Following application of the PSANZ classification system to stillbirths and neonatal

deaths, mapping of the categories to ICD-PM should be undertaken for global reporting requirements. Jurisdictions may wish to classify according to ICD-PM simultaneously with the PSANZ system to assist in global reporting and to inform future improvements in classification.

PSANZ-PDC Classification including rules and definitions (v4)

1 Congenital anomaly

1.1 Structural anomaly
- 1.11 Nervous system
- 1.12 Cardiovascular system
- 1.13 Genitourinary system
- 1.14 Gastrointestinal system
- 1.15 Musculoskeletal
  - 1.151 Congenital diaphragmatic hernia
  - 1.152 Gastroschisis/omphalocele
- 1.16 Respiratory system (include congenital pulmonary airway malformation (CPAM))
- 1.17 Haematological
- 1.18 Multiple Congenital anomaly (no chromosomal/genetic cause or not tested)
- 1.19 Other congenital abnormality
  - 1.192 Idiopathic hydrops fetalis
  - 1.193 Fetal tumour (include sacro-coccygeal teratoma)
  - 1.198 Other specified
  - 1.199 Congenital anomaly, unspecified

1.2 Chromosomal anomaly
- 1.21 Down syndrome (trisomy 21)
- 1.22 Edward syndrome and Patau syndrome (trisomy 18, trisomy 13)
- 1.23 Other trisomies and partial trisomies of the autosomes, not elsewhere classified (includes pathogenic duplications, unbalanced translocations and insertions)
- 1.24 Monosomies and deletions from the autosomes, not elsewhere classified (includes pathogenic deletions e.g. 22q11.2 deletion syndrome (diGeorge syndrome), Wolff-Hirschorn syndrome, Cri-du-chat syndrome
- 1.25 Turner syndrome (monosomy X)
- 1.26 Other sex chromosome abnormalities (e.g. Klinefelter syndrome)
- 1.28 Other chromosomal abnormalities, not elsewhere specified (includes Fragile X syndrome, imprinting syndromes, triploidy)
- 1.29 Unspecified

1.3 Genetic anomaly
- 1.31 Genetic condition, specified (includes inborn errors of metabolism e.g. Tay-Sachs disease;)
- 1.32 Syndrome/association with demonstrated chromosomal/gene anomaly
- 1.39 Genetic condition, unspecified

Definitions and Rules:

This category includes deaths in which a major congenital anomaly, whether structural or chromosomal, is considered to have been the reason for the death. All categories correspond

to the ICD10 numbering in Chapter XVII Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99) as presented in ICD-PM[11]

If termination of pregnancy was undertaken as a result of the anomaly include the digit "09" at the end the numerical classification e.g. Termination of Trisomy 21 (Down Syndrome) 1.2109. All terminations of pregnancy for congenital anomalies regardless of the causal link to perinatal death are also classified here. With mapping to ICD coding, non-lethal abnormalities may be identified.

Chromosomal and genetic testing are categorised separately, in recognition of advances in prenatal screening and testing. The scope of genetic testing is widening to include some conditions that may not manifest with structural anomalies in the prenatal period (e.g. Fragile X syndrome). If there is both a chromosomal/genetic and structural abnormality, code for the chromosome or genetic condition with the structural condition as an associated condition. Results of genetic testing of unknown significance are captured under associated conditions.

The chromosomal abnormality category excludes deaths where molecular karyotyping identifies an anomaly which is not thought to be causal. Findings of genetic testing of unknown significance (variations of uncertain or unknown significance, VUS) are classified as associated conditions. Where there is both a chromosomal and a structural abnormality, classify according to the chromosome abnormality with the structural abnormality as an associated condition.

Specific examples:

Down syndrome (Trisomy 21) is classified as a Chromosome abnormality (Down syndrome 1.21). If a cardiac anomaly is also present, this would be an associated condition (1.12 cardiovascular system).

Vater and *Vacterl* are 1.18 Congenital malformations affecting multiple systems, specified. For syndromes where DNA testing is available and has been confirmed for VATER or CHARGE association classify as genetic condition 1.31, specified.

Hydrops Fetalis: Antibody related hydrops (Immune Hydrops) e.g. Rhesus or Kell incompatibility and Bart's haemoglobinopathy (alpha thalassemia) is coded under as 1.17.

Non immune hydrops if due to chromosomal/genetic anomalies, classify under 1.2 and appropriate sub-classification, e.g. 1.25 Turner syndrome.

Idiopathic hydrops fetalis as 1.192 Other specific congenital anomaly, hydrops fetalis, idiopathic.

If the hydrops is secondary to underlying structural pathology e.g. congenital heart abnormality, neuromuscular disorders, skeletal dysplasia (achondrogenesis) or infection–classify in appropriate systems.

Hydrops associated with monochorionic twins classify under 6.1 category.

Multiple anomalies: Where the multiple anomalies are a part of a chromosomal anomaly found in the decedent, e.g. cleft lip and palate with heart defect as in velocardiofacial syndrome associated with 22q11 deletion, they should be classified under Category 1.2 but only if chromosome testing confirms deletion.

Anterior wall defects: Omphalocoele (exomphalos), gastroschisis, and congenital diaphragmatic hernia are now classified under musculoskeletal anomalies (Category 1.15), in line with ICD10-PM.

If omphalocoele is an isolated anomaly classify 1.15; if associated with multiple structural anomalies classify as 1.18; if associated with aneuploidy e.g. trisomy 18, classify as 1.22.

Acquired CNS anomalies: Infection-related abnormalities should be classified under Category 2, e.g. microcephaly/hydrocephaly secondary to CMV or toxoplasma infections should be classified as Category 2.21 and 2.3 respectively.

Congenital intracranial haemorrhage/injury may be classified as Category 7.5 *Fetal antenatal intracranial injury.*

Disruptions due to amniotic band disruption sequence may cause extensive asymmetric injury to the cranium and brain. It may also present as anencephaly or encephalocele. Classify under Category 7.5 *Fetal antenatal intracranial injury* but if due to alloimmune thrombocytopenia Code as 1.17 Haematological.

Neuromuscular disorders: Classify under 1.11. These are a complex group that may include primary muscle anomalies, CNS anomalies – both acquired and primary - and metabolic abnormalities. Some are syndromic with recognised recurrence risk. Associated anomalies may include pulmonary hypoplasia, hydrops and cleft palate. The cause of death may have been respiratory failure, but the death should be classified as the underlying abnormality.

If the underlying aetiology is known classify accordingly – e.g. *Fetal antenatal intracranial injury* Category 7.5.

Unspecified Congenital Abnormalities: Category 1.19 *Congenital anomaly, unspecified* covers those cases where an abnormality was stated as the cause but where insufficient information was available to classify under other categories.

2 Perinatal infection

2.1 Bacterial
- 2.11 Group B Streptococcus
- 2.12 E coli
- 2.13 Listeria monocytogenes
- 2.14 Spirochaetal e.g. Syphilis
- 2.18 Other bacterial
- 2.19 Unspecified bacterial

2.2 Viral
- 2.21 Cytomegalovirus
- 2.22 Parvovirus
- 2.23 Herpes simplex virus
- 2.24 Rubella virus
- 2.25 Zika virus
- 2.28 Other viral
- 2.29 Unspecified viral

2.3 Protozoal e.g. Toxoplasma

2.5 Fungal

2.8 Other specified organism

2.9 Other unspecified organism

Definitions and Rules

In order to qualify for this category, there must be evidence of fetal or neonatal infection as in Table 1. Determination of perinatal infection.

This category aims to identify all perinatal deaths due to infection as the primary cause including perinatal deaths with infection following spontaneous preterm labour or rupture of the membranes. Deaths in preterm infants following spontaneous rupture of the membranes or labour not fulfilling the definition of infection should be classified under Category 10 *Spontaneous Preterm*.

Category 2.8 *Other specified organism* includes deaths due to other identified organisms other than those in Categories 2.1 to 2.5. Category 2.9 *Other unspecified organism* includes cases where there is an obvious infection however the organism was either not identified or not specified.

Examples:

Classify here: Prelabour rupture of the membranes at term, with birth following 24 hours of membrane rupture, neonatal pneumonia identified within 48 hours of birth, subsequent neonatal death, group B Streptococcus identified on vaginal and placental cultures. Classify as subcategory 2.11 Group B Streptococcus and PSANZ-NDC subcategory 4.13.

Classify here: Spontaneous rupture of membranes preterm followed by spontaneous labour at 26 weeks and stillbirth. Membranes were ruptured for 12 hours prior to birth. Fetal pneumonia was detected at autopsy and growth of E Coli from the lungs. Placental pathology showed chorioamnionitis and funisitis. Classify 2.12 with an associated condition as Category 10.11 *Spontaneous preterm, with chorioamnionitis on placental histopathology*.

Classify here: Spontaneous rupture of the membranes at 24 weeks gestation. Clinical chorioamnionitis ensued after 6 days of membrane rupture. Induction of labour was undertaken

resulting in birth of a liveborn infant. Birthweight was 650gms. Active resuscitation was unsuccessful. No autopsy or placental pathology was undertaken. Classify as Category 2.11 with an associated category of Spontaneous preterm Category 10.13 and PSANZ-NDC unspecified congenital infection 4.19 with an associated classification of NDC 2.2 *Extreme prematurity – Unsuccessful resuscitation.*

Classify here: Spontaneous rupture of membranes at 14 weeks, with severe chorioamnionitis at 22 weeks. Labour was induced (with a live baby) and the baby was born without signs of life, the birthweight was 350gms. Autopsy findings of *E.coli* growth from lung fluid. Placental histopathology showed chorioamnionitis and funisitis. Classify as Category 2.1209.

Do not classify here: Spontaneous rupture of membranes at 21 weeks, with spontaneous onset of labour and birth at 22 weeks gestation. Baby was born without signs of life with a birthweight was 450gms. No autopsy was undertaken. Placental histopathology showed chorioamnionitis (no funisitis), no organism was grown. Classify as Category 10.11

Do not classify here: Neonatal death from late onset (≥48 hrs of age) Group B Streptococcal disease in a term infant. Classify under Category 12. *Neonatal death with no obstetric antecedent factor* and PSANZ-NDC as 4.4. The organism involved (GBS) may be classified as an associated condition under NDC associated factors using Category 2 sub classifications as a pragmatic way of collecting organisms in acquired infection. Alternately (and more appropriately), the organism should be included in a minimum dataset for all perinatal deaths.

Death type	Criteria for Perinatal and Acquired Infection category
Fetal	1. Histological confirmation of inflammation in cord (funisitis) or fetus (pneumonitis or pneumonia) with or without microbiological evidence of infection or 2a. Convincing clinical evidence of primary maternal infection and 2b. Positive culture of a pathogen from mother or placenta (specimen taken aseptically between amnion and chorion)
Neonatal	**A. Congenital** Early onset infection (within 48 hours of birth), defined as: 1. Clinical signs in neonate consistent with sepsis and 2. Haematological changes consistent with sepsis and one or more of the following: 3a. Positive culture of a pathogen (bacterial or viral) from the neonate or 3b. Pathological evidence at autopsy or 3c. Positive serology or 3d. Positive culture of a pathogen from the mother or the placenta or 3e. Pneumonia without specified bacterial or viral pathogens **NB:** Some congenital viral infections may have onset later than 48 hours after birth **B. Acquired** Onset of infection at 48 hours or later, with criteria as above, but excluding 3d

Table 1. Determination of perinatal infection

3 Hypertension

3.1 Chronic hypertension: essential
3.2 Chronic hypertension: secondary, e.g. renal disease
3.3 Chronic hypertension: unspecified
3.4 Gestational hypertension
3.5 Pre-eclampsia
3.6 Pre-eclampsia superimposed on chronic hypertension
3.9 Unspecified hypertension

Definitions

The classification of *Hypertension* follows that of the Society of Obstetric Medicine of Australia and New Zealand[12] with the exceptions that unspecified subcategories have been included. The definitions are as follows:

Hypertension is diagnosed when the systolic blood pressure is ≥140 mm Hg and /or diastolic blood pressure (Korotkoff V) is ≥90 mm Hg. These blood pressures should be confirmed by repeated readings over several hours in a clinic or day assessment unit or after rest in hospital.

Gestational hypertension is defined as hypertension arising in pregnancy after 20 weeks gestation without any other feature of the multisystem disorder pre-eclampsia and which resolves within 3 months postpartum.

Pre-eclampsia may be defined as hypertension arising after 20 weeks gestation and the onset after 20 weeks gestation of one or more of: proteinuria, renal insufficiency, liver disease, neurological problems, haematological disturbances, fetal growth restriction. The hypertension will have returned to normal within 3 months postpartum.

Rules

This category includes deaths where the hypertensive disorder is considered the factor initiating the chain of events leading to the death. If placental abruption complicates a hypertensive disorder, the death is classified here, as the abruption is attributed to the hypertensive disorder. Specific placental pathology can be coded as associated conditions (see PSANZ-SB&ND Associated conditions list page 34)

This category excludes the circumstance when the hypertension is secondary to an underlying systemic disorder, e.g. Diabetes, where this is severe and uncontrolled (in which case, classify as subcategory 5.2 *Diabetes*, under *Maternal Conditions*). However, if the systemic disorder such as diabetes or gestational diabetes is mild or well controlled, and the death appeared to be due to hypertension or its complications, classify in this category. This category also includes hypertension secondary to renal disease as this often presents first with hypertension.

4 Antepartum haemorrhage (APH)

4.1 Placental abruption
4.2 Placenta praevia
4.3 Vasa praevia
4.9 APH of undetermined origin

Definitions

Placental abruption: The diagnosis of placental abruption is made clinically. Confirmation by evaluation of the placenta after delivery is not essential for assigning the death to abruption. Clinically features are classically with vaginal bleeding (although the bleeding may be concealed), abdominal pain, uterine contractions and tenderness[13].

Placenta praevia: Placenta praevia is defined as a placenta that lies wholly or partly within the lower uterine segment diagnosed on ultrasound[13]. With improved diagnosis and management stillbirth as a result of bleeding for placental praevia is now rare.

Vasa praevia: Vasa praevia is the presence of unsupported fetal vessels below the fetal presenting part, where the cord insertion is velamentous[13]. Classically, vaginal bleeding following amniotomy with subsequent fetal bradycardia suggests vasa praevia. The diagnosis of vasa praevia can be confirmed by Doppler and endovaginal ultrasound studies if aberrant vessels over the internal cervical os are suspected[13].

APH of undetermined origin: This category is used where insufficient information is available on the reason for the bleeding. However, there is convincing clinical evidence that the stillbirth was as a result of the bleeding[13].

Rules

This category includes all perinatal deaths where the primary factor leading to the death was an APH.

Convincing clinical signs of abruption alone is sufficient to assign the category of 4.1 Abruption. If abruption occurs as a complication of a hypertensive disorder, the death is attributed to the hypertensive disorder (Category 3) with Category 4.1 Placental abruption as an associated condition. Other placental pathology thought to be contributory may also be classified under associated conditions Category 9.

Examples:

Classify here: A women presents at 38 weeks' gestation with abdominal pain, tense abdomen and uterine contractions and a fetal death diagnosed. Placental macroscopic examination showed a large adhesive clot however placental histopathology was inconclusive. Classify as 4.1 Placental abruption.

5 Maternal Conditions

5.1 Termination of pregnancy for maternal psychosocial indications
5.2 Diabetes
  5.21 Gestational diabetes
  5.22 Pre-existing diabetes
5.3 Maternal injury
  5.31 Accidental
  5.32 Non-accidental
5.4 Maternal sepsis
5.5 Antiphospholipid syndrome
5.6 Obstetric cholestasis
5.8 Other specified maternal conditions
  5.81 Maternal suicide
  5.88 Other specified maternal medical or surgical conditions

Definitions and Rules

Category 5 includes perinatal deaths attributed to any medical or surgical condition in the mother, or to its complications or treatment, excluding conditions elsewhere classified i.e. APH, hypertension. The subcategory 5.1 excludes terminations of pregnancy undertaken for medical indication including congenital and other complications (e.g. prolonged preterm rupture of membranes (PPROM) with severe infection) where a pregnancy is terminated and the fetus is not expected to survive. In this scenario the death is classified under the specific condition including termination of pregnancy due to a congenital anomaly (classified under Congenital Anomaly, Category 1) and other conditions such as severe chorioamnionitis following preterm rupture of the membranes at 20 weeks (classify 10.1 Spontaneous preterm); adding the coding number "9" to identify termination as described under "General rules for applying the PSANZ PDC System" on page 4.

Renal disease is not included as a separate subcategory here, but under Hypertension, subcategory 3.2, as it usually presents first as hypertension. Maternal conditions should only be attributed here if there is a high probability that they were the cause of death, e.g. a well-documented history of lupus obstetric syndrome with a previous stillbirth. Maternal substance use or smoking may be classified as an associated condition if there is a significant history (including alcohol, cocaine, and marijuana) and where it is reasonable to assume that the fetal or neonatal death may be linked.

Examples:

Classify here: Fetal death as a result of severe uncontrolled Type I Diabetes with mild pre-eclampsia classify as subcategory 5.22 with an associated condition of Hypertension, Category 3.5.

6 Complications of multiple pregnancy

6.1 Monochorionic twins
- 6.11 Twin to twin transfusion syndrome (TTTS)
- 6.12 Selective fetal growth restriction (FGR) (i.e. affecting only one twin)
- 6.13 Monoamniotic twins (including cord entanglement)
- 6.18 Other
- 6.19 Unknown or unspecified

6.2 Dichorionic twins
- 6.21 Early fetal death in a multiple pregnancy (<20 weeks gestation)
- 6.22 Selective fetal growth restriction (FGR)
- 6.28 Other
- 6.29 Unknown or unspecified

6. 3 Complications of higher order multiples (3 or more fetuses)
- 6.31 Twin to twin transfusion syndrome (TTTS)
- 6.32 Selective fetal growth restriction (FGR)
- 6.33 Monoamniotic multiples (including cord entanglement)
- 6.34 Early fetal death in a multiple pregnancy (<20 weeks gestation)
- 6.38 Other
- 6.39 Unknown or unspecified

6.4 Complications where chorionicity is unknown

6.8 Other

6.9 Unspecified

Rules

For 6.12, 6.22 and 6.32 read Explanatory Notes under Associated Condition, Section 15, Fetal Growth Restriction.

Where one of the twins (or multiples) is growth restricted as a result of twin to twin transfusion syndrome, classify as 6.11, 6.31 and not 6.12 or 6.32 respectively. Where one or more of the twins (or multiples) is growth restricted from a known underlying cause, classify elsewhere as appropriate, e.g. classify under Category 9 if there is placental disease in one of dichorionic twins.

7 Specific perinatal conditions

7.1 Fetomaternal haemorrhage

7.2 Antepartum cord or fetal vessel complications (excludes monochorionic twins or higher order multiples)

- 7.21 Cord vessel haemorrhage
- 7.22 Cord occlusion (True knot with evidence of occlusion or other)
- 7.28 Other cord complications
- 7.29 Unspecified cord complications

7.3 Uterine abnormalities

- 7.31 Developmental anatomical abnormalities (e.g. bicornuate uterus)
- 7.38 Other
- 7.39 Unspecified

7.4 Alloimmune disease

- 7.41 Rhesus isoimmunisation
- 7.42 Other red cell antibody
- 7.43 Alloimmune thrombocytopenia
- 7.48 Other
- 7.49 Unspecified

7.5 Fetal antenatal intracranial injury

- 7.51 Subdural haematoma
- 7.52 Fetal antenatal ischaemic brain injury
- 7.53 Fetal antenatal haemorrhagic brain injury

7.6 Other specific perinatal conditions

- 7.61 Complications of antenatal, diagnostic or therapeutic procedures:
  - 7.611 Complications of prenatal diagnostic procedures (e.g. amniocentesis, chorionic villus sampling,) (e.g. rupture of membranes after amniocentesis)
  - 7.612 Complications of fetal ultrasound guided needle interventions (e.g. FBS/fetal transfusion, thoracocentesis, vesicocentesis, fetal cardiac valvoplasty, division of amniotic bands, fetal skin biopsy, unipolar/bipolar diathermy, RFA procedures)
  - 7.613 Complications of fetal shunt interventions (e.g. pleuroamniotic shunt, vesicoamniotic shunt)
  - 7.614 Complications of minimally invasive fetoscopic interventions (e.g. fetoscopic laser surgery for TTTS, FETO for CDH, laser ablation of posterior urethral valves)
  - 7.615 Complications of open maternal fetal surgery (e.g. open maternal fetal surgery for spina bifida)
  - 7.618 Other
- 7.62 Termination of pregnancy for suspected but unconfirmed congenital anomaly
- 7.63 Amniotic band
- 7.68 Other

7. 9 Unspecified

Definitions

Category 7.22 Cord occlusion: A cord knot is where the cord becomes tangled with itself (or another cord in a multiple pregnancy) such that the vessels of the cord may be compromised. To be considered significant there should be evidence of congestion or haemorrhage in the cord, and/or changes in the placenta such as fetal vessel thrombosis or villous oedema to suggest vascular compromise. A knot could cause death without these changes but not every knot causes fetal compromise and therefore should not be accepted as a cause of death without further evidence as above, or strong clinical suspicion by the delivering clinician based on CTG or other changes during delivery. Cord accidents usually only account for a few percent of perinatal deaths.

Other cord compression: For stillbirths, and also neonatal deaths as a result of hypoxic ischaemic encephalopathy (HIE), where the cord is found to be tightly around neck or body with skin blanching (indicating significant cord compression) classify as 7.28.

Category 7.21 includes cord haemorrhage following cordocentesis, umbilical cord ulceration leading to cord haemorrhage, and torn velamentous vessels.

Rules

This category includes deaths in which the specific perinatal condition present was thought to be the cause of death. The category excludes perinatal deaths with a major congenital anomaly. Cord complications during labour and other complications of twins e.g. head entrapment in labour should be categorised under *Hypoxic Peripartum Death*, subcategory 8.18.

Examples:

Do not classify here: Spontaneous prelabour rupture of membranes (ROM) at 33 weeks, with immediate cord prolapse and fetal death. Categorise as Spontaneous Preterm Category 10 as the cord complication occurred as a result of the preterm ROM. Cord prolapse is classified as an associated condition.

8 Hypoxic peripartum death

8.1 With intrapartum complications (sentinel events)
- 8.11 Uterine rupture
- 8.12 Cord prolapse
- 8.13 Shoulder dystocia
- 8.14 Complications of breech presentation
- 8.15 Birth trauma
- 8.16 Intrapartum haemorrhage
- 8.18 Other

8.2 Evidence of significant fetal compromise (excluding other complications)

8.3 No intrapartum complications and no evidence of significant fetal compromise identified

8.9 Unspecified hypoxic peripartum death

Definitions and rules

This category includes both intrapartum fetal deaths and neonatal deaths as a result of acute or chronic hypoxia in babies without major congenital anomalies or other major conditions such as antepartum haemorrhage at a gestation in which survival in the context of the birth would be expected (typically of >28 weeks gestation or >1000g birthweight). If placental pathology is identified which resulted in fetal compromise and death then classify under the relevant category i.e. Category 9 Placental pathology or Category 4 Antepartum haemorrhage.

Where intrapartum fetal death or neonatal death occurs following preterm spontaneous onset of labour or rupture of membranes which fulfils the definition of Infection then classify under Category 2. If not fulfilling the criteria for infection and less than 24 weeks then classify under Category 10 *Spontaneous preterm.*

Neonatal deaths as a result of hypoxic ischaemic encephalopathy and otherwise unexplained severe cardiorespiratory depression at birth are included here. Where possible, evidence for intrapartum hypoxia should include fetal, umbilical artery or early neonatal (within one hour) blood gases showing evidence of a severe metabolic acidosis. Otherwise peripartum death might also be due to non-hypoxic causes, e.g. infection or chronic ischaemia but wrongly assumed to be due to acute hypoxia.

There may have been intrapartum complications (subcategory 8.1), or no intrapartum complications but with evidence of non-reassuring fetal status (subcategory 8.2), or no intrapartum complications or evidence of non-reassuring fetal status (subcategory 8.3). A specific major intrapartum complication, such as uterine rupture, cord prolapse or shoulder dystocia, is required for inclusion as subcategory 8.1. However, if there were no apparent intrapartum complications (as defined in category 8.1) but there was evidence of placental insufficiency antenatally, then the death should be attributed to Category 9. In this case Category 8 is captured as an associated condition.

If there is insufficient information about fetal wellbeing or intrapartum complications, classify as subcategory 8.9 *Unspecified hypoxic peripartum death.*

Evidence of non-reassuring fetal status is defined as abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intrapartum complications.

The term 'non-reassuring fetal status' has been used in preference to the term 'fetal distress' as 'clinical signs often poorly predict a compromised fetus and continued use of this latter term may encourage wrong assumptions or inappropriate management'[14,15].

Examples:

Classify here: No known problems prior to labour at gestation 38 weeks. Severe fetal heart rate decelerations in second stage of labour, without other major complication. Baby is born with no signs of life with a birthweight of 3500gm, placental histopathology did not identify any significant pathology and no autopsy was performed. Classify as subcategory 8.2.

Classify here: No known problems prior to labour at 36 weeks. No evidence of intrapartum fetal distress. At birth, the baby shows signs of severe respiratory depression and hypoxia. Subsequently develops encephalopathy and multiorgan failure and dies on Day 10 of life. Placental histopathology did not identify any significant pathology and no autopsy was performed. Classify as subcategory 8.3 and PSANZ NDC as 5.1.

Do not classify here: Spontaneous membrane rupture at 22 weeks' gestation, severe oligo hydramnios with positional deformities shown on ultrasound at 26 weeks. Labour and birth at 26 weeks gestation of a baby boy weighing 700gms and was not able to be resuscitated. Placental pathology showed chorioamnionitis but no organisms identified on placental culture or baby blood cultures. Classify as 10.11 *Spontaneous preterm* and PSANZ NDC as Category 2.2 *Not resuscitated.*

Do not classify here: No complications during pregnancy. Spontaneous preterm labour and birth at 38 weeks gestation. Intrapartum fetal distress in second stage and delivered by forceps. Baby boy weighing 2200gms, Apgars 1 and 4, mechanically ventilated and admitted to NICU. Seizures commenced at 2 hrs and active management ceased at 24 hrs due to poor prognosis. Placental pathology showed fetal vascular malperfusion and mild chorioamnionitis however no organisms were identified on culture of the placental or baby. Classify as 9.2 *Placental dysfunction* and PSANZ NDC 5.1 *Hypoxic ischaemic encephalopathy/Perinatal asphyxia*

9 Placental dysfunction or causative placental pathology

9.1 Maternal vascular malperfusion
9.2 Fetal vascular malperfusion
9.3 High grade villitis of unknown etiology (VUE)
9.4 Massive perivillous fibrin deposition/maternal floor infarction
9.5 Severe chronic intervillositis (Histiocytic intervillositis)
9.6 Placental hypoplasia (small-for gestation placenta)
9.7 No causal placental pathology demonstrated, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)
9.8 Placental pathological examination was not performed, with antenatal evidence of poor placental function was identified (such as abnormal fetal umbilical artery Doppler)
9.9 Other placental pathology (e.g. multiple pathologies with evidence of loss of placental function leading to death)

Definitions

This category is based on the Amsterdam Placental Workshop Group Consensus Statement[9].

Category 9.1 *Maternal vascular malperfusion (MVM).* Placental features considered to be indicative of MVM include both gross and microscopic findings. Gross findings include placental hypoplasia, infarction, and retroplacental haemorrhage.

Any infarction seen in a preterm placenta and, at term, anything more than 5% of non-peripheral infarction should be classified as a cause. Although marginal infarcts in a term placenta may have less meaning than in a preterm placenta, they should be classified as an associated condition. *Microscopic findings* include abnormalities of villous development, which can be separated into distal villous hypoplasia, and accelerated villous maturation (vide infra), and infarcts. It should be recognized that many of these histologic findings will coexist in some placentas.

Category 9.6 Placental hypoplasia is reflected by a placental weight that is low for the stated gestational age and context (weight <10th centile) and/or a thin cord (<10th centile or <8-mm diameter at term).

Category 9.7 and 9.8 includes stillbirths or neonatal deaths where clinical evidence of poor placental function sufficient to explain the death was identified however significant causal pathology of the placental was not demonstrated or placental histopathology was not performed. Clinical evidence of poor placental function is defined as evidence of placental disease either on antenatal ultrasound studies or biochemistry. This former can include evidence of reduced maternal (uterine artery) or fetal (umbilical artery, ductus venosus, middle cerebral artery Doppler) vascular perfusion on Doppler studies. The latter can include angiogenesis-related factors such as s-Flt-1/PIGF; further clinical evaluations may clarify which biochemical markers robustly identify placental dysfunction.

Category 9.9 includes multiple pathologies with evidence of loss of placental function leading to death. It excludes pathologies listed in 9.1 to 9.8. Where one or more pathologies listed under 9.1-9.8 are identified, a single pathology must be classified as the primary cause of death with the additional pathologies classified as associated conditions (see Category 16 page 34).

Rules

This category includes perinatal deaths where placental dysfunction is considered the underlying cause of the death. It excludes perinatal deaths as a result of an identified maternal or fetal condition where the death is classified according to the condition (e.g. Pre-Eclampsia, Pre-existing hypertension). It should exclude pathology which is not thought to be causal, and also amniotic fluid infection/acute chorioamnionitis. Placental pathology which is thought to be contributory rather than causal should be classified as an associated condition (See Associated conditions page 34).

It is acknowledged that multiple pathologies may exist. In these circumstances a dominate pathology needs to be identified and classified as the main cause and others as associated conditions. This category overrides deaths following intrapartum related events as defined in Category 8 Hypoxic peripartum deaths.

Examples:

Classify here: Normal pregnancy. Spontaneous preterm labour and birth at 40 weeks gestation. Non-reassuring fetal status in second stage ensued and birth was by emergency caesarean section. Baby boy weighing 2600gms, Apgars 2 and 4, mechanically ventilated and admitted to NICU with subsequent diagnoses of meconium aspiration and persistent pulmonary hypertension of the newborn. Despite intensive care the baby died at 12 hrs of age. Placental pathology showed massive perivillous fibrin deposition/maternal floor infarction and mild chorioamnionitis, no organisms were identified on placental culture or baby blood cultures. Classify as 9.4 *Massive perivillous fibrin deposition/maternal floor infarction* and PSANZ NDC 3.3 *Primary persistent pulmonary hypertension,* with an Associated condition of *Fetal growth restriction.*

Do not classify here: Normal pregnancy until maternal presentation at 40 weeks' gestation with decreased fetal movements and abdominal pain. Antepartum fetal death was diagnosed and spontaneous labour ensued shortly after. A baby girl was born, mildly macerated, weighing 3400gms. Placental pathology showed massive abruption. Maternal investigations were normal. No organisms were identified on placental culture or baby blood cultures. Classify as *APH Abruption* 4.1.

10 Spontaneous preterm labour or rupture of membranes (<37 weeks gestation)

10.1 Spontaneous preterm
- 10.11 With histological chorioamnionitis
- 10.12 Without histological chorioamnionitis
- 10.13 With clinical evidence of chorioamnionitis, no examination of placenta
- 10.17 No clinical signs of chorioamnionitis, no examination of placenta
- 10.19 Unspecified or not known whether placenta examined

10.2 Spontaneous preterm preceded by premature cervical shortening

Definitions

Clinical evidence of chorioamnionitis is defined as maternal fever (≥38^{o}C) associated with one or more of the following symptoms or signs: maternal or fetal tachycardia, uterine tenderness, malodorous amniotic fluid, and maternal leukocytosis or raised C-reactive protein[16-18].

The diagnosis of histological chorioamnionitis should only be made when there is histological evidence of inflammation or microbiological evidence of infection of the placenta and membranes.

The subcategory of premature cervical shortening is reserved for those circumstances where the primary event appears to be cervical change based on clinical or ultrasound findings. This may occur as consequence of pre-existing damage to the cervix from a surgical procedure, due to a congenital structural cervical anomaly (with or without uterine anomaly) or clinically determined from previous obstetric history and/or clinical factors in the current pregnancy.

Rules

Deaths of normally formed, appropriately grown preterm babies following spontaneous onset of preterm labour or spontaneous rupture of membranes, irrespective of induction of labour or mode of delivery (e.g. elective caesarean section). There should be no evidence of fetal or neonatal infection (see Table 1 Determination of perinatal infection), otherwise classify under Category 2 *Perinatal Infection*. Careful examination of the placenta macroscopically and microscopically is recommended.

In cases where there is histological evidence of chorioamnionitis with or without evidence of clinical chorioamnionitis, classify as subcategory 10.11. In cases of clinical chorioamnionitis where placental pathological examination was not performed or it is not known whether the placenta was examined, classify as subcategory 10.13.

Where cervical incompetence is followed by spontaneous preterm labour or ROM classify as 10.2 as opposed to 10.1. There may be some bleeding at the time of onset of labour, or earlier in pregnancy, but not in amounts to warrant the antecedent cause being attributed to *Antepartum Haemorrhage* Category 4. Early bleeding, which is often associated with preterm premature rupture of the membranes may be classified as an associated condition (see page 34).

Examples:

Classify here: Spontaneous labour at 26 weeks, no apparent explanation, and membranes intact. Vaginal delivery after 6 hours of membrane rupture, no evidence of intrapartum hypoxia or chorioamnionitis; subsequent early neonatal death from respiratory distress syndrome. Classify here as subcategory 10.12 *Spontaneous preterm with intact membranes, or membrane rupture, without chorioamnionitis on placental histopathology* and NDC: Category 3.1

Do not classify here: Spontaneous onset of labour at 28 weeks with intact membranes. No cause identified for preterm labour. Delivery following 24 hours of membrane rupture. Maternal intrapartum pyrexia. Chorioamnionitis and funisitis on placental histology, no organism identified. Classify as Category 2.9 *Perinatal Infection; other unspecified organism*

Do not classify here: Alive at the onset of spontaneous labour at 31 weeks, no apparent explanation, and membranes intact. After 12 hrs, continuous intrapartum fetal monitoring showed deep decelerations and emergency caesarean section undertaken. Baby girl weighing 1700g was stillborn and could not be resuscitated. Placental pathology showed chorioamnionitis (no funisitis) no organisms were identified, and no other pathology was demonstrated. No autopsy was performed. Macroscopic examination of the baby was normal, no maceration. Classify as Category 8.2 *Hypoxic peripartum death; Evidence of significant fetal compromise (excluding other complications).*

11 Unexplained antepartum fetal death

11.1 Unexplained antepartum fetal death despite full investigation
11.2 Unclassifiable antepartum fetal death with incomplete investigation
11.3 Unclassifiable antepartum fetal death due to unknown level of investigation

Rules

This category applies to fetal death prior to the onset of labour where no cause for the death was identified. Antepartum fetal death with associated placental pathology (i.e. not thought to be causative) are coded as associated conditions.

Category 11.1 Unknown antepartum fetal death despite full investigation.

An antepartum fetal death where no cause of death was identified following (as a minimum): comprehensive maternal and pregnancy history; histopathology of the placenta and cord; full autopsy; karyotype/cytogenetics; and testing for Feto-Maternal Haemorrhage (Kleihauer or flow cytometry).

Category 11.2 is used where none or some of the above investigations were performed and Category 11.3 is used where it is unknown/unclear if these investigations were performed or the results were unavailable.

Whether or not each of the above tests were performed should be recorded to identify areas of practice improvements and future research. The minimum dataset for perinatal deaths as defined in the Australian Perinatal Mortality Audit Tool APMAT (*see Appendix E – Australian Perinatal Mortality Audit Tool*) and the New Zealand PMMRC audit form[19] (*Appendix F – Rapid reporting form for a perinatal death – baby* and *Appendix G – Rapid reporting form for a perinatal death - mother)* includes these data fields.

Examples:

Classify here: Intrauterine Fetal Death (IUFD) at 37 weeks, with no maternal conditions, no antepartum haemorrhage, with membranes intact, before onset of labour, where no cause of death was identified following full investigation (*comprehensive maternal and pregnancy history; histopathology of the placenta and cord; full autopsy; karyotype/cytogenetics; and Kleihauer*) Classify as Unexplained Antepartum Fetal Death, subcategory 11.1**.**

Intrauterine Fetal Death (IUFD) at 40 weeks, with no maternal conditions, no antepartum haemorrhage, with membranes intact, before onset of labour, where no cause of death was identified and perinatal death investigations were incomplete (e.g. *No karyotype/cytogenetics*) Classify as Unexplained Antepartum Fetal Death, subcategory 11.2**.**

Do not classify here: Spontaneous ROM at 27 weeks, no significant maternal conditions present, subsequent IUFD prior to onset of labour. No chorioamnionitis on examination of the placenta. Classify as subcategory 10.12 *Spontaneous preterm labour or ROM (<37 weeks gestation); without histological chorioamnionitis*.

12 Neonatal death without obstetric antecedent

12.1 Neonatal death with no obstetric antecedent factors despite full investigation
12.2 Neonatal death unclassifiable as to obstetric antecedent with incomplete investigation
12.3 Neonatal death unclassifiable as to obstetric antecedent due to unknown level of investigation

Rules

This category includes neonates where no obstetric antecedent factors (according to the PDC list) were identified as contributing to the death.

Category 12.1 applies to a neonatal death where not obstetric antecedent factor was identified following negative findings for the following (as a minimum): comprehensive maternal and pregnancy history and full autopsy.

Category 12.2 is used where the full autopsy was not performed and Category 11.3 where it is unknown if they were performed or the results were unavailable.

NB: Whether a PDC code is assigned or not, all neonates require a neonatal cause of death according to the PSANZ NDC to be assigned. The NDC provides information on the causes and associated conditions present in the neonatal period.

Examples:

Classify here: Baby boy born at term weighing 3.5kg was discharged home well on Day 2 of life. On day 27, the baby was found dead in his cot by the parents and following full investigation was classified as SIDS. Please refer to the NDC to classify the neonatal cause of death.

Classify here: Baby boy born at 38 weeks weighing 3kg was discharged home well. On day 10, the baby became unwell and died. Blood cultures and CSF were positive for Group B Streptococcus. Please refer to the NDC to classify the neonatal cause of death and classify as 4.1.

Do not classify here: Neonatal death on Day 7 of a 29 week baby girl with severe fetal growth restriction and reverse end diastolic flow delivered by emergency caesarean section who developed fulminating necrotising enterocolitis. Placental pathology showed high grade villitis of unknown etiology (VUE). Classify as Category 9.3 with the PSANZ Associated condition of *Fetal growth restriction* and NDC Category 6.1 *Necrotising enterocolitis.*

2 PSANZ-NDC Classification including rules and definitions (v4)

The Neonatal Death Classification has been developed for use in conjunction with the PSANZ Perinatal Death Classification in order to identify the underlying and associated neonatal conditions as well as the underlying and associated maternal conditions for neonatal deaths. For example, a mother who has an antepartum haemorrhage at 32 weeks gestation delivers a 1500g infant who thrives in the neonatal nursery but subsequently acquires a lethal nosocomial infection: the obstetric antecedent is antepartum haemorrhage, but neonatal death classification is subcategory 4.4 *Acquired Bacteria.* Both APH and neonatal nosocomial infection are important conditions on which to focus prevention strategies.

1 Congenital anomaly (please refer to PDC)

2 Periviable infants (typically <24 weeks)

2.1 Not resuscitated (including infants where there is an antenatal plan for no resuscitation at birth)
2.2 Unsuccessful resuscitation
2.9 Unspecified or not known whether resuscitation attempted

This group includes infants deemed too immature or too small for resuscitation or continued life support beyond the delivery room. Resuscitation in this context means the use of positive pressure ventilation.

3 Cardio-respiratory disorders

3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)
3.2 Meconium aspiration syndrome
3.3 Primary persistent pulmonary hypertension
3.4 Pulmonary hypoplasia
3.5 Pulmonary haemorrhage
3.6 Air leak syndromes
  3.61 Pneumothorax
  3.62 Pulmonary interstitial emphysema
  3.68 Other
3.7 Patent ductus arteriosus
3.8 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)
3.9 Other
  3.91 Neonatal anaemia/hypovolaemia

Definitions and Rules

Subcategory 3.1 *Hyaline membrane disease / Respiratory Distress Syndrome (RDS)* is used for deaths of infants who were receiving mechanical ventilation for acute RDS at the time of death or at the time of the complication such as pulmonary haemorrhage, sepsis, pneumothorax or necrotizing enterocolitis.

Neonates with resolving RDS, i.e. who are past the acute phase of the disease and are stable or improving, but who are still on low rate ventilation for immature lungs, extreme prematurity or apnoea, or who no longer require mechanical ventilation, and who developed a complication which led to the death should be classified according to that particular complication.

3.4 Pulmonary hypoplasia; this category includes pulmonary hypoplasia secondary to preterm prolonged rupture of the membranes. Congenital pulmonary airway malformation (CPAM), formerly known as congenital cystic adenomatoid malformation of the lung (CCAM) would be classified as 1.16. Congenital diaphragmatic hernia is classified as 1.151

Categorisation as chronic neonatal lung disease (subcategory 3.5) should be reserved for infants with deteriorating lung function and major chest X-ray changes consistent with bronchopulmonary dysplasia.

Examples:

Classify here: A 26-week gestation infant with RDS receives mechanical ventilation (SIPPV R50, P20/5, Fi02 0.4), develops complications of pneumothorax requiring drainage, followed by a patent ductus arteriosus and dies on day 2 of life is classified as Category 3.1 with associated conditions classified as 3.61 *Pneumothorax* and 3.7 *Patent ductus arteriosus.*

Do not classify here: A 26 week gestation infant with RDS weaning off mechanical ventilator has a Grade IV Intraventricular Haemorrhage (IVH) with ventricular dilation on ultrasound on Day 5. She is successfully weaned to CPAP on Day 7 but requires re-ventilation for sepsis on Day 10 and on Day 21 has developing BPD and post hemorrhagic hydrocephalus (PHH) following which ventilation is withdrawn. Classification is dependent on the major reason for withdrawal of support. In this case 5.3 *Post haemorrhagic hydrocephalus* with an associated classification of 3.8 *Chronic neonatal lung disease and 4.49 Sepsis.*

4 Neonatal infection

4.1 Congenital/Perinatal bacterial infection (early onset<48 hrs)
- 4.11 Blood stream infection/septicaemia
  - 4.111 Positive culture of a pathogen
  - 4.112 Clinical signs of sepsis + ancillary evidence but culture negative
- 4.12 Bacterial meningitis
- 4.13 Bacterial pneumonia
- 4.15 Multiple site bacterial infection
- 4.18 Other congenital bacterial infection e.g. gastroenteritis, osteomyelitis, cerebral abscess
- 4.19 Unspecified congenital infection

4.2 Congenital/Perinatal viral infection

4.3 Congenital fungal, protozoan, parasitic infection

4.4 Acquired bacterial infection (late onset>48hrs)
- 4.41 Blood stream infection/septicaemia
  - 4.411 Positive culture of a pathogen
  - 4.412 Clinical signs of sepsis + ancillary evidence but culture negative
- 4.42 Bacterial meningitis
- 4.43 Bacterial pneumonia
- 4.48 Other acquired bacterial infection e.g. gastroenteritis, osteomyelitis
- 4.49 Unspecified acquired infection

4.5 Acquired viral infection

4.6 Acquired fungal, protozoan, parasitic infection

Rules

This category is intended to be used in conjunction with the PDC Category 2 *Perinatal Infection* to identify the organism causing the infection resulting in the death (including for an acquired infection). To take a pragmatic approach to storage of these data within the current system structure, in the case of a neonatal death from infection, the relevant NDC code can be stored as the primary neonatal condition and the PDC Category 2 code as an associated condition.

Determination of congenital and acquired neonatal infection
A. Congenital Early onset infection (within 48 hours of birth), defined as: 1. Clinical signs in neonate consistent with sepsis and 2. Haematological changes consistent with sepsis and one or more of the following: 3a. Positive culture of a pathogen (bacterial or viral) from the neonate or 3b. Pathological evidence at autopsy or 3c. Positive serology or 3d. Positive culture of a pathogen from the mother or the placenta. Swap taken aseptically between amnion and chorion. or 3e. Pneumonia without specified bacterial or viral pathogens NB: Some congenital viral infections may have onset later than 48 hours after birth. B. Acquired/nosocomial Onset of infection at 48 hours or later, with criteria as above, but excluding 3d.

Table 4. Determination of infection

5 Neurological

5.1 Hypoxic ischaemic encephalopathy/Perinatal asphyxia
5.2 Cranial haemorrhage
- 5.21 Intraventricular haemorrhage
- 5.22 Subgaleal haemorrhage
- 5.23 Subarachnoid haemorrhage
- 5.24 Subdural haemorrhage
- 5.28 Other intracranial haemorrhage

5.3 Post haemorrhagic hydrocephalus
5.4 Periventricular leukomalacia
5.8 Other

Definitions and Rules:

Hypoxic ischaemic encephalopathy/Perinatal asphyxia:

Inclusion as hypoxic ischaemic encephalopathy or perinatal asphyxia usually requires a defining asphyxial event +/- evidence of severe non-reassuring fetal status and encephalopathy.

Examples of defining asphyxial events:

Massive antepartum haemorrhage from abruption (4.1), placenta praevia (4.2) or ruptured vasa praevia (4.3), breech presentation (8.14) or delivery with complications, e.g. cervical constriction ring or difficult delivery, feto-maternal haemorrhage (7.1), twin-twin transfusion (6.11).

Where possible, evidence for perinatal asphyxia should include fetal, umbilical artery or early neonatal blood gases (within one hour) showing evidence of a severe metabolic acidosis. Otherwise peripartum death might also be due to non-hypoxic causes, e.g. infection or chronic ischaemia but wrongly assumed to be due to acute hypoxia. In the absence of a defining asphyxial event every effort must be undertaken to exclude alternative diagnosis.

6 Gastrointestinal

6.1 Necrotising enterocolitis (NEC)
6.2 Short gut syndrome
6.3 Gastric or intestinal perforation (excluding NEC)
6.4 Gastrointestinal haemorrhage
6.8 Other

Definitions and Rules

When Short gut syndrome is a consequence of NEC or gastroschisis (1.152) then classify as Category 6.2 Short gut syndrome for the cause and other conditions as associated. Short gut syndrome Category 6.2 includes major intestinal infarction (such as midgut volvulus (1.14).

7 Other

7.1 Sudden unexpected death in infancy (SUDI)
- 7.11 Sudden Infant Death Syndrome (SIDS)
  - 7.112 SIDS Category IA: Classic features of SIDS present and completely documented
  - 7.113 SIDS Category IB: Classic features of SIDS present but incompletely documented
  - 7.114 SIDS Category II: Infant deaths that meet category I except for one or more features
- 7.12 Unclassified Sudden Infant Death in the neonatal period
  - 7.121 Bed sharing/unsafe sleep
  - 7.122 Not bed sharing
- 7.19 Unknown/Undetermined

7.2 Multisystem failure
- 7.21 Secondary to intrauterine growth restriction
- 7.28 Other specified
- 7.29 Unspecified/undetermined primary cause or trigger event

7.3 Trauma
- 7.31 Accidental
- 7.32 Non accidental
- 7.39 Unspecified

7.4 Treatment complications
- 7.41 Surgical
- 7.42 Medical

7.5 Unsuccessful resuscitation in infants of 28 weeks gestation or more without an obvious sentinel event

7.8 Other specified

Definitions

7.1 *SIDS* and 7.91 *Unclassified Sudden Infant Death* are defined according to the new SIDS classification system by Krous et al[20].

General Definition of SIDS

SIDS is defined as the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.

Category IA SIDS: Classic Features of SIDS Present and Completely Documented

Category IA includes infant deaths that meet the requirements of the general definition and also all of the following requirements.

Clinical:
- More than 21 days and <9 months of age;
- Normal clinical history, including term pregnancy(gestational age of $\geq$ 37 weeks);
- Normal growth and development.
- No similar deaths among siblings, close genetic relatives (uncles, aunts or first-degree cousins), or other infants in the custody of the same caregiver.

Circumstances of Death:

- Investigation of the various scenes where incidents leading to death might have occurred and it is determined that they do not provide an explanation for the death.
- Found in a safe sleeping environment, with no evidence of accidental death.

Autopsy:

- There is an absence of potentially fatal pathologic findings. Minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial haemorrhage is a supportive but not obligatory or diagnostic finding.
- There is no evidence of unexplained trauma, abuse, neglect, or unintentional injury.
- There is no evidence of substantial thymic stress effect (thymic weight of <15g and/or moderate/severe cortical lymphocyte depletion). Occasional "starry sky" macrophages or minor cortical depletion is acceptable.
- Results of toxicologic, microbiologic, radiologic, vitreous chemistry, and metabolic screening studies are negative.

Category IB SIDS: Classic Features of SIDS Present but Incompletely Documented

Category IB includes infant deaths that meet the requirements of the general definition and also meet all of the criteria for category IA except that investigation of the various scenes where incidents leading to death might have occurred was not performed and or ≥ 1 of the following analyses was not performed: toxicologic, microbiologic, radiologic, vitreous chemistry, or metabolic screening studies.

Category II SIDS

Category II includes infant deaths that meet category I criteria except for ≥ 1 of the following.

Clinical:

- Age range outside that of category 1A or 1B (i.e., 0-21 days or 270 days [9 months] through first birthday);
- Similar deaths among siblings, close relatives, or other infants in the custody of the same caregiver that are not considered suspect for infanticide or recognised genetic disorders;
- Neonatal or perinatal conditions (for example, those resulting from preterm birth) that have resolved by the time of death.

Circumstances of Death:

- Mechanical asphyxia or suffocation caused by overlaying not determined with certainty.

Autopsy:

- Abnormal growth and development not thought to have contributed to death;
- Marked inflammatory changes or abnormalities not sufficient to be unequivocal causes of death.

Unclassified Sudden Infant Death

The unclassified category includes deaths that do not meet the criteria for category I or II SIDS but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases for which autopsies were not performed.

Post-resuscitation cases

Infants found in extremis who are resuscitated and later die ("temporarily interrupted SIDS") may be included in the aforementioned categories, depending on the fulfilment of relevant criteria.

Rules

Subcategory 7.92 *Other Unknown/Undetermined* has been included to identify unknown causes of death which do not fulfil the criteria of Category 7.91. Subcategory 7.4 *Other accident, poisoning or violence (postnatal)* excludes cases of antepartum deaths which should be classified in Category 5 *Maternal Conditions* under subcategory 5.3 *Maternal injury.* Subcategory 7.8 *Other specified* is used to classify other identified conditions which are not included in subcategories 7.1 to 7.4.

PSANZ Associated Conditions

Following classification of the underlying cause of death according to the PSANZ-PDC for stillbirths and neonatal deaths, and in addition a PSANZ NDC for neonatal deaths, associated conditions thought to be contributory (but not causal) to the death should be classified. The associated condtions list includes the PSANZ-PDC categories and, in addition for neonatal deaths, the PSANZ-NDC categories and other conditions which may be contributory to stillbirth as listed below in Categories 13-16.

Associated conditions for both stillbirths and neonatal deaths

Categories 1 -11 PSANZ PDC Plus the following additional categories:

13 Genetic testing results not diagnostic

13.1 Copy number variant of unknown or uncertain significance
13.2 No mutation identified matching phenotype
13.3 Tested for genetic mutations but failed
13.4 Not tested or not known if tested for genetic mutations

Explanatory/clarifying notes:

Where a pathogenic or a likely pathogenic mutation has been identified, this would have been classified under Category 1.2 Chromosomal anomaly as stated in the Definitions and Rules section of Category 1 Congenital anomaly. 1.31 and 1.34 are self-explanatory. 13.3 tested for genetic mutations but failed, refer to those tests that may have failed due to culture failure (with conventional cytogenetics) or poor DNA (with molecular techniques)

14 Associated placental pathology

14.1 Delayed villous maturation
14.2 Large chorioangioma
14.3 Early bleeding often leading to preterm prelabour ROM
14.8 Other associated placental pathology

Explanatory/clarifying notes:

Early bleeding is defined as bleeding in the second trimester (often on one or more occasions) which does not immediately lead to spontaneous birth or rupture of membranes.

15 Associated cord pathology

15.1 True knot (excluding histological evidence of causation)
15.2 Hypercoiled cord
15.3 Tethered cord
15.4 Velamentous insertion
15.8 Other associated cord pathology

16 Fetal Growth Restriction (FGR)

16.1 Autopsy evidence (brain:liver ratio equal to or greater than 4:1)
16.2 Antenatal ultrasound evidence of FGR
16.3 Clinical examination of the baby (by paediatrician, pathologist)
16.4 Birthweight (less than 10th centile for gestational age)
16.41 Customised centiles[21]
16.42 Population centiles[22,23]

Explanatory/clarifying notes:

Fetal growth restriction is defined as:

1. A brain:liver ratio equal to or greater than 4:1 at autopsy
   AND/OR
1. Where antenatal ultrasound assessment has shown evidence of FGR (e.g. reduced growth velocity on serial biometry and/or abnormal utero-placental blood flow on Doppler ultrasound and reduced amniotic fluid volume)
   AND/OR
2. Clinical examination of the baby (by paediatrician, pathologist)
   AND/OR
3. Birthweight <10th centile for gestational age for livebirths or non-macerated stillbirths

Classifying FGR in stillbirths

It is also recommended that for fetal deaths, where possible, the gestational age on the date of death and not date of birth be used to define the presence of FGR.

For macerated stillbirths, in the absence of prior ultrasound evidence of FGR and where no autopsy has been performed or the brain:liver ratio is less than 4:1, the death should be classified as Unexplained Antepartum Death (Category 11), as the weight discrepancy may be a post mortem effect.

Customised or non-customised centiles

Either customised or non-customised centiles charts can be used to classify FGR as an associated condition under 16.2.1 or 16.2.2 respectively. Customised birthweight (CBW) centiles are being increasingly used to determine the presence of FGR[21]. However controversy around the use of customised centiles continues[24,25] including concerns that customisation may mask pathology[24,26]. It is recommended that the variables required for calculation of CBW (maternal age, ethnicity, height, weight, and fetal gestation and gender) be routinely collected to enable evaluation of birthweight according to CBW centiles. The recommended Australia population standards are those published by Dobbins et al[22] and for preterm birth by Fenton et al[23].

17 Maternal risk factors (optional category)

17.1 Smoking
17.2 Substance use
17.3 High BMI
17.4 Maternal mental health disorder
17.5 Socioeconomic deprivation
17.6 Refugee or asylum seeker

Ideally risk factors would be included as part of a minimum dataset for all livebirths and stillbirths to enable ongoing assessment of the contribution of these factors to perinatal deaths. Further, inclusion of the PSANZ classification in this dataset for each perinatal death will provide a rich source of information for understanding causal pathways for maternal risk factors.

Associated conditions for neonatal deaths only

NDC Categories 1- 6

In addition to the above for associated maternal/fetal conditions the NDC Categories 1- 6 can be used to assign associated neonatal conditions.

PSANZ Classification System — QUICK REFERENCE SHEET Version 4.0

The current version for use is version 4. Version 5 is intended for use across Australia and Aotearoa New Zealand for perinatal deaths occurring for births from 1 January 2025.

PSANZ-PDC

1 Congenital Anomaly
- 1.1 Structural anomaly
  - 1.11 Nervous system
  - 1.12 Cardiovascular system
  - 1.13 Genitourinary system
  - 1.14 Gastrointestinal system
  - 1.15 Musculoskeletal
    - 1.151 Congenital diaphragmatic hernia
    - 1.152 Gastroschisis/omphalocele
  - 1.16 Respiratory system (include congenital pulmonary airway malformation (CPAM))
  - 1.17 Haematological
  - 1.18 Multiple Congenital anomaly (no chromosomal/genetic cause or not tested)
  - 1.19 Other congenital abnormality
    - 1.192 Idiopathic hydrops fetalis
    - 1.193 Fetal tumour (include sacro-coccygeal teratoma)
    - 1.198 Other specified
    - 1.199 Congenital anomaly, unspecified
- 1.2 Chromosomal anomaly
  - 1.21 Down syndrome (trisomy 21)
  - 1.22 Edward syndrome and Patau syndrome (trisomy 18, trisomy 13)
  - 1.23 Other trisomies and partial trisomies of the autosomes, not elsewhere classified (includes pathogenic duplications, unbalanced translocations and insertions)
  - 1.24 Monosomies and deletions from the autosomes, not elsewhere classified (includes pathogenic deletions e.g. 22q11.2 deletion syndrome (diGeorge syndrome), Wolff-Hirschorn syndrome, Cri-du-chat syndrome
  - 1.25 Turner syndrome (monosomy X)
  - 1.26 Other sex chromosome abnormalities (e.g. Klinefelter syndrome)
  - 1.28 Other chromosomal abnormalities, not elsewhere specified (includes Fragile X syndrome, imprinting syndromes, triploidy)
  - 1.29 Unspecified
- 1.3 Genetic anomaly
  - 1.31 Genetic condition, specified (e.g. Tay-Sachs disease; includes inborn errors of metabolism)
  - 1.32 Syndrome/association with demonstrated chromosomal/gene anomaly.
  - 1.39 Genetic condition, unspecified

2 Perinatal Infection
- 2.1 Bacterial
  - 2.11 Group B Streptococcus
  - 2.12 E coli
  - 2.13 Listeria monocytogenes
  - 2.14 Spirochaetal e.g. Syphilis
  - 2.18 Other bacterial
  - 2.19 Unspecified bacterial
- 2.2 Viral
  - 2.21 Cytomegalovirus
  - 2.22 Parvovirus
  - 2.23 Herpes simplex virus
  - 2.24 Rubella virus
  - 2.25 Zika virus
  - 2.28 Other viral
  - 2.29 Unspecified viral
- 2.3 Protozoal e.g. Toxoplasma
- 2.5 Fungal
- 2.8 Other specified organism
- 2.9 Other unspecified organism

3 Hypertension
- 3.1 Chronic hypertension: essential
- 3.2 Chronic hypertension: secondary, e.g. renal disease
- 3.3 Chronic hypertension: unspecified
- 3.4 Gestational hypertension
- 3.5 Pre-eclampsia
- 3.6 Pre-eclampsia superimposed on chronic hypertension
- 3.9 Unspecified hypertension

4 Antepartum Haemorrhage (APH)
- 4.1 Placental abruption
- 4.2 Placenta praevia
- 4.3 Vasa praevia
- 4.9 APH of undetermined origin

5 Maternal Conditions
- 5.1 Termination of pregnancy for maternal psychosocial indications
- 5.2 Diabetes
  - 5.21 Gestational diabetes
  - 5.22 Pre-existing diabetes
- 5.3 Maternal injury
  - 5.31 Accidental
  - 5.32 Non-accidental
- 5.4 Maternal sepsis
- 5.5 Antiphospholipid syndrome
- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions
  - 5.81 Maternal suicide
  - 5.82 Other specified maternal medical or surgical conditions

6 Complications of multiple pregnancy
- 6.1 Monochorionic twins
  - 6.11 Twin to twin transfusion syndrome (TTTS)
  - 6.12 Selective fetal growth restriction (FGR) (i.e. affecting only one twin)
  - 6.13 Monoamniotic twins (including cord entanglement)
  - 6.18 Other
  - 6.19 Unknown or unspecified
- 6.2 Dichorionic twins
  - 6.21 Early fetal death in a multiple pregnancy (<20 weeks gestation)
  - 6.22 Selective fetal growth restriction (FGR)
  - 6.28 Other
  - 6.29 Unknown or unspecified
- 6. 3 Complications of higher order multiples (3 or more fetuses)
  - 6.31 Twin to twin transfusion syndrome (TTTS)
  - 6.32 Selective fetal growth restriction (FGR)
  - 6.33 Monoamniotic multiples (including cord entanglement)
  - 6.34 Early fetal death in a multiple pregnancy (<20 weeks gestation)
  - 6.38 Other
  - 6.39 Unknown or unspecified
- 6.4 Complications where chorionicity is unknown
- 6.8 Other
- 6.9 Unspecified

7 Specific perinatal conditions
- 7.1 Fetomaternal haemorrhage
- 7.2 Antepartum cord or fetal vessel complications (excludes monochorionic twins or higher order multiples)
  - 7.21 Cord vessel haemorrhage
  - 7.22 Cord occlusion (True knot with evidence of occlusion or other)
  - 7.28 Other cord complications
  - 7.29 Unspecified cord complications
- 7.3 Uterine abnormalities
  - 7.31 Developmental anatomical abnormalities (e.g. bicornuate uterus)
  - 7.38 Other
  - 7.39 Unspecified
- 7.4 Alloimmune disease
  - 7.41 Rhesus isoimmunisation
  - 7.42 Other red cell antibody
  - 7.43 Alloimmune thrombocytopenia
  - 7.48 Other
  - 7.49 Unspecified
- 7.5 Fetal antenatal intracranial injury
  - 7.51 Subdural haematoma
  - 7.52 Fetal antenatal ischaemic brain injury
  - 7.53 Fetal antenatal haemorrhagic brain injury
- 7.6 Other specific perinatal conditions
  - 7.61 Complications of antenatal, diagnostic or therapeutic procedures:
    - 7.611 Complications of prenatal diagnostic procedures (e.g. amniocentesis, chorionic villus sampling,) (e.g. rupture of membranes after amniocentesis)
    - 7.612 Complications of fetal ultrasound guided needle interventions (e.g. FBS/fetal transfusion, thoracocentesis, vesicocentesis, fetal cardiac valvoplasty, division of amniotic bands, fetal skin biopsy, unipolar/bipolar diathermy, RFA procedures)
    - 7.613 Complications of fetal shunt interventions (e.g. pleuroamniotic shunt, vesicoamniotic shunt)
    - 7.614 Complications of minimally invasive fetoscopic interventions (e.g. fetoscopic laser surgery for TTTS, FETO for CDH, laser ablation of posterior urethral valves)
    - 7.615 Complications of open maternal fetal surgery (e.g. open maternal fetal surgery for spina bifida)
    - 7.618 Other
  - 7.62 Termination of pregnancy for suspected but unconfirmed congenital anomaly.
  - 7.63 Amniotic band
  - 7.68 Other
- 7. 9 Unspecified

8 Hypoxic peripartum death
- 8.1 With intrapartum complications (sentinel events)
  - 8.11 Uterine rupture
  - 8.12 Cord prolapse
  - 8.13 Shoulder dystocia
  - 8.14 Complications of breech presentation
  - 8.15 Birth trauma
  - 8.16 Intrapartum haemorrhage
  - 8.18 Other
- 8.2 Evidence of significant fetal compromise (excluding other complications)
- 8.3 No intrapartum complications recognised and no evidence of significant fetal compromise identified
- 8.9 Unspecified hypoxic peripartum death

9 Placental dysfunction or causative placental pathology
- 9.1 Maternal vascular malperfusion
- 9.2 Fetal vascular malperfusion
- 9.3 High grade villitis of unknown etiology (VUE)
- 9.4 Massive perivillous fibrin deposition/maternal floor infarction
- 9.5 Severe chronic intervillositis (Histiocytic intervillositis)
- 9.6 Placental hypoplasia
- 9.7 No causal placental pathology demonstrated, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)
- 9.8 Placental pathological examination was not performed, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)
- 9.9 Other placental pathology (e.g. multiple pathologies with evidence of loss of placental function leading to death)

10 Spontaneous preterm labour or rupture of membranes (<37 weeks gestation)
- 10.1 Spontaneous preterm
  - 10.11 With histological chorioamnionitis
  - 10.12 Without histological chorioamnionitis
  - 10.13 With clinical evidence of chorioamnionitis, no examination of placenta
  - 10.17 No clinical signs of chorioamnionitis, no examination of placenta
  - 10.19 Unspecified or not known whether placenta examined

PSANZ Classification System — QUICK REFERENCE SHEET Version 4.0

The current version for use is version 4. Version 5 is intended for use across Australia and Aotearoa New Zealand for perinatal deaths occurring for births from 1 January 2025.

10.2 Spontaneous preterm preceded by premature cervical shortening

11 Unexplained antepartum fetal death
11.1 Unexplained antepartum fetal death despite full investigation
11.2 Unclassifiable antepartum fetal death with incomplete investigation
11.3 Unclassifiable antepartum fetal death due to unknown level of investigation

12 Neonatal death without obstetric antecedent
12.1 Neonatal death with no obstetric antecedent factors despite full investigation
12.2 Neonatal death unclassifiable as to obstetric antecedent with incomplete investigation
12.3 Neonatal death unclassifiable as to obstetric antecedent due to unknown level of investigation

PSANZ-NDC

1 Congenital Anomaly (Please refer to PSANZ PDC)

2 Periviable infants (typically <24 weeks)
2.1 Not resuscitated (including infants where there is an antenatal plan for no resuscitation at birth or in the circumstance of re-directed care)
2.2 Unsuccessful resuscitation
2.9 Unspecified or not known whether resuscitation attempted

3 Cardio-respiratory disorders
3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)
3.2 Meconium aspiration syndrome
3.3 Primary persistent pulmonary hypertension
3.4 Pulmonary hypoplasia
3.5 Pulmonary haemorrhage
3.6 Air leak syndromes
- 3.61 Pneumothorax
- 3.62 Pulmonary interstitial emphysema
- 3.68 Other

3.7 Patent ductus arteriosus
3.8 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)
3.9 Other
- 3.91 Neonatal anaemia/hypovolaemia

4 Neonatal infection
4.1 Congenital/Perinatal bacterial infection (early onset<48 hrs)
- 4.11 Blood stream infection/septicaemia
  - 4.111 Positive culture of a pathogen
  - 4.112 Clinical signs of sepsis + ancillary evidence but culture negative
- 4.12 Bacterial meningitis
- 4.13 Bacterial pneumonia
- 4.15 Multiple site bacterial infection
- 4.18 Other congenital bacterial infection e.g. gastroenteritis, osteomyelitis, cerebral abscess
- 4.19 Unspecified congenital infection

4.2 Congenital/Perinatal viral infection
4.3 Congenital fungal, protozoan, parasitic infection
4.4 Acquired bacterial infection (late onset>48hrs).
- 4.41 Blood stream infection/septicaemia
  - 4.411 Positive culture of a pathogen
  - 4.412 Clinical signs of sepsis + ancillary evidence but culture negative
- 4.42 Bacterial meningitis
- 4.43 Bacterial pneumonia
- 4.48 Other acquired bacterial infection e.g. gastroenteritis, osteomyelitis
- 4.49 Unspecified acquired infection

4.5 Acquired viral infection
4.6 Acquired fungal, protozoan, parasitic infection

5 Neurological
5.1 Hypoxic ischaemic encephalopathy/Perinatal asphyxia
5.2 Cranial haemorrhage
- 5.21 Intraventricular Haemorrhage
- 5.22 Subgaleal Haemorrhage
- 5.23 Subarachnoid Haemorrhage
- 5.24 Subdural Haemorrhage
- 5.28 Other intracranial haemorrhage

5.3 Post haemorrhagic hydrocephalus
5.4 Periventricular leukomalacia
5.8 Other

6 Gastrointestinal
6.1 Necrotising enterocolitis (NEC)
6.2 Short gut syndrome
6.3 Gastric or intestinal perforation (excluding NEC)
6.4 Gastrointestinal haemorrhage
6.8 Other

7 Other
7.1 Sudden unexpected death in infancy (SUDI)
- 7.11 Sudden Infant Death Syndrome (SIDS)
  - 7.112 SIDS Category IA: Classic features of SIDS present and completely documented.
  - 7.113 SIDS Category IB: Classic features of SIDS present but incompletely documented.
  - 7.114 SIDS Category II: Infant deaths that meet category I except for one or more features.
- 7.12 Unclassified Sudden Infant Death in the neonatal period
  - 7.121 Bed sharing
  - 7.122 Not bed sharing
- 7.19 Unknown/Undetermined

7.2 Multisystem failure
- 7.21 Secondary to intrauterine growth restriction
- 7.28 Other specified
- 7.29 Unspecified/undetermined primary cause or trigger event

7.3 Trauma
- 7.31 Accidental
- 7.32 Non accidental
- 7.39 Unspecified

7.4 Treatment complications
- 7.41 Surgical
- 7.42 Medical

7.5 Unsuccessful resuscitation in infants of 28 weeks gestation or more without an obvious sentinel event
7.8 Other specified

PSANZ ASSOCIATED CONDITIONS

Associated conditions for both stillbirths and neonatal deaths

Categories 1 -11 PSANZ PDC

13 Genetic testing results not diagnostic
13.1 Copy number variant of unknown or uncertain significance
13.2 No mutation identified matching phenotype
13.3 Tested for genetic mutations but failed
13.4 Not tested or not known if tested for genetic mutations

14 Associated placental pathology
14.1 Delayed villous maturation
14.2 Large chorioangioma
14.3 Early bleeding often leading to preterm prelabour ROM
14.8 Other associated placental pathology

15 Associated cord pathology
15.1 True knot (excluding histological evidence of causation)
15.2 Hypercoiled cord
15.3 Tethered cord
15.4 Velamentous insertion
15.8 Other cord associated cord pathology

16 Fetal Growth Restriction
16.1 Autopsy evidence (brain:liver ratio equal to or greater than 4:1)
16.2 Antenatal ultrasound evidence of FGR
16.3 Clinical examination of the baby (by paediatrician, pathologist)
16.4 Birthweight (less than 10th centile for gestational age)
- 16.41 Customised centiles
- 16.42 Population centiles

17 Maternal risk factors (optional category)
17.1 Smoking
17.2 Substance use
17.3 High BMI
17.4 Maternal mental health disorder
17.5 Socioeconomic deprivation
17.6 Refugee or asylum seeker

Associated conditions for neonatal deaths only

NDC Categories 1- 6
In addition to the above for associated maternal/fetal conditions the NDC Categories 1- 6 can be used to assign associated neonatal conditions

PERINATAL SOCIETY of Australia and New Zealand PSANZ | SANDA Stillbirth and Neonatal Death Alliance | Stillbirth CENTRE OF RESEARCH EXCELLENCE

PSANZ CLASSIFICATION SYSTEM FOR STILLBIRTHS AND NEONATAL DEATHS

Version 5.0, February 2024

Introduction

Accurate classification of the causes of the stillbirths and neonatal deaths is the cornerstone of prevention and the ability to compare causes of death across and within countries is key to this effort. There have been more than 80 classification systems for causes of perinatal death reported globally[1], none of which is clearly superior. The WHO recommend the use of the WHO–ICD for perinatal mortality (ICD-PM)[2], which uses ICD rules and classifies a single underlying cause of perinatal death based only on death certificate data. While the ICD-PM holds promise for consistent global reporting of causes of perinatal death, the system has limitations[3-5], particularly for well-resourced settings where more information is available to allow more specific classification of causes [6].

The Perinatal Society of Australia and New Zealand (PSANZ) Classification System performs well against other systems[7] and until further enhancements are made to the ICD system, the PSANZ Classification System remains the recommended system for causes of perinatal deaths in Australia and New Zealand. However, in order to facilitate global comparisons and to inform future improvements to ICD-PM, simultaneous application of ICD-PM and the PSANZ system or later mapping from PSANZ to ICD-PM is optimal.

The PSANZ Classification System for Stillbirths and Neonatal Deaths was first released in 2003, and subsequently revised in 2004, 2009 and 2018. This is the fifth version of the PSANZ system and is intended to for use be used across Australia and Aotearoa New Zealand for perinatal deaths occurring for births from 1 January 2025.

Purpose, principles, and structure

Purpose

The purpose of the PSANZ Perinatal Death Classification System is to ensure comprehensive and consistent data on causes and associated conditions for stillbirths and neonatal deaths across Australia and New Zealand to enable benchmarking and monitoring of causes of death to inform policy, practice, and research, to help parents understand why the death occurred and to assist in future pregnancy planning.

Principles

The key principles of the PSANZ system are:

- To identify an underlying cause of death for stillbirths and neonatal deaths
- To identify up to two associated conditions for stillbirths and neonatal deaths
- To enable reporting by ICD-PM through identifying timing of death and mapping of categories to ICD-PM.

Including the assigned PSANZ system category codes as part of routinely collected individual birth record data across ANZ jurisdictions will enable reporting by timing of death (antepartum,

intrapartum, early and late neonatal deaths or timing of death unknown) and also allows more detailed analyses by demographic and clinical factors to aid identify where attention is most needed.

Structure

The PSANZ System for stillbirths and neonatal deaths consists of two main sets of conditions (categories) and one set of associated conditions (contributory).

The two main category grouping are: 1) The Perinatal Death Classification (PDC) which includes maternal/fetal causes of stillbirths and neonatal deaths; and 2) The Neonatal Death Classification (NDC) including neonatal causes of death.

The PSANZ Associated Conditions list includes both the PDC and NDC categories plus other associated factors e.g. maternal risk factors and placental pathologies.

What has changed in this update?

In this update, changes have been made to categories, definitions, and rules of the system to address recent feedback from jurisdictional committees across ANZ. Changes include:

- Two new codes, one in PDC Category 2 Perinatal Infection and the other in PDC Category 5 Maternal Conditions, have been added to code perinatal deaths directly and indirectly relating to coronavirus.
- Category 1 (Congenital anomaly) has been revised to include craniofacial abnormalities and to include "other" musculoskeletal conditions that are not Congenital Diaphragmatic Hernia or Gastroschisis.
- Improvement in the rules and criteria for coding an infection, including the role of Polymerase Chain Reaction (PCR) in identifying infections.
- Code 5.1 Termination of pregnancy for maternal psychosocial reasons has been separated into 5.11 termination of pregnancy for maternal mental health indication and 5.12 termination of pregnancy for circumstantial indication, to align with recent changes in the national best endeavours data set (NBEDS).
- PSANZ PDC Category 6 Monochorionic twins now includes codes for twin anemia-polycythaemia sequence (TAPS) and early fetal death in a multiple pregnancy (<20 weeks gestation).
- PSANZ PDC Category 7 includes Gestational alloimmune liver disease (GALD)
- Improvements in the rules around coding placental hypoplasia (Category 9.6)
- PSANZ NDC Category 7 Other now includes multisystem failure secondary to prematurity.
- Improvements in the definition and rules around coding a termination of pregnancy.
- The PSANZ Associated conditions cord pathologies list now includes marginal cord insertion and maternal conditions list include minimal or no antenatal care and separates smoking into smoking cigarettes and vaping.

Previously, the PSANZ Classification System was included in Section 7 of the *Care Around Stillbirth and Neonatal Death (CASaND) Clinical Practice Guideline*. The PSANZ Classification System now sits as an appendix in the 2024 edition of the Guideline. Formatting changes have been made to enhance readability of the system and reduce duplication.

This update of the PSANZ Classification System for Stillbirth and Neonatal Death been undertaken by the PSANZ Perinatal Mortality Committee, supported by the NHMRC Stillbirth Centre of Research Excellence in Stillbirth. For information on changes to the PSANZ Classification System made during previous revisions, please contact the Stillbirth CRE (email: stillbirthcre@mater.uq.edu).

General rules for applying the PSANZ PDC System

Classification of underlying cause and associated conditions

In accordance with ICD-PM, the PSANZ Classification System identifies a single underlying cause of death for stillbirths and neonatal deaths as well as the presence of associated conditions. For all stillbirths and neonatal deaths, a maternal/fetal condition according to the PDC is assigned and, in addition for neonatal deaths, the underlying neonatal condition which caused the death is assigned according to the NDC. Therefore, for neonatal deaths the PSANZ system at least two conditions are assigned; the neonatal condition which resulted in the death and a maternal/fetal condition (according to the PDC). If no maternal/fetal condition is identified the classification category of "no obstetric antecedent" is applied.

Definitions

Underlying cause of death: According to ICD

> "the disease or injury which initiated the train of morbid events leading directly to a person's death or the circumstances of the accident or violence which produced the fatal injury, as represented by a code[8]"

Associated conditions are defined as conditions which were considered to have contributed to the death but are not considered to be the main underlying cause. Conditions which were present but not considered to be contributory are not classified as associated conditions.

Please refer to the PSANZ Associated Conditions list (see page 35).

Terminations of pregnancy

Definition: The deliberate ending of a pregnancy in which there is a live fetus, with the primary intent that this will result in the death of the fetus and the removal or expulsion by surgical or medical means.

In multiple pregnancies procedures may be performed which intentionally result in the death of a fetus or fetuses which remain *in utero* for a time. In these cases, once the pregnancy ends these losses should be classified as a termination of pregnancy.

A termination of pregnancy may be undertaken for a number of reasons, including but not limited to:

- The diagnosis of a life-limiting fetal congenital anomality or condition, or an anomaly or condition considered by the parents to be incompatible with an appropriate quality of life
- The presence of maternal psychosocial or mental health issues
- The woman's decision to end the pregnancy
- A risk to the woman's life e.g. induction of labour without expectation of fetal survival in the case of severe pre-eclampsia at pre-viable gestations, or prolonged premature rupture of membranes with severe infection.

The Australian Institute of Health and Welfare (AIHW) are currently reviewing the definition of 'termination of pregnancy' included in AIHW reporting products. The definition is expected to be finalised in early 2024. The definition of 'termination of pregnancy' used in this version of the PSANZ Classification System will be updated to fully align with the AIHW definition once it has been finalised.

Classification: All terminations of pregnancy are identified by the inclusion of a "9" code applied to the 4th decimal place of the relevant PDC code. "009" would be applied to two-digit codes, "09" would be applied to three-digit codes and "9" would be applied to four-digit codes i.e., 1.1 becomes

1.1009; 1.83 becomes 1.8309; 6.111 becomes 6.1119. The termination of pregnancy identifier "9" should not be applied to category 8, category 11 or category 12 codes.

Classification numbering approach

As far as possible, the subcategory .8 has been used for 'Other conditions' and .9 for 'Unspecified conditions' within its category, as has been the case in the ICD classification.

If data are entered with a decimal point, a subcategory such as 'Structural anomaly' (Category 1, *Congenital Anomaly*) would be 1.1, but as a 4-digit numeric would be 0110. Similarly, subcategory 'Group B Streptococcus' (Category 2, *Perinatal Infection*) would be 2.11 or 0211.

Inclusion in routine perinatal data collections at the individual case record level

It is recommended that PSANZ classification codes are included within routine perinatal data collections in each region for every perinatal death to enable disaggregation to better identify areas to focus prevention e.g. by Indigenous and socioeconomic status and other risk factors, and timing of death. The ability to analyse causes of perinatal deaths by timing of death (i.e. antepartum, intrapartum, neonatal, or unknown) is consistent with ICD-PM rules.

Reporting according to ICD-PM

Reporting by ICD-PM system enables international comparisons and should be based on the causes of perinatal deaths following thorough investigation and perinatal mortality committee review. Following application of the PSANZ classification system to stillbirths and neonatal deaths, mapping of the categories to ICD-PM should be undertaken for global reporting requirements. Jurisdictions may wish to classify according to ICD-PM simultaneously with the PSANZ system to assist in global reporting and to inform future improvements in classification.

PSANZ-PDC Classification including rules and definitions (v5)

1 Congenital anomaly

1.1 Structural anomaly
- 1.11 Nervous system
- 1.12 Cardiovascular system
- 1.13 Genitourinary system
- 1.14 Gastrointestinal system
- 1.15 Musculoskeletal
  - 1.151 Congenital diaphragmatic hernia
  - 1.152 Gastroschisis/omphalocele
  - 1.158 Other
- 1.16 Respiratory system (include congenital pulmonary airway malformation (CPAM))
- 1.17 Haematological
- 1.18 Multiple Congenital anomaly (no chromosomal/genetic cause or not tested)
- 1.19 Other congenital abnormality
  - 1.192 Idiopathic hydrops fetalis
  - 1.193 Fetal tumour (include sacro-coccygeal teratoma)
  - 1.194 Craniofacial abnormality
  - 1.198 Other specified
  - 1.199 Congenital anomaly, unspecified

1.2 Chromosomal anomaly
- 1.21 Down syndrome (trisomy 21)
- 1.22 Edward syndrome and Patau syndrome (trisomy 18, trisomy 13)
- 1.23 Other trisomies and partial trisomies of the autosomes, not elsewhere classified (includes pathogenic duplications, unbalanced translocations and insertions)
- 1.24 Monosomies and deletions from the autosomes, not elsewhere classified (includes pathogenic deletions e.g. 22q11.2 deletion syndrome (diGeorge syndrome), Wolff-Hirschorn syndrome, Cri-du-chat syndrome
- 1.25 Turner syndrome (monosomy X)
- 1.26 Other sex chromosome abnormalities (e.g. Klinefelter syndrome)
- 1.28 Other chromosomal abnormalities, not elsewhere specified (includes Fragile X syndrome, imprinting syndromes, triploidy)
- 1.29 Unspecified

1.3 Genetic anomaly
- 1.31 Genetic condition, specified (includes inborn errors of metabolism e.g. Tay-Sachs disease)
- 1.32 Syndrome/association with demonstrated chromosomal/gene anomaly
- 1.39 Genetic condition, unspecified

Definitions and Rules:

This category includes deaths in which a major congenital anomaly, whether structural or chromosomal, is considered to have been the reason for the death. All categories correspond to the ICD10 numbering in Chapter XVII Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99) as presented in ICD-PM[9].

If termination of pregnancy was undertaken as a result of the anomaly include the digit "09" at the end the numerical classification e.g. Termination of Trisomy 21 (Down Syndrome) 1.2109. All terminations of pregnancy for congenital anomalies regardless of the causal link to perinatal death are also classified here. With mapping to ICD coding, non-lethal abnormalities may be identified.

Chromosomal and genetic testing are categorised separately, in recognition of advances in prenatal screening and testing. The scope of genetic testing is widening to include some conditions that may not manifest with structural anomalies in the prenatal period (e.g. Fragile X syndrome). If there is both a chromosomal/genetic and structural abnormality, code for the chromosome or genetic condition with the structural condition as an associated condition. Results of genetic testing of unknown significance are captured under associated conditions.

The chromosomal abnormality category excludes deaths where molecular karyotyping identifies an anomaly which is not thought to be causal. Findings of genetic testing of unknown significance (variations of uncertain or unknown significance, VUS) are classified as associated conditions. Where there is both a chromosomal and a structural abnormality, classify according to the chromosome abnormality with the structural abnormality as an associated condition.

Specific examples:

Down syndrome (Trisomy 21) is classified as a Chromosome abnormality (Down syndrome 1.21). If a cardiac anomaly is also present, this would be an associated condition (1.12 cardiovascular system).

Vater and *Vacterl* are 1.18 Congenital malformations affecting multiple systems, specified. For syndromes where DNA testing is available and has been confirmed for VATER or CHARGE association classify as genetic condition 1.31, specified.

Hydrops Fetalis: Antibody related hydrops (Immune Hydrops) e.g. Rhesus or Kell incompatibility and Bart's haemoglobinopathy (alpha thalassemia) is coded under as 1.17.

Non immune hydrops if due to chromosomal/genetic anomalies, classify under 1.2 and appropriate sub-classification, e.g. 1.25 Turner syndrome.

Idiopathic hydrops fetalis as 1.192 Other specific congenital anomaly, hydrops fetalis, idiopathic.

If the hydrops is secondary to underlying structural pathology e.g. congenital heart abnormality, neuromuscular disorders, skeletal dysplasia (achondrogenesis) or infection–classify in appropriate systems.

Hydrops associated with monochorionic twins classify under 6.1 category.

Multiple anomalies: Where the multiple anomalies are a part of a chromosomal anomaly found in the decedent, e.g. cleft lip and palate with heart defect as in velocardiofacial syndrome associated with 22q11 deletion, they should be classified under Category 1.2 but only if chromosome testing confirms deletion.

Anterior wall defects: Omphalocoele (exomphalos), gastroschisis, and congenital diaphragmatic hernia are now classified under musculoskeletal anomalies (Category 1.15), in line with ICD10-PM.

If omphalocoele is an isolated anomaly classify 1.15; if associated with multiple structural anomalies classify as 1.18; if associated with aneuploidy e.g. trisomy 18, classify as 1.22.

Other skeletal anomalies documented on antenatal ultrasound but not confirmed by genetic testing can be classified as 1.158 *Other*.

Acquired CNS anomalies: Infection-related abnormalities should be classified under Category 2, e.g. microcephaly/hydrocephaly secondary to CMV or toxoplasma infections should be classified as Category 2.21 and 2.3 respectively.

Congenital intracranial haemorrhage/injury may be classified as Category 7.5 *Fetal antenatal intracranial injury.*

Disruptions due to amniotic band disruption sequence may cause extensive asymmetric injury to the cranium and brain. It may also present as anencephaly or encephalocele. Classify under Category 7.5 *Fetal antenatal intracranial injury* but if due to alloimmune thrombocytopenia Code as 1.17 Haematological.

Neuromuscular disorders: Classify under 1.11. These are a complex group that may include primary muscle anomalies, CNS anomalies – both acquired and primary - and metabolic abnormalities. Some are syndromic with recognised recurrence risk. Associated anomalies may include pulmonary hypoplasia, hydrops and cleft palate. The cause of death may have been respiratory failure, but the death should be classified as the underlying abnormality.

If the underlying aetiology is known classify accordingly – e.g. *Fetal antenatal intracranial injury* Category 7.5.

Unspecified Congenital Abnormalities: Category 1.19 *Congenital anomaly, unspecified* covers those cases where an abnormality was stated as the cause but where insufficient information was available to classify under other categories.

2 Perinatal infection

2.1 Bacterial
- 2.11 Group B Streptococcus
- 2.12 E coli
- 2.13 Listeria monocytogenes
- 2.14 Spirochaetal e.g. Syphilis
- 2.18 Other bacterial
- 2.19 Unspecified bacterial

2.2 Viral
- 2.21 Cytomegalovirus
- 2.22 Parvovirus
- 2.23 Herpes simplex virus
- 2.24 Rubella virus
- 2.25 Zika virus
- 2.26 Coronavirus
- 2.28 Other viral
- 2.29 Unspecified viral

2.3 Protozoal e.g. Toxoplasma

2.5 Fungal

2.8 Other specified organism

2.9 Other unspecified organism

Definitions and Rules

In order to qualify for this category, there must be evidence of fetal or neonatal infection as in Table 1. Determination of perinatal infection.

This category aims to identify all perinatal deaths due to infection as the primary cause including perinatal deaths with infection following spontaneous preterm labour or rupture of the membranes. Deaths in preterm infants following spontaneous rupture of the membranes or labour not fulfilling the definition of infection should be classified under Category 10 *Spontaneous Preterm*.

Category 2.8 *Other specified organism* includes deaths due to other identified organisms other than those in Categories 2.1 to 2.5. Category 2.9 *Other unspecified organism* includes cases where there is an obvious infection however the organism was either not identified or not specified.

Examples:

Classify here: Prelabour rupture of the membranes at term, with birth following 24 hours of membrane rupture, neonatal pneumonia identified within 48 hours of birth, subsequent neonatal death, group B Streptococcus identified on vaginal and placental cultures. Classify as subcategory 2.11 Group B Streptococcus and PSANZ-NDC subcategory 4.13.

Classify here: Spontaneous rupture of membranes preterm followed by spontaneous labour at 26 weeks and stillbirth. Membranes were ruptured for 12 hours prior to birth. Fetal pneumonia was detected at autopsy and growth of E Coli from the lungs. Placental pathology showed acute chorioamnionitis (maternal inflammatory response) and funisitis (fetal inflammatory response). Classify 2.12 with an associated condition as Category 10.11 *Spontaneous preterm, with chorioamnionitis on placental histopathology*.

Classify here: Spontaneous rupture of the membranes at 24 weeks gestation. Clinical chorioamnionitis ensued after 6 days of membrane rupture. The mother had been given antibiotics. Induction of labour was undertaken resulting in birth of a liveborn infant in a poor condition with a heart rate of 20bpm. Birthweight was 650gms. Active resuscitation was unsuccessful. No autopsy was performed. Placental histopathology showed acute chorioamnionitis (maternal inflammatory response). Culture showed no growth. Classify as Category 2.19 with an associated category of Spontaneous preterm Category 10.13 and PSANZ-NDC unspecified congenital infection 4.19 with an associated classification of NDC 2.2 *Extreme prematurity – Unsuccessful resuscitation.*

Classify here: Spontaneous rupture of membranes at 14 weeks, with severe clinical chorioamnionitis at 22 weeks with maternal fever, rigors and raised white cell count and c-reactive protein. Labour was induced (with a live baby) and the baby was born without signs of life, the birthweight was 350gms. Autopsy findings of *E.coli* growth from lung fluid. Placental histopathology showed acute chorioamnionitis (maternal inflammatory response) and funisitis (fetal inflammatory response). Classify as Category 2.1209.

Classify here: 30 year old woman, first pregnancy, no other medical complications. Contracted delta strain of Covid at 24 weeks. Unwell but did not require hospital admission. Antenatal US at 26 weeks performed after decreased fetal movements confirming fetal death in utero. Placental histopathology shows massive perivillous fibrin deposition, chronic histiocytic intervillositis, trophoblast necrosis. Classify as Category 2.26.

Do not classify here: Spontaneous rupture of membranes at 21 weeks, with spontaneous onset of labour and birth at 22 weeks gestation. Baby was born without signs of life with a birthweight was 450gms. No autopsy was undertaken. Placental histopathology showed acute chorioamnionitis (maternal inflammatory response) (no vasculitis or funisitis [fetal inflammatory response]), no organism was grown. Classify as Category 10.11

Do not classify here: Neonatal death from late onset (≥48 hrs of age) Group B Streptococcal disease in a term infant. Classify under Category 12. *Neonatal death with no obstetric antecedent factor* and PSANZ-NDC as 4.4. The organism involved (GBS) may be classified as an associated condition under NDC associated factors using Category 2 sub classifications as a pragmatic way of collecting organisms in acquired infection. Alternately (and more appropriately), the organism should be included in a minimum dataset for all perinatal deaths.

Death type	Criteria for Perinatal and Acquired Infection category
Fetal	1. Histological confirmation of a fetal inflammatory response in the cord/chorionic plate (stage 1 – 3, e.g. any vasculitis +/- funisitis) or fetus (pneumonitis or pneumonia) with or without microbiological evidence of infection or 2a. Clinical evidence of primary maternal infection and 2b. Positive culture of a pathogen +/- positive Polymerase Chain Reaction (PCR) testing from mother or placenta (specimen taken aseptically between amnion and chorion)
Neonatal	**A. Congenital** Early onset infection (within 48 hours of birth), defined as: 1. Clinical signs in neonate consistent with sepsis and 2. Haematological changes consistent with sepsis and one or more of the following: 3a. Positive culture +/- positive Polymerase Chain Reaction (PCR) testing of a pathogen (bacterial or viral) from the neonate or 3b. Pathological evidence at autopsy or 3c. Positive serology or 3d. Positive culture +/- positive Polymerase Chain Reaction (PCR) testing of a pathogen from the mother or the placenta or 3e. Pneumonia without specified bacterial or viral pathogens **NB:** Some congenital viral infections may have onset later than 48 hours after birth **B. Acquired** Onset of infection at 48 hours or later, with criteria as above, but excluding 3d

Table 1. Determination of perinatal infection

3 Hypertension

3.1 Chronic hypertension: essential
3.2 Chronic hypertension: secondary, e.g. renal disease
3.3 Chronic hypertension: unspecified
3.4 Gestational hypertension
3.5 Pre-eclampsia
3.6 Pre-eclampsia superimposed on chronic hypertension
3.9 Unspecified hypertension

Definitions

The classification of *Hypertension* follows that of the Society of Obstetric Medicine of Australia and New Zealand[10] with the exceptions that unspecified subcategories have been included. The definitions are as follows:

Hypertension is diagnosed when the systolic blood pressure is ≥140 mm Hg and /or diastolic blood pressure (Korotkoff V) is ≥90 mm Hg. These blood pressures should be confirmed by repeated readings over several hours in a clinic or day assessment unit or after rest in hospital.

Gestational hypertension is defined as hypertension arising in pregnancy after 20 weeks gestation without any other feature of the multisystem disorder pre-eclampsia and which resolves within 3 months postpartum.

Pre-eclampsia may be defined as hypertension arising after 20 weeks gestation and the onset after 20 weeks gestation of one or more of: proteinuria, renal insufficiency, liver disease, neurological problems, haematological disturbances, fetal growth restriction. The hypertension will have returned to normal within 3 months postpartum.

Rules

This category includes deaths where the hypertensive disorder is considered the factor initiating the chain of events leading to the death. If placental abruption complicates a hypertensive disorder, the death is classified here, as the abruption is attributed to the hypertensive disorder. Specific placental pathology can be coded as associated conditions (see PSANZ-SB&ND Associated conditions list page 34)

This category excludes the circumstance when the hypertension is secondary to an underlying systemic disorder, e.g. Diabetes, where this is severe and uncontrolled (in which case, classify as subcategory 5.2 *Diabetes*, under *Maternal Conditions*). However, if the systemic disorder such as diabetes or gestational diabetes is mild or well controlled, and the death appeared to be due to hypertension or its complications, classify in this category. This category also includes hypertension secondary to renal disease as this often presents first with hypertension.

4 Antepartum haemorrhage (APH)

4.1 Placental abruption
4.2 Placenta praevia
4.3 Vasa praevia
4.9 APH of undetermined origin

Definitions

Placental abruption: The diagnosis of placental abruption is made clinically. Confirmation by evaluation of the placenta after delivery is not essential for assigning the death to abruption. Clinically features are classically with vaginal bleeding (although the bleeding may be concealed), abdominal pain, uterine contractions and tenderness[11].

Placenta praevia: Placenta praevia is defined as a placenta that lies wholly or partly within the lower uterine segment diagnosed on ultrasound[11]. With improved diagnosis and management stillbirth as a result of bleeding for placental praevia is now rare.

Vasa praevia: Vasa praevia is the presence of unsupported fetal vessels below the fetal presenting part, where the cord insertion is velamentous[11]. Classically, vaginal bleeding following amniotomy with subsequent fetal bradycardia suggests vasa praevia. The diagnosis of vasa praevia can be confirmed by Doppler and endovaginal ultrasound studies if aberrant vessels over the internal cervical are suspected[11].

APH of undetermined origin: This category is used where insufficient information is available on the reason for the bleeding. However, there is convincing clinical evidence that the stillbirth was as a result of the bleeding[11].

Rules

This category includes all perinatal deaths where the primary factor leading to the death was an APH.

Convincing clinical signs of abruption alone is sufficient to assign the category of 4.1 Abruption. If abruption occurs as a complication of a hypertensive disorder, the death is attributed to the hypertensive disorder (Category 3) with Category 4.1 Placental abruption as an associated condition. Other placental pathology thought to be contributory may also be classified under associated conditions Category 9.

Examples:

Classify here: A women presents at 38 weeks' gestation with abdominal pain, tense abdomen and uterine contractions and a fetal death diagnosed. Placental macroscopic examination showed a large adhesive clot however placental histopathology was inconclusive. Classify as 4.1 Placental abruption.

5 Maternal Conditions

5.1 Termination of pregnancy
- 5.1.1 Termination of pregnancy for maternal mental health indication
- 5.1.2 Termination of pregnancy for maternal circumstantial indication

5.2 Diabetes
- 5.21 Gestational diabetes
- 5.22 Pre-existing diabetes

5.3 Maternal injury
- 5.31 Accidental
- 5.32 Non-accidental

5.4 Maternal sepsis
- 5.41 Maternal sepsis due to Coronavirus
- 5.42 Maternal sepsis due to other organism

5.5 Antiphospholipid syndrome

5.6 Obstetric cholestasis

5.8 Other specified maternal conditions
- 5.81 Maternal suicide
- 5.82 Other specified maternal medical or surgical conditions
- 5.83 Maternal attempted suicide

Definitions and Rules

Category 5 includes perinatal deaths attributed to any medical or surgical condition in the mother, or to its complications or treatment, excluding conditions elsewhere classified i.e. APH, hypertension. Termination of pregnancy for psychosocial reasons have been subdivided into 5.11 termination of pregnancy for maternal mental health indication and 5.12 termination of pregnancy for circumstantial indication. We recognise that these reasons may co-exist and both codes may be selected. Discretion should be used when classifying the primary cause of death. The subcategory 5.1 excludes terminations of pregnancy undertaken for medical indication including congenital and other complications (e.g. prolonged preterm rupture of membranes (PPROM) with severe infection) where a pregnancy is terminated and the fetus is not expected to survive. In this scenario the death is classified under the specific condition including termination of pregnancy due to a congenital anomaly (classified under Congenital Anomaly, Category 1) and other conditions such as severe chorioamnionitis following preterm rupture of the membranes at 20 weeks (classify 10.1 Spontaneous preterm); adding the coding number “9” to identify termination as described under “General rules for applying the PSANZ PDC System” on pages 3- 4.

Renal disease is not included as a separate subcategory here, but under Hypertension, subcategory 3.2, as it usually presents first as hypertension. Maternal conditions should only be attributed here if there is a high probability that they were the cause of death, e.g. a well-documented history of lupus obstetric syndrome with a previous stillbirth. Maternal substance use or smoking may be classified as an associated condition if there is a significant history (including alcohol, cocaine, and marijuana) and where it is reasonable to assume that the fetal or neonatal death may be linked.

Maternal attempted suicide should be coded as 5.83. Intentional self-harm that is not attempted suicide should not be coded here. Intentional self-harm refers to the deliberate, direct destruction of the body that results in tissue damage. When this occurs, there may be a variety of intentions however the persons intention is NOT to kill themselves.

Examples:

Classify here: Fetal death as a result of severe uncontrolled Type I Diabetes with mild pre-eclampsia classify as subcategory 5.22 with an associated condition of Hypertension, Category 3.5.

Classify here: An unvaccinated woman in second pregnancy with pre-existing asthma contracted COVID-19 with significant deterioration while in the intensive care unit. Urgent caesarean section performed prior to commencing maternal extracorporeal membrane oxygenation (ECMO) at 23 weeks gestation. Infant not resuscitated. Classify as subcategory 5.41.

6 Complications of multiple pregnancy

6.1 Monochorionic twins
- 6.11 Twin to twin transfusion syndrome (TTTS)
- 6.12 Selective fetal growth restriction (FGR) (i.e. affecting only one twin)
- 6.13 Monoamniotic twins (including cord entanglement)
- 6.14 Twin anemia-polycythaemia sequence
- 6.15 Early fetal death in a multiple pregnancy (<20 weeks gestation)
- 6.18 Other
- 6.19 Unknown or unspecified

6.2 Dichorionic twins
- 6.21 Early fetal death in a multiple pregnancy (<20 weeks gestation)
- 6.22 Selective fetal growth restriction (FGR)
- 6.28 Other
- 6.29 Unknown or unspecified

6. 3 Complications of higher order multiples (3 or more fetuses)
- 6.31 Twin to twin transfusion syndrome (TTTS)
- 6.32 Selective fetal growth restriction (FGR)
- 6.33 Monoamniotic multiples (including cord entanglement)
- 6.34 Early fetal death in a multiple pregnancy (<20 weeks gestation)
- 6.38 Other
- 6.39 Unknown or unspecified

6.4 Complications where chorionicity is unknown

6.8 Other

6.9 Unspecified

Rules

For 6.12, 6.22 and 6.32 read Explanatory Notes under Associated Condition, Section 15, Fetal Growth Restriction.

Where one of the twins (or multiples) is growth restricted as a result of twin-to-twin transfusion syndrome, classify as 6.11, 6.31 and not 6.12 or 6.32 respectively. Where one or more of the twins (or multiples) is growth restricted from a known underlying cause, classify elsewhere as appropriate, e.g. classify under Category 9 if there is placental disease in one of dichorionic twins.

7 Specific perinatal conditions

7.1 Fetomaternal haemorrhage

7.2 Antepartum cord or fetal vessel complications (excludes monochorionic twins or higher order multiples)

- 7.21 Cord vessel haemorrhage
- 7.22 Cord occlusion (True knot with evidence of occlusion or other)
- 7.28 Other cord complications
- 7.29 Unspecified cord complications

7.3 Uterine abnormalities

- 7.31 Developmental anatomical abnormalities (e.g. bicornuate uterus)
- 7.38 Other
- 7.39 Unspecified

7.4 Alloimmune disease

- 7.41 Rhesus isoimmunisation (Rh haemolytic disease)
- 7.42 Other red cell antibody
- 7.43 Alloimmune thrombocytopenia
- 7.44 Gestational alloimmune liver disease (GALD)
- 7.48 Other
- 7.49 Unspecified

7.5 Fetal antenatal intracranial injury

- 7.51 Subdural haematoma
- 7.52 Fetal antenatal ischaemic brain injury
- 7.53 Fetal antenatal haemorrhagic brain injury

7.6 Other specific perinatal conditions

- 7.61 Complications of antenatal, diagnostic or therapeutic procedures:
  - 7.611 Complications of prenatal diagnostic procedures (e.g. amniocentesis, chorionic villus sampling,) (e.g. rupture of membranes after amniocentesis)
  - 7.612 Complications of fetal ultrasound guided needle interventions (e.g. FBS/fetal transfusion, thoracocentesis, vesicocentesis, fetal cardiac valvoplasty, division of amniotic bands, fetal skin biopsy, unipolar/bipolar diathermy, RFA procedures)
  - 7.613 Complications of fetal shunt interventions (e.g. pleuroamniotic shunt, vesicoamniotic shunt)
  - 7.614 Complications of minimally invasive fetoscopic interventions (e.g. fetoscopic laser surgery for TTTS, FETO for CDH, laser ablation of posterior urethral valves)
  - 7.615 Complications of open maternal fetal surgery (e.g. open maternal fetal surgery for spina bifida)
  - 7.618 Other
- 7.62 Termination of pregnancy for suspected but unconfirmed congenital anomaly
- 7.63 Amniotic band
- 7.68 Other

7. 9 Unspecified

Definitions

Category 7.22 Cord occlusion: A cord knot is where the cord becomes tangled with itself (or another cord in a multiple pregnancy) such that the vessels of the cord may be compromised. To be considered significant there should be evidence of congestion or haemorrhage in the cord, and/or changes in the placenta such as fetal vessel thrombosis or villous oedema to suggest vascular compromise. A knot could cause death without these changes but not every knot causes fetal compromise and therefore should not be accepted as a cause of death without further evidence as above, or strong clinical suspicion by the delivering clinician based on CTG or other changes during delivery. Cord accidents usually only account for a few percent of perinatal deaths.

Other cord compression: For stillbirths, and also neonatal deaths as a result of hypoxic ischaemic encephalopathy (HIE), where the cord is found to be tightly around neck or body with skin blanching (indicating significant cord compression) classify as 7.28.

Category 7.21 includes cord haemorrhage following cordocentesis, umbilical cord ulceration leading to cord haemorrhage, and torn velamentous vessels.

Rules

This category includes deaths in which the specific perinatal condition present was thought to be the cause of death. The category excludes perinatal deaths with a major congenital anomaly. Cord complications during labour and other complications of twins e.g. head entrapment in labour should be categorised under *Hypoxic Peripartum Death*, subcategory 8.18.

Examples:

Do not classify here: Spontaneous prelabour rupture of membranes (ROM) at 33 weeks, with immediate cord prolapse and fetal death. Categorise as Spontaneous Preterm Category 10 as the cord complication occurred as a result of the preterm ROM. Cord prolapse is classified as an associated condition.

8 Hypoxic peripartum death

8.1 With intrapartum complications (sentinel events)
- 8.11 Uterine rupture
- 8.12 Cord prolapse
- 8.13 Shoulder dystocia
- 8.14 Complications of breech presentation
- 8.15 Birth trauma
- 8.16 Intrapartum haemorrhage
- 8.18 Other

8.2 Evidence of significant fetal compromise (excluding other complications)

8.3 No intrapartum complications and no evidence of significant fetal compromise identified

8.9 Unspecified hypoxic peripartum death

Definitions and rules

This category includes both intrapartum fetal deaths and neonatal deaths as a result of acute or chronic hypoxia in babies without major congenital anomalies or other major conditions such as antepartum haemorrhage at a gestation in which survival in the context of the birth would be expected (typically of >28 weeks gestation or >1000g birthweight). If placental pathology is identified which resulted in fetal compromise and death then classify under the relevant category i.e. Category 9 Placental pathology or Category 4 Antepartum haemorrhage.

Where intrapartum fetal death or neonatal death occurs following preterm spontaneous onset of labour or rupture of membranes which fulfils the definition of Infection then classify under Category 2. If not fulfilling the criteria for infection and less than 24 weeks then classify under Category 10 *Spontaneous preterm.*

Neonatal deaths as a result of hypoxic ischaemic encephalopathy and otherwise unexplained severe cardiorespiratory depression at birth are included here. Where possible, evidence for intrapartum hypoxia should include fetal, umbilical artery or early neonatal (within one hour) blood gases showing evidence of a severe metabolic acidosis. Otherwise peripartum death might also be due to non-hypoxic causes, e.g. infection or chronic ischaemia but wrongly assumed to be due to acute hypoxia.

There may have been intrapartum complications (subcategory 8.1), or no intrapartum complications but with evidence of non-reassuring fetal status (subcategory 8.2), or no intrapartum complications or evidence of non-reassuring fetal status (subcategory 8.3). A specific major intrapartum complication, such as uterine rupture, cord prolapse or shoulder dystocia, is required for inclusion as subcategory 8.1. However, if there were no apparent intrapartum complications (as defined in category 8.1) but there was evidence of placental insufficiency antenatally, then the death should be attributed to Category 9. In this case Category 8 is captured as an associated condition.

If there is insufficient information about fetal wellbeing or intrapartum complications, classify as subcategory 8.9 *Unspecified hypoxic peripartum death.*

Evidence of non-reassuring fetal status is defined as abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intrapartum complications.

The term 'non-reassuring fetal status' has been used in preference to the term 'fetal distress' as 'clinical signs often poorly predict a compromised fetus and continued use of this latter term may encourage wrong assumptions or inappropriate management'[12,13].

Examples:

Classify here: No known problems prior to labour at gestation 38 weeks. Severe fetal heart rate decelerations in second stage of labour, without other major complication. Baby is born with no signs of life with a birthweight of 3500gm, placental histopathology did not identify any significant pathology and no autopsy was performed. Classify as subcategory 8.2.

Classify here: No known problems prior to labour at 36 weeks. No evidence of intrapartum fetal distress. At birth, the baby shows signs of severe respiratory depression and hypoxia. Subsequently develops encephalopathy and multiorgan failure and dies on Day 10 of life. Placental histopathology did not identify any significant pathology and no autopsy was performed. Classify as subcategory 8.3 and PSANZ NDC as 5.1.

Do not classify here: Spontaneous membrane rupture at 22 weeks' gestation, severe oligo hydramnios with positional deformities shown on ultrasound at 26 weeks. Labour and birth at 26 weeks gestation of a baby boy weighing 700gms and was not able to be resuscitated. Placental pathology showed acute chorioamnionitis (maternal inflammatory response) but no organisms identified on placental culture or baby blood cultures. Classify as 10.11 *Spontaneous preterm* and PSANZ NDC as Category 2.2 *Not resuscitated.*

Do not classify here: No complications during pregnancy. Spontaneous preterm labour and birth at 38 weeks gestation. Intrapartum fetal distress in second stage and delivered by forceps. Baby boy weighing 2200gms, Apgars 1 and 4, mechanically ventilated and admitted to NICU. Seizures commenced at 2 hrs and active management ceased at 24 hrs due to poor prognosis. Placental pathology showed fetal vascular malperfusion and mild chorioamnionitis (maternal inflammatory response); however, no organisms were identified on culture of the placental or baby. Classify as 9.2 *Placental dysfunction* and PSANZ NDC 5.1 *Hypoxic ischaemic encephalopathy/Perinatal asphyxia*.

9 Placental dysfunction or causative placental pathology

9.1 Maternal vascular malperfusion
9.2 Fetal vascular malperfusion
9.3 High grade villitis of unknown etiology (VUE)
9.4 Massive perivillous fibrin deposition/maternal floor infarction
9.5 Severe chronic intervillositis (Histiocytic intervillositis)
9.6 Placental hypoplasia (small-for gestation placenta)
9.7 No causal placental pathology demonstrated, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)
9.8 Placental pathological examination was not performed, with antenatal evidence of poor placental function was identified (such as abnormal fetal umbilical artery Doppler)
9.9 Other placental pathology (e.g. multiple pathologies with evidence of loss of placental function leading to death)

Definitions

This category is based on the Amsterdam Placental Workshop Group Consensus Statement[14].

Category 9.1 *Maternal vascular malperfusion (MVM).* Placental features considered to be indicative of MVM include both gross and microscopic findings. Gross findings include placental hypoplasia, infarction, and retroplacental haemorrhage.

Any infarction seen in a preterm placenta and, at term, anything more than 5% of non-peripheral infarction should be classified as a cause. Although marginal infarcts in a term placenta may have less meaning than in a preterm placenta, they should be classified as an associated condition. *Microscopic findings* include abnormalities of villous development, which can be separated into distal villous hypoplasia, and accelerated villous maturation (vide infra), and infarcts. It should be recognized that many of these histologic findings will coexist in some placentas.

Category 9.6 Placental hypoplasia is reflected by a placental weight that is low for the stated gestational age and context (weight <10th centile) and/or a thin cord (<10th centile or <8-mm diameter at term). When no other placental pathologies listed under 9.1-9.5, 9.7, 9.8 are identified, placental hypoplasia should be classified as the primary cause of death.

Category 9.7 and 9.8 includes stillbirths or neonatal deaths where clinical evidence of poor placental function sufficient to explain the death was identified however significant causal pathology of the placental was not demonstrated or placental histopathology was not performed. Clinical evidence of poor placental function is defined as evidence of placental disease either on antenatal ultrasound studies or biochemistry. This former can include evidence of reduced maternal (uterine artery) or fetal (umbilical artery, ductus venosus, middle cerebral artery Doppler) vascular perfusion on Doppler studies. The latter can include angiogenesis-related factors such as s-Flt-1/PIGF; further clinical evaluations may clarify which biochemical markers robustly identify placental dysfunction.

Category 9.9 includes multiple pathologies with evidence of loss of placental function leading to death. It excludes pathologies listed in 9.1 to 9.8. Where one or more pathologies listed under 9.1-9.8 are identified, a single pathology must be classified as the primary cause of death with the additional pathologies classified as associated conditions (see Category 16 page 34).

Rules

This category includes perinatal deaths where placental dysfunction is considered the underlying cause of the death. It excludes perinatal deaths as a result of an identified maternal or fetal condition where the death is classified according to the condition (e.g. Pre-Eclampsia, Pre-existing hypertension). It should exclude pathology which is not thought to be causal, and also amniotic fluid infection/acute chorioamnionitis. Placental pathology which is thought to be contributory rather than causal should be classified as an associated condition (See Associated conditions page 34).

It is acknowledged that multiple pathologies may exist. In these circumstances a dominate pathology needs to be identified and classified as the main cause and others as associated conditions. This category overrides deaths following intrapartum related events as defined in Category 8 Hypoxic peripartum deaths.

Examples:

Classify here: Normal pregnancy. Spontaneous preterm labour and birth at 40 weeks gestation. Non-reassuring fetal status in second stage ensued and birth was by emergency caesarean section. Baby boy weighing 2600gms, Apgars 2 and 4, mechanically ventilated and admitted to NICU with subsequent diagnoses of meconium aspiration and persistent pulmonary hypertension of the newborn. Despite intensive care the baby died at 12 hrs of age. Placental pathology showed massive perivillous fibrin deposition/maternal floor infarction and mild chorioamnionitis (maternal inflammatory response), no organisms were identified on placental culture or baby blood cultures. Classify as 9.4 *Massive perivillous fibrin deposition/maternal floor infarction* and PSANZ NDC 3.3 *Primary persistent pulmonary hypertension,* with an Associated condition of *Fetal growth restriction.*

Do not classify here: Normal pregnancy until maternal presentation at 40 weeks' gestation with decreased fetal movements and abdominal pain. Antepartum fetal death was diagnosed and spontaneous labour ensued shortly after. A baby girl was born, mildly macerated, weighing 3400gms. Placental pathology showed massive abruption. Maternal investigations were normal. No organisms were identified on placental culture or baby blood cultures. Classify as *APH Abruption* 4.1.

10 Spontaneous preterm labour or rupture of membranes (<37 weeks gestation)

10.1 Spontaneous preterm
- 10.11 With histological chorioamnionitis (maternal inflammatory response)
- 10.12 Without histological chorioamnionitis (maternal inflammatory response)
- 10.13 With clinical evidence of chorioamnionitis, no examination of placenta
- 10.17 No clinical signs of chorioamnionitis, no examination of placenta
- 10.19 Unspecified or not known whether placenta examined

10.2 Spontaneous preterm preceded by premature cervical shortening

Definitions

Clinical evidence of chorioamnionitis is defined as maternal fever (≥38^{o}C) associated with one or more of the following symptoms or signs: maternal or fetal tachycardia, uterine tenderness, malodorous amniotic fluid, and maternal leukocytosis or raised C-reactive protein[15-17].

The diagnosis of histological chorioamnionitis (maternal inflammatory response) should only be made when there is histological evidence of inflammation of infection of the placenta and membranes.

The subcategory of premature cervical shortening is reserved for those circumstances where the primary event appears to be cervical change based on clinical or ultrasound findings. This may occur as consequence of pre-existing damage to the cervix from a surgical procedure, due to a congenital structural cervical anomaly (with or without uterine anomaly) or clinically determined from previous obstetric history and/or clinical factors in the current pregnancy.

Rules

Deaths of normally formed, appropriately grown preterm babies following spontaneous onset of preterm labour or spontaneous rupture of membranes, irrespective of induction of labour or mode of delivery (e.g. elective caesarean section). There should be no evidence of fetal or neonatal infection (see Table 1 Determination of perinatal infection), otherwise classify under Category 2 *Perinatal Infection*. Careful examination of the placenta macroscopically and microscopically is recommended.

In cases where there is histological evidence of chorioamnionitis (maternal inflammatory response) with or without evidence of clinical chorioamnionitis, classify as subcategory 10.11. If an organism is identified, consider whether it meets the definition of infection under category 2. In cases of clinical chorioamnionitis where placental pathological examination was not performed or it is not known whether the placenta was examined, classify as subcategory 10.13.

Where cervical incompetence is followed by spontaneous preterm labour or ROM classify as 10.2 as opposed to 10.1. There may be some bleeding at the time of onset of labour, or earlier in pregnancy, but not in amounts to warrant the antecedent cause being attributed to *Antepartum Haemorrhage* Category 4. Early bleeding, which is often associated with preterm premature rupture of the membranes may be classified as an associated condition (see page 34).

Examples:

Classify here: Spontaneous labour at 26 weeks, no apparent explanation, and membranes intact. Vaginal delivery after 6 hours of membrane rupture, no evidence of intrapartum hypoxia or chorioamnionitis; subsequent early neonatal death from respiratory distress syndrome. Classify here as subcategory 10.12 *Spontaneous preterm with intact membranes, or membrane rupture, without chorioamnionitis (maternal inflammatory response) on placental histopathology* and NDC: Category 3.1

Classify here: Spontaneous onset of labour at 22 weeks thought to have been caused by COVID-19 infection. Baby weighing 390g was stillborn. Baby does not have COVID-19 by PCR assessment. Placental histopathology shows evidence of acute chorioamnionitis (maternal inflammatory response) but no evidence of placentitis or other histopathological evidence of COVID-19 infection. Classify here as subcategory 10.11 *Spontaneous preterm with histological acute chorioamnionitis (maternal inflammatory response)*.

Do not classify here: Spontaneous onset of labour at 28 weeks with intact membranes. No cause identified for preterm labour. Delivery following 24 hours of membrane rupture. Maternal intrapartum pyrexia. Acute chorioamnionitis (maternal inflammatory response) and vasculitis +/-funisitis (fetal inflammatory response) on placental histology, no organism identified. Classify as Category 2.9 *Perinatal Infection; other unspecified organism*.

Do not classify here: Alive at the onset of spontaneous labour at 31 weeks, no apparent explanation, and membranes intact. After 12 hrs, continuous intrapartum fetal monitoring showed deep decelerations and emergency caesarean section undertaken. Baby girl weighing 1700g was stillborn and could not be resuscitated. Placental pathology showed acute chorioamnionitis (maternal inflammatory response) (no funisitis [fetal inflammatory response]) no organisms were identified, and no other pathology was demonstrated. No autopsy was performed. Macroscopic examination of the baby was normal, no maceration. Classify as Category 8.2 *Hypoxic peripartum death; Evidence of significant fetal compromise (excluding other complications).*

11 Unexplained antepartum fetal death

11.1 Unexplained antepartum fetal death despite full investigation
11.2 Unclassifiable antepartum fetal death with incomplete investigation
11.3 Unclassifiable antepartum fetal death due to unknown level of investigation

Rules

This category applies to fetal death prior to the onset of labour where no cause for the death was identified. Antepartum fetal death with associated placental pathology (i.e. not thought to be causative) are coded as associated conditions.

Category 11.1 Unknown antepartum fetal death despite full investigation.

An antepartum fetal death where no cause of death was identified following (as a minimum): comprehensive maternal and pregnancy history; histopathology of the placenta and cord; full autopsy; karyotype/cytogenetics; and testing for Feto-Maternal Haemorrhage (Kleihauer or flow cytometry).

Category 11.2 is used where none or some of the above investigations were performed and Category 11.3 is used where it is unknown/unclear if these investigations were performed or the results were unavailable.

Whether or not each of the above tests were performed should be recorded to identify areas of practice improvements and future research. The minimum dataset for perinatal deaths as defined in the Australian Perinatal Mortality Audit Tool APMAT (*see Appendix E – Australian Perinatal Mortality Audit Tool*) and the New Zealand PMMRC audit form[18] (*Appendix F – Rapid reporting form for a perinatal death – baby* and *Appendix G – Rapid reporting form for a perinatal death - mother)* includes these data fields.

Examples:

Classify here: Intrauterine Fetal Death (IUFD) at 37 weeks, with no maternal conditions, no antepartum haemorrhage, with membranes intact, before onset of labour, where no cause of death was identified following full investigation (*comprehensive maternal and pregnancy history; histopathology of the placenta and cord; full autopsy; karyotype/cytogenetics; and Kleihauer*) Classify as Unexplained Antepartum Fetal Death, subcategory 11.1**.**

Intrauterine Fetal Death (IUFD) at 40 weeks, with no maternal conditions, no antepartum haemorrhage, with membranes intact, before onset of labour, where no cause of death was identified and perinatal death investigations were incomplete (e.g. *No karyotype/cytogenetics*) Classify as Unexplained Antepartum Fetal Death, subcategory 11.2**.**

Do not classify here: Spontaneous ROM at 27 weeks, no significant maternal conditions present, subsequent IUFD prior to onset of labour. No acute chorioamnionitis (maternal inflammatory response) on examination of the placenta. Classify as subcategory 10.12 *Spontaneous preterm labour or ROM (<37 weeks gestation); without histological acute chorioamnionitis (maternal inflammatory response)*.

12 Neonatal death without obstetric antecedent

12.1 Neonatal death with no obstetric antecedent factors despite full investigation
12.2 Neonatal death unclassifiable as to obstetric antecedent with incomplete investigation
12.3 Neonatal death unclassifiable as to obstetric antecedent due to unknown level of investigation

Rules

This category includes neonates where no obstetric antecedent factors (according to the PDC list) were identified as contributing to the death.

Category 12.1 applies to a neonatal death where not obstetric antecedent factor was identified following negative findings for the following (as a minimum): comprehensive maternal and pregnancy history and full autopsy.

Category 12.2 is used where the full autopsy was not performed and Category 11.3 where it is unknown if they were performed or the results were unavailable.

NB: Whether a PDC code is assigned or not, all neonates require a neonatal cause of death according to the PSANZ NDC to be assigned. The NDC provides information on the causes and associated conditions present in the neonatal period.

Examples:

Classify here: Baby boy born at term weighing 3.5kg was discharged home well on Day 2 of life. On day 27, the baby was found dead in his cot by the parents and following full investigation was classified as SIDS. Please refer to the NDC to classify the neonatal cause of death.

Classify here: Baby boy born at 38 weeks weighing 3kg was discharged home well. On day 10, the baby became unwell and died. Blood cultures and CSF were positive for Group B Streptococcus. Please refer to the NDC to classify the neonatal cause of death and classify as 4.1.

Do not classify here: Neonatal death on Day 7 of a 29-week baby girl with severe fetal growth restriction and reverse end diastolic flow delivered by emergency caesarean section who developed fulminating necrotising enterocolitis. Placental pathology showed high grade villitis of unknown etiology (VUE). Classify as Category 9.3 with the PSANZ Associated condition of *Fetal growth restriction* and NDC Category 6.1 *Necrotising enterocolitis.*

PSANZ-NDC Classification including rules and definitions

The Neonatal Death Classification has been developed for use in conjunction with the PSANZ Perinatal Death Classification in order to identify the underlying and associated neonatal conditions as well as the underlying and associated maternal conditions for neonatal deaths. For example, a mother who has an antepartum haemorrhage at 32 weeks gestation delivers a 1500g infant who thrives in the neonatal nursery but subsequently acquires a lethal nosocomial infection: the obstetric antecedent is antepartum haemorrhage, but neonatal death classification is subcategory 4.4 *Acquired Bacteria.* Both APH and neonatal nosocomial infection are important conditions on which to focus prevention strategies.

1 Congenital anomaly (please refer to PDC)

2 Periviable infants (typically <24 weeks)

2.1 Not resuscitated (including infants where there is an antenatal plan for no resuscitation at birth)
2.2 Unsuccessful resuscitation
2.9 Unspecified or not known whether resuscitation attempted

This group includes infants deemed too immature or too small for resuscitation or continued life support beyond the delivery room. Resuscitation in this context means the use of positive pressure ventilation.

3 Cardio-respiratory disorders

3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)
3.2 Meconium aspiration syndrome
3.3 Primary persistent pulmonary hypertension
3.4 Pulmonary hypoplasia
3.5 Pulmonary haemorrhage
3.6 Air leak syndromes
  3.61 Pneumothorax
  3.62 Pulmonary interstitial emphysema
  3.68 Other
3.7 Patent ductus arteriosus
3.8 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)
3.9 Other
  3.91 Neonatal anaemia/hypovolaemia

Definitions and Rules

Subcategory 3.1 *Hyaline membrane disease / Respiratory Distress Syndrome (RDS)* is used for deaths of infants who were receiving mechanical ventilation for acute RDS at the time of death or at the time of the complication such as pulmonary haemorrhage, sepsis, pneumothorax or necrotizing enterocolitis.

Neonates with resolving RDS, i.e. who are past the acute phase of the disease and are stable or improving, but who are still on low rate ventilation for immature lungs, extreme prematurity or apnoea, or who no longer require mechanical ventilation, and who developed a complication which led to the death should be classified according to that particular complication.

3.4 Pulmonary hypoplasia; this category includes pulmonary hypoplasia secondary to preterm prolonged rupture of the membranes. Congenital pulmonary airway malformation (CPAM), formerly known as congenital cystic adenomatoid malformation of the lung (CCAM) would be classified as 1.16. Congenital diaphragmatic hernia is classified as 1.151.

Categorisation as chronic neonatal lung disease (subcategory 3.5) should be reserved for infants with deteriorating lung function and major chest X-ray changes consistent with bronchopulmonary dysplasia.

Examples:

Classify here: A 26-week gestation infant with RDS receives mechanical ventilation (SIPPV R50, P20/5, Fi02 0.4), develops complications of pneumothorax requiring drainage, followed by a patent ductus arteriosus and dies on day 2 of life is classified as Category 3.1 with associated conditions classified as 3.61 *Pneumothorax* and 3.7 *Patent ductus arteriosus.*

Do not classify here: A 26-week gestation infant with RDS weaning off mechanical ventilator has a Grade IV Intraventricular Haemorrhage (IVH) with ventricular dilation on ultrasound on Day 5. She is successfully weaned to CPAP on Day 7 but requires re-ventilation for sepsis on Day 10 and on Day 21 has developing BPD and post hemorrhagic hydrocephalus (PHH) following which ventilation is withdrawn. Classification is dependent on the major reason for withdrawal of support. In this case 5.3 *Post haemorrhagic hydrocephalus* with an associated classification of 3.8 *Chronic neonatal lung disease and 4.49 Sepsis.*

4 Neonatal infection

4.1 Congenital/Perinatal bacterial infection (early onset<48 hrs)
- 4.11 Blood stream infection/septicaemia
  - 4.111 Positive culture +/- positive Polymerase Chain Reaction (PCR) testing of a pathogen
  - 4.112 Clinical signs of sepsis + ancillary evidence but culture +/- Polymerase Chain Reaction (PCR) negative
- 4.12 Bacterial meningitis
- 4.13 Bacterial pneumonia
- 4.15 Multiple site bacterial infection
- 4.18 Other congenital bacterial infection e.g. gastroenteritis, osteomyelitis, cerebral abscess
- 4.19 Unspecified congenital infection

4.2 Congenital/Perinatal viral infection

4.3 Congenital fungal, protozoan, parasitic infection

4.4 Acquired bacterial infection (late onset>48hrs)
- 4.41 Blood stream infection/septicaemia
  - 4.411 Positive culture +/- positive Polymerase Chain Reaction (PCR) testing of a pathogen
  - 4.412 Clinical signs of sepsis + ancillary evidence but culture +/- Polymerase Chain Reaction (PCR) testing negative
- 4.42 Bacterial meningitis
- 4.43 Bacterial pneumonia
- 4.48 Other acquired bacterial infection e.g. gastroenteritis, osteomyelitis
- 4.49 Unspecified acquired infection

4.5 Acquired viral infection

4.6 Acquired fungal, protozoan, parasitic infection

Rules

This category is intended to be used in conjunction with the PDC Category 2 *Perinatal Infection* to identify the organism causing the infection resulting in the death (including for an acquired infection). To take a pragmatic approach to storage of these data within the current system structure, in the case of a neonatal death from infection, the relevant NDC code can be stored as the primary neonatal condition and the PDC Category 2 code as an associated condition. In cases of late-onset sepsis where organism is not acquired from the mother, it is recommended that the organism is documented through an additional textbox.

Determination of congenital and acquired neonatal infection
A. Congenital Early onset infection (within 48 hours of birth), defined as: 1. Clinical signs in neonate consistent with sepsis and 2. Haematological changes consistent with sepsis and one or more of the following: 3a. Positive culture +/- positive PCR testing of a pathogen (bacterial or viral) from the neonate or 3b. Pathological evidence at autopsy or 3c. Positive serology or 3d. Positive culture +/- positive PCR testing of a pathogen from the mother or the placenta. Swap taken aseptically between amnion and chorion. or 3e. Pneumonia without specified bacterial or viral pathogens NB: Some congenital viral infections may have onset later than 48 hours after birth. B. Acquired/nosocomial Onset of infection at 48 hours or later, with criteria as above, but excluding 3d.

Table 4. Determination of infection

5 Neurological

5.1 Hypoxic ischaemic encephalopathy/Perinatal asphyxia
5.2 Cranial haemorrhage
- 5.21 Intraventricular haemorrhage
- 5.22 Subgaleal haemorrhage
- 5.23 Subarachnoid haemorrhage
- 5.24 Subdural haemorrhage
- 5.28 Other intracranial haemorrhage

5.3 Post haemorrhagic hydrocephalus
5.4 Periventricular leukomalacia
5.8 Other

Definitions and Rules:

Hypoxic ischaemic encephalopathy/Perinatal asphyxia:

Inclusion as hypoxic ischaemic encephalopathy or perinatal asphyxia usually requires a defining asphyxial event +/- evidence of severe non-reassuring fetal status and encephalopathy.

Examples of defining asphyxial events:

Massive antepartum haemorrhage from abruption (4.1), placenta praevia (4.2) or ruptured vasa praevia (4.3), breech presentation (8.14) or delivery with complications, e.g. cervical constriction ring or difficult delivery, feto-maternal haemorrhage (7.1), twin-twin transfusion (6.11).

Where possible, evidence for perinatal asphyxia should include fetal, umbilical artery or early neonatal blood gases (within one hour) showing evidence of a severe metabolic acidosis. Otherwise peripartum death might also be due to non-hypoxic causes, e.g. infection or chronic ischaemia but wrongly assumed to be due to acute hypoxia. In the absence of a defining asphyxial event every effort must be undertaken to exclude alternative diagnosis.

6 Gastrointestinal

6.1 Necrotising enterocolitis (NEC)
6.2 Short gut syndrome
6.3 Gastric or intestinal perforation (excluding NEC)
6.4 Gastrointestinal haemorrhage
6.8 Other

Definitions and Rules

When Short gut syndrome is a consequence of NEC or gastroschisis (1.152) then classify as Category 6.2 Short gut syndrome for the cause and other conditions as associated. Short gut syndrome Category 6.2 includes major intestinal infarction (such as midgut volvulus (1.14).

7 Other

7.1 Sudden unexpected death in infancy (SUDI)
- 7.11 Sudden Infant Death Syndrome (SIDS)
  - 7.112 SIDS Category IA: Classic features of SIDS present and completely documented
  - 7.113 SIDS Category IB: Classic features of SIDS present but incompletely documented
  - 7.114 SIDS Category II: Infant deaths that meet category I except for one or more features
- 7.12 Unclassified Sudden Infant Death in the neonatal period
  - 7.121 Bed sharing/unsafe sleep
  - 7.122 Not bed sharing
- 7.19 Unknown/Undetermined

7.2 Multisystem failure
- 7.21 Secondary to intrauterine growth restriction
- 7.22 Secondary to prematurity
- 7.28 Other specified
- 7.29 Unspecified/undetermined primary cause or trigger event

7.3 Trauma
- 7.31 Accidental
- 7.32 Non accidental
- 7.39 Unspecified

7.4 Treatment complications
- 7.41 Surgical
- 7.42 Medical

7.5 Unsuccessful resuscitation in infants of 28 weeks gestation or more without an obvious sentinel event

7.8 Other specified

Definitions

7.1 *SIDS* and 7.91 *Unclassified Sudden Infant Death* are defined according to the new SIDS classification system by Krous et al[19].

General Definition of SIDS

SIDS is defined as the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.

Category IA SIDS: Classic Features of SIDS Present and Completely Documented

Category IA includes infant deaths that meet the requirements of the general definition and also all of the following requirements.

Clinical:
- More than 21 days and <9 months of age;
- Normal clinical history, including term pregnancy (gestational age of $\geq$ 37 weeks);
- Normal growth and development.

- No similar deaths among siblings, close genetic relatives (uncles, aunts or first-degree cousins), or other infants in the custody of the same caregiver.

Circumstances of Death:

- Investigation of the various scenes where incidents leading to death might have occurred and it is determined that they do not provide an explanation for the death.
- Found in a safe sleeping environment, with no evidence of accidental death.

Autopsy:

- There is an absence of potentially fatal pathologic findings. Minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial haemorrhage is a supportive but not obligatory or diagnostic finding.
- There is no evidence of unexplained trauma, abuse, neglect, or unintentional injury.
- There is no evidence of substantial thymic stress effect (thymic weight of <15g and/or moderate/severe cortical lymphocyte depletion). Occasional "starry sky" macrophages or minor cortical depletion is acceptable.
- Results of toxicologic, microbiologic, radiologic, vitreous chemistry, and metabolic screening studies are negative.

Category IB SIDS: Classic Features of SIDS Present but Incompletely Documented

Category IB includes infant deaths that meet the requirements of the general definition and also meet all of the criteria for category IA except that investigation of the various scenes where incidents leading to death might have occurred was not performed and or ≥ 1 of the following analyses was not performed: toxicologic, microbiologic, radiologic, vitreous chemistry, or metabolic screening studies.

Category II SIDS

Category II includes infant deaths that meet category I criteria except for ≥ 1 of the following.

Clinical:

- Age range outside that of category 1A or 1B (i.e., 0-21 days or 270 days [9 months] through first birthday);
- Similar deaths among siblings, close relatives, or other infants in the custody of the same caregiver that are not considered suspect for infanticide or recognised genetic disorders;
- Neonatal or perinatal conditions (for example, those resulting from preterm birth) that have resolved by the time of death.

Circumstances of Death:

- Mechanical asphyxia or suffocation caused by overlaying not determined with certainty.

Autopsy:

- Abnormal growth and development not thought to have contributed to death;
- Marked inflammatory changes or abnormalities not sufficient to be unequivocal causes of death.

Unclassified Sudden Infant Death

The unclassified category includes deaths that do not meet the criteria for category I or II SIDS but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases for which autopsies were not performed.

Post-resuscitation cases

Infants found in extremis who are resuscitated and later die ("temporarily interrupted SIDS") may be included in the aforementioned categories, depending on the fulfilment of relevant criteria.

Rules

Subcategory 7.92 *Other Unknown/Undetermined* has been included to identify unknown causes of death which do not fulfil the criteria of Category 7.91. Subcategory 7.4 *Other accident, poisoning or violence (postnatal)* excludes cases of antepartum deaths which should be classified in Category 5 *Maternal Conditions* under subcategory 5.3 *Maternal injury.* Subcategory 7.8 *Other specified* is used to classify other identified conditions which are not included in subcategories 7.1 to 7.4.

PSANZ Associated Conditions

Following classification of the underlying cause of death according to the PSANZ-PDC for stillbirths and neonatal deaths, and in addition a PSANZ NDC for neonatal deaths, associated conditions thought to be contributory (but not causal) to the death should be classified. The associated condtions list includes the PSANZ-PDC categories and, in addition for neonatal deaths, the PSANZ-NDC categories and other conditions which may be contributory to stillbirth and neonatal deaths as listed below in Categories 13-16.

Associated conditions for both stillbirths and neonatal deaths

Categories 1 -11 PSANZ PDC Plus the following additional categories:

13 Genetic testing results not diagnostic

13.1 Copy number variant of unknown or uncertain significance
13.2 No mutation identified matching phenotype
13.3 Tested for genetic mutations but failed
13.4 Not tested or not known if tested for genetic mutations

Explanatory/clarifying notes:

Where a pathogenic or a likely pathogenic mutation has been identified, this would have been classified under Category 1.2 Chromosomal anomaly as stated in the Definitions and Rules section of Category 1 Congenital anomaly. 1.31 and 1.34 are self-explanatory. 13.3 tested for genetic mutations but failed, refer to those tests that may have failed due to culture failure (with conventional cytogenetics) or poor DNA (with molecular techniques)

14 Associated placental pathology

14.1 Delayed villous maturation
14.2 Large chorioangioma
14.3 Early bleeding often leading to preterm prelabour ROM
14.8 Other associated placental pathology

Explanatory/clarifying notes:

Early bleeding is defined as bleeding in the second trimester (often on one or more occasions) which does not immediately lead to spontaneous birth or rupture of membranes.

15 Associated cord pathology

15.1 True knot (excluding histological evidence of causation)
15.2 Hypercoiled cord
15.3 Tethered cord
15.4 Velamentous insertion
15.5 Marginal cord insertion
15.8 Other associated cord pathology

16 Fetal Growth Restriction (FGR)

16.1 Autopsy evidence (brain:liver ratio equal to or greater than 4:1)
16.2 Antenatal ultrasound evidence of FGR
16.3 Clinical examination of the baby (by paediatrician, pathologist)
16.4 Birthweight (less than 10th centile for gestational age)
16.41 Customised centiles[20]
16.42 Population centiles[21,22]

Explanatory/clarifying notes:

Fetal growth restriction is defined as:

1. A brain:liver ratio equal to or greater than 4:1 at autopsy
   AND/OR
1. Where antenatal ultrasound assessment has shown evidence of FGR (e.g. reduced growth velocity on serial biometry and/or abnormal utero-placental blood flow on Doppler ultrasound and reduced amniotic fluid volume)
   AND/OR
2. Clinical examination of the baby (by paediatrician, pathologist)
   AND/OR
3. Birthweight <10th centile for gestational age for livebirths or non-macerated stillbirths

Classifying FGR in stillbirths

It is also recommended that for fetal deaths, where possible, the gestational age on the date of death and not date of birth be used to define the presence of FGR.

For macerated stillbirths, in the absence of prior ultrasound evidence of FGR and where no autopsy has been performed or the brain:liver ratio is less than 4:1, the death should be classified as Unexplained Antepartum Death (Category 11), as the weight discrepancy may be a post mortem effect.

Customised or non-customised centiles

Either customised or non-customised centiles charts can be used to classify FGR as an associated condition under 16.2.1 or 16.2.2 respectively. Customised birthweight (CBW) centiles are being increasingly used to determine the presence of FGR[20]. However controversy around the use of customised centiles continues[23,24] including concerns that customisation may mask pathology[23,25]. It is recommended that the variables required for calculation of CBW (maternal age, ethnicity, height, weight, and fetal gestation and gender) be routinely collected to enable evaluation of birthweight according to CBW centiles. The recommended Australia population standards are those published by Dobbins et al[21] and for preterm birth by Fenton et al[22].

17 Maternal risk factors (optional category)

17.1 Smoking
17.1.1 Cigarette
17.1.2 Vape
17.2 Substance use (including alcohol)
17.3 BMI ≥ 30
17.4 Maternal mental health disorder
17.5 Socioeconomic deprivation
17.6 Refugee or asylum seeker

17.7 Minimal or no antenatal care

Explanatory/clarifying notes:

Ideally risk factors would be included as part of a minimum dataset for all livebirths and stillbirths to enable ongoing assessment of the contribution of these factors to perinatal deaths. Further, inclusion of the PSANZ classification in this dataset for each perinatal death will provide a rich source of information for understanding causal pathways for maternal risk factors. In order to improve our understanding of maternal risk factors, they should always be coded as an associated condition when present, irrespective of whether the condition is thought to have contributed to the death.

Body mass Index (BMI) calculation should be based on the women's weight measured at their booking visit. Code 17.3 should be used in cases where the woman's booking BMI is ≥ 30.

Associated conditions for neonatal deaths only

NDC Categories 1- 6, Sub-categories 7.2-7.8

In addition to the above for associated maternal/fetal conditions the NDC Categories 1- 6 and sub-categories 7.2-7.8 can be used to assign associated neonatal conditions. Sub-categories 7.1 cannot be used as an associated neonatal condition.

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PSANZ Classification System – QUICK REFERENCE SHEET Version 5.0

The current version for use is version 4. Version 5 is intended for use across Australia and Aotearoa New Zealand for perinatal deaths occurring for births from 1 January 2025.

PSANZ-PDC

1 Congenital Anomaly
- 1.1 Structural anomaly
  - 1.11 Nervous system
  - 1.12 Cardiovascular system
  - 1.13 Genitourinary system
  - 1.14 Gastrointestinal system
  - 1.15 Musculoskeletal
    - 1.151 Congenital diaphragmatic hernia
    - 1.152 Gastroschisis/omphalocele
    - 1.158 Other
  - 1.16 Respiratory system (include congenital pulmonary airway malformation (CPAM))
  - 1.17 Haematological
  - 1.18 Multiple Congenital anomaly (no chromosomal/genetic cause or not tested)
  - 1.19 Other congenital abnormality
    - 1.192 Idiopathic hydrops fetalis
    - 1.193 Fetal tumour (include sacro-coccygeal teratoma)
    - 1.194 Craniofacial abnormality
    - 1.198 Other specified
    - 1.199 Congenital anomaly, unspecified
- 1.2 Chromosomal anomaly
  - 1.21 Down syndrome (trisomy 21)
  - 1.22 Edward syndrome and Patau syndrome (trisomy 18, trisomy 13)
  - 1.23 Other trisomies and partial trisomies of the autosomes, not elsewhere classified (includes pathogenic duplications, unbalanced translocations and insertions)
  - 1.24 Monosomies and deletions from the autosomes, not elsewhere classified (includes pathogenic deletions e.g. 22q11.2 deletion syndrome (diGeorge syndrome), Wolff-Hirschorn syndrome, Cri-du-chat syndrome
  - 1.25 Turner syndrome (monosomy X)
  - 1.26 Other sex chromosome abnormalities (e.g. Klinefelter syndrome)
  - 1.28 Other chromosomal abnormalities, not elsewhere specified (includes Fragile X syndrome, imprinting syndromes, triploidy)
  - 1.29 Unspecified
- 1.3 Genetic anomaly
  - 1.31 Genetic condition, specified (e.g. Tay-Sachs disease; includes inborn errors of metabolism)
  - 1.32 Syndrome/association with demonstrated chromosomal/gene anomaly.
  - 1.39 Genetic condition, unspecified

2 Perinatal Infection
- 2.1 Bacterial
  - 2.11 Group B Streptococcus
  - 2.12 E coli
  - 2.13 Listeria monocytogenes
  - 2.14 Spirochaetal e.g. Syphilis
  - 2.18 Other bacterial
  - 2.19 Unspecified bacterial
- 2.2 Viral
  - 2.21 Cytomegalovirus
  - 2.22 Parvovirus
  - 2.23 Herpes simplex virus
  - 2.24 Rubella virus
  - 2.25 Zika virus
  - 2.26 Coronavirus
  - 2.28 Other viral
  - 2.29 Unspecified viral
- 2.3 Protozoal e.g. Toxoplasma
- 2.5 Fungal
- 2.8 Other specified organism
- 2.9 Other unspecified organism

3 Hypertension
- 3.1 Chronic hypertension: essential
- 3.2 Chronic hypertension: secondary, e.g. renal disease
- 3.3 Chronic hypertension: unspecified
- 3.4 Gestational hypertension
- 3.5 Pre-eclampsia
- 3.6 Pre-eclampsia superimposed on chronic hypertension
- 3.9 Unspecified hypertension

4 Antepartum Haemorrhage (APH)
- 4.1 Placental abruption
- 4.2 Placenta praevia
- 4.3 Vasa praevia
- 4.9 APH of undetermined origin

5 Maternal Conditions
- 5.1 Termination of pregnancy
  - 5.11 Termination of pregnancy for maternal mental health indication
  - 5.12 Termination of pregnancy for maternal circumstantial indication
- 5.2 Diabetes
  - 5.21 Gestational diabetes
  - 5.22 Pre-existing diabetes
- 5.3 Maternal injury
  - 5.31 Accidental
  - 5.32 Non-accidental
- 5.4 Maternal sepsis
  - 5.41 Coronavirus
  - 5.42 Maternal sepsis due to other organism
- 5.5 Antiphospholipid syndrome
- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions
  - 5.81 Maternal suicide
  - 5.82 Other specified maternal medical or surgical conditions
  - 5.83 Maternal attempted suicide

6 Complications of multiple pregnancy
- 6.1 Monochorionic twins
  - 6.11 Twin to twin transfusion syndrome (TTTS)
  - 6.12 Selective fetal growth restriction (FGR) (i.e. affecting only one twin)
  - 6.13 Monoamniotic twins (including cord entanglement)
  - 6.14 Twin anemia-polycythaemia sequence
  - 6.15 Early fetal death in a multiple pregnancy (<20 weeks gestation)
  - 6.18 Other
  - 6.19 Unknown or unspecified
- 6.2 Dichorionic twins
  - 6.21 Early fetal death in a multiple pregnancy (<20 weeks gestation)
  - 6.22 Selective fetal growth restriction (FGR)
  - 6.28 Other
  - 6.29 Unknown or unspecified
- 6. 3 Complications of higher order multiples (3 or more fetuses)
  - 6.31 Twin to twin transfusion syndrome (TTTS)
  - 6.32 Selective fetal growth restriction (FGR)
  - 6.33 Monoamniotic multiples (including cord entanglement)
  - 6.34 Early fetal death in a multiple pregnancy (<20 weeks gestation)
  - 6.38 Other
  - 6.39 Unknown or unspecified
- 6.4 Complications where chorionicity is unknown
- 6.8 Other
- 6.9 Unspecified

7 Specific perinatal conditions
- 7.1 Fetomaternal haemorrhage
- 7.2 Antepartum cord or fetal vessel complications (excludes monochorionic twins or higher order multiples)
  - 7.21 Cord vessel haemorrhage
  - 7.22 Cord occlusion (True knot with evidence of occlusion or other)
  - 7.28 Other cord complications
  - 7.29 Unspecified cord complications
- 7.3 Uterine abnormalities
  - 7.31 Developmental anatomical abnormalities (e.g. bicornuate uterus)
  - 7.38 Other
  - 7.39 Unspecified
- 7.4 Alloimmune disease
  - 7.41 Rhesus isoimmunisation (Rh haemolytic disease)
  - 7.42 Other red cell antibody
  - 7.43 Alloimmune thrombocytopenia
  - 7.44 Gestational alloimmune liver disease (GALD)
  - 7.48 Other
  - 7.49 Unspecified
- 7.5 Fetal antenatal intracranial injury
  - 7.51 Subdural haematoma
  - 7.52 Fetal antenatal ischaemic brain injury
  - 7.53 Fetal antenatal haemorrhagic brain injury
- 7.6 Other specific perinatal conditions
  - 7.61 Complications of antenatal, diagnostic or therapeutic procedures:
    - 7.611 Complications of prenatal diagnostic procedures (e.g. amniocentesis, chorionic villus sampling,) (e.g. rupture of membranes after amniocentesis)
    - 7.612 Complications of fetal ultrasound guided needle interventions (e.g. FBS/fetal transfusion, thoracocentesis, vesicocentesis, fetal cardiac valvoplasty, division of amniotic bands, fetal skin biopsy, unipolar/bipolar diathermy, RFA procedures)
    - 7.613 Complications of fetal shunt interventions (e.g. pleuroamniotic shunt, vesicoamniotic shunt)
    - 7.614 Complications of minimally invasive fetoscopic interventions (e.g. fetoscopic laser surgery for TTTS, FETO for CDH, laser ablation of posterior urethral valves)
    - 7.615 Complications of open maternal fetal surgery (e.g. open maternal fetal surgery for spina bifida)
    - 7.618 Other
  - 7.62 Termination of pregnancy for suspected but unconfirmed congenital anomaly.
  - 7.63 Amniotic band
  - 7.68 Other
- 7. 9 Unspecified

8 Hypoxic peripartum death
- 8.1 With intrapartum complications (sentinel events)
  - 8.11 Uterine rupture
  - 8.12 Cord prolapse
  - 8.13 Shoulder dystocia
  - 8.14 Complications of breech presentation
  - 8.15 Birth trauma
  - 8.16 Intrapartum haemorrhage
  - 8.18 Other
- 8.2 Evidence of significant fetal compromise (excluding other complications)
- 8.3 No intrapartum complications recognised and no evidence of significant fetal compromise identified
- 8.9 Unspecified hypoxic peripartum death

9 Placental dysfunction or causative placental pathology
- 9.1 Maternal vascular malperfusion
- 9.2 Fetal vascular malperfusion
- 9.3 High grade villitis of unknown etiology (VUE)
- 9.4 Massive perivillous fibrin deposition/maternal floor infarction
- 9.5 Severe chronic intervillositis (Histiocytic intervillositis)
- 9.6 Placental hypoplasia (small-for gestation placenta)
- 9.7 No causal placental pathology demonstrated, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)
- 9.8 Placental pathological examination was not performed, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)
- 9.9 Other placental pathology (e.g. multiple pathologies with evidence of loss of placental function leading to death)

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10 Spontaneous preterm labour or rupture of membranes (<37 weeks gestation)
10.1 Spontaneous preterm
10.11 With histological chorioamnionitis (maternal inflammatory response)
10.12 Without histological chorioamnionitis (maternal inflammatory response)
10.13 With clinical evidence of chorioamnionitis, no examination of placenta
10.17 No clinical signs of chorioamnionitis, no examination of placenta
10.19 Unspecified or not known whether placenta examined
10.2 Spontaneous preterm preceded by premature cervical shortening

11 Unexplained antepartum fetal death
11.1 Unexplained antepartum fetal death despite full investigation
11.2 Unclassifiable antepartum fetal death with incomplete investigation
11.3 Unclassifiable antepartum fetal death due to unknown level of investigation

12 Neonatal death without obstetric antecedent
12.1 Neonatal death with no obstetric antecedent factors despite full investigation
12.2 Neonatal death unclassifiable as to obstetric antecedent with incomplete investigation
12.3 Neonatal death unclassifiable as to obstetric antecedent due to unknown level of investigation

PSANZ-NDC

1 Congenital Anomaly (Please refer to PSANZ PDC)

2 Periviable infants (typically <24 weeks)
2.1 Not resuscitated (including infants where there is an antenatal plan for no resuscitation at birth)
2.2 Unsuccessful resuscitation
2.9 Unspecified or not known whether resuscitation attempted

3 Cardio-respiratory disorders
3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)
3.2 Meconium aspiration syndrome
3.3 Primary persistent pulmonary hypertension
3.4 Pulmonary hypoplasia
3.5 Pulmonary haemorrhage
3.6 Air leak syndromes
3.61 Pneumothorax
3.62 Pulmonary interstitial emphysema
3.68 Other
3.7 Patent ductus arteriosus
3.8 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)
3.9 Other
3.91 Neonatal anaemia/hypovolaemia

4 Neonatal infection
4.1 Congenital/Perinatal bacterial infection (early onset<48 hrs)
4.11 Blood stream infection/septicaemia
4.111 Positive culture +/- positive Polymerase Chain Reaction (PCR) testing of a pathogen
4.112 Clinical signs of sepsis + ancillary evidence but culture +/- Polymerase Chain Reaction (PCR) negative
4.12 Bacterial meningitis
4.13 Bacterial pneumonia
4.15 Multiple site bacterial infection
4.18 Other congenital bacterial infection e.g. gastroenteritis, osteomyelitis, cerebral abscess
4.19 Unspecified congenital infection
4.2 Congenital/Perinatal viral infection
4.3 Congenital fungal, protozoan, parasitic infection
4.4 Acquired bacterial infection (late onset>48hrs).
4.41 Blood stream infection/septicaemia
4.411 Positive culture +/- positive Polymerase Chain Reaction (PCR) testing of a pathogen
4.412 Clinical signs of sepsis + ancillary evidence but culture +/- Polymerase Chain Reaction (PCR) negative
4.42 Bacterial meningitis
4.43 Bacterial pneumonia
4.48 Other acquired bacterial infection e.g. gastroenteritis, osteomyelitis
4.49 Unspecified acquired infection
4.5 Acquired viral infection
4.6 Acquired fungal, protozoan, parasitic infection

5 Neurological
5.1 Hypoxic ischaemic encephalopathy/Perinatal asphyxia
5.2 Cranial haemorrhage
5.21 Intraventricular Haemorrhage
5.22 Subgaleal Haemorrhage
5.23 Subarachnoid Haemorrhage
5.24 Subdural Haemorrhage
5.28 Other intracranial haemorrhage
5.3 Post haemorrhagic hydrocephalus
5.4 Periventricular leukomalacia
5.8 Other

6 Gastrointestinal
6.1 Necrotising enterocolitis (NEC)
6.2 Short gut syndrome
6.3 Gastric or intestinal perforation (excluding NEC)
6.4 Gastrointestinal haemorrhage
6.8 Other

7 Other
7.1 Sudden unexpected death in infancy (SUDI)
7.11 Sudden Infant Death Syndrome (SIDS)
7.112 SIDS Category IA: Classic features of SIDS present and completely documented.
7.113 SIDS Category IB: Classic features of SIDS present but incompletely documented.
7.114 SIDS Category II: Infant deaths that meet category I except for one or more features.
7.12 Unclassified Sudden Infant Death in the neonatal period
7.121 Bed sharing
7.122 Not bed sharing
7.19 Unknown/Undetermined
7.2 Multisystem failure
7.21 Secondary to intrauterine growth restriction
7.22 Secondary to prematurity
7.28 Other specified
7.29 Unspecified/undetermined primary cause or trigger event
7.3 Trauma
7.31 Accidental
7.32 Non accidental
7.39 Unspecified
7.4 Treatment complications
7.41 Surgical
7.42 Medical
7.5 Unsuccessful resuscitation in infants of 28 weeks gestation or more without an obvious sentinel event
7.8 Other specified

PSANZ ASSOCIATED CONDITIONS

Associated conditions for both stillbirths and neonatal deaths

Categories 1 -11 PSANZ PDC

13 Genetic testing results not diagnostic
13.1 Copy number variant of unknown or uncertain significance
13.2 No mutation identified matching phenotype
13.3 Tested for genetic mutations but failed
13.4 Not tested or not known if tested for genetic mutations

14 Associated placental pathology
14.1 Delayed villous maturation
14.2 Large chorioangioma
14.3 Early bleeding often leading to preterm prelabour ROM
14.8 Other associated placental pathology

15 Associated cord pathology
15.1 True knot (excluding histological evidence of causation)
15.2 Hypercoiled cord
15.3 Tethered cord
15.4 Velamentous insertion
15.5 Marginal cord insertion
15.8 Other associated cord pathology

16 Fetal Growth Restriction
16.1 Autopsy evidence (brain:liver ratio equal to or greater than 4:1)
16.2 Antenatal ultrasound evidence of FGR
16.3 Clinical examination of the baby (by paediatrician, pathologist)
16.4 Birthweight (less than 10th centile for gestational age)
16.41 Customised centiles
16.42 Population centiles

17 Maternal risk factors (optional category)
17.1 Smoking
17.1.1 Cigarette
17.1.2 Vape
17.2 Substance use (including alcohol)
17.3 BMI ≥30
17.4 Maternal mental health disorder
17.5 Socioeconomic deprivation
17.6 Refugee or asylum seeker
17.7 Minimal or no antenatal care

Associated conditions for neonatal deaths only

NDC Categories 1- 6, Sub-categories 7.2-7.8
In addition to the above for associated maternal/fetal conditions the NDC Categories 1- 6 and sub-categories 7.2-7.8 can be used to assign associated neonatal conditions.
Sub-category 7.1 cannot be used as an associated neonatal condition.

Definitions of Australian state and territory and Aotearoa New Zealand reports on rates and causes of stillbirths and neonatal deaths

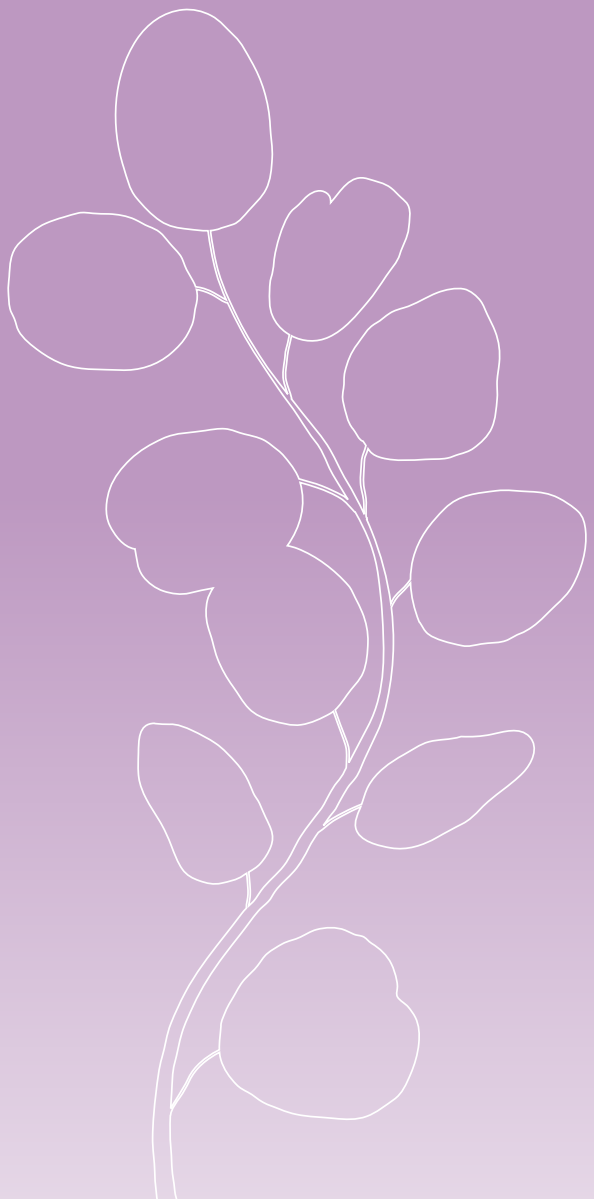
		NEW SOUTH WALES	VICTORIA	QUEENSLAND	WESTERN AUSTRALIA	SOUTH AUSTRALIA	NORTHERN TERRITORY	TASMANIA	AUSTRALIAN CAPITAL TERRITORY	AOTEAROA NEW ZEALAND
	Date of most recent publication (year)	2022	2022	2021	2022	2023	2023	2022	2018	2022
	Most recent time period of deaths included in report	2020	2020	2019	2018	2020	2020	2020	2015	2020
PERINATAL DEATH RATES	**Stillbirth definition reported**	The complete expulsion or extraction from its mother of a product of conception of at least 20 weeks gestation or 400 grams birthweight who did not, at any time after birth, breathe, or show any evidence of life such as a heartbeat.	The birth of an infant of at least 20 weeks' gestation or, if gestation is unknown, weighing at least 400 grams, who shows no signs of life at birth. Supplementary tables also report stillbirth rates using the criteria of birth weight ≥ 500g or, if birth weight unknown, gestation ≥ 22 weeks.	A baby who has shown no sign of respiration or heartbeat, or other sign of life after completely leaving the child's mother and who has been gestated for 20 weeks or more or weighs 400g or more.	The complete expulsion or extraction from its mother of an infant weighing at least 400 grams birthweight or at least 20 weeks gestation, which shows no sign of life from the time of birth	Birth of a fetus at or after 20 weeks gestation or with a birthweight of 400g or more, with no signs of life at birth. Also report stillbirth rates using the criteria: birth weight ≥ 500g and/or born at ≥ 22 weeks gestation, and the criteria of birth weight ≥ 1000g and/or born at ≥ 28	A child of at least 20 weeks gestation or with a birthweight of at least 400 grams at birth that exhibits no sign of respiration or heartbeat, or other sign of life, at birth (fetal death).	A fetal death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or 400 grams or more birthweight. The death is indicated by the fact that after such other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.	Refers to death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400g or more of birthweight; the death is indicated by the fact that after separation the fetus does not breathe or pulsation of the umbilical cord, or definite movement of voluntary muscles (WHO definition). Note: Births that occur after 20 weeks gestation where death has occurred prior to 20 weeks gestation been included in this report.	Fetal death is the death of a fetus at 20 weeks gestation or beyond (≥20 weeks) or weighing at least 400g if gestation is unknown. Fetal death includes stillbirth and termination of pregnancy.
	Neonatal death definition reported	The death of a liveborn baby within the first 28 days of life	Death of a liveborn infant less than 28 days after birth. For reporting purposes, live births less than 20 weeks' gestation, or if gestation is unknown, weighing less than 400 g,	Deaths of live-born babies of any weight or gestation within the first 28 days of life.	The death of a live born infant within 28 days of birth. The report excludes births less than 20 weeks gestation and less than 400g birthweight.	Death of a live born infant within 27 days of birth, where the day of birth is day zero. The report excludes births less than 20 weeks gestation and less than 400g birthweight.	Death of a live-born baby within 28 days of birth. The report excludes births less than 20 weeks gestation.	A death occurring within 28 days of birth in an infant born of at least 20 weeks gestation, or birthweight at least 400 g.	The death of an infant within 28 days of birth. The report excludes births less than 20 weeks gestation.	The death of any baby showing signs of life at 20 weeks gestation or beyond, or weighing at least 400g if gestation is unknown, that occurs up until midnight of the 27th day of life.
	Rates of stillbirth and neonatal death reported	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

		NEW SOUTH WALES	VICTORIA	QUEENSLAND	WESTERN AUSTRALIA	SOUTH AUSTRALIA	NORTHERN TERRITORY	TASMANIA	AUSTRALIAN CAPITAL TERRITORY	AOTEAROA NEW ZEALAND
	Rates of stillbirth and neonatal death reported	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Rates of perinatal deaths reported with or without terminations of pregnancies included	Reported rates include TOPs.	Rates excluding TOPs for maternal psychosocial indication are reported. Rates including TOPs are reported in supplementary tables.	Rates including and excluding TOPs are reported.	Reported rates include TOPs.	Rates including and excluding TOPs are reported.	Reported rates include TOPs.	Reported rates include TOPs.	Rates including and excluding TOPs are reported.	Rates including and excluding TOPs are reported.
	Identifies rates of perinatal deaths by SEIFA, or Indigenous, or other ethnic backgrounds	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
	Reports on risk factors for perinatal deaths	No	Yes (smoking status only)	Yes	Yes	No	No	No	Yes (mothers age and smoking status)	Yes (maternal age, parity and socioeconomic deprivation/maternal residence)
CAUSE OF DEATH (COD)	**COD reported using the PSANZ Classification system**	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
	COD reported for stillbirths and neonatal deaths	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
	COD reported with or without termination of pregnancies	COD reported for all perinatal deaths, including TOPs.	COD reporting excludes TOPs for psychosocial situation.	COD reported for all perinatal deaths, including TOPs.	COD reported for all perinatal deaths, including TOPs. COD also reported for selected perinatal deaths ≥ 23 weeks, excluding TOPs.	COD reported for all perinatal deaths, including TOPs.	No	COD reported for all perinatal deaths, including TOPs.	COD reported for all perinatal deaths, including TOPs.	COD reported with and without TOPs
	Reports on rates of investigations	No	Autopsy and placental pathology rates reported	Autopsy rates reported	Autopsy rates reported	Autopsy and placental pathology rates reported	No	Autopsy rates reported	Autopsy rates reported	No
CONTRIBUTING FACTORS RELATING TO CARE	**Identifies contributing factors relating to care (substandard care)**	No	Yes	Yes	Yes	No	No	Unclear	No	No
	Approach to identifying contributing factors	N/A	Perinatal deaths, excluding TOP for maternal psychosocial indication or congenital anomaly, were reviewed at the jurisdictional level using the APMCAT.	Selected perinatal deaths occurring after 34 weeks gestation, excluding congenital anomalies, were reviewed at the jurisdictional level using the APMCAT.	Selected perinatal deaths occurring ≥23 weeks gestation, excluding TOPs, were reviewed at the jurisdictional level. System used to identify contributing factors is unclear.	N/A	N/A	Unclear	N/A	N/A

2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline



Section 8: Organisational recommendations

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

Background

Maternal and newborn services need to create the conditions and formal structures to support and enable healthcare professionals to provide high quality care around stillbirth and neonatal death.[1] Studies identify education, training, resources, and support as critical enablers for best practice care,[2-4] including development and implementation of local protocols and policies consistent with current evidence.

Working in perinatal loss care and supporting parents and families/whānau following a baby's death can be intense and complex. At every stage, the actions of healthcare professionals and their timing are critical to high quality care.[5] Healthcare professionals have a major role in supporting parents to make decisions that minimise regret and avoid missed opportunities.[6,7] Recognising and finding ways to manage the impact of perinatal death on healthcare professionals is also essential for the optimal care of parents and wellbeing of healthcare professionals.

Many countries have principles and recommendations to guide best practice care around stillbirth and neonatal death. In Australia, in addition to the Stillbirth CRE/PSANZ Guidelines,[8] there are the Stillbirth Clinical Care Standard of the Australian Commission on Safety and Quality in Health Care[9] and the Sands Australian Principles of Bereavement Care (Miscarriage, Stillbirth and Neonatal Death).[10] Peak professional bodies in the USA,[11] the UK,[12] and Canada[13] have developed guidelines for care after stillbirth. In the UK, a National Bereavement Care Pathway[14] provides standards for best practice care. Common to all guidelines is the need for healthcare professionals to have access to support and resources to provide high quality care including designated bereavement rooms, opportunities for training and education, and access to self-care and emotional wellbeing support.

Acknowledging the shared responsibility between the organisation and individual healthcare professionals is critical to developing an environment that enables and supports sustainable best practice care.

Objective

The objective of this section is to support organisations in providing a service-wide approach to the provision of respectful and supportive care.

A note about terminology

This guideline uses parent-centred language that is intended to be inclusive of all affected by loss. We use the term 'woman' throughout the guideline to refer to the person who is pregnant and gives birth.[15] We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth identify as a woman. The term 'parent' is used to refer to expectant and bereaved mothers, fathers, and partners. It is important to recognise individuals who identify themselves as parents. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents.[16]

This guideline uses 'baby' when referring to stillbirth and neonatal death because these terms are preferred by many bereaved parents. Terms such as 'fetus' may add to parents' distress because this language denies personhood[16] and is inconsistent with recognition of parenthood that is crucial to providing respectful and supportive care.

This guideline uses 'healthcare professional' to denote all those working with bereaved parents and family/whānau (see Glossary).

Approach to care

All maternal and newborn services should establish and foster a commitment to delivering best practice care around stillbirth and neonatal death. Services can support staff providing perinatal loss care by establishing and maintaining systems and practical resources, and through ongoing training.[17] Support strategies should be documented in organisational polices,[18] which are implemented, evaluated and updated as required.[19]

A multidisciplinary team is integral to caring for parents and families/whānau when a baby dies. This team may include medical, nursing, midwifery, and social work care professionals as well as peer supporters, volunteers, and community members. Cultural, religious, and spiritual variation around practices relating to childbirth, death and dying require flexibility and individualised approaches.[20] Poor coordination of care and lack of healthcare professional knowledge or skill in managing care or in interactions with parents can exacerbate family/whānau trauma and add to healthcare professional stress. Lack of a single point of contact is commonly reported by parents and adds to frustration and feelings of distress. Parents value continuity of carer because of the comfort of a familiar face and knowing they will not need to repeat their story.[21]

"The hospital I was at also had signs on the door with a teddy bear and a tear… [staff] know to be sensitive."[16]

A dedicated and appropriate space is essential for provision of best practice care. A recognisable marker that designates pregnancy or newborn loss should be used to identify designated bereavement spaces, medical records or any other item that is appropriate and accepted by parents.[22] All staff (both clinical and nonclinical, including volunteers) should be aware of this marker/identifier to ensure sensitive care and support.

All major maternity hospitals should develop specialist bereavement support services with staff trained in perinatal loss care.[5] These staff have an important role in the ongoing training and support of all healthcare professionals who have contact with bereaved parents. Smaller facilities or those located in rural or remote areas should ensure protocols are in place for care after perinatal loss and in subsequent pregnancies that include working with larger centres with appropriate expertise. This may include the use of telehealth. For some Aboriginal people and Torres Strait Islander communities, telehealth consultations may include important people in the community such as Elders or Traditional Healers. Better collaborative care at the interface between hospital and community is also essential to addressing the ongoing support needs of bereaved parents.

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.

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.

Evidence-based recommendation 8.5
Evidence quality: Moderate confidence
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/or spiritual rituals or ceremonies.

Maternal and newborn services should have processes in place to ensure all parents have access to memory making opportunities such a bereavement photographs and videos, hand and footprints, casts/moulds of hands and feet. Parents also value the opportunity to spend time with their baby in natural environments or settings. All services should have established processes to facilitate commemorative rituals.

Some parents may be apprehensive about creating mementos and may choose not to take these home with them. It is crucial that all services have processes in place for the storage of mementos in case the families wish to collect these in the future.

Parents will need to make "memories of a lifetime" in a very limited span of time.[8]

In Australia, **Red Nose's Treasured Babies Program** and **Angel Gowns Australia** provide bereaved families with gifts of handmade clothing and Angel boxes for their baby. **Miracle Babies Foundation** also provides memory boxes for newborn loss. **Bears of Hope**, **Possum Portraits**, and **Huggable Hearts** also support bereaved families with mementos and keepsakes for lasting memories. In Aotearoa New Zealand, **Baby Loss NZ**, **Sands New Zealand**, and **A Star is Born** provide memory making services.

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.

Evidence-based recommendation 8.7
Evidence quality: Moderate confidence
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.

Education and training for healthcare professionals

Education, training, and support are critical enablers for best practice care following perinatal death. This includes formal educational initiatives and informal debriefing and sharing of experiences with colleagues. Studies show opportunities for professional development and training enable healthcare professionals to build confidence and knowledge to feel more equipped to deliver care,[19,23-28] build self-awareness of their own needs[29,30] and to feel supported in their role by their workplace.[31-33] This supports workforce capacity and sustainability.[4,34,35]

Healthcare professionals have a major role in helping parents to make decisions that minimise regret and avoid missed opportunities.[6,7,36] Inappropriate or insensitive care can disempower parents. This can make an already potentially traumatic event worse for bereaved parents.[17] Healthcare professionals must be prepared for a wide range of responses that may not reflect their own values or expectations.[26] Providing perinatal loss care is a stressful and challenging area of practice for many healthcare professionals and they require skills to support parents, including knowing where and how to seek their own support, and the ability to develop resilience to ensure the longevity of their career and to avoid burnout. Providing appropriate and high quality perinatal loss care requires healthcare professionals to understand the law, policy, practices, and clinical care standards related to reporting perinatal deaths. This is particularly pertinent for termination of pregnancy for medical reasons.

Healthcare professionals often report feeling underprepared to provide perinatal loss care,[37] 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 experienced healthcare professionals.[37] Healthcare professionals' perceptions may contribute to low autopsy rates, which have been steadily decreasing across many high-income country settings.[38,39]

Healthcare professionals play a central role across the continuum of care from the moment of bad news, through birth and postpartum, and into future pregnancies.[8]

This may be because of perceived lack of qualifications and training to discuss autopsy with parents, a desire to avoid uncomfortable discussion, and fear of adding stress and burden on bereaved parents and families/whānau. Further, healthcare professionals may underestimate the value of investigations such as perinatal autopsy.[40] Training for staff in developing a rapport with parents and addressing emotional distress may help to overcome barriers to consent for an autopsy.[28] It is also important for healthcare professionals to be aware of and understand cultural, religious, or spiritual influences on decision making around investigations, such as need for burial to occur within a specified time and for the baby's body to remain intact.[41] Having a dedicated role/service within maternal and newborn services can help services ensure optimal care in investigation of perinatal deaths. Ideally, this role/service would include training for staff to meet the needs of parents and families/whānau regarding options for postmortem investigations.

In Australia, the National Stillbirth Action and Implementation Plan (the Plan) proposes the development and implementation of a national evidence-based, culturally safe education program for care around stillbirth and neonatal death.[42] IMPROVE is a national educational program based on the *Care Around Stillbirth and Neonatal Death (CASaND) Clinical Practice Guideline* of the Stillbirth CRE and PSANZ.[43] The Plan also recommends undergraduate education in stillbirth prevention and management.

Healthcare professionals in Australia and Aotearoa New Zealand can access online training resources to learn how to provide culturally responsive best practice care. The **WellMob** website contains resources for non-Indigenous health workers in Australia. Developed by Aboriginal and Torres Strait Islander people, the WellMob training resources can help health workers understand cultural identity, grief and Sorry Business, appropriate language use, the impact of trauma and intergenerational trauma, and other social and emotional wellbeing topics. The ***Australian Refugee Health Practice Guide*** contains information to support healthcare professionals to take a trauma-informed approach to care for women of refugee background. In Aotearoa New Zealand, healthcare professionals can complete **Working with Māori e-learning modules** to learn how to provide respectful health care that includes parent-centred decision making. The modules are endorsed by the Royal New Zealand College of General Practitioners.

IMPROVE is offered as a face-to-face workshop and is based on the SCORPIO (Structured, Clinical, Objective Referenced, Problem-based, Integrated and Organised) educational model designed for skills training. This workshop involves small groups of learners rotating between six interactive learning stations that are each facilitated by an experienced educator. IMPROVE workshops have been run in Canada, Fiji, Spain, United Kingdom, the Netherlands, and Vietnam, with content updated to align with the local context. Evaluations of the IMPROVE workshops conducted between May 2012 and May 2015 found high levels of satisfaction with the workshop and increased confidence following completion of the workshop.[44] The IMPROVE educational program is also available as an e-learning module in Australia and Aotearoa New Zealand. Like the face-to-face workshop, this online training package of six courses is designed to support healthcare professionals respond to

women and families/whānau who have experienced stillbirth, conduct and better understand perinatal autopsy and mortality reviews, and communicate findings with bereaved parents. The e-learning component of IMPROVE was launched in December 2019 and recently evaluated by 1,339 participants (1,074 midwives [80.2%]) in Australia and Aotearoa New Zealand.[45] Most participants evaluated the program as helpful and useful (94.7%), engaging (90.9%), and likely to lead to change in their clinical practice (80.7%).

In Australia, other educational training programs include the **Stillbirth Investigations and Bereavement Care education program**, **ISLA Grief and Loss** training for maternity services. Miracle Babies Foundation deliver **The Butterfly Initiative** course to provide guidance to healthcare professionals in providing bereavement support to families/whānau who experience the loss of a baby in a multiple pregnancy. InUTERO provides healthcare professional education for stillbirth awareness for prevention.[46,47] The **Perinatal Training Centre** provides a relationship-based training program for perinatal loss.

In Aotearoa New Zealand, **VCA – Vicki Culling Associates** provides education and training for perinatal and infant loss and range of **resources** for whānau. VCA also provides a **Baby Loss Directory** of support organisations and services.

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.

Evidence-based recommendation 8.9
Evidence quality: Moderate confidence
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.

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.

Supporting healthcare professional wellbeing

The nature of providing care around the time a baby dies is intense and complex. Healthcare professionals in maternity and newborn care provide significant support to parents and families/whānau and play a central role across the continuum of care from the moment of the bad news, through birth and the postpartum period, and into subsequent pregnancies.[48]

"If you're not caring for yourself, then you're less able to care for others."[44]

However, many healthcare professionals receive little training in caring for themselves, despite this being a professional requirement in many national and international quality standards and guidelines.[8,9,49] Healthcare professionals report feelings of guilt, frustration, and helplessness, alongside feelings of sadness and distress when supporting parents who experience perinatal death.[2,4] Unless acknowledged and addressed, these emotional effects can lead healthcare professionals to feel overwhelmed, to distance themselves from grieving parents, and to experience compassion fatigue and burnout.[50]

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.

In Australia and Aotearoa New Zealand, free confidential peer support for healthcare professionals is also available via **Hand-n-Hand Peer support** (Helping Australian & New Zealand Nurses and Doctors). In Australia, CRANAplus's Bush Support Line provides free confidential 24/7 telephone psychological support for all rural and remote health workers and their families/whānau. Other resources are listed on the **Royal Australian and New Zealand College of Obstetricians and Gynaecologists** website.

Review processes and quality improvement

It is important that all perinatal deaths are carefully reviewed through appropriate processes to provide answers for families/whānau about why their baby died, and to identify improvements in care for future families/whānau. The perinatal mortality audit review process has been shown to improve care that services and healthcare professionals provide to parents and families/whānau when their baby dies.[51,52] Refer to *Section 7* for more information on the perinatal mortality review process and engagement with parents.

Parent experiences of care are integral to quality improvement practices in maternal and newborn services. Most bereaved parents want to provide feedback to health services about the care they received when their baby died and appreciate being sensitively asked to share their experiences. Patient-reported outcome measures (PROMs) are an effective method of assessing quality of care and can inform practice improvements from an individual level to a system level.

Good feedback mechanisms provide parents with opportunities to inform service improvements and feel listened to.[51]

In Australia, the Stillbirth Clinical Care Standard recommends health services use the Australian Hospital Patient Experience Question Set (AHPEQS)[9,53] to understand care experiences. In the UK, the National Bereavement Care Pathway recommends services use the Maternity Bereavement Experience Measure (MBEM).[14] Parent experience measures are being adapted and co-designed for Australian services as part of a national perinatal loss care pathway similar to that implemented in the UK.[14,54,55]

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 in the provision of care around stillbirth and neonatal death. The audit program should include parent experiences of care.

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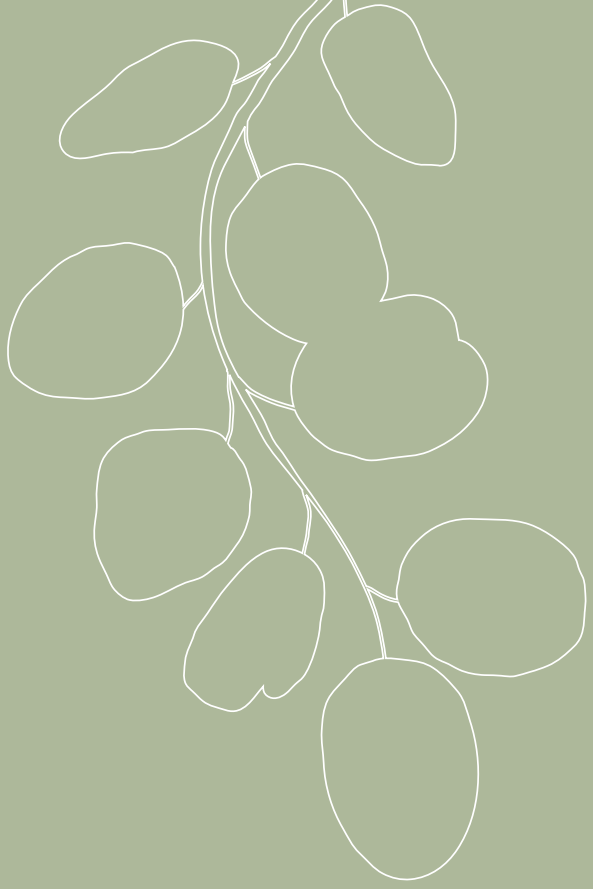

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