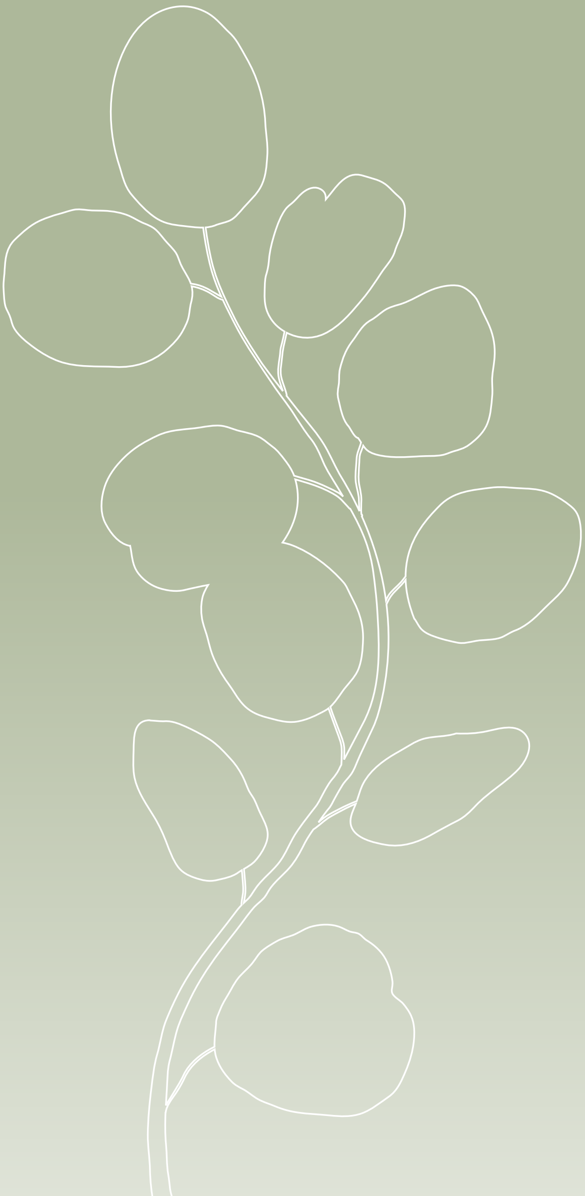
2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Administrative report



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

Stillbirth
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Contents

Scope and purpose

The 2024 edition of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline* (CASaND Guideline) is the fourth edition of the CASaND Guideline. The first edition of the CASaND Guideline was released in 2008 under the auspices of the Perinatal Society of Australia and New Zealand Mortality Special Interest Group (PSANZ-PMG) by the Centre for Clinical Studies, Mater Health Services, Brisbane (through funding from the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, Sands Queensland, SIDS and Kids, and the Mater Foundation). The guideline has been updated three times by Mater Research under the auspices of PSANZ, with the third revision being a partnership between the PSANZ Stillbirth and Neonatal Death Alliance (previously PSANZ-PMG) and the NHMRC Centre of Research Excellence in Stillbirth (Stillbirth CRE).

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.

This edition incorporates the latest evidence for care of parents and families/whānau who experience stillbirth or neonatal death with a systematic review of the evidence conducted between 2022 and 2023. This edition of the guideline is structured 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 death audit and classifications
- Section 8: Organisational recommendations.

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

The 2024 edition of the Guideline is the first edition to meet guideline development requirements to seek approval by the National Health and Medical Research Council (NHMRC) in Australia – a priority action identified in the Australian National Stillbirth Action and Implementation Plan (the Plan). The Plan highlights the need for all families/whānau who experience stillbirth to receive personalised, respectful, supportive, and holistic clinical and community care.

Expected benefits of guideline implementation

Parents who experience the death of a baby consistently link their grief with the quality of care they received in maternal and newborn settings. There is large variation in knowledge and clinical practice, with healthcare professionals often ill-equipped to provide respectful and supportive bereavement care, including breaking bad news and supporting grieving parents through complex and difficult decisions. Tailored support for culturally diverse populations is essential.

Effective implementation of the guideline is expected to provide:

- better parent experiences of care received across maternal newborn services and psychosocial outcomes following a perinatal death
- optimal care and outcomes for parents in future pregnancies
- more effective approaches to prevention of perinatal deaths through better information on causes and contributing factors.

Although the guideline is intended for use in Australia and Aotearoa New Zealand, effective implementation of recommendations for perinatal death investigations and audits in these countries is likely to make major contributions to the global evidence base and inform practice globally. The guideline *Implementation and dissemination plan* describes the approach for dissemination of the guideline and for a national approach to implementation.

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.

Target audience and population

Primary audience

The guideline is aimed primarily at healthcare professionals who care for parents and families/whānau in maternal and newborn 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 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 policymakers, health systems 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.

Target population

The target population of this guideline are parents and family/whānau who experience stillbirth or neonatal death in Australia or Aotearoa New Zealand. 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.1,2
- **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.[1,2]

The definition of stillbirths and neonatal deaths includes those deaths which occur following a termination of pregnancy of 20 or more completed weeks of gestation or of 400 g or more birthweight.

Research Questions

The topics under investigation for this evidence review build on the main topics addressed in the previous edition of this guideline.[3] There is greater focus on culturally safe and responsive care, perinatal palliative care, care in subsequent pregnancies, and new techniques for investigations. The broad topics and research questions formulated by the Guideline Development Committee are listed in Table 1.

Table 1: Broad topics and research questions for the 2024 CASaND Guideline update

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

PERINATAL LOSS CARE
BREAKING BAD NEWS
What are the care and support considerations for communicating bad or unexpected news to parents and families/whānau during the antenatal or neonatal period?
What are the considerations for communicating with parents and families/whānau around time delays, and are there strategies healthcare professionals can use to limit delays?
SHARED DECISION MAKING
How can healthcare professionals provide care within a shared decision-making framework engaging parents to the extent they wish and providing adequate information? Does this lead to improved outcomes for parents and families/whānau?
How do healthcare professionals ensure the 'right' decision-makers are in the mix?
What are the shared decision-making considerations and specific information and support needs of parents following termination of pregnancy for fetal anomaly?

EFFECTIVE COMMUNICATION

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

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

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

BIRTH CARE PLANNING

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

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

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

SPACE AND SURROUNDINGS

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

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

RECOGNITION AND PARENTHOOD

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

What mementoes do parents value and how should these be collected? Are there important considerations for healthcare professionals to be aware of when supporting parents and families/whānau to create memories with their baby?

What are the unique issues and considerations around care for parents with a twin/multiple pregnancy where one (or more) baby has died?

EFFECTIVE SUPPORT

What physical care and support is needed by parents after birth and in the postnatal period, including support in making informed decisions around lactation management?

What are the psychosocial support needs of parents following stillbirth or neonatal death and what forms of psychosocial support are most beneficial?

How can healthcare professionals identify parents who may be at risk of experiencing complicated bereavement and how to ensure referral to appropriate care?

What support is needed by family members (including grandparents and siblings) following the death of a baby?

What is the optimal follow-up for parents after discharge from hospital?

What considerations are there in the provision of perinatal loss care and support for parents who have experienced a termination of pregnancy following diagnosis of fetal anomaly?
COMMUNICATION BETWEEN HEALTHCARE PROFESSIONALS
How do you ensure healthcare professionals are appropriately resourced to provide the best possible care to bereaved parents and families/whānau?
How does an organisation ensure continuity of experienced carer and continuity of care planning during the perinatal loss experience?
Does use of a universal symbol or other identifier (in clinical charts, physical spaces) of a perinatal loss care plan improve outcomes and satisfaction with care for parents and families/whānau?
What are the responsibilities for sharing information with other healthcare professionals to ensure appropriate handover to community-based care and support?

PERINATAL PALLIATIVE CARE
What are the information and support needs of parents and families/whānau who choose a palliative care approach following diagnosis of a life-limiting condition either before or after birth?
Who are the right people to have in the right team and what is the right place for a perinatal palliative care approach?
What barriers are experienced by parents in accessing and engaging with palliative care? What barriers are experienced by healthcare professionals in providing perinatal palliative care services?
What forms of psychosocial support benefit parents and families/whānau?
What are the training and support needs of healthcare professionals providing perinatal palliative care?

CARE IN SUBSEQUENT PREGNANCIES
What approaches/models of care and referral pathways benefit parents in a subsequent pregnancy following stillbirth or neonatal death?
What is the role of preconception counselling and does this support parents' decision-making around interventions in future pregnancies?
What is the role of antepartum surveillance in a subsequent pregnancy following stillbirth or neonatal death, including additional antenatal care visits and additional ultrasound scans?
What targeted interventions and preventative strategies are available for parents with risk factors for adverse outcomes including risk factors based on previous cause of death?
What considerations will impact on timing and mode of birth in a subsequent pregnancy following stillbirth or neonatal death? What resources are helpful for healthcare professionals and parents to make these decisions?
What are the psychosocial needs of parents during a subsequent pregnancy following stillbirth or neonatal death and what forms of support improve psychosocial outcomes?

PERINATAL DEATH INVESTIGATIONS
What is the value of individual or groups of investigations for stillbirth and/or neonatal death including partial/limited autopsy compared with full autopsy?
What is the value of performing genome sequencing for high-risk neonates and does specific medical situations determine the need for genome sequencing for high-risk neonates?
Does a non-selective vs. selective or sequential approach to stillbirth and/or neonatal death investigations result in improved understanding of causes, parents' satisfaction with adequacy of investigation, and better planning for future pregnancies?
What is the value of performing skin swabs for high-risk neonates (including rectal, skin, surface, ear, nose, mouth, wound or throat) and do specific medical situations determine the need for skin swabs of high-risk neonates?
What trends are apparent and which interventions assist in improving understanding of local practices around perinatal autopsy?
What are the barriers to undertaking autopsies?
How should transfer of a baby for autopsy be carried out? How will this differ for regional and remote settings?
Which aspects of the autopsy examination are valuable in determining the cause of death?
What are minimum standards and important elements of a quality autopsy examination following a perinatal death?
What training/expertise is required to undertake a high-quality perinatal autopsy?
What is the optimal reporting format for a perinatal autopsy?
What is the appropriate timeframe for results of a perinatal autopsy to be made available?
What are minimum standards for autopsy examination in the event of Sudden Unexpected Death in Infancy or death with suspected genetic metabolic disorders?
What are the educational and training needs of healthcare professionals around investigations for perinatal death?
What strategies and considerations improve communication with parents about the option of an autopsy examination for their baby?
How can shared decision-making around investigations of the baby's death be effectively offered and achieved?
What types of information should healthcare professionals provide to meet the individual needs (e.g., literacy level, culturally appropriate) and preferences (e.g., written, audio) of parents?
What information should be provided to parents about the range of investigation options available to them, and who should provide information about which, if any, investigations are most likely to be useful?
Are telehealth reviews an acceptable option for providing parents with information about investigation options? Is this an acceptable option for discussing results of investigations with parents?
What is the optimal content of consent forms for perinatal autopsy and other investigations?
What is the value of providing a plain language summary of the perinatal autopsy to parents?
What information should be provided to parents when their baby needs to be transported to another service/setting for investigations (such as autopsy and medical imaging)?

PERINATAL MORTALITY AUDIT AND CLASSIFICATIONS
What are the different types of perinatal mortality reviews currently being done?
Do perinatal mortality audit programs reduce perinatal deaths?
What aspects of audit contribute most to reducing perinatal death?
Which findings from perinatal mortality audit meetings can be effectively implemented?
What needs to be sent to the jurisdictional perinatal mortality council or respective body?
What is the best mechanism of providing this information within other reporting requirements?
What would need to occur for a national online tool to be used, and to include jurisdictional requirements?
What are the essential requirements of perinatal mortality audit meetings, including meeting composition, to ensure optimal outcomes?
Which training programs for healthcare professionals result in improved care and outcomes after perinatal deaths?
Are there aspects of training programs that are particularly effective?
How is the value of locally approved service/unit-based training assessed and are they effective?
What strategies increase/optimise reporting?
What information is required to prepare and complete a perinatal mortality audit?
What is the minimal investigation required to accurately classify the causes of stillbirth and neonatal deaths?
Should a standard of relevant documentation be developed?
What are the most important strategies to ensure clear and accurate documentation in the medical record at the time of the perinatal death?
Should a proforma for verbal autopsy be developed?
When should a perinatal death be reviewed?
What should happen if there are delays?
What needs to be done to improve the quality of death certificate data on causes of death?
Who is the ideal person to complete the medical certificate?
Should the death certificate be routinely modified after investigations and audit have been complete?
Which approaches and processes for perinatal mortality audit improve parents' experience of care?
Does parent engagement in perinatal audit process for their baby's death result in improved outcomes for parents and high-quality audit?
What are the key aspects that are important in terms of supporting and communicating with families/whānau throughout the process?
Is there a role for a care coordinator within this process?

PERINATAL MORTALITY AUDIT AND CLASSIFICATIONS
What are optimal approaches to, and timing of, providing parents with the results of investigations (and audit) and what needs to be presented and discussed?
What are parents' understanding and acceptance of the cause of death?
How should contributing factors be communicated to the family?
What is parents' understanding, acceptance and utility of the contributing factors provided?
What are the benefits of an open disclosure framework in discussions with parents following a perinatal death?
What are the considerations prior to undertaking open disclosure?
What are the risks and benefits of open disclosure?
What are the various approaches (benefit, risk of different approaches) to work out the best case-by-case individual process?
Should senior clinicians notify the general practitioner and other relevant healthcare professionals of the death as soon as possible? When is the ideal time for this to occur?
Following discharge hospitals after a perinatal death, what actions, and when, do clinicians need to provide to other health providers?
Should a comprehensive summary be provided to relevant healthcare professionals after the audit meeting, where appropriate and relevant? What should this contain?
Should a comprehensive clinical summary be provided by senior clinicians to the general practitioner and other relevant health care providers of outcomes of follow-up appointments and results as available, including subsequent pregnancy care plans?
What is the optimal classification system for identifying causes of perinatal deaths to inform policy and practice change and future research to reduce perinatal deaths?
Does a hierarchical system have benefits over a non-hierarchical system in terms of reliability and accuracy?
What distinguishes causes and associated factors?
How does the PSANZ system compare to ICD-PM in terms of cause of death outcomes? Including proportion of unexplained stillbirths. Can the PSANZ system be accurately mapped retrospectively to ICD-PM?
What is the optimal classification system for identifying contributing factors relating to care in perinatal deaths to inform policy and practice change and future research to reduce perinatal deaths?
How should perinatal death be defined to enhance practice change and research?
Which definition should be used, should there be conditional definitions e.g., termination of pregnancy for medical reasons, gestational cohorts?

ORGANISATIONAL RECOMMENDATIONS
What are the clinical standards for maternal and newborn services providing perinatal loss care including legal and reporting requirements?
How can parent experiences be incorporated into maternal and newborn service improvements?
What strategies and resources can services implement to support the emotional wellbeing of healthcare professionals and reduce adverse consequences such as compassion fatigue and burnout?
What are the training and education needs of healthcare professionals and what elements of training lead to improved outcomes for parents and families/whānau?

Stakeholder involvement

Guideline Development Committee

Guideline development was guided and overseen by a Guideline Development Committee (see Appendix 1A for group membership). Guideline Development Committee members were delegates from key stakeholder organisations, professional/industry colleges, and individuals across Australia and Aotearoa New Zealand who represent the views and work of bereaved parents, perinatal bereavement support organisations, healthcare professionals, researchers, and policy makers.

Membership included representation from Aboriginal and Torres Strait Islander, Māori, migrant and refugee, and rural and remote communities across Australia and Aotearoa New Zealand. The Stillbirth CRE sent formal invitations to each key stakeholder organisation and college seeking representatives to join the Development Committee. Individual healthcare professionals, researchers, policy makers and bereaved parents were directly approached and invited to join the Committee.

Committee terms of reference:

- participate respectfully in group discussions
- understand the evidence on which the guideline is based
- understand and adhere to agreed methods of communication and methods of document generation and review.

Committee member participation:

- comment on guideline documents between meetings
- suggest sources of evidence, which may be seminal studies or contemporary best practice
- contribute to drafting of recommendations
- comment on the draft guideline
- action tasks assigned during meetings.

The Guideline Development Committee met every two to four weeks via videoconference to review and provide guidance on the evidence synthesis process and development of guideline content including evidence-based and consensus-based recommendations.

Expert Working Groups

Guideline development was also informed by five Expert Working Groups: cultural considerations, perinatal death investigations, perinatal palliative care, perinatal loss care, and care in subsequent pregnancies. Expert Working Group members consisted of members of the Guideline Development Committee as well as other healthcare professionals, researchers, bereaved parents/family members who collaborate with the Stillbirth CRE. The purpose of the Expert Working Groups was to support the Technical Working Group conducting the systematic review of evidence and provide guidance and feedback on a specific topic area related to their expertise. These groups generally met once a month or on an ad hoc basis, between committee meetings.

Technical Working Group

The Technical Working Group (Appendix 1A) coordinated meetings, led evidence evaluation processes (literature searches, screening, synthesis), and ensured project deliverables were met

Consumer representatives

Bereaved parents were consulted through the Stillbirth CRE national network and included membership on the Committee and/or Expert Advisory Groups. Consumers were able to contribute to the development of the Guideline (to the extent that they wished) including reviewing draft content, providing guidance and feedback throughout the development process, and sharing their personal experiences. Individuals were directly approached by the Stillbirth CRE and invited to join.

Engagement and consultation with priority population groups was conducted through the Cultural Considerations Expert Working Group and the Stillbirth CRE's national Indigenous Advisory Group and Migrant and Refugee (M&R) Advisory Group. Individuals and representatives of stakeholder organisations were invited to join the Cultural Considerations Expert Working Group. Members based in Aotearoa New Zealand were engaged to bring Aotearoa New Zealand perspectives to the Guideline and inform recommendations. This project also leveraged current consultation work of the CRE's Indigenous and M&R Advisory Groups and partnerships to ensure culturally safe engagement. We will also draw on consultation conducted for the guideline update which has a stronger focus on provision of culturally appropriate care.

Rigour of development

This section provides a summary of the process for reviewing the evidence for this edition of the Guideline. Further detail is provided in the Technical Reports. The assessment of evidence for this guideline update was based on evidence from systematic searches of peer-reviewed evidence in databases. Seminal literature published prior to 2017 was included in the guideline if there was no more recent evidence on that topic. Grey literature such as unpublished manuscripts, other standards/guidelines, organisational websites were also considered and included in the detailed evidence synthesis in each technical report. Only peer-reviewed evidence was assigned to evidence-based recommendations. With much of the literature consisting of qualitative studies, we also incorporated these data and formulated consensus-based recommendations. The different types of recommendations are clearly identified in the guideline and accompanying technical reports.

Search methods

PICO (population, intervention, comparator, outcome) criteria were formulated from each research question. The database search strategies incorporated all PICO criteria and were restricted to publications in English (see technical report for each section for details). Searches were conducted between March 2022 and September 2023 in the following databases:

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

Studies identified in database searches were imported to Covidence (**https://www.covidence.org/**) and duplicate citations were removed. The remaining citations were screened by the review team. The Technical Working Group strategically searched websites for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for each section of the guideline. Each technical report has a PRISMA flowchart that shows the systematic process of identification and screening of evidence for the report topic.

Evidence selection criteria

The main inclusion/exclusion criteria for each of the research question areas were as follows:

- **Target population** – stillbirth, neonatal death including perinatal death following termination of pregnancy.
- **Intervention** – studies exploring care following stillbirth or neonatal death in maternal or newborn settings, including yield and value (e.g. investigations).
- **Outcomes** – outcomes, processes and care experiences of parents, family members, healthcare professionals.
- **Language** – English

Studies identified in database searches were imported to Covidence (**https://www.covidence.org/**) and duplicate citations were removed. The remaining citations were screened by the review team. The Technical Working Group strategically searched websites for grey literature, and Committee members were encouraged to identify grey literature and articles of interest for each section of the guideline. Each technical report has a PRISMA flowchart that shows the systematic process of identification and screening of evidence for the report topic.

Assessment of evidence

Studies were assessed using critical appraisal checklist tools from the **Joanna Briggs Institute**. Diagnostic evaluation studies were assessed using the QUADAS-2 tool. All components of the quality assessment were incorporated into the GRADE-CERQual assessment of recommendations.

Development of 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.

Recommendations relating to perinatal death investigations generated the most discussion because of their technical nature and advances in medical investigation techniques and approaches. The Guideline Development Committee consulted with national (Royal College of Pathologists of Australasia) and international (Royal Australian and New Zealand College of Obstetricians and Gynaecologists) peak industry bodies when refining existing recommendations and developing new recommendations.

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. 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 and rapid update of some recommendations, and identification of additional topics for future consideration.

Clarity of presentation

Specific and unambiguous recommendations

The wording of the evidence-based and consensus-based recommendations is based on these principles:

- Recommendations are succinct and action-oriented where possible
- Recommendations contain clear actions that match the strength of the available evidence
- Recommendations specify, where relevant, timing of the action.

Management options

The different options for managing care scenarios are clearly articulated via the structure of the Guideline and the wording of the recommendations.

Identifiable key recommendations

- The evidence-based recommendations and consensus-based recommendations are clearly identified by colour coding and use of separate numbering systems
- The strength of the evidence is clearly identified for each recommendation
- A list of all recommendations is in the Executive Summary.

Applicability

Facilitators and barriers to application of the CASaND guideline

Facilitators to application

- Engagement of key stakeholders in guideline review and development
- Integration of guideline with IMPROVE eLearning and face-to-face workshops
- Co-development of guideline companion resources with key stakeholders.
- Access to Stillbirth CRE and other parent resources.

Barriers to application

- Resource limitations particularly for smaller services in rural regions
- Cost and limited availability of some investigations (such as exome sequencing and MRI)
- Stillbirth and neonatal death are devastating, but relatively rare, which means some healthcare professionals may rarely or never encounter these. However, the enormity of perinatal loss requires health services to adequately prepare and train healthcare professionals (including practical strategies for avoiding burnout)
- Delays in communicating investigation findings to parents and families.

Editorial independence

Funding body

Financial support

The Stillbirth CRE acknowledges the total amount of financial support of $261,260.00 plus GST received from the Australian Government Department of Health and Aged Care. Funding and support were also provided by NHMRC (NHMRC Investigator Grant - APP 2010136; NHRMC Centre of Research Excellence in Stillbirth - APP 2006523), Mater Research, and Mater Foundation. Commissioning of the guideline development to the Stillbirth CRE, as the national centre for care around stillbirth and neonatal death, ensures editorial independence from the Commonwealth as the funding body.

Competing interests

All members of the Guideline Development Committee involved in the guideline development process were asked to declare any conflicts of interest in writing at the start of the guideline development. As per NHMRC requirements, all committee members were required to complete the Declaration of Interest form.

Processes put in place to manage any potential conflicts of interest that may arise during the development of the Guideline was managed by the Development Committee and Technical Working Group. Prior to each committee meeting, the Technical Working Group circulated a detailed agenda of topics for discussion. At the commencement of each meeting, the Chair prompted attendees to review the agenda and declare any competing interests pertinent to the guideline topics under discussion. No conflicts of interest/competing interests were noted during the guideline development process (Table 2).

Table 2. Competing interests of Guideline Development Committee members

REPRESENTATIVE	ORGANISATION	COMPETING INTEREST
Professor Vicki Flenady	Stillbirth CRE, Director Committee co-chair	Nil
Professor Adrienne Gordon	Committee co-chair	Nil
Professor Philippa Middleton	SAHMRI; Stillbirth CRE – Principal Investigator	Nil
Associate Professor Fran Boyle	Institute for Social Science Research, University of Queensland; Stillbirth CRE -Principal Investigator and co-lead care after stillbirth program Red Nose National Scientific Advisory Group board member	Nil

REPRESENTATIVE	ORGANISATION	COMPETING INTEREST
Dr Anneka Bowman	Aboriginal Communities and Families Health Research Alliance (ACRA) South Australian Health and Medical Research Institute (SAHMRI) Perinatal Society of Australia and New Zealand (PSANZ)	Nil
Leigh Brezler (March – July 2022)	Stillbirth Foundation Australia	Nil
Nicola Bright	Bereaved Māori parent	Nil
Dr Vicki Culling	Director and principal educator, Vicki Culling Associates Ltd (VCA)	Training and education for health and caring professionals in perinatal loss, grief and bereavement support
Debbie Davies	PMMR national coordinator Perinatal bereavement midwife specialist	Nil
Amelia Druhan	CRANAplus	Nil
Professor David Ellwood	Co-Director, Stillbirth CRE Professor of obstetrics & gynaecology, Griffith University Director of Maternal-fetal medicine, Gold Coast Health	Stillbirth researcher and involved in clinical care of bereaved parents after both stillbirth and neonatal death
Dr Andrew Watkins	PSANZ Perinatal Palliative Care SIG	Nil
Professor Stacy Goergen	Monash Imaging, Monash Health Royal Australian and New Zealand College of Radiologists Monash University	Nil
Dr Nicole Hall (March –– September 2022)	Royal Australian College of General Practitioners	Nil
Professor Belinda Jennings	Flinders University Australian College of Midwives	Nil
Aditi Lohan	Institute for Social Science Research, University of Queensland	Nil

REPRESENTATIVE	ORGANISATION	COMPETING INTEREST
Dr Siobhan Loughnan	Stillbirth CRE – Associate Investigator	Nil
Keren Ludski	CEO, Red Nose	Nil
Dr Diane Payton	Paediatric and perinatal pathologist, Royal Brisbane Women's Hospital and Queensland Children's Hospital	Nil
Evelyn Pe	Mater Migrant and Refugee Group	Nil
Tani Paxton	Midwifery advisor, Australian College of Midwives	Nil
Associate Professor Sean Seeho	Stillbirth CRE Education Committee, co-chair Chair, Stillbirth Foundation Australia	Nil
Skye Stewart	Indigenous Advisory Group, Stillbirth CRE	Nil
Deanna Stuart-Butler	Indigenous Advisory Group Chair, Stillbirth CRE	Nil

Independent expert review

Throughout the development process, the Technical Working Group engaged with Australian and international experts to ensure alignment with international guidelines and latest evidence (for example, the Royal College of Obstetricians and Gynaecologists [RCOG] guideline). During public consultation, expert reviewers (independent of guideline development) assessed the evidence synthesis and recommendations using the AGREE II instrument.

Public consultation of the draft guideline

The draft guideline was available for 30-day public consultation between 21 August and 26 September 2023. Interested parties were invited to provide feedback via an online form (Qualtrics XM). The Stillbirth CRE emailed a link to the form to key organisations, professional colleges, parent support and advocacy organisations, and individuals with lived experience of stillbirth and neonatal death.

More than 60 individuals and organisations provided responses over the public consultation period. Individual responses were received from a range of healthcare professionals including bereavement midwives, obstetricians, neonatologists, geneticists, psychologists, psychiatrists, social workers, and bereaved parents. The guideline *Public consultation summary report* details submissions received and lists organisations who provided feedback.

During the public consultation period, the Technical Working Group continued to undertake consultation with the Department of Health and Aged Care (through members of the Guideline Development Committee) and with professional colleges (through members of the Guideline Development Committee and Expert Working Groups). This included pathologists and radiologists who were given opportunity to comment on recommendations relating to interventions relevant to their practice. The content of the guideline and recommendations were amended in line with guidance and advice received during consultations.

Public consultations identified the following strengths of the guideline:

- use of sensitive and inclusive language
- greater focus on Aboriginal and Torres Strait Islander peoples and Māori whānau
- well-presented layout and structure
- helpful and practical resources, in particular parent-facing resources including the parent versions of the Guideline *'Guiding Conversations'* and *'Jiba Pepeny (Star Baby)'* for Aboriginal families.
- comprehensive and detailed summary of the evidence.

Public consultations identified the following key concerns about the guideline:

- Respondents sought clarification of the definitions for perinatal death particularly around gestational criteria for neonatal death, which is used for statistical purposes. Definitions can have legal and reporting implications and burial/cremation requirements in accordance with state legislation. This also has significant impacts on parents accessing parental/bereavement leave
- Application of guideline recommendations to Aotearoa New Zealand care settings and acknowledgement of practice variations was requested. This included requests for a greater focus on culturally responsive and safe care for Māori whānau and other ethnic groups in Aotearoa New Zealand. The Cultural Considerations Expert Working Group was convened to review all public consultation feedback and revise guideline content and recommendations
- All editing concerns such as typographical errors, grammatical issues, formatting have been addressed. We have also addressed minor comments around improving graphic design and structure to improve user experience.

See the Guideline *Public consultation summary report* for more detailed information.

Dissemination and implementation

Together, the Stillbirth CRE and PSANZ will promote and disseminate the 2024 edition of the CASaND Guideline using a multifaceted and multimodal approach that caters to all the guideline's target audience.

The following strategies will be used to disseminate and promote the final guideline, including companion resources:

- **Launch activities** – launch event, media release and media engagement; social media and communications toolkit
- **Post-launch dissemination** – email distribution (newsletter), Federal Parliamentarians "introduction kit" to enable local connections, Blog, Plain language summary, web-based tool
- **Face-to-face activities** – workshop/seminar/meeting, webinar, conference
- **Via networks** – partner organisations including academic and research institutions, professional member organisations, parent support and advocacy organisations
- **Scientific outlets** – registration on guideline databases, journal publications

A key strength of the CASaND guideline is its sustainability and integration with aligned plans and programs. This includes:

- alignment with four action areas of the National Stillbirth Action and Implementation Plan (the Plan)
- funding from the Department of Health and Aged Care, through the Plan, to enhance and expand the national IMPROVE (IMproving Review and Outcomes Via Education) education program including new training and education modules to address:
  - culturally safe and responsive care of Aboriginal and Torres Strait Islander peoples, migrant and refugee communities, and those living in rural and remote regions
  - early pregnancy loss
  - care in subsequent pregnancieswellbeing of healthcare professionals.
- tools and resources that have been co-developed with industry and consumer stakeholders.

See the Guideline *Implementation and dissemination plan* for more detailed information on the approach for dissemination of the guideline and national approach to implementation.

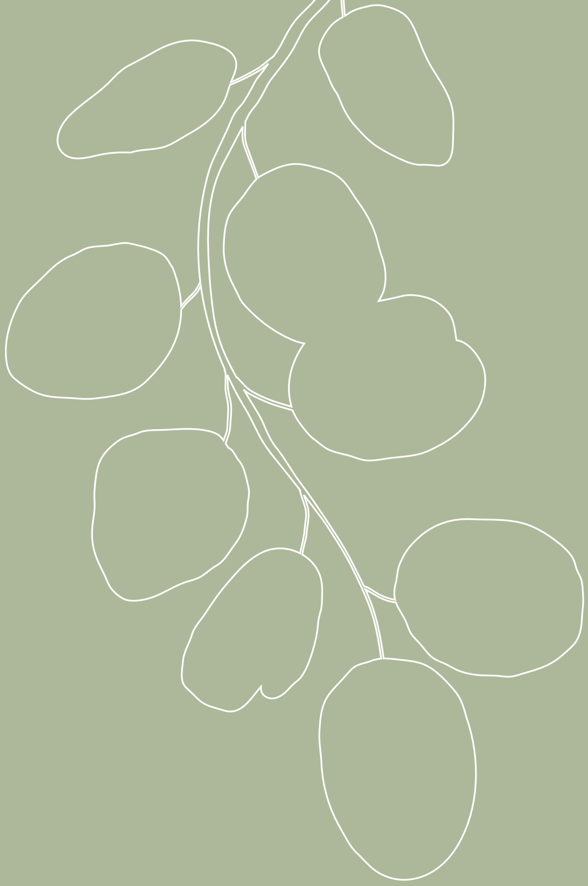
Endorsing organisations

The following organisations and colleges have provided endorsement of this Guideline:

- Australian and New Zealand Neonatal Network (ANZNN)
- Australian College of Midwives (ACM)
- Australasian Sonographers Association (ASA)
- CRANAplus
- International Stillbirth Alliance (ISA)
- Miracle Babies Foundation
- National Aboriginal Community Controlled Health Organisation (NACCHO)
- Pink Elephants Support Network (PESN)
- Red Nose Australia
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
- Royal Australian and New Zealand College of Radiologists (RANZCR)
- Royal Australian College of General Practitioners (RACGP)
- Royal College of Pathologists of Australasia (RCPA)
- Stillbirth Foundation Australia (SFA)
- Women’s Healthcare Australasia (WHA).

References

1. Perinatal and Maternal Mortality Review Committee. *Fifteenth annual report of the Perinatal and Maternal Mortality review Committee. Te Pūrongo ā-Tau Tekau mā mā Rima o te Komiti Arotake Mate Pēpi, Mate Whaea Hoki: Reporting Mortality and Morbidity 2020. Te Tuku Pūrongo mō te Mate me te Whakamate 2020.* 2022; Available from: **https://www.hqsc.govt.nz/assets/Our-work/Mortality-review-committee/PMMRC/Publications-resources/15thPMMRC-report-final.pdf**
2. Australian Institute of Health and Welfare. *Australia's mothers and babies: Definitions.* 2023; Available from: **https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/technical-notes/definitions**
3. Flenady, V., et al., *Clinical practice guideline for care around stillbirth and neonatal death.* Vol. 3.4. 2020, Brisbane: NHMRC Centre of Research Excellence.



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