

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Version 3.3, December 2019

Endorsed by



Produced by:

This clinical guideline was produced by the Perinatal Society of Australia and New Zealand (PSANZ) Care around the time of stillbirth and neonatal death guidelines group, under the auspices of the Stillbirth and Neonatal Death Alliance (SANDA) of PSANZ and in partnership with the Centre of Research Excellence in Stillbirth. Support for guideline development was received from PSANZ

Endorsed by:

The clinical guideline has been endorsed by: Australian College of Midwives (ACM); Australian and New Zealand Neonatal Network; Queensland Maternal and Perinatal Quality Council; Red Nose; Sands; Stillbirth Foundation Australia; South Australian Maternal and Perinatal Mortality Committee; Tasmanian Council of Obstetric and Paediatric Mortality and Morbidity; Women's Healthcare Australasia; Victorian Consultative Council on Obstetric and Paediatric Morbidity and Mortality; and The Royal Australian and New Zealand College of Obstetricians and Gynaecologists.

Suggested citation:

Flenady V, Oats J, Gardener G, Masson Vicki, McCowan Lesley, Kent A, Tudehope David, Middleton P, Donnelly N, Boyle F, Horey D, Ellwood D, Gordon A, Sinclair L, Humphrey M, Zuccollo J, Dahlstrom J, Mahomed K, Henry S, Khong Y for the PSANZ Care around the time of stillbirth and neonatal death guidelines group. Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death. Version 3, NHMRC Centre of Research Excellence in Stillbirth. Brisbane, Australia, March 2018.

Disclaimer:

The main objective of the guideline is to assist clinicians in the investigation and audit of perinatal deaths, including communication with the parents, to enable a systematic approach to perinatal mortality audit in Australia and New Zealand. The overall aim is to reduce the risk of perinatal death and provide appropriate assistance to parents.

The guideline is not intended to be prescriptive, but is designed to provide reliable, up-to-date information enabling integration of best evidence, clinicians' judgement and individual choice in arriving at decisions about care. Clinical practice guidelines may be considered as generally recommended practice. Inevitably, given the nature and sensitivity of the subject and the lack of high quality studies, some contentious issues remain. The Working Party welcomes comments which will assist with further refinement of the Guideline in the future. Comments should be sent to Vicki Flenady, Email: stillbirthcre@mater.uq.edu.au with 'Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death' in the subject line.

Further information:

Requests for further information, comments or suggestions are encouraged and can be forwarded to:

*Centre of Research Excellence in Stillbirth, Mater Research Institute
Level 3, Aubigny Place, South Brisbane, QLD 4101 Australia
Phone +61 7 3163 2463
Email: stillbirthcre@mater.uq.edu.au*

SECTION 1

OVERVIEW AND SUMMARY OF RECOMMENDATIONS

1.1 Introduction

The loss of a child who is either stillborn or dies in the neonatal period has enormous psychosocial impact on parents and their care providers¹, and wide-ranging economic impact on health systems and society at large². The care that parents receive is critically important to how they cope with this tragedy². However, care often does not meet parent's needs.

Stillbirths make up the majority of perinatal deaths where efforts to improve the quality of data on causes and contributing factors is critically important. Many stillbirths are not appropriately investigated or classified in terms of their cause, with around 50% at term classified as “unexplained”³. The lack of a diagnosis adds to parents' distress, as they struggle to understand “what went wrong” and “will it happen again” in a subsequent pregnancy. In 20-30% of stillbirths, deficiencies in the quality of care are implicated. National perinatal mortality audit programs can help to reduce these deaths^{4,5}.

This update of the guideline has been undertaken through a partnership between PSANZ and the NHMRC Stillbirth Centre of Research Excellence in Stillbirth.

For further assistance and clarification in this section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death, see *Appendices A – Y*.

1.2 Objective of the guideline

The overarching objective of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to ensure best practice across Australia and New Zealand (ANZ) around the time of a perinatal death to improve maternity and newborn care for bereaved parents and families and to improve the quality of data on causes of stillbirth and neonatal deaths through appropriate investigation, audit and classification.

With effective implementation of this guideline the anticipated benefits are:

- Effective monitoring to reducing perinatal deaths;
- Increased understanding of causes to further reduce perinatal deaths; and
- Better care and outcomes in future pregnancies.
- Improved psychosocial outcome for parents and families;

1.3 Intended audience

The intended audience for the guideline is clinicians providing maternity and newborn care in hospitals in Australia and New Zealand.

1.4 Structure of the guidelines

This first section contains an overview of the guideline including a summary of key recommendations. The guideline is presented in 7 Sections as follows:

Section 1 - Overview and summary of recommendations;

Section 2 - Institutional perinatal mortality audit;

Section 3 - Psychological and social aspects of perinatal bereavement;

Section 4 - Perinatal autopsy examination;

Section 5 - Investigations for stillbirth;

Section 6 - Investigation of neonatal deaths; and

Section 7 - Perinatal mortality classifications.

Resources are provided to assist clinicians in implementation of the recommendations and to enhance the quality of information available for audit and research activities. To ensure the guideline remains relevant and useful, review, and revision as required, is planned as a minimum every two years. To ensure the most up-to-date version of the guideline is easily accessible, the guideline will not be produced as a bound document but rather each section will be made available in a downloadable format from the Stillbirth CRE (<https://www.stillbirthcre.org.au/>) and PSANZ website: <https://psanz.com.au/>

1.5 Definitions of stillbirth and neonatal death

Differences in definitions and reporting processes across regions within ANZ make comparisons of perinatal mortality rates difficult, and it is hoped that these differences will be addressed by the various reporting agencies.

In Australia, according to the Australian Institute of Health and Welfare (AIHW)⁶, perinatal deaths consist of stillbirths (the death of an unborn baby at 20 or more completed weeks gestation or at least 400 grams birthweight) and neonatal deaths (the death of a live born baby within 28 days of birth). However regional differences exist.

In New Zealand, perinatal death consists of fetal death (the death of a fetus of from 20 weeks gestation or weighing at least 400 grams if gestation is unknown⁷) and early neonatal death (the death of a liveborn baby that occurs before the 7th day of life⁵). Perinatal related mortality is fetal and neonatal deaths (up to 28 days) at 20 weeks or beyond, or weighing at least 400g if gestation is unknown. Fetal death includes stillbirth and termination of pregnancy⁸.

Please refer to *Appendix T – Australian and New Zealand definitions of perinatal mortality* for a summary of definitions across the jurisdictions.

1.6 Rates and causes of stillbirth and neonatal death

Australia and New Zealand have one of the lowest perinatal mortality rates in the world, however areas for further improvement are clear; notably the slow progress in reducing the rates of stillbirth - similar to many high income countries⁹. Stillbirths make up the majority of perinatal deaths and have been identified as an unaddressed global public health problem^{10,11}. In Australia and New Zealand, one in 165 women who reach 20 weeks gestation will have a stillbirth and for many, the loss occurs unexpectedly towards the end of pregnancy and a cause is never identified^{5,12-14}.

At the time of updating these guidelines, the most recent national data available in Australia was for the year 2014⁶ where there were 312,548 births, and 2986 perinatal deaths giving a perinatal mortality rate (PMR) of 9.6 per 1000 births including 2200 stillbirths (7.0 per 1000 births) and 786 neonatal deaths (2.5 per 1000 livebirths). The first comprehensive report on stillbirths was in Australia was in 2014¹⁵ and for perinatal deaths was released in 2016 covering the period 1993–2012¹⁶.

In New Zealand in 2014, there were 58,647 births and 656 perinatal deaths, giving a PMR of 11.2 per 1000 (8.1 and 3.1/1000 for fetal and neonatal death rates respectively)⁵.

For Indigenous and other disadvantaged women in both settings (similar to other high income settings), the risk of perinatal death is around double^{5,6,9,17}.

Using the PSANZ classification system the leading causes of stillbirth are congenital anomaly and spontaneous preterm. However in approximately 20-30% of stillbirths, a cause is never identified. Similarly, for neonatal mortality, the main cause of death using the PSANZ PDC is congenital anomaly and spontaneous preterm¹⁶.

Contributing factors relating to care (also called sub-optimal, avoidable or suspected preventable factors) have been reported in approximately 30-50% of perinatal deaths^{5,18-20}. Recent reports have reinforced that prevention is possible and that there is clear potential to reduce these deaths through improved quality of care driven by high quality perinatal mortality audit (e.g. the Bacchus Marsh enquiry into cases of substandard care in Victoria, the perinatal mortality report from Western Australia²¹, and the confidential enquiries from the UK²² and NZ⁸).

1.7 Changes in this update

In this update, revisions have been made to all sections. The changes are listed within each of the sections.

1.8 Summary of key recommendations

Section 2: Hospital Perinatal Mortality Audit

Section 2 Recommendations

- 1 All hospitals where births occur should implement a formal process for perinatal mortality audit of all perinatal deaths occurring in that hospitals. The process should be overseen by an interdisciplinary Perinatal Mortality Steering Committee.
- 2 Staff should be provided with appropriate training on best practice around the time of a perinatal death through the IMPROVE Program and access to support.
- 3 The review of perinatal deaths should occur as soon as possible after the death aiming to have results in time for the initial follow-up visit with parents. It may be necessary to re-review the death if test results are delayed.
- 4 A comprehensive clinical summary, including a detailed interview with the mother as soon as possible after the death, should be completed for every perinatal death to facilitate institutional audit using the recommended paper-based form or on-line tool (APMAT) which, following the completion of the audit, should be provided to the jurisdictional perinatal mortality council or respective body. Clinicians should ensure clear and accurately documentation in the medical record at the time of the event to facilitate this process.
- 5 The perinatal mortality audit meetings should have an experienced chairperson capable of ensuring a no-blame environment within an appropriate legal framework.

- 6** As part of the audit meeting, the PSANZ Classification system should be used to assign the cause of death and associated conditions for every perinatal death
- 7** As part of the audit meeting, the presence of contributing factors relating to care should be assessed and documented for every perinatal death using the format recommended in this guideline.
- 8** Recommendations emanating from the audit process should be carefully developed and accompanied by an implementation plan which should be completed within a nominated time frame e.g. following the PDSA and SMART cycles.
- 9** Initiate discussions with parents as soon as possible after the perinatal death, using an open disclosure framework
- 10** Senior clinicians should schedule follow-up meetings with the parents following perinatal death when relevant tests and reviews are complete, involving other specialists and additional investigations if indicated.
- 11** Senior clinicians should notify the General Practitioner and other relevant care providers of the death as soon as possible and a comprehensive clinical summary sent to them promptly after the audit meeting.
- 12** The Consultant responsible for care should complete or supervise completion of the Medical Certificate of Perinatal Death. The death certificate should be revised as required based on the outcome of the perinatal mortality audit meeting.
- 13** To ensure consistency and comparability in perinatal death data across ANZ, the definitions recommended in this guideline are used including presenting data with and without the inclusion of perinatal deaths resulting from termination of pregnancy.

Section 3: Respectful and supportive perinatal bereavement care

For foundations of care please refer to Section 3

Section 3 Recommendations

Good communication

- 1** Be empathic, factual and responsive. Answer parents' questions, acknowledge when something is unknown or uncertain and undertake to obtain information that parents may need.
- 2** Include both parents in communication and decision making, if appropriate, and ask if they wish to have a support person present. Acknowledge different grief responses and support parents to express their emotions and concerns.
- 3** Use the word "baby" and ask the parents if they have a name for their baby. If so, ask for permission to call the baby by that name. Do not refer to the baby as a "fetus" or "it" or by the baby's condition (e.g., "24-weeker").
- 4** Give parents clear information in a sensitive and timely manner using understandable and non-technical language.
- 5** Be aware that stress and grief can greatly affect how people absorb, retain and respond to information:
 - Repeat information and check with parents their understanding and need for further information
 - Use open questions (e.g., "What concerns you most right now?" or "What would be most helpful to know?") to assist in tailoring information
 - Give parents time to process information at their own pace and allow time for parents to ask questions
 - Anticipate intense emotional responses, including anger. Be able to support parents in their grief and consider including an experienced colleague who has understanding of the parents' circumstances.
- 6** Support verbal information with accurate and parent-centred written or electronic information that parents can read when they are ready.

Breaking bad news

- 7** When breaking bad news, communicate clearly, sensitively and honestly. Advise parents that there may be periods of silence during procedures, such as scanning. Prioritise access to a health care professional who is able to discuss findings with parents.
- 8** Minimise delays and keep parents informed. Do not leave parents on their own without information. If a mother has attended alone, offer to contact her partner or other support person and ensure she is supported until that person arrives. Advise

parents if uncertainty exists, assure parents that everything possible is being done to ascertain the baby's condition and offer to stay for support or to answer questions.

Cultural safety

9 Provide culturally safe care by:

- Avoiding cultural stereotypes and culture-based assumptions and recognising that diversity exists within cultural groups and between individuals
- Asking all parents whether they have any religious, cultural or spiritual needs and facilitating requests where possible
- Offering to contact appropriate support services to assist with cultural needs if the parents wish
- Determining with the parents whether an interpreter is needed and, if so, engage an accredited interpreter (some women may not wish to have a male interpreter)
- Being aware of particular needs of vulnerable groups who may have a history of trauma and loss

Space and Surroundings

10 Identify an appropriate space for breaking bad news and all subsequent discussions with parents. Ideally, these spaces should be:

- Private and quiet
- Conducive to unrushed and uninterrupted time
- Separate from other pregnant women and newborn babies
- Suitable for extended family to gather
- Free of items or equipment that could be confronting or upsetting to bereaved parents

11 Establish what parents want for their care around the time of birth, including whether they would prefer to be away from the maternity ward if this is possible. Make provision for the mother's partner or other support person to stay in her room if she wishes.

12 Enable parents to spend as much time as they wish in private with their baby who is dying or who has died, including the option to take their baby home:

- For a baby who has died, discuss practical matters with parents when they are ready, including care and transport of the baby's body, and relevant legal issues
- For a baby with a life-limiting condition, consider and offer the option of perinatal palliative care in the family home, involving palliative care teams if available and ensuring parents have the support they need

Good communication between health care professionals

- 13** Designate a lead contact person with training in bereavement care to be available to the parents and other members of the care team to promote continuity of care. Ensure that more than one person is trained for this role to avoid compassion fatigue.
- 14** With the mother's agreement, use a universal bereavement symbol that can be placed discreetly in the woman's room and on her medical records to indicate a baby has died or is expected to die and ensure the symbol is recognised and understood by all staff who interact with the parents.
- 15** With the mother's agreement, advise relevant health care professionals involved in her care (including general practitioner, child health and other community services) of the baby's death or impending death so that existing appointments are cancelled, and other types of appropriate follow-up are activated. Where possible, this should occur prior to hospital discharge.

Shared decision making

- 16** Support parents to make their own decisions and take care to avoid assumptions about what parents will choose. Ask parents what is important to them and what concerns they have. Keep in mind that parents may not yet know what their needs are and provide guidance and support as they absorb information.
- 17** Consult parents about all decisions, with the understanding that they may not be ready to make decisions and may need more information and time
- 18** Acknowledge that parents may feel uncertain or uncomfortable about their decisions. Use "other people" framing (e.g., "Other parents have sometimes found it helpful to ...") to help normalise decisions and help parents explore options and clarify what is important to them.
- 19** Ask whether parents want others to be involved in decision making (e.g., family members, other support persons, community elders or spiritual leaders) while also letting parents have time to themselves.
- 20** Provide opportunities for parents to ask questions and explore their concerns more than once with an informed, experienced and trusted health care professional. Provide opportunities for parents to revisit their decisions, but inform them of time critical issues (e.g., time to autopsy; how baby's condition may change).

Decisions about timing, mode and place of birth

- 21** Provide clear and understandable information about options for timing, mode and place of birth, and pain relief options that take into account parents' wishes, goals and concerns. Advise parents that a labour and vaginal birth may provide physical and emotional benefit, compared to a caesarean section without indication

- 22** If parents wish, develop with them a birth plan that incorporates planning for the baby's death, including the type of care to be delivered to a baby born alive, interactions with the baby, and any cultural, spiritual or other rituals.

Decisions about investigations after death

- 23** Discuss the value of an autopsy with parents in all cases of perinatal death and offer them the option of the procedure. Explain the various autopsy options, including less invasive and stepwise examinations. Where possible, the discussion should be led by a senior clinician who has established a rapport and understanding with the parents.
- 24** Provide written or electronic information to supplement and support discussions with parents about autopsy to help in their decision about autopsy for their baby.
- 25** Assure parents that their baby will be treated with care and respect at all times and that everything possible will be done to understand the cause of the death, including standard investigations and review of the care provided.
- 26** Address issues that may be important to parents including knowing where the baby is, whether they can accompany the baby to the mortuary, and whether they can see the baby again.
- 27** Provide parents with a preliminary plain language report of the autopsy examination as soon as possible after the examination. The report should be carefully explained to the parents by a senior clinician who has established a rapport and understanding with the parents.
- 28** Establish clear processes and timelines for informing parents of investigation results beyond hospital discharge.

Recognition of parenthood

- 29** Validate parenthood and support memory making by:
- Assuring parents that their baby will be treated with care and respect at all times
 - Using gentle and caring language and actions when interacting with the baby
 - Providing information about the baby (e.g., weight, length, hair colour)
 - Supporting parenting activities such as holding, bathing, dressing, and undressing the baby
 - Offering all parents the opportunity to see and hold their baby immediately after birth, including skin-to-skin contact with their baby
- 30** Support parents' decisions to see and hold or not see and hold their baby recognising that either option is valid and that parents may also change an initial decision.
- 31** Prepare parents for seeing and holding their baby by giving relevant information about the baby's physical appearance, size, tone and temperature.

- 32** Ensure that all parents are offered (on more than one occasion):
- Opportunities to spend time with their baby, including taking the baby home or to another place important to the family.
 - Photographs that tell the story of their baby, including: the labour and birth; photographs of their baby, themselves and others with their baby; and, in the case of a multiple birth, photographs of the babies together (including any surviving babies). Advise parents of any free photography service for bereaved parents.
 - Tangible mementoes of the baby (e.g., identification tags, cot cards, lock of hair, hand and footprints).
 - Opportunities to involve siblings and other family members.
 - Opportunities for commemorative rituals such as naming ceremony, blessing or baptism.
- 33** Discuss with parents options for storing mementoes of their baby with their hospital records, for possible collection at a later date, if they choose not to take these items home.
- 34** Be knowledgeable and provide information about burial, cremation, and funeral options that are available for babies and support parents in making an unhurried decision.
- Effective support**
- 35** Provide parents with guidance about common perinatal grief responses and what to expect, including written or electronic information to review when they are ready.
- 36** Sensitively address mothers' postnatal physical care needs, including lactation, vaginal bleeding, wound care, contraception, and physical activity.
- 37** Address practical support needs including sources of financial support, options for accommodation and assistance if parents are away from their local home environment, birth and death certificates, birth registration, and medical certificates for employers.
- 38** Ensure parents leave hospital with contact details for 24-hour follow-up support and written information about ongoing sources of support (telephone, online and face-to-face), including parent support organisations. Recognise that parent support needs and preferences vary and that written information complements, but does not replace, empathic face-to-face communication.
- 39** Ensure mothers receive at least one follow-up call or visit from an appropriately skilled health care professional after their discharge from hospital.
- 40** Offer all parents a follow-up review meeting held within 12 weeks of the baby's death, led by a health care professional who is experienced in providing feedback to parents, known to the parents where relevant, and able to address the clinical and emotional

aspects of their baby's death. Recognise the importance of follow-up meetings for parents:

- Provide parents with clear verbal and written details of the process for follow-up appointments
- Ensure all available results are assembled and provide information about any delays or interim results
- Address implications for future pregnancies, including recommendations for pre-conception and maternity care

- 41** Establish and use referral pathways for parents who may be at risk of complicated bereavement due to factors relating to the death, medical or personal history, social circumstances or other stressors.

Organisational response

- 42** Each maternity facility should establish and foster a commitment to delivering best practice perinatal bereavement care. Evidence-based policy and guidelines should be available to and used by all relevant staff.

- 43** Training and support of staff is critical for the delivery of best practice perinatal bereavement care:

- All clinicians providing maternity and newborn care should attend the [IMproving Perinatal Mortality Review and Outcomes Via Education \(IMPROVE\) Workshops educational program](#)
- All health care professionals in maternity settings should have training in bereavement care that addresses the emotional, physical and practical aspects of perinatal death and relevant local policies
- Formal and peer support should be readily available for health care professionals working with perinatal death
- Mentoring, supervision and specialist training should be supported to build capacity, sustainability and excellence in perinatal bereavement care
- Opportunities should be provided for students and new graduates to gain appropriate training and mentoring in perinatal bereavement care

- 44** Each maternity facility should establish and implement local protocols and policies relating to:

- The use of a universal symbol for recognition by all staff who interact with parents to indicate that a baby has died or has a life-limiting condition
- Options for perinatal palliative care when a baby has a life-limiting condition
- The management of mementoes, including their storage on behalf of parents
- Resources for perinatal bereavement care, including accurate and up-to-date written informational resources that are offered to all parents
- Contact details for health care professionals trained in high-risk pregnancies available at all times to provide advice (e.g., when an anomaly is suspected, or diagnosis of stillbirth needs confirmation)

- Referral pathways for parents who may be at risk for complicated bereavement
 - Use of appropriate communication technology such as telehealth services for facilities in rural and remote locations
- 45** Make available appropriate spaces and surroundings, including accommodation, for parents whose baby has died or requires end-of-life care.
- 46** Ensure all health care professionals who support bereaved families are familiar with the processes and arrangements for conducting perinatal autopsy, including the baby's care.
- 47** Establish commemorative rituals, such as an annual Remembrance Service, for parents whose babies have died.
- 48** Develop links and partnerships with relevant local services for perinatal palliative care and post-hospital bereavement care and support, including parent support organisations
- 49** Establish data collection processes to routinely monitor and evaluate quality of bereavement care from parent and health care professional perspectives and regularly report on outcomes.
-

Section 4: Perinatal Postmortem Examination

Section 4 Recommendations

- 1 Clinicians should discuss the value of an autopsy with parents in all cases of perinatal death and offer them the option of the procedure.
- 2 To increase the rates of perinatal autopsy:
 - Clinicians should collaborate with pathologists and parent based organisations to raise public awareness of the value of perinatal autopsy and to advocate for high standards in perinatal autopsy at local and government level.
 - Clinical leaders should promote formal and informal educational opportunities for clinicians on: post-mortem examination procedures; the potential benefits of an autopsy; compassionate counselling and obtaining parental consent; and address specific local barriers to the conduct of perinatal autopsy.All clinicians providing maternity and newborn care should attend the IMproving Perinatal Mortality Revue and Outcomes Via Education (IMPROVE) Workshops educational program (<https://sanda.psanz.com.au/improve/>).
- 3 Seek advice from the coroner or an experienced coronial officer if any doubt exists as to whether a death should be referred to the coroner.
- 4 Clinicians need to be aware of costs associated with transferring an infant from non-metropolitan areas to tertiary centres for autopsies within their region and inform parents of any personal cost implications relevant to their decision-making.
- 5 The Guidelines on Autopsy Practice produced by the Royal College of Pathologists²³ should be used for guidance on minimum standards until guidelines for Australia and New Zealand are developed.
- 6 Specific protocols developed for post-mortem examination in the event of Sudden Unexpected Death in Infancy and death with suspected genetic metabolic disorders should be followed.
- 7 A perinatal/paediatric pathologist should perform or supervise all perinatal post-mortems. Clinicians should request autopsies from the service providing the highest quality.
- 8 Transport to a centre with appropriate expertise should be arranged to ensure that all perinatal post-mortem examinations are of sufficient quality. Transport should be arranged with a registered undertaker.
- 9 A comprehensive maternal history should accompany the baby for a post-mortem examination including:
 - Clinical/obstetric history including relevant previous obstetric history
 - Copies of all ultrasound reports
 - Copy of the death certificate if available
 - Copy of amniocentesis report if available.

- 10** Guidelines for post-mortem reports produced by the Royal College of Pathologists²⁴ should be used as a guide for reporting of perinatal post-mortem examinations.
- 11** Ideally, a preliminary post-mortem report should be forwarded to the referring clinician within three working days of the post-mortem. The final report should be forwarded to the referring clinician ideally within eight weeks of the autopsy.
- 12** The post-mortem report should be made available to the parents at a time when the primary care clinician is present to discuss the findings.
- 13** A Plain Language Report (PLR) should be available to parents on request.
- 14** A request for the General Practitioner (GP) to receive a copy of the report (including the PLR, if available) should be explicit on the request form, as they are the main care provider on discharge.
- 15** Where possible, a senior clinician who has established a rapport and understanding with the parents should discuss the value of an autopsy and offer the option of the procedure. Such clinicians should have high level communication skills and knowledge of all post-mortem examinations, and preferably witnessed several perinatal autopsies.
- 16** Any clinician approaching parents for autopsy consent should discuss:
 - Options for full, Less invasive autopsies (LIA), minimally invasive autopsies (MIA), Non-invasive autopsies (NIA) or stepwise post-mortem examinations
 - Issues related to retained tissues, organs and DNA for genetic and other tests
 - The value of autopsy
 - Possibility that cause of death may not be determined
 - Possibility that some potential causes of death could be excluded
 - Information gained may not directly benefit the family but may benefit others
 - Possible implications for future pregnancies
 - The care and respect that will be given to the baby
- 17** Discussion with parents should be supplemented by written information explaining autopsies to help in their decision on autopsy for their baby.
- 18** When consent is obtained for specific organ/s to be retained for further examination, parents should be offered the option of either delaying the funeral until the organs can be returned to the body or specifying their preferred method of organ disposal.
- 19** Consent for the autopsy which clearly outlines the extent of the investigation should be recorded on an approved consent form, relevant to the jurisdiction.
- 20** Where possible the pathologist should be available to discuss the autopsy with the parents before and/or after the procedure and, where feasible, the requesting clinician should attend the autopsy and provide the parents with a preliminary report immediately after the examination.

- 21** | Placentas should be sent for examination by the perinatal/paediatric pathologist regardless of whether consent for an autopsy has been gained following stillbirths, neonatal deaths in the delivery room or birth of high risk infants.
 - 22** | Consent should be sought from parents for less invasive testing if permission for an autopsy is not obtained, including: external examinations by skilled clinician; an MRI scan; babygram; ultrasound scan; post-mortem needle biopsy; laparoscopic autopsy and small incision access.
 - 23** | When an MRI scan is undertaken it should be undertaken as soon as possible after a stillbirth.
-

Section 5: Investigations for Stillbirth

Section 5 Recommendations

- 1** A non-selective approach according to the recommended core investigations should be adopted for all stillbirths (unless the cause of death has been unequivocally determined antenatally). These investigations are:
 - Comprehensive maternal (medical, social, family) and pregnancy history
 - Kleihauer-Betke test/Flow cytometry for fetal to maternal haemorrhage
 - External examination of the baby performed by the attending clinician
 - Clinical photographs of the baby
 - Autopsy
 - Detailed macroscopic examination of the placenta and cord
 - Placental histopathology
 - Cytogenetics (Chromosomal microarray (CMA) or karyotype if CMA is not available).
- 2** Further sequential and/or selective investigations should be undertaken according to the particular clinical scenario based on a comprehensive history, and information gained from core investigations.
- 3** An external examination of the baby should be performed at birth by the attending clinician using the recommended checklist (*Please refer to Appendix D – Clinical examination of baby checklist*) and clearly documented in the medical record. Where the family has consented to autopsy, all information gained from the initial external examination (along with comprehensive maternal (medical, social, family) and pregnancy history) should be forwarded to the pathology service to guide this procedure.
- 4** Following a stillbirth, the placenta, membranes and cord should be kept refrigerated and, where feasible, sent fresh and unfixed for macroscopic and histological examination by a perinatal pathologist. The pathology service should be informed if the parents have requested return of the placenta following examination.
- 5** Clinicians should discuss the value of a full autopsy with parents in all cases of perinatal death where the cause of death is not already known. If the parents decline a full autopsy, a limited/partial autopsy should be offered.

Section 6: Investigations of Neonatal Death

Section 6 Recommendations

- 1 Obstetric and neonatal care teams should collaborate closely to ensure that all relevant maternal (pregnancy and birth) and neonatal factors are considered in the investigation of the neonate. Comprehensive maternal medical, social and antenatal history including results of all investigations documented in the medical record by obstetric staff. A comprehensive neonatal history including death scene analysis is always required.
- 2 A detailed external examination of the baby must be performed by a perinatal pathologist, neonatologist or paediatrician where possible. *(Please see Appendix D – Clinical examination of baby checklist).*
- 3 Accurate anthropometric parameters of birth weight, length and head circumference plotted on appropriate gender specific birth growth charts.
- 4 A newborn screening blood sample should be taken for all neonatal deaths.
- 5 Clinicians should discuss the value of an autopsy with parents in all cases of a neonatal death and offer the option of the procedure.
(Please see Section 4; Perinatal postmortem examination).
- 6 Following consent from the parents, clinical photographs should be taken for later review, particularly in the circumstance of birth in non-tertiary hospital settings. These photos are additional to the bereavement photographs, and should be clearly labelled and filed in the medical record (not given to the parents) and be available for members of expert PNM committee to view. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality must be considered.
- 7 For neonates at high risk of death at the time of birth, or in birth suite, targeted investigations based on the presenting scenario should be undertaken.
 - Detailed external examination of the baby by a neonatologist or paediatrician (where possible) with clear documentation of findings in the medical record
 - Where possible, cord blood gas analysis that includes both arterial and venous samples
 - Newborn screening blood sample
 - Detailed macroscopic examination of the placenta and cord with findings documented in the medical record by obstetric staff
 - Histopathological examination of fresh and unfixed placenta, cord and membranes.
 - Autopsy.
- 8 Clinicians should initiate investigations specific to the circumstances of the birth (see Section 6.7 for targeted investigations).

- 9** Clinicians should investigate possible thrombophilic disorders in mothers with preeclampsia or with a personal/family history of thrombosis, or following the birth of an infant with severe growth restriction.
- 10** Selective screening in addition to placental examination for thrombophilic disorders should be undertaken following the birth of high risk neonate or a neonatal death:
 - Anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1 antibodies
 - Microarray/karyotype
 - Autopsy
- 11** Investigation for maternal diabetes, if not previously undertaken, should include:
 - Maternal HbA_{1c} level (as soon as possible after delivery); and
 - If the HbA_{1c} level is raised, a fasting blood glucose should be undertaken and, if abnormal, a glucose tolerance test performed 6-8 weeks postnatally.
- 12** Other causes of macrosomia, such as Beckwith Wiedemann syndrome, should be investigated if there is no maternal or paternal diabetic history.
- 13** In the case of a suspected genetic metabolic disorder, Clinicians should discuss individual cases with their State Laboratory to identify the optimum tests to request and consult a clinical metabolic specialist if more expert guidance required.
- 14** All tissue samples should be stored and transported to a Specialist Metabolic Laboratory for investigation.
- 15** When a lethal genetic metabolic disorder is suspected prior to birth, clinicians should:
 - Seek consent from the parents for a metabolic autopsy
 - Consult a metabolic physician or a histopathologist before collecting the following samples:
 - Blood sample (0.8ml) in lithium heparin tube (refrigerate)
 - Urine sample (5-10ml)
 - Knee cartilage and/or skin biopsy (3 x 2 mm punch biopsies) (sent to cytogenetics with request for fibroblast culture and store)
 - Liver and muscle biopsies (for electron microscopy, histopathology and enzymology).
- 16** Investigation of any sudden unexpected neonatal death should include:
 - Coroner notification
 - Thorough maternal and infant medical histories
 - Full autopsy examination by a forensic pathologist skilled in perinatal autopsy or a forensic pathologist in conjunction with a perinatal pathologist
 - Investigation of the various scenes where incidents leading to the death might have occurred including the infants sleeping environment.
- 17** Investigations for genetic metabolic disorders should be undertaken for all sudden unexpected neonatal deaths.

Section 7: Perinatal Mortality Classification

Section 7 Recommendations

- 1** All stillbirths and neonatal deaths should be classified according to the PSANZ SB&ND classification system to identify a single underlying cause of death for both stillbirths and neonatal deaths.
- 2** Following classification of a single underlying cause, up to two associated factors which contributed to the death (i.e. not considered as the underlying cause) should be classified using the PSANZ SB&ND associated conditions list.
- 3** The classification of stillbirths and neonatal deaths should be based on the best available information from a comprehensive history and appropriate investigation (as recommended in Sections 4 and 5 of this guideline) and should form part of a formal institutional clinical audit process as outlined in Section 2 of this guideline.
- 4** The classification should be included in the routine perinatal data collections across jurisdictions for every perinatal death to enable comprehensive reporting regionally and nationally including disaggregation and identification of timing of the death (i.e. antepartum, intrapartum, early and late neonatal deaths).
- 5** Following application of the PSANZ SB&ND system, mapping to ICD-PM categories should be undertaken to enable high quality global reporting.

1.9 References

1. Homer CSE, Malata A, ten Hoop-Bender P. Supporting women, families, and care providers after stillbirths. *The Lancet* 2016; **387**(10018): 516-7.
2. Heazell AE, Siassakos D, Blencowe H, et al. Stillbirths: economic and psychosocial consequences. *The Lancet* 2016; **387**.
3. Ibiebele I, Boyle FM, Horey D, et al. Predictors of autopsy following stillbirth in Queensland, Australia: A population-based study. *Aust N Z J Obstet Gynaecol* 2017; **57**(1): 33-9.
4. Kerber K, Mathai M, Lewis G, et al. Counting every stillbirth and neonatal death through mortality audit to improve quality of care for every pregnant woman and her baby. *BMC Pregnancy and Childbirth* 2015; **15** (Suppl 2).
5. Perinatal and Maternal Mortality Review Committee. Tenth annual report of the Perinatal and Maternal Mortality Review Committee: Reporting mortality: Reporting mortality 2014. Wellington, NZ: Health Quality & Safety Commission, 2016.
6. Australian Institute of Health and Welfare. Australia's mothers and babies 2014—in brief. Canberra: AIHW; 2016.
7. Births, Deaths, Marriages, and Relationships Registration Act 1995. New Zealand; April 2015.
8. PMMRC. Ninth annual report of the Perinatal and Maternal Mortality Review Committee: Reporting mortality 2013. Wellington: Health Quality & Safety Commission, 2015.
9. Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, Coory M, for the Lancet Ending Preventable Stillbirths series study group. Stillbirths: Recall to action in high-income countries. *The Lancet* 2016; **387**(10019): 691-702.
10. Lawn JE, Blencowe H, Waiswa P, et al. Stillbirths: rates, risk factors, and acceleration towards 2030. *The Lancet* 2016; **387**(10018): 587-603.
11. Horton R, Samarasekera U. Stillbirths: ending an epidemic of grief. *The Lancet* 2016; **387**(10018): 515-6.
12. Monk A, Harris K, Donnelly N, et al. Perinatal deaths in Australia 1993–2012. Canberra: AIHW, 2016.
13. Hilder L, Li Z, Zeki R, Sullivan EA. Stillbirths in Australia, 1991–2009. Canberra: AIHW, 2014.
14. AIHW. Australia's mothers and babies 2013—in brief. Canberra: AIHW, 2015.
15. AIHW, Hilder L, Li Z, Zeki R, Sullivan E. Stillbirths in Australia, 1991–2009. Canberra: AIHW National Perinatal Epidemiology and Statistics Unit., 2014.
16. AIHW, Monk A, Harris K, et al. Perinatal deaths in Australia, 1993–2012. Canberra: AIHW, 2016.
17. Ibiebele I, Coory M, Boyle FM, Humphrey M, Vlack S, Flenady V. Stillbirth rates among Indigenous and non-Indigenous women in Queensland, Australia: is the gap closing? *BJOG* 2015; **122**(11): 1476-83.
18. CESDI - Confidential Enquiry into Stillbirths and Deaths in Infancy. 8th Annual Report. London: Maternal and Child Health Research Consortium, 2001.
19. CCOPMM. Annual Report for the Year 2000. Melbourne: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity, 2003.
20. Richardus JH, Graafmans WC, Bergsjø P, et al. Suboptimal care and perinatal mortality in ten European regions: methodology and evaluation of an international audit. *J Matern Fetal Neonatal Med* 2003; **14**(4): 267-76.
21. Gee V. Perinatal, Infant and Maternal Mortality in Western Australia, 2006-2010. Perth, Western Australia; 2013.
22. Draper ES KJ, Kenyon S. (Eds.) on behalf of MBRRACE-UK. MBRRACE-UK Perinatal Confidential Enquiry: Term, singleton, normally formed, antepartum stillbirth Leicester: The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester, 2015.

23. The Royal College of Pathologists. Guidelines on autopsy practice: Report of a working group of the Royal College of Pathologists. 2002. http://www.rcpath.org/activities/publications/autopsy_practice_sept2002.html2004).
24. The Royal College of Pathologists. Guidelines for post mortem reports. London: The Royal College of Pathologists, 1993.

1.10 Appendices

Appendix A – Stillbirth investigations algorithm

Appendix B – Estimation of severity of feto-maternal haemorrhage

Appendix C – Placental examination; Accoucheur flow chart

Appendix D – Clinical examination of baby checklist

Appendix E – Australian perinatal mortality audit tool

Appendix F – New Zealand rapid reporting form for a perinatal death - baby

Appendix G – New Zealand Rapid reporting form for a perinatal death - mother

Appendix H – Instructions on taking clinical photographs

Appendix I – Autopsy clinical summary form

Appendix J – Perinatal mortality classifications: Quick reference sheet

Appendix K – WHO mortality audit meeting code of practice declaration

Appendix L – Birthweight percentiles

Appendix M – Infant autopsy consent brochure

Appendix N – Information for health professionals seeking consent

Appendix O – RCPATH Guidelines for Autopsy Investigation of Fetal and Perinatal Death

Appendix P – Placental histopathology reporting form

Appendix Q – Suspected genetic metabolic disorders

Appendix R – Screening for genetic metabolic disorders

Appendix S – Components of the genetic autopsy for investigations of metabolic disorders

Appendix T – Australian and New Zealand definitions of perinatal mortality

Appendix U – Changes on this version of the classifications

Appendix V – Development of PSANZ Perinatal Death Classification and PSANZ Neonatal Death Classification

Appendix W – Methods

Appendix X – Glossary of terms and abbreviations

Appendix Y – Contact details and regional coordinators 2018