

## Future directions

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

### Monitoring progress and evaluation of the guideline

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

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

### Perinatal loss care

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

### Birth planning after stillbirth or diagnosis of a life limiting condition

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

## Cultural diversity

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

## Social and emotional support for perinatal grief

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

## Perinatal palliative care

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

## Care in subsequent pregnancies

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

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

## Understanding through investigations and audit why a baby died

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### Understanding causal pathways

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

### Investigations for perinatal death

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

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

### Genomics

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

### Perinatal mortality audit

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

### Classification systems

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

## Organisational enablers and quality improvement processes

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

## References

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1. Gower, S., et al., Subsequent pregnancy after stillbirth: a qualitative narrative analysis of Canadian families' experiences. *BMC Pregnancy Childbirth*, 2023. **23**(1): p. 208 doi: 10.1186/s12884-023-05533-5.
2. Nijkamp, J.W., et al., Perinatal death investigations: What is current practice? *Seminars in Fetal & Neonatal Medicine*, 2017. **22**(3): p. 167-175 doi: 10.1016/j.siny.2017.02.005.
3. Krogh, L.Q., et al., Full-term induction of labor vs expectant management and cesarean delivery in women with obesity: systematic review and meta-analysis. *American Journal of Obstetrics & Gynecology MFM*, 2023. **5**(5): p. 100909 doi: 10.1016/j.ajogmf.2023.100909.