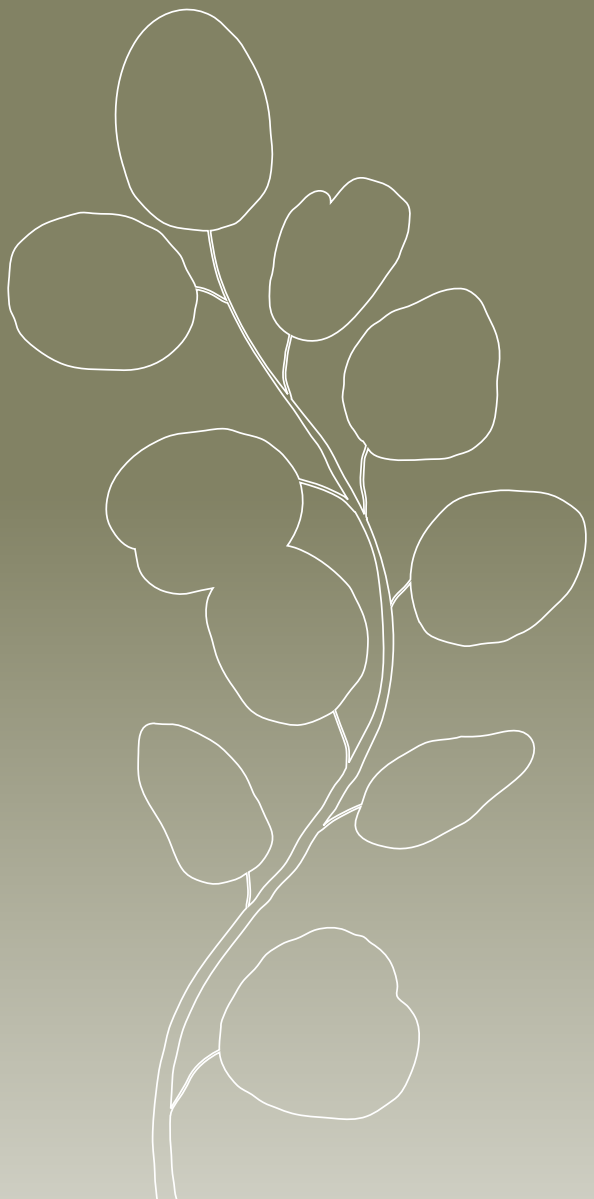
2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Public consultation: Summary of submissions



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

Contents

Public consultation process

A bi-national public consultation was undertaken from 21 August 2023 to 26 September 2023 in Australia and Aotearoa New Zealand. The purpose of this consultation was to receive feedback on the 2024 draft edition of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline* including all supporting resources and technical reports.

Key organisations, professional colleges, parent support and advocacy organisations, and individuals with lived experience of stillbirth and neonatal death were invited to review the draft guideline. Public consultation was promoted by the Stillbirth Centre of Research Excellence in Stillbirth (Stillbirth CRE) and partner networks via email, digital newsletters, social media, and conference presentations. Public consultation was also promoted and made available via the National Health and Medical Research Council webpages and newsletter. In addition, Guideline Development Committee members and members of the Expert Working Groups further disseminated notice of the public consultation period among their colleagues and networks.

Most responses were submitted via an online feedback form. General and demographic questions included:

- Discipline (e.g. midwifery, neonatology, research)
- Type of loss (if the respondent indicated that they were a bereaved parent)
- Length of time worked in field
- Location and state/territory.

Respondents were asked to provide open-ended comments and suggestions on the content, recommendations and accompanying technical reports and some appendices. Respondents were also asked to rate on a four-point Likert scale (poor, average, good, excellent) the presentation of content (look and feel), quality of content, style of language and terminology used, and ease of use for all healthcare professionals, and overall rating of each section. To facilitate review and navigation, each section of the guideline was able to be accessed and feedback submitted individually. Respondents were also asked to indicate any key research papers that were missing from the guideline. Feedback was also received via email.

Overview of submissions received

A total of 65 individuals and organisations provided responses over the public consultation period. Most submissions were received via the online feedback form, and some were received via email. Individual responses were received from a range of healthcare professionals including bereavement midwives, obstetricians, neonatologists, psychologists, psychiatrists, social workers, and bereaved parents. Responses were received from the following organisations:

Professional colleges, organisations, and associations:

- Australian and New Zealand Neonatal Network (ANZNN)
- Australian College of Midwives (ACM)*
- Australian College of Rural and Remote Medicine (ACRRM)
- Australian Institute of Health and Welfare (AIHW)
- Australasian Sonographers Association
- Clinical Excellence Commission, NSW
- CRANAplus*
- National Aboriginal Community Controlled Health Organisation (NACCHO)
- New Zealand College of Midwives
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)*
- Royal College of Pathologists of Australasia*
- Royal College of Radiologists*

Health services

- Mater Mothers' Hospital, Brisbane Qld*
- Mater Refugee Midwifery Clinic, Brisbane Qld
- Mercy Hospital, Vic.

Support and advocacy organisations:

- Karitane
- Miracle Babies Foundation
- PANDA
- Pink Elephants Support Network
- Red Nose*
- Sands New Zealand
- Stillbirth Foundation Australia*
- The Perinatal Loss Centre

*Representation on the Guideline Development Committee.

Summary of key issues

All comments and feedback received for each section of the guideline are documented in Tables 1 to 8. Key issues identified during public consultation were:

- Respondents sought clarification of the definitions for perinatal death particularly around the use of gestational age and birthweight criteria. This 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. Variation in definitions for statistical purposes across jurisdictions may also result in difficulty in interpretation of perinatal mortality rates. This variation includes the inclusion, or not, of perinatal deaths resulting from a termination of pregnancy and the use of gestational age and/or birthweight criteria. This has been clarified across the guideline. See Table 1.
- 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 Guideline 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, and formatting have been addressed (note: these comments have not been included in Tables 1-8). We have also addressed minor comments around improving graphic design and structure to improve user experience and facilitate implementation.

Summary of key strengths

Overall, the draft guideline was received well during public consultation and respondents highlighted many strengths in this edition of the guideline. Many respondents commented on the comprehensive information and guidance provided across the continuum of care for bereaved parents and family/whānau. When asked to rate the presentation of content, quality of content, style of language and terminology, and ease of use for healthcare professionals, most respondents rated each section as 'good' to 'excellent' for all sections. Positive elements identified during public consultation included:

- Greater focus on culturally responsive care for Aboriginal and Torres Strait Islander families and Māori whānau.

> "Appreciated the inclusion of acknowledgement of country. Appreciated culturally appropriate and sensitive language."
>
> **–Midwife, Aus**

> Appreciated culturally appropriate and sensitive language
> **–Midwife, Aus**
> "Wow Wow Wow. I cannot get past the fact that there is going to be a support guide for us First Nations people after stillbirth. Working within maternity care, focusing on First Nations families has meant I have sadly needed to support families following stillbirth. I always felt at a loss in terms of providing stillbirth care, not because I didn't feel like I wasn't capable but because there is nothing tangible (like a guide or resource) that I could hand to families that could add as an extra support. We NEED this. Just looking at the front page with the artwork and the words, I can tell it is healing and gentle".
> **–First Nations Midwife, Aus**

- Most respondents highlighted that the document was well presented and easy to read. Respondents also appreciated the use of sensitive, thoughtful parent-centred language throughout the guideline and the value provided by including parent quote and important statements in the design of the guideline.

> "It is excellent to see the adoption of the term baby as opposed to fetus in recognition that baby is the terminology that is preferred by bereaved parents, the centre of this work." **–Nursing and Midwifery Organisation, Aus**

> "Appreciated the careful and explicit descriptions of language and empathetic language use." **–Midwife, Aus**

> "The format was well presented easy to read." **–Midwife, Aus**

- Respondents also highlighted the range of resources to support implementation of recommendations.

> "It is beautifully written, and the parent resources are great." **–Midwife, Aus**

> "Both the Guiding Conversations and Jiba Pepeny booklets are excellent resources for parents, but also for health care workers to get an idea of the information that parents/families might need or want. The images, language and layouts used are calming yet engaging. I highly commend the authors on the obviously massive amount of work and effort that has gone into developing these resources, and I look forward to using them to assist and support parents and families through such a difficult time." **–Midwife, Aus**

Table 1. Submissions received for Section 1: Introduction and summary of recommendations

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
1.1	Individual	Midwifery (Aus)	• I was particularly impressed with the image and content from page iii (Acknowledgement of traditional people). I found the colouring, font and layout of Section 1 easy to engage with. • I appreciated the use of specific terminology (baby, parent, whānau) and explanation of why those terms were used. I especially appreciated the recognition of health care workers who look after bereaved parents. I think the Glossary and Abbreviations list is a useful tool, and covers many terms commonly used in perinatal loss, and also some that may not be so common. • Both the Guiding Conversations and Jiba Pepeny booklets are excellent resources for parents, but also for health care workers to get an idea of the information that parents/families might need or want. The images, language and layouts used are calming yet engaging. I highly commend the authors on the obviously massive amount of work and effort that has gone into developing these resources, and I look forward to using them to assist and support parents and families through such a difficult time. • An extensive and thorough summary of information, accessible and easy to read. Some minor editing needed (consistent punctuation). • An easily accessible document, which stands alone as a summary of the guidelines available to any healthcare professional. The inclusion of information about the guideline (previous versions etc) could potentially appear as a formal document, rather than a guideline to care (from Section 2 onwards). Perhaps a change of title to “Summary of the guideline and Approach to Care”	Noted.	Revisions have been made to the content to support usability for healthcare professionals.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
1.2	Individual	Midwifery (Aus)	• Appreciated the inclusion of acknowledgement of country. • Appreciated the careful and explicit description of terminology and definitions • Appreciated culturally appropriate and sensitive language • The structure of the section was easy to follow, under appropriate headings • Appreciated the careful and explicit descriptions of language and empathetic language use	Noted.	No change.
1.3	Individual	Obstetrics (NZ)	• Very comprehensive but also too lengthy	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals.
1.4	Individual	Midwifery (Aus)	• The format was well presented easy to read	Noted.	No change.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
1.5	Individual	Neonatology (NZ)	• Why did you use New Zealand throughout the document? can we not use Te Reo and use Aotearoa? why is Māori not defined in your glossary. As the indigenous peoples of Aotearoa we should be acknowledged. Aboriginal and Torres Strait Islander people are acknowledged. • I am somewhat surprised to hear that there might be an expectation that a death certificate might be amended after a perinatal morbidity and mortality committee meeting (Revise the death certificate based on the outcome of the perinatal mortality audit meeting and ensure a revised copy is sent to the parents). I am not sure of the legal implications of this in Aotearoa. • [Appendix 1D: Future directions] I am disappointed to see that in the future research section Māori does not appear at all. Surely there are really important whānau questions that need to be explored. Otherwise we run the risk of perpetuating and sustaining a system that only benefits those who it already benefits.	Noted.	Aotearoa New Zealand has been included throughout the guideline. The glossary has been updated. Based on consultation with the Development Committee, some maternity services have already implemented this recommendation and found it to be very helpful. It was acknowledged that there is an associated increase in workload including appropriate communication and support for families to ensure they are aware of and understand the amendments. The Future directions document (Appendix 1D) has also been revised to include greater focus on research priorities for Māori whānau and other cultural groups in Aotearoa New Zealand.
1.6	Individual	Midwifery (Aus)	• Wonderful thorough document. • Extensive list of appropriate HCPs and researchers	Noted.	No change.

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1.7	Individual	Nursing / Policy (Aus)	• Content and structure is sufficient. The inclusion of the Star Baby Booklet is commended. • Aboriginal and Torres Strait Islander people should be referred to as First Nations people where possible (unless naming conventions determine otherwise). • References to cultural awareness training should be built upon to include cultural safety. It is critical that healthcare services and providers are culturally safe; going beyond awareness of other cultures to include an understanding of their own implicit biases and privilege. • Bereavement care must be culturally safe. Please refer to the Clinical Care Standards for Stillbirth (https://www.safetyandquality.gov.au/standards/clinical-care-standards/stillbirth-clinical-care-standard) which discusses the importance of Sorry Business for First Nations families and other important cultural practices.	The cultural safety expert advisory group and Stillbirth CRE Indigenous Advisory Group have recommended use of the term 'Aboriginal and Torres Strait Islander peoples' for the purpose of this guideline. The Clinical Care Standards for Stillbirth have been referenced and cross-checked to ensure alignment with this guideline.	The glossary outlines use of the term Aboriginal and Torres Strait Islander peoples in this guideline. We acknowledge that some groups prefer use of First Nations people. Minor revisions to *Section 2: Approach to care* to ensure implicit biases and privilege is covered; and *Section 8: Organisational recommendations* to ensure education and training includes cultural safety.
1.8	Individual	Midwifery (Aus)	• [Parent resource: Jiba Pepeny: Star Baby] Wow Wow Wow. I cannot get past the fact that there is going to be a support guide for us First Nations people after stillbirth. Working within maternity care, focusing on First Nations families has meant I have sadly needed to support families following stillbirth. I always felt at a loss in terms of providing stillbirth care, not because I didn't feel like I wasn't capable but because there is nothing tangible (like a guide or resource) that I could hand to families that could add as an extra support. We NEED this. Just looking at the front page with the artwork and the words, I can tell it is healing and gentle.	Noted.	No change.

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1.9	Organisation	Midwifery (Aus)	• (line 202 & 203): neonatal death is defined as the death of a neonate or newborn in the first 28 days of life - I think it would be good to add 'regardless of gestation' after this definition. So "neonatal death is defined as the death of a neonate or newborn in the first 28 days of life, regardless of gestation". • However, you need to be happy with HCP's stating a 19-week live birth as a NND. • (281-284) Neonatal death: 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 - HOWEVER, isn't a 19-week livebirth also a NND? This is how I report these to CCOPMM - as a NND. • (line 291): omit word 'severe'. Some parents terminate with mild abnormalities. • the preferred term to use where possible in this guideline is stillbirth. Do you mean 'baby' instead (not stillbirth)? • Page 10: Neonatal definition - exclude the 20 week rule (as stated above)? • Page 11: Stillbirth definition - Birth following a fetal death prior to birth of a baby - this is 'wordy'. Can you make it clearer e.g. Stillbirth - a fetal death prior to birth of a baby of 20 or more completed weeks of gestation or of 400 grams or more birthweight.	Noted. Definitions included in the public consultation process were from the **AIHW** and **NZ PMMRC** which are used for statistical purposes.	The definitions have been revised to address all feedback received through public consultation regarding definitions. The definition used in the Guideline are consistent with registration requirements for a perinatal death. We have also highlighted the variation in definitions across jurisdictions in Australia and in Aotearoa New Zealand and summarised the definitions in current use in the technical report (see *Section 7: Perinatal mortality audit and classification*).

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1.10	Individual	Midwifery (Aus)	• I strongly believe there needs to be more clarification around at what point/gestation a baby is confirmed deceased. It is my belief that the gestation at which the "fetus is expelled from the other" is the gestation that is documented for legal and reporting purposes. e.g. a baby has confirmed to have passed away in utero at 19+5 weeks gestation, but the mother does not give birth until 20+1 weeks gestation. In my clinical workplace I have seen examples of this situation reported as both a miscarriage (date of death confirmed at 19+5) and not registered. Others have documented it as a stillbirth (date of death confirmed at 20+1) and registered as a stillbirth with BDM and family eligible for parental leave, birth certificate etc. • [Parent resources] Guiding conversations booklet is such an invaluable resource. I have used it as both a clinician (midwife) and as a bereaved mother. Reading the booklet was extremely different when approaching it from these different roles. I have implemented this booklet in my workplace and advocate it to be given early and gone through with the families. I have had excellent feedback from parents who have said it helped them think about and make decisions regarding things they had never contemplated and having the prior knowledge and time for planning, were grateful to have the opportunities to discuss these decisions before they had to be made.	Noted.	The definitions have been revised to address all feedback received through public consultation. The definition used in the Guideline are consistent with registration requirements for a perinatal death. We have also highlighted the variation in definitions across jurisdictions in Australia and in Aotearoa New Zealand and summarised the definitions in current use in the technical report (see *Section 7: Perinatal mortality audit and classification*). For example, variation exists in the use of in the use of gestational age (GA) and birth weight (BW) with some using either or and others using BW only if GA is unknown.

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1.12	Individual	Midwifery (Aus)	• Line 105: We also know that these population groups are resilient, caring and proud: this is really lovely to include. • Line 109: I like this: healthcare professionals caring for families following the death of a baby, this provides an opportunity to remain curious, strive for better, and be reflective in their own practice • Line 162: Red Nose have supported grieving families in Australia for more than 40 years: this is not a well-known organisation in WA. Should consider more education around their support and how to contact them etc	Noted.	National bereavement support services have been included in relevant sections of the guideline to support healthcare professionals in providing appropriate support options to parents and families/ whānau. *Section 8: Organisational recommendations* has also been revised to include greater focus on education for healthcare professionals around available community-based support organisations.
1.14	Individual	Neonatology (NZ)	• should read Te Tiriti o Waitangiâ not Treaty • Line 104 -112: whilst I absolutely acknowledge the inequities sadly faced by these communities, this somewhat diminishes the loss experienced by families not in these groups.	Noted.	Revisions to content have been made.
1.15	Individual	Anonymous (Aus)	• Please acknowledge the role of Aboriginal and Torres Strait Islander Health Workers (AHWs) and Practitioners (AHPs), as well as Aboriginal Liaison Officers (ALOs) in the hospital setting.	Noted.	The target audience has been revised in *Section 1: Introduction* and all relevant sections to include a broader range of roles including AHWs, AHPs, and ALOs.
1.16	Individual	Midwifery (Aus)	• It is beautifully written, and the parent resources are great.	Noted.	No change.
1.17	Individual	Midwifery (Aus)	• The feeling of very acute hospital focus. Would like to link community services • Use of interpreter and how to use them.	Noted.	Content has been revised across sections to include a greater focus on community settings including the interfaces between hospitals and community-based services.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
1.18	Individual	Neonatology (Aus)	• Overall, quite wordy • There is a lot of text to read. I wonder if that will be a barrier to its use in routine clinical practice	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals.
1.19	Individual	Maternal Fetal Medicine (Aus)	• Comprehensive and well-written. • Use of the term “whanau” first appears page iii/21 in the acknowledgement. Support and acknowledge the importance of this word. It appears as “whanau” on this page but throughout document as “whānau” - which is correct? For those not familiar with this word, should it be interpreted as it is unclear if it describes “families” only or “parents and families”. Are there other words that could be included of significance? – e.g. the word for baby, mother or father.	Noted.	The term whānau has been included in the glossary.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
1.20	Organisation	Rural and remote health (Aus)	• Excellent. • [Parent resources] Excellent for use in Maternity skills education programs. • [Appendix 1D: Future directions] Research questions for consideration: What levels of perinatal loss training is provided to medical, nursing, midwifery and allied health undergraduates? What is the (potential) impact of perinatal loss training for hospital services teams (admin /coal face) impacting outcomes? Is our system failing? Why are women seeking peer facilitated bereavement training? • Healthcare professionals to denote all those working with bereaved parents and family/ whānau. It's important to make a distinction between health professionals with recognised training and others working with bereaved parents as not all are health professionals. • Pg 17: Healthcare Professionals as written Health professionals Any health workers requires clarification AND consider adding Aboriginal Health Practitioners (AHP) to Aboriginal Health Workers (AHW) as they are an additional & separate role and include capitals for each word in their titles as above • Perinatal palliative care - Perinatal palliative care aims to improve the QoL of neonatal patient. Define QoL as first use in this document. • Pre-eclampsia: Description needs to move down one line and perhaps be reword definition around postnatal time frames and signs which can vary greatly. • Termination of pregnancy due to Fetal Anomaly (TOPFA) - Termination of pregnancy for fetal abnormality may only be considered if there is a substantial risk that the child, if born, would suffer physical or mental abnormalities that would result in serious handicap. Perhaps replace handicap with disability. • •[Appendix 1C: Jiba Pepeny (Star Baby)] I know it wasn't open for feedback and it's late, but I wanted to commend you on this brilliant resource....	Noted.	*Future directions* (Appendix 1D) has been revised. *Section 4: Perinatal palliative care* has also been revised and acronyms defined. Definitions are addressed in the Glossary.
1.21	Organisation	Pathology (Aus)	• MOST IMPORTANT - under Perinatal Autopsy. The placenta is ALWAYS relevant and should ALWAYS be examined as part of a perinatal autopsy	Noted.	*Section 6: Investigations for perinatal death* has been revised.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
1.22	Individual	Anonymous (Aus)	• Thanks for opportunity to review this excellent document. It is noted that it is evidence based and a comprehensive resource for all clinicians across Australia. The guidelines are supported in principle, but their application will depend on them not being counter to WA legislation. • The comments below are provided to assist/enable improvement for the document resulting from the time spent in review. • 20 weeks and 0 days gestation are included in the national data for stillbirth. • Birthweight is only used to include infants if the gestation is unable to be determined e.g. a fetus known to be from a pregnancy of less than 20 weeks that weighs 400 grams or more (i.e., hydrops) is not included. • Page 3, Line 270 the definition for Stillbirth is inconsistent with the definition provided for Neonatal death. That is, should be any death of a fetus from 20 or more completed weeks of gestation or if gestational age unknown, weighing 400 g or more at birth • Page 3, Line 276 should be >= 20 weeks gestational age, OR >= 400 g weight • Page 3, Line 289 Termination of pregnancy should be from 20 weeks • Note that changes to legislation in WA are pending that will prevent DoH collection of perinatal death data for termination of pregnancy. • In the definition for fetus there is a statement that stillbirth is used instead. Stillbirth is not in any way equivalent to fetus unborn baby that may or may not be deceased in utero. A stillbirth is a baby born without signs of life, it is not a fetus as it is not unborn. • Definition of MITS. What is meant by low- and middle-income country settings? Does country refer to rural areas or nations? Should the income part of the phrase refer to people? • The definition of a multidisciplinary team is not really a definition. It also does not describe how a multidisciplinary team enables parents and families to receive well-coordinated care in the right place and time.	Noted.	The definitions have been revised to address all feedback received through public consultation. The definition used in the Guideline are consistent with registration requirements for a perinatal death. We have also highlighted the variation in definitions across jurisdictions in Australia and in Aotearoa New Zealand and summarised the definitions in current use in the technical report (see *Section 7: Perinatal mortality audit and classification*). For example, variation exists in the use of gestational age (GA) and birth weight (BW) with some using either or and others using BW only if GA is unknown. The Glossary has been updated. *Section 6: Investigations for perinatal death* has also been revised and clarification around low- and middle-income settings provided. Definition for low- and middle-income country has been added to the Glossary.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• Suggest the definition for neonatal death is reworded to prevent interpretation of birthweight of 400 grams occurring in first 28 days and not death. • Definition of perinatal autopsy Suggest removal of fetus or from the following text: following the death of a fetus or baby including: external examination, examination of all of the internal organs (usually via two or more incisions), examining small samples of tissue under a microscope, medical photographs, other tests such as genetic investigations. Tests may also be done for infection and other possible teratogens, causes of death or complications. The placenta where relevant will also be examined • Suggest defining the word “teratogens” as it is used in another definition • Definition of perinatal palliative care references QoL. This term should be written in full or further defined. Also prefer that neonatal patients be called infants before 28 days of age in line with other preferred terminology described before this. • Perhaps add definition for perinatal as previously defined antenatal and then reference perinatal in other terms without explaining what it means. • Should RANZCOG be included in definitions with ACOG and RCOG? • Perhaps add to definition of religious considerations the example of special time for burial or period between death and burial. • Suggest rewriting definition for SGA to be like A condition diagnosed when a baby has a birthweight less than the 10th centile of population-based birthweight centiles for babies of same sex and gestational age. • Suggest rewriting definition for Stillbirth to be like a baby born with no signs of life at 20 or more completed weeks of gestation or where gestation unknown, of 400 grams or more birthweight. • Recommendations read very well and should be easily applied.		
1.23	Organisation	Sonography (Aus)	• Use more inclusive language congenital anomalies not abnormalities. • Definition of TOPFA (pg. 12 of 21)- word abnormality is not considered inclusive terminology- anomaly/variation. • Well-written.	Noted.	Revisions have been made to terminology and definitions used throughout the Guideline.

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1.24	Individual	Health and Social Policy (Aus)	• This is a comprehensive document. The length and density of the content would see it be more of a reference document rather than used directly in the clinical space.	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals.
1.25	Organisation	Nursing and Midwifery (Aus)	• It is excellent to see the adoption of the term baby as opposed to fetus in recognition that baby is the terminology that is preferred by bereaved parents, the centre of this work. • It is good to see the voices of Aboriginal women recognised in this document noting the higher risk of stillbirth experienced by First Nations women in Australia. • The guideline is comprehensive, family and women-centred and has considered how best to address the needs of groups who may have specific considerations. Acceptability, accessibility and cultural safety are central to the guideline and are well aligned with the National Stillbirth Action and Implementation Plan. The guideline encompasses many valuable resources for clinicians, including technical reports and resources, which can be used directly with families. Incorporating the importance of ongoing grief support and forward pregnancy planning is good to see, with appropriate referral services outlined in the guideline. The needs of families and clinicians is comprehensively covered with appropriate linkages to the evidence base identified.	Noted.	No changes.
1.26	Anonymous	Aus	• Consider if 'culturally safe and responsive care' is the best term.	We acknowledge the importance of highlighting culturally safe and responsive care for all families/whānau. The guideline group discussed this in detail and sought advice from relevant individuals who advised this terminology.	No change to subheading in *Section 2: Approach to care*; however, consideration and revisions to content has been conducted to ensure culturally safe care is clear.

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1.27	Organisation	Obstetrics & Gynaecology (Aus/NZ)	• In line with RANZCOG's Clinical Guideline for Abortion Care: an evidence-based guideline on abortion care in Australia and Aotearoa New Zealand, the College advises that the phrase "termination of pregnancy" be replaced with "abortion". • Section 1, page 3, line 289, Termination of pregnancy for medical reasons (i.e. fetal anomaly). The College believes the wording used in this section suggests that fetal anomaly is the only medically valid indication to end a pregnancy, with the expectation of perinatal death. Semantics need to be carefully considered when discussing a sensitive topic such as this. The College suggests rewording this section as the current phrasing could be negatively perceived by people who end a pregnancy for reasons other than fetal anomalies. Examples such as a suspected intrauterine sepsis, extreme early-onset preeclampsia, or maternal psychiatric illness, among others, may consequently be perceived as "not for medical reasons".	Noted.	No change. This guideline uses parent-centred language that is intended to be inclusive of all affected by loss. The guideline group discussed this in detail and sought advice from relevant individuals who advised the use of the terms "Termination of pregnancy" rather than "abortion". Revisions have been made to the definition of *Termination of pregnancy* throughout this guideline to include termination for maternal indications. Reference to the RANZCOG Guideline has also been included in *Section 2: Approach to care*.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
1.28	Organisation	Midwifery (NZ)	• The College commends CRE and PSANZ on the wide diversity of representation on the guideline development committee (including Māori representation), and we note the depth of Aboriginal/Torres Strait Islander representation within the CRE committee. However we would have expected to see more New Zealand midwifery representation and other New Zealand maternity clinicians on the expert working group, and we would recommend inclusion of Māori representation within the CRE also. A tikanga Māori expert would have brought a valuable contribution to the expert working group. • Some of the consensus-based recommendations appear to be more appropriate for an Australian context and don't necessarily translate well to the New Zealand maternity context. For example, the word 'accoucher' (Appendix 6E) is not generally used in Aotearoa New Zealand. Another example of this is recommendation 2.2 (recommending continuity of carer, such as a bereavement midwife,) - in New Zealand continuity of care is usually already provided by a Lead Maternity Carer who is most often a community-based midwife.	Noted. The Guideline Development Committee and Cultural considerations expert working group included NZ midwives and Māori parent representatives. However, we acknowledge the importance of wider representation of Tikanga Māori experts and look forward to continuing collaborations and partnerships in the dissemination and implementation of the Guideline and future editions. PSANZ is in the process of reestablishing bi-national advisory groups for Indigenous groups.	*Section 1: Introduction* has now been revised. The Executive summary now provides a summary of the recommendations, which should support usability. The appendix has been renamed to 'Placental examination for healthcare professionals' (Appendix 6D). Lead maternity carer (community-based midwife) has been included.

Table 2. Submissions received for Section 2: Approach to care

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
2.1	Individual	Neonatology (NZ)	• There is a lack of consistency in this section. For example, whānau (extended family networks) is finally mentioned yet I think this isn't in the previous glossary (I would need to go back and look and to be honest I am not going to). I also note the use of whakapapa is used which is appropriate but again is this defined in the glossary? • I would suggest that you move towards a Whānau collective approach as at the moment some of what is written focuses on the individual parents and for some of us things are viewed much more collectively & that does not seem to be reflected in this document currently. • There is a lack of calling out about the paucity of research for whānau Māori in this area. There is only 1 study (I think) from Aotearoa, and it highlights to me that we do not really know what whānau need or want as we haven't asked the question. I think this section needs to acknowledge that there are major gaps in our knowledge currently.	Noted. We acknowledge the importance of a whānau-centred approach to guideline development and look forward to addressing this in future editions.	The glossary has been updated. The *Future directions* document (Appendix 1D) has also been revised to include greater focus on research priorities for Māori whānau and other cultural groups in Aotearoa New Zealand.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
2.2	Individual	Midwifery (Aus)	• Appreciated clearly outlined aims and objectives • Appreciated the frequent reminders e.g. page 2/18 between lines 53 and 54 “this guideline acknowledges all parents who experience the death of a baby during pregnancy or soon after birth” with the use of empathetic and kind language - good use of inclusive language also. • Paragraph beginning on page 4/18 line 77 talking about continuum of care - when this practice guideline is published online, perhaps could hyperlinks be created to link relevant paragraphs to glossary/ abbreviations where appropriate? • Recommendations seem appropriate, but perhaps vague in practical application? It allows a health professional to seek out avenues of planning but doesn’t specifically name or include other professions, where to access information regarding cultural specifications (e.g. based on region, hospital or healthcare services) - which is allowing the care team to individualise care according to particular needs and wishes - • Often in practice, it is such a difficult job to present all these options to parents to make these decisions - often there is also a time constraint which we need to be aware of (e.g. if death in utero occurs, a baby’s appearance can deteriorate quickly which makes certain traditions or memory creation details very difficult if not impossible if the baby is not delivered within the week. If there some kind of database or list of relevant cultural support workers or how to access this information, health professionals can also present these options to the parents in a time appropriate way, and it can be useful for health professionals to have this kind of awareness or access to this kind of information if they are working rurally etc or if the cultural specifications are known. • I think section seems quite straightforward in the delivery of evidence based and consensus-based recommendations.	Noted.	Content has been revised and professional editing conducted to improve readability and usability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals. Recommendations and summary content has been revised throughout the guideline to ensure they are clear, concise, and practical. We acknowledge the challenges faced by many healthcare professionals and organisations in delivering best practice care and have included links to resources and support services. This is addressed in Consensus-based recommendation 8.3 in *Section 8: Organisational recommendations*.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
2.3	Individual	Neonatology (NZ)	• Include Community First Response organisations e.g. St Johns ambulance services • No mention of NZ equivalent organisations e.g. Wheturangitia, Sands, Baby Loss NZ. • Can LWL be accessed online from NZ? Is there an equivalent? • From around the time a baby dies seems potentially too late to include early grief counselling with life-limiting diagnoses that may progress to consideration of termination • Cannot include Māori whānau in this sentence when specific Aboriginal ceremonies and rituals are referenced or termed “sorry business“ Māori do not use this term and have different rituals they would consider important. Definitely should be given the place to practise these rituals, but please consider referencing Māori in a separate sentence or do not use the term “sorry business” here.	Noted.	Community First Response organisations has been included in the *Target Audience* definition throughout the Guideline. Transport has been briefly covered in this edition of the Guideline and will be expanded in the next edition. Content has been revised including reference to specific bereavement support organisations in Aotearoa New Zealand; availability of LWL (Australia); clarification around support provided along the continuum of care; and cultural considerations including sorry business for Aboriginal and Torres Strait Islander families and karakia and observation of tikanga for Māori whānau.
2.4	Anonymous	Aus	• Recommendations are simple and easy to understand. The inclusion of quotes reinforces the recommendations. • The inclusion of the technical report and evidence synthesis is helpful and provides great background.	Noted.	No change.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
2.5	Individual	Nursing / psychology & bereaved parent (Aus)	• There are too many words on each page it's an incredibly wordy document and the information your providing doesn't seem that groundbreaking or new I think you can revise this down. • The choice of the brown makes me feel weighed down and is not making me want to read the document. A new colour choice might be better. • The use of the quotes was good as it broke up the heavily worded pages. I feel they (recommendations) are not engaging as there is too much on each page.	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals. The colour of this section has been changed.
2.6	Individual	Midwifery (Aus)	• Bears of Hope and Pillars of Strength noted- please consider other resources- precious wings etc. State funded program will be a more localised approach.	Noted.	No change. As this is a national guideline, state-based support programs are not listed.
2.7	Organisation	Parenting (Aus)	• Include mental health telehealth options to postnatal as well. Not only antenatal here, or link to the other sections. • Recommendation 2.1: A multidisciplinary team should oversee care across the continuum from diagnosis until death - what death – infant, mother, or does it not matter? • Recommendation 2.12 - maybe add link services available. • Evidence of birth trauma may assist additional information.	Noted.	National perinatal mental health support organisations have been included. Recommendations have been revised to be clear and concise.
2.8	Individual	Neonatology	• Still very wordy. Might be helpful to highlight most important aspects and shorten some parts. • Recommendations not always clear; Example: "Offer parents culturally and linguistically appropriate information about perinatal grief". Very general advice, but little hands-on information (where to find what).	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals. Parent-facing resources have been included in this Guideline and others have been referred to where available.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
2.9	Individual	Neonatology (Aus)	• A lot of detail in the sections. I wonder about listing all the recommendations for this section at the beginning of the section and then discuss recommendation by recommendation. • Recommendations are relevant	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals.
2.10	Individual	Aus	• It is good to see there is increased attention and recommendations regarding grief and care for fathers and extended family in the guideline.	Noted.	No change.
2.11	Organisation	Rural and remove health (Aus)	• [Technical report] Page 5, Section 1 - Outcomes, processes, and experiences of culturally safe care for aspects of care associated with doulas (perhaps also add Djäkamirr here - Caretaker of Pregnancy and Birth) or get guidance on including this	Noted.	We found no evidence for doulas as part of our systematic review of the evidence. We will address this in the next edition.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
2.12	Individual	Perinatal research (Aus)	• A note about terminology. The authors are to be congratulated on their crafting of the language in these guidelines. Keeping fathers and mothers while acknowledging the variability in family types is an elegant solution. • On page 7 Pillars of Strength is listed as providing support for bereaved fathers. The Department of Health funded SMS4dads program (www.sms4dads.com), in partnership with Red Nose, also provides text-based support for fathers who have experienced perinatal loss. • The recommendations are largely accurate and relevant. Except for this one: Under "Social and emotional support for perinatal grief", you list some of the evidence for addressing fathers' grief in the guidelines. Yet the recommendation 2.8 on page 8 is only a 'Consensus-Based Recommendation "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". Is the reason for not listing this recommendation as evidence-based because a systematic review failed to find sufficient evidence? If so, it would be useful to see a reference to this process somewhere in the document. • While the use of parent's in the document is appropriate, it is important for the credibility of the Guidelines for evidence to be accurately cited. The statement on page 8 that "In a recent randomised controlled trial, parents 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 the usual care control condition is inaccurate." The study by Loughnan et al, which was presented at The Australasian Marce Society and Helen Mayo House Joint Perinatal Mental Health Conference in September 2023, reported that of the 95 parents in the study, 89 (94%) were mothers. The statement on page 8 should be corrected to reflect the study population.	Noted.	Content has been revised to address comments. SMS4Dads is not currently available for fathers to sign up to following loss and so has not been included in this edition of the guideline. Pillars of Strength have amalgamated with Red Nose so have been removed from the section. LWL has been revised to specify bereaved mothers.
2.13	Organisation	Health (Aus)	Recommendations are relevant and easy to understand.	Noted.	No change.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
2.14	Organisation	Perinatal mental health (Aus)	• Expand Section 2.4 to include information on mental health conditions including acute stress reaction, adjustment disorder and fear of childbirth following stillbirth (Gutteridge & Richens, 2022; Haynes, 2022; Herbert et al., 2022; Kothari et al., 2022; Lewkowitz et al., 2019). • From a strengths-based mental health lens, consider conducting a review of the literature on post-traumatic growth (PTG) following stillbirth for potential inclusion in this section (Hurst & Kannagara, 2022; Ryninks et al., 2022). There is robust evidence for post-traumatic growth following bereavement, and PTG following perinatal loss is an important, emerging area of research. • Any review of Section 2.4 should include community consultation with peer workers and bereaved parents who have lived experience of mental health conditions following stillbirth. • If these mental health conditions are to be included in the Guide, add definitions for each to the glossary (acute stress reaction, adjustment disorder, post-traumatic growth, and secondary tokophobia/fear of childbirth). • PANDA also has capacity to provide telephone-based counselling and peer support to bereaved parents via our National Perinatal Mental Health Helpline. PANDA often refers recently bereaved parents to peer and counselling support services like Red Nose. However, for bereaved parents across the continuum of interpregnancy care who may not have access to/be eligible for support from other services listed in the Practice Guidelines (for example, parents planning to conceive or pregnant again after loss) PANDA would like to be considered for inclusion in the CASaND Clinical Practice Guidelines as a mental health and wellbeing support option. • We also note that the COPE Australian Clinical Practice Guidelines: Mental Health Care in the Perinatal Period does not yet include interpregnancy care continuum practice guidance for supporting parents who have experienced mental health decline associated with perinatal loss, including stillbirth but also miscarriage, termination, neonatal and infant death. PANDA will advocate for the inclusion of this essential practice guidance during the next Clinical Practice Guidelines review in 2027.	Noted.	We will address additional mental health conditions in the next edition of the Guideline. Some studies have been included in the evidence synthesis as part of the recent top-search. Other suggested studies do not meet certain forms of inclusion criteria. The COPE perinatal mental health clinical practice guideline has been removed from this edition of the guideline as it does not address mental health and wellbeing following perinatal loss. Post-traumatic growth following bereavement has been included in *Appendix 1D: Future directions.* PANDA national helpline has been included as a mental health and wellbeing support option.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• Additional references: – Gutteridge, K., & Richens, Y. (2020). Who's Afraid of the Big Bad Birth?: Childbirth Trauma, Fear and Tokophobia. Understanding Anxiety, Worry and Fear in Childbearing: A Resource for Midwives and Clinicians, 121-146. – Haynes, E. (2022). Maternal Trauma. In Motherhood and Mental Illness (pp. 43-54). Routledge. – Herbert, D., Young, K., PietrusiÅ„ska, M., & MacBeth, A. (2022). The mental health impact of perinatal loss: A systematic review and meta-analysis. Journal of Affective Disorders, 297, 118-129. – Hurst, R., & Kannangara, C. (2022). Post-traumatic growth from grief: A narrative literature review. Mental Health and Social Inclusion. – Kothari, A., Bruxner, G., Dulhunty, J. M., Ballard, E., & Callaway, L. (2022). Dads in Distress: symptoms of depression and traumatic stress in fathers following poor fetal, neonatal, and maternal outcomes. BMC Pregnancy and Childbirth, 22(1), 956. – Ryninks, K., Wilkinson-Tough, M., Stacey, S., & Horsch, A. (2022). Comparing posttraumatic growth in mothers after stillbirth or early miscarriage. Plos one, 17(8), e0271314. – Lewkowitz, A. K., Rosenbloom, J. I., Keller, M., Lopez, J. D., Macones, G. A., Olsen, M. A., & Cahill, A. G. (2019). 121: Is stillbirth associated with increased risk of severe psychiatric illness within the subsequent year?. American Journal of Obstetrics & Gynecology, 220(1), S96.		

Table 3. Submissions received for Section 3: Perinatal loss care

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
3.1	Individual	Nursing & health research (Aus)	• Easy to read and understand. • They (recommendations) are very helpful and valuable, especially for junior staff who may never had to deal with the loss before, it gives them ideas to guide them in the process. • [Technical report] Very thorough dissemination of information. • Great piece of work.	Noted.	No change.
3.2	Individual	Midwifery (Aus)	• Use the word mother consistently. It is mothers that experience lactation after the death of their baby. One of my clients has just experienced the loss of her baby and it meant so much to her that she is her baby's mother. Please do not erase women.	Noted.	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 identifies 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.
3.3	Individual	Neonatology (NZ)	• Again there are Kupu in this section that are not in the glossary (at least there is explanations in brackets which is better than section 2).	Noted.	The glossary has been updated.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
3.4	Individual	Midwifery (Aus)	• Reminder at the start of the section about the use of the word 'health professional' to describe any member of the care team was helpful to keep in mind during the section. • Appreciated the use of language to validate parenthood. • Appreciated reminders that memory creation should be parent-led. • Recommendations were accurate and relevant. Helpful and easy to understand and implement in practice.	Noted.	No changes.
3.5	Individual	Bereaved parent / Nursing (Aus)	• I have one suggestion; in the memories an audio recording and heart rhythm of the baby's heart is an additional way to provide a hugely meaningful memento. The fundamental nature of a heartbeat would be an enduring memory for a parent. It may be a reasonable practice to record a baby's heartbeat from CTG as a routine practice. • Additional references: – **https://www.nature.com/articles/s41390-019-0638-7** – **https://www.researchgate.net/publication/346829146_Heartbeat_Recording_and_Composing_in_Perinatal_Palliative_Care_and_Hospice_Music_Therapy** – Kiefer, E.P. (2021) HEARTBEAT RECORDINGS IN MUSIC THERAPY: A SEQUENTIALEXPLANATORY MIXED METHODS STUDY – **https://ehospice.com/inter_childrens_posts/heartbeat-music-memory-making/** • This is beautifully done. I wish I had received care like this after my baby died 12 years ago. As a NPICU RN, I feel we can often do this better, and I will be taking this guideline to my work.	Noted.	Content has been revised and memento example has been included in *Section 4: Perinatal palliative care.*
3.6	Anonymous	Aus	• Memory boxes are also provided by Miracle Babies Foundation.	Noted.	This has been updated throughout the Guideline.
3.7	Individual	Midwifery (Aus)	• Excellent recommendations. • Realistic alternatives for ongoing care provisions with Hospital to Home and Federally funded programs.	Noted.	No change.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
3.8	Individual	Bereaved parent / Midwifery (Aus)	• Section 3 is a well collaborated document. It outlines the important areas of perinatal loss care and provides clinicians a guide on how to deliver this care, regardless of resources available. Remote located HCP and those living in cities will benefit from this section.	Noted.	No change.
3.9	Anonymous	Neonatology (Aus)	• Comprehensive. • Helpful to have the links included as you have done for resources available in Australia and NZ.	Noted.	Links to NZ resources and support organisations have been included.
3.10	Individual	Neonatology (Aus)	• This reads well and provides helpful suggestions for a clinician.	Noted.	No change.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
3.11	Individual	Bereaved parent / Midwifery (Aus)	• Need to add the word “labour” to this section: Page 3 line 84. • Communication during the disclosure of death, and labour and birth care should always be respectful, honest, and free from distractions. • Consensus based recommendation 3.7: Antenatal care plan including individualised preparation and support for labour and birth. • Recommendations for care during labour are missing. Please see below for quotes and recommendations from the “birthing in grief study” funded by the Stillbirth foundation ref 26. • Evidence-Based Recommendation 3.10 Evidence quality: moderate confidence Advise parents that a labour and vaginal birth may provide physical and emotional benefit, compared to a caesarean section without obstetric indication. However, parents’ values, preferences, and wishes need to be respected. QUOTE My Mum was horrified [about not being able to have a caesarean], she was just “why would the hospital not just be giving you a caesarean and getting the baby out, why would they be making you go through this?” But I’d explained to her, we had been given that option, but we’d also been advised, or gently encouraged, towards having a vaginal birth. [Birthing parent] • Evidence-Based Recommendation 3.11 Evidence Quality: Moderate Confidence Provide parents with information about what usually happens when labouring with a baby who is going to be stillborn, applicable to their particular situation. Information should be given in a range of formats bearing in mind parents often report impaired clarity of thought. Parents should be given as much time as they need to make decisions about options offered. QUOTE: so just laying it out on the table. Giving you the information, giving you some time to process it and then coming back and saying now would you like A or B, and guiding that I suppose. [Birthing parent].	Noted.	Content and recommendations have been revised according to comments. Warland et al 2023 recently published paper has been incorporated into the evidence synthesis, recommendation, and chapter.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• Evidence-Based Recommendation 3.12 Evidence Quality: Moderate Confidence Advise parents that the full range of pharmacological and non-pharmacological pain relief options (including labour and birth in water) are available for them. That they may choose a different option than they had previously planned and that they will not be locked in any particular option as labour progresses. Offer strong pain relief /sedation with caution as this may interfere with later recall of the only memories they have of their baby. • Evidence-Based Recommendation 3.14 Evidence Quality: Moderate Confidence Validate Parenthood by: Caring for parents as any other labouring parents. Parents want care providers to facilitate their choices, their sense of control, their autonomy and their agency. They want to feel that they received the best care available. QUOTE 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. [Birthing Parent] • Need to provide more on care during labour • Additional references: – Warland J, Nagappa K, Tapper G, Squire G, Stokes T, Criddle S, Butt J, Atkinson J, Cooper M. (2022) Water immersion for Stillbirth? A case report. ACM News Autumn issue 13-15 – This manuscript is currently under review following a request to revise and resubmit once published it provides more detail than ref 26 and should replace it: Warland J, Collier A, Pollock D, Horey D, Boyle F Parents description of labouring and birthing a stillborn baby: findings from the birthing in grief study. Currently under review following revision ANZJOG MS # ANZJOG-2023-0039.R1		

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
3.12	Individual	Aus	• This Perinatal Loss Care Section needs much more information included on lactation after infant death. For many mothers it is a double grief the loss of their baby and the loss of breastfeeding for which their breasts have prepared. Colostrum can be produced from 16 weeks which can be quite a shock for mothers experiencing a birth from 16+ weeks gestation. • Section 3 provides a great deal of detail for immediate post loss care but needs further guidelines in the area of ongoing care, particularly around lactation after bereavement. – Line 461 - The list of physical effects and changes should include the body's preparation for lactation and how to manage this. – Line 473 mentions that many bereaved parents will experience the onset of lactation. This can be a shocking and unexpected additional distress to a mother whose baby dies after 16 weeks gestation. Discussion and management of lactation should therefore be included as part of best practice care. – Lines 473-5 This document acknowledges that information and support around the management of lactation is reported as being inadequate. Yet this document does not fully address the lactation concerns of bereaved parents or provide the full range of options and adequate guidance for health professionals working with these families. The topic of lactation after bereavement is relevant to almost all parents experiencing stillbirth or neonatal death. This topic is important enough to include a separate section with detailed information and guidelines for health workers.	Noted.	The Lactation after loss content has been revised to address these comments and additional references have been added.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			– Section 3 would be easier to navigate with a front-page index with page numbers for the topics - background/terminology/breaking bad news/care planning and decision-making/labour and birth/ memory-making and spending time with baby/collection and creation of mementos/postnatal care and physical recovery/LACTATION AFTER BEREAVEMENT/Leaving hospital and ongoing support. – Line 482 The full range of options includes immediate suppression of lactation using medication, gradual suppression as the mother works through her grief process, using breastmilk to make mementos, ongoing lactation and donation of milk to a milk bank or through a community-based sharing network. – Line 486 Provide information on donating expressed breastmilk to milk banks and to community networks such as Eats on Feets https://www.eatsonfeets.org/ and Human milk for Human babies https://www.hm4hb.net/ – Mothers who choose to express their breastmilk should be assisted with information about hiring or buying a breast pump. – Line 542 The Home Program should also include lactation support as required, provided by appropriately trained health workers with referrals to the Australian Breastfeeding Association Helpline and resources. – Line 511 Consensus-Based Recommendation 3.22: Provide information on the full scope of lactation management options. This recommendation should include provide information on the FULL scope of lactation management - including immediate suppression of lactation using medication, gradual suppression as the mother works through her grief process, using breastmilk to make mementos, ongoing lactation and donation of milk to a milk bank or through a community-based sharing network.		

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			– Additional recommendation 3.23: Refer mothers who plan to express breastmilk to community support from the Australian Breastfeeding Association's Helpline, website and booklets. – It is pleasing to see the use of the term parent and baby. Whether or not they have a living child, they will always be a parent. And whether or not the child is viable it will always be their baby. – Additional references: In addition to reference 59. Carroll, K., et al., The "Lactation After Infant Death (AID) Framework": A guide for online health information provision about lactation after stillbirth and infant death. Journal of Human Lactation, 2020. 36(3): p. 480â€"491 doi:10.1177/0890334420926946, the recent work by Dr Katherine Carroll and Dr Debbie Noble-Carr can provide additional information and resources on the topic of lactation after infant death. See their current projects and papers at https://sociology.cass.anu.edu.au/research/projects/lactation-after-infant-death.		
3.13	Organisation	Health and Social Policy (Aus)	• This is a comprehensive document. The length and density of the content would see it be more of a reference document rather than used directly in the clinical space.	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals.
3.14	Organisation	Nursing / Midwifery (Aus)	• Great to see inclusion of valuable and practical resources.	Noted.	No change.
3.15	Organisation	Rural and remote health (Aus)	• Leaving hospital and ongoing support ...could include more guidance on the remote context including emotional care and logistics involved in returning from the referral hospital to a remote community along with communication & support to women, family & primary health care teams involved.	Noted.	Content has been revised across sections to include a greater focus on community settings and rural and remote considerations. We will address this in the next edition of the Guideline.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
3.16	Anonymous	Sonography (Aus)	• Good recommendations. • I like the addition of the parent reflections in the green font.	Noted.	No change.
3.17	Organisation	Midwifery (NZ)	• Clinical guidance for health practitioners in relation to labour and birth management when facilitating a stillbirth is notably absent. For example, the method of induction of labour and usual parameters in relation to frequency of medication dosages and acceptable contraction patterns may differ from care when a live baby is being born. An evidence review and accompanying recommendations on induction of labour method following fetal demise would be beneficial.	Noted.	This guideline refers to the RCOG guideline for induction of labour recommendations as no specific research question was included in this edition of the guideline. Content has been revised to reference the RCOG guideline. Induction of labour following fetal demise has been included in future directions and will be included in subsequent editions of the guideline.

Table 4. Submissions received for Section 4: Perinatal palliative care

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
4.1	Individual	Neonatology (Aus)	• Straight forward and easy to read. • Well documented dissemination of literature. • I think potentially a section on babies who are sick and who are likely not going to survive their stay in the neonatal intensive care unit and how potential clinicians can broach the subject of moving towards a palliative care pathway. • The other change of wording would be in the Approach to care section - Bereaved parents report benefit in having a perinatal palliative care coordinator (often a midwife) - maybe include nurse in this section as often babies are moved towards a palliative care pathway in the NICU, and their care coordinator may well be a nurse. • [Appendix 4A: Example of a perinatal palliative care plan] Easy to follow.	Noted.	Revisions have been made to the content of *Section 4: Perinatal palliative care* to include greater focus on communication and care before the baby's birth and after the baby's birth. Nurse has been included as an example of a perinatal palliative care coordinator.
4.2	Individual	Neonatology (NZ)	• I am not sure about the language and wording of this section. It talks about family centred care rather than whānau centred care and also about individuals so that it does not necessarily have a collective approach to whānau. • [Technical report] Again there are gaping great evidence free zones for Whānau Māori and this document does not speak to this. • This is the neonatal nurses palliative care model for Aotearoa I would suggest this is an excellent resource and I will be using this - **https://www.nzno.org.nz/Portals/0/Files/Documents/Groups/Neonatal%20Nurses/Resources/2016-03%20Final%20Neonatal%20Palliative%20Care%20Nov%202015.pdf**	Noted.	This is a bi-national guideline so the terms family and whānau have both been used throughout the guideline. Revisions have been made to *Future directions* (Appendix 1D) to include greater focus on research priorities for Māori whānau and other cultural groups in Aotearoa New Zealand. We have now referenced the neonatal nurses palliative care model for Aotearoa New Zealand in *Section 4: Perinatal palliative care.*
4.3	Individual	Midwifery (Aus)	• Helpful. • It is wonderful to have parents as central and outlined/specified as parent-led cares as the framework for palliation.	Noted.	No change.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
4.4	Individual	Project officer (Aus)	• Not clear how the care plan template is to be used. Is it a prompt or support for development of local resources.	Noted.	The care plan template has been renamed to support usability. It is now called 'Example of a perinatal palliative care plan'.
4.5	Organisation	Parenting (NSW)	• Feedback from the perinatal mental health team - Palliative is a strong word in antenatal period we are aware that the framework uses this word… • Maybe add a bit on community-based care and emotional support needs in community - examples and add an internal link in the document to section 8. • Need a bit more on community planning - longer term. Does the parent know where to seek help in 6 months' time - PIMH For When service, PANDA, SANDS etc. MH access line, Plunket tresilian, karitane.	Noted.	This section has been revised and includes reference to national parent bereavement support services. Use of sensitive and compassionate language has been highlighted. Further information on best practice care is provided in *Section 3: Perinatal loss care.*
4.6	Anonymous	Neonatology (Aus)	• Missing is communication tips. Whilst there are similarities to the communication processes articulated in the section relating to stillbirth and neonatal death, there are differences for a palliative care discussion. I think it would enhance this chapter to include some of these nuances.	Noted.	This section has been revised to incorporate additional content particularly around good communication.
4.7	Individual	Executive Director (Aus)	• This is a comprehensive document. The length and density of the content would see it be more of a reference document rather than used directly in the clinical space.	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals.
4.8	Individual	Nursing / midwifery (Aus)	• This section clearly identifies the need for obstetric and midwifery teams to collaborate and refer within the multidisciplinary team, including specialists in palliative care in both the acute and community setting. The guideline clearly communicates the requirement for considered planning and appropriate support during diagnosis, pregnancy, birth, the postnatal period, palliation and in the months and years following the loss of a child.	Noted.	No change.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
4.9	Individual	Neonatology (Aus)	• It's generally good but I don't think it communicates adequately that lifesaving or life-prolonging interventions can be occurring side-by-side with palliative care (e.g. can have a palliative care plan and also have surgery or NICU care). It very much reads as you either have "active" interventions or palliative approach. The reality is that both may be occurring at the same time, or that different approaches may occur at different phases. • Recommendations are accurate and relevant. • Suggest also considering more inclusive language. The birth parent may not identify as a mother (or even as a woman) or may be a surrogate. • It would be helpful to have this available as a fillable or blank document also.	Noted.	This section has been revised to address this comment and includes additional content to support perinatal palliative care practices. We use parent-centred language with the aim to be inclusive of all individuals and this has been explained at the start of the chapter

Table 5. Submissions received for Section 5: Care in subsequent pregnancies

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
5.1	Individual	Bereaved parent (Aus)	• As a parent of a stillborn baby at 38 weeks gestation and subsequent healthy birth of a child 2 years later, my personal experience identified the lack of easy access to heartbeat monitoring equipment. I had difficulty feeling the movements of my subsequent baby, even in the later stages of pregnancy. On a daily basis I would wake, heart racing, thinking I had killed my baby during my sleep. This was a constant source of anxiety for me and was often felt daily. When I enquired at the hospital about loaning heart rate monitor equipment, I was told it was not available nor advised due to errors in using it properly and the potential of obtaining a false result, which would increase my anxiety. However, the only alternative was driving myself to the hospital on a daily, sometimes multiple times a day to check my unborn baby's heartbeat. This to me was unsustainable due to cost of parking at the hospital and time away from work. As the only option, this intensified my anxiety levels and I feel there needs to be more easily accessible, free alternatives if anxiety levels are to be improved.	Noted.	The lack of evidence to support home monitoring in a subsequent pregnancy has been included, and additional support needs of parents highlighted.
5.2	Individual	Maternal fetal medicine (Aus)	• It would be helpful to define interpregnancy interval - there is some confusion about whether it means delivery to conception, or delivery to delivery. • Line 206 "Serial fetal biometry measurements are recommended for detecting SGA/FGR. Additional ultrasound investigations such as uterine artery Doppler, middle cerebral 208 artery Doppler, cerebroplacental ratio and ductus venous Doppler may be used to assist in the investigation and management of established FGR." is not consistent with the recommendation in line 224 "Monitor fetal biometry, amniotic fluid, and fetal Doppler flow velocimetry at a minimum of every 4 weeks from 24 weeks' gestation". I recognize that this is a practice difference between Australia and NZ, and that in Australia, UA PI is usually measured at every growth scan, but this is not an evidence-based practice, and is not routine practice in NZ.	Noted.	Interpregnancy interval has now been defined. Recommendations around gestational diabetes and aspirin have been revised to state that this test should be considered. We have also revised the Stillbirth investigations flowchart to reflect these comments (Appendix 6A).

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• Rec 5:10, line 237, is not consistent. Aspirin is recommended for placental dysfunction, but not recommended for FGR. • Line 34 “Previous intrapartum stillbirth, especially at pre-viable gestational ages, has a very high risk of recurrence”. It would be helpful to include an approximate numerical risk here. “very high” , to some readers, may indicate >50%, and I suspect this is not the correct perception. Absolute risk should be provided in addition to relative risk. • I have concerns about the recommendation to advise early OGTT in all women, in addition to later OGTT. In countries where routine diabetes screening doesn’t take place, e.g. UK, this may be of more relevance, but if the woman had negative testing in the pregnancy resulting in stillbirth, it is difficult to see why she would have GDM at an earlier gestation in this pregnancy. In addition, there is limited if any data to support the role of GDM in perinatal loss. (please contact me if ref needed, but HAPO is the clearest data - no additional PNM in untreated GDM). • In addition, more recent trials of early GDM testing (Simons, NEJM 2023) have not supported clear benefits to early GDM testing. If the woman had a negative GTT in the last pregnancy, or delivered in mid trimester before GDM diagnosed, it is difficult to see why early GDM testing is appropriate, except to diagnose new onset T2DM, in which case a fasting or HbA1c is a better test. • There will always be a few exceptions e.g. macrosomia in the previous pregnancy without diabetes testing performed, but these are very small in number to mandate an unpleasant, time-consuming test in all women with previous loss.		
5.3	Individual	Obstetrics (NZ)	• Please review recommendations around aspirin. In NZ is common to recommend 100 and National guidelines refer to 100-150 mg. I also believe it says is not recommended to prevent FGR which is confusing.	Noted.	This recommendation has been revised.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
5.4	Individual	Neonatology (NZ)	• What is the geographic availability of these sorts of clinics for planning a repeat pregnancy after a loss? Many parts of Aotearoa can't access the urban centres and the combination of indignity and rurally contributes directly to access challenges. I didn't see this highlighted in these documents.	Noted.	We will address this in the next edition of the Guideline.
5.5	Individual	Midwifery (Aus)	• Appreciated recency of references. • Appreciated the inclusion of examples of pre-pregnancy planning from Australia and outside of Australia. • Relevant and insightful. • Could be more specific examples.	Noted.	No change.
5.6	Individual	Clinical service (Aus)	• Pregnancy after loss clinics do have limitations with provided pre-pregnancy counselling, continuity of care, clinical and emotional support between appointments and point-of care ultrasounds. Consider Obstetric screening, assessment and recommendation to sit outside this document. Due to frequent changes in evidence-based care provisions this could change prior to and during this document time frame.	Noted.	Limitations have been acknowledged in this section.
5.7	Organisation	Parenting (NSW)	• As we are a community and tertiary organization, we hope that more community supports planning examples can be provided. • Page 8 section: language was very technical in parts medical language maybe add some emotional softer language. • When using the word mother baby attachment/dyad use parents in case there is a dad-to-dad dyad relationship. • Very wordy but good evidence. Can we have consistency in format of the technical reports in each section - maybe in a table.	Noted.	Revisions have been made to this section to support usability and ensure recommendations are clear and concise.
5.8	Individual	Neonatology (Aus)	• Well-written no additional comments	Noted.	No change.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
5.9	Individual	Bereaved parent / Midwifery (Aus)	• Seems a little light on detail when compared to other chapters in this guideline. • Add support during labour and birth of a subsequent baby as care providers need to know this is often a challenging time for parents. • Consider adding things like understanding that intense flashbacks can be triggered by labour and birth. Talking to parents ahead of time about whether they want to choose ...or avoid... the same birthing room, same staff. • Often a tour of birth suite (when not in labour) can assist parents to know how they might cope being in that environment once labour starts. • Many parents find it helpful to have the CTG turned up loud so they can hear the heartbeat, others prefer music, most want to avoid a silent room as this refresh's memories of a silent room last time. • It's very important that the care extends to management of labour and birth and possibly even the immediate postpartum period. Care providers need to be aware that this is a time of PTSD triggers that many find difficult to deal with. • At the very least care providers should gently inquire how the family are coping with this time of very intense reminders. The new baby may very well hold a family resemblance to the baby who dies. Parents may have difficulty feeling comfortable when their baby is asleep. They may "see" their deceased baby and worry that their new baby won't wake up. There may also be breastfeeding difficulties (my body doesn't sustain babies)… all things care providers should know don't you think? • Didn't cite Shakespear's et al: Shakespeare et al The RESPECT Study for consensus on global bereavement care after stillbirth International Journal of Gynecology and Obstetrics 3 Feb 2020 **https://doi.org/10.1002/ijgo.13110** • I was a little surprised not to see more of Joann O'Leary's work cited suggest you add at the very least: O'LEARY, J, 2005. The trauma of ultrasound during a pregnancy following perinatal loss. Journal of Loss and Trauma, 10(2), pp.183-204. • Also much of the parents experience and quotes for this chapter can be gathered from: O'Leary J, Parker L, Murphy M and Warland J (2020) Different pregnancy, Different Baby: Pregnancy and parenting after loss Rowman & Littlefield USA	Noted.	Content has been revised to incorporate these considerations. References have been included in the evidence synthesis and technical report. The O'Leary study from 2005 does not meet inclusion criteria.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
5.10	Individual	Nursing & midwifery (Aus)	• 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. Theoretically this makes sense, however operationalising this could be difficult. Some COC models have very limited access. As such, CRE could consider recommending that services specifically and systematically prioritise access to first preference of care for women who have experienced perinatal loss. Not all women will want continuity of care/r models as their first preference, but for those who do wish to have access, they should have priority.	Noted.	Recommendations with resource limitations have been identified in the implementation and dissemination plan, including continuity of care.
5.11	Organisation	Rural and remote health (Aus)	• Evidence-Based Recommendation 5.3: Provide care in a subsequent pregnancy within a continuity of care and carer model with a multidisciplinary focus and appropriate to cultural, religious, and spiritual needs of each family/whānau. Perhaps add named Midwife if possible here.	Noted.	This has been addressed in the content summary before the recommendation.
5.12	Individual	Clinical genetics (Aus)	• Consider inclusion of reference to genomic testing utilising DNA obtained from the couples prior loss to help determine recurrence risk; • Reference to reproductive carrier screening to help determine risk of inherited disorders. • Research suggests that approximately 1 in 20 Australians carry cystic fibrosis, spinal muscular atrophy (SMA) or fragile X syndrome (FXS), and approximately 1 in 240 couples are high risk of both being carriers of one of these three conditions. From November 1st 2023, MBS changes will come into effect that will allow three-screen reproductive carrier testing. • Research from our Genomic Autopsy Study has shown that genomic testing, when delivered adjunct to a perinatal autopsy, can provide a definitive or candidate genetic diagnosis in approximately half of all cases where standard of care testing (e.g. microarray or specific condition panel testing) did not. • One third of (likely) diagnoses were inherited in an autosomal recessive manner, with a further 10% of cases demonstrating either autosomal dominant with reduced penetrance or X-linked recessive inheritance. Taken together, these results indicate that approximately	Noted.	Preconception counselling has been addressed in this section. Byrne et al 2023 has been included in the Guideline.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			40% of diagnosed cases from our cohort received a clinically actionable result from trio genomic testing that could assist in the delivery of a future healthy baby. • Additional reference: Byrne A et al, Genomic autopsy to identify underlying causes of pregnancy loss and perinatal death. Nat Med. 2023 Jan;29(1):180-189. doi: 10.1038/s41591-022-02142-1. Epub 2023 Jan 19. Erratum in: Nat Med. 2023 Jul 10;: PMID: 36658419; PMCID: PMC10333122.		
5.13	Anonymous	Psychology (Aus)	Improving care in subsequent pregnancies for women who have experienced stillbirth. In order to support improved outcomes, women, birthing people and their families require continuity of mental health care. The period following stillbirths/neonatal deaths through to subsequent pregnancies does not meet the criteria for public health community services (e.g. Acute Care Mental Health teams or Perinatal and Infant Mental Health Services). As such these women are often left without the appropriate mental health care they require. This is further compounded for those in lower socioeconomic, regional and remote, First Nations and CALD populations. Community services are focused on severe and acute presentations and whilst stillbirth/ neonatal death is recognised as an area of complexity it does not reflect the type of care provided by these services. The consequences of stillbirth and neonatal death, have a significant impact on family systems, additional children's mental health and economic factors that in order to negate requires early intervention. Whilst the immediate needs of physical health care may be met in the days and few weeks following stillbirth ongoing care is required around the mental wellbeing of the woman or birth person. This should extend into subsequent pregnancies to beyond the postnatal period. The statistics have been clearly laid out: • Up to 70% of women will experience clinically significant grief-related depressive symptoms in the year after stillbirth • Five-fold increased chance of having a stillborn baby in their next pregnancy • Increased risk of preterm birth, low birthweight, placental abruption, pre-eclampsia, gestational diabetes and other adverse pregnancy outcomes • In addition, many women experience high levels of anxiety in subsequent pregnancies.	Noted.	Content has been revised across sections to include a greater focus on community settings including the interfaces between hospitals and community-based services.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• The rate of deaths among Indigenous children aged 0-4 was 2.1 times as high as the rate of non-Indigenous children in 2015â€“2019. • Between 2010 and 2019 there was no significant change in the mortality rate for Indigenous children aged 0â€“4. However, the rate for non-Indigenous children declined by 28%, resulting in a widening of the gap (by 58%). • A key component of improving pregnancy outcomes is early and ongoing engagement in antenatal care, which is facilitated by the provision of culturally appropriate and evidence-based care relevant to the local community. • A 40-session model of care would assist in appropriately dealing with care around still birth and neonatal death. This covers not only the immediate grief period but also that of subsequent high-risk points for declining mental wellbeing such as in subsequent pregnancies and the postnatal period.		
5.14	Organisation	Obstetrics & Gynaecology	• Recommendation 5.9 initially advises tailoring fetal monitoring to individual circumstances and carefully considering factors like obstetric history and the circumstances surrounding stillbirth or neonatal death. However, it subsequently contradicts this by prescribing a specific monitoring protocol in the first bullet point. The College believes a universally prescribed approach for monitoring may not always be appropriate in all clinical scenarios. To address ambiguity, RANZCOG proposes removing the first bullet point to encourage evidence driven, patient centric care. • RANZCOG cautions that the language used in recommendation 5.11 may improperly suggest routine use of low-molecular-weight heparin (LMWH) for women with a thrombophilia and previous stillbirth. The College finds no evidence to suggest that LMWH reduces the risk of stillbirth in most women with thrombophilia. Unless evidence can be found to support the contrary, RANZCOG advises amending this recommendation so as not to suggest LMWH be used routinely. To the College's knowledge, the only cited study suggesting a benefit is the Cochrane Review conducted by Kaandorp et al (Stef P Kaandorp 1, 2010). This study primarily focussed on miscarriage more than stillbirth, thus is of limited relevance in this context.	Noted.	Recommendation 5.9 has been revised. There has been no change to recommendation 5.11, although we agree with the comment regarding the role of LMWH, the recommendation does not recommend this.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
5.15	Organisation	Midwifery (NZ)	• Recommendation 5.9 commences with guidance on individual risk assessment and care planning which is then contradicted with a standardised recommendation on the frequency of ultrasound during a subsequent pregnancy that may not be appropriate in all cases (for example previous lethal congenital anomaly). • Recommendation 5.10 includes a statement that low dose aspirin is not recommended for prevention of fetal growth restriction – this contradicts the newly released Small for Gestational Age and Fetal Growth Restriction Clinical Practice Guideline in New Zealand which does recommend LDA to reduce the risk of developing FGR.	Noted.	This has been revised to ensure recommendation and summary of evidence is clear and concise. We have now referred to the NZ guideline recommending LDA to reduce the risk of developing FGR.

Table 6. Submissions received for Section 6: Investigations for perinatal death

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
6.1	Individual	Midwifery (Aus)	I noted the lack of amniocentesis to investigate cause of stillbirth- is this now considered irrelevant practice? (for microarray, TORCH, bacterial screen).	Noted.	No change.
6.2	Anonymous	Aus	Some education of parents that even a baby of non-viable gestation may be born alive and make voluntary movements/attempts at breathing.	Noted.	Content has been revised.
6.3	Anonymous	Aus	Excellent.	Noted.	No change.
6.4	Anonymous	Neonatology (Aus)	Comprehensive no suggested changes. Tables summarising information of suggested tests very helpful.	Noted.	No change.
6.5	Individual	Maternal fetal medicine (Aus)	• Well-written and comprehensive. • Any mention of paediatricians or staff caring for neonates to communicate with obstetricians/ staff caring for mothers to ensure appropriate investigations performed? Often clinically this may not be well-done e.g. if neonatal infection is suspected • Post-mortem ultrasound – - "This may detect fetal abnormalities and allows a fetal growth assessment" – - post-mortem detects far fewer fetal abnormalities and not reliable for key structures (e.g. heart) and will never replace autopsy or MRI – - it is important here to emphasise measurement of amniotic fluid here as in the recommendation as while performing an ultrasound does allow a fetal growth assessment, surely a birthweight is more relevant and does not replace placental histopathology. • "6.11 EBR Cytogenic testing should be performed for all perinatal deaths by either conventional karyotyping or by chromosomal microarray" - needs clarifying relative to any prenatal chromosomal testing that has been performed. – CMA limits are not stated which are relevant e.g. - not exclude rearrangements nor confirms non-dysjunction as a cause for common trisomies, which mandates parental karyotyping in these cases if not also done	Noted.	The chapter has been updated to specifically mention the importance of communication between obstetric and neonatal teams. The recommendation has been revised to clarify the role of ultrasound in this situation. The text and recommendation have been updated.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			– placental mosaicism could be discussed briefly in cases of fetal growth restriction to support placental microarray – the additional value of microarray is that testing rarely fails as there is abundant DNA from the placenta etc; karyotyping/ conventional cytogenetics even on the placenta commonly fails especially if there are any delays in processing overcoming the statement of "logistic concerns"; should de-emphasize karyotyping • "6.12 CBR In perinatal deaths where there may be a genetic cause, parents should be referred to a geneticist" - clinicians have to suspect that a genetic cause exists to refer. Is the language correct? Consider "In perinatal deaths where a genetic cause may exist, parents should be referred to a geneticist..." • The perinatal autopsy section is a bit clunky and not so well organised. • "Approximately half of perinatal autopsies may not reach minimum standards. In one study, identification of the cause of death was confirmed in up to 42% of previously unexplained stillbirths when performed by a perinatal pathologist in consultation with a geneticist." - is this study reporting on standards? and if so, what should be the standard rate for identification or a cause for death? – " the shortage of trained perinatal pathologists, some countries including Australia and New Zealand, have considerable wait times for autopsy results" - this is a standard issue. – "However, some studies have shown less favourable results for autopsy" - is this a standard issue? or a selection/ caseload bias? This statement is not helpful truly in this context if "Recommendation 6.13 is Autopsy should be offered to all parents " – should there be a list of indications for postmortem just like placental histopathology? • "6.16 EBR A comprehensive clinical summary should accompany the baby for autopsy and magnetic resonance imaging "use of MRI here occurs before MRI is really discussed and makes it seem like a standard. Consider removing MRI and including "all imaging"		Minor revisions have been made to address the language around referring parents to a geneticist. The perinatal autopsy section has been revised for clarity. There is a lack of data to be able to clearly define in what circumstances a postmortem may be more valuable. However, consideration of its value when an antenatal diagnosis has been made has been included. These recommendations have been changed.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• Placenta and cord: – there is no statement about cord complications. – this is controversial given the frequency of "cord around the neck" relevant to it as a contributor to cause of death. However guidance is useful in this document if only to improve the documentation (clinical and pathological)/clinical photography regarding cord accidents and relevance to cause of death. • "6.25 CBR A fetal MRI should be offered to parents prior to a planned termination of pregnancy where appropriate MRI services are available." – not sure of this recommendation or its point in isolation. – relevance to confirming prenatal diagnosis? or excluding additional abnormalities (relevant to parental decision-making regarding autopsy)? – clarify if to exclude additional abnormalities which may be important if parents were to decline autopsy. • [Appendix 6N: Indications for placental examination by the pathologist] Good. Consider an appendix for Indications for autopsy.		This has been updated to acknowledge the importance of the attending clinician at birth examining the cord for entanglement and suggest taking photos where appropriate. This recommendation has been clarified and moved to the text in the section on additional investigations.
6.6	Organisation	Pathology (Aus)	• Of specific note, I recommend removing line 323 which is in direct conflict with all documents included in Section 6. The related reference states: 'The perinatal autopsy is an important tool in the investigation of fetal and neonatal death, and a complete understanding of its risks and benefits is necessary for providers of perinatal care.' The overall reference may not relate to Australian data as all perinatal autopsies are now performed in specialist centres. This unqualified statement is destructive and would be confusing to healthcare professionals; the Government's goal is to increase the number of autopsies and investigations to reduce the overall number of perinatal deaths. • *A comprehensive history:* postmortem imaging is not part of 'A comprehensive history' - it is a radiological investigation which should be incorporated into 'Postmortem antenatal fetal ultrasound' (below) - this section should be retitled 'Postmortem radiological investigations'	Noted.	This section has been revised accordingly.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• *Recommend* removing lines 274 & 275, instead include: 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. • *Line 293:* Result timelines vary greatly between laboratories - it is not appropriate to provide this indicative timeline. • *Line 324:* Why include this statement considering EBR 6.13 below states Autopsy should be offered to all parents... etc ? what does 'may not reach minimum standard' mean? • *Line 438:* It should also be noted that MRI services are not routinely available at all birthing centres. • *Line 450:* It should also be noted that MRI services are not routinely available at all birthing centres. • all recommendations are easy to understand and implement in practice. I have specific recommendations outlined in PDF comments. • *Recommendation 6.16:* Not all jurisdictions are able to offer MRI - why not change to 'radiological investigations'? • [Appendix 6A: Stillbirth investigations flowchart] Recommend removing this document. There are significant variations in the content of this flowchart to the one RCPA provided to Stillbirth CRE which will be published in the RCPA Perinatal Death Investigations Training and Development Package. If the Intended Audience for this CPG is targeted at doctors, midwives, and nurses, I fail to understand the need to include this flowchart at all as the core investigations are outlined on Pages 5 and 9. The utility of the information of the investigations in 6B are only of value for pathologists/scientists. Replace with RCPA investigations flowchart.		MRI has been recommended as the imaging modality of choice. Also mentioned are the issues with availability. Other radiological approaches are mentioned. The Stillbirth investigations flowchart was developed for frontline healthcare professionals and provides a list of core investigations and specific clinical scenarios to guide additional investigations. This flowchart will support implementation of guideline recommendations in practice and is supported by summary information in the section. This flowchart has been further revised by the Investigations expert advisory group and remains in this edition of the guideline. The neonatal death investigations table has been modified into a flowchart to align with the stillbirth investigations flowchart design to support ease of use.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• [Appendix 6C: Estimation of severity of feto-maternal *haemorrhage*] Recommend removing this document "Kleihauer Betke/ FMH" is performed in the laboratory; the results are made available with relevant reference intervals on the pathology report. • [Appendix 6F: Instructions on taking clinical photographs] Identification first para: If there is no individual *medical* record number, write the maternal medical record number with the baby's date and time of birth." • [Appendix 6F: Instructions on taking clinical photographs] Identification second para: Often stillborn babies do not receive a medical record number. In this scenario, refer to local unit policies/*guidelines* to generate a unique record for the baby, including time of birth, and mother's medical record number to identify the body. • [Appendix 6F: Instructions on taking clinical photographs] Position after seventh dot point, leave a space and start a line without a dot point e.g. *"Additionally, staff should…*", then use the three dot points listed below. • [Appendix 6F: Instructions on taking clinical photographs] General comments. In final dot point, remove duplicate dot point e.g… "Ensure a documentation trail for storage." • [Appendix 6K: Trying to find answers when your baby dies] Suggest changes as follows: Introductory para: remove (sometimes called a postmortem examination) as this is restated below in "What is an autopsy?" first para. • [Appendix 6H: Birthweight percentiles] Recommend standardising Figure titles as follows: – Figure 1. Fenton preterm growth chart for boys. – Figure 2. Fenton preterm growth chart for girls. • [Appendix 6K: Trying to find answers when your baby dies] *"What is an autopsy?"* Second para. Most parents will be asked to decide whether or not they agree to their baby having an autopsy, as well as the type of autopsy.		After consulting with the Guideline Development Committee and investigations EWG, it was agreed that Appendix 6C was important to help healthcare professionals understand the test. This appendix remains in the guideline. Revisions have been made to other appendices and resources included in this section of the guideline. Most of the suggested changes below (pages 55-58) to Appendix 6F, 6H, 6K, 6L and 6N have been incorporated.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• [Appendix 6K: Trying to find answers when your baby dies] *"Where does an autopsy take place?"* Suggest changing to: *"Where is an autopsy performed?"* Autopsies are performed at a specialised service. This may be within the facility where your baby was born, or if necessary, your baby will be transferred to a facility where this specialised service is available. • [Appendix 6K: Trying to find answers when your baby dies] *"Full autopsy"* - second para, second sentence. These small samples will be examined under a microscope by a pathologist to help provide further information which may provide the most likely cause of death for your baby. • [Appendix 6K: Trying to find answers when your baby dies] *"External examination only"* - first sentence. You may decide you only want an external examination of your baby's body. • [Appendix 6K: Trying to find answers when your baby dies] *"External examination only"* - last sentence. However, MRI scans are not available at every facility/service. • [Appendix 6K: Trying to find answers when your baby dies] *"When do I need to decide?* "Your health care team will usually discuss the option of autopsy with you soon after your baby's death. Generally, it is best for an autopsy to be conducted as soon as practically possible; the sooner the autopsy is completed, the greater the opportunity to gather and analyse all the vital information which may provide the most likely cause of death." • [Appendix 6L: Discussing postmortem investigations with parents] Throughout document, utilise post-mortem or postmortem, but not both. • [Appendix 6L: Discussing postmortem investigations with parents] Additionally, autopsy is sometimes used in one sentence, then postmortem in the next and may be confusing to some readers. • [Appendix 6L: Discussing postmortem investigations with parents] Suggest changes as follows: First para, third sentence. *"Sensitivity and compassion are critically important when providing information to parents around the death of a baby."*		

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• [Appendix 6L: Discussing postmortem investigations with parents] *"Why is it important to offer bereaved parents post-mortem examinations?"* First sentence. Provision of information on why postmortem investigations are performed will help parents to make the right decision for their baby. • [Appendix 6L: Discussing postmortem investigations with parents] *"What are the options?"* First para. 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. • [Appendix 6L: Discussing postmortem investigations with parents] *"What are the options?"* Second para. As soon as possible after diagnosis of a fetal death in utero, a fetal postmortem ultrasound should be performed by a skilled health care professional; this may help to identify selected abnormalities. • [Appendix 6L: Discussing postmortem examinations with parents] *"What are the options?"* Third para. Placental examination is one of the most important investigations. Parents should be offered the option of taking the placenta home after examination. • [Appendix 6L: Discussing postmortem investigations with parents] *"What are the options?"* Sixth para. Third sentence. Full body X-ray imaging of the baby (also known as a "babygram"), is helpful where skeletal abnormalities may be suspected. • [Appendix 6L: Discussing postmortem investigations with parents] *"Barriers to autopsy."* The most common reason for parents to decline a full autopsy is concern about the invasiveness of the procedure. • [Appendix 6L: Discussing postmortem investigations with parents] *"How do I discuss postmortem investigations with parents?"* Third para. Second sentence. 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. • [Appendix 6L: Discussing postmortem investigations with parents] *"How do I discuss postmortem investigations with parents?"* Fifth para. Second sentence. It is important not to make assumptions about religious or cultural practices based on the parent stated or apparent religion or ethnicity.		Appendix 6N will remain in the guideline as it was developed in consultation with perinatal pathologists.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• [Appendix 6L: Discussing postmortem investigations with parents] "*Information you need to have."* Fourth dot point. Confirmation that their baby will be returned to the parents for burial or cremation according to their wishes. • [Appendix 6L: Discussing postmortem investigations with parents] *"Information you need to have."* Fifth dot point. Confirmation that they will be able to see and hold their baby after the autopsy. • [Appendix 6L: Discussing postmortem investigations with parents] *"Reporting results."* Last sentence. Ensure parents understand that sometimes no explanation is found for the cause of death. • [Appendix 6N: Indications for placental examination by the pathologist] Recommend removing this document. Placental examination is considered a "core investigation" undertaken initially by attending Obs/Gynae, and again by perinatal pathologist, therefore no' indications' are required. • [Investigations for neonatal deaths and high-risk newborns table] Recommend removing this document. The information in this draft chart is so poorly presented, it is difficult to imagine anyone utilising it without a ruler at the very least.		This table has been revised and is now presented in a flowchart to improve usability and align with the Stillbirth investigations flowchart.
6.7	Individual	Pathology (Aus)	• Professionals who do not wish to place additional burden on bereaved parents. • Clinical photographs are taken as part of all autopsies - so do not need to be undertaken by clinical team unless there is not permission for autopsy • Line 323 - "Approximately half of perinatal autopsies may not reach minimum standards." should be removed as it is not the conclusion of this paper. See below Ref 38 as below with paper conclusion: 38. Pacheco, M.C., R.C.J.A.o.P. Reed, and L. Medicine, Pathologist effort in the performance of fetal, perinatal, and pediatric autopsies: a survey of practice. 2017. 141(2): p. 209-214. Conclusions: Fetal, perinatal, and pediatric autopsies are time intensive and frequently complex. They have high clinical value, guiding risk assessment and reproductive decision-making by families. Understanding the time contribution by pathologists allows departments and hospitals to predict staffing. • I would certainly NOT regard this as satisfactory - all that is happening is a genetic anomaly is being excluded – possibly Rural and remote considerations for perinatal autopsy	Noted.	Revisions have been made to the section summary and appendices.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• In settings where a perinatal pathologist may not be available, the Genetics Committee of the Society • 370 of Obstetricians and Gynaecologists of Canada recommend that gestational age and biometry be • 371 documented, photographs and X-rays be taken, and tissue sampling (either from placenta, umbilical • 372 cord, or skin) be performed. Communication with a medical genetics services (on-call service available • 373 in tertiary care centres) can facilitate these investigations and help coordinate further evaluations when clinically indicated. **Appendices:** • Appendix 6A: Stillbirth investigations flowchart - HbA1c is an investigation of the mother - not the baby. • Appendix 6D: Placental examination for healthcare professionals (previously Accoucheur flowchart - do NOT sample the umbilical cord for genetics - sample the placenta - 1cm cubed fetal from the fetal surface into the placenta but not to the maternal surface near the cord insertion • Appendix 6K: Trying to find answers when your baby dies - correct but the way it is written is deceiving - incision in the back of the head - yes but it goes from ear to ear. Small samples for looking at under the microscope - all the organs are removed - examined and returned except for the sample for histology. This is not what can be clearly understood by saying small biopsies are taken to examine under the microscope. • Appendix 6N: Indications for placental examination by the pathologist - probably should separate the intrauterine growth restriction and the >50% a bit further.		
6.8	Organisation	Research (Aus)	• 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 unwarranted variation in the prevention and investigation of stillbirth, and to support best practice in bereavement care after any perinatal loss. It contains 10 quality statements that describe the care that should be offered to women who are pregnant or planning a pregnancy, and those who have experienced any perinatal loss.	Noted.	The Guideline is consistent with the Stillbirth Clinical Care Standard. Through a comprehensive review of the literature and consultation with experts in the field (including members of RCPA and RANZCR) it was agreed that MRI

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• The Care Around Stillbirth and Neonatal Death (CASAND) Clinical Practice Guideline is one of the key evidence sources that underpins the recommendations in the Standard, along with the Clinical Practice Guidelines: Pregnancy Care (Pregnancy Care Guidelines) by the Department of Health and Aged Care. • The CASAND guideline has been specifically referred to in the supporting information for the following quality statements: – Quality statement 7 - "Discussing investigations for stillbirth." – Quality statement 8 - "Reporting, documenting and communicating stillbirth investigation results." – Quality statement 9 - "Bereavement care and support after perinatal loss." • The Stillbirth Clinical Care Standard currently recommends postmortem magnetic resonance imaging (MRI) as an alternative investigation that should be considered in the context of parents declining full autopsy. This is consistent with the advice in the third edition of the CASAND guideline (2019) and also Evidence Based Recommendation 6.23 in the public consultation draft. However, Consensus Based Recommendation 6.24 states that postmortem MRI should be offered to parents "as an adjunct to autopsy" (i.e. not just if parents decline autopsy). It is unclear whether this recommendation may be interpreted by clinicians to mean that all parents should be offered postmortem MRI as part of the standard suite of investigations after stillbirth. This will likely have implications for recommendations in the Stillbirth Clinical Care Standard, and importantly resourcing within healthcare services to facilitate access to this investigation. Advice received from the Stillbirth Clinical Care Standard Topic Working Group and other key stakeholders during development of the Standard highlighted that access to postmortem MRI is limited, even in metropolitan settings, and that accordingly, this investigation should be reserved for use only in the context of parents declining autopsy.		may provide additional information above autopsy in some circumstances – mainly where there are suspected brain abnormalities in the presence of fetal maceration. However, we continue to recommend autopsy as the gold standard investigation for perinatal deaths and where parents decline include a MRI as one of the alternatives. This section has been amended to include both scenarios: i.e. 1) offered where parents decline autopsy, and 2) offered as adjunct where a) resource available and b) may offer additional information.

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6.9	Individual	Genetics (Aus)	• Introductory guidelines suggest the use of perinatal death to cover stillbirth, neonatal death and termination of pregnancy for medical reasons (i.e. fetal anomaly), yet general wording used throughout the guidelines specifies stillbirth and neonatal death, omitting termination of pregnancy. • Considerations for inclusion within the "Genome sequencing" section • Research from our Genomic Autopsy Study has shown that genomic testing, when delivered adjunct to a perinatal autopsy, can provide a definitive or candidate genetic diagnosis in approximately half of all cases where standard of care testing (e.g. microarray or specific condition panel testing) did not. – Majority of (likely) pathogenic variants (57.7%) occurred de novo, supporting the need to perform genomic testing as a parental-proband trio. – No mention of termination of pregnancy prior to Recommendation 6.25, yet over one third of perinatal deaths are due to congenital abnormalities, many of which result from a termination of pregnancy. In support, a large proportion of our pregnancy loss cohort are couples who have elected to medically terminate a pregnancy due to severe congenital abnormalities identified on ultrasound. – Diagnostic yield of genomic testing was higher when one or more congenital abnormalities were present, or organ systems were affected. Stillbirths with no associated congenital abnormalities had the lowest diagnostic yield (8%). • In association with national clinical geneticists, we have included further information gained from our national study to "Genomic Sequencing", paragraph 2. Genomic sequencing is increasingly used in the perinatal setting to understand the cause of fetal anomalies detected on ultrasound when cytogenetic testing is uninformative (DOI: 10.3389/fgene.2023.1099995). Additionally, research from the Genomic Autopsy Study published in Nature Medicine (https://doi.org/10.1038/s41591-022-02142-1) has shown that genomic testing, when delivered adjunct to a perinatal autopsy, can provide a definitive or candidate genetic diagnosis in approximately 50% of all cases where standard of care testing	Noted.	Definitions have been revised throughout the guideline. Additional information has been included for genetic studies. After a careful review of recent research and in-depth discussions with the perinatal death investigations working group, it was felt that MRI may be more helpful than an autopsy in some circumstances, for example suspected brain anomalies where the baby is macerated. The additional studies have been included in the guideline.

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			(e.g. microarray or specific condition panel testing) did not. The majority (57.7%) of pathogenic or likely pathogenic variants occurred de novo, supporting the need to perform genomic testing as a parental-proband trio. The diagnostic yield of genomic testing was higher when one or more congenital abnormalities were present, or organ systems were affected. When delivered as standard-of-care, the high yield of trio genomic testing in the setting of congenital abnormalities provides many families with more accurate recurrence risk and reproductive options for future pregnancies. Stillbirths with no associated congenital abnormalities had the lowest diagnostic yield (8%). • [Appendix 6A: Stillbirth investigations flowchart] "placenta" include option of microarray, with or without karyotype. • [Appendix 6A: Stillbirth investigations flowchart] Suspected or confirmed fetal anomalies better placed under "Baby" heading, with arrow also traversing from "placenta."		
6.10	Individual	Executive Director (Aus)	• This is a comprehensive document. The length and density of the content would see it be more of a reference document rather than used directly in the clinical space. • Page 7 of 25 (line 228): Current wording: Examination *of the placenta and cord at birth should be undertaken by the attending clinician at the…*" Suggested wording: *"Examination of the placenta and cord at birth should be undertaken by the attending clinician."* • Page 11 of 25 (line 395): Current wording: *"mother/birth parent."* Suggested wording: *"woman/birth parent."*	Noted.	Content has received revisions and professional editing to improve readability. Hyperlinks will be integrated into the web-based tool to facilitate ease of use by healthcare professionals. Revisions have been made to this section.
6.11	Individual	Neonatology (NZ)	• I have real concerns that the access to postmortem is not being considered from an equity perspective. If you have a pepi who then needs to travel without whānau to have a postmortem, then it might limit agreement. What is the ethnicity distribution of who accesses postmortem? I would suspect that white privilege is present. We need to highlight this as something we need to work on and how in our system will this support access? • [Appendix 6H: Birthweight percentiles] Are they Eurocentric? are we using the GROW ones?	Noted.	Content has been revised. A greater focus on equitable access to postmortem investigations will be addressed in the next edition of the Guideline. The Birthweight percentiles appendix is the Fenton preterm growth chart.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
6.12	Individual	Maternal fetal medicine (Aus)	• The document [appendix] 6O "Indications for placental examination" seems to be out of place. • Given that placental histopathology is recommended for all deaths, I am not clear why a list of indications for placental histopathology is provided. If it refers to pregnancies which do not end in death, it does not seem to be relevant to this guideline, or evidence based. I do not think it should be included in the guideline. • [Technical Report] The section of Anti D after a fetal death seems to be misplaced - line 758. It should be in a section discussing management after death, not investigation of the death. • [Appendix 6N: Indications for placental examination] should be removed.	Indications for placental examination was included in the context of high-risk newborn who may later die where this examination may provide important information to understand the cause of death.	We have now included information on Anti D under *Additional investigations* in *Section 6: Investigations for perinatal death.*
6.13	Individual	Neonatology (NZ)	• Lines 46-50: This paragraph combines two separate issues in one sentence. Whether it is challenging to the healthcare professional should not preclude the discussion being had. Suggest rewording to *"Whether to have an autopsy is one of the most difficult decisions a parent must make following the death of their baby. Despite being potentially a very challenging conversation for healthcare professionals, who do not wish to place additional burden on bereaved parents, discussion and parent-centred decision making should be offered."* • Lines 89-90: does NZ have better access to high quality imaging or should this sentence include Australia and New Zealand. • Lines 571-57: too many [and]. Metabolic disease may cause a baby to be both weak and floppy[.] [remove and]. Respiratory failure at birth or shortly afterwards [remove and] should be investigated for peroxisomal disorders, non-ketotic hyperglycinaemia, lipid 574 and storage disorders and mitochondrial disease.	Noted.	Changes made to sentence structure.
6.14	Organisation	Midwifery & clinical educator	• Consensus-Based Recommendation 6.22 420 Maternal and newborn services should ensure appropriate education on the local coronial process for 421 perinatal deaths is provided for all healthcare professionals. Who/what/how? • Healthcare professionals should seek advice from the coroner if any doubt exists as to whether a death should be referred to the coroner.....what does this look like in the remote context?	Noted. As processes differ across jurisdictions, each maternity service should have protocols in place for referral of a perinatal deaths to the coroner.	Rural and remote considerations have been addressed throughout the Guideline.

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				In the remote context, as in other contexts, a phone contact is available for the coroner's office to discuss the circumstances of the death. The coroner will then make a decision about whether an inquiry is necessary. Smaller services could discuss the case with the relevant tertiary centre if in doubt.	
6.15	Organisation	Obstetrics & Gynaecology	• Recommendation 6.15 appears to contain two recommendations, the first of which is incomplete. • Recommendation 6.25: RANZCOG would like to clarify whether fetal MRI is indicated prior to all abortions for fetal anomaly or only in select cases. If the latter is the case, the College proposes clarifying the recommendation to be more explicit about the circumstances in which this is indicated.	Noted.	Recommendation 6.15 has been revised. Regarding recommendation 6.25, we have included a discussion about the role of fetal MRI under 'additional investigations' and suggest that this is helpful when a brain anomaly is suspected. The recommendation has been removed in the final version of this section.
6.16	Organisation	Midwifery (NZ)	• Throughout the guideline the language used tends to state that referral *"should be made"* in various clinical situations. The College recommends that this be replaced with *"referral should be offered/recommended"*. For example, recommendation 6.3 (regarding detailed antepartum ultrasound assessment) states that ultrasound *"should be performed"* - we would suggest rewording this to say, *"should be recommended and performed with the pregnant woman/ person's consent."* • Recommendation 6.23 (when parents decline autopsy) sits underneath an extensive explanation following 6.22 (when parents' consent to autopsy). It would be more intuitive if these two recommendations sat together at the top of the page, followed by the technical detail.	Noted.	This has been revised.

Table 7. Submissions received for Section 7: Perinatal mortality audit and classification

Note. Feedback relating to resources not open for public consultation and developed by other organisations have not been included. Feedback will be shared with relevant organisations. For example, feedback relating to the PSANZ classification system will be tabled at the PSANZ PMC committee meeting in October 2023.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
7.1	Individual	Maternal fetal medicine (Aus)	• Well written and comprehensive. • This point needs emphasising in the document: 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 and seek further guidance where needed • Is it clearly stated how each individual/ family has different needs and the approach to them need to be tailored? or is this just assumed? • This guideline is very detailed in all parts to the point of being compulsive/ obsessional in an approach • Recommendations 7.19 - A comprehensive clinical summary should be sent to the general practitioner and all care providers - this should be available and easily accessed in the healthcare record	Noted.	We feel that these comments have been addressed in the guideline. No changes required.
7.2	Individual	Neonatology (NZ)	• What is missing here is that reports such as PMMRC have not lead to improvement for whānau Māori - the same rates occur. The reports such report this with no change - some might ask what is the point? It's unethical to keep reporting this with no changes occurring. I would like see this document improved with clarity about accountability and not just reporting more of the same. We need to see true system change. • What about the law in Aotearoa as the PMMRC process cannot be shared outside of the meeting so how are whānau included? Also the suggestion of changing death certificates must also be addressed legally, I am not sure this is possible in Aotearoa. • Additional references: – Fiona Cram, Kendall Stevenson, Stacie Geller, E. Jane MacDonald & Beverley Lawton (2019) A qualitative inquiry into women's experiences of severe maternal morbidity, Kōtuitui: New Zealand Journal of Social Sciences Online, 14:1, 52-67, DOI: 10.1080/1177083X.2018.1528990	This guideline section is targeted to clinicians undertaking local audit. We discuss how a lack of accountability/ implementation of change at the local level is a barrier to audit. We include 3 steps in the audit cycle about identifying recommendations, implementing changes and re-evaluating. A number of local maternity services already revise death certificates following the perinatal mortality audit	No changes to content. Additional references (Geller et al 2018; and Lawton et al 2023) have been incorporated into the technical report evidence synthesis, where relevant.

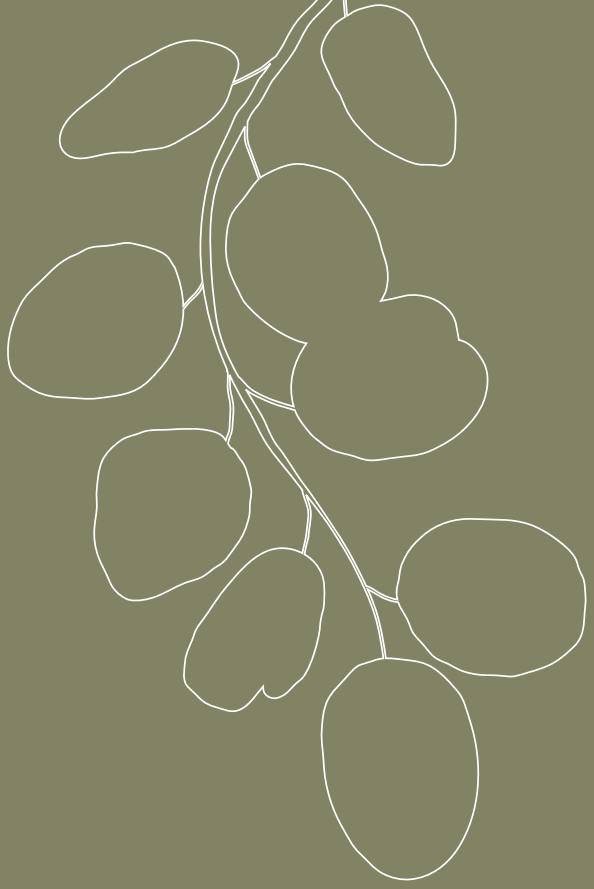
ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			– Geller, S.E., Koch, A.R., Garland, C.E. et al. A global view of severe maternal morbidity: moving beyond maternal mortality. Reprod Health 15 (Suppl 1), 98 (2018). **https://doi.org/10.1186/s12978-018-0527-2** – Preventability of severe acute maternal morbidity Beverley Lawton, FRNZCGP Evelyn Jane MacDonald, FAChSHM Selina Ann Brown, RN Richard Alan Dinsdale, FCIC Carolyn Lee Coles, M Stacie E. Geller, PhD Published:February 10 2014DOI: **https://doi.org/10.1016/j.ajog.2013.12.032** – Lawton, B., MacDonald, E.J., Filoche, S., Stanley, J., Meeks, M., Stone, P., Storey, F. and Geller, S.E. (2022), Examining the potential preventability of adverse fetal/neonatal outcomes associated with severe maternal morbidity. Aust N Z J Obstet Gynaecol, 62: 71-78. **https://doi.org/10.1111/ajo.13404** • There is significant literature missing. We need to move from just reporting to change and accountability.	meeting, as they find a high proportion of death certificates require updating. Based on discussions with maternity services, the committee feel that the recommendation to revise death certificates should remain as is.	
7.3	Individual	Neonatology (NZ)	• Guideline present Australian data only. PMMRC has easily accessible data for NZ statistics to be included here are well.	Noted.	NZ statistics have been incorporated into the audit chapter, where relevant.
7.4	Organisation	Rural and remote health (Aus)	• More guidance on investigations that are time critical (i.e. prior to retrieval) in the remote context.	Noted.	Guidance for undertaking investigations in rural and remote settings has been included.

Table 8. Submissions received for Section 8: Organisational recommendations

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
8.1	Anonymous	NZ	• Good structure and layout. • Implementing bereavement midwife will be difficult to operationalise. Prefer language to be a designated support person allows for more flexibility with employment. This could be a social worker, counsellor, Aboriginal Health practitioner or midwife. • I am curious regarding the national training package. Sands are in the process of updating their bereavement care package which is excellent.	Noted.	Revisions have been made to include Lead Maternity Carer throughout the guideline for NZ settings.
8.2	Individual	Neonatology (NZ)	• I would like to see this section much clearer about organisational responsibility for equity. If we want the system to meet whānau needs then we need a process to ensure this occurs. Otherwise, we will just have a system that perpetuates white privilege. • There is a paucity of information around whānau Māori in the literature and this is not highlighted. While there is reporting on what is present it then misses the points that there is limited evidence.	Noted.	The limited evidence around Māori whānau is highlighted in the *Future Directions* appendix.
8.3	Organisation	Parent support (NSW)	• The first section in background mentions maternity and nuance services, does this include community health services child and family health services secondary services in general practitioners. • General practitioners provide recommendations in a high-quality way that needs to be considered. • I would recommend in this section unpacking a bit more around community support for bereaved parents a bit of a summary section that you could link to the rest of the document. • This would provide a good element of the work in this space. • Also continuity of care for community extends to the subsequent pregnancy's - this could be or linked and included here. • 210: really good section on education I'm wondering where supervision for the workforce and the impact of accumulative trauma vicarious trauma can sit within this document. It might be an organizational responsibility as well to ensure staff are supported. The regional hospitals as you note find elements of this section challenging the ability to do memory boxes perhaps may need assistance for these rural remote Community Hospital facilities.	Noted.	Content has been revised across sections to include a greater focus on community settings including the interfaces between hospitals and community-based services. National support organisations and services have been included. This edition of the guideline has a greater focus on healthcare professional wellbeing and self-care.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
			• Continue to include community services that will support the health and well-being of the family and perinatal and infant mental health monitoring. As suggested in previous sections Karitane tresillian, panda, For When PIMH care navigation line - universal services child family health nursing and general practitioners.		
8.4	Individual	Bereaved parent / midwifery (Aus)	• The national stillbirth action plan not only recommends that current maternity care providers are upskilled with things like the IMPROVE and SBB education programs but that undergraduate education in stillbirth prevention and management is addressed. It is probably therefore important to include what is happening currently in undergrad education and recommendations around that. • InUTERO is still offered by StillAware for clinician education in the area of Stillbirth awareness for prevention - Warland J, Dorrian J, Pollock D, Foord C. (2020) InUTERO: The effectiveness of an educational half day stillbirth awareness workshop for maternity care providers. Nurse Education Today, Feb;85:104298. • Also the precursor for inUTERO - Warland J, Glover P, (2015) Talking to pregnant women about stillbirth: Evaluating the effectiveness of an information workshop for midwives using pre and post intervention surveys. Nurse Education Today. 35 (10) e21-e25 • Papers and evidence about teaching undergrads sensitive material: – Heath M, Due C, Hamood W, Hutchinson A, Leiman T, Maxfield K, Warland J, (2017) Teaching sensitive material: A multi-disciplinary perspective. ERGO 4 (1): 3-11 • Finally the state of play of undergrad education for midwives in Australia: – Warland J, Glover P, (2019) Tertiary EducAtion Regarding Stillbirth for Student Midwives: the TEARS 4 SMs project. Women and Birth 3293: e409-e412. – Postle, M.V., 2023. Senior Midwives' experiences and perspectives regarding student midwives and perinatal loss care. Women and Birth, 36, p.S27.	Noted.	Content has been revised and additional references included. Some of the suggested references do not meet inclusion criteria.

ID	TYPE OF SUBMISSION	DISCIPLINE (COUNTRY)	CONSULTATION COMMENT	GUIDELINE DEVELOPMENT COMMITTEE RESPONSE	ACTIONS TAKEN
8.5	Organisation	Rural and remote health (Aus)	• Consensus-Based Recommendation 8.1 (line 137): 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." More could be included about nonmaternal & newborn services where stillbirths occur particularly in remote settings. • Consensus-Based Recommendation 8.11 (line 288): "Ensure all healthcare professionals who provide care around stillbirth and neonatal death have access to formal and peer support and be encouraged to prioritise their social and emotional wellbeing." Can you include exemplars of what this may look like and perhaps recommend clinical supervision/ formal debriefing being made available?	Noted.	Brief inclusion. We will address this in the next edition of the Guideline.
8.6	Anonymous	Aus	• Good content. • Clear, concise and accurate recommendations.	Noted.	No change.
8.7	Individual	Psychology (Aus)	• Whilst we acknowledge that stillbirth investigations are helpful, decision making around the choice to pursue investigation should be supported by a collaborative care approach including perinatal mental health clinician. Women and families are particularly vulnerable at this stage extending beyond the hospital's involvement in care. Moreover, decision making can be impacted by mental health status. Mental health support is crucial to informed decision making during this difficult period.	Noted.	The importance of a multidisciplinary care team, including mental healthcare professionals, is highlighted throughout the guideline.



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