

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 1

Overview and Summary of Recommendations

Version 3.4, January 2020

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.

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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:

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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.
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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.
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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 Review 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.
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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.

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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

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 2

Institutional Perinatal Mortality Audit

Version 3.4, January 2020

Endorsed by



SECTION 2

INSTITUTIONAL PERINATAL MORTALITY AUDIT

2.1 Introduction

This section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death presents recommendations on perinatal mortality audit in maternity hospitals, including classification of causes, associated conditions and contributing factors. Perinatal mortality audit is:

“a process to document the medical causes of each death and contributing systemic failures in order to identify solutions and take action. It is not a solution in itself. It is a systematic way of improving quality of care through collecting and analysing data, linking solutions and ensuring accountability for changes in care”¹.

The critical analysis of each death in a no-blame, interdisciplinary setting has the potential to “tell a story about what could have been done differently to unlock the solutions that should have been available for each woman and baby to prevent perinatal deaths”¹. Audit, when combined with feedback to care providers, can change practice and improve health outcomes, particularly when combined with an action plan and clear measurable targets².

The 2016 Lancet series on stillbirth highlighted the importance of high quality audit in reducing stillbirths³. In New Zealand, stillbirth rates at term have declined over the seven years since national perinatal audit began⁴. Perinatal mortality audits in the Netherlands⁵, the UK⁶, and New Zealand⁴ show substandard care factors are present in a high proportion of cases (20-30%, and up to 60% for intrapartum stillbirths). In Australia, while a national perinatal audit program is yet to be implemented, state committees produce regular reports on rates and causes of perinatal mortality⁷⁻¹⁴ and in Victoria¹⁰ and Western Australia⁷ health departments routinely undertake perinatal mortality audits.

In this section of the PSANZ Guideline for Care Around Stillbirth and Neonatal Death, practice recommendations are supplemented by audit tools checklists to assist clinicians to implement the guideline recommendations (See *Appendices E - G, J, K and T*).

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

2.2 Objective of this section

The main objective of Section 2 of the PSANZ Guideline for Care Around Stillbirth and Neonatal Death is to improve the quality of data collected on causes and contributing factors relating to care for stillbirths and neonatal deaths for the purposes of:

- Helping parents to understand why the death occurred and to assist in future pregnancy planning;
- Improving the quality of care parents receive after their child is either stillborn or dies in the neonatal period;
- Assisting in implementing audit as a tool for quality improvement in general; and

- Reducing stillbirths and neonatal deaths by improving clinical practice and informing appropriate research through enhancing the conduct of appropriate research, epidemiology and health surveillance and regional/international comparisons

2.3 What has changed in this update?

In this update, changes have been made to align the guideline with the recently developed WHO guideline “The WHO Stillbirth and Neonatal Death Review Tool”¹. While key recommendations are unchanged from the previous version, additional advice and justification is provided to enhance the conduct of high quality perinatal mortality audit at the facility level. Further, the recommended tool for systematic review of contributing factors has been revised to align with that used by the New Zealand Perinatal and Maternal Mortality Review Committee (PMMRC)⁴. As with other sections of this guideline, we have revised the formatting and reduced duplication across the different sections to enhance readability.

2.4 Research gaps

While perinatal mortality audit is accepted as an essential component of care and case studies across countries highlight the yield in terms of identifying substandard care factors, further high quality studies are needed to determine its value in improving practice and health outcomes¹⁵. Research to identify the optimal approaches to classification of perinatal deaths is also needed¹⁶. Additionally, outcomes associated with involving parents in perinatal mortality audit¹⁷ and methods to improve autopsy counselling and consent requires further research¹⁸.

2.5 Establishing a hospital based perinatal mortality audit program

Hospital leadership and support

Successful perinatal audit programs are those that are thoughtfully planned and where strong leadership is provided by committed health professionals. Poorly planned programs in which no action is taken following the review, result in disinterest and demoralised staff^{1,19}.

The perinatal mortality audit program should be linked with local standards in clinical quality and safety activities including the findings of root cause analysis (RCA)^{20,21} where undertaken, and the implementation of the perinatal audit review recommendations to improve practice and to avoid the same clinical errors occurring in future.

The audit program should have established systems for clear reporting of de-identified audit findings to the health service board’s quality (clinical governance) committee or lead. Further, systems for authorisation, implementation and evaluation of those recommendations and a process of escalation and reporting processes where serious system failures or misconduct are identified.

Hospital-based perinatal mortality audit programs should be overseen by an interdisciplinary perinatal mortality audit steering committee. The hospital administration needs to provide the committee with adequate support and governance to:

- Ensure an appropriate legal and ethical framework is in place;
- Encourage staff to actively support and participate in the audit program, enabling relevant clinical staff to attend the audit meetings;
- Ensure appropriate scheduling of meetings so the maximum number of key staff can attend, and cases are reviewed within an acceptable time frame;

- Ensure adequate staffing and resources are available for administration of meetings, and for data collection, analysis and report preparation, and organisation of meetings.

Membership and Roles of the Perinatal Mortality Audit Steering Committee, Audit and Educational meetings

The Perinatal Mortality Steering Committee should include an interdisciplinary team of key stakeholders with responsibility and authority to ensure recommendations are translated into actions.

Membership Perinatal Mortality Steering Committee may include representatives from: administration, neonatology/paediatrics, obstetrics, midwifery/nursing, pathology, clinical genetics, pharmacy, epidemiology/ statistics, social worker, general practice, but the committee should not be too large. The involvement of parents and/ or community representatives is gaining increasing interest and requires further exploration of potential benefits¹⁶.

The Perinatal Mortality Steering Committee members attend and oversee each *Perinatal Mortality Audit meeting* where individual perinatal deaths are reviewed in detail. Other members of staff may be invited to attend depending on the cases being reviewed.

The Perinatal Mortality Audit meetings are distinct from other *perinatal mortality educational meetings* which may be undertaken to present aggregate data on rates and trends in perinatal deaths and to assist in dissemination of recommendations and practice change and are open to all interested parties, including students. With appropriate mentorship, the Perinatal Mortality Audit meetings may also be helpful as an educational activity for students.

Smaller regional facilities and regional groups of facilities with smaller numbers of staff and infrequent perinatal deaths may combine the functions of the Perinatal Mortality Audit Steering Committee and the Perinatal Mortality Audit meetings.

Role of the Perinatal Mortality Steering Committee

- Establish and oversee the audit process including assigning responsibility and providing training and oversight of tasks such as data collection;
- Arrange a schedule of perinatal mortality audit meetings, setting the ground rules for and identifying an appropriate chairperson, and inviting relevant participants;
- Oversee the development and facilitate the dissemination and implementation of practice recommendations emanating from the audit;
- Oversee the production of reports on the outcome of the audit program including those required to relevant health department agencies;
- Oversee the implementation of the PSANZ Clinical Practice Guidelines for Care Around Stillbirth and Neonatal Death using the IMPROVE educational program²²;
- Oversee the revision and resubmission of the perinatal death certificate if required based on findings of the audit meeting; and
- Ensure that all staff members have access to adequate support following a perinatal death.

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.

2.6 Regional and national considerations

Aggregated high quality audit can reveal common modifiable factors and potential solutions e¹. Consistent data systems and approaches provide a powerful tool for practice change to reduce perinatal deaths. Hospital-based perinatal mortality audit programs should be supported by, and feed into, regional and national audit programs overseen by key stakeholder committees. This process has been established in New Zealand (since 1994) with clear benefits⁴ and is currently being considered for Australia. In Australia production of an annual perinatal mortality report for Australia by the Australian Institute of Health and Welfare (AIHW) and establishment of a national advisory committee, and piloting of an on-line perinatal audit database through a NHMRC grant²³ are in progress. Establishing perinatal mortality audit at the national level will require support from national bodies, including ministries of health and professional colleges³.

2.7 The perinatal mortality audit cycle steps

We propose a seven-step cycle based on the cycle developed by the WHO¹; an additional step is included on feedback to parents. The seven steps are as follows: (1) identifying and scheduling the review of all perinatal deaths; (2) collecting and managing the information; (3) analysing information; (4) recommending solutions; (5) feedback and communication with parents; (6) implementing solutions; and (7) evaluating both the process and the outcomes and refining as indicated (Figure 1).



Figure 1 Steps in the perinatal mortality audit cycle

Step 1: Identify cases and schedule the review

- Establish a system to quickly identify all cases of perinatal deaths.
- Flag priority cases for rapid review (e.g. unexpected deaths in late gestation and intrapartum deaths).

The review of a perinatal death should be undertaken in a timely manner so that it occurs within recent memory of those involved and enables information from the review to be incorporated into discussion with the parents at their follow-up visit. A review should take place as soon as results are available from initial investigations. A further review of the death by the Mortality Committee, once the results of all investigations are available, may be necessary to finalise the cause of death and to ensure further follow-up is arranged as required. Timely review of the death may also facilitate appropriate counselling and support for staff.

Section 2 Recommendations

- 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.

Step 2: Collect and manage the information

- Complete a comprehensive clinical summary for every perinatal death

Consultation with the woman (and her partner) about the course of events leading to the death should be undertaken as soon as possible and findings included in the case summary.

- Identify and train staff in data collection for perinatal mortality audit

This should include collecting a thorough history from the mother as soon as possible.

The Australian Perinatal Mortality Audit Tool (APMAT) (see *Appendix E – Australian perinatal mortality audit tool*) and New Zealand Rapid Reporting Form for a Perinatal Death (see *Appendix F (baby)* and *Appendix G (mother)*) have been designed to capture a standardised data set that should be collected for all perinatal deaths. This form is designed to fulfil requirements of health departments to ensure high quality data on causes of perinatal death nationally. To facilitate the data collection process clinicians should ensure that all relevant clinical details are documented clearly and accurately in the medical record at the time of the event and that all relevant documentation is completed according to local policy.

Data on each case should be:

- Recorded electronically;
- Include rates, causes, and contributing factors
- Link with other routinely collected data to minimise additional workload from the audit process

Section 2 Recommendations

- 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, NZ Rapid reporting forms for a perinatal death) 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.

Step 3 Review and analyse the information

Generally, proceedings of the hospital Perinatal Mortality Audit meetings should include review of all perinatal deaths occurring in that hospital. Maternity services (particularly smaller hospitals) may choose to combine the audit meetings with another hospital committee or a regional mortality review committee.

- Develop a format for review of perinatal deaths, taking into account principles of confidentiality and impartiality, and any specific policy or legislative requirements relevant to the jurisdiction.

The aim of a perinatal mortality audit meeting is to provide an atmosphere of confidentiality and security that will encourage health care providers and managers to communicate openly and honestly with their colleagues. To achieve this, assurance should be sought by the administration of the institution that any information and discussion arising from the formal review will not be used in legal proceedings. As mechanisms for establishing perinatal mortality committees with the appropriate protection differ across Australia and New Zealand (ANZ), committees should seek advice from their respective health departments. It is the responsibility of each hospital's management to ensure that committee members and their deliberations are appropriately indemnified if required while undertaking this kind of audit on their behalf. Having case presentations which are completely anonymous may be helpful. However, within a single hospital, it is difficult to achieve a truly anonymous review.

Section 2 Recommendations

- 5 | The perinatal mortality audit meetings should have an experienced chairperson capable of ensuring a no-blame environment within an appropriate legal framework.

Chair and “rules of the meeting”

Review by a multidisciplinary team has been shown to increase the yield of information about the cause of deaths from mortality review²⁴. Multidisciplinary involvement provides an opportunity for all members of the team providing care to participate in a comprehensive assessment of the standards of care and to consider strategies for care improvement where necessary. Perinatal mortality audit meetings should be multidisciplinary, involve those health care professionals familiar with the circumstances of the perinatal death, and be conducted with a “no-blame” approach. The chairperson should be skilled in chairing meetings of a highly sensitive nature and accepted by peers to appropriately guide the discussion. While a senior medical practitioner usually fulfils the role of the chairperson, it is also important to involve nurses and midwives in this role¹. Having participants agree to a code of practice for review meetings and ensuring confidentiality as much as possible can contribute to an environment where audit is more likely to be successful²⁵ (see *Appendix K – WHO mortality audit meeting code of practice declaration*).

Assigning the cause of death

Every perinatal death occurring in the facility should be reviewed at the audit meeting and classified as to the causes of death according to the Perinatal Society of Australia and New Zealand (PSANZ)-Perinatal Death Classification (PDC) and Neonatal Death Classification (NDC). (Please refer to *Appendix E – Australian perinatal mortality audit tool*; *Appendix J – Perinatal mortality classifications: Quick reference sheet*). After review and classification of the cause of death, the death certificate may need to be revised and resubmitted (see item 6 below). For global comparisons, WHO recommends use of the ICD for perinatal mortality (ICD PM) which draws on the cause of death assigned on the death certificate. To ensure accuracy in cause of death data for perinatal deaths, the ICD PM²⁶ should be assigned after the audit meeting based on a revised death certificate where required. The purposes of the ICD and PSANZ system differ somewhat and these are discussed in more detail in Section 7 of the guideline.

Section 2 Recommendations

- 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

Systems Review - Determining the presence of contributing factors relating to care

The circumstances surrounding perinatal deaths should be considered to identify areas for practice improvement using the PSANZ Contributing Factors Relating to Care tool (included in *Appendix E – Australian perinatal mortality audit tool* to classify the type of factors present and also their relation to the death. Recommendations for practice improvement emanating from this review need to be carefully formulated (see below). This review should take into account recommendations of facility-based RCA if one was conducted. Determining whether contributory factors are present is an essential element of the review process that requires a systematic approach. PSANZ has adopted the tool used in New Zealand by the PMMRC²⁷ with a minor modification to include grades of certainty in the final decision of avoidability of the death. This has now been recommended for use by the AIHW for all Australian perinatal mortality committees.

Contributory factors are defined as modifiable components of the health system and issues of quality of care that cover a broad spectrum of organisation and/or management, personnel and access and/or engagement with care factors. The presence of these factors does not imply that a death could have been prevented if they were not present but rather that the risk of death may have been reduced. A death is considered potentially avoidable if the absence of the contributory factors may have prevented the death²⁷. Contributory factors may be highly specific to the death or generalised to the system(s). Identifying contributory factors that occur, and are inherent in, the system is an important part of the review. These factors are sub-classified into organisational and management, personnel and those relating to barriers to access and/or engagement in care. When assessing the presence of contributing factors relating to clinical care, best practice standards should be used as a benchmark, including hospital protocols and relevant national and international guidelines. Consideration of aspects of care provided after the death that may be improved in the future should also be undertaken and recommendations made to address these e.g. communication, counselling and bereavement support and investigations performed. It is important that the classification and coding of the contributing factors – and the preventability assessment – is performed consistently. This will allow reliable analysis and comparison of data relating to contributing factors.

Section 2 Recommendations

- 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.

Step 4 Recommend solutions

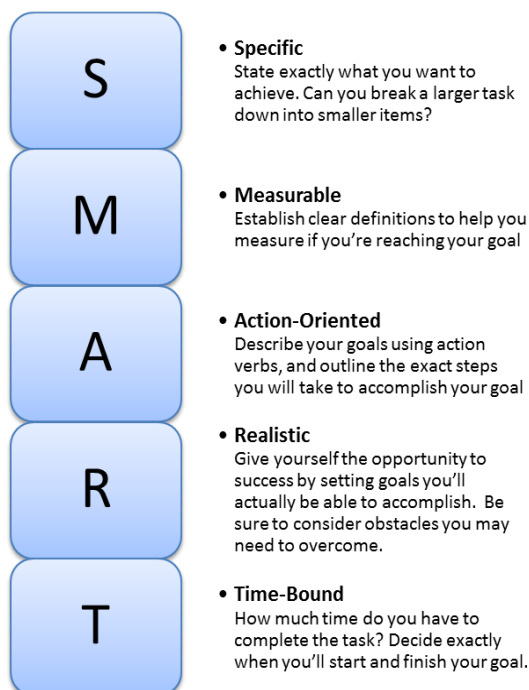


Figure 2 SMART criteria

The Perinatal Mortality Steering Committee should oversee the development of recommendations for action/solutions to problems identified. The SMART (specific, measurable, appropriate, relevant, and timely)²⁸ criteria (Figure 2) can help to ensure the proposed actions are achievable.

Section 2 Recommendations

- 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.

Step 5 Communication and feedback to parents

Discussions between the parents and the main responsible health care provider about the death should be initiated as soon as possible after every perinatal death, using an open disclosure framework²⁹,

Meetings should preferably be led by the senior clinician responsible for care and include explanation and information appropriate to the parents' needs as well as an agreed plan for follow up meetings. It is important for the clinicians to acknowledge at this early meeting that there may be little information about the cause of death but that more information will be provided as results of investigations are available. Early feedback to the General Practitioner and

other relevant clinicians is important. Other key considerations in communication with parents are as follows:

- Follow-up meetings with parents to outline and explain the circumstances of the case should be scheduled with the senior clinicians who provided care present (obstetric, midwifery and paediatric)
- Where possible, someone with specific expertise in interpreting the results of perinatal death investigations and providing feedback on the outcome of the audit review should also attend
- Schedule these meetings after all relevant test results are available and following Perinatal Mortality Audit meeting review. Additional visits may need to be arranged if final results are delayed.
- Inform parents if the results of key investigations (such as autopsy) will not be available at the time of the scheduled meeting and offer them an additional or alternate time to receive those results

In cases of a congenital abnormality it may be appropriate to discuss the need for genetic counselling with a geneticist prior to the follow-up appointment with the senior clinician who provided care. The geneticist can then either attend the follow-up consultation or a further appointment can be offered at the time. Depending on the results of the initial investigation, it may also be necessary to arrange further tests.

Section 2 Recommendations

- 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.

Step 6 Implement changes

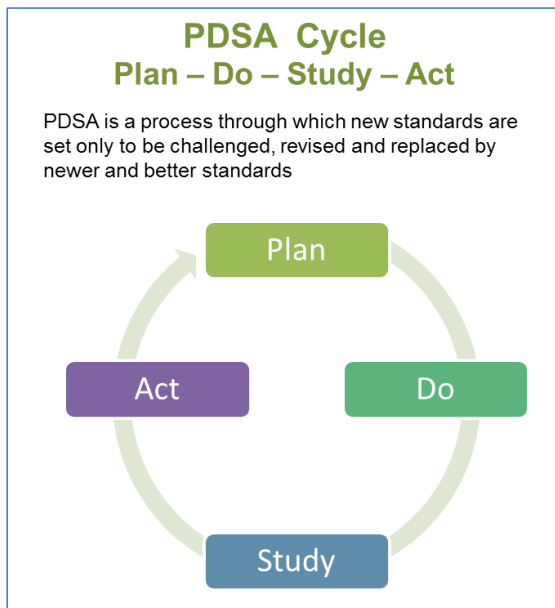


Figure 3 PDSA CYCLE

A process of feedback to clinicians needs to be in place so that individual practice and hospital policy can be improved as a result of the review process. Educational meetings, in addition to the perinatal mortality audit meetings, which engage a wider group of clinicians across the hospital may be helpful in translating findings from the audit into practice. The PDSA cycle is one method to assist in this process (Figure 3).

Step 7 Evaluate and refine the process

The final step in the audit cycle involves examining how successful each step of the process has been and in particular how effective it has been in changing practices and policies when required. An electronic data system is necessary to enable easy access to aggregate data to assess time trends in rates and causes of perinatal deaths and contributing factors. WHO has suggested a list of questions to help users assess and reflect on progress (Box 1)³⁰.

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

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

Source:³⁰

2.8 Completion of perinatal death certificates

The Royal College of Pathologists Australasia (RCPA) recommends that death certificates be issued or supervised by the senior clinician responsible for care³¹. As Perinatal Death Certificates are often issued prior to the results of investigations (particularly autopsy and placental pathology), this may result in significant error in cause of death data³²⁻³⁴. Review by a multidisciplinary clinical group has been shown to increase the value of post-mortem examinations in determining an accurate cause of death. Therefore it is essential that the audit meeting includes reviewing the details on death certificates for all perinatal deaths²⁴ and revisions made as required. The process of revising death certificates varies across regions. It is recommended that the Perinatal Mortality Committee become familiar with the process within their region and implement a process that ensures that a revised death certificate is submitted when required and to advise parents and their General Practitioners.

Section 2 Recommendations

- 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.

2.9 Definitions for registration and reporting of births and perinatal deaths

The definitions below are those from the AIHW³⁵ and New Zealand³⁶. Please note that definitions vary across jurisdictions in ANZ, please refer to *Appendix T – Australian and New Zealand definitions of perinatal mortality* for regional definitions.

Registration

The following definitions and examples are provided for clarification of the requirements for registration of births and perinatal deaths. While these terms are required for legal purposes care should be taken to use language appropriate for the intended audience, particularly in communication with parents, when relevant.

Livebirth

A livebirth is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered liveborn³⁷.

Neonatal death

Neonatal death is defined as liveborn infant dying within 28 completed days of life regardless of gestation³⁸. Early neonatal death is death of a live born baby within 7 days of birth. Late neonatal death is death of a live born baby after 7 is completed days and before 28 completed days.

The Medical Certificate of Cause of Perinatal Death (MCCPD) for stillbirths neonatal death³⁹ is required by the ABS for all neonatal deaths according to the above definition. This definition applies regardless of the birthweight or gestational age and also for resuscitated stillbirths.

Example 1: Resuscitated stillbirth

Where an infant is stillborn and, following active resuscitation, a heartbeat is detected, the birth is required to be registered as a livebirth. If the infant subsequently dies up to 28 days of age registration as a neonatal death is necessary.

Fetal death (stillbirth)

In Australia:

Death, before the complete expulsion or extraction from its mother, of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birthweight. Death is indicated by the fact that, after such separation, the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles⁴⁰.

The MCCPD is required by the Australian Bureau of Statistics (ABS) for all stillbirths according to the above definition. This definition applies regardless of the known or presumed timing of the death in utero. Examples are provided here of circumstances which may require clarification. There are some variations in approaches across regions e.g. in QLD the Registrar of Births Deaths and marriages does not require a death certificate for stillbirths where the death is known to occur prior to 20 weeks gestation regardless of the timing of birth. However, the QLD Health Department's Perinatal Data Collection still requires these deaths to be registered if the stillbirth is birthed is 20 weeks or greater, or weighs 400 grams or more.

In New Zealand:

A stillbirth is 'a dead fetus that'

(a) weighed 400 grams or more when it issued from its mother, or

(b) issued from its mother after the 20th week of pregnancy. (Births, Deaths and Marriages Registration Act 1995)

And, Stillbirths must be registered according to the legal requirements of this Act. They require a birth registration (stillbirth), but not a death registration³⁶.

Example 1: Fetus papyraceous

In the case of a birth after 20 weeks gestation where the birth weight is less than 400g and where a fetal death may have occurred at some time before the birth, the birth is considered a stillbirth. However, in the case of fetus papyraceous where the fetus is not readily recognisable, the requirement for registration varies across jurisdictions.

Example 2: Multiple pregnancy

2A: In the case of a twin pregnancy with a fetal death of Twin 1 at 19 weeks and spontaneous onset of labour and delivery at 23 weeks gestation where Twin 2 is live born weighing 550g and Twin 1 weighs 200g, Twin 1 is registered as a stillbirth and Twin 2 as a livebirth.

2B: In the case of a twin pregnancy with a fetal death and spontaneous delivery of Twin 1 at 19 weeks weighing 200g and subsequent fetal death and delivery of Twin 2 at 21 weeks weighing 300g, Twin 1 is not required to be registered, however Twin 2 must be registered as a stillbirth.

Reporting to enhance comparability across ANZ

Variation due to different definitions used for reporting of perinatal deaths makes comparisons across ANZ problematic (*Appendix T – Australian and New Zealand definitions of perinatal mortality*). To ensure consistency and comparability, it is recommended that reporting of stillbirths and neonatal deaths adhere to the above recommended definitions. Further, aggregate data on rates and causes should identify perinatal deaths resulting from a termination of pregnancy (TOP), presenting data with and without the inclusion of terminations. The PSANZ classification enables identification of TOP for each condition in this system (please refer to Section 7).

Section 2 Recommendations

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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.

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2.12 Acknowledgements

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2.13 Appendices

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 J – Perinatal mortality classifications: Quick reference sheet

Appendix K – WHO mortality audit meeting code of practice declaration

Appendix T – Australian and New Zealand definitions of perinatal mortality

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 3

Respectful and Supportive Perinatal Bereavement Care

Version 3.4, February 2019

Endorsed by:



&

The Perinatal and Infant Mortality Committee of Western Australia

SECTION 3

RESPECTFUL AND SUPPORTIVE PERINATAL BEREAVEMENT CARE

3.1 Introduction

The death of a baby is a highly distressing event for parents and families. Initial feelings of shock, disbelief, confusion and guilt can be overwhelming and may have lasting psychological and social consequences¹⁻⁵. This section of the guideline aims to improve the quality of bereavement care for parents who experience stillbirth or neonatal death. Earlier pregnancy losses can have a similar impact but are not within the scope of this guideline.

Caring for parents who experience perinatal loss can be extremely challenging for health care professionals. It also can be seen as a privilege to provide compassionate care for families at such an important time in their lives⁶⁻⁹. The quality of care can have immediate and long-term consequences for families, both beneficial and otherwise^{1,10,11}.

The update of this section of the guideline has been undertaken through a partnership between the [Perinatal Society of Australia and New Zealand \(PSANZ\)](#) and the [NHMRC Stillbirth Centre of Research Excellence \(Stillbirth CRE\)](#). [Sands Australia](#) and [Women's Healthcare Australasia](#) were also key partners. A guideline update group comprising more than 50 members who represented bereaved parent support organisations, clinicians from a variety of relevant disciplines, policy makers and researchers provided expert input and advice based on their experience of perinatal bereavement care.

The content of this section of the guideline aligns with the *Principles of Bereavement Care* developed by Sands Australia¹², which embody a core set of expectations for bereavement care based on wide consultation with parents who have experienced perinatal death. The *Principles of Bereavement Care* outline the care bereaved parents need, while this section of the guideline provides the foundations and best evidence to guide clinicians in the delivery of that care.

The content of this section of the guideline aligns with and draws on recent key international initiatives, including:

- [Respectful Maternity Care Charter: The Universal Rights of Childbearing Women](#)¹³;
- [National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death](#)¹⁴; and
- the Research of Evidence based Stillbirth care Principles to Establish global Consensus on respectful Treatment (RESPECT) working group.

3.2 What has changed in this update?

Since the last version of this section of the guidelines, a number of systematic reviews of bereavement research associated with perinatal death have been published and their findings

have been incorporated into this update. We have introduced a framework for care based on four core goals of care, revised the formatting, and reduced duplication.

3.3 Objective of this section

The main objective of section 3 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to assist health care professionals and maternity services provide the best possible care for women and families faced with the death of a baby before or soon after birth.

The recommendations for respectful and supportive perinatal bereavement care are based on 10 foundations for care and an organising framework that sets out four overarching goals of care¹⁵:

- Good communication
- Shared decision making
- Recognition of parenthood
- Effective support

These goals of care are distinct but inter-related. A fifth goal of the framework – Organisational response – acknowledges the wider systems context in which care is provided.

Each of the five goals encompasses specific practices and actions that can be implemented in maternity care settings. These practices and actions are presented as 49 recommendations (41 for health care professionals and 8 for use by maternity services).

The first part of this section presents the foundations for care and introduces the organising framework. The second part presents the recommendations and more detailed guidance.

A note about the evidence

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

A Cochrane review to assess the effectiveness of interventions intended to provide psychological support or counselling to mothers, fathers or families after perinatal loss, found no eligible randomised controlled trials¹⁶. The review authors acknowledged the challenge of conducting experimental study designs in this area and the need to rely on non-randomised and observational studies to guide practice. There is a growing body of research which helps to inform best practice care around stillbirth and neonatal deaths. We have drawn on this body of research evidence and the insights from an experienced multidisciplinary team in developing the recommendations in this section.

3.4 Understanding perinatal grief

Grief is a normal response following the death of a baby and high levels of distress are a normal part of the grieving process¹⁻⁵. Parents grieve the loss of their baby, as well as hopes and dreams for the future. The death of a baby challenges the natural order of life and raises uncertainties about the future, including expectations of pregnancy and parenthood. For some parents, their baby's death may be their first experience of the death of a close family

member. Parents usually have little or no preparation for what to expect or how to manage the intensity of their grief.

Perinatal loss is often poorly understood and may be associated with stigma and misperceptions^{1,4,17,18}. Parents may feel blamed, or blame themselves, for their baby's death and feel a sense of failure, shame or guilt that their baby died^{1,5,19}. Lack of acknowledgement of their baby, the extent of their loss, and their identity as bereaved parents can lead to disenfranchised grief²⁰ where parents feel their grief is not legitimate or socially acceptable. Validating perinatal loss is an essential part of improving support and reducing the sense of isolation that is commonly described by parents^{1,11,21}.

No single approach will meet the needs of all parents and perinatal bereavement care cannot be reduced to a checklist of activities²². Respectful and supportive care is personalised and takes account of the needs, preferences, circumstances and cultural context of each bereaved parent^{10,23}. Grief is a uniquely individual experience and it is important to avoid making assumptions about how parents will grieve or the support they will need. For example, gestational age of the baby, the type of loss or the presence of surviving children are not good predictors of the intensity of parental grief^{5,17,24}.

Many theories and models of loss and grief have been developed and refined over time to help explain the grieving process and to guide practice in bereavement care.

(A short overview of current theoretical perspectives that are relevant to perinatal bereavement care is provided as an appendix to this document.)

3.5 Role of health care professionals

Health care professionals from many disciplines are typically involved with bereaved parents during and immediately following the death of a baby. At every stage, the actions of health care professionals, and their timing, are critical to high quality care^{10,25}.

Health care professionals have a major role in helping parents to make decisions that minimise regret and avoid missed opportunities^{11,25}. Inappropriate or insensitive care can disempower parents. This can make an already potentially traumatic event worse for bereaved parents¹¹. Health care professionals must be prepared for a wide range of responses that may not reflect their own values or expectations²⁶.

Providing perinatal bereavement care is a stressful and challenging area of practice for many health care professionals. Health professionals require skills to support parents and this includes knowing where and how to seek their own support and the ability to develop resilience to ensure the longevity of their career and to avoid burnout.

Studies show that health care professionals commonly report feelings of guilt, frustration and helplessness, alongside feelings of sadness and distress when supporting parents who experience perinatal death⁷⁻⁹. Unless acknowledged and addressed, these emotional impacts can lead health care professionals to feel overwhelmed, to distance themselves from grieving parents, and to experience burnout.

Health care professionals may also be affected by grief and loss in their own lives. These personal experiences can affect the quality of care given to families in a positive way but can

also increase the vulnerability of health care professionals. Supporting health care professionals experiencing their own loss is necessary for the optimal care of parents.

However, health care professionals also describe positive aspects of caring for bereaved parents^{9,10}. These include the knowledge that they had provided best possible care and supported families at a time of great need.

Education, training, resources and support are identified as critical enablers for best practice care following perinatal death. These include both formal educational initiatives and informal debriefing and sharing of experiences with colleagues. Organisational responses are important to support health care professionals and to prevent burnout among those working in highly emotionally demanding roles, including those who deal regularly with perinatal loss⁷⁻⁹.

3.6 Foundations for care

This section of the guideline is based on 10 broad foundations for care. These are themes that are prominent and consistent in the published literature^{5,10,17,23,27-29}, and widely perceived as essential for perinatal bereavement care that is respectful and supportive.

Respectful and supportive perinatal bereavement care:

- Addresses the psychosocial, physical and practical needs of parents and families with consideration of parent preferences, circumstances and cultural context. Care begins with the first signs of concern about a baby, continues through pregnancy to birth, postnatal care and longer-term support including subsequent pregnancies.
- Acknowledges the baby and the impact of the baby's death on parents.
- Recognises that perinatal bereavement may be associated with intense grief and may include high levels of anxiety, depression, guilt, anger and self-blame.
- Understands that perinatal deaths can profoundly affect health care professionals and that support for health care professionals is essential for the optimal care of parents.
- Involves empathic and compassionate communication, appropriate non-verbal communication and respect for privacy. Both spoken and written communication needs to be understandable and to avoid euphemisms (e.g., "lost the baby") and other terms that may be ambiguous or unfamiliar to parents (e.g., "fetal demise").
- Recognises that parents come from a wide range of cultural and spiritual backgrounds, so it is important to check with parents to gain understanding of their needs, and not make assumptions.
- Includes shared decision making by:
 - Recognising the many difficult and complex decisions faced by parents
 - Respecting different approaches to making decisions
 - Understanding that parents' concerns, preferences, goals and wishes may change
 - Adequate time, information and support from health care professionals.
- Ensures care practices and approaches that respect all babies and acknowledge parenthood are integral to perinatal bereavement care.
- Recognises parenthood by offering and supporting options for parents to create memories from spending time with their baby and collecting mementoes of their baby to the extent that they wish.

- Recognises that organisational support and financial commitment is required to create the necessary conditions and structures to enable the implementation, monitoring and evaluation of best practice perinatal bereavement care.

3.7 Framework for respectful and supportive care

The organising framework developed by PSANZ and the Stillbirth CRE (Figure 1) addresses four core goals of care:

- Good communication
- Shared decision making
- Recognition of parenthood
- Effective support

These inter-related goals of care are relevant to all interactions with bereaved parents. The fifth goal of the framework – Organisational response – acknowledges the wider systems context in which care is provided. Each of the goals has associated practices and actions that are reflected in the following guidance and recommendations.



Figure 1 Framework for the practice of respectful and supportive care after perinatal loss¹⁵

Good communication is a core component of respectful and supportive perinatal bereavement care and is the issue most often raised in studies of parents’ experiences of care^{10,11,30}. Good communication involves finding the right words, the right approach, and attention both to what is said and how it is said. Health care professionals cannot take away parents’ emotional pain

and distress, but by communicating in a sensitive and compassionate manner they can provide comfort and avoid adding further distress

Shared decision making is “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences”³¹. A systematic review found decisional conflict, limited information, and less involvement in decision making predicted regret about medical decisions³². In the context of perinatal loss, the value parents place on supported and informed decision making is well-documented^{10,33}.

Recognition of parenthood begins by acknowledging the deceased baby, the relationship that parents may already have established with the baby, and the enormity of the loss that has occurred. Care practices that honour their baby and acknowledge parenthood are central to the respectful and supportive care of parents^{17,27,28}. Treating the baby with the care and respect that would be accorded to a living baby may help to validate and normalise parents’ experiences. Some actions are easy for health care professionals to implement and are impactful, such as calling the baby by name, talking to the baby and dressing the baby. Health care professionals play an important role in empowering parents to engage in normal parenting activities. A culturally sensitive approach and appropriate discussions with all parents are essential to ensuring parents’ preferences and concerns are understood and met.

Effective support addresses the short and long-term needs of parents and other family members. Support should be based on the recognition that parents have experienced the birth and death of a baby with consideration to psychological, physical health and practical support needs¹⁰. Parents require immediate support to be able to manage the initial stage of their grief and pathways to support in their community once they have left hospital^{10,34}.

Organisational response is necessary to create the conditions and formal structures that support and enable health care professionals in the provision of high quality perinatal bereavement care¹⁰. Acknowledging that respectful and supportive perinatal bereavement care is a responsibility shared between the organisation and individual health care providers is critical to developing an environment that enables and supports sustainable best practice care.

3.8 Good communication

Good communication involves finding the right words and the right approach with attention to what is said and how. Studies of parents’ experiences of perinatal bereavement care repeatedly highlight three critical elements of good communication: sensitivity and compassion; clear understandable information; and respect for individual needs and preferences^{10,11,17,28,35}.

Information about a baby’s diagnosis and prognosis is often complex and uncertain¹⁷. Parents want health care professionals to communicate with honesty and compassion³⁶ and to show emotion, empathy and human reactions²⁸.

Where appropriate it is important to involve both parents in communication, information provision and decision making to ensure the loss of partners is recognised^{28,30}. Studies of fathers’ reactions to perinatal death highlight what is often a strong need to protect their partner. It is important to assist partners to find ways to do this and to express their own needs^{5,10,37}. The death of a baby affects families and the needs of siblings, grandparents and other family members should be considered^{28,37}.

Family structures and dynamics differ and health care professionals need to establish who is to be involved in communication and decision making. Children may be conceived in different ways (e.g., use of reproductive technologies, surrogacy arrangements) with implications for who is affected by the death. A sensitive approach is needed based on recognition of the added difficulties that may be experienced by some groups of parents including single mothers, same-sex parents and those from other marginalised groups who may experience added difficulties, including stigma and lack of recognition of their loss³⁸.

Careful consideration should be given to wording and terminology used when communicating with parents and families. When referring to the baby it is preferable to use the word “baby” instead of using words such as “fetus”, “miscarriage” or “it”, or terms such as “23- weeker”²². Asking parents if they have a name for the baby and for permission to call the baby by name acknowledges parenthood and use of the baby’s name creates identity and conveys respect to the baby and parents^{11,22,39,40}.

A systematic review of 28 studies placed high confidence in the finding that the timing, amount and quality of information provided have a considerable impact on the wellbeing of parents facing a severe or life-limiting prenatal diagnosis and on their understanding of the situation¹⁷. Parents wanted specific and detailed information about diagnosis, prognosis and options presented in clear and comprehensible language. Following stillbirth, clear, easily understandable and structured information given sensitively at appropriate times is consistently shown to help parents through their experience¹⁰.

In all communication with parents, it is important to remember that stress and grief can greatly reduce people’s ability to absorb, process and retain information^{28,30}. Extreme emotional distress combined with sudden exposure to complex and unfamiliar medical information can leave parents overwhelmed and with limited capacity to process and make sense of information⁴¹.

Parents may need information to be given more than once and supporting verbal information with written or electronic resources, including reliable internet sites, is widely shown to be of benefit for parents^{17,28,39}. Written resources enable parents to revisit information when ready and as needed, reinforce information given by health care professionals, and can be used as discussion initiators with care providers and others⁴¹. Many parents will turn to the internet for additional information and having appropriate information from health care providers may help reduce confusion and distress that may arise from online information¹⁷. Written information should be clearly and sensitively written with medical terms explained in understandable language⁴¹.

Most parents want to be kept informed and to be given as much information as possible⁴¹, but how much information to give and how to convey it must be guided by parents’ needs. The goal for health care professionals is to establish the level of detail and complexity desired by families and adapt to their needs³⁶.

Cues from parents regarding their emotional state should guide the timing and delivery of information²⁸. Pausing to ask questions to check what parents have understood and how the information is being processed or perceived, both cognitively and emotionally can guide health care professionals in tailoring information^{22,30,36}. Specific techniques for establishing parents’ informational needs include using open questions to ask parents what they understand the

situation to be, what it means, what they want to know, and what concerns them most at this time^{17,22}.

No parent is prepared for the news of the death, or possible death, of their baby and intense shock and grief are to be expected. Health care professionals need to be prepared for a wide range of grief responses and avoid assumptions about parents' responses. It is important that health care providers do not impose their own views or values, but support parents to express their emotions and concerns¹⁰. Parents' responses include shock and disbelief, distress, anger, blame, guilt. The raw emotions of grief may be accompanied by crying and other intense responses. Health care professionals may feel powerless to 'solve' the situation, but parents will value staff members who remain calm and supportive and allow them to express their thoughts and feelings. It is important for health care providers to be able to acknowledge emotions such as anger as valid and natural parent responses²⁸.

Recommendations for 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 using terms such as "23-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

Respectful and supportive perinatal bereavement care begins at the point of diagnosis of a baby's death or life-limiting condition and the health care professionals involved will depend on the setting. Being told of a baby's death or life-limiting condition is a life-changing moment for parents. A review of 25 qualitative studies concluded that the way the diagnosis of stillbirth is conveyed impacts on parents' experience of care and their psychological wellbeing²⁸.

How news is communicated to parents has both immediate and lasting impacts. Parents often recall in detail many years later the circumstances in which they were told of their baby's death, the words used and the actions and attitudes of those involved^{11,30,42}.

Verbal and nonverbal communication that conveys care, empathy, and understanding is essential at the time of diagnosis. Words, signs and gestures from clinicians are noticed and interpreted by parents and expressions of empathy and acknowledgement of the parents' feelings were valued^{11,17}. As in all communication, health care professionals should use clear and comprehensible language and avoid medical terms that parents may not understand^{28,41}.

Delays in receiving information are worrying and distressing for parents. Signs of a problem may first be discovered by sonographers or other health care professionals who may not be empowered or authorised to communicate their observations to parents^{42,43}. Parents may be extremely sensitive to verbal and non-verbal messages, such as sudden silence or concerned tone¹⁷. Advising parents that there may be periods of silence during scanning and other procedures is recommended^{29,44}.

Parents want health care professionals to be transparent, even when the situation is uncertain, and to be assured that all possible is being done³⁹. When left without information, parents may feel health care professionals are withholding information from them or are using "diversionary or avoidance tactics" which can lead to feelings of mistrust^{11,28,42}.

When a problem is suspected, it may be advisable to use a transition, such as "I have a few concerns about what I am seeing. I'd like to call the doctor in for another opinion"⁴⁵.

Thoughtful communication is essential throughout the diagnostic process, using an approach such as the following⁴⁵: (a) acknowledge the parents' feelings, perhaps saying, "I can see you are concerned" or "I can imagine that this might feel stressful"; (b) assure the parents that everything is being done to ascertain the baby's condition by saying something like, "I'm going to get another technician/doctor here to help me interpret what I'm seeing" or "I need to get another machine to get a better look"; (c) confirm that the parents will get the information as soon as it is possible, perhaps saying, "I'm going to step out and talk with the doctor who will back here in just a few minutes to talk with you and answer any questions you have"; and (d) support the parents by asking if anything is needed while waiting to get the results of the exam. A mother should not be left alone, and another staff member should be called to stay with her if her partner or other support person is not present.

In an integrative review of 33 studies of parents' experiences of prenatal diagnosis, an almost universal finding related to the need for immediate and detailed information when an anomaly is detected or suspected³⁹. Communicating detailed information and giving answers to parents' initial questions may increase parents' confidence in health care professionals³⁹. Accordingly, it is essential that parents have quick access to an appropriately trained health care professional who is equipped to provide information when an anomaly is suspected, or diagnosis of stillbirth

needs confirmation. Parents should be kept updated even if health care professionals are waiting for confirmation or further details³⁹. When a diagnosis of stillbirth has been confirmed it is vital that parents are informed without delay and are supported so they do not feel abandoned, or that their care has been de-prioritised^{10,23,29}.

Balancing the provision of immediate and detailed information may present a challenge if the mother has attended alone. Asking if she would like to have another support person present before discussing the findings may provide her with some control over the situation and help to alleviate distress and anxiety^{28,39}. When bad news is delivered, it is important that health care professionals check with parents whether they would like them to stay for support or to answer questions before leaving the room. When left alone, parents should feel assured that they have access to health care professionals and know when to expect a health care professional to return.

Recommendations 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

Providing care in a culturally diverse population requires health care professionals to acknowledge and address a wide range of beliefs and practices that may be important to parents and families around the time of a baby's death. Health care professionals should take care not to impose western or other mainstream perspectives of grief and bereavement on parents. Cultural stereotypes and culture-based assumptions should also be avoided as diversity exists within all cultural groups. For all parents, it is important not to make assumptions, but to ask about their needs and seek further guidance where appropriate.

Rituals, customs and beliefs can help parents as they grieve for their baby. These may be important during the birth, at the time of death, or at a later time and might include speaking to baby in their own language, or performing other cultural, spiritual or religious rituals while in hospital^{28,40}.

The key task for health care professionals is to establish what families want. This involves asking parents whether there are rituals or practices that are important to their culture or belief system and that they wish to see happen^{28,37}. Open questions help to explore with families their needs

and preferences and to identify appropriate actions, which may include contacting appropriate spiritual, religious or cultural support services or engaging an accredited interpreter.

Recommendation for 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

Spaces and surroundings

The physical environment for the care of bereaved parents will depend on the timing of the perinatal death and the setting and model of care. Regardless of the circumstances, physical spaces and surroundings are essential to support good communication. The physical environment for the care of bereaved parents should provide “privacy not abandonment” in the form of spaces that balance the family’s need for privacy and comfort with their need for access to appropriately trained health care professionals¹⁰.

Appropriate spaces need to be available for conducting difficult conversations across the full spectrum of care²². This includes breaking bad news and all subsequent discussions as well as maternity care. Seeing and hearing other mothers and babies may add greatly to parents’ distress and parents may find it distressing to return to the unit where their baby was born for follow-up meetings^{10,11,28}. This should be considered when choosing the location of all meetings with parents.

Around the time of birth, a designated bereavement suite for parents is considered the ideal for parents experiencing stillbirth¹⁰. This should be a purpose-built room, separate from busy birth suites and wards, but with access to staff for necessary physical and emotional care. Some mothers may prefer the option of care away from the maternity ward, but this should not be assumed suitable for all. For some mothers, being away from the maternity ward may be experienced as isolating or reinforce a sense of failure from a lack of recognition of status as a mother^{11,28}. It is therefore important to establish what parents would prefer.

In settings where a designated bereavement suite is not available, suitable areas must be made available to ensure parents have privacy to support each other. Capacity for extended family members and other support persons to gather should also be considered.

In cases where a baby is dying, a room connected to the nursery, or a perinatal loss unit, can ensure the family is well supported during the difficult time of the baby's impending death and afterwards. It may be possible for some parents to take their baby home and thought should be given to the option of perinatal palliative care in the family home, if desired by the family. Perinatal palliative care is associated with positive outcomes and is well-received by many parents when appropriate support and resources are available to make this a feasible choice for parents^{5,37,40}. Parents may understandably feel apprehensive about taking their baby home to die. Exploring with parents their concerns and ensuring practical and psychosocial support including access to suitable community palliative care services.

When a baby has died, parents should be given the option to take their baby to their family home, or to another place that holds meaning for the family, if they wish. Health care professionals should discuss this option with parents and provide accurate information about care of the baby's body, changes to expect, transportation issues and associated legal matters.

Recommendations for 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

Communication between health care professionals

Continuity of care and carer is valued by parents who feel reassured by meeting with familiar staff throughout their care^{10,11,28}. Continuity of staff and appropriate handover and documentation processes should be in place to reduce the burden for parents of having to repeat their story.

Appropriate documentation is also necessary to ensure all staff are aware that a loss has occurred. A universal bereavement symbol, such as a teardrop or butterfly sticker, may be placed in the mother's room and displayed on all medical records and charts to communicate the occurrence of perinatal death²⁷. It is essential that all staff who come into contact with the mother are aware of the meaning of the symbol so that they can act in a thoughtful and responsive manner²⁷. Door signs and stickers should be used discreetly and with the mother's agreement as their use may distress some parents²⁸.

Timely communication with relevant care providers is essential to ensure appropriate support is activated. Communication between hospital- and community-based health care providers is an important part of continuity of care and this needs to occur in a streamlined and standardised way^{10,14,34}. While some mothers may appreciate the cancellation of existing antenatal appointments, it is important to discuss this with mothers as some may prefer to contact providers themselves.

Recommendations for 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.

Complex circumstances

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

Multiple births: Parents of twins or higher order births may experience conflicting emotions when one or more of their babies die and one or more survive. Common emotions may include

guilt relating to the amount of time spent with a deceased baby, or for not devoting enough time to a surviving baby because they are grieving; fear of a surviving baby also dying; and feeling torn between spending time with their living and deceased babies.

Acknowledging such conflicting feelings is important, to validate both the baby who has died and the parents' grief for that child, particularly when the response of others may be to focus on the surviving baby.

Maternal illness: Provisions should be made in the event that the mother is unwell following the birth. In instances where a mother is admitted to Intensive Care Unit or transferred to another hospital, every effort must be made to ensure appropriate and timely communication to ensure she is kept informed and involved in decision making³⁷. Opportunities for her to have access to her baby and to delay decisions where possible need to be considered and discussed with the mother, her partner and other family members as appropriate.

Perinatal death usually refers only to the death of a baby. However, maternal death, while rare in Australia, has a devastating impact on families, with an increased incidence of previous experience of maternal death in refugee and some immigrant populations, impacting on their care requirements. Early referral to relevant family support teams is imperative and will be explored further in future PSANZ guidelines.

Previous loss experiences: Parental response to the death of a baby may be intensified by a previous perinatal or child death or other pregnancy-related losses, including miscarriage or difficulties conceiving⁴⁶. Parents may experience resurgence of previous loss and grief, which can complicate their current loss. Some parents may have clear ideas regarding the way in which they choose to manage the death of their baby due to their past experience. It is important for health care professionals to respect parents' wishes, provide appropriate support and information and to be guided by the parent's response.

3.9 Shared decision making

Parents face many difficult and emotionally-charged decisions when their unborn child has died or is diagnosed with a life-limiting condition. Social stigma and complex medical, ethical and legal dimensions may add to parents' distress around decisions such as whether to terminate or continue a pregnancy or whether to initiate or withdraw treatment^{5,17,37,40}. Decisions will often need to be made about the mode and timing of the baby's birth along with decisions about end-of-life care. Decisions after a baby has died include those relating to seeing and holding the baby, autopsy and other investigations, and funeral arrangements.

While the decisions faced will vary according to the baby's diagnosis, all will require information and non-judgemental support⁴⁰. Expressing understanding, normalising and validating parents' decisions is important. For example, parents appreciated confirmation by health care professionals that it was normal to have ambivalent feelings about whether to continue or terminate a pregnancy for fetal anomaly¹⁷.

Conventional best practice in Australia and New Zealand assumes autonomy in decision making, where parents are seen as the primary decision makers, best qualified to speak for their child. However, for many parents the approach to decision making may be relational, where relationships with family, including the impact of decisions on other family members are strong

considerations^{22,40}. Personal values, extended family, societal norms, religious beliefs, and legal issues are just some of the factors that will influence each parents' decision making⁴⁰. For some parents the locus of decision making and support may rest with extended family, with particular family members, or with input from religious or community advisers. Cultural and religious beliefs may have much bearing on decision making. For example, discussion about cessation or limitation of treatment may not be an option in some parents' belief systems.

Supporting parents in decision making requires more than a one-off conversation. Giving parents options, time to consider those options, and opportunities to discuss and revisit their decisions is essential¹⁰. Providing options is critical as parents are often not in a position to recognise what is possible and what ultimately might be important to them.

Exploring with parents their decision making styles, their values and preferences promotes the tailoring of information and approaches to suit their individual needs^{22,28}. This involves asking parents what they want to know and how they want to make decisions. Questions such as the following may be helpful to explore with parents their decision making needs²²: "Some parents want to know all the numbers and statistics while others want the big picture, what kind of parent are you?" "Some parents want doctors to give them all the information and make these decisions on their own, other parents want to take these decisions with doctors. Other parents want doctors to give them recommendations. What kind of parent are you?" It is also important to recognise that there may be differences between partners and that ways of making decisions may change over time or depending on the decision to be made.

Recommendations for 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

If the baby has died before labour has started, then including parents in decision making about the timing, mode and place of birth may increase their sense of empowerment and control¹⁷. Ideally, discussions about birth should take place before labour commences to enable both practical and emotional planning.

A systematic review of 29 studies focused on the care of parents who continued pregnancy following prenatal diagnosis of a baby's life-limiting condition found consensus in the literature that a birth plan should be created⁴⁰. Equally important is planning for the baby's death³⁷. At a suitable time, sensitive discussion should take place to explore parents' needs and wishes in relation to relevant issues including: how and where the birth will occur; the involvement of other family members, including siblings; care for the baby, including end-of-life care; care of the family, including spiritual and social support and interactions with the baby; and organ donation where appropriate^{17,28,37,40}.

Little information is available about the birth planning needs of parents who chose to terminate their pregnancy but the limited evidence available suggests that, as for all parents, they may appreciate being presented with options and being able to make their own decisions about them¹⁷.

Clear information about birth options should be given to parents and the risks and benefits of each should be explained²³. Unless clinically indicated, vaginal birth is the recommended mode of birth for most women to reduce risks related to morbidity and future pregnancy⁴⁷. Psychological benefits may also be associated with vaginal birth¹⁰. Parents of a stillborn baby may not expect to have to go through labour and vaginal birth and may assume that their baby will be delivered by caesarean section^{10,11}. It is important that health care professionals seek to understand the various reasons why parents may request a caesarean birth rather than a vaginal birth, so as to provide effective counselling that addresses parents' concerns and assists them in making an informed decision^{23,29}. Support and information from health care professionals may help parents who feel emotionally unprepared for a vaginal birth¹⁰.

When a baby is not expected to survive for long after birth, decisions may need to centre on the desire of parents to meet their baby while alive. The majority of authors consider that, in such instances, caesarean section should be provided as an option for women together with appropriate discussion to ensure they are aware of the risks of the procedure⁴⁰.

Decisions about the length of time between diagnosis and the induction of labour and birthing may need to be made and sufficient time for discussion and decision making is important^{11,17,28}. Some parents may wish to consider whether the birth occurs straight away or whether to go home for a period of time before the birth. This can give parents time to consider the information they have been given, to share the news with extended family and/or other children, and gather support²⁸.

Sedation and pain relief options

Options for pain relief should be available and the advantages and disadvantages of each should be discussed with all parents^{10,23}. Careful consideration needs to be given to the potential for sedation to lead to later regrets about lost opportunities for interacting and spending time with the baby.

Recommendations for 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 autopsy and other investigations

Parents should be assured that everything possible will be done to understand the cause of their baby's death and that this will include standard investigations and a review of the care provided to facilitate improvements to future care. It should be explained that the hospital has a clinical meeting where all the results of the investigations are reviewed by a team of experienced clinicians and that the findings of that meeting will be discussed with parents at a follow-up visit.^{23,29}

Clear information should be given regarding how and when parents will receive results of investigations that take place. Uncertainty around timeframes and lengthy waiting times for results are a commonly reported source of distress for many parents^{29,48,49}. It is important that parents are assured that they will receive results as soon as they are available and that preliminary results may be available within days but that others may take longer.

Autopsy remains the gold standard investigation for perinatal deaths⁵⁰ and should be offered to parents in all cases of perinatal death by a health care professional who is trained in consent, understands the parents' situation and is able to answer parents' immediate questions^{23,50}. Parents usually want an explanation for why their baby died and also to help planning with future pregnancies^{28,51} but there are many influences on parents' decisions about consent for autopsy^{10,49,50,52}. Barriers to autopsy may be perceived differently by health care professionals and parents and assumptions should not be made about what is important to parents.

When approaching decision making about autopsy for their baby, parents may feel strongly for or against, or somewhere in between and many will feel overwhelmed⁴⁹. Finding out where parents are on the decision spectrum and exploring with them their views and concerns can assist health care professionals to provide information and support that matches parents' needs. Parents who choose not to have an autopsy for their baby may experience later regret¹⁰. Ensuring parents feel fully informed and adequately involved in the decision making process may minimise regret, regardless of the decision made⁴⁹.

Where individual, religious and cultural beliefs make autopsy unacceptable to parents, these beliefs and the decision against autopsy should be respected²³. Less invasive approaches may be more acceptable to those who decline autopsy and these options should be discussed with parents⁵⁰. Less invasive approaches may include limited autopsies that take an organ-specific approach, minimally invasive autopsies that use a laparoscopic or keyhole approach to obtain

organ samples, or non-invasive autopsies that use detailed external, placental and umbilical cord examinations and external measurements, skin/needle blood sampling, clinical photography, and radiological investigations.

The way in which autopsy is discussed is a major influence on parents' decision making. Discussion about autopsy should involve a trusted and knowledgeable health care professional who is empathic to the parents' situation and able to provide the information needed to assist them in reaching their decision⁵⁰. Sufficient time must be allocated to explain the options available, including less invasive and stepwise examinations, and to explore concerns and answer questions^{48,50}.

Parents should be assured that decisions are not required immediately and discussions should take place on multiple occasions to enable parents to consider the information they have received and to follow-up on matters of concern to them^{10,50}. Cues from parents should be used to guide the timing and amount of detail presented and it may be helpful to provide information in an incremental manner^{10,28}. Information provided verbally should be supported by parent-centred information in written or electronic formats⁵⁰.

Health care professionals should be mindful of their influence on parents' decision making. Ambivalence about the value of the procedure on the part of health care professionals can be one of the most common barriers to autopsy consent following stillbirth⁵⁰. It is important to convey to parents an understanding of the value of autopsy and that it is useful and respectful²⁹.

Parents should be assured that their baby will be treated with respect and dignity. Health care professionals should discuss practical matters and concerns that are commonly held by parents. These include issues relating to the length of time parents can have with the baby without the autopsy results being affected, where the baby will be and for how long, the method of transport for the baby, whether they can see and hold their baby after the autopsy, and possible implications for funeral arrangements. Where possible personal contact with the perinatal pathologist undertaking the examination, may assist to address questions and concerns.

Recommendations for 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.

3.10 Recognition of parenthood

Actions that validate the baby's existence and recognise parenthood are highly valued by many parents. Being the parent of a baby who is stillborn, or unlikely to survive, does not diminish the identity of parenthood and parents want their baby to be acknowledged as their child^{17,27,28,35}.

Recognising parenthood requires actions by health care professionals that support the creation of lasting memories. These actions enable parents to meet and get to know their baby, to have contact with their baby and engage in parenting activities, and to collect tangible mementoes of their baby.

Among the parenting activities that parents may value are:

- Creating memories and getting to know the baby through information about the baby
- Seeing and holding the baby and spending time with the baby
- Dressing and taking care of the baby
- Taking photos and collecting mementoes
- Arranging a commemorative service, funeral or other mourning rituals.

Giving parents options and supporting them to explore what is appropriate and meaningful for them is critical. Parents generally appreciate supportive suggestions and guidance about how they might engage in parenting activities with their baby²⁸. Health care professionals need to "ask the family what they want while realizing that they may not know"³⁷. Regardless of the type of loss, parents generally appreciate being presented with options and support to help them make their own decisions about parenting activities^{11,17}.

Conveying to parents the value of memory creation starts with the actions of health care professionals. These actions include showing respect to the baby by using the same tenderness and respect afforded to any baby. Sensitive conversation about their baby and their experience may help normalise and validate parents' feelings and wishes to engage in parenting activity^{11,28}. Actions that are easy to implement but impactful include: calling the baby by name; dressing the baby; and giving parents information about the baby.

Health care professionals should take time to explore with parents their concerns and preferences and areas of uncertainty or apprehension regarding parenting activities. Recounting what other parents have found beneficial may help parents in their decision making. Follow-up

on initial refusals to engage in parenting activities is important to give parents the chance to change their decisions.

Some parents may choose not to engage in parenting activities or memory creation. While this may be difficult for health care professionals, it is important to acknowledge that cultural, religious and personal values may influence parents' decisions about interactions with their baby. Some widely accepted activities that are valued by many parents may not be acceptable in some cultures or for some parents³⁷. As for so many aspects of perinatal bereavement care, the role of the health care professional is always to ask and facilitate, rather than to expect or impose a particular course of action.

Seeing and holding the baby

One of the most important decisions facing parents around the time of stillbirth or following a baby's death is whether or not they will see and hold the baby. A review of research on the consequences for parents of seeing and holding their stillborn baby shows mixed findings and little clear guidance for parents or clinicians⁵³. While several studies have addressed the question of whether parents should see and hold their stillborn baby, others have argued that the more important question relates to how health care professionals can best inform and support parents in their decision^{25,54}.

Above all, skilled and compassionate care that prepares, guides and supports parents is essential^{25,55}. The way contact is offered may greatly affect parents' decisions and experiences of time with their baby. Parents may initially be hesitant or fearful of seeing their deceased baby, and will look to staff for advice and support²⁵. Where parents are uncertain, normalising and offering contact as a routine practice may be helpful to parents. Open-ended questions and sensitive discussion is likely to be more appropriate than a closed-ended question such as "*Do you want to see your baby?*" that could unintentionally lead parents to decline. Parents who decline initially should be assured that they can change their decision and continuing sensitive conversation about the baby is important regardless of the decision made²⁸.

A review of 11 studies of the impact of seeing and holding on mental health and wellbeing confirmed that, for many parents, seeing and holding the baby is a positive and highly valued experience⁵³. Another review of studies of parents' experiences found parents were more likely to regret not seeing than seeing their baby and to wish that they had been able to spend more time with their baby¹¹. Health care professionals need to ensure that parents feel adequately supported and prepared to meet their baby and to engage in parenting activities that are meaningful to them. Supportive actions include: preparing parents to meet their baby with sensitive discussion about issues of temperature, appearance and feel of the baby²⁵; allowing parents and other family members as much time with their baby as they wish; and using cues from parents to achieve the right balance between privacy and access to health care professionals⁵⁵. Health professionals can also support parents to integrate siblings (or other family members) and help them "to be a family for a little while"²².

Mementoes and photographs

Supporting parents in creating memories through collecting mementoes such as photographs, hand and footprints, baby identification bracelet and a range of other tangible items is widely supported in the literature^{23,27,28,40,55-57}. Systematic reviews conclude that memory-making

should be an option for parents that is offered more than once¹⁰ and that health professionals' involvement and commitment to memory making is an essential component of appropriate and compassionate care²⁵.

High quality photographs provide lasting and valuable memories for many parents^{58,59} and every effort should be made to ensure there is opportunity for photographs to be taken. Health care professionals should support parents in taking photos and should be prepared to assist parents by taking photos for them.

A range of photographs should be considered including:

- The baby individually, as well as with parents (and extended family if suitable);
- Images of babies together if the death is one or more of a multiple pregnancy (this may necessitate discussion with staff in critical care nurseries if one or more baby is born alive);
- Photos with mementoes such as quilt, teddy, special clothes;
- Photographs during the birth (if appropriate).

Photos should be taken with sensitivity. Where possible parents should be offered the service of a professional photographer, including local volunteer services that provide compassionate bereavement photography, to ensure images are of the highest possible quality⁵⁸. Photos should capture the baby in natural positions, including being held and wherever possible, disfigurements concealed.

Photographs are greatly valued by many parents and should always be offered. Where parents refuse or are uncertain, sensitive enquiry is important to establish and explore parents' concerns. A minority of parents may refuse photos due to cultural beliefs or personal preference and this decision must be respected⁵⁸.

Parents who initially choose not to gather mementoes or photos should be given the option of revisiting this decision at a later time. The option for safe storage of mementoes and photographs of the baby for collection when they are ready should be made available to parents^{11,28,58}.

Commemorative rituals

All parents should be supported in arranging bereavement rituals that meet their spiritual, religious and cultural needs³⁷. These rituals may include blessings, naming services, or baptism. Health care professionals have an important role in opening conversations and providing options and information to enable parents to participate in decisions about funeral and other memorial options^{37,59}.

Parents should be informed in a sensitive way that burial or cremation is a legal requirement for a baby who dies at greater than 20 weeks gestation or weight of 400 grams. In most instances these arrangements need to be made with a registered funeral or cremation service. Staff should be able to discuss information about options for funeral arrangements in a clear and empathic way and provide written information that includes the range of available options and contact details for relevant services^{10,37}. Information about financial support should also be offered to parents where available⁵⁹.

It is important to assure parents that there is no urgency for decisions to be made regarding funeral arrangements. Parents should be given adequate time to consider the available options¹¹, to spend further time with their baby prior to the funeral if they wish, and to prepare aspects of the funeral service itself.

Recommendations for 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** Provide parents with information about burial, cremation, and funeral options that are available for babies and support them in making an unhurried decision.

3.11 Effective support

Effective support involves facilitating immediate and ongoing emotional, informational and practical support to assist parents and other family members. The care provided needs to acknowledge that parents have experienced the birth and death of a baby and to address the psychosocial, practical and physical aspects of postnatal support¹⁰.

Emotional and psychological support

Few parents will be prepared for the intensity of grief that can accompany the death of a baby. Anticipatory guidance regarding the grieving process should begin as soon as a diagnosis is confirmed^{34,37}. It may also be helpful to prepare parents for interactions with others by: offering support to tell siblings and other family members²⁸; discussing how mothers, fathers and other family members may express grief differently; and that family and friends may find it difficult to know how to respond^{5,17,37}.

When a baby dies, and where parents have had to make the difficult decision of whether or not to continue a pregnancy, there may be a fear of stigma and judgement from others. Providing support and guidance in managing the responses of others, including selective disclosure of information, may be helpful to some parents^{5,17}.

All parents should receive information that addresses psychological and practical aspects of support. This information should be provided verbally and supported in written or electronic form for parents to take home and use as needed and when they are ready. Supporting parents requires a family-centred approach that also considers the support needs of siblings, grandparents and other family members^{34,37}.

A “flexible menu of support offerings” that recognises a continuum of support needs and the importance of collaboration between hospital, community and families should be made available to all parents^{34,55}. Little evidence exists to indicate who is most likely to benefit from different types of psychological support^{23,60} and not all parents will require formal interventions³⁴. Some parents may find the support they need in their natural support networks while others may benefit from specific supportive interventions or a combination of supports that will meet their needs at different times³⁴.

Parent support groups and the support of those who have had similar experiences will be helpful for many parents^{10,60}. A list of parent support organisations and their range of services should be provided together with an offer to make a direct referral. Key organisations include [Sands Australia](#), [Sands New Zealand](#), [Bears of Hope](#) and [RedNose](#).

Information about referrals to psychologists, social workers or counsellors with specialist experience and expertise in perinatal loss and grief should also be provided for parents to take up if and when desired¹¹. Direct referral pathways should be in place for women who require immediate support or who may be at risk of complicated grief due to aspects of the loss or social circumstances^{34,35,60}.

Practical support

Parents should be given easy access to reliable and current sources of information to manage practical issues such as registration of the baby's birth or other paperwork that may be required¹¹. Costs associated with funeral or burial and time away from work may be substantial¹ and avenues for government assistance or entitlements, including parental leave, should be broached sensitively with parents¹⁰. Parents who are away from their local home environments will have particular practical support needs that may need to be addressed.

Preparing parents for how to manage public interactions, including responding to questions about the baby from those unaware of the baby's death may be helpful. So too may be suggestions regarding timing of appointments with health care providers, such as making the appointment last in the day to avoid other pregnant women in waiting rooms.

Physical support

Maternal physical recovery and what to expect postnatally should be addressed with all women¹⁰. Providing information about lactation, vaginal bleeding and wound care is critical as not all women will be prepared for these experiences, which can be both physically painful and emotionally distressing for mothers whose baby has died. Verbal and written information should be provided and care taken to ensure the information is appropriate for mothers who have experienced the death of a baby. Generic information about these issues may be distressing for bereaved mothers^{11,28}. All women should be offered lactation suppression in the absence of contraindications²³, comfort measures and consultation with a lactation specialist if available. Women should also be advised of the importance of a post-natal check with their general practitioner or obstetrician at six weeks following the birth and encouraged to maintain contact with their primary care provider (e.g., community midwife, community health nurse, general practitioner).

A limited amount of evidence has suggested that different forms of physical activity may appeal to and be a helpful coping strategy for women following stillbirth^{11,28,60}.

Parents describe a reduction in their sense of isolation, improved coping and personal growth when cared for and supported by staff in the transition from hospital to community³⁴. Parents may appreciate individual follow-up contact with the attending maternity care providers to ask further questions and to talk about their experiences. Both outreach to parents from health care providers and the availability of a single point of contact for parents in the follow-up period is recommended^{10,28,37}.

A meta-synthesis of 20 findings pertaining to care after stillbirth parents' support needs may be ongoing and continue well beyond hospital discharge through to subsequent pregnancies¹¹. This should be reflected in clear care pathways that support the transition from hospital to community^{10,29,34}.

Follow-up appointment

A follow-up appointment to address clinical and emotional aspects of care should be offered to all families who experience perinatal death to help parents understand what happened to their baby, to resolve uncertainty and to assist the grieving process^{10,34,37}. Within six to ten weeks of the death is common practice¹⁰. Where the availability of results influences timing, parents

should be kept informed of any delays and the meeting should occur no later than 12 weeks after the death.

The meeting with parents should be led by a health care professional with experience in perinatal bereavement care and involve members of the multidisciplinary care team, including those known to the family where appropriate^{10,23}.

The critical importance of the meeting for many parents should be acknowledged. Good preparation and structure for the appointment is an essential requirement to support parents¹⁰. Parents should be aware of the meeting purpose and process and kept informed of any delays with investigation results. The venue for the meeting should be carefully considered to avoid unnecessary distress that may be caused by returning to the hospital and the sights and sounds of a maternity care setting. Timing the appointment for either the beginning or end of the day may help to avoid such distress.

Elements of the follow up appointment should include:

- discussion of events leading up to the baby's death;
- discussion regarding decisions and interventions provided during the mother's care;
- results of maternal clinical investigations and perinatal post-mortem investigations;
- implications for future pregnancies;
- referral for further testing or consultation if needed; and
- discussion of parents' grief and coping and recommendations or referral for on-going support if necessary.

Subsequent pregnancy

The vast majority of couples who experience a perinatal loss will consider a subsequent pregnancy at some time in the future. Decisions about embarking on a new pregnancy and the subsequent pregnancy itself presents a range of issues and challenges for parents. Heightened levels of anxiety, fear, worry and uncertainty are common among parents who have experienced perinatal death^{61,62}

Acknowledging and conveying an understanding of the fears and concerns held by parents in relation to a new pregnancy is part of ongoing perinatal bereavement care, as is providing parents with access to advice and support when needed^{11,28}.

Currently, there is little clear evidence to guide the provision of psychosocial support in a subsequent pregnancy. A separate guideline to improve the quality of both clinical and psychosocial care in subsequent pregnancies is being developed by PSANZ and the Stillbirth CRE.

Recommendations for 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.

3.12 Organisational response

The final recommendations in this section of the guideline are directed at the organisational level and are intended to support maternity care services in developing a service-wide approach to the provision of respectful and supportive perinatal bereavement care.

Organisational support drives the quality of perinatal bereavement care by creating the conditions and formal structures that enable health care professionals to provide optimal care. Policies that reflect current evidence in perinatal bereavement care should be in place and easily accessible to all staff to achieve optimal standards of care for all parents^{10,11,28,37}.

Best practice care relies on building a culture that values bereavement care and recognises the importance of institutional support for health care professionals who work in this challenging area⁷⁻⁹. Acknowledging that respectful and supportive perinatal bereavement care is a

responsibility shared between the organisation and individual health care providers is critical to developing an environment that enables and supports sustainable best practice care.

Recognising and finding ways to manage the impacts of perinatal death on health care professionals is essential for the optimal care of parents and for the wellbeing of care providers. Systematic reviews identify education, training and support as critical enablers for best practice care following perinatal death⁷⁻¹⁰. These include both formal educational initiatives and informal debriefing and sharing of experiences with colleagues.

Studies highlight the importance of a dual focus for health care professional training^{7-9,28,37}. As well as addressing the delivery of emotional and practical aspects of care for bereaved parents, training should address the emotional impacts of perinatal death on health care providers and strategies to promote self-care and build resilience among staff.

Organisational-level measures have been shown to be beneficial in preventing burnout, compassion fatigue or secondary traumatic stress in the context of perinatal loss^{9,37}. These include: ready access to debriefing and support; clinical supervision and mentoring with more experienced senior colleagues^{9,34}; and flexibility to enable rotation of health care professionals to avoid repeated exposure and to build confidence and experience across staff^{7,34}.

Students and newly graduated health care professionals should be included in training, education and mentoring opportunities. Gaining experience at an early stage is important for preparing health care professionals to provide best possible care when they are confronted with perinatal death^{63,64}.

All major maternity hospitals should consider developing specialist bereavement support services and employing staff with specific training in bereavement care¹⁰. These staff have an important role in the ongoing training and support of all health care professionals who have contact with bereaved parents. Outreach to smaller hospitals might also be considered an extension of that role, including use of telehealth, to address issues of access for smaller facilities or those located in rural or remote areas.

Organisational responses include developing and implementing local protocols and policies that are consistent with current evidence. Attention should be given to issues that have been highlighted in earlier parts of this section of the guideline with arrangements made to suit the local contexts and conditions of different maternity services.

At a minimum, local policies should address: planning and action at hospital level to ensure the availability of best possible spaces and surroundings to meet the needs of parents and their health care professionals across the full spectrum of bereavement care^{10,40}; the use of a universal symbol to indicate that a baby has died or has a life-limiting condition^{27,28}; the safe and reliable storage of images and mementoes for parents who may request these at a later time^{11,28,58}; and the availability and consistent use of up-to-date parent-centred informational resources¹⁰. Appropriate linkages should be made with other local services for perinatal palliative care and post-hospital care and support, including parent support organisations^{34,55}.

Better collaborative care at the interface between hospital and community is essential to addressing the ongoing support needs of bereaved parents^{10,34}. Standard and consistent approaches to managing the transition following hospital discharge and the continuity and transition across caregivers are required²⁹.

Recognition and honouring of the baby by hospital staff is a source of comfort for many parents. Commemorative rituals such as remembrance books and memorial services serve an important purpose by offering a permanent and formal reminder of the baby who has died and should be made available to all bereaved parents^{14,34}.

Information should routinely be sought from parents about their views and experiences of care, ideally using a set of standardised questions to promote comparison and benchmarking across different maternity services⁶⁵. Results from the recent PARENTS 1 study (Parents' Active Role and Engagement in The review of their Stillbirth/perinatal death) highlights the importance of including a parent summary of events as part of the formal perinatal mortality review process and making feedback from the review process available to parents⁴⁴. Information received from parents can help to identify and address areas that may need attention and to develop local services as part of ongoing quality improvement in perinatal bereavement care. A future update of this guideline will incorporate recommendations on how to engage parents in this process following consultation with parents and their care providers in Australia and New Zealand.

Recommendations for 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 health care professionals in maternity settings should complete the IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) Workshops educational program or other training in perinatal bereavement care that meets appropriate standards, reflects current evidence, and addresses 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.

3.13 References

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Jane Dahlstrom	Pam McGrath	Barb Vernon
Deborah de Wilde	Jonathan Morris	Sue Vlack
Paula Dillon	Heidi Mules	Andrew Watkins
Natasha Donnelly	Ned Mules	Lizelle Weber
Pamela Douglas	Belinda Norman	Lisa Wilmott
Chris Edwards	Jenny Patterson	Vicki Xafis
David Ellwood	Danielle Pollock	

3.16 Appendix

Theoretical Perspectives on Perinatal Bereavement

Many theories and models of loss and grief have been developed and refined over time to help explain the grieving process. These can be useful in helping to understand parents' responses to perinatal loss and in guiding practice. However, it is important to remember that theories make general statements which are open to testing and are not meant to be applied in a rigid way. No theory or model will fully account for the individuality and diversity of parents' grief. It is also important to note that theories of loss and grief are usually based on a Western worldview and that the experience and expression of grief and the needs of parents may differ greatly across cultures.

Three current theoretical perspectives that may help guide practice in perinatal bereavement care are: attachment theory; the continuing bonds perspective; and the dual process model.

Attachment theory provides an explanation of the nature of human relationships and of grief and mourning. Bowlby's theory of attachment⁶⁶⁻⁶⁹ centres on the emotional bonds between parents and their children. The loss, or threatened loss, of these bonds is at the core of parental grief.

Maternal attachment has been shown to begin well before birth and to be strengthened through interactions between the mother and unborn child during pregnancy and following the birth. These interactions include planning a pregnancy, confirming and accepting the pregnancy, feeling the baby move, accepting the baby as an individual, giving birth, seeing and touching the baby, and taking care of the baby. Fathers and other family members may also form close bonds and attachments with the baby both prior to and following the birth.

Applied to perinatal bereavement care practice, recognising that parents may have formed high levels of attachment long before the birth of their baby is critical to understanding and acknowledging the depth of loss that parents may experience when a baby dies⁷⁰.

The **Continuing Bonds** perspective⁷¹ stems from attachment theory and supports the idea that attachments do not end when a loved one dies. People often maintain ongoing, but redefined, relationships with those who have died. The concept of continuing bonds challenges the once widely held notion that relinquishing attachment is necessary for grief resolution. The continuing bonds perspective suggests that parental attachment does not end with a baby's death. This perspective is supported by numerous studies that show the high value placed by many bereaved parents on creating memories of their baby and their strong desire to maintain a lifelong connection with their child^{27,57,58}.

Applied to perinatal bereavement care practice, health care professionals can enable continuing bonds by giving parents opportunities to connect with their baby and create lasting and meaningful memories. This may include giving information about the baby, using the baby's name, enabling engagement in normal parenting activities, and the gathering of mementoes.

The **Dual Process Model (DPM)** of bereavement^{72,73} describes two categories of stressors associated with major loss. *Loss-oriented stressors* relate directly to the loss and, in the context of perinatal bereavement, include high levels of distress, pain and yearning as parents grieve for

their lost child. *Restoration-oriented stressors* relate to managing the loss and include the practical issues, problem-solving and decision making that accompany any major loss. The DPM views oscillation between loss-oriented stressors and restoration-oriented stressors as integral to coping by enabling balance between confronting the reality of the loss and engagement in more practical activities⁷². The DPM helps account for different expressions of grief, including gender and cultural differences, by describing both instrumental (“doing something”) and intuitive (“expressing emotions”) styles of grieving⁷⁴.

Applied to perinatal bereavement care practice, the DPM can guide approaches to supporting bereaved parents by recognising that that grief responses and support needs may differ for each individual parent and for the same parent over time. Emotional and practical issues may each take precedence at different times.

A further perspective on loss and grief emphasises people’s capacity for resilience following major bereavement^{75,76}. Much remains to be understood about how to promote resilience following loss, but supportive and respectful care and the attitudes and communication skills of health care professionals are important factors for long-term wellbeing^{10,27}. A review of research into grief support around the time of perinatal death, identified three consistent themes in providing care for bereaved parents: a deep respect for the individuality and diversity of grief; respect for the deceased baby; and recognition of the healing power and resilience of the human spirit¹⁶.

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 4

Perinatal Autopsy Including Placental Assessment

Version 3.2, January 2020

Endorsed by



SECTION 4

PERINATAL AUTOPSY INCLUDING PLACENTAL ASSESSMENT

4.1 Introduction

The perinatal autopsy remains the gold standard in diagnostic evaluation of the causes of perinatal death¹⁻³. Information gained from an autopsy can assist in the understanding of events surrounding the death and enable consideration of potential risk recurrence and appropriate management strategies in future pregnancy planning. Despite the value that perinatal autopsies offer, two challenges persist; low autopsy rates and the quality of post-mortem examinations.

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

To view further information on the described guidelines in this section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death see *Appendices G-Q*.

4.2 Objective of this section

The main objective of section 4 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to assist clinicians to improve standards for perinatal autopsy examination. This includes communication with parents, which directly affect autopsy rates.

For further information regarding communication with parents after a perinatal death please refer to Chapter 3 - Psychological and social aspects of perinatal bereavement.

4.3 What has changed in this update?

In this update, based on the findings of an updated literature review, the recommendations have remained unchanged. We have revised the formatting and reduced duplication across the different sections of the guidelines to enhance readability.

4.4 Purpose of perinatal autopsy

The purpose of any autopsy examination extends beyond diagnosis of the cause of death⁴⁻⁹.

The main purposes of an autopsy are to:

- Identify an accurate cause of death^{4,5,7,9}
- Exclude some potential causes of death¹⁰
- Identify disorders that have implications for counselling and monitoring in future pregnancies¹⁰⁻¹⁶
- Provide other information related to the death, including excluding possibilities that may alleviate feelings of guilt^{1,8,9,11,16}
- Obtain tissues for genetic tests (see *Appendix S – Components of the genetic autopsy for investigations of metabolic disorders*)
- Assist grieving by helping parents' understanding of the events surrounding the death^{1,11,16,17}
- Contribute to research, for example, by the recognition of new disease entities and expansion of knowledge on known diseases^{14,15,18-24}

- Inform clinical audit of perinatal deaths, including deaths due to iatrogenic conditions²⁰ and to confirm antenatal diagnoses or suspected fetal pathology^{21,22}
- Teach pathologists and medical students^{10,11,25}
- Avoid inaccuracies in data on causes of death for audit activities and subsequent public health policy²⁶⁻²⁹.
- Inform medico-legal processes, for example, provide information in coronial investigations or cases of litigation^{10,16}.

Value of an autopsy including placental examination

The autopsy examination remains the gold standard for identifying cause of perinatal death^{1,2}. The value of a perinatal autopsy has been demonstrated in several studies where the information obtained changed diagnoses or provided important additional findings^{17,21,30-38}. A review of 27 studies found that perinatal autopsy revealed a change in diagnosis or additional findings in 22% to 76% of cases³⁰. Another review of 53 studies, across a broad range of health care settings, on diagnostic errors detected at autopsy demonstrated a median error rate of 23.5% for major errors (clinically missed diagnoses involving a principal underlying disease or primary cause of death) and 9% for Class 1 errors (major error that, had they been detected during life, “would”, “could”, “possibly” or “might” have affected patient prognosis or outcome). This study also showed some decrease in error rate over time however the rate remained sufficiently high, supporting the ongoing use of autopsy³⁹. Value from an adequate numbers of perinatal autopsies to ensure standards in perinatal pathology has also been suggested⁴⁰.

A systematic review concluded that pathology of the placenta, cord, or membranes is attributed as a cause or contributory to stillbirth in 11% to 65%⁴¹. Placental histopathology can be causal and associated with factors associated with causing neonatal morbidity and mortality including: fetal growth restriction; pre-eclampsia; infection; conditions as a result of hypoxia such as necrotising enterocolitis and cerebral palsy; and infants who fail to respond to resuscitation^{23,37}

Pathways to an autopsy

An autopsy results from one of two major pathways: with parent consent or mandated by the coroner. Informed parental consent is essential for any post-mortem examinations that are not coroner-mandated (see Section 3).

Coroner-mandated autopsy

The purpose of a coroner's autopsy is to determine the cause of death, and specifically whether it was natural or unnatural. Each jurisdiction has reasons for notification and so it is important to reference the Coroner’s act for your state or territory. Some examples are:

- Babies dead on arrival at hospital
- Unattended stillbirths
- Deaths after an operation, anaesthetic or invasive procedure
- Deaths as a result of accident
- Unnatural, criminal or suspicious deaths, e.g. neglect, abuse, poisoning
- Deaths caused by drugs, prescribed or otherwise
- Deaths as a result of medical mishap
- Deaths in which the doctor is uncertain of the cause of death and unable to confidently complete the death certificate
- Unexpected death on the ward¹⁰.

If there is any doubt as to whether a death should be referred to the coroner, discussion with an experienced coronial officer or with the coroner is advised.

Coroners should ideally arrange for paediatric pathologists to perform the autopsy⁴, and provide results to relevant clinicians rather than use general or forensic pathologists.

The Coroner’s act for each state and territory can accessed via the relevant links listed:

State/Territory	Web site address/URL
Victoria	http://www.coronerscourt.vic.gov.au/find/legislation/
South Australia	https://www.legislation.sa.gov.au/LZ/C/A/CORONERS%20ACT%202003.aspx
Queensland	https://www.legislation.qld.gov.au/LEGISLTN/CURRENT/C/CoronersA03.pdf
New South Wales	http://www.legislation.nsw.gov.au/#/view/act/2009/41/whole
Western Australia	https://www.slp.wa.gov.au/legislation/statutes.nsf/main_mrtitle_201_homepage.html
Tasmania	http://www.thelaw.tas.gov.au/tocview/index.w3p;cond=;doc_id=73%2B%2B1995%2BAT%40EN%2B20160707000000;histon=;pdfauthverid=;prompt=;rec=;rtfauthverid=;term=;webauthverid=
Northern Territory	http://www.austlii.edu.au/au/legis/nt/consol_act/ca120/
Australian Capital Territory	http://www.legislation.act.gov.au/a/1997-57/
New Zealand	http://www.legislation.govt.nz/act/public/2006/0038/latest/whole.html

4.5 Different types of autopsy

Autopsies are generally defined in terms of their extent. The “gold standard” is the ‘classical’ conventional or full autopsy, which involves the combination of review of the clinical notes and maternal investigations, placental examination and examination of the baby. In a full autopsy examination of the baby includes external examination (including measurements and clinical photographs), radiological investigations, evisceration, dissection and organ examination including detailed histological evaluation. Other special tests like microbiology, molecular karyotyping/cytogenetics and molecular studies may also need to be performed. All other forms of autopsy are compared to the full autopsy in terms of the level of examination and degree of invasiveness³.

Less invasive autopsies (LIA) include all post-mortem examinations that take an approach other than a full autopsy. LIA include limited and minimally invasive or non-invasive autopsies. Limited

4

autopsies take an organ-specific approach and usually require some form of surgical incision. For example, the examination involves an incision to look at the heart or brain only. Minimally invasive autopsies (MIA) do not make a large surgical incision but use a laparoscopic or keyhole approach to obtain organ samples with radiological guidance. Non-invasive autopsies (NIA) use no internal examination, but instead rely on the detailed external, placental and umbilical cord examinations and external measurements, skin/needle blood sampling, clinical photography, and radiological investigations that are performed. Radiology may also include conventional radiographs, computed tomography, or magnetic resonance imaging^{42,43} (see 4.13 below). Stepwise post-mortem may include sampling tissue immediately after death (for example for metabolic reasons) then performing the full autopsy.

4.6 Autopsy rates

While data to establish an optimal perinatal autopsy rate is lacking, the Working Party of the Royal College of Pathologists⁵ recommended a rate of 75%. However, perinatal autopsy rates have steadily declined over recent years to rates much lower than this recommendation in many regions. A 2.8% per year decline over the decade 1990-1999 was reported by one tertiary setting in the UK¹⁷. Reports of perinatal autopsy rates more than a decade ago ranged from 33% to 67%^{17,23,24,44}. An analysis of perinatal deaths in Australia from 2011-2012 showed an overall perinatal autopsy rate of 38.7% (42.3% stillbirth and 28.2% neonatal deaths). Over half (57.5%) of all perinatal deaths were recorded as not having an autopsy performed⁴⁵.

Why the decline in autopsy rates?

Consent is the major limiting factor to achieving adequate autopsy rates^{16,46}. Consent for autopsy is difficult for both clinicians and parents. Parents are confronted by a proposed process that appears intrusive, and that requires them to understand detailed consent procedures when they are in a state of grief¹⁰ while clinicians are reluctant to place further burden on parents⁴⁷.

Adverse publicity generated from inquiries into autopsy practices in the United Kingdom over retained organs⁴⁸⁻⁵⁰ and the inquiry at the NSW Institute of Forensic Pathology⁵¹ are believed to have adversely influenced clinicians' willingness to seek consent and parents' acceptance of the procedure^{52,53}. Practice improvements resulted from the NSW inquiry but complexity in the consent process also increased, which may have created an additional deterrent for clinicians⁸. However, clinician reluctance to seek consent because of the added burden placed on families may be misplaced. A survey of UK parents found significantly more parents who did not have an autopsy were dissatisfied with their decision (OR=2.43, 95% CI 1.53-3.87)⁵⁴. The low autopsy rate may also indicate that clinicians are ambivalent about the value of an autopsy^{10,55,56} or may be reluctant to discuss difficult issues with families where no pre-existing relationship exists

Other factors identified as possibly affecting clinicians' willingness to approach parents for consent for autopsy include: lower gestational age at death^{17,57}; clinician discipline and seniority^{16,57}; and workforce shortages⁸.

Khong *et al* found that obstetricians and neonatologists were less averse to seeking consent for perinatal autopsies than midwives and neonatal nurses who were more influenced by those factors unfavourable to consent-seeking¹⁶. Obstetricians and neonatologists surveyed considered nurses and midwives influential in parents' decision-making about autopsy¹⁶.

Provision of educational opportunities for all members of clinical teams, both formal (during undergraduate and post graduate training) and informal (through day-to-day positive reinforcement from clinical leaders) is crucial to increasing the rates of perinatal autopsy.

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 Otcomes 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.

4.7 Costs of a post-mortem examination and transport

Diverse arrangements exist across Australia regarding payment for autopsy⁸. The cost of autopsy are estimated to be around \$1500⁵⁸ – \$2600⁵⁹. Currently the post-mortem examination of a stillborn baby is not adequately covered under Medicare and consequently the costs for the post-mortem examination need to be covered either by the institution state health departments or their designated authorities.

Recommendation

- 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.

4.8 Quality of perinatal autopsies and minimum standards

Research on the quality of perinatal autopsies is limited however the available data suggests that approximately half may not reach minimum standards^{23,55,60}. Approaching parents for consent when a quality post-mortem service is not available raises important ethical questions² that demand attention to the requirements of minimum standards.

The post-mortem examination of an infant is very different to that performed on an adult^{5,61-63}, and ideally should be performed by a paediatric pathologist. Pathologists with paediatric training find a higher incidence of causes of death in infants⁶⁴, provide a much higher proportion of adequate reports^{65,66}, and the causes of death based on perinatal/paediatric pathologists reports are infrequently revised by the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) review panel⁶⁷. There are currently no guidelines for Australia and New Zealand on quality and minimum standards for perinatal autopsies. Until the availability of such guidelines, the Guidelines on Autopsy Practice produced by the Royal College of Pathologists should be used for guidance⁴.

Appropriate clinical information is an essential part of a good quality post mortem. The history of the pregnancy, results of antenatal investigations and circumstances of perinatal loss are vital in determining the relevant questions to be addressed by the post mortem and enable judicious use of investigations (please refer to *Appendix I – Autopsy clinical summary form*). Transportation of the baby to a centre with appropriate perinatal pathology expertise should be offered to parents where this expertise does not exist in the birth facility. Transport should be arranged with a registered undertaker.

There is growing use of new molecular techniques in the assessment of perinatal deaths. Chromosomal microarray is fast becoming standard practice as it detects a significant number of pathological changes not seen with standard karyotyping, although balanced chromosomal translocations and triploidy may not be detected⁶⁸. However, this is a developing technology and the range of normal and pathological variants are yet to be established. Interpretation can be time consuming. Next generation sequencing is already used diagnostically with large studies funded in the US and under discussion in the UK and Australia for more routine⁶⁹. Material like cartilage or skin can be used for these techniques. This needs to be retained and should be included in the consent process.

Following recent reviews the use of microarray is becoming standard⁶⁸. Identification of previously undiagnosed genetic disorders always was part of the post mortem process making a full informed consent difficult. However the parents should be informed that material for DNA and genetic tests is likely to be retained, and should be if there are features suggesting a genetic cause. Consent for further genetic testing may be sought by the genetics team after the autopsy using material retained at autopsy.

Specific autopsy protocols have been developed for examinations when genetic metabolic disorders are suspected⁷⁰ and in the event of a Sudden Unexpected Deaths in Infancy⁷¹. Please refer to these protocols for full details.

(Please see Appendix Q – Suspected genetic metabolic disorders)

(Please see:

- *Appendix O – RCPATH guidelines for autopsy investigation of fetal and perinatal death*
- *Appendix Q – Suspected genetic metabolic disorders*
- *Appendix I – Autopsy clinical summary form*

Recommendations

- 5 The Guidelines on Autopsy Practice produced by the Royal College of Pathologists⁵ 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 reports⁹
 - Copy of the death certificate if available
 - Copy of amniocentesis report if available.

4.9 Post-mortem reporting

A preliminary report is usually available within three days of the examination, and should include a summary of the clinical history, samples taken and further tests requested, and macroscopic findings. The final report may take up different times in different jurisdictions; up to eight weeks in most cases although more complex genetic or metabolic workups can take six to 12 months. The post-mortem report includes demographic details, a clinical summary, and findings of the external and internal examination including: organ weights; microscopic findings; results of ancillary examinations such as cytogenetics; microbiology; radiology a summary of findings; a commentary to suggest the most likely pathophysiological pathway; and a cause of death if appropriate. Other details ideally recorded are mode of identification, a list of samples taken, a record of X-rays and photographs taken, and details of the consent and any limitations imposed¹⁰.

Delays with and poor communication of results can be a source of much distress to parents^{72,73}. Establishing clear processes and timelines for informing parents of results may help to alleviate such distress.

A plain language report (PLR) may be helpful to parents⁸. A copy of the PLR, if available, and full autopsy report should also be sent to the GP. Autopsy reports should not be sent directly to the parents but provision should be made to discuss the findings with the parents, even if the results are inconclusive⁷⁴. Parents should be advised in instances where, based on the findings of investigations, a revised death certificate may be submitted. Such discussions should take

place at a suitable venue (e.g., away from antenatal clinics). Parents should be advised in instances where, based on the findings of investigations, a revised death certificate will be submitted.

Recommendations

- 10** Guidelines for post-mortem reports produced by the Royal College of Pathologists⁴ 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.

4.10 Communication and consent

All hospital perinatal autopsy examinations require written consent from parent(s) following informed discussion⁴⁷, although little is known on the best ways to inform parents making decisions about autopsy or other post-mortem examinations and we rely on the knowledge and experience of those involved at the time⁷⁵. Such knowledge and experience can be highly variable among health professionals⁵⁴.

The influences on parents' decision-making regarding autopsy are complex and diverse^{72,73,76}. Assumptions need to be avoided as barriers perceived by clinicians are often different from those reported by parents⁷². Parents are often overwhelmed and need clear, easily understandable and structured information presented verbally and in written form⁷². Parents should be given written information explaining autopsies to assist in their decision about an autopsy examination for their baby (please refer to *Appendix M – Infant autopsy consent brochure*). The extent of the examination including retention of organs and DNA needs to be clearly explained and documented in the consent form. Options for a full, limited or stepwise autopsy should be explained. Parents need to be counselled that limited autopsy may result in the loss of important information. Written consent from parents is also required for peri-mortem investigations such as clinical photographs, tissue and blood sampling by cardiac puncture. Written consent is not required for histopathological examination of the placenta, however parents should be informed that this is a part of the routine investigation that may provide valuable information⁷⁷.

Parents want to know why their baby died and a desire for information is a strong motivating factor for consent to autopsy; concerns about the invasiveness of the procedure and a desire to

protect the baby from unnecessary harm are major barriers to consent (Lewis et al., 2017). A UK survey that included 460 parents, found professional advice influenced the decisions about autopsy for more than one in five parents (22%). The majority of parents were satisfied with their decision related to autopsy, although those who did not have an autopsy were more likely to be dissatisfied⁵⁴. Regret is more common among parents who have not had an autopsy even when a cause of death is not found, although sample sizes are commonly small or skewed^{54,78,79}. Informed discussion with the parents should include the possibility that a cause of death may not be found, but that the information obtained may benefit other babies in the future. Clinicians need to be aware of religious and cultural beliefs and values which may influence parents' decisions^{8,11}. It is important and appropriate to ask parents what is important to them.

Where possible, consent from parents should be sought by an experienced clinician who has rapport with them. Responsibility for obtaining informed consent lies with the primary attending physician^{2,10} and in most cases the consultant clinician should approach the parents, although this may be delegated to another attending clinician (e.g. midwife, nurse)⁸⁰. Clinicians seeking consent should be prepared to answer in a sensitive manner questions about what actually happens to the baby during the procedure and how the baby may look after the examination⁸⁰. Therefore, all clinicians seeking consent should have in-depth knowledge of post-mortem procedures and, preferably, have witnessed several autopsy examinations. Discussion with parents about consent for all post-mortem examination needs to take into account the importance of partnerships in decision making⁸¹. Parents are likely to need practical information about the process and the implications of their decision, such as advice on how long the baby can remain in the hospital or be taken home without adversely affecting post-mortem results, whether they will be able to see the baby again, and if any costs might be involved.

(Please refer to Appendix N – Information for health professionals seeking consent.)

Recommendations

- 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.

4.11 Placenta, membranes and cord histopathology

Examination of the placenta, membranes and cord should occur after all births. The placenta is also an integral part of the post-mortem examination and, ideally, all placentas should be retained for a few days after birth to allow for subsequent retrieval should an infant deteriorate. This may happen with sepsis or metabolic disorder¹⁰. The placenta, membrane and cord should be sent to the pathologist fresh and unfixed for histopathological examination once samples have been collected for cytogenetics and microbiology. A perinatal/paediatric pathologist should undertake the examination²³. A standardised reporting form for placental histopathology is provided to enable high quality reporting (Please see *Appendix P – Placental histopathology reporting form*).

Placental examination by a perinatal/paediatric pathologist should be performed for specific maternal, placental, fetal and neonatal indications⁸².

Maternal indications include:

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

Fetal and neonatal indications include:

- Admission to neonatal intensive care
- Failure to respond to resuscitation
- Spontaneous or iatrogenic preterm birth
- Fetal compromise including growth restriction
- Severe cardiorespiratory depression at birth

- Signs consistent with congenital infection
- Severe growth restriction
- Diagnosis of hydrops fetalis
- Suspected severe anaemia
- Suspected or known major congenital abnormalities
- Death.

Placental indications include:

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

Recommendation

- 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.

4.12 Alternative investigations: When permission for autopsy is not obtained

If permission for an autopsy is not obtained, other less invasive testing may assist to establish whether any important abnormalities have been missed. These options should be offered to parents as these alternatives permit detailed investigation of the baby while respecting the wishes of parents⁸³. However, a Working Group of the Royal College of Paediatrics and Child Health found little evidence for valid alternatives to the paediatric post-mortem⁶¹. Parents should be informed at the time of consent about the possibility of missing an important finding when a full post-mortem investigation is not undertaken. All alternative investigations are subject to the same requirements of informed consent as autopsy examinations.

External examination

Examination by an experienced clinician (by a perinatal/paediatric pathologist, clinical geneticists or paediatrician) is of particular importance when an autopsy examination is declined⁸⁴. Clinicians should discuss the importance of this examination with the parents and arrange for an appropriately skilled clinician to perform it.

Please refer to Chapter 5 - Investigation of stillbirths and Chapter 6 - Investigation of neonatal deaths for further details

Babygram

Parents who decline an autopsy should be provided with further information about and asked to consent to the use of a full body X-ray (babygram) as an alternative non-invasive investigation. A babygram may detect abnormalities (mainly skeletal) which may not be detected on an

external examination. The Wisconsin Stillbirth Service Program has estimated that approximately 20% of unselected stillborn babies will have abnormalities which are detectable on X-ray⁸⁴.

Please refer to Chapter 5 - Investigation of stillbirths for further details.

Ultrasound scan

A detailed ultrasound examination of the infant at the time of confirmation of an intrauterine death or after the birth may identify fetal abnormalities not identified by an external examination⁸⁵.

Please refer to Chapter 5 - Investigation of stillbirths for further details.

Magnetic Resonance Imaging (MRI)

Magnetic Resonance Imaging (if available) may be offered to parents who decline an autopsy investigation. The investigation should be undertaken as soon as possible after a stillbirth. Clinicians should explain to the parents that a full autopsy remains the gold standard as the MRI does not supply tissue samples and therefore important information may be missed.

A comprehensive overview presented the advantages and disadvantages of the post-mortem MRI¹. The major advantages of post-mortem MRI included the non-invasive nature of the examination and the detection of pathologies and malformations of the central nervous system. The disadvantages included the lack of tissue sampling; limitations in detection of complex cardiac malformations, and other abnormalities (e.g. tracheo-oesophageal fistula, bowel perforations) which are undetectable by post-mortem MRI; and lack of experience in perinatal post-mortem MRI. The authors concluded that a full autopsy remains the gold standard; however, MRI may play an important role when an autopsy is declined¹.

More recent literature comparing MRI with autopsy in accurately identifying cause of death or most clinically significant abnormality in stillborn fetuses found that sensitivity for MRI was 69%, and specificity was 95%⁸⁶. Following on from these results, one large study showed that concordance for detection of major pathological abnormalities between full autopsy and MRI is near 43% for stillbirth ≤ 24 weeks' gestation, and 63% for stillbirths > 24 weeks' gestation⁸⁷. However the discordance between MRI and full autopsy is relatively high, 23% for stillbirth ≤ 24 weeks' gestation, and 33% for stillbirths > 24 weeks' gestation⁸⁷, suggesting that MRI only may not be an optimal substitution for full autopsy. Current ongoing studies are exploring yield of techniques combining computed tomography (CT) scans with MRI to guide biopsy sampling, so-called virtual autopsy⁸⁸. It is possible that MRI in combination with additional techniques may provide an option for cause of death investigations when full or partial autopsy is declined

Clinical photographs

Following consent from parents, clinical photographs should be taken for later review, particularly for births that occur in non-tertiary hospital settings. These photos are additional to the bereavement photographs and should not be given to the parents. They should be clearly labelled and filed in the medical record. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality should be considered.

Please refer to Chapter 5 - Investigation of stillbirths and Chapter 6 - Investigation of neonatal deaths for further details.

Other alternatives to a full post-mortem examination

Post-mortem needle biopsy; laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected abnormalities. Recent studies suggest that minimally invasive post-mortem examinations may be a valuable investigation to determine cause of death in stillbirth if a full post-mortem is declined⁸⁷.

Section 4 Recommendation

- 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.

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4.16 Appendices

Appendix I – Autopsy clinical summary form

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

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 5

Investigations for stillbirth

Version 3.2, January 2020

Endorsed by



SECTION 5

INVESTIGATIONS FOR STILLBIRTH

5.1 Introduction

This section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death presents recommended investigations to be undertaken following fetal death/stillbirth. Accurate identification of the cause of stillbirth is the cornerstone to prevention and is critically important to parents to help them to understand why their baby has died and to plan future pregnancies. The high proportion of unexplained stillbirths reported globally is an impediment to these goals¹. Wide variation in reported causes of stillbirth internationally has been attributed to different approaches to investigation. However, the classification system used also plays a role². Please refer to Section 7 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death for further details on classification of stillbirths and neonatal deaths.

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

In this section of the PSANZ Guideline for Care Around Stillbirth and Neonatal Death, for practice recommendations to assist clinicians to implement the guideline recommendations see *Appendices A - T*.

5.2 Objective of this section

The objective of this section is to provide guidance on the investigations to perform following a stillbirth to identify an accurate cause of death. Detailed objectives are:

- To provide quality information for parents to help understand why the death occurred;
- To inform future pregnancy planning;
- To inform care in future pregnancies; and
- To inform strategies for prevention at the population-level, and future research.

5.3 What has changed in this update?

The findings of a recent literature review have informed changes in this update. Readability has also been enhanced and reduced duplication across the different sections of the guidelines.

Several investigations previously recommended as core investigations following all stillbirths are now recommended as selective investigations only. These investigations (e.g. thrombophilia studies, tests for infectious diseases, Haemoglobin A1c (HbA1c), liver function and bile acid tests) should be undertaken on the basis of the results of core investigations. Maternal ultrasound scan, full blood count, renal and thyroid function testing are no longer recommended investigations for determining the causes of stillbirth. Amniocentesis for cytogenetic analyses and microbiological studies are no longer recommended.

5.4 Research gaps

Due to the lack of high-quality studies on appropriate diagnostic testing following stillbirth, contentious issues remain and, consequently, components of stillbirth investigation protocols internationally vary^{3,4}. While there are limited data on costs of stillbirth investigations, one study from the US by Michalski et al in 2002 suggest that a specific comprehensive investigation

protocol was of sufficient economic value to be incorporated into routine antenatal care⁵. Others report that a selective⁶ or sequential approach to testing may be appropriate^{7,8}. The findings of the National Health and Medical Research Council (NHMRC)-funded study on the yield and costs and benefits of stillbirth investigations across maternity settings in Australia and a Cochrane systematic review of the evidence for test protocols⁴ are expected in 2017 and 2018.

5.5 Approach to investigation of stillbirth

The recommended investigations following stillbirth include those that should be routine for the majority of stillbirths (core investigations) and those that should be carried out based on information revealed from core investigations, or in the presence of specific clinical scenarios (sequential or selective investigations) (see Figure 1).

Situations will exist where the cause of a fetal death is already known (e.g. unequivocal diagnosis from prenatal testing), however, as selective investigative approaches may result in important diagnoses being missed⁹, a non-selective approach using the core investigations should be the standard in the absence of unequivocal diagnosis from prenatal testing. The relative merits of not following this approach should be considered on an individual-case basis and involve consultation with the family. Depending on the particular circumstances of a perinatal death (e.g. family wishes, access to services), it may not be feasible for some stillbirth investigations to be carried out.

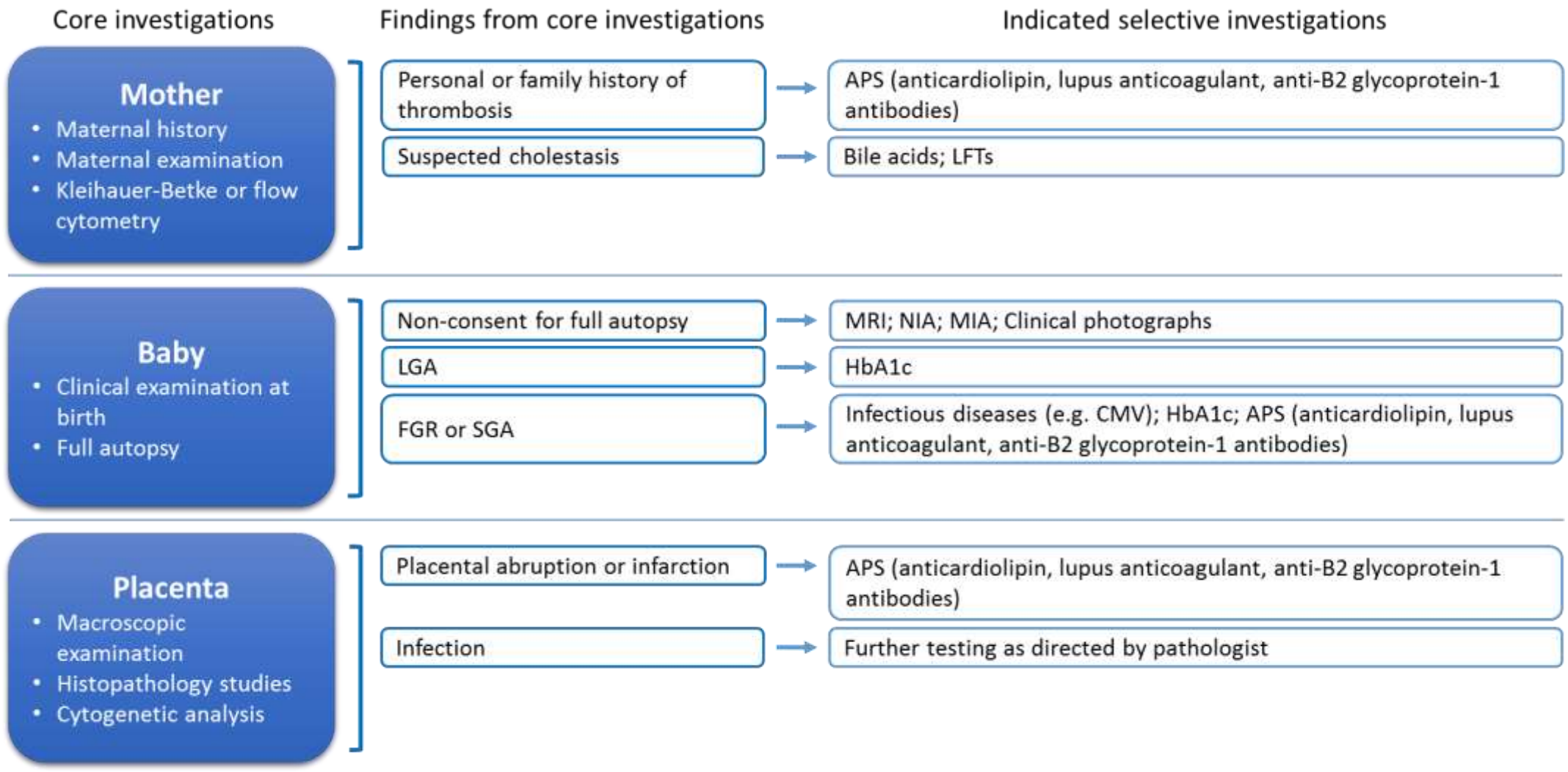
This Guideline provides checklists and data collection forms (*see Appendix A – T*) to assist clinicians with uniform investigation and reporting of stillbirths.

Section 5 Recommendations for stillbirth investigations

- 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.
-



APS: Antiphospholipid syndrome; CMA: Chromosomal microarray; CMV: Cytomegalovirus; FGR: Fetal growth restriction; LFTs: Liver Function Tests; LGA: Large-for gestational-age; HbA1c: Haemoglobin A1c; MIA: Minimally-invasive autopsy; MRI: Magnetic Resonance Imaging; NIA: Non-invasive autopsy; SGA: Small for gestational age.

Figure 1: Stillbirth investigations algorithm

5.6 Core investigations for all stillbirths

After the diagnosis of stillbirth, and at an appropriate time, the responsible clinician should explain to the parents the value of performing the recommended core investigations as outlined below.

Maternal history

A comprehensive maternal (medical, social, family) and pregnancy history should be taken following all perinatal deaths.

Please refer to *Appendix E – Australian perinatal mortality audit tool*; and *Appendix G – New Zealand Rapid reporting form for a perinatal death - mother*

Fetal-maternal haemorrhage (FMH)

In a large study from Ireland over 25 years, fetal-maternal haemorrhage (FMH) accounted for 4.1% of antepartum stillbirths, mostly at term gestations (74%), with multiple gestations being up to six times as likely to be affected as singleton pregnancies¹⁰. Another case controlled study also noted that women with FMH were more likely to work outside the home during pregnancy than women without evidence of FMH¹¹. By general consensus, >50ml is considered a significant fetal haemorrhage, although various studies use limits ranging from 30 to 150ml^{12,13}. However, as the impact of a haemorrhage of a given volume is dependent on gestational age, fetal size and total blood volume, individual assessments need to be calculated¹⁴.

A Kleihauer-Betke test or flow cytometry to detect FMH should be performed following the diagnosis of any fetal death, preferably prior to birth^{7,15-18}. Limited evidence suggests that this may also be useful postpartum^{18,19}.

Please refer to Appendix B – Estimation of severity of feto-maternal haemorrhage.

Autopsy

Please refer to *Section 4 Perinatal autopsy examination for further details on the post-mortem examination* and *Section 3 Psychological and social aspects of perinatal bereavement*, *Appendix M – Infant autopsy consent brochure* and *Appendix N – Information for health professionals seeking consent* for information brochures for parents and professionals about post-mortem examinations.

The following should accompany the infant for autopsy examination:

- Autopsy consent form
- Placenta (fresh and unfixed)
- Comprehensive maternal (medical, social, family) and pregnancy history
- Copies of the death certificate
- Copies of all antenatal ultrasound reports (including post-mortem ultrasound if undertaken)
- Copy of prenatal karyotyping results if available
- Findings from initial external examination performed at birth by attending clinician using the checklist provided (*Please refer to Appendix D – Clinical examination of baby checklist*).

External examination of the baby

A comprehensive external examination of the baby is an essential component of the investigation of a stillbirth^{15,20-28}. A report on a large case series from the Wisconsin Stillbirth Service Program (WiSSP) suggested that approximately 25% of stillborn infants were found, on clinical examination, to have demonstrable abnormalities and also indicated that lack of external examination would have resulted in approximately 4% of diagnoses being missed²⁹.

A detailed external examination of the baby is a component of a full autopsy. As the perinatal pathologist is the most appropriate person to carry out the external examination, parents who have declined a full autopsy should be asked for their consent for the baby to have a detailed external examination by a perinatal pathologist. This should not replace the initial external examination performed at birth by the attending clinician, which may provide important information to guide the full autopsy. In the circumstance where it is not possible for a pathologist to perform the examination, then a neonatologist or paediatrician or clinical geneticist should conduct the examination. A proforma is provided to assist the midwife/doctor in carrying out the procedure.

Please refer to Appendix D – Clinical examination of baby checklist.

Clinical photographs

Clinical photographs should be taken for every stillborn baby for later review. The clinical photographs are additional to the bereavement photographs, and should be clearly labelled and filed in the medical record. The WiSSP case series indicates that 28% of all stillborn babies had observable abnormalities identifiable on photographs and photographs were critical in establishing a diagnosis in approximately 5% of cases²⁹. Consent from the parents for clinical photographs should be documented in the medical record.

Please refer to Appendix H – Instructions on taking clinical photographs

Placental and cord investigations by clinician

At time of birth, the clinician should undertake:

- A detailed macroscopic examination of the placenta and cord and document the normal and abnormal findings;
- Sampling of cord and placental tissue for chromosomal analysis (only if the placenta is not being sent to the pathology service). If a prenatal karyotype has already been performed, these samples should still be taken for DNA extraction and storage;
- Following a stillbirth, the placenta, membranes and cord should be sent fresh and unfixed for macroscopic and histological examination. If removal of an entangled cord from the baby is necessary, then clinical photographs should be taken first.

Please refer to Appendix C – Placental examination; Accoucheur flow chart.

Placenta, membranes and cord histopathology

Examination of the placenta, membranes and cord should occur for all stillbirths. The placenta, membrane and cord should be sent to the pathologist fresh and unfixed for histopathological examination once samples have been collected for cytogenetics and microbiology. A perinatal/paediatric pathologist should undertake the examination³⁰. For further details, please

refer to Section 4. A standardised reporting form for placental histopathology is provided to enable high quality reporting (See *Appendix P – Placental histopathology reporting form*).

Cytogenetic investigations

Chromosome microarray (CMA), in contrast to conventional culture karyotyping, uses DNA and does not require viable cells, which means that chromosomal abnormalities can be detected in macerated stillbirth samples³¹⁻³³. Microarray is also superior to karyotype as it can detect additional genetic abnormalities, including microdeletions and microduplications³². Targeted genetic testing using fetal and/or placental DNA (e.g. for monogenic disorders) will always have a place where a specific phenotype is suspected or when the family history is informative.

Advances in molecular genetic testing using DNA have facilitated a greater depth of testing of both the fetal and placental genome. New technologies currently under evaluation include exome and whole genome sequencing³⁴. Such advances have highlighted the importance of storing fetal and placental DNA for later evaluation where a cause for fetal death remains unknown.

Specific advice around extended genetic investigation cannot be prescribed at this time as data are limited, and access is variable and costs are generally high. It is therefore recommended that each service explore genetic testing options available to them both locally and further afield through transportation of tissue or DNA samples.

5.7 Selective investigations based on findings of core investigations

Congenital infections

Routine testing of all stillbirths for infection is no longer recommended^{7,18}. Targeted investigation should be undertaken if infection is suspected on the basis of maternal history, autopsy and/or placental findings¹⁸ and/or a small for gestational age (SGA) baby. To assign infection as the cause of death, positive serology should be supported by autopsy and/or placental findings consistent with infection^{17,18}. Detailed information about specific infections is outlined below.

Cytomegalovirus (CMV)

Cytomegalovirus is the most frequent infectious cause of newborn developmental abnormalities in the developed world³⁵. A prospective study of more than 10,000 women found an increase in fetal loss associated with infection in early pregnancy³⁶. CMV DNA can be detected in a high proportion of fetal or placental tissue samples and a strong association between CMV infection in pregnancy and stillbirth is suggested³⁷. CMV can also infect the placenta and is associated with villitis³⁸. Congenital CMV may also be discovered in cases where there are no obvious macroscopic sequelae³⁹. Maternal CMV serology CMV should be considered where placental histopathology shows evidence of CMV infection and/or when the baby is SGA.

Toxoplasmosis

Congenital toxoplasmosis can cause miscarriage, stillbirth, neurological disability and visual impairment but the majority of fetuses infected will not have sequelae. As toxoplasmosis is not

a common cause of stillbirth⁴⁰, routine testing in the absence of other indications is not recommended.

Parvovirus (B19)

Parvovirus (B19) can cause severe fetal anaemia, nonimmune hydrops and fetal death^{40,41}. One study found parvovirus to be the cause of death in 10% of all non-malformed fetal deaths that occurred between 10 and 24 weeks of gestation and referred for pathological examination⁴². A small proportion of susceptible pregnant women (1%-3%) will develop serologic evidence of parvovirus infection in pregnancy, of which the transmission rate to the fetus is between 17% and 33%⁴³⁻⁴⁵. The spontaneous loss rate of fetuses affected by Parvovirus B19 after 20 weeks gestation is 2.3%^{44,46,47}. However, where parvovirus has caused stillbirth, signs of the disease will be evident following examination of the baby and/or placenta. Routine testing following stillbirth in the absence of other indications is therefore not recommended. Testing for parvovirus should be recommended where severe anaemia and/or non-immune hydrops is found^{7,18}.

Rubella

Rubella is associated with a wide variety of fetal abnormalities including stillbirth^{48,49}. However with universal vaccination, congenital rubella infection in developed countries is rare⁵⁰. Most pregnant women are immune and, if they have not been tested during the initial routine antenatal blood testing, testing for rubella should be done only if indicated on the basis of core investigations.

Syphilis

Congenital syphilis may result in fetal loss/neonatal death, prematurity and major long term sequelae in surviving children. In a South American study, even after controlling for congenital anomalies, gestational age, maternal age, and previous stillbirth, gestational syphilis was significantly associated with stillbirth (odds ratio 1.88, 95% confidence interval 1.25-2.83; P=0.002)⁵¹. This increase in mortality with congenital syphilis has also been confirmed in a systematic review on this topic⁵². Antenatal screening for syphilis for all women is currently recommended to facilitate treatment early in pregnancy. Syphilis remains an uncommon cause of stillbirth in developed settings¹⁸ and routine testing following stillbirth in the absence of other indications is not currently recommended.

Other investigations

Blood group and antibody screen

A maternal blood group and antibody screen is recommended as a routine antenatal test at booking and again in the 3rd trimester of pregnancy. If a blood group and antibody screen has not been performed antenatally, it should be performed selectively to exclude haemolytic disease of the fetus due to maternal sensitisation to red cell antigens⁵³ where the baby is anaemic, jaundiced and/or hydropic.

Thrombophilia testing

Inherited thrombophilia⁵⁴ has been associated with a number of adverse pregnancy outcomes including stillbirth, but the relationship remains controversial and the role of testing is still debated. The role of treatment for women with inherited thrombophilia and adverse pregnancy outcomes also remains controversial⁵⁵⁻⁵⁷.

The most common acquired thrombophilia is the antiphospholipid syndrome (APS). The diagnosis of APS includes venous or arterial thrombosis and/or fetal loss in the presence of antiphospholipid antibodies (anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1). Confirmation of the presence of antiphospholipid antibodies is required at a minimum of 12 weeks apart, after an initial positive test. APS is associated with both early and late fetal loss, pre-eclampsia and placental insufficiency. The prevalence of antiphospholipid antibodies is estimated to be 5% while the syndrome affects 0.5%⁵⁸. In a systematic review, the presence of antiphospholipid antibodies was significantly associated with late fetal loss⁵⁹.

The presence of thrombophilia may be most significant where placental pathology is apparent¹⁸. In a small prospective cohort study, 64% of women who had a stillbirth of placental cause had at least one thrombophilia⁶⁰. This proportion was increased to 70% when looking specifically at preterm stillbirths of placental cause. A population based study in Finland found an almost four-fold increased risk of Factor V Leiden mutation among women with unexplained stillbirth⁶¹. The prevalence of this mutation was over ten-fold among women with an unexplained stillbirth in the presence of placental lesions. More recently, a population-based case-control study within the Stillbirth Collaborative Research Network found the only heritable thrombophilia associated with stillbirth was Factor V Leiden mutation, and the association was statistically weak⁵⁵.

Given the evidence, routine testing for thrombophilic disorders following stillbirth without other indications is not currently justified. Testing for APS (anticardiolipin, lupus anticoagulant, and anti-B2 glycoprotein-1 antibodies)^{60,62} is recommended selectively where stillbirth occurs in the presence of one or more of the following: (1) family history of thrombosis; (2) personal history of venous thrombosis; (3) fetal growth restriction; (4) placental abruption or (5) placental infarction^{8,54}. Other thrombophilia studies, such as Prothrombin G20210A mutation^{60,63-65} and Factor V Leiden mutation^{55,61,65}, should be carried out as indicated and in accordance with individual jurisdiction guidance.

Haemoglobin A1c (HbA1c)

Increased risk of fetal morbidity and mortality for women with pre-existing diabetes is well known. A stillbirth rate of 35 per 1000 births for Type 2 diabetic mothers has been reported⁶⁶, and a systematic review has shown that women with pre-existing diabetes have an almost three-fold increased risk of stillbirth⁶⁷. There is some evidence to indicate that gestational diabetes mellitus (GDM) is also associated with increased perinatal mortality⁶⁸, and poor detection and management of the condition has been documented in association with term antepartum stillbirth⁶⁹. It is recognised that some women with GDM have unrecognised type 2 diabetes, with unfavourable pregnancy outcomes⁷⁰. HbA1c provides information about maternal glycaemia over the previous 3 months by reflecting the average glucose concentration over the life of the red cells⁷¹. Therefore, it may provide information regarding the contribution of maternal diabetes to a fetal death. One study suggested that pregnant women with an HbA1c of $\geq 5.4\%$

(36 mmol/mol) may have gestational diabetes⁷². Another study also noted that although HbA1c cannot replace Oral Glucose Tolerance Test (OGTT) in the diagnosis of GDM, it can be used as a screening test if a cut-off of 5.3% is used⁷³. In such women an OGTT should be performed postnatally. Nonetheless, diabetes has not been shown to be a common cause of stillbirth⁷. Routine HbA1c following stillbirth without other indication is not currently justified^{7,18}. It is recommended that HbA1c be carried out where SGA, FGR or SGA is detected. Please refer to the Australian Diabetes in Pregnancy Society Guidelines or the New Zealand Screening, Diagnosis and Management of GDM Guideline for further information^{68,74,75}.

Thyroid function test

Overt hyper and hypothyroidism are both associated with stillbirth⁷⁶. However the effect on stillbirth of subclinical hypothyroidism or a positive thyroid antibody test in pregnancy is not clear^{77,78}. Due to this very low risk of stillbirth, routine screening of thyroid function in a clinically euthyroid woman after stillbirth is of limited value⁷⁹.

Liver function tests and bile acids

Abnormalities in liver function tests are markers for viral hepatitis, acute fatty liver of pregnancy, HELLP syndrome and obstetric cholestasis (OC)^{80,81}. Obstetric cholestasis (OC) is a pregnancy-specific liver disease, characterised by maternal pruritus and raised serum bile acids. Risk factors for OC include ethnicity, history of previous liver and/or gallbladder disease including hepatitis B and C, prior OC and multiple pregnancy. A large prospective study of has confirmed the association between severe OC and adverse perinatal outcomes including⁸². The association was maintained despite bile acid testing being non-fasting. Liver function and (non-fasting) bile acid testing is therefore recommended following the diagnosis of fetal death if there is a maternal history of pruritus.

Drug screen

Illicit drug use including amphetamine, methamphetamine, cocaine, pethidine, meperidine, hydrocodone, and tetrahydrocannabinolic acid may contribute to a range of adverse pregnancy outcomes, and use of these substances has been associated with a 2-3 fold increased risk of stillbirth⁸³. While screening for illicit substance use is not recommended as a routine investigation following stillbirth, testing should be considered where indicated on the basis of maternal history.

5.8 Alternative investigations: When permission for full autopsy is not obtained

Parents should be informed about the possibility of missing an important finding when a full autopsy is not undertaken. If permission for a full autopsy is not obtained, an external examination, X-ray (babygram) and clinical photos (as described above) are important investigations to perform^{6,84}.

Where available, Magnetic Resonance Imaging (MRI) should be offered to parents who decline an autopsy⁸⁵. MRI may be diagnostic in some cases (e.g. where intracranial abnormalities are detected)⁸⁵⁻⁸⁷. Clinicians should however explain to parents that a full autopsy remains the gold standard, as MRI does not supply tissue samples and therefore important information may be

missed. Other alternatives to a full post-mortem examination including post-mortem needle biopsy; laparoscopic autopsy, and small incision access for focussed investigation of suspected abnormalities.

Please refer to Section 4 Autopsy examination for further details on alternate investigations to autopsy.

5.9 Storage of plasma and amniotic fluid

Unexplained fetal death is currently the subject of extensive research. Storage of placental and fetal DNA, blood and amniotic fluid allows for future testing for other potential factors that are currently not identified. Even if it is not initially possible to provide an explanation as to the cause of death, parents and siblings may benefit from future research findings if material is stored appropriately. Any storage of human samples requires informed consent to be obtained.

The Stillbirth Centre of Research Excellence in Stillbirth is developing a national collaboration in placental sample storage for research purposes.

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5.13 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

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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

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Appendix Q – Suspected genetic metabolic disorders

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

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Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 6

Investigations of neonatal death

Version 3.3, August 2020

Endorsed by



SECTION 6

INVESTIGATION OF NEONATAL DEATHS

6.1 Introduction

In Australia, neonatal death is defined as the death of a live born baby within 28 days of birth. Neonatal death can be further categorised as early (within 7 days of birth) or late (after 7 completed days and before 28 completed days of birth). Post neonatal death is the death of an infant occurring after day 28 and up to one year of age¹.

Neonatal deaths can result from disorders of the neonate, placenta or mother. The majority of neonatal deaths are due to major congenital anomalies and complications of preterm birth. Due to the presence of a wide range of aetiological, clinical and geographic circumstances across the spectrum of neonatal deaths, the nature of investigations undertaken following death may vary widely. For example, the investigation of the sudden collapse and death of a newborn receiving standard hospital postnatal care will require a very different investigative approach to that of an infant born at 24 weeks gestation who eventually succumbs to the complications of prematurity after a lengthy course of neonatal intensive care.

Therefore, it is not feasible or appropriate to develop a comprehensive standardised protocol for investigation of neonatal deaths that accommodates all scenarios. Decisions regarding appropriate investigations should be made by the clinical team providing care based on the individual circumstances and accessing additional specialist expertise as required. This could include a neonatologist (even if the death occurs outside a tertiary centre), a clinical geneticist and/or a metabolic physician.

However, the importance of a high quality autopsy to accurately determine the cause of a neonatal death must be stressed. Neonatal care providers are encouraged to discuss the value of an autopsy with the parents for all neonatal deaths.

For further discussion on post-mortem examination and placental pathology please refer to Section 4; Perinatal post-mortem examination and/or Section 5; Investigation of stillbirths.

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

To view further information on the described guidelines in this section of the PSANZ PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death see *Appendices A-Q*.

6.2 Objective of this section

This section of the guideline provides a list of core investigations, based on the consensus of the Working Party, which should be undertaken at the birth of high risk newborns. Investigation of at risk neonates who subsequently die will commence shortly after birth. Investigations that may be considered in certain clinical scenarios are also provided.

For further information regarding communication with parents after a perinatal death please refer to Chapter 3 Psychological and social aspects of perinatal bereavement.

6.3 What has changed in this update?

In this update, based on the findings of an updated literature review, the recommendations have remained unchanged. We have revised the formatting and reduced duplication across the different sections of the guidelines to enhance readability.

6.4 Newborns at high risk of mortality and place of death

Newborns at high risk of mortality include those where there is:

- Extreme prematurity, either pre-viable or in grey zone of viability (≤ 24 weeks)
- Severe cardiorespiratory depression at birth, including overwhelming sepsis
- Signs consistent with congenital infection
- Severe growth restriction
- Hydrops fetalis and severe anaemia
- Lethal congenital anomalies.

A large proportion of neonatal deaths occur outside of the neonatal nurseries². Neonatal Deaths occur in a variety of settings including:

- Birth suite - predominantly in the subcategories of congenital anomaly and extreme prematurity and others with severe cardiorespiratory depression
- Babies admitted to the neonatal intensive care unit
- Postnatal ward
 - Palliative care involving parental wishes
 - Sudden unexpected death in first 48 hours
- At home - deaths after hospital discharge may be planned (palliative care) or unexpected.

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*).

6.5 Further investigations for high risk newborns at the time of birth

Further investigations at the time of birth may provide valuable information in specific situations, which are detailed below, particularly in the event of neonatal death, where consent for autopsy is not obtained.

Suspected congenital infection including birth after clinical chorioamnionitis and spontaneous preterm labour and delivery and severe cardiorespiratory depression at birth

- Maternal low vaginal/anorectal culture for Group B streptococcus (GBS) and vaginal culture for other common bacterial pathogens associated with perinatal death (e.g. E coli, Klebsiella);
- Maternal blood cultures
- Infant blood samples for haematological assessment (full blood count with nucleated red cell count), CRP, and antibody screen and;
- Baby blood taken with aseptic technique for microbiological culture (cord blood not recommended)
- Placental swab taken between amnion and chorion using aseptic technique for aerobic and anaerobic bacterial and fungal culture (ideally taken by pathologist with macroscopic placental examination)

- Placental macroscopic and histological examination (*see Appendix P – Placental histopathology reporting form*) specifically for maternal and fetal inflammatory responses; and
- If viral infection is suspected a placental biopsy should be sent for appropriate PCR or viral culture
- Maternal serology for Cytomegalovirus, Toxoplasma, Parvovirus B19, Rubella, Syphilis and Zika (if not already undertaken in this pregnancy);
- If infection suspected before birth consider amniotic fluid for multiplex PCR.

Severe fetal growth restriction

Studies to identify possible thrombophilic disorders should be considered in mothers with preeclampsia or with a personal/family history of thrombosis, or following the birth of an infant with severe growth restriction^{3,4}. These should include initial testing followed by further testing at 8-12 weeks postpartum as required (see section 5 Selective screening for thrombophilic disorders following birth of a high risk neonate or a neonatal death may be helpful in assisting parents and clinicians to understand the cause of death, plan future pregnancies and give consideration to the risks and benefits of antithrombotic therapy⁵).

Screening

Please see Section 5; Stillbirth investigations algorithm for further details of screening Section 5; Investigation of stillbirth for further discussion on Thrombophilia.

Section 6 Recommendations

- 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

Suspected major congenital anomalies

With the advances in Maternal Fetal Medicine the majority will have been investigated and diagnosed antenatally.

- Maternal serology for Cytomegalovirus, Toxoplasma, Parvovirus B19, Rubella and Syphilis (if not already undertaken in this pregnancy);
- Viral placental culture and placental biopsy for viral PCR if viral infection suspected
- Infant blood samples for haematological assessment (full blood count with nucleated red cell count), blood group, DCT and antibody screen and microbiological culture and CRP;

- Infant cord or peripheral blood sample for chromosomal analysis; microarray /karyotype
- placental histopathology to determine possible causes for growth restriction
- routine and specific clinical photographs to display dysmorphic features
- for hydropic infants blood test for Transferrin Isoforms for Carbohydrate deficient glycoprotein disorders (CDG), chromosomes, comparative genomic hybridization array
- Glycosylated Hb (HbA1C) may be indicated
- Consultation with geneticist and access to syndrome identification digital technology
- Consider investigation for genetic metabolic disorder.

Severe cardiorespiratory depression

- Maternal low vaginal/anorectal culture for GBS and vaginal culture for other common bacterial pathogens associated with perinatal death (e.g. E-coli, Klebsiella)(2);
- Maternal serology for Cytomegalovirus, Toxoplasma, Parvovirus B19, Rubella and Syphilis if not undertaken in this pregnancy;
- Infant blood samples for haematological assessment (full blood count with nucleated red cell count); CRP, blood group, DCT and antibody screen and microbiological culture;
- Placental swabs between the amnion and chorion using aseptic technique for aerobic and anaerobic bacterial and fungal cultures. (*See Appendix C – Placental examination; Accoucheur flow chart*); and
- Consider investigation for genetic metabolic disorder and blood sample for chromosomal analysis.

Birth trauma

While this has declined in high income countries over recent decades, deaths still occur particularly associated with instrumental and assisted deliveries. Acquired prepartum lesions rarely cause the infant to have a low Apgar score. The exception is severe damage to the brainstem and basal ganglia. Traumatic injury to the brain is most commonly subdural haemorrhage.

Careful autopsy, particularly of the neck and paravertebral tissues, spinal cord, brainstem and nerve roots is important when trauma is suspected.

These NNDs usually necessitate escalated enquiry such as Root Cause Analysis and/or Coronal investigation.

Macroscopic infant

The increased risk of perinatal morbidity and mortality with maternal diabetes is well known^{6,7}. As universal screening for diabetes is not currently implemented throughout Australia and New Zealand it is essential that the possibility of undiagnosed maternal diabetes is excluded; HbA1C monitors glycaemia over the previous 3 months by reflecting the average glucose concentration over the life of the red cells.

If there is no clear maternal diabetic history, other causes of macrosomia such as Beckwith Wiedemann syndrome with close examination for syndromic features and placental changes should be considered.

Section 6 Recommendations

- 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.

Suspected genetic metabolic disorders

To ensure a precise diagnosis, peri mortem evaluation of infants suspected of genetic metabolic disorders is required. Parental consent needed for post-mortem examinations and for any tissue and blood samples taken prior to death. Clinicians need to counsel parents sensitively about the importance of an accurate diagnosis for future genetic risks in this very distressing time. Metabolic disease may cause a baby to be both weak and floppy and respiratory failure at birth or shortly afterwards and should be investigated for peroxisomal disorders, non-ketotic hyperglycinaemia, lipid and storage disorders and mitochondrial disease

Due to the complexity and number of different possible diseases, it is strongly recommended that clinicians discuss each individual case with the State Laboratory to identify the optimum tests to request. Should more expert guidance be required a clinical metabolic specialist should be consulted.

Peri-mortem investigation by the clinician should include the following:

Christodoulou and Wilcken⁸ highlight the need for an increased index of suspicion for genetic metabolic disorders (inborn errors of metabolism) in neonatal cases. The authors describe predominant clinical or biochemical presentations of genetic metabolic disorders in the neonatal period and recommend a protocol for screening for these disorders and also for a genetic autopsy.

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

The predominant clinical or biochemical presentations of genetic metabolic disorders are as follows: acute encephalopathy: hypoglycaemia, hyperammonaemia, ketosis, disorders of acid-base balance, seizures as an early predominant feature; acute hepatocellular disease; sudden death; severe hypotonia; non-immune hydrops fetalis; facial dysmorphism, with or without congenital malformations⁸.

Please see Appendix C – Placental examination; Accoucheur flow chart and Appendix H – Instructions on taking clinical photographs.

Section 6 Recommendations

- 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).

6.5.1 Sudden unexpected neonatal collapse in the first weeks of life

The sudden unexpected death of a neonate requires comprehensive investigation as to the cause of the death. Although, Sudden Infant Death Syndrome (SIDS) is rare in the neonatal period since implementation of Back to Sleep campaigns, there has been a proportionate increase in the number of cases occurring at less than one month of age^{8,9}. It is important that all unexpected deaths are investigated fully prior to designation to the category of SIDS and the role of infection/inflammation examined¹⁰. Based on epidemiological and population characteristics classification of these deaths is incorporated into the PSANZ classification systems^{11,12}. The classification includes a category for unclassified sudden death where no cause for the death was identified and where inadequate investigation was undertaken. Classification of deaths into this category will hopefully decrease in number with appropriate investigations ensuring that a diagnosis is found in most cases.

The Royal College of Pathologists and The Royal College of Paediatrics and Child Health have published a comprehensive protocol for care and investigation for sudden unexpected deaths in infancy. Please refer to this document for further details¹³.

For further details on the classification of SIDS, please refer to Section 7 Perinatal death classifications.

Section 6 Recommendations

- 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.
-

6.6 Alternative investigations: When permission for autopsy not obtained

If permission for an autopsy is not obtained, an external examination, detailed ultrasound of the infant, babygram, and clinical photos (as described above) are important tests to perform. Other alternatives to a full post-mortem examination including Post-mortem needle biopsy; laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected anomalies.

Magnetic Resonance Imaging (if available) may be offered to parents who decline an autopsy investigation. Clinicians should however explain to the parents that a full autopsy remains the gold standard as the MRI does not supply tissue samples and therefore important information may be missed MRI should only be offered when available and if radiologists experienced in reporting post mortem MRIs. Parents should be informed about the possibility of missing an important finding when an autopsy is not undertaken.

Please refer to Section 4; Perinatal postmortem examination for further details on alternate investigations to autopsy

6.7 References

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6.8 Section authors

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6.9 Acknowledgements

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6.10 Appendices

Appendix A – Stillbirth investigations algorithm

Appendix C – Placental examination; Accoucheur flow chart

Appendix D – Clinical examination of baby checklist

Appendix H – Instructions on taking clinical photographs

Appendix P – Placental histopathology reporting form

Appendix R – Screening for genetic metabolic disorders

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

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 7

The PSANZ classification system for stillbirths and neonatal deaths

Version 4.3, August 2020

Endorsed by



SECTION 7

THE PSANZ CLASSIFICATION SYSTEM FOR STILLBIRTHS AND NEONATAL DEATHS

7.1 Introduction

This section of the Perinatal Society of Australia and New Zealand (PSANZ) Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death presents the third revision of the PSANZ Classification System for causes of stillbirths and neonatal deaths. The system was first released in May 2003.

Accurate classification of the causes of the stillbirths and neonatal deaths is the cornerstone of prevention and the ability to compare causes of death across and within countries is key to this effort. The main driver for the PSANZ system is the limitations of the International Classification of Disease (ICD) for classifying perinatal deaths¹⁻³. This has also been the case globally, with over 80 disparate systems recently identified, none of which appear optimal³. The new adaptation of ICD 10 by WHO – ICD for perinatal mortality (ICD-PM)⁴, which is recommended for use as part of perinatal mortality audit, holds promise for consistent global reporting of causes of perinatal deaths. Initial piloting of ICD-PM has highlighted important areas for improvement when ICD is next updated⁵. The ICD-PM uses ICD rules based only on death certificate data⁴ and classifies the underlying cause of perinatal death. In Australia, death certificate reporting of causes of perinatal deaths (particularly stillbirths) is often inaccurate and overestimates the proportion of unexplained up to 50%⁶. This inaccuracy is partly a systems issue in that the mandated timing of completion of the death certificate precedes results of investigations, including autopsy, becoming available and also the lack of supervision and training in completion.

Until further enhancements are made to the ICD system, the PSANZ Classification System for Stillbirths and Neonatal deaths is recommended as the primary system for causes of perinatal deaths in Australian and New Zealand (ANZ). However, in order to facilitate global comparisons and to inform future improvements to ICD-PM, simultaneous application of ICD-PM and the PSANZ system or later mapping from PSANZ to ICD-PM is optimal. The ICD-PM (as for the PSANZ system) should be based on the findings of adequate investigation into the causes of death including committee review of the death (see Section 2 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death).

The PSANZ system has been shown to perform well against other systems^{3,7}. In a recent evaluation of global classification systems for perinatal deaths against expert consensus of a quality system, some limitations were identified including the need for better definitions and rules. In this update, an attempt has been made to address these limitations. Accurate classification of stillbirths and neonatal deaths is only possible following adequate investigation and review of the clinical circumstances of the death and is an integral part of high quality perinatal mortality audit.

The standardised perinatal mortality data collection forms for New Zealand (*see Appendix F – New Zealand rapid reporting form for a perinatal death – baby* and *Appendix G – New Zealand rapid reporting form for a perinatal death – mother*) and for Australia (The Australian Perinatal Mortality Audit Tool (*see Appendix E – Australian perinatal mortality audit tool*)) should be completed by the hospital perinatal committees to enhance the quality of classification of death.

For a history on the development of the PSANZ PDC and a summary of the changes made to the system since its inception please refer to *Appendix V – Development of PSANZ Perinatal Death Classification and PSANZ Neonatal Death Classification*.

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

7.2 Principles, structure and performance indicators

Principles

The key principles of the PSANZ system are:

- To identify an underlying cause of death for stillbirths and neonatal deaths
- To identify up to two associated conditions for stillbirths and neonatal deaths
- To enable reporting by ICD-PM through identifying timing of death and mapping of categories to ICD-PM.

Including the assigned PSANZ system category codes as part of routinely collected individual birth record data across ANZ jurisdictions will enable reporting by timing of death (ante partum, intrapartum, early and late neonatal deaths or timing of death unknown) and also allows more detailed analyses by demographic and clinical factors to aid identify where attention is most needed.

Structure

The PSANZ System for stillbirths and neonatal deaths consists of two main sets of conditions (categories) and one set of associated conditions (contributory).

The two main category grouping are: 1) The Perinatal Death Classification (PDC) which includes maternal/fetal causes of stillbirths and neonatal deaths; and 2) The Neonatal Death Classification (NDC) including neonatal causes of death.

The PSANZ Associated Conditions list includes both the PDC and NDC categories plus other associated factors e.g. maternal risk factors and placental pathologies.

Performance indicators

Evaluation of the PSANZ system is being planned including the following measures of success:

- 10% or less deaths classified as *Other unspecified*
- 20% or less stillbirths classified as *Unexplained* with full investigation
- Ease of use by clinicians
- Valued by end-users
- Good to excellent agreement between classifiers assigned within the major categories
- Good alignment with ICD-PM

7.3 Objective of this section

The main objective of section 7 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to present the PSANZ system for stillbirths and neonatal deaths and to provide detailed instructions for use to ensure consistent and comprehensive data on the underlying causes and associated conditions of stillbirths and neonatal deaths across Australia and New Zealand.

7.4 What has changed in this update?

In this update, changes have been made to categories based on new knowledge around the causes of perinatal death and to address deficiencies identified in a recent evaluation⁸.

The PSANZ system no longer uses a hierarchical approach between categories but rather employs rules around common scenarios when multiple factors are involved. This is to ensure consistency with the ICD principles of identifying an underlying cause of death.

Improvements in classification of placental pathology have been made although limitations remain and further research and consistency with reporting are needed to better define placental categories⁹. The 'Unexplained Antepartum Stillbirth' category now excludes stillbirths as a result of placental insufficiency and identifies those which were inadequately investigated. Placental pathology is now identified in more detail as Category 9 Placental dysfunction, replacing the previous category of 'Fetal Growth Restriction' (FGR). If present, FGR is now classified as an associated condition. The list of associated conditions has been expanded to include placental pathology thought to be contributory but not causal. Congenital anomalies have been updated to include more detail on chromosome and genetic conditions in line with advances in prenatal testing, and to align categories with *ICD-10 version 2016 Chapter XVII Congenital malformations, deformations and chromosomal abnormalities* (<http://apps.who.int/classifications/icd10/browse/2016/en#/XVII>).

The subcategories on the duration of membrane rupture (MR) in Category 10 Spontaneous preterm have been removed and a subcategory to identify cervical shortening preceding MR has been added. The Congenital anomaly category (Category 1) has been revised to acknowledge developments in genetic testing. Lastly, a new category (Category 6) to capture complications of multiple pregnancy.

The PSANZ Associated Conditions list includes both the PDC and NDC categories plus other associated factors e.g. maternal risk factors and placental pathologies.

As with other sections of this guideline, the formatting has been revised to enhance readability and reduce duplication across the different sections of the guideline. Please refer to *Appendix U – Changes on this version of the classifications system* to see a full list of changes in this revision.

Section 7 Recommendations for all perinatal deaths

- 1 All stillbirths and neonatal deaths should be classified according to the PSANZ classification system to identify a single underlying cause of death for both stillbirths and neonatal deaths and up to two associated factors which contributed to the death.
- 2 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.
- 3 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)
- 4 Following application of the PSANZ system, mapping to ICD-PM categories should be undertaken to enable high quality global reporting. This will often require alteration to the cause of death on the perinatal death certificate.

7.5 Purpose of the PSANZ System

The purpose of the PSANZ Perinatal Death Classification System is to ensure comprehensive and consistent data on causes and associated conditions for stillbirths and neonatal deaths across Australia and New Zealand to enable benchmarking and monitoring of causes of death to inform policy, practice and research, to help parents understand why the death occurred and to assist in future pregnancy planning.

7.6 General rules for applying the PSANZ PDC System

Classification of underlying cause and associated conditions

In accordance with ICD-PM, the PSANZ Classification System identifies a single underlying cause of death for stillbirths and neonatal deaths as well as the presence of associated conditions. For all stillbirths and neonatal deaths a maternal/fetal condition according to the PDC is assigned and, in addition for neonatal deaths, the underlying neonatal condition which caused the death is assigned according to the NDC. Therefore, for neonatal deaths the PSANZ system at least two conditions are assigned; the neonatal condition which resulted in the death and a maternal/fetal condition (according to the PDC). If no maternal/fetal condition is identified the classification category of “no obstetric antecedent” is applied.

Definitions

Underlying cause of death: According to ICD

“the disease or injury which initiated the train of morbid events leading directly to a person's death or the circumstances of the accident or violence which produced the fatal injury, as represented by a code¹⁰”

Associated conditions are defined as conditions which were considered to have contributed to the death but are not considered to be the main underlying cause. Conditions which were present but not considered to be contributory are not classified as associated conditions.

Please refer to the PSANZ Associated Conditions list (see page 35).

Classification of terminations of pregnancy

All terminations of pregnancy are identified by the inclusion of an “009” for two-digit codes and a “09” for the three digit codes and “9” for four digit codes i.e. 1.1 becomes 1.1009; 1.83 becomes 1.8309; 6.111 becomes 6.1119. This includes induction of labour without expectation of fetal survival e.g. in the case of severe pre-eclampsia at pre-viable gestations, or prolonged premature rupture of membranes with severe infection.

Classification numbering approach

As far as possible, the subcategory .8 has been used for ‘Other conditions’ and .9 for ‘Unspecified conditions’ within its category, as has been the case in the ICD classification.

If data are entered with a decimal point, a subcategory such as ‘Structural anomaly’ (Category 1, *Congenital Anomaly*) would be 1.1, but as a 4 digit numeric would be 0110. Similarly subcategory ‘Group B Streptococcus’ (Category 2, *Perinatal Infection*) would be 2.11 or 0211.

Inclusion in routine perinatal data collections at the individual case record level

It is recommended that PSANZ classification codes are included within routine perinatal data collections in each region for every perinatal death to enable disaggregation to better identify areas to focus prevention e.g. by Indigenous and socioeconomic status and other risk factors, and timing of death. The ability to analyse causes of perinatal deaths by timing of death (i.e. antepartum, intrapartum, neonatal, or unknown) is consistent with ICD-PM rules.

Reporting according to ICD-PM

Reporting by ICD-PM system enables international comparisons and should be based on the causes of perinatal deaths following thorough investigation and perinatal mortality committee review. Following application of the PSANZ classification system to stillbirths and neonatal deaths, mapping of the categories to ICD-PM should be undertaken for global reporting requirements. Jurisdictions may wish to classify according to ICD-PM simultaneously with the PSANZ system to assist in global reporting and to inform future improvements in classification.

7.7 PSANZ-PDC Classification including rules and definitions

1 Congenital anomaly

- 1.1 Structural anomaly
 - 1.11 Nervous system
 - 1.12 Cardiovascular system
 - 1.13 Genitourinary system
 - 1.14 Gastrointestinal system
 - 1.15 Musculoskeletal
 - 1.151 Congenital diaphragmatic hernia
 - 1.152 Gastroschisis/omphalocele
 - 1.16 Respiratory system (include congenital pulmonary airway malformation (CPAM))
 - 1.17 Haematological
 - 1.18 Multiple Congenital anomaly (no chromosomal/genetic cause or not tested)
 - 1.19 Other congenital abnormality
 - 1.192 Idiopathic hydrops fetalis
 - 1.193 Fetal tumour (include sacro-coccygeal teratoma)
 - 1.198 Other specified
 - 1.199 Congenital anomaly, unspecified
- 1.2 Chromosomal anomaly
 - 1.21 Down syndrome (trisomy 21)
 - 1.22 Edward syndrome and Patau syndrome (trisomy 18, trisomy 13)
 - 1.23 Other trisomies and partial trisomies of the autosomes, not elsewhere classified (includes pathogenic duplications, unbalanced translocations and insertions)
 - 1.24 Monosomies and deletions from the autosomes, not elsewhere classified (includes pathogenic deletions e.g. 22q11.2 deletion syndrome (diGeorge syndrome), Wolff-Hirschorn syndrome, Cri-du-chat syndrome)
 - 1.25 Turner syndrome (monosomy X)
 - 1.26 Other sex chromosome abnormalities (e.g. Klinefelter syndrome)
 - 1.28 Other chromosomal abnormalities, not elsewhere specified (includes Fragile X syndrome, imprinting syndromes, triploidy)
 - 1.29 Unspecified
- 1.3 Genetic anomaly
 - 1.31 Genetic condition, specified (includes inborn errors of metabolism e.g. Tay-Sachs disease;)
 - 1.32 Syndrome/association with demonstrated chromosomal/gene anomaly
 - 1.39 Genetic condition, unspecified

Definitions and Rules:

This category includes deaths in which a major congenital anomaly, whether structural or chromosomal, is considered to have been the reason for the death. All categories correspond to the ICD10 numbering in Chapter XVII Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99) as presented in ICD-PM¹¹

If termination of pregnancy was undertaken as a result of the anomaly include the digit "09" at the end the numerical classification e.g. Termination of Trisomy 21 (Down Syndrome) 1.2109. All terminations of pregnancy for congenital anomalies regardless of the causal link to perinatal death are also classified here. With mapping to ICD coding, non-lethal abnormalities may be identified.

Chromosomal and genetic testing are categorised separately, in recognition of advances in prenatal screening and testing. The scope of genetic testing is widening to include some conditions that may not manifest with structural anomalies in the prenatal period (e.g. Fragile X syndrome). If there is both a chromosomal/genetic and structural abnormality, code for the chromosome or genetic condition with the structural condition as an associated condition. Results of genetic testing of unknown significance are captured under associated conditions.

The chromosomal abnormality category excludes deaths where molecular karyotyping identifies an anomaly which is not thought to be causal. Findings of genetic testing of unknown significance (variations of uncertain or unknown significance, VUS) are classified as associated conditions. Where there is both a chromosomal and a structural abnormality, classify according to the chromosome abnormality with the structural abnormality as an associated condition.

Specific examples:

Down syndrome (Trisomy 21) is classified as a Chromosome abnormality (Down syndrome 1.21). If a cardiac anomaly is also present, this would be an associated condition (1.12 cardiovascular system).

Vater and *Vacterl* are 1.18 Congenital malformations affecting multiple systems, specified. For syndromes where DNA testing is available and has been confirmed for VATER or CHARGE association classify as genetic condition 1.31, specified.

Hydrops Fetalis: Antibody related hydrops (Immune Hydrops) e.g. Rhesus or Kell incompatibility and Bart's haemoglobinopathy (alpha thalassemia) is coded under as 1.17.

Non immune hydrops if due to chromosomal/genetic anomalies, classify under 1.2 and appropriate sub-classification, e.g. 1.25 Turner syndrome.

Idiopathic hydrops fetalis as 1.192 Other specific congenital anomaly, hydrops fetalis, idiopathic.

If the hydrops is secondary to underlying structural pathology e.g. congenital heart abnormality, neuromuscular disorders, skeletal dysplasia (achondrogenesis) or infection—classify in appropriate systems.

Hydrops associated with monochorionic twins classify under 6.1 category.

Multiple anomalies: Where the multiple anomalies are a part of a chromosomal anomaly found in the decedent, e.g. cleft lip and palate with heart defect as in velocardiofacial syndrome associated with 22q11 deletion, they should be classified under Category 1.2 but only if chromosome testing confirms deletion.

Anterior wall defects: Omphalocele (exomphalos), gastroschisis, and congenital diaphragmatic hernia are now classified under musculoskeletal anomalies (Category 1.15), in line with ICD10-PM.

If omphalocele is an isolated anomaly classify 1.15; if associated with multiple structural anomalies classify as 1.18; if associated with aneuploidy e.g. trisomy 18, classify as 1.22.

Acquired CNS anomalies: Infection-related abnormalities should be classified under Category 2, e.g. microcephaly/hydrocephaly secondary to CMV or toxoplasma infections should be classified as Category 2.21 and 2.3 respectively.

Congenital intracranial haemorrhage/injury may be classified as Category 7.5 *Fetal antenatal intracranial injury*.

Disruptions due to amniotic band disruption sequence may cause extensive asymmetric injury to the cranium and brain. It may also present as anencephaly or encephalocele. Classify under Category 7.5 *Fetal antenatal intracranial injury* but if due to alloimmune thrombocytopenia Code as 1.17 Haematological.

Neuromuscular disorders: Classify under 1.11. These are a complex group that may include primary muscle anomalies, CNS anomalies – both acquired and primary - and metabolic abnormalities. Some are syndromic with recognised recurrence risk. Associated anomalies may include pulmonary hypoplasia, hydrops and cleft palate. The cause of death may have been respiratory failure but the death should be classified as the underlying abnormality.

If the underlying aetiology is known classify accordingly – e.g. *Fetal antenatal intracranial injury* Category 7.5.

Unspecified Congenital Abnormalities: Category 1.19 *Congenital anomaly, unspecified* covers those cases where an abnormality was stated as the cause but where insufficient information was available to classify under other categories.

2 Perinatal infection

- 2.1 Bacterial
 - 2.11 Group B Streptococcus
 - 2.12 E coli
 - 2.13 Listeria monocytogenes
 - 2.14 Spirochaetal e.g. Syphilis
 - 2.18 Other bacterial
 - 2.19 Unspecified bacterial
- 2.2 Viral
 - 2.21 Cytomegalovirus
 - 2.22 Parvovirus
 - 2.23 Herpes simplex virus
 - 2.24 Rubella virus
 - 2.25 Zika virus
 - 2.28 Other viral
 - 2.29 Unspecified viral
- 2.3 Protozoal e.g. Toxoplasma
- 2.5 Fungal
- 2.8 Other specified organism
- 2.9 Other unspecified organism

Definitions and Rules

In order to qualify for this category, there must be evidence of fetal or neonatal infection as in Table 1. Determination of perinatal infection.

This category aims to identify all perinatal deaths due to infection as the primary cause including perinatal deaths with infection following spontaneous preterm labour or rupture of the membranes. Deaths in preterm infants following spontaneous rupture of the membranes or labour not fulfilling the definition of infection should be classified under Category 10 *Spontaneous Preterm*.

Category 2.8 *Other specified organism* includes deaths due to other identified organisms other than those in Categories 2.1 to 2.5. Category 2.9 *Other unspecified organism* includes cases where there is an obvious infection however the organism was either not identified or not specified.

Examples:

Classify here: Prelabour rupture of the membranes at term, with birth following 24 hours of membrane rupture, neonatal pneumonia identified within 48 hours of birth, subsequent neonatal death, group B Streptococcus identified on vaginal and placental cultures. Classify as subcategory 2.11 Group B Streptococcus and PSANZ-NDC subcategory 4.13.

Classify here: Spontaneous rupture of membranes preterm followed by spontaneous labour at 26 weeks and stillbirth. Membranes were ruptured for 12 hours prior to birth. Fetal pneumonia was detected at autopsy and growth of E Coli from the lungs. Placental pathology showed chorioamnionitis and funisitis. Classify 2.12 with an associated condition as Category 10.11 *Spontaneous preterm, with chorioamnionitis on placental histopathology*.

Classify here: Spontaneous rupture of the membranes at 24 weeks gestation. Clinical chorioamnionitis ensued after 6 days of membrane rupture. Induction of labour was undertaken resulting in birth of a liveborn infant. Birthweight was 650gms. Active resuscitation was unsuccessful. No autopsy or placental pathology was undertaken. Classify as Category 2.11 with an associated category of Spontaneous preterm Category 10.13 and PSANZ-NDC unspecified congenital infection 4.19 with an associated classification of NDC 2.2 *Extreme prematurity – Unsuccessful resuscitation*.

Classify here: Spontaneous rupture of membranes at 14 weeks, with severe chorioamnionitis at 22 weeks. Labour was induced (with a live baby) and the baby was born without signs of life, the birthweight was 350gms. Autopsy findings of *E.coli* growth from lung fluid. Placental histopathology showed chorioamnionitis and funisitis. Classify as Category 2.1209.

Do not classify here: Spontaneous rupture of membranes at 21 weeks, with spontaneous onset of labour and birth at 22 weeks gestation. Baby was born without signs of life with a birthweight was 450gms No autopsy was undertaken. Placental histopathology showed chorioamnionitis (no funisitis), no organism was grown. Classify as Category 10.11

Do not classify here: Neonatal death from late onset (≥ 48 hrs of age) Group B Streptococcal disease in a term infant. Classify under Category 12. *Neonatal death with no obstetric antecedent factor* and PSANZ-NDC as 4.4. The organism involved (GBS) may be classified as an associated condition under NDC associated factors using Category 2 sub classifications as a pragmatic way of collecting organisms in acquired infection. Alternately (and more appropriately), the organism should be included in a minimum dataset for all perinatal deaths

Death type	Criteria for Perinatal and Acquired Infection category
Fetal	1. Histological confirmation of inflammation in cord (funisitis) or fetus (pneumonitis or pneumonia) with or without microbiological evidence of infection or 2a. Convincing clinical evidence of primary maternal infection and 2b. Positive culture of a pathogen from mother or placenta (specimen taken aseptically between amnion and chorion)
Neonatal	<p>A. Congenital Early onset infection (within 48 hours of birth), defined as:</p> <ol style="list-style-type: none"> 1. Clinical signs in neonate consistent with sepsis and 2. Haematological changes consistent with sepsis and one or more of the following: <ol style="list-style-type: none"> 3a. Positive culture of a pathogen (bacterial or viral) from the neonate or 3b. Pathological evidence at autopsy or 3c. Positive serology or 3d. Positive culture of a pathogen from the mother or the placenta or 3e. Pneumonia without specified bacterial or viral pathogens <p>NB: Some congenital viral infections may have onset later than 48 hours after birth</p> <p>B. Acquired Onset of infection at 48 hours or later, with criteria as above, but excluding 3d</p>

Table 1. Determination of perinatal infection

3 Hypertension

- 3.1 Chronic hypertension: essential
- 3.2 Chronic hypertension: secondary, e.g. renal disease
- 3.3 Chronic hypertension: unspecified
- 3.4 Gestational hypertension
- 3.5 Pre-eclampsia
- 3.6 Pre-eclampsia superimposed on chronic hypertension
- 3.9 Unspecified hypertension

Definitions

The classification of *Hypertension* follows that of the Society of Obstetric Medicine of Australia and New Zealand¹² with the exceptions that unspecified subcategories have been included. The definitions are as follows:

Hypertension is diagnosed when the systolic blood pressure is ≥ 140 mm Hg and /or diastolic blood pressure (Korotkoff V) is ≥ 90 mm Hg. These blood pressures should be confirmed by repeated readings over several hours in a clinic or day assessment unit or after rest in hospital.

Gestational hypertension is defined as hypertension arising in pregnancy after 20 weeks gestation without any other feature of the multisystem disorder pre-eclampsia and which resolves within 3 months postpartum.

Pre-eclampsia may be defined as hypertension arising after 20 weeks gestation and the onset after 20 weeks gestation of one or more of: proteinuria, renal insufficiency, liver disease, neurological problems, haematological disturbances, fetal growth restriction. The hypertension will have returned to normal within 3 months postpartum.

Rules

This category includes deaths where the hypertensive disorder is considered the factor initiating the chain of events leading to the death. If placental abruption complicates a hypertensive disorder, the death is classified here, as the abruption is attributed to the hypertensive disorder. Specific placental pathology can be coded as associated conditions (see PSANZ-SB&ND Associated conditions list page 34)

This category excludes the circumstance when the hypertension is secondary to an underlying systemic disorder, e.g. Diabetes, where this is severe and uncontrolled (in which case, classify as subcategory 5.2 *Diabetes*, under *Maternal Conditions*). However, if the systemic disorder such as diabetes or gestational diabetes is mild or well controlled, and the death appeared to be due to hypertension or its complications, classify in this category. This category also includes hypertension secondary to renal disease as this often presents first with hypertension.

4 Antepartum haemorrhage (APH)

- 4.1 Placental abruption
- 4.2 Placenta praevia
- 4.3 Vasa praevia
- 4.9 APH of undetermined origin

Definitions

Placental abruption: The diagnosis of placental abruption is made clinically. Confirmation by evaluation of the placenta after delivery is not essential for assigning the death to abruption. Clinically features are classically with vaginal bleeding (although the bleeding may be concealed), abdominal pain, uterine contractions and tenderness¹³.

Placenta praevia: Placenta praevia is defined as a placenta that lies wholly or partly within the lower uterine segment diagnosed on ultrasound¹³. With improved diagnosis and management stillbirth as a result of bleeding for placenta praevia is now rare.

Vasa praevia: Vasa praevia is the presence of unsupported fetal vessels below the fetal presenting part, where the cord insertion is velamentous¹³. Classically, vaginal bleeding following amniotomy with subsequent fetal bradycardia suggests vasa praevia. The diagnosis of vasa praevia can be confirmed by Doppler and endovaginal ultrasound studies if aberrant vessels over the internal cervical os are suspected¹³.

APH of undetermined origin: This category is used where insufficient information is available on the reason for the bleeding. However, there is convincing clinical evidence that the stillbirth was as a result of the bleeding¹³.

Rules

This category includes all perinatal deaths where the primary factor leading to the death was an APH.

Convincing clinical signs of abruption alone is sufficient to assign the category of 4.1 Abruption. If abruption occurs as a complication of a hypertensive disorder, the death is attributed to the hypertensive disorder (Category 3) with Category 4.1 Placental abruption as an associated condition. Other placental pathology thought to be contributory may also be classified under associated conditions Category 9.

Examples:

Classify here: A woman presents at 38 weeks' gestation with abdominal pain, tense abdomen and uterine contractions and a fetal death diagnosed. Placental macroscopic examination showed a large adhesive clot however placental histopathology was inconclusive. Classify as 4.1 Placental abruption.

5 Maternal Conditions

- 5.1 Termination of pregnancy for maternal psychosocial indications
- 5.2 Diabetes
 - 5.21 Gestational diabetes
 - 5.22 Pre-existing diabetes
- 5.3 Maternal injury
 - 5.31 Accidental
 - 5.32 Non-accidental
- 5.4 Maternal sepsis
- 5.5 Antiphospholipid syndrome
- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions
 - 5.81 Maternal suicide
 - 5.88 Other specified maternal medical or surgical conditions

Definitions and Rules

Category 5 includes perinatal deaths attributed to any medical or surgical condition in the mother, or to its complications or treatment, excluding conditions elsewhere classified i.e. APH, hypertension. The subcategory 5.1 excludes terminations of pregnancy undertaken for medical indication including congenital and other complications (e.g. prolonged preterm rupture of membranes (PPROM) with severe infection) where a pregnancy is terminated and the fetus is not expected to survive. In this scenario the death is classified under the specific condition including termination of pregnancy due to a congenital anomaly (classified under Congenital Anomaly, Category 1) and other conditions such as severe chorioamnionitis following preterm rupture of the membranes at 20 weeks (classify 10.1 Spontaneous preterm); adding the coding number “9” to identify termination as described under “General rules for applying the PSANZ PDC System” on page 4.

Renal disease is not included as a separate subcategory here, but under Hypertension, subcategory 3.2, as it usually presents first as hypertension. Maternal conditions should only be attributed here if there is a high probability that they were the cause of death, e.g. a well-documented history of lupus obstetric syndrome with a previous stillbirth. Maternal substance use or smoking may be classified as an associated condition if there is a significant history (including alcohol, cocaine, and marijuana) and where it is reasonable to assume that the fetal or neonatal death may be linked.

Examples:

Classify here: Fetal death as a result of severe uncontrolled Type I Diabetes with mild pre-eclampsia classify as subcategory 5.22 with an associated condition of Hypertension, Category 3.5.

6 Complications of multiple pregnancy

- 6.1 Monochorionic twins
 - 6.11 Twin to twin transfusion syndrome (TTTS)
 - 6.12 Selective fetal growth restriction (FGR) (i.e. affecting only one twin)
 - 6.13 Monoamniotic twins (including cord entanglement)
 - 6.18 Other
 - 6.19 Unknown or unspecified
- 6.2 Dichorionic twins
 - 6.21 Early fetal death in a multiple pregnancy (<20 weeks gestation)
 - 6.22 Selective fetal growth restriction (FGR)
 - 6.28 Other
 - 6.29 Unknown or unspecified
- 6.3 Complications of higher order multiples (3 or more fetuses)
 - 6.31 Twin to twin transfusion syndrome (TTTS)
 - 6.32 Selective fetal growth restriction (FGR)
 - 6.33 Monoamniotic multiples (including cord entanglement)
 - 6.34 Early fetal death in a multiple pregnancy (<20 weeks gestation)
 - 6.38 Other
 - 6.39 Unknown or unspecified
- 6.4 Complications where chorionicity is unknown
- 6.8 Other
- 6.9 Unspecified

Rules

For 6.12, 6.22 and 6.32 read Explanatory Notes under Associated Condition, Section 15, Fetal Growth Restriction.

Where one of the twins (or multiples) is growth restricted as a result of twin to twin transfusion syndrome, classify as 6.11, 6.31 and not 6.12 or 6.32 respectively. Where one or more of the twins (or multiples) is growth restricted from a known underlying cause, classify elsewhere as appropriate, e.g. classify under Category 9 if there is placental disease in one of dichorionic twins.

7 Specific perinatal conditions

- 7.1 Fetomaternal haemorrhage
- 7.2 Antepartum cord or fetal vessel complications (excludes monochorionic twins or higher order multiples)
 - 7.21 Cord vessel haemorrhage
 - 7.22 Cord occlusion (True knot with evidence of occlusion or other)
 - 7.28 Other cord complications
 - 7.29 Unspecified cord complications
- 7.3 Uterine abnormalities
 - 7.31 Developmental anatomical abnormalities (e.g. bicornuate uterus)
 - 7.38 Other
 - 7.39 Unspecified
- 7.4 Alloimmune disease
 - 7.41 Rhesus isoimmunisation
 - 7.42 Other red cell antibody
 - 7.43 Alloimmune thrombocytopenia
 - 7.48 Other
 - 7.49 Unspecified
- 7.5 Fetal antenatal intracranial injury
 - 7.51 Subdural haematoma
 - 7.52 Fetal antenatal ischaemic brain injury
 - 7.53 Fetal antenatal haemorrhagic brain injury
- 7.6 Other specific perinatal conditions
 - 7.61 Complications of antenatal, diagnostic or therapeutic procedures:
 - 7.611 Complications of prenatal diagnostic procedures (e.g. amniocentesis, chorionic villus sampling,) (e.g. rupture of membranes after amniocentesis)
 - 7.612 Complications of fetal ultrasound guided needle interventions (e.g. FBS/fetal transfusion, thoracocentesis, vesicocentesis, fetal cardiac valvoplasty, division of amniotic bands, fetal skin biopsy, unipolar/bipolar diathermy, RFA procedures)
 - 7.613 Complications of fetal shunt interventions (e.g. pleuroamniotic shunt, vesicoamniotic shunt)
 - 7.614 Complications of minimally invasive fetoscopic interventions (e.g. fetoscopic laser surgery for TTTS, FETO for CDH, laser ablation of posterior urethral valves)
 - 7.615 Complications of open maternal fetal surgery (e.g. open maternal fetal surgery for spina bifida)
 - 7.618 Other
 - 7.62 Termination of pregnancy for suspected but unconfirmed congenital anomaly
 - 7.63 Amniotic band
 - 7.68 Other
- 7.9 Unspecified

Definitions

Category 7.22 Cord occlusion: A cord knot is where the cord becomes tangled with itself (or another cord in a multiple pregnancy) such that the vessels of the cord may be compromised. To be considered significant there should be evidence of congestion or haemorrhage in the cord, and/or changes in the placenta such as fetal vessel thrombosis or villous oedema to suggest vascular compromise. A knot could cause death without these changes but not every knot causes fetal compromise and therefore should not be accepted as a cause of death without further evidence as above, or strong clinical suspicion by the delivering clinician based on CTG or other changes during delivery. Cord accidents usually only account for a few percent of perinatal deaths.

Other cord compression: For stillbirths, and also neonatal deaths as a result of hypoxic ischaemic encephalopathy (HIE), where the cord is found to be tightly around neck or body with skin blanching (indicating significant cord compression) classify as 7.28.

Category 7.21 includes cord haemorrhage following cordocentesis, umbilical cord ulceration leading to cord haemorrhage, and torn velamentous vessels.

Rules

This category includes deaths in which the specific perinatal condition present was thought to be the cause of death. The category excludes perinatal deaths with a major congenital anomaly. Cord complications during labour and other complications of twins e.g. head entrapment in labour should be categorised under *Hypoxic Peripartum Death*, subcategory 8.18.

Examples:

Do not classify here: Spontaneous prelabour rupture of membranes (ROM) at 33 weeks, with immediate cord prolapse and fetal death. Categorise as Spontaneous Preterm Category 10 as the cord complication occurred as a result of the preterm ROM. Cord prolapse is classified as an associated condition.

8 Hypoxic peripartum death

- 8.1 With intrapartum complications (sentinel events)
 - 8.11 Uterine rupture
 - 8.12 Cord prolapse
 - 8.13 Shoulder dystocia
 - 8.14 Complications of breech presentation
 - 8.15 Birth trauma
 - 8.16 Intrapartum haemorrhage
 - 8.18 Other
- 8.2 Evidence of significant fetal compromise (excluding other complications)
- 8.3 No intrapartum complications and no evidence of significant fetal compromise identified
- 8.9 Unspecified hypoxic peripartum death

Definitions and rules

This category includes both intrapartum fetal deaths and neonatal deaths as a result of acute or chronic hypoxia in babies without major congenital anomalies or other major conditions such as antepartum haemorrhage at a gestation in which survival in the context of the birth would be expected (typically of >28 weeks gestation or >1000g birthweight). If placental pathology is identified which resulted in fetal compromise and death then classify under the relevant category i.e. Category 9 Placental pathology or Category 4 Antepartum haemorrhage.

Where intrapartum fetal death or neonatal death occurs following preterm spontaneous onset of labour or rupture of membranes which fulfils the definition of Infection then classify under Category 2. If not fulfilling the criteria for infection and less than 24 weeks then classify under Category 10 *Spontaneous preterm*.

Neonatal deaths as a result of hypoxic ischaemic encephalopathy and otherwise unexplained severe cardiorespiratory depression at birth are included here. Where possible, evidence for intrapartum hypoxia should include fetal, umbilical artery or early neonatal (within one hour) blood gases showing evidence of a severe metabolic acidosis. Otherwise peripartum death might also be due to non-hypoxic causes, e.g. infection or chronic ischaemia but wrongly assumed to be due to acute hypoxia.

There may have been intrapartum complications (subcategory 8.1), or no intrapartum complications but with evidence of non-reassuring fetal status (subcategory 8.2), or no intrapartum complications or evidence of non-reassuring fetal status (subcategory 8.3). A specific major intrapartum complication, such as uterine rupture, cord prolapse or shoulder dystocia, is required for inclusion as subcategory 8.1. However, if there were no apparent intrapartum complications (as defined in category 8.1) but there was evidence of placental insufficiency antenatally, then the death should be attributed to Category 9. In this case Category 8 is captured as an associated condition.

If there is insufficient information about fetal wellbeing or intrapartum complications, classify as subcategory 8.9 *Unspecified hypoxic peripartum death*.

Evidence of non-reassuring fetal status is defined as abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intrapartum complications.

The term 'non-reassuring fetal status' has been used in preference to the term 'fetal distress' as 'clinical signs often poorly predict a compromised fetus and continued use of this latter term may encourage wrong assumptions or inappropriate management'^{14,15}.

Examples:

Classify here: No known problems prior to labour at gestation 38 weeks. Severe fetal heart rate decelerations in second stage of labour, without other major complication. Baby is born with no signs of life with a birthweight of 3500gm, placental histopathology did not identify any significant pathology and no autopsy was performed. Classify as subcategory 8.2.

Classify here: No known problems prior to labour at 36 weeks. No evidence of intrapartum fetal distress. At birth, the baby shows signs of severe respiratory depression and hypoxia. Subsequently develops encephalopathy and multiorgan failure and dies on Day 10 of life. Placental histopathology did not identify any significant pathology and no autopsy was performed. Classify as subcategory 8.3 and PSANZ NDC as 5.1.

Do not classify here: Spontaneous membrane rupture at 22 weeks' gestation, severe oligo hydramnios with positional deformities shown on ultrasound at 26 weeks. Labour and birth at 26 weeks gestation of a baby boy weighing 700gms and was not able to be resuscitated. Placental pathology showed chorioamnionitis but no organisms identified on placental culture or baby blood cultures. Classify as 10.11 *Spontaneous preterm* and PSANZ NDC as Category 2.2 *Not resuscitated*.

Do not classify here: No complications during pregnancy. Spontaneous preterm labour and birth at 38 weeks gestation. Intrapartum fetal distress in second stage and delivered by forceps. Baby boy weighing 2200gms, Apgars 1 and 4, mechanically ventilated and admitted to NICU. Seizures commenced at 2 hrs and active management ceased at 24 hrs due to poor prognosis. Placental pathology showed fetal vascular malperfusion and mild chorioamnionitis however no organisms were identified on culture of the placental or baby. Classify as 9.2 *Placental dysfunction* and PSANZ NDC 5.1 *Hypoxic ischaemic encephalopathy/Perinatal asphyxia*

9 Placental dysfunction or causative placental pathology

- 9.1 Maternal vascular malperfusion
- 9.2 Fetal vascular malperfusion
- 9.3 High grade villitis of unknown etiology (VUE)
- 9.4 Massive perivillous fibrin deposition/maternal floor infarction
- 9.5 Severe chronic intervillitis (Histiocytic intervillitis)
- 9.6 Placental hypoplasia (small-for gestation placenta)
- 9.7 No causal placental pathology demonstrated, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)
- 9.8 Placental pathological examination was not performed, with antenatal evidence of poor placental function was identified (such as abnormal fetal umbilical artery Doppler)
- 9.9 Other placental pathology (e.g. multiple pathologies with evidence of loss of placental function leading to death)

Definitions

This category is based on the Amsterdam Placental Workshop Group Consensus Statement⁹.

Category 9.1 *Maternal vascular malperfusion (MVM)*. Placental features considered to be indicative of MVM include both gross and microscopic findings. Gross findings include placental hypoplasia, infarction, and retroplacental haemorrhage.

Any infarction seen in a preterm placenta and, at term, anything more than 5% of non-peripheral infarction should be classified as a cause. Although marginal infarcts in a term placenta may have less meaning than in a preterm placenta, they should be classified as an associated condition. *Microscopic findings* include abnormalities of villous development, which can be separated into distal villous hypoplasia, and accelerated villous maturation (vide infra), and infarcts. It should be recognized that many of these histologic findings will coexist in some placentas.

Category 9.6 Placental hypoplasia is reflected by a placental weight that is low for the stated gestational age and context (weight <10th centile) and/or a thin cord (<10th centile or <8-mm diameter at term).

Category 9.7 and 9.8 includes stillbirths or neonatal deaths where clinical evidence of poor placental function sufficient to explain the death was identified however significant causal pathology of the placental was not demonstrated or placental histopathology was not performed. Clinical evidence of poor placental function is defined as evidence of placental disease either on antenatal ultrasound studies or biochemistry. This former can include evidence of reduced maternal (uterine artery) or fetal (umbilical artery, ductus venosus, middle cerebral artery Doppler) vascular perfusion on Doppler studies. The latter can include angiogenesis-related factors such as s-Flt-1/PlGF; further clinical evaluations may clarify which biochemical markers robustly identify placental dysfunction.

Category 9.9 includes multiple pathologies with evidence of loss of placental function leading to death. It excludes pathologies listed in 9.1 to 9.8. Where one or more pathologies listed under 9.1-9.8 are identified, a single pathology must be classified as the primary cause of death with the additional pathologies classified as associated conditions (see Category 16 page 34).

Rules

This category includes perinatal deaths where placental dysfunction is considered the underlying cause of the death. It excludes perinatal deaths as a result of an identified maternal or fetal condition where the death is classified according to the condition (e.g. Pre-Eclampsia, Pre-existing hypertension). It should exclude pathology which is not thought to be causal, and also amniotic fluid infection/acute chorioamnionitis. Placental pathology which is thought to be contributory rather than causal should be classified as an associated condition (See Associated conditions page 34).

It is acknowledged that multiple pathologies may exist. In these circumstances a dominant pathology needs to be identified and classified as the main cause and others as associated conditions. This category overrides deaths following intrapartum related events as defined in Category 8 Hypoxic peripartum deaths.

Examples:

Classify here: Normal pregnancy. Spontaneous preterm labour and birth at 40 weeks gestation. Non-reassuring fetal status in second stage ensued and birth was by emergency caesarean section. Baby boy weighing 2600gms, Apgars 2 and 4, mechanically ventilated and admitted to NICU with subsequent diagnoses of meconium aspiration and persistent pulmonary hypertension of the newborn. Despite intensive care the baby died at 12 hrs of age. Placental pathology showed massive perivillous fibrin deposition/maternal floor infarction and mild chorioamnionitis, no organisms were identified on placental culture or baby blood cultures. Classify as 9.4 *Massive perivillous fibrin deposition/maternal floor infarction* and PSANZ NDC 3.3 *Primary persistent pulmonary hypertension*, with an Associated condition of *Fetal growth restriction*.

Do not classify here: Normal pregnancy until maternal presentation at 40 weeks' gestation with decreased fetal movements and abdominal pain. Antepartum fetal death was diagnosed and spontaneous labour ensued shortly after. A baby girl was born, mildly macerated, weighing 3400gms. Placental pathology showed massive abruption. Maternal investigations were normal. No organisms were identified on placental culture or baby blood cultures. Classify as *APH Abruption 4.1*.

10 Spontaneous preterm labour or rupture of membranes (<37 weeks gestation)

- 10.1 Spontaneous preterm
 - 10.11 With histological chorioamnionitis
 - 10.12 Without histological chorioamnionitis
 - 10.13 With clinical evidence of chorioamnionitis, no examination of placenta
 - 10.17 No clinical signs of chorioamnionitis, no examination of placenta
 - 10.19 Unspecified or not known whether placenta examined
- 10.2 Spontaneous preterm preceded by premature cervical shortening

Definitions

Clinical evidence of chorioamnionitis is defined as maternal fever ($\geq 38^{\circ}\text{C}$) associated with one or more of the following symptoms or signs: maternal or fetal tachycardia, uterine tenderness, malodorous amniotic fluid, and maternal leukocytosis or raised C-reactive protein¹⁶⁻¹⁸.

The diagnosis of histological chorioamnionitis should only be made when there is histological evidence of inflammation or microbiological evidence of infection of the placenta and membranes.

The subcategory of premature cervical shortening is reserved for those circumstances where the primary event appears to be cervical change based on clinical or ultrasound findings. This may occur as consequence of pre-existing damage to the cervix from a surgical procedure, due to a congenital structural cervical anomaly (with or without uterine anomaly) or clinically determined from previous obstetric history and/or clinical factors in the current pregnancy.

Rules

Deaths of normally formed, appropriately grown preterm babies following spontaneous onset of preterm labour or spontaneous rupture of membranes, irrespective of induction of labour or mode of delivery (e.g. elective caesarean section). There should be no evidence of fetal or neonatal infection (see Table 1 Determination of perinatal infection), otherwise classify under Category 2 *Perinatal Infection*. Careful examination of the placenta macroscopically and microscopically is recommended.

In cases where there is histological evidence of chorioamnionitis with or without evidence of clinical chorioamnionitis, classify as subcategory 10.11. In cases of clinical chorioamnionitis where placental pathological examination was not performed or it is not known whether the placenta was examined, classify as subcategory 10.13.

Where cervical incompetence is followed by spontaneous preterm labour or ROM classify as 10.2 as opposed to 10.1. There may be some bleeding at the time of onset of labour, or earlier in pregnancy, but not in amounts to warrant the antecedent cause being attributed to *Antepartum Haemorrhage* Category 4. Early bleeding, which is often associated with preterm premature rupture of the membranes may be classified as an associated condition (see page 34).

Examples:

Classify here: Spontaneous labour at 26 weeks, no apparent explanation, and membranes intact. Vaginal delivery after 6 hours of membrane rupture, no evidence of intrapartum hypoxia or chorioamnionitis; subsequent early neonatal death from respiratory distress syndrome. Classify here as subcategory 10.12 *Spontaneous preterm with intact membranes, or membrane rupture, without chorioamnionitis on placental histopathology* and NDC: Category 3.1

Do not classify here: Spontaneous onset of labour at 28 weeks with intact membranes. No cause identified for preterm labour. Delivery following 24 hours of membrane rupture. Maternal intrapartum pyrexia. Chorioamnionitis and funisitis on placental histology, no organism identified. Classify as Category 2.9 *Perinatal Infection; other unspecified organism*

Do not classify here: Alive at the onset of spontaneous labour at 31 weeks, no apparent explanation, and membranes intact. After 12 hrs, continuous intrapartum fetal monitoring showed deep decelerations and emergency caesarean section undertaken. Baby girl weighing 1700g was stillborn and could not be resuscitated. Placental pathology showed chorioamnionitis (no funisitis) no organisms were identified, and no other pathology was demonstrated. No autopsy was performed. Macroscopic examination of the baby was normal, no maceration. Classify as Category 8.2 *Hypoxic peripartum death; Evidence of significant fetal compromise (excluding other complications)*.

11 Unexplained antepartum fetal death

- 11.1 Unexplained antepartum fetal death despite full investigation
- 11.2 Unclassifiable antepartum fetal death with incomplete investigation
- 11.3 Unclassifiable antepartum fetal death due to unknown level of investigation

Rules

This category applies to fetal death prior to the onset of labour where no cause for the death was identified. Antepartum fetal death with associated placental pathology (i.e. not thought to be causative) are coded as associated conditions.

Category 11.1 Unknown antepartum fetal death despite full investigation.

An antepartum fetal death where no cause of death was identified following (as a minimum): comprehensive maternal and pregnancy history; histopathology of the placenta and cord; full autopsy; karyotype/cytogenetics; and testing for Feto-Maternal Haemorrhage (Kleihauer or flow cytometry).

Category 11.2 is used where none or some of the above investigations were performed and Category 11.3 is used where it is unknown/unclear if these investigations were performed or the results were unavailable.

Whether or not each of the above tests were performed should be recorded to identify areas of practice improvements and future research. The minimum dataset for perinatal deaths as defined in the Australian Perinatal Mortality Audit Tool APMAT (*see Appendix E – Australian Perinatal Mortality Audit Tool*) and the New Zealand PMMRC audit form¹⁹ (*Appendix F – Rapid reporting form for a perinatal death – baby and Appendix G – Rapid reporting form for a perinatal death - mother*) includes these data fields.

Examples:

Classify here: Intrauterine Fetal Death (IUFD) at 37 weeks, with no maternal conditions, no antepartum haemorrhage, with membranes intact, before onset of labour, where no cause of death was identified following full investigation (*comprehensive maternal and pregnancy history; histopathology of the placenta and cord; full autopsy; karyotype/cytogenetics; and Kleihauer*) Classify as Unexplained Antepartum Fetal Death, subcategory 11.1.

Intrauterine Fetal Death (IUFD) at 40 weeks, with no maternal conditions, no antepartum haemorrhage, with membranes intact, before onset of labour, where no cause of death was identified and perinatal death investigations were incomplete (e.g. *No karyotype/cytogenetics*) Classify as Unexplained Antepartum Fetal Death, subcategory 11.2.

Do not classify here: Spontaneous ROM at 27 weeks, no significant maternal conditions present, subsequent IUFD prior to onset of labour. No chorioamnionitis on examination of the placenta. Classify as subcategory 10.12 *Spontaneous preterm labour or ROM (<37 weeks gestation); without histological chorioamnionitis.*

12 Neonatal death without obstetric antecedent

- 12.1 Neonatal death with no obstetric antecedent factors despite full investigation
- 12.2 Neonatal death unclassifiable as to obstetric antecedent with incomplete investigation
- 12.3 Neonatal death unclassifiable as to obstetric antecedent due to unknown level of investigation

Rules

This category includes neonates where no obstetric antecedent factors (according to the PDC list) were identified as contributing to the death.

Category 12.1 applies to a neonatal death where not obstetric antecedent factor was identified following negative findings for the following (as a minimum): comprehensive maternal and pregnancy history and full autopsy.

Category 12.2 is used where the full autopsy was not performed and Category 11.3 where it is unknown if they were performed or the results were unavailable.

NB: Whether a PDC code is assigned or not, all neonates require a neonatal cause of death according to the PSANZ NDC to be assigned. The NDC provides information on the causes and associated conditions present in the neonatal period.

Examples:

Classify here: Baby boy born at term weighing 3.5kg was discharged home well on Day 2 of life. On day 27, the baby was found dead in his cot by the parents and following full investigation was classified as SIDS. Please refer to the NDC to classify the neonatal cause of death.

Classify here: Baby boy born at 38 weeks weighing 3kg was discharged home well. On day 10, the baby became unwell and died. Blood cultures and CSF were positive for Group B Streptococcus. Please refer to the NDC to classify the neonatal cause of death and classify as 4.1.

Do not classify here: Neonatal death on Day 7 of a 29 week baby girl with severe fetal growth restriction and reverse end diastolic flow delivered by emergency caesarean section who developed fulminating necrotising enterocolitis. Placental pathology showed high grade villitis of unknown etiology (VUE). Classify as Category 9.3 with the PSANZ Associated condition of *Fetal growth restriction* and NDC Category 6.1 *Necrotising enterocolitis*.

2 PSANZ-NDC Classification including rules and definitions

The Neonatal Death Classification has been developed for use in conjunction with the PSANZ Perinatal Death Classification in order to identify the underlying and associated neonatal conditions as well as the underlying and associated maternal conditions for neonatal deaths. For example, a mother who has an antepartum haemorrhage at 32 weeks gestation delivers a 1500g infant who thrives in the neonatal nursery but subsequently acquires a lethal nosocomial infection: the obstetric antecedent is antepartum haemorrhage, but neonatal death classification is subcategory 4.4 *Acquired Bacteria*. Both APH and neonatal nosocomial infection are important conditions on which to focus prevention strategies.

1 Congenital anomaly (please refer to PDC)

2 Perivable infants (typically <24 weeks)

- 2.1 Not resuscitated (including infants where there is an antenatal plan for no resuscitation at birth)
- 2.2 Unsuccessful resuscitation
- 2.9 Unspecified or not known whether resuscitation attempted

This group includes infants deemed too immature or too small for resuscitation or continued life support beyond the delivery room. Resuscitation in this context means the use of positive pressure ventilation.

3 Cardio-respiratory disorders

- 3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)
- 3.2 Meconium aspiration syndrome
- 3.3 Primary persistent pulmonary hypertension
- 3.4 Pulmonary hypoplasia
- 3.5 Pulmonary haemorrhage
- 3.6 Air leak syndromes
 - 3.61 Pneumothorax
 - 3.62 Pulmonary interstitial emphysema
 - 3.68 Other
- 3.7 Patent ductus arteriosus
- 3.8 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)
- 3.9 Other
 - 3.91 Neonatal anaemia/hypovolaemia

Definitions and Rules

Subcategory 3.1 *Hyaline membrane disease / Respiratory Distress Syndrome (RDS)* is used for deaths of infants who were receiving mechanical ventilation for acute RDS at the time of death or at the time of the complication such as pulmonary haemorrhage, sepsis, pneumothorax or necrotizing enterocolitis.

Neonates with resolving RDS, i.e. who are past the acute phase of the disease and are stable or improving, but who are still on low rate ventilation for immature lungs, extreme prematurity or apnoea, or who no longer require mechanical ventilation, and who developed a complication which led to the death should be classified according to that particular complication.

3.4 Pulmonary hypoplasia; this category includes pulmonary hypoplasia secondary to preterm prolonged rupture of the membranes. Congenital pulmonary airway malformation (CPAM), formerly known as congenital cystic adenomatoid malformation of the lung (CCAM) would be classified as 1.16. Congenital diaphragmatic hernia is classified as 1.151

Categorisation as chronic neonatal lung disease (subcategory 3.5) should be reserved for infants with deteriorating lung function and major chest X-ray changes consistent with bronchopulmonary dysplasia.

Examples:

Classify here: A 26-week gestation infant with RDS receives mechanical ventilation (SIPPV R50, P20/5, FiO2 0.4), develops complications of pneumothorax requiring drainage, followed by a patent ductus arteriosus and dies on day 2 of life is classified as Category 3.1 with associated conditions classified as 3.61 *Pneumothorax* and 3.7 *Patent ductus arteriosus*.

Do not classify here: A 26 week gestation infant with RDS weaning off mechanical ventilator has a Grade IV Intraventricular Haemorrhage (IVH) with ventricular dilation on ultrasound on Day 5. She is successfully weaned to CPAP on Day 7 but requires re-ventilation for sepsis on Day 10 and on Day 21 has developing BPD and post hemorrhagic hydrocephalus (PHH) following which ventilation is withdrawn. Classification is dependent on the major reason for withdrawal of support. In this case 5.3 *Post haemorrhagic hydrocephalus* with an associated classification of 3.8 *Chronic neonatal lung disease* and 4.49 *Sepsis*.

4 Neonatal infection

- 4.1 Congenital/Perinatal bacterial infection (early onset<48 hrs)
 - 4.11 Blood stream infection/septicaemia
 - 4.111 Positive culture of a pathogen
 - 4.112 Clinical signs of sepsis + ancillary evidence but culture negative
 - 4.12 Bacterial meningitis
 - 4.13 Bacterial pneumonia
 - 4.15 Multiple site bacterial infection
 - 4.18 Other congenital bacterial infection e.g. gastroenteritis, osteomyelitis, cerebral abscess
 - 4.19 Unspecified congenital infection
- 4.2 Congenital/Perinatal viral infection
- 4.3 Congenital fungal, protozoan, parasitic infection
- 4.4 Acquired bacterial infection (late onset>48hrs)
 - 4.41 Blood stream infection/septicaemia
 - 4.411 Positive culture of a pathogen
 - 4.412 Clinical signs of sepsis + ancillary evidence but culture negative
 - 4.42 Bacterial meningitis
 - 4.43 Bacterial pneumonia
 - 4.48 Other acquired bacterial infection e.g. gastroenteritis, osteomyelitis
 - 4.49 Unspecified acquired infection
- 4.5 Acquired viral infection
- 4.6 Acquired fungal, protozoan, parasitic infection

Rules

This category is intended to be used in conjunction with the PDC Category 2 *Perinatal Infection* to identify the organism causing the infection resulting in the death (including for an acquired infection). To take a pragmatic approach to storage of these data within the current system structure, in the case of a neonatal death from infection, the relevant NDC code can be stored as the primary neonatal condition and the PDC Category 2 code as an associated condition.

Determination of congenital and acquired neonatal infection

A. Congenital

Early onset infection (within 48 hours of birth), defined as:

1. Clinical signs in neonate consistent with sepsis

and

2. Haematological changes consistent with sepsis

and one or more of the following:

3a. Positive culture of a pathogen (bacterial or viral) from the neonate

or

3b. Pathological evidence at autopsy

or

3c. Positive serology

or

3d. Positive culture of a pathogen from the mother or the placenta. Swap taken aseptically between amnion and chorion.

or

3e. Pneumonia without specified bacterial or viral pathogens

NB: Some congenital viral infections may have onset later than 48 hours after birth.

B. Acquired/nosocomial

Onset of infection at 48 hours or later, with criteria as above, but excluding 3d.

Table 4. Determination of infection

5 Neurological

- 5.1 Hypoxic ischaemic encephalopathy/Perinatal asphyxia
- 5.2 Cranial haemorrhage
 - 5.21 Intraventricular haemorrhage
 - 5.22 Subgaleal haemorrhage
 - 5.23 Subarachnoid haemorrhage
 - 5.24 Subdural haemorrhage
 - 5.28 Other intracranial haemorrhage
- 5.3 Post haemorrhagic hydrocephalus
- 5.4 Periventricular leukomalacia
- 5.8 Other

Definitions and Rules:

Hypoxic ischaemic encephalopathy/Perinatal asphyxia:

Inclusion as hypoxic ischaemic encephalopathy or perinatal asphyxia usually requires a defining asphyxial event +/- evidence of severe non-reassuring fetal status and encephalopathy.

Examples of defining asphyxial events:

Massive antepartum haemorrhage from abruption (4.1), placenta praevia (4.2) or ruptured vasa praevia (4.3), breech presentation (8.14) or delivery with complications, e.g. cervical constriction ring or difficult delivery, feto-maternal haemorrhage (7.1), twin-twin transfusion (6.11).

Where possible, evidence for perinatal asphyxia should include fetal, umbilical artery or early neonatal blood gases (within one hour) showing evidence of a severe metabolic acidosis. Otherwise peripartum death might also be due to non-hypoxic causes, e.g. infection or chronic ischaemia but wrongly assumed to be due to acute hypoxia. In the absence of a defining asphyxial event every effort must be undertaken to exclude alternative diagnosis.

6 Gastrointestinal

- 6.1 Necrotising enterocolitis (NEC)
- 6.2 Short gut syndrome
- 6.3 Gastric or intestinal perforation (excluding NEC)
- 6.4 Gastrointestinal haemorrhage
- 6.8 Other

Definitions and Rules

When Short gut syndrome is a consequence of NEC or gastroschisis (1.152) then classify as Category 6.2 Short gut syndrome for the cause and other conditions as associated. Short gut syndrome Category 6.2 includes major intestinal infarction (such as midgut volvulus (1.14)).

7 Other

- 7.1 Sudden unexpected death in infancy (SUDI)
 - 7.11 Sudden Infant Death Syndrome (SIDS)
 - 7.112 SIDS Category IA: Classic features of SIDS present and completely documented
 - 7.113 SIDS Category IB: Classic features of SIDS present but incompletely documented
 - 7.114 SIDS Category II: Infant deaths that meet category I except for one or more features
 - 7.12 Unclassified Sudden Infant Death in the neonatal period
 - 7.121 Bed sharing/unsafe sleep
 - 7.122 Not bed sharing
 - 7.19 Unknown/Undetermined
- 7.2 Multisystem failure
 - 7.21 Secondary to intrauterine growth restriction
 - 7.28 Other specified
 - 7.29 Unspecified/undetermined primary cause or trigger event
- 7.3 Trauma
 - 7.31 Accidental
 - 7.32 Non accidental
 - 7.39 Unspecified
- 7.4 Treatment complications
 - 7.41 Surgical
 - 7.42 Medical
- 7.5 Unsuccessful resuscitation in infants of 28 weeks gestation or more without an obvious sentinel event
- 7.8 Other specified

Definitions

7.1 *SIDS* and 7.91 *Unclassified Sudden Infant Death* are defined according to the new SIDS classification system by Krous et al²⁰.

General Definition of SIDS

SIDS is defined as the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.

Category IA SIDS: Classic Features of SIDS Present and Completely Documented

Category IA includes infant deaths that meet the requirements of the general definition and also all of the following requirements.

Clinical:

- More than 21 days and <9 months of age;
- Normal clinical history, including term pregnancy(gestational age of ≥ 37 weeks);
- Normal growth and development.

- No similar deaths among siblings, close genetic relatives (uncles, aunts or first-degree cousins), or other infants in the custody of the same caregiver.

Circumstances of Death:

- Investigation of the various scenes where incidents leading to death might have occurred and it is determined that they do not provide an explanation for the death.
- Found in a safe sleeping environment, with no evidence of accidental death.

Autopsy:

- There is an absence of potentially fatal pathologic findings. Minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial haemorrhage is a supportive but not obligatory or diagnostic finding.
- There is no evidence of unexplained trauma, abuse, neglect, or unintentional injury.
- There is no evidence of substantial thymic stress effect (thymic weight of <15g and/or moderate/severe cortical lymphocyte depletion). Occasional “starry sky” macrophages or minor cortical depletion is acceptable.
- Results of toxicologic, microbiologic, radiologic, vitreous chemistry, and metabolic screening studies are negative.

Category IB SIDS: Classic Features of SIDS Present but Incompletely Documented

Category IB includes infant deaths that meet the requirements of the general definition and also meet all of the criteria for category IA except that investigation of the various scenes where incidents leading to death might have occurred was not performed and or ≥ 1 of the following analyses was not performed: toxicologic, microbiologic, radiologic, vitreous chemistry, or metabolic screening studies.

Category II SIDS

Category II includes infant deaths that meet category I criteria except for ≥ 1 of the following.

Clinical:

- Age range outside that of category 1A or 1B (i.e., 0-21 days or 270 days [9 months] through first birthday);
- Similar deaths among siblings, close relatives, or other infants in the custody of the same caregiver that are not considered suspect for infanticide or recognised genetic disorders;
- Neonatal or perinatal conditions (for example, those resulting from preterm birth) that have resolved by the time of death.

Circumstances of Death:

- Mechanical asphyxia or suffocation caused by overlaying not determined with certainty.

Autopsy:

- Abnormal growth and development not thought to have contributed to death;
- Marked inflammatory changes or abnormalities not sufficient to be unequivocal causes of death.

Unclassified Sudden Infant Death

The unclassified category includes deaths that do not meet the criteria for category I or II SIDS but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases for which autopsies were not performed.

Post-resuscitation cases

Infants found in extremis who are resuscitated and later die (“temporarily interrupted SIDS”) may be included in the aforementioned categories, depending on the fulfilment of relevant criteria.

Rules

Subcategory 7.92 *Other Unknown/Undetermined* has been included to identify unknown causes of death which do not fulfil the criteria of Category 7.91. Subcategory 7.4 *Other accident, poisoning or violence (postnatal)* excludes cases of antepartum deaths which should be classified in Category 5 *Maternal Conditions* under subcategory 5.3 *Maternal injury*. Subcategory 7.8 *Other specified* is used to classify other identified conditions which are not included in subcategories 7.1 to 7.4.

7.8 PSANZ Associated Conditions

Following classification of the underlying cause of death according to the PSANZ-PDC for stillbirths and neonatal deaths, and in addition a PSANZ NDC for neonatal deaths, associated conditions thought to be contributory (but not causal) to the death should be classified. The associated conditions list includes the PSANZ-PDC categories and, in addition for neonatal deaths, the PSANZ-NDC categories and other conditions which may be contributory to stillbirth as listed below in Categories 13-16.

Associated conditions for both stillbirths and neonatal deaths

Categories 1 -11 PSANZ PDC Plus the following additional categories:

13 Genetic testing results not diagnostic

- 13.1 Copy number variant of unknown or uncertain significance
- 13.2 No mutation identified matching phenotype
- 13.3 Tested for genetic mutations but failed
- 13.4 Not tested or not known if tested for genetic mutations

Explanatory/clarifying notes:

Where a pathogenic or a likely pathogenic mutation has been identified, this would have been classified under Category 1.2 Chromosomal anomaly as stated in the Definitions and Rules section of Category 1 Congenital anomaly. 1.31 and 1.34 are self-explanatory. 13.3 tested for genetic mutations but failed, refer to those tests that may have failed due to culture failure (with conventional cytogenetics) or poor DNA (with molecular techniques)

14 Associated placental pathology

- 14.1 Delayed villous maturation
- 14.2 Large chorioangioma
- 14.3 Early bleeding often leading to preterm prelabour ROM
- 14.8 Other associated placental pathology

Explanatory/clarifying notes:

Early bleeding is defined as bleeding in the second trimester (often on one or more occasions) which does not immediately lead to spontaneous birth or rupture of membranes.

15 Associated cord pathology

- 15.1 True knot (excluding histological evidence of causation)
- 15.2 Hypercoiled cord
- 15.3 Tethered cord
- 15.4 Velamentous insertion
- 15.8 Other associated cord pathology

16 Fetal Growth Restriction (FGR)

- 16.1 Autopsy evidence (brain:liver ratio equal to or greater than 4:1)
- 16.2 Antenatal ultrasound evidence of FGR
- 16.3 Clinical examination of the baby (by paediatrician, pathologist)
- 16.4 Birthweight (less than 10th centile for gestational age)
 - 16.41 Customised centiles²¹
 - 16.42 Population centiles^{22,23}

Explanatory/clarifying notes:

Fetal growth restriction is defined as:

1. A brain:liver ratio equal to or greater than 4:1 at autopsy
AND/OR
1. Where antenatal ultrasound assessment has shown evidence of FGR (e.g. reduced growth velocity on serial biometry and/or abnormal utero-placental blood flow on Doppler ultrasound and reduced amniotic fluid volume)
AND/OR
2. Clinical examination of the baby (by paediatrician, pathologist)
AND/OR
3. Birthweight <10th centile for gestational age for livebirths or non-macerated stillbirths

Classifying FGR in stillbirths

It is also recommended that for fetal deaths, where possible, the gestational age on the date of death and not date of birth be used to define the presence of FGR.

For macerated stillbirths, in the absence of prior ultrasound evidence of FGR and where no autopsy has been performed or the brain:liver ratio is less than 4:1, the death should be classified as Unexplained Antepartum Death (Category 11), as the weight discrepancy may be a post mortem effect.

Customised or non-customised centiles

Either customised or non-customised centiles charts can be used to classify FGR as an associated condition under 16.2.1 or 16.2.2 respectively. Customised birthweight (CBW) centiles are being increasingly used to determine the presence of FGR²¹. However controversy around the use of customised centiles continues^{24,25} including concerns that customisation may mask pathology^{24,26}. It is recommended that the variables required for calculation of CBW (maternal age, ethnicity, height, weight, and fetal gestation and gender) be routinely collected to enable evaluation of birthweight according to CBW centiles. The recommended Australia population standards are those published by Dobbins et al²² and for preterm birth by Fenton et al²³.

17 Maternal risk factors (optional category)

- 17.1 Smoking
- 17.2 Substance use
- 17.3 High BMI
- 17.4 Maternal mental health disorder
- 17.5 Socioeconomic deprivation
- 17.6 Refugee or asylum seeker

Ideally risk factors would be included as part of a minimum dataset for all livebirths and stillbirths to enable ongoing assessment of the contribution of these factors to perinatal deaths. Further, inclusion of the PSANZ classification in this dataset for each perinatal death will provide a rich source of information for understanding causal pathways for maternal risk factors.

Associated conditions for neonatal deaths only

NDC Categories 1- 6

In addition to the above for associated maternal/fetal conditions the NDC Categories 1- 6 can be used to assign associated neonatal conditions

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7.12 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 2017

Stillbirth Investigations Flowchart

Core investigations

Mother

- Maternal history
- Maternal examination
- Kleihauer-Betke or flow cytometry

Baby

- Clinical examination at birth
- Full autopsy

Placenta

- Macroscopic examination
- Histopathology studies
- Cytogenetic analysis

Findings from core investigations

Personal or family history of thrombosis

Suspected cholestasis

Non-consent for full autopsy

LGA

FGR or SGA

Placental abruption or infarction

Infection

Indicated selective investigations

APS (anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1 antibodies)

Bile acids; LFTs

MRI; NIA; MIA; Clinical photographs

HbA1c

Infectious diseases (e.g. CMV); HbA1c; APS (anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1 antibodies)

APS (anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1 antibodies)

Further testing as directed by pathologist

APS: Antiphospholipid syndrome; CMA: Chromosomal microarray; CMV: Cytomegalovirus; FGR: Fetal growth restriction; LFTs: Liver Function Tests; LGA: Large-for gestational-age; HbA1c: Haemoglobin A1c; MIA: Minimally-invasive autopsy; MRI: Magnetic Resonance Imaging; NIA: Non-invasive autopsy; SGA: Small for gestational age

1: Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Perinatal Mortality Audit Third Edition, December 2017

APPENDIX B

ESTIMATION OF SEVERITY OF FETO-MATERNAL HAEMORRHAGE

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

Percent Fetal Blood = $\frac{\text{Fetal Cells}}{\text{Volume Lost Maternal Cells}} \times 1800 \times 1.22 \times \frac{100}{2 \times 100}$
150 x fetal wt in kg

Or, to simplify,

Percent Fetal Blood = $\frac{\text{Fetal Cells}}{\text{Volume Lost Maternal Cells in kg}} \times 3200 \div \text{fetal wt}$

So, for example, if the Kleihauer-Betke shows that 200 of 5000 cells counted are fetal and the fetus weighs 2.0 kg, then the estimate of percent blood volume loss would be:

$200/4800 \times 3200 \div 2.0$, or 66%.

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

Taken from **Fetal-Maternal Hemorrhage and Stillbirth**

Richard M. Pauli, M.D., Ph.D.

<http://www2.marshfieldclinic.org/wissp/wisspers/93940001.htm>

APPENDIX C: ACCOUCHEUR PLACENTAL EXAMINATION AND PREPARATION FOR PATHOLOGY

Maternal Sticker
(Inc Name, DOB, UR, Address, Telephone Number)

Please complete details as required

Singleton Multiple Baby number..... (e.g. Twin 1)

Step 1 Accoucheur examination of the placenta, membranes and cord using sterile gloves

Cord insertion (Circle) Eccentric / Central / Marginal / Velamentous / Other.....

Cord appearance (Circle) Thin / Thick / Meconium Stained / Other.....

No. of cord vessels **Total cord length**.....cm **Cord knots (Circle)** Yes / No

Placental dimensionscm **Placental weight**gms **Placental odour**.....

Maternal surface (Circle all that apply) Intact / Incomplete / Gritty / Fatty Infarcts / Retroplacental Clot / Succenturiate / Circumvallate / Bipartite



Step 2 Tissue sampling for chromosomal analysis

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

- Collect a 1cm³ sample of the middle of the umbilical cord, using a sterile surgical knife and dissecting forceps.
- Place in either a designated cytogenetics bottle or a sterile container, with either sterile saline solution or Hank's solution. Then seal the bottle and label with maternal name, medical record number, date and time of collection and multiple number if appropriate



Step 3 Send Placenta, Membrane and Cord to the Pathology fresh and unfixed for histopathological examination

APPENDIX D: CLINICAL EXAMINATION OF BABY CHECKLIST

Please tick appropriate box and complete details as required

Maternal Sticker

(Inc Name, DOB, UR, Address, Telephone Number)

<p>Baby measurements</p> <p>1. Crown – heel (stretched) cms</p> <p>2. Head circumference cms</p> <p>3. Weight gms</p> <p>If Stillbirth</p> <p>Estimated date of IUFD:/...../.....</p> <p>Maceration degree</p> <p>Fresh; no skin peeling <input type="checkbox"/></p> <p>Slight; focal minimal skin slippage..... <input type="checkbox"/></p> <p>Mild; some skin sloughing, moderate skin slippage..... <input type="checkbox"/></p> <p>Moderate; much skin sloughing but no secondary comprehensive changes or decomposition <input type="checkbox"/></p> <p>Marked, advanced..... <input type="checkbox"/></p> <hr/> <p>HEAD AND FACE</p> <p>Head</p> <p>Relatively normal <input type="checkbox"/> Collapsed <input type="checkbox"/></p> <p>Anencephalic <input type="checkbox"/> Hydrocephalic <input type="checkbox"/></p> <p>Abnormal shape <input type="checkbox"/></p> <p>If abnormally shaped, describe:</p> <hr/> <p>Eyes</p> <p>Normal <input type="checkbox"/> Prominent <input type="checkbox"/> Sunken <input type="checkbox"/></p> <p>Straight <input type="checkbox"/> Far apart <input type="checkbox"/> Close together <input type="checkbox"/></p> <p>Upslanting <input type="checkbox"/> Downslanting <input type="checkbox"/></p> <p>Globes normal <input type="checkbox"/> Absent <input type="checkbox"/></p> <p>Eyes very small <input type="checkbox"/> Very large <input type="checkbox"/></p> <p>Lens opacity <input type="checkbox"/> Corneal opacity <input type="checkbox"/></p> <p>Eyelids fused <input type="checkbox"/> Other <input type="checkbox"/></p> <p>If other, describe:</p> <hr/> <p>Nose</p> <p>Normal <input type="checkbox"/> Abnormally small <input type="checkbox"/></p> <p>Asymmetric <input type="checkbox"/> Abnormally large <input type="checkbox"/></p> <p>Nostrils</p> <p>Apparently patent <input type="checkbox"/> Obstructed <input type="checkbox"/></p> <p>Single nostril <input type="checkbox"/> Other <input type="checkbox"/></p> <p>If other, describe:</p> <hr/> <p>Mouth</p> <p>Normal size <input type="checkbox"/> Large <input type="checkbox"/> Small <input type="checkbox"/></p> <p>Upper Lip</p> <p>Intact <input type="checkbox"/> Cleft <input type="checkbox"/></p> <p>If cleft, location:</p> <p>Left <input type="checkbox"/> Right <input type="checkbox"/></p> <p>Bilateral <input type="checkbox"/> Midline <input type="checkbox"/></p> <p>Palate</p> <p>Intact <input type="checkbox"/> Cleft <input type="checkbox"/></p> <p>Mandible</p> <p>Normal <input type="checkbox"/> Large <input type="checkbox"/></p> <p>Small <input type="checkbox"/> Other <input type="checkbox"/></p> <p>If other, describe:</p> <hr/> <p>Ears</p> <p>Normal <input type="checkbox"/> Preauricular tags <input type="checkbox"/></p> <p>Lowset <input type="checkbox"/> Preauricular pits <input type="checkbox"/></p> <p>Other <input type="checkbox"/> Posteriorly rotated <input type="checkbox"/></p> <p>If other, describe:</p>	<p>Singleton <input type="checkbox"/> Multiple <input type="checkbox"/> Baby number (e.g. Twin 1)</p> <hr/> <p>NECK</p> <p>Normal <input type="checkbox"/></p> <p>Mass <input type="checkbox"/></p> <p>Describe:</p> <hr/> <p>CHEST</p> <p>Normal <input type="checkbox"/> Long & narrow <input type="checkbox"/></p> <p>Short & broad <input type="checkbox"/> Other <input type="checkbox"/></p> <p>If Spina bifida, describe:</p> <hr/> <p>ABDOMEN</p> <p>Normal <input type="checkbox"/> Flattened <input type="checkbox"/></p> <p>Distended <input type="checkbox"/> Hemia <input type="checkbox"/></p> <p>Omphalocele <input type="checkbox"/> Gastroschisis <input type="checkbox"/></p> <hr/> <p>BACK</p> <p>Normal <input type="checkbox"/> Spina bifida <input type="checkbox"/></p> <p>If Spina bifida, describe:</p> <p>Scoliosis <input type="checkbox"/> Kyphosis <input type="checkbox"/></p> <p>Other <input type="checkbox"/></p> <p>If other, describe:</p> <hr/> <p>GENITALIA</p> <p>Anus</p> <p>Normal <input type="checkbox"/> Imperforate <input type="checkbox"/> Other <input type="checkbox"/></p> <p>If other, describe:</p> <hr/> <p>Gender</p> <p>Male <input type="checkbox"/> Female <input type="checkbox"/> Ambiguous <input type="checkbox"/></p> <p>Male</p> <p>Penis</p> <p>Normal <input type="checkbox"/> Very small <input type="checkbox"/></p> <p>Hypospadias <input type="checkbox"/> Chordee <input type="checkbox"/></p> <p>Hypospadias, level of opening</p> <p>Scrotum</p> <p>Normal <input type="checkbox"/> Abnormal <input type="checkbox"/></p> <p>If abnormal, describe</p> <p>Testes</p> <p>Descended <input type="checkbox"/> Undescended <input type="checkbox"/></p> <p>Other <input type="checkbox"/></p> <p>If other, describe:</p> <hr/> <p>Female</p> <p>Urethral opening</p> <p>Present <input type="checkbox"/> Absent/unidentifiable <input type="checkbox"/></p> <p>Vaginal introitus</p> <p>Present <input type="checkbox"/> Absent/unidentifiable <input type="checkbox"/></p> <p>Clitoris</p> <p>Present <input type="checkbox"/> Unidentifiable <input type="checkbox"/></p> <p>Enlarged <input type="checkbox"/> Other <input type="checkbox"/></p> <p>If other, describe:</p> <p>Ambiguous sex</p>	<p>LIMBS</p> <p>Length</p> <p>Normal <input type="checkbox"/> Short <input type="checkbox"/> Long <input type="checkbox"/></p> <p>If Short, what segments seem short</p> <p>Form</p> <p>Normal <input type="checkbox"/> Asymmetric <input type="checkbox"/> Missing parts <input type="checkbox"/></p> <p>If other, describe:</p> <hr/> <p>HANDS</p> <p>Length</p> <p>Appearance: Normal <input type="checkbox"/> Abnormal <input type="checkbox"/></p> <p>If abnormal, describe:</p> <hr/> <p>Fingers</p> <p>Number present:</p> <p>If not 4 + 4, describe</p> <p>Unusual form of fingers <input type="checkbox"/></p> <p>Unusual position of fingers <input type="checkbox"/></p> <p>Abnormal webbing or syndactyly <input type="checkbox"/></p> <p>If abnormal, describe</p> <hr/> <p>Thumbs</p> <p>Number present:</p> <p>If not 1+ 1 describe</p> <p>Unusual position <input type="checkbox"/></p> <p>Looks like a finger <input type="checkbox"/></p> <p>If abnormal, describe</p> <hr/> <p>Finger nails</p> <p>All present <input type="checkbox"/></p> <p>If not describe</p> <hr/> <p>FEET</p> <p>Appearance Normal <input type="checkbox"/> Abnormal <input type="checkbox"/></p> <p>If abnormal, describe</p> <hr/> <p>Toes</p> <p>Number present:</p> <p>If not 5+ 5 describe</p> <p>Spacing: Normal <input type="checkbox"/> Abnormal <input type="checkbox"/></p> <p>If abnormal, describe</p> <hr/> <p>Toe nails</p> <p>All present <input type="checkbox"/></p> <p>If not describe</p> <hr/> <p>Revised gestational age</p> <p>Based on</p> <p>Examined by: (Print name)</p> <p>Date:</p> <p>Summary of key findings:</p> <p>.....</p> <p>.....</p>
---	---	---

Type of Perinatal Death

STILLBIRTH (Fetal death):

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

Please select type:

- Antepartum fetal death
- Intrapartum fetal death
- Termination of pregnancy
- Unknown

NEONATAL DEATH

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

Please select type:

- Non-admitted neonatal death
- Neonatal death in hospital
- Unknown

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

Section 1: CLINICAL DATA RELEVANT TO PERINATAL DEATH

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

Baby Details

1) Case Number _____

2) Was this a multiple pregnancy

- Yes No (go to Question 3) Unknown (go to Question 3)

a) Plurality of pregnancy

- Twin Triplet Quadruplet
 Quintuplet Sextuplet Unknown
 Other _____

b) Birth Order

- First Second Third
 Other (please specify) _____

c) Chorionicity

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

3) Baby Urn _____

4) Type of Death

- Undetermined
 Stillbirth (fetal death)

If yes, please specify the timing of the fetal death:

- Antepartum fetal death
 Intrapartum fetal death
 Unknown

Neonatal death

If yes, please specify the hospital episode for neonatal/post neonatal death

- Hospital other
 Hospital of birth
 Home
 Unknown

Postneonatal Death

If yes, please specify the hospital episode for neonatal/postneonatal death

- Hospital other
 Hospital of birth
 Home
 Unknown

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

- Yes No (go to Question 6) Unknown (go to Question 6)

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

- Congenital abnormality Medical/pregnancy condition Psychosocial reason
 Unknown

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

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

6) Date of baby's birth _____

7) Time of baby's birth _____

8) Gender

- Male Female Intersex or indeterminate
 Unknown

9) Indigenous status

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

10) Calculated gestation of pregnancy at birth _____

11) Birth weight (g) _____

12) Did this baby have a major congenital abnormality

- Yes No Unknown

13) Was this death unexpected

- Yes No Unknown
 Cannot be determined

Mother's Details

14) Mother

Surname: _____

Given name(s): _____

Other(s): _____

15) Mother's Unit Record No: _____

16) Mother's Date of Birth: _____

17) Usual residential address of mother at time of birth

Country: _____

Town/City/Locality: _____

State: _____

Post Code: _____

18) Indigenous status

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

19) Mother's understanding of spoken English

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

Previous Pregnancies

20) Number of mother's previous pregnancies: _____

Unknown

21) Mother's parity (Do not include current pregnancy): _____

Unknown

	Date of Birth	Place of birth (see options below)	Gestation (weeks)	Pregnancy Outcome (codes below)	Type of birth (codes below)	Birth weight (grams)	Complications (e.g. FGR) (codes below)
1.							
2.							
3.							
4.							
5.							
6.							
7.							
8.							

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

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

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

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

Current Pregnancies

(This section is not required for terminations of pregnancy for maternal psychological reasons)

22) Mother's height: _____ cm

23) Mother's weight :

Current (around time of birth): _____ kg

At booking (antenatal visit): _____ kg

24) Artificial reproductive technology in this pregnancy?

Yes

No (*go to Question 25*)

Unknown (*go to Question 25*)

If yes, please specify fertility treatment

- Ovulation induction agents Donor insemination Embryo transfer to fallopian tubes (TEST) (ZIFT)
 Embryo transfer to uterus (GIFT) In vitro fertilisation other/unspecified Intracytoplasmic sperm injection (ICSI)
 Other _____

25) What was the mother's smoking status and history during pregnancy?

- Smoking during pregnancy Never smoked Stopped before this pregnancy
 Stopped smoking during the first 20 weeks of pregnancy Stopped smoking after the first 20 weeks of pregnancy Unknown

26) Did the mother drink alcohol during this pregnancy?

- Yes No (*go to Question 27*) Unknown (*go to question 27*)

If yes, specify the average number of standard alcoholic drinks per week

First trimester: _____ standard drinks per week or Unknown

Month prior to birth: _____ standard drinks per week or Unknown

27) Did the mother use illicit drugs during this pregnancy

- Yes No (*go to Question 28*) Unknown (*go to Question 28*)

Please specify

	<u>First trimester</u>	<u>Month prior to birth</u>
Heroin	<input type="checkbox"/>	<input type="checkbox"/>
Cannabis	<input type="checkbox"/>	<input type="checkbox"/>
Amphetamines	<input type="checkbox"/>	<input type="checkbox"/>
Ecstasy	<input type="checkbox"/>	<input type="checkbox"/>
Hallucinogens	<input type="checkbox"/>	<input type="checkbox"/>
Cocaine	<input type="checkbox"/>	<input type="checkbox"/>
Chroming/Petrol/Paint	<input type="checkbox"/>	<input type="checkbox"/>
Methadone	<input type="checkbox"/>	<input type="checkbox"/>
Herbal Highs	<input type="checkbox"/>	<input type="checkbox"/>
Unknown	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>

28) Has the mother suffered family violence during this pregnancy

- Yes No Not Asked Unknown

29) Place of birth

Please select from both columns

	<u>Intended place of birth before labour</u>	<u>Actual place of birth</u>
Hospital, excluding birth centre	<input type="checkbox"/>	<input type="checkbox"/>
Birth centre, attached to hospital	<input type="checkbox"/>	<input type="checkbox"/>
Birth centre, free standing	<input type="checkbox"/>	<input type="checkbox"/>
Home (other)	<input type="checkbox"/>	<input type="checkbox"/>
Home- private midwife care	<input type="checkbox"/>	<input type="checkbox"/>
Home- public homebirth program	<input type="checkbox"/>	<input type="checkbox"/>
In transit	<input type="checkbox"/>	<input type="checkbox"/>
Unknown	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/> _____	<input type="checkbox"/> _____

30) Model of antenatal maternity care

	<u>Booking</u>	<u>At birth</u>
Private obstetrician (specialist care)	<input type="checkbox"/>	<input type="checkbox"/>
Private midwifery care	<input type="checkbox"/>	<input type="checkbox"/>
General Practitioner obstetrician care	<input type="checkbox"/>	<input type="checkbox"/>
Shared care	<input type="checkbox"/>	<input type="checkbox"/>
Combined care	<input type="checkbox"/>	<input type="checkbox"/>
Public hospital maternity care	<input type="checkbox"/>	<input type="checkbox"/>
Public hospital high risk maternity care	<input type="checkbox"/>	<input type="checkbox"/>
Team midwifery care	<input type="checkbox"/>	<input type="checkbox"/>

- Midwifery group practice caseload care
- Remote area maternity care
- Private obstetrician and privately practicing midwife joint care
- No antenatal care provider
- If other, please specify _____ _____

31) Maternal outcome

- Alive and generally well Alive but serious morbidity Died

Mothers Medical History

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

- Yes No (*go to Question 33*) Unknown (*go to Question 33*)

If yes, please specify:

- | | Yes | No | Unknown |
|--|--------------------------|--------------------------|--------------------------|
| a) Asthma | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Diabetes pre pregnancy (type 1 or 2) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) If yes, is the diabetes well controlled | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ii) How is the diabetes managed | | | |
| <input type="checkbox"/> Insulin | | | |
| <input type="checkbox"/> Oral hypoglycaemic | | | |
| <input type="checkbox"/> Diet and exercise | | | |
| <input type="checkbox"/> Unknown | | | |
| <input type="checkbox"/> Other (<i>please specify</i>) _____ | | | |
| c) Epilepsy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Heart condition (congenital or acquired) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Hypertension | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f) Thyroid abnormality | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) <i>If yes, please specify</i> | | | |
| <input type="checkbox"/> Hyperthyroidism | | | |
| <input type="checkbox"/> Hypothyroidism | | | |
| <input type="checkbox"/> Unknown | | | |
| g) Inflammatory bowel disease | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h) Systemic lupus erythematosus | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) Other autoimmune disorder | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j) Mental health disorder | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) <i>If yes, please specify</i> | | | |
| <input type="checkbox"/> Depression | | | |
| <input type="checkbox"/> Psychotic disorder | | | |
| <input type="checkbox"/> Other (<i>please specify</i>) _____ | | | |
| k) Renal disease | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l) Venous thromboembolism | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m) Haematological disorders | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) <i>If yes, please specify</i> | | | |
| <input type="checkbox"/> Anaemia | | | |
| <input type="checkbox"/> Thalassaemia trait | | | |
| <input type="checkbox"/> Thrombophilia | | | |
| <input type="checkbox"/> Other (<i>please specify</i>) _____ | | | |
| n) Cervical surgery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o) Uterine surgery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| p) Urinary tract infection | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| q) Uterine abnormality | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| r) Other: _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Further medical conditions: _____

33) Family history of thrombosis?

Yes No Unknown

Obstetric Conditions

34) Obstetric complications during this pregnancy and obstetric consultation

Indicate all conditions known to be present during this pregnancy

a) Hypertension Yes No Unknown

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

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

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

- Yes
- No
- Already under obstetric care
- Unknown

b) HELLP Syndrome Yes No Unknown

i) *If yes, was there consultation with an obstetrician for HELLP syndrome*

- Yes
- No
- Already under obstetric care
- Unknown

c) Preterm labour Yes No Unknown

i) *If yes, was there consultation with an obstetrician for preterm labour*

- Yes
- No
- Already under obstetric care
- Unknown

d) Pre-labour rupture of membranes Yes No Unknown

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

ii) *Was there consultation with an obstetrician for pre-labour rupture or membranes*

- Yes
- No
- Already under obstetric care
- Unknown

e) Obstetric cholestasis Yes No Unknown

i) *If yes, was there consultation with an obstetrician for obstetric cholestasis*

- Yes
- No
- Already under obstetric care
- Unknown

f) Vaginal bleeding Yes No Unknown

i) *If yes, what gestation did vaginal bleeding occur*

- Before 20 weeks
- At or after 20 weeks
- Unknown

ii) *Reasons for vaginal bleeding*

- Abruption
- Placenta praevia
- Vasa praevia
- Uterine rupture
- Cervical cause
- Unknown
- Other (please specify): _____

iii) *Was there consultation with an obstetrician for vaginal bleeding*

- Yes
- No
- Already under obstetric care
- Unknown

g) Placental praevia without haemorrhage Yes No Unknown

i) *If yes, was there consultation with an obstetrician for placental praevia without haemorrhage*

- Yes
- No
- Already under obstetric care
- Unknown

h) Gestational diabetes Yes No Unknown

i) *If yes, please indicate*

First HbA1C measure during pregnancy _____

Last HbA1C measured during pregnancy _____

ii) *How was the diabetes managed*

- Insulin
- Oral hypoglycaemic
- Diet and exercise
- Unknown
- Other (please specify): _____

iii) *Was there consultation with an obstetrician for gestational diabetes*

- Yes
- No
- Already under obstetric care
- Unknown

i) Multiple pregnancy Yes No Unknown

i) *If yes, was there consultation with an obstetrician for multiple pregnancy*

- Yes
- No
- Already under obstetric care
- Unknown

j) Prolonged pregnancy (<41 weeks) Yes No Unknown

i) *If yes, was there consultation with an obstetrician for prolonged pregnancy*

- Yes
- No
- Already under obstetric care

Unknown

k) Breech presentation Yes No Unknown

i) *If yes, was there consultation with an obstetrician for breech presentation*

- Yes
- No
- Already under obstetric care
- Unknown

l) Unstable lie Yes No Unknown

i) *If yes, was there consultation with an obstetrician for unstable lie*

- Yes
- No
- Already under obstetric care
- Unknown

m) Size of fetus Yes No Unknown

i) *If yes, please specify the size of the fetus*

- Large
- Small
- Unknown

ii) *Was there consultation with an obstetrician for size of fetus*

- Yes
- No
- Already under obstetric care
- Unknown

n) Decreased fetal movements Yes No Unknown

i) *If yes, was there consultation with an obstetrician for decreased fetal movements*

- Yes
- No
- Already under obstetric care
- Unknown

o) Polyhydramnios Yes No Unknown

i) *If yes, was there consultation with an obstetrician for polyhydramnios*

- Yes
- No
- Already under obstetric care
- Unknown

p) Oligohydramnios Yes No Unknown

i) *If yes, was there consultation with an obstetrician for oligohydramnios*

- Yes
- No
- Already under obstetric care
- Unknown

q) Non-reassuring CTG Yes No Unknown

i) *If yes, was there consultation with an obstetrician for non-reassuring CTG*

- Yes
- No
- Already under obstetric care
- Unknown

r) Fetal abnormality Yes No Unknown

i) *If yes, was there consultation with an obstetrician for fetal abnormality*

- Yes
- No
- Already under obstetric care
- Unknown

s) Other obstetric conditions Yes No Unknown

Please specify: _____

i) *If yes, was there consultation with an obstetrician for other obstetric conditions*

- Yes
- No
- Already under obstetric care
- Unknown

35) Were there any medical complications during this pregnancy

Yes No (*go to Question 36*) Unknown (*go to Question 36*)

If yes, indicate all medical complications known to be present during this pregnancy:

a) Confirmed maternal infection Yes No Unknown

i) *If yes, what type of infection*

- Pyelonephritis
- Lower urinary tract infection
- Unknown
- Other (*please specify:*) _____

ii) *Was there consultation with an obstetrician for confirmed maternal infection*

- Yes
- No
- Already under obstetric care
- Unknown

b) Trauma Yes No Unknown

i) *If yes, what type of infection*

- Vehicular
- Fall
- Violent personal injury
- Unknown
- Other (*please specify:*) _____

ii) *Was there consultation with an obstetrician for trauma*

- Yes
- No
- Already under obstetric care
- Unknown

c) Renal Yes No Unknown

i) *Was there consultation with an obstetrician for renal complications*

- Yes
- No
- Already under obstetric care
- Unknown

d) Cardiac Yes No Unknown

i) *Was there consultation with an obstetrician for cardiac complications*

- Yes
- No
- Already under obstetric care

Unknown

36) Were there other reason for obstetric consultations

Yes No (*go to Question 37*) Unknown (*go to Question 37*)

If yes, what was/were the reason(s) for the obstetric consultation? Please select all that applicable:

- | | | |
|---|---|---------------------------------------|
| <input type="checkbox"/> Mother's request | <input type="checkbox"/> Previous pre-term birth | <input type="checkbox"/> Raised BMI |
| <input type="checkbox"/> Previous perinatal death | <input type="checkbox"/> Previous caesarean section | <input type="checkbox"/> Surgery |
| <input type="checkbox"/> Recurrent miscarriage | <input type="checkbox"/> Other poor obstetric history | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Previous intrauterine growth restriction | <input type="checkbox"/> Mother's age ≥ 35 years | <input type="checkbox"/> Other: _____ |

37) Was the mother referred to another healthcare service during pregnancy

Yes No (*go to Question 38*) Unknown (*go to Question 38*)

If yes, what healthcare service was the mother referred to? Please select all that applicable:

- Medical service (please specify reason for referral to medical services)
-
- | | | |
|---|---|----------------------------------|
| <input type="checkbox"/> Mental health | <input type="checkbox"/> Previous caesarean section | <input type="checkbox"/> Surgery |
| <input type="checkbox"/> Drug and alcohol | <input type="checkbox"/> Other poor obstetric history | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Social Worker | <input type="checkbox"/> Mother's age ≥ 35 years | |
| <input type="checkbox"/> Other: _____ | | |

Antenatal Procedures

38) Antenatal visits

Yes No (*go to Question 39*) Unknown (*go to Question 39*)

If yes, please indicate:

- a) Total number of visits recorded: _____
- b) Gestation at first antenatal visit: _____ weeks _____ days or Unknown

39) Antenatal procedures

Please indicate all procedures undertaken in pregnancy excluding those after fetal death in utero

- | | | | |
|---|------------------------------|-----------------------------|----------------------------------|
| a) First trimester screening ultrasound scan | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| b) Morphology/anomaly ultrasound scan at 18-20 weeks' gestation | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| c) Total Number of antenatal ultrasound scans (exclude those performed after fetal death) | Number of ultrasounds _____ | | <input type="checkbox"/> Unknown |
| d) Chorion villus sampling | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |

If yes, what were the CV results?

- Normal
 Abnormal
 Uncertain
 Unknown

What was the chromosomal microarray results?

- Not performed
 Normal
 Abnormal
 Uncertain
 Unknown

- | | | | |
|---|------------------------------|-----------------------------|----------------------------------|
| e) Cervical suture (vaginal or transabdominal) | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| <i>If yes, what was the dates of cervical suture:</i> _____ | | or | <input type="checkbox"/> Unknown |
| f) Amniocentesis | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |

If yes, what were the Amniocentesis results?

- Normal
- Abnormal
- Uncertain
- Unknown

What were the chromosomal microarray results?

- Not performed
- Normal
- Abnormal
- Uncertain
- Unknown

- g) Doppler studies** Yes No Unknown
- If yes, what were the studies performed?*
- Umbilical artery doppler Normal Abnormal Unknown
 - Uterine artery doppler Normal Abnormal Unknown
 - Middle-cerebral artery doppler Normal Abnormal Unknown
 - Other: _____ Normal Abnormal Unknown
 - Unknown
- h) External cephalic version** Yes No Unknown
- If yes, what was the dates this was performed: _____ or _____* Unknown
- i) Fetocide** Yes No Unknown
- j) Amnioreduction** Yes No Unknown
- k) Laser treatment** Yes No Unknown
- l) Intrauterine fetal blood transfusion** Yes No Unknown
- m) Ligation of vessels for twin to twin transfusion** Yes No Unknown
- n) Other: _____** Yes No Unknown

40) Were maternal corticosteroids given in pregnancy

- Yes No (*go to Question 41*) Unknown (*go to Question 41*)

If yes, please indicate:

- a)** Course of corticosteroids started at what gestation: _____ weeks _____ days or _____ Unknown
- b)** Was course of corticosteroids completed Yes No Unknown

Mothers Medications

41) Were medications and supplements taken in this pregnancy

Please indicate all over the counter and traditional medicines taken in the pregnancy

- Yes No (*go to Question 42*) Unknown (*go to Question 42*)

If yes, please select medications:

- | | | |
|--|---|--|
| <input type="checkbox"/> ACE inhibitor | <input type="checkbox"/> Antihypertensives | <input type="checkbox"/> Magnesium sulphate |
| <input type="checkbox"/> Glyceryl trinitrate | <input type="checkbox"/> Nifedepine | <input type="checkbox"/> Salbutamol |
| <input type="checkbox"/> Ritodrine | <input type="checkbox"/> Other tocolytic | <input type="checkbox"/> Steroids other than fetal lung maturation |
| <input type="checkbox"/> Valproate | <input type="checkbox"/> Anticonvulsant/other | <input type="checkbox"/> Infertility treatment |
| <input type="checkbox"/> Antiemetics | <input type="checkbox"/> Antibiotics | <input type="checkbox"/> Antidepressants |
| <input type="checkbox"/> Sedatives or anxiolytics | <input type="checkbox"/> Indomethacin | <input type="checkbox"/> NSAID/other |
| <input type="checkbox"/> Aspirin | <input type="checkbox"/> Clexane | <input type="checkbox"/> Heparin |
| <input type="checkbox"/> Warfarin | <input type="checkbox"/> Narcotics | <input type="checkbox"/> Non-narcotic analgesia |
| <input type="checkbox"/> Other <i>Please indicate:</i> _____ | | |

42) Was folic acid taken pre pregnancy?

- Yes No Unknown

43) Was folic acid taken during the first trimester

Yes

No

Unknown

Labour and Birth

(This section is not required for terminations of pregnancy for maternal psychological reasons)

44) Date of admission to hospital for birth episode

Date: _____

Unknown

Time: _____

Unknown

45) Primary caregiver at onset of labour

Obstetrician

Midwife

General Practitioner

No intrapartum care provider

Unknown

Other: _____

46) Onset of labour

Spontaneous (*go to Question 47*)

Induced

No labour (*go to Question 50*)

Unknown (*go to Question 47*)

If induced, please provide the following information:

a) Date of induction of labour: _____

Unknown

b) Time of induction of labour: _____

Unknown

c) Specify methods used to induce labour

Oxytocin

Prostaglandins

Artificial rupture of membranes (ARM)

Balloon

Unknown

Other: _____

d) Main indication for induction

Prolonged pregnancy

Prelabour rupture of membranes

Diabetes

Hypertensive disorders

Multiple pregnancy

Chorioamnionitis (includes suspected)

Cholestasis of pregnancy

Antepartum haemorrhage

Maternal age

Body Mass Index (BMI)

Maternal mental health indication

Previous adverse perinatal outcome

Other maternal obstetric or medical indication

Fetal compromise (includes suspected)

Fetal growth restriction (includes suspected)

Fetal macrosomia (includes suspected)

Fetal death

Fetal congenital anomaly

Administrative or geographical indication

Maternal choice in the absence of any obstetric, medical, fetal, administrative, or geographical indication

Unknown

Other: _____

47) Labour augmentation

Yes

No (*go to Question 48*)

Unknown (*go to Question 48*)

If yes, please select method used to augment labour

Oxytocin

Prostaglandins

Artificial rupture of membranes (ARM)

Please specify the day of ARM

Date: _____

Unknown

Other: _____

48) Analgesia during labour

Yes

No (*go to Question 49*)

Unknown (*go to Question 49*)

If yes, please indicate type of analgesia administered

Nitrous oxide

Systemic opioids

Epidural or caudal

Spinal

Combined spinal/epidural

Unknown

Other: _____

49) Did part of labour occur in bath/pool Yes No (*go to Question 50*) Unknown (*go to Question 50*)

If yes, was the baby born in the bath/pool? Yes No Unknown

50) Was there fetal monitoring during the labour Yes No (*go to Question 51*) Unknown (*go to Question 51*)

If yes, what was the method of fetal monitoring

- Intermittent auscultation Admission cardiotocography Intermittent cardiotocography
 Continuous external cardiotocography Internal cardiotocography (scalp electrode) Fetal blood sampling
 Unknown Other: _____

51) What was the method of birth of this baby

- Vaginal- non-instrumental (*go to Question 52*)
 Vaginal- forceps (*go to Question 51a*)
 Vaginal- vacuum extraction (*go to Question 51a*)
 Vaginal- forceps and vacuum extraction (*go to Question 51a*)
 Planned caesarean- no labour (*go to Question 51b*)
 Planned caesarean- labour (*go to Question 51b*)
 Unplanned caesarean- labour (*go to Question 51b*)
 Unplanned caesarean- no labour (*go to Question 51b*)
 Unknown (*go to Question 52*)

a) Was anaesthetics administered? Yes No Unknown

If yes, please select which method

- Local anaesthetic to perineum Pudendal block Epidural or caudal block
 Spinal block General anaesthesia Combined spinal-epidural block
 Unknown Other: _____

b) What was the main indication for caesarean

- Fetal compromise Suspected fetal macrosomia Malpresentation
 Lack of progress; less than or equal to 3cm cervical dilatation Lack of progress in the first stage; greater than 3cm to less than 10cm cervical dilatation Lack of progress in the second stage
 Placenta praevia Placental abruption Vasa praevia
 Antepartum/intrapartum haemorrhage Multiple pregnancy Unsuccessful attempt at assisted delivery
 Cord prolapse Previous adverse perinatal outcome Previous caesarean section
 Previous severe perineal trauma Previous shoulder dystocia Maternal choice in the absence of any obstetric, medical, surgical, psychological indications
 Other: _____

i) Were forceps or vacuum tried first?

- Forceps Vacuum Forceps and vacuum
 No instrumental attempted before caesarean Unknown

ii) Was anaesthetics administered? Yes No Unknown

If yes, please select which method

- Local anaesthetic to perineum Pudendal block Epidural or caudal block
 Spinal block General anaesthesia Combined spinal-epidural block
 Unknown Other: _____

52) What was the birth presentation

- Vertex Breech Face
Brow Unknown Other:
-

53) Complications in labour/birth

- Yes No (*go to Question 54*) Unknown (*go to Question 54*)

If yes, please indicate relevant option

- APH Cord entanglement/prolapse Meconium stained liquor
Shoulder dystocia Fetal bradycardia Failure to progress/dystocia
Non-reassuring CTG Unknown Other:
-

54) Labour and membrane rupture duration

- a) First stage of labour duration: _____ hours _____ minutes Unknown
b) Second stage of labour duration known: _____ hours _____ minutes Unknown
c) Duration of membrane rupture prior to birth: _____ days _____ hours _____ minutes Unknown

55) Were antibiotics given in labour

- Yes No (*go to Question 56*) Unknown (*go to Question 56*)

a) If yes, what was the indication?

- Group B streptococcus Prolonged rupture of membranes Clinical chorioamnionitis
Suspected or confirmed infection Unknown Other _____

b) Date antibiotics given: _____ Unknown

Baby Resuscitation at Birth

(This section is not required for terminations of pregnancy for maternal psychological reasons)

56) Apgar scores

Please indicate a score between 1-10 with no decimals

- a) 1 min: _____ Unknown
b) 5 min: _____ Unknown
c) 10 min: _____ Unknown
d) 15 min: _____ Unknown

57) Did the baby receive any resuscitation at birth?

- Yes No (*go to Question 58*) Unknown (*go to Question 58*)

a) If yes, what was the outcome of the resuscitation?

- Baby resuscitated and stayed with mother Baby resuscitated and transferred to neonatal special or intensive care nursing Baby was no able to be resuscitated
Unknown

b) What was the method of resuscitation at birth?

- Continuous positive airway pressure with air CPAP with oxygen Endotracheal intubation and IPPR with oxygen
Endotracheal intubation and IPPR with air External cardiac massage and ventilation Intermittent positive pressure respiration bag and mask with air

- Intermittent positive pressure respiration bag and mask with oxygen
- Medications
Which medications?
- Adrenalin
- Narcotic antagonist
- Sodium bicarbonate
- Volume expander
- Unknown
- Other: _____
- Oxygen therapy
- Unknown
- Suction
- Other: _____

c) What was the professional category of the most senior staff member at the resuscitation?

- Student
- Paediatric registrar
- Consultant paediatrician
- Midwife
- Obstetric registrar
- Neonatal consultant
- Paediatric resident
- Obstetric consultant
- Unknown

58) Were cord gases taken at birth? Yes No (*go to Question 59*) Unknown (*go to Question 59*)

If yes, please indicate:

- a) ph- arterial: _____ Unknown
- b) Base deficit- arterial: _____ Unknown
- c) Lactate- arterial: _____ Unknown
- d) CO₂- arterial: _____ Unknown
- e) ph- venous: _____ Unknown
- f) Base deficit- venous: _____ Unknown
- g) Lactate- venous: _____ Unknown
- h) CO₂- venous: _____ Unknown

Neonatal/Post Neonatal Care

59) Was the baby transferred from place of birth (e.g. via NETS) prior to death to a higher level of care? Yes No (*go to Question 60*) Unknown (*go to Question 60*)

a) If yes, what was the main reason for the transfer?

- Prematurity
If yes, please specify
- Less than 28 weeks gestation
- 28-31 weeks gestation
- 32-36 weeks
- Unknown
- Respiratory
If yes, please specify
- Hyaline membrane disease (respiratory distress syndrome)
- Meconium aspiration
- PPHN
- Pneumothorax
- Congenital adenomatoid lesion of the lung
- Tracheoesophageal fistula
- Other: _____
- Unknown
- Cardiac
If yes, please specify
- Coarctation of the aorta

- Transposition of the great arteries
- Tetralogy of Fallot
- Hypoplastic left heart
- Atrioventricular septal defect
- Other: _____
- Unknown

- Gastrointestinal
 - If yes, please specify*
 - Necrotising enterocolitis
 - Pyloric stenosis
 - Other: _____
 - Unknown

- Neurological
 - If yes, please specify*
 - HIE
 - Seizures
 - Intraventricular haemorrhage
 - Other intracranial haemorrhage
 - Neuromuscular disorder
 - Other: _____
 - Unknown

- Musculoskeletal
 - If yes, please specify*
 - Congenital diaphragmatic hernia
 - Gastroschisis
 - Omphalocele
 - Other: _____
 - Unknown

- Sepsis
 - If yes, please specify*
 - GBS
 - E. Coli
 - Other: _____
 - Unknown

- Metabolic
 - If yes, please specify*
 - Hypoglycaemia
 - Hyponatraemia
 - Other: _____
 - Unknown

- Haematology
 - If yes, please specify*
 - Rh isoimmunisation
 - ABO isoimmunisation
 - Alloimmune thrombocytopenia
 - Other: _____
 - Unknown

- Other: _____
- Unknown

b) On what date was the baby transferred: _____

Unknown

60) Neonatal Diagnosis (select all applicable)

- Prematurity
 - If yes, please specify*
 - Less than 28 weeks gestation
 - 28-31 weeks gestation
 - 32-36 weeks
 - Unknown

- Respiratory
If yes, please specify
- Hyaline membrane disease (respiratory distress syndrome)
 - Meconium aspiration
 - PPHN
 - Pneumothorax
 - Congenital adenomatoid lesion of the lung
 - Tracheoesophageal fistula
 - Other: _____
 - Unknown

- Cardiac
If yes, please specify
- Coarctation of the aorta
 - Transposition of the great arteries
 - Tetralogy of Fallot
 - Hypoplastic left heart
 - Atrioventricular septal defect
 - Other: _____
 - Unknown

- Gastrointestinal
If yes, please specify
- Necrotising enterocolitis
 - Pyloric stenosis
 - Other: _____
 - Unknown

- Neurological
If yes, please specify
- HIE
 - Seizures
 - Intraventricular haemorrhage
 - Other intracranial haemorrhage
 - Neuromuscular disorder
 - Other: _____
 - Unknown

- Musculoskeletal
If yes, please specify
- Congenital diaphragmatic hernia
 - Gastroschisis
 - Omphalocele
 - Other: _____
 - Unknown

- Sepsis
If yes, please specify
- GBS
 - E. Coli
 - Other: _____
 - Unknown

- Metabolic
If yes, please specify
- Hypoglycaemia
 - Hyponatraemia
 - Other: _____
 - Unknown

- Haematology
If yes, please specify
- Rh isoimmunisation
 - ABO isoimmunisation
 - Alloimmune thrombocytopenia

- Other: _____
 Unknown
 Other: _____
 Unknown

61) Did the baby receive any neonatal treatment Yes No (*go to Question 62*) Unknown (*go to Question 62*)

If yes, please specify

- | | | |
|--|--|---------------------------------------|
| <input type="checkbox"/> IV therapy | <input type="checkbox"/> Antibiotics | <input type="checkbox"/> Nitric Oxide |
| <input type="checkbox"/> Inotropes | <input type="checkbox"/> Mechanical ventilation | <input type="checkbox"/> Phototherapy |
| <input type="checkbox"/> Extracorporeal membrane oxygenation | <input type="checkbox"/> Therapeutic hypothermia | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Other: _____ | | |

62) Were active life supporting measures withdrawn? Yes No (*go to Question 63*) Unknown (*go to Question 63*)

- a) If yes, on what date were the measures withdrawn: _____ Unknown
- b) At what time were the measures withdrawn: _____ Unknown

63) Please provide summary of significant neonatal events

64) Place of neonatal/post neonatal death

- | | | |
|----------------------------------|---|--|
| <input type="checkbox"/> Home | <input type="checkbox"/> Emergency department | <input type="checkbox"/> NICU |
| <input type="checkbox"/> PICU | <input type="checkbox"/> SCN | <input type="checkbox"/> Paediatric ward |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> Other: _____ | |

Maternal Investigations after Stillbirth or Neonatal Death

(This section is not required for terminations of pregnancy for maternal psychological reasons)

65) Maternal blood tests

a) Was a full blood count performed? Yes No Unknown

If yes, please indicate:

- i) Hb: _____ g/L Unknown
- ii) WCC: _____ x10⁹ Unknown
- iii) Platelets: _____ x10⁹ Unknown

b) Was a blood group and antibody screen performed? Yes No Unknown

i) If yes, what was the blood group?

- | | | |
|--------------------------------------|-------------------------------------|--------------------------------------|
| <input type="checkbox"/> A positive | <input type="checkbox"/> A negative | <input type="checkbox"/> AB positive |
| <input type="checkbox"/> AB negative | <input type="checkbox"/> B positive | <input type="checkbox"/> B negative |
| <input type="checkbox"/> O positive | <input type="checkbox"/> O negative | <input type="checkbox"/> Unknown |

ii) What was the antibody screen?

Positive

Negative

Unknown

Please specify antibody:

- D RHESUS
- C (LITTLE C) RHESUS
- K- KELL
- C (BIG C) REHSUS
- E (LITTLE E) RHESUS
- E (BIG E) RHESUS
- JKA- KDD
- JKB- KDD
- FYA- DUFFY
- FYB- DUFFY
- Other: _____

Please note, Question c) is a core test for all stillbirths

c) Was testing for maternal fetal haemorrhage performed? Yes No Unknown

If yes, please indicate:

i) Date tests performed: _____ Unknown

ii) What was the results of testing for maternal fetal haemorrhage? Positive Negative Unknown

iii) Please state which test was performed to detect maternal fetal haemorrhage

Kleinhauer-Betke

Flow cytometry

Unknown

Other: _____

iv) Was the estimated fetal to maternal transfusion volume more than 1 ml? Yes No Unknown

If yes, what was the estimated volume of maternal transfusion?: _____

d) Renal function tests? Yes No Unknown

If yes, please indicate:

i) Creatinine: _____ umol/L Unknown

ii) Uric acid (Urate): _____ mmol/L Unknown

iii) Urea: _____ mmol/L Unknown

e) Liver function test Yes No Unknown

If yes, please indicate:

i) AST: _____ umol/L Unknown

ii) ALT: _____ U/L Unknown

iii) Bilirubin Total: _____ umol/L Unknown

f) HBA1c? Yes No Unknown

If yes, what was the result: _____ mmol/mol or % or Unknown

g) Thyroid function test? Yes No Unknown

If yes, please indicate:

i) TSH: _____ mU/L Unknown

ii) Free T4: _____ pmol/L Unknown

h) Bile acids? Yes No Unknown

If yes, please indicate:

i) Results: _____ umol/L Unknown

ii) Type of test Fasting Non-fasting Unknown

i) CMV Yes No Unknown

If yes, please indicate:

i) CMV-IgM result Reactive Non-reactive Unknown

ii) CMV-IgG result Reactive Non-reactive Unknown

iii) CMV avidity testing Yes No Unknown
If yes, result?: _____

j) Toxoplasma Yes No Unknown
If yes, please indicate:
 i) Toxoplasma- IgM result Reactive Non-reactive Unknown
 ii) Toxoplasma- IgG result Reactive Non-reactive Unknown
 iii) Toxoplasma avidity testing Yes No Unknown
If yes, result?: _____

k) Parvovirus B19 Yes No Unknown
If yes, please indicate:
 i) Parvovirus B19- IgM result Reactive Non-reactive Unknown
 ii) Parvovirus B19-IgG result Reactive Non-reactive Unknown
 iii) Parvovirus B19 avidity testing Yes No Unknown
If yes, result?: _____

l) Rubella
 Performed at routine antenatal screen Yes No Unknown

If yes or performed at routine antenatal screen, please indicate result:

Immune Not immune Indeterminate Unknown

m) Syphilis serology
 Performed at routine antenatal screen Yes No Unknown

If yes or performed at routine antenatal screen, please indicate result:

Positive Negative Unknown

n) Thrombophilia tests at time of birth Yes No Unknown
If yes, please indicate:
 i) Anticardiolipin antibodies Positive Negative Unknown
 ii) Lupus anticoagulant Positive Negative Unknown
 iii) APC resistance Positive Negative Unknown

If positive, Factor V Leiden?

Yes
Result?
 Positive
 Negative
 Unknown

iv) AntiB2 glycoprotein-1antibodies Positive Negative Unknown
If yes, result?: _____

66) Was Thrombophilia testing undertaken around the time of the follow-up visit Yes No (*go to Question 67*) Unknown (*go to Question 67*)

If yes, please indicate:

a) Anticardiolipin antibodies Yes No Unknown

If yes, please indicate:

i) Date : _____ Unknown

ii) Results Positive Negative Unknown

iii) AntiB2 glycoprotein-1antibodies Yes No Unknown

If yes, please indicate:

(1) Date: _____ Unknown

(2) Results Positive Negative Unknown

67) Were there any other maternal investigations performed to investigate the cause of death Yes No (*go to Question 68*) Unknown (*go to Question 68*)

a) If yes, please specify other investigations: _____

b) If yes, please specify the results: _____

External Examination of the Baby, Cord, Placenta and Membranes by Clinician
(Core tests required for all stillbirths)

68) Was an external examination of the baby performed? Yes No (*go to Question 71*) Unknown (*go to Question 71*)

If yes, please indicate:

a) Were any external abnormalities identified on external examination of the baby? Yes No Unknown

If yes, please specify: _____

b) Length: _____ cm Unknown

c) Head circumference: _____ cm Unknown

69) Was an examination of the placenta, cord and membrane performed? Yes No (*go to Question 72*) Unknown (*go to Question 72*)

If yes, please indicate:

a) Placenta weight: _____ gm Unknown

b) Cord length: _____ cm Unknown

c) Were any placental abnormalities noted on external examination Yes No Unknown

If yes, please specify

- | | | |
|--|--|---|
| <input type="checkbox"/> Incomplete | <input type="checkbox"/> Retroplacental clot | <input type="checkbox"/> Gritty/Calcified |
| <input type="checkbox"/> Ragged membranes | <input type="checkbox"/> Offensive odour | <input type="checkbox"/> Vasa praevia |
| <input type="checkbox"/> Succenturiate lobe/bi-lobed | <input type="checkbox"/> Circumvallate | <input type="checkbox"/> Bipartite |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> Other: _____ | |

d) Were any features apparent in the umbilical cord? Yes No Unknown

If yes, please specify

- | | | |
|---|--|---|
| <input type="checkbox"/> Hyper-coiled appearance | <input type="checkbox"/> Hypo-coiled appearance | <input type="checkbox"/> Marginal cord insertion |
| <input type="checkbox"/> Velamentous cord insertion | <input type="checkbox"/> Abnormal cord length- short | <input type="checkbox"/> Abnormal cord length- long |
| <input type="checkbox"/> Unusual cord thickness- thin | <input type="checkbox"/> Unusual cord thickness- thick | <input type="checkbox"/> Meconium stained |
| <input type="checkbox"/> Two vessels in the cord | <input type="checkbox"/> True knot- loose | <input type="checkbox"/> True knot- tight |
| <input type="checkbox"/> Unknown | <input type="checkbox"/> Other: _____ | |

e) Was the cord wrapped around the neck or other structure? No Nuchal cord Unknown Other: _____

If yes to nuchal cord, how many times was the cord wrapped around the neck? _____ or Unknown

f) Were there any membrane abnormalities identified? Yes No Unknown

If yes, please specify

- | | | |
|--|---|--|
| <input type="checkbox"/> Abnormal colour- green | <input type="checkbox"/> Malodour | <input type="checkbox"/> Retro-membranous blood- fresh |
| <input type="checkbox"/> Retro-membranous blood- old | <input type="checkbox"/> Spotty (e.g. Amnion nodosum) | <input type="checkbox"/> Unknown |

Other: _____

70) External examination of the baby by expert in addition to clinician at birth?

Yes

No (*go to Question 73*)

Unknown (*go to Question 73*)

If yes, please indicate

a) External examination performed by

Perinatal/Paediatric pathologist

Pathologist other

Pathologist unspecified

Clinical geneticist

Paediatrician

Neonatologist

Unknown

Other: _____

b) Were abnormalities identified

Yes

No

Unknown

If yes, please specify: _____

Placental Histopathology and Autopsy

(This section is not required for terminations of pregnancy for maternal psychological reasons)

(Core tests required for all stillbirths)

71) Placental and cord histopathology

a) Placental histopathology

Not performed

Normal

Abnormal

Uncertain

Unknown

If abnormal, please specify

Funisitis

Chorioamnionitis

Acute villitis

Placental abscesses

Infarct- single

Infarct- multiple

Massive perivillous fibrin

Histiocytic intervillitis

Maternal floor infarction

Villitis of unknown aetiology

Fetal thrombotic vasculopathy

Retroplacental haemorrhage

Chorioangioma

Metastatic tumour

Haemosiderin laden macrophages

Unknown

Other : _____

b) Placental swab for culture

Not performed

No pathogen

Pathogen

Uncertain

Unknown

If pathogen found, please specify

Group B Streptococcus

Group A Streptococcus

Other Streptococcus

E coli

Trichomonas Vaginalis

Gardnerella Vaginalis

Chlamydia Trachomatis

Ureaplasma Urealyticum

Mycoplasma Hominis

Candida

Neisseria Gonorrhoea

Herpes

Pseudomonas

Klebsiella

Clostridium

Proteus

Bacteroids

Enterococcus

Fusobacterium

Enterobacterium

Hep A

Hep B

Hep C

HIV

Syphilis- Treponema Pallidum

Rubella

CMV

Toxoplasma Gondii

Parvovirus

Listeria

Varicella

Malaria

Echovirus

Chlamydia Psittaci

Haemophilus

Unknown

Other: _____

c) Other site culture taken by pathologist

Yes

No

Unknown

If yes, please specify

i) Site of other culture taken: _____

ii) Results of other culture taken

- No pathogen
 Pathogen
 Uncertain
 Unknown

If pathogen, please specify

- | | | |
|---|---|---|
| <input type="checkbox"/> Group B Streptococcus | <input type="checkbox"/> Group A Streptococcus | <input type="checkbox"/> Other Streptococcus |
| <input type="checkbox"/> E coli | <input type="checkbox"/> Trichomonas Vaginalis | <input type="checkbox"/> Gardbnerella Vaginalis |
| <input type="checkbox"/> Chlamydia Trachomatis | <input type="checkbox"/> Ureaplasma Urealyticum | <input type="checkbox"/> Mycoplasma Hominis |
| <input type="checkbox"/> Candida | <input type="checkbox"/> Neisseria Gonorrhoea | <input type="checkbox"/> Herpes |
| <input type="checkbox"/> Pseudomonas | <input type="checkbox"/> Klebsiella | <input type="checkbox"/> Clostridium |
| <input type="checkbox"/> Proteus | <input type="checkbox"/> Bacteroids | <input type="checkbox"/> Enterococcus |
| <input type="checkbox"/> Fusobacterium | <input type="checkbox"/> Enterobacterium | <input type="checkbox"/> Hep A |
| <input type="checkbox"/> Hep B | <input type="checkbox"/> Hep C | <input type="checkbox"/> HIV |
| <input type="checkbox"/> Syphilis- Treponema Pallidum | <input type="checkbox"/> Rubella | <input type="checkbox"/> CMV |
| <input type="checkbox"/> Toxoplasma Gondii | <input type="checkbox"/> Parvovirus | <input type="checkbox"/> Listeria |
| <input type="checkbox"/> Varicella | <input type="checkbox"/> Malaria | <input type="checkbox"/> Echovirus |
| <input type="checkbox"/> Chlamydia Psittaci | <input type="checkbox"/> Haemophilus | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Other: _____ | | |

- d) Genetic testing**
 Yes
 No
 Unknown

If yes, please specify the following

i) Culture karyotype

- Not performed
 Normal
 Abnormal
 Uncertain
 Unknown

Please specify abnormal or uncertain results: _____

ii) Chromosomal microarray

- Not performed
 Normal
 Abnormal
 Uncertain
 Unknown

Please specify abnormal or uncertain results: _____

iii) Other genetic testing (please specify): _____

- Not performed
 Normal
 Abnormal
 Uncertain
 Unknown

Please specify abnormal or uncertain results: _____

72) Autopsy

a) Were parents offered the option of an autopsy examination

- Yes (*go to Question 74ai-ii*)
 No (*go to Question 74aiii-iv*)
 Unknown (*go to Question 74b*)

i) Parental consent for an autopsy examination

- Yes- full (*go to Question (1)*)
 Yes- limited (*please describe autopsy limitations*)(*go to Question (1) and (3)*):

- No (*go to Question (2) and (3)*)
 Unknown (*go to Question 74b*)

(1) *If yes-full or yes-limited, please specify the following*

1. What were the autopsy results

- No abnormality
 Abnormal
 Inconclusive
 Unknown

If abnormal or inconclusive, please describe: _____

2. What was the autopsy examination and clinical diagnosis

- | | | | | |
|--|--|---|---|----------------------------------|
| <input type="checkbox"/> Confirms clinical diagnosis (no change in counselling for future pregnancies) | <input type="checkbox"/> Changes clinical diagnosis (diagnosis changed enough to alter counselling for future pregnancies) | <input type="checkbox"/> Additional information (clinical diagnosis not altered but additional) | <input type="checkbox"/> Additional information (clinical diagnosis not altered but additional clinical findings e.g. | <input type="checkbox"/> Unknown |
|--|--|---|---|----------------------------------|

from Pm information)

clinical findings e.g. Abnormalities)

Abnormalities)

(2) If no, please specify the following

1. What was the most relevant reason why the parents did not consent to an autopsy examination

- | | | | | |
|---|---|--|--|--|
| <input type="checkbox"/> Inexperience of staff in counselling about autopsy | <input type="checkbox"/> Lack of rapport with the parents | <input type="checkbox"/> Lack of diagnostic value in this case | <input type="checkbox"/> Staff workload | <input type="checkbox"/> Parent emotional distress |
| <input type="checkbox"/> Religious or cultural beliefs | <input type="checkbox"/> Time to receive results | <input type="checkbox"/> Negative perceptions in general about autopsy | <input type="checkbox"/> Multiple pregnancy fetocide | <input type="checkbox"/> Unknown |
- Other: _____

(3) If yes-limited or no, please provide comments on the barriers to approach and consent for autopsy in this case :

ii) Who sought consent for autopsy

- | | | | |
|---|----------------------------------|--|---|
| <input type="checkbox"/> Junior medical staff | <input type="checkbox"/> Midwife | <input type="checkbox"/> Nurse | <input type="checkbox"/> Obstetric specialist |
| <input type="checkbox"/> Obstetric registrar | <input type="checkbox"/> GP | <input type="checkbox"/> Paediatrician | <input type="checkbox"/> Unknown |
- Other: _____

If yes-limited or no, please provide comments on the barriers to approach and consent for autopsy in this case :

iii) Please indicate the most relevant reason from the clinical staff perspective why the option of an autopsy was not offered in this case

- | | | | | |
|---|---|--|--|--|
| <input type="checkbox"/> Inexperience of staff in counselling about autopsy | <input type="checkbox"/> Lack of rapport with the parents | <input type="checkbox"/> Lack of diagnostic value in this case | <input type="checkbox"/> Staff workload | <input type="checkbox"/> Parent emotional distress |
| <input type="checkbox"/> Religious or cultural beliefs | <input type="checkbox"/> Time to receive results | <input type="checkbox"/> Negative perceptions in general about autopsy | <input type="checkbox"/> Multiple pregnancy fetocide | <input type="checkbox"/> Unknown |
- Other: _____

iv) Please provide comments on the barriers to approach and consent for autopsy in this case:

b) Was a Babygram (skeletal survey) performed?

- Not performed
 Yes- No abnormality
 Yes- Abnormal
 Yes- Inconclusive
 Unknown

If yes-abnormal or yes-inconclusive, please specify results:

Baby Pathology and Imaging

(This section is not required for terminations of pregnancy for maternal psychological reasons)

Please note, Question 73 is a core test for all stillbirths

73) What were the clinical photographs?

- Not taken Normal Abnormal Unknown

If abnormal, please specify: _____

74) Swabs of ear and throat taken for culture?

- No (*go to Question 77*) Yes, no pathogens (*go to Question 77*) Yes, pathogen isolated

- Uncertain (*go to Question 77*) Unknown (*go to Question 77*)

If yes, pathogens isolated, please specify:

- | | | |
|---|---|---|
| <input type="checkbox"/> Group B Streptococcus | <input type="checkbox"/> Group A Streptococcus | <input type="checkbox"/> Other Streptococcus |
| <input type="checkbox"/> E coli | <input type="checkbox"/> Trichomonas Vaginalis | <input type="checkbox"/> Gardbnerella Vaginalis |
| <input type="checkbox"/> Chlamydia Trachomatis | <input type="checkbox"/> Ureaplasma Urealyticum | <input type="checkbox"/> Mycoplasma Hominis |
| <input type="checkbox"/> Candida | <input type="checkbox"/> Neisseria Gonorrhoea | <input type="checkbox"/> Herpes |
| <input type="checkbox"/> Pseudomonas | <input type="checkbox"/> Klebsiella | <input type="checkbox"/> Clostridium |
| <input type="checkbox"/> Proteus | <input type="checkbox"/> Bacteroids | <input type="checkbox"/> Enterococcus |
| <input type="checkbox"/> Fusobacterium | <input type="checkbox"/> Enterobacterium | <input type="checkbox"/> Hep A |
| <input type="checkbox"/> Hep B | <input type="checkbox"/> Hep C | <input type="checkbox"/> HIV |
| <input type="checkbox"/> Syphilis- Treponema Pallidum | <input type="checkbox"/> Rubella | <input type="checkbox"/> CMV |
| <input type="checkbox"/> Toxoplasma Gondii | <input type="checkbox"/> Parvovirus | <input type="checkbox"/> Listeria |
| <input type="checkbox"/> Varicella | <input type="checkbox"/> Malaria | <input type="checkbox"/> Echovirus |
| <input type="checkbox"/> Chlamydia Psittaci | <input type="checkbox"/> Haemophilus | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Other: _____ | | |

75) Magnetic resonance imaging?

- Not performed (*go to Question 78*) Normal (*go to Question 78*) Abnormal
- Inconclusive Unknown (*go to Question 78*)

If abnormal or inconclusive, please specify:

76) Were cord and cardiac blood samples taken?

- Yes, cord Yes, cardiac No (*go to Question 79*) Unknown (*go to Question 79*)

If cord or cardiac blood samples were taken, was a full blood count with smear done (nucleated red count)?

- Yes No Unknown

If yes, please specify:

- a) Hb: _____ g/L Unknown
- b) WCC: _____ x10⁹ Unknown
- c) Platelets: _____ x10⁹ Unknown

77) Genetic testing of the baby- tissue or blood?

- Yes No (*go to Question 80*) Unknown (*go to Question 80*)

If yes, please specify:

a) Specimen from the baby for the genetic testing

- Cord Blood Skin
- Cartilage Unknown Other: _____

b) Type of genetic testing

- Karyotype Chromosomal microarray Unknown Other: _____

What were the results of the testing?

- Normal Abnormal Uncertain Unknown

If abnormal or uncertain, please describe: _____

78) Were any other investigations performed?

- Yes No (*go to Question 81*) Unknown (*go to Question 81*)

If yes, please specify investigations and results:

Case Documents

79) Please attach an autopsy, placental pathology and other relevant pathology results

Case Summary

80) Please provide a brief summary of key clinical events including factors which you consider may have contributed to the death. Please also provide any information you think relevant that was not covered in the previous questions, which you consider may have contributed to the outcome.

Hospital Review Details

81) Was this case referred to the coroner?

- Yes No (*go to Question 84*) Unknown (*go to Question 84*)

If yes, was this the coroner's case?

- Yes No Unknown

Please provide details: _____

82) Sentinel event report

- Yes No (*go to Question 85*) Unknown (*go to Question 85*)

If yes, please provide details: _____

83) Root cause analysis report

- Yes No (*go to Question 86*) Unknown (*go to Question 86*)

If yes, please provide details: _____

84) Date scheduled for hospital committee review: _____ Unknown

85) Responsibility for the completion of the data

a) Name: _____

b) Designation: _____

c) Date completed: _____

Section 2: MATERNITY SERVICE REPORT

COMPLETE THIS SECTION AT PERINATAL MORTALITY COMMITTEE REVIEW

Mothers Surname: <i>(If multiple birth, indicate birth number of this baby)</i>	
Date of perinatal death	
Gestation	
Facility reporting	

Death certificate details:

- 1) Main disease or condition in fetus or infant: _____

- 2) Other diseases or conditions in fetus or infant: _____

- 3) Main maternal disease or condition affecting fetus or infant: _____

- 4) Other maternal diseases or conditions affecting fetus or infant: _____

- 5) Other relevant circumstances: _____

Classification of Cause of Death

- 6) **PSANZ Perinatal Death Classification** – Primary condition. Presumed at time of death (PSANZ-PDC)

Category classification

Please insert full numerical code _____

Please insert full text _____

NB. If stillbirth, go to question 8.

- 7) **PSANZ Neonatal Death Classification** – Primary condition. Presumed at time of death (PSANZ-NDC)

Category classification

Please insert full numerical code _____

Please insert full text _____

- 8) **Level of understanding of the diagnosis at time of death** (rated by clinician completing the death certificate)

Well understood

Poorly understood

Not understood

Not recorded

Unknown

- 9) **PSANZ Perinatal Death Classification** – Primary condition. (PSANZ-PDC)

Category classification

Please insert full numerical code _____

Please insert full text _____

10) Were any associated conditions present according to PSANZ-PDC which contributed to the death?

- Nil One Two
 Three Not Recorded Unknown

a) PSANZ Perinatal Death Classification (PSANZ-PDC) – Associated condition 1

Category classification

Please insert full numerical code _____

Please insert full text _____

b) PSANZ Perinatal Death Classification (PSANZ-PDC) – Associated condition 2

Category classification

Please insert full numerical code _____

Please insert full text _____

c) PSANZ Perinatal Death Classification (PSANZ-PDC) – Associated condition 3

Category classification

Please insert full numerical code _____

Please insert full text _____

NB. If stillbirth, go to question 13.

11) PSANZ Neonatal Death Classification – Primary condition. (PSANZ-NDC)

Category classification

Please insert full numerical code _____

Please insert full text _____

12) Were any associated conditions present according to PSANZ-NDC which contributed to the death?

- Nil One Two
 Three Not Recorded Unknown

a) PSANZ Neonatal Death Classification (PSANZ-NDC) – Associated condition 1

Category classification

Please insert full numerical code _____

Please insert full text _____

b) PSANZ Neonatal Death Classification (PSANZ-NDC) – Associated condition 2

Category classification

Please insert full numerical code _____

Please insert full text _____

c) PSANZ Neonatal Death Classification (PSANZ-NDC) – Associated condition 3

Category classification

Please insert full numerical code _____

Please insert full text _____

13) Was the perinatal death referred to the coroner?

Yes

No

Unknown

14) Please list any associated conditions present according to the PSANZ-NDC which contributed to the death (following the outline in question 2 including the sub classifications)

Factors Related to Care

1) Were factors relating to organisational and/or management identified? (e.g. inadequate supervision of staff, lack of appropriate clinical management protocols, lack of communication between services)

Yes

No (go to Question 5)

Unknown (go to question 5)

If yes, please specify each question based on the following rates:

1- Insignificant. Sub-optimal factors identified but unlikely to have contributed to the outcome

2- Possible- Sub-optimal factors identified might have contributed to the outcome

3- Significant. Sub-optimal factors identified were likely to have contributed to the outcome

4- Undetermined. Insufficient information available

5- Unknown

	Please rate	Please state the specific factors and include any relevant comments
<input type="checkbox"/> Poor organisational arrangements of staff		_____ _____ _____
<input type="checkbox"/> Inadequate education and training		_____ _____ _____
<input type="checkbox"/> Lack of policies, protocols or guidelines		_____ _____ _____
<input type="checkbox"/> Inadequate number of staff		_____ _____ _____

<input type="checkbox"/> Poor access to senior clinical staff		_____ _____ _____
<input type="checkbox"/> Failure or delay in emergency response		_____ _____ _____
<input type="checkbox"/> Delay in procedure (e.g. Caesarean section)		_____ _____ _____
<input type="checkbox"/> Inadequate systems/process for sharing of clinical information between services		_____ _____ _____
<input type="checkbox"/> Delayed access to test results or inaccurate results		_____ _____ _____
<input type="checkbox"/> Equipment (e.g. faulty equipment, inadequate maintenance or lack of equipment)		_____ _____ _____
<input type="checkbox"/> Building and design functionality (e.g. space, privacy, ease of access, lighting, noise, power failure, operating theatre in distant location)		_____ _____ _____
<input type="checkbox"/> Other: _____		_____ _____ _____
<input type="checkbox"/> Unknown		

2) Were factors relating to personnel identified? (staff factors relating to professional care and service provision)

- Yes No (*go to Question 6*) Unknown (*go to question 6*)

If yes, please specify each question based on the following rates:
1- Insignificant. Sub-optimal factors identified but unlikely to have contributed to the outcome
2- Possible- Sub-optimal factors identified might have contributed to the outcome
3- Significant. Sub-optimal factors identified were likely to have contributed to the outcome
4- Undetermined. Insufficient information available
5- Unknown

	Please rate	Please state the specific factors and include any relevant comments
<input type="checkbox"/> Knowledge and skills of staff were lacking		_____ _____ _____
<input type="checkbox"/> Delayed emergency response by staff		_____ _____ _____
<input type="checkbox"/> Failure to maintain competence		_____ _____ _____
<input type="checkbox"/> Communication between staff was inadequate		_____ _____ _____

<input type="checkbox"/> Failure to seek help/supervision		_____ _____ _____
<input type="checkbox"/> Failure to follow recommended best practise		_____ _____ _____
<input type="checkbox"/> Lack of recognition of complexity or seriousness of condition by care giver		_____ _____ _____
<input type="checkbox"/> Other: _____ _____ _____		_____ _____ _____
<input type="checkbox"/> Unknown		

3) Were barriers to accessing/engaging with care identified? (e.g. no, infrequent or late booking for antenatal care, women decline treatment/advice)

- Yes No (**go to Question 7**) Unknown (**go to Question 7**)

If yes, please specify each question based on the following rates:
1- Insignificant. Sub-optimal factors identified but unlikely to have contributed to the outcome
2- Possible- Sub-optimal factors identified might have contributed to the outcome
3- Significant. Sub-optimal factors identified were likely to have contributed to the outcome
4- Undetermined. Insufficient information available

	Please rate	Please state the specific factors and include any relevant comments
<input type="checkbox"/> No antenatal care		_____ _____ _____
<input type="checkbox"/> Infrequent or late booking		_____ _____ _____
<input type="checkbox"/> Declined treatment or advice		_____ _____ _____
<input type="checkbox"/> Obesity impacted on delivery of optimal care (e.g. USS)		_____ _____ _____
<input type="checkbox"/> Substance use		_____ _____ _____
<input type="checkbox"/> Family violence		_____ _____ _____

<input type="checkbox"/> Lack of recognition by the woman or family of the complexity or seriousness of the condition		_____ _____ _____
<input type="checkbox"/> Maternal mental illness		_____ _____ _____
<input type="checkbox"/> Cultural barriers		_____ _____ _____
<input type="checkbox"/> Language barriers		_____ _____ _____
<input type="checkbox"/> Not eligible to access free care		_____ _____ _____
<input type="checkbox"/> Environmental (e.g. isolated, long transfer, weather prevented transport)		_____ _____ _____
<input type="checkbox"/> Other: _____ _____ _____		_____ _____ _____
<input type="checkbox"/> Unknown		

Recommendations for Improvement

4) How many recommendations resulted from the review meeting: _____

5) Please list the recommendations and the action required

6) Has the action/s been completed?

Yes

No

Unknown

If yes, please specify the action taken and the date the action was taken:

If no, why has this action not been completed:

Further Comment

7) Please provide any further comments on factors which you consider may have contributed to the death:

Perinatal Mortality Review Administration Details

8) Location of perinatal mortality review: _____

9) Date of review: _____

10) Have the [parents been provided with an update on results as required?

11) Has the GP and other relevant care providers been sent a case summary?

12) Responsibility for completion of data

Name: _____

Designation: _____

Date completed: _____

RAPID REPORTING FORM FOR A PERINATAL DEATH - BABY

Please use the "Guidelines for the completion of the mother and baby forms following a perinatal death March 2016 Version 10" to help completion of this form. You can obtain these guidelines from www.otago.ac.nz/pmmrc

Both the PMMRC mother and baby forms need to be completed by the Lead Maternity Carer or other clinician for any baby dying from 20 weeks gestation (i.e.: $\geq 20^0$, or if **gestation is unknown** a birth weight $\geq 400\text{gm}$) including all terminations, to before 28 completed days of life (i.e.: up to midnight on the 27th day).

This Baby Form can be submitted electronically after submitting the Mother form.
(If sending in written forms please send this in with the Mother form) address and fax number at end of form.

PLEASE COMPLETE WITHIN 48 HOURS OF THE BABY'S DEATH IF POSSIBLE

Personally identifiable information (of the mother, baby or lead maternity carer) collected on this form will be kept confidential. The information included in reports by the PMMRC is grouped and non-identifiable.

1. Mother's NHI:

2. Baby's NHI:

3. Mother's first name(s): Surname:

Mother's other name(s):

4. Baby's first name(s): Surname:

Baby's other name(s):

5. Sex:

Male Female Indeterminate Unknown

6. Baby's ethnicity (*Select all relevant*)

New Zealand European

Māori

Samoan

Cook Island Māori

Tongan

Niuean

Chinese

Indian

Other (such as Dutch, Japanese, Tokelauan), Please state:

Source of ethnicity information: *(Select all relevant)*

- | | |
|--|---|
| <input type="checkbox"/> Parents | <input type="checkbox"/> LMC notes |
| <input type="checkbox"/> Family/Whanau | <input type="checkbox"/> Clinical notes |
| <input type="checkbox"/> DHB Patient Registration Form | <input type="checkbox"/> NHI details |
| <input type="checkbox"/> Other please state: _____ | |

7. Live or still birth *(Select one of the following)*

- Stillbirth
- Live birth
- Unknown

8. Was this birth the result of a termination of pregnancy?

Yes No Unknown

9. Date and time of birth:

Date: // (DD/MM/YYYY)

Time: : hrs (24hour Clock)

10. Gestation at birth:

week's days Unknown

Best estimate of gestational age based on:

- Ultrasound in first trimester
- Ultrasound \leq 20 weeks gestation
- Ultrasound > 20 weeks gestation
- Last menstrual period
- Clinical examination at birth

11. Baby's Birthweight:

gm Unknown

12. If this was multiple pregnancy birth order of the deceased fetus/baby:

First Second Other

13. When did death occur?

- Antepartum
- Intrapartum – first stage
- Intrapartum – second stage
- Intrapartum - Unknown
- Neonatal
- Unknown

(Answer Question 14 if stillbirth, if not go to Question 15)

14. Estimated gestational age at time of fetal death

week's days Unknown

(If live birth or unknown answer Question 15)

15. Place of death for live born babies:

- Home
- Hospital
- Other

If other please state:

(If "Hospital" selected in Question 15 answer the below)

Area of hospital where baby died

- Delivery suite
- Postnatal ward
- Neonatal unit
- Children's ward
- Operating theatre
- Antenatal ward
- Emergency department
- PICU
- Other

If other please state:

16. Baby Examination:

Were there any external abnormalities noted on external examination of the baby?

Yes No

If yes, please specify _____

17. Post-mortem examination:

Parents offered a post-mortem examination? Yes No Unknown

If yes, who discussed/offered the post-mortem? *(Please select all relevant)*

- | | |
|--|--|
| Fetal Medicine Specialist <input type="checkbox"/> | Paediatric/Neonatal SMO <input type="checkbox"/> |
| Perinatal Pathologist <input type="checkbox"/> | Paediatric Registrar <input type="checkbox"/> |
| Obstetric SMO <input type="checkbox"/> | Paediatric SHO <input type="checkbox"/> |
| Obstetric Registrar <input type="checkbox"/> | Midwife LMC <input type="checkbox"/> |
| Obstetric SHO <input type="checkbox"/> | Midwife Core <input type="checkbox"/> |

Other

If other please state: Yes No Unknown

If yes, did the Parents consent to a post-mortem?

Death referred to the Coroner?

18. If neonatal death date and time of death:

Date: / / (DD/MM/YYYY)

Time: : Hrs (24hour Clock)

19. Apgar scores:

1 minute
5 minutes
10 minutes
15 minutes
20 minutes

(If the score for 5 minutes is less than 9 then answer the 3 below)

20. Cord gases: Not taken

	Arterial	Venous
pH	<input type="text"/> . <input type="text"/> <input type="text"/>	<input type="text"/> . <input type="text"/> <input type="text"/>
Base deficit	+ / - <input type="text"/> <input type="text"/> . <input type="text"/>	+ / - <input type="text"/> <input type="text"/> . <input type="text"/>
CO ₂	<input type="text"/> <input type="text"/> . <input type="text"/>	<input type="text"/> <input type="text"/> . <input type="text"/>
Lactate	<input type="text"/> <input type="text"/> . <input type="text"/>	<input type="text"/> <input type="text"/> . <input type="text"/>

21. Was the baby resuscitated at birth?

Yes No Unknown

(If "Yes" for Question 21 select one of the below)

Baby resuscitated and transferred to another clinical care area

Baby unable to be resuscitated

22. Were maternal corticosteroids given antenatally?

Yes No Unknown

(If "Yes" is selected answer the below)

Course of corticosteroids started at what gestation? week's days

Was course of corticosteroids completed?

23. Was the baby transferred from their place of birth prior to death?

Yes No Unknown

(If "Yes" is selected for Question 23 answer the below)

24. Where was the baby transferred to? (Select one)

NICU/SCU* *Neonatal Intensive Care Unit/Special Care Unit

SCBU** **Special Care Baby Unit

Post natal ward

Home

Died in transfer

Tertiary Services

Other

If other please state:

(If baby not transferred after birth answer the below)

25. Why wasn't the baby transferred?

Died at place of birth

Died in birthing unit/theatre

Other If other please state:

26. Summary

Please provide any information you think relevant, that was not covered in the previous questions, which you consider may have contributed to the outcome.

Form completed by:

Name:

Designation:

**Contact details: Phone -
Email -**

Date:

Please send (mail or fax) the completed form to:

National Coordination Service
Perinatal and Maternal Mortality Review Committee (PMMRC)
Department of Obstetrics and Gynaecology
University of Auckland
Private Bag 92019
Auckland 1142
Phone: 09 923 4440 Fax: 09 305 59
2018

PMMRC

Perinatal and Maternal Mortality Review Committee

RAPID REPORTING FORM FOR A PERINATAL DEATH - MOTHER

Please use the "Guidelines for the completion of the mother and baby forms following a perinatal death March 2014 Version 10" to help completion of this form. You can obtain these guidelines from www.otago.ac.nz/pmmrc

Both the PMMRC mother and baby forms need to be completed by the Lead Maternity Carer or other clinician for any baby dying from 20 weeks gestation (i.e. $\geq 20^0$, or **if gestation is unknown** a birth weight $\geq 400\text{gm}$) including all terminations, to before 28 completed days of life (i.e. up to midnight on the 27th day).

This Mother form should be submitted electronically before the Baby form is submitted.

Compulsory entries are: - Number of babies born in this pregnancy, number of perinatal losses linked to this pregnancy and Mother's NHI

We understand that you may not know the answer to some of the questions but we would appreciate it if you can answer as much as possible.

If sending in written copies please send this together with the PMMRC Baby Form (see address and fax numbers at back of form).

PLEASE COMPLETE WITHIN 48 HOURS OF THE BABY'S DEATH IF POSSIBLE

Personally identifiable information (of the mother, baby or lead maternity carer) collected on this form will be kept confidential. The information included in reports by the PMMRC is grouped and non-identifiable.

1. How many perinatal losses are linked to this pregnancy
2. Mother's NHI:
3. First name(s): Surname:
Mother's other name(s):
4. Date of birth: // (DD/MM/YYYY)
5. Usual residential address at time of delivery:
Property /house name
Flat/Unit number
Street Number/rapid number (rural)
Street name
Suburb /locality
Town/City
Country (if not New Zealand)
Post Code

6. Ethnicity: (Select all relevant)

- New Zealand European
- Māori
- Samoan
- Cook Island Māori
- Tongan
- Niuean
- Chinese
- Indian
- Other (such as Dutch, Japanese, Tokelauan),

If other please state:

Please state the country of birth?

- New Zealand
- Australia
- England
- China
- India
- South Africa
- Samoa
- Cook Islands
- Other Please specify: _____

Source of ethnicity information: (Select all relevant)

- Woman
- Family/Whanau
- DHB Patient Registration Form
- Other please state: _____
- LMC notes
- Clinical notes
- NHI details

7. Maternal height cms **and weight** kg (earliest measured in pregnancy)

(If not available please measure height and weight)

8. Past obstetric history: previous pregnancies:

Gravidity: **Parity:** *(Do not include index pregnancy in parity. Multiple births counted as one)*

Unknown

Date of Delivery	Place of birth (Please state)	Gestation (weeks)	Pregnancy Outcome (see below for codes)	Method of delivery (see below for codes)	Birth weight	SGA <10 th centile	Complications (see below for codes)

Pregnancy Outcome – LB = Live born, SM = spontaneous miscarriage, TOP = termination of pregnancy, E = ectopic pregnancy, SB = stillbirth, END = early neonatal death (<7 days age), LND = late neonatal death (7 days – 27 days), CYD = Child and Youth Death (28 days – 24 years), U = unknown
Method of Delivery NVD = Normal vaginal delivery, OV = Operative vaginal delivery, VB = Vaginal breech, CS = Caesarean Section, U = unknown
Complications - NIL = No complications, HE = hyperemesis, APH = Ante partum haemorrhage/Abruption, CxS = cervical stitch, GDM = Gestational diabetes, PET = Pre-eclampsia, Other = please comment in summary section, U = unknown

***All the following questions relate to this pregnancy**

9. Family violence

Has mother suffered family violence during this pregnancy?

Yes No Not Asked Unknown

(If the answer was "Yes" to the above answer the question below)

Was she offered referral to a relevant support services?

Yes Yes but declined No Unknown

10. History of infertility for >12 months before this pregnancy:

Yes No Unknown

11. Fertility treatment for this pregnancy: (Select all relevant)

Artificial insemination - donor

Artificial insemination – husband/partner

Clomiphene citrate

Follicle-stimulating hormone

Intra-cytoplasmic sperm injection

In vitro fertilisation If yes, how many embryos were transferred?

Surgery to increase fertility

Insulin sensitisers e.g. Metformin,

Letrozole

Other

If other please state:

Was treatment in New Zealand? Yes No Unknown

If overseas, please state where _____

12. Intended place of birth:

- Home
- Birthing Unit
- Hospital level 1
- Hospital level 2
- Hospital level 3
- Other
- Unknown
- Not registered

Please state name of place/unit/hospital:

13. Actual place of birth:

- Home
- Birthing Unit
- Hospital level 1
- Hospital level 2
- Hospital level 3
- Other
- Fetus still in utero
- Unknown

Please state name of unit/hospital:

(If the intended place of birth is different to the actual place of birth then answer the below question)

14. When did mother's transfer to actual place of birth occur?

- Before labour
- In labour
- Unknown

15. Lead Maternity Carer

Please select the mother's lead maternity carer (LMC) at time of first registration and at birth?

(Select one in each column)

LMC at booking

LMC at birth*

- | | | |
|------------------------|--------------------------|--------------------------|
| Not registered | <input type="checkbox"/> | <input type="checkbox"/> |
| Self-employed midwife | <input type="checkbox"/> | <input type="checkbox"/> |
| DHB care | <input type="checkbox"/> | <input type="checkbox"/> |
| General Practitioner | <input type="checkbox"/> | <input type="checkbox"/> |
| Obstetrician (private) | <input type="checkbox"/> | <input type="checkbox"/> |
| Unknown | <input type="checkbox"/> | <input type="checkbox"/> |

***For 'LMC at booking' to be different to 'LMC at birth' a new registration must have been completed.**

16. Please indicate who was clinically responsible for the woman's care at time of birth *(Select one)*

- | | |
|------------------------|--------------------------|
| No care | <input type="checkbox"/> |
| Self-employed midwife | <input type="checkbox"/> |
| DHB care | <input type="checkbox"/> |
| General Practitioner | <input type="checkbox"/> |
| Obstetrician (private) | <input type="checkbox"/> |
| Unknown | <input type="checkbox"/> |

If clinical responsibility is different, to 'LMC at booking' when did this transfer of clinical responsibility occur?

- a) Antenatal** **b) Intrapartum**

17. Antenatal Procedures: *(Select all relevant)*

Yes

- | | | |
|--|--------------------------|---|
| Scan at ≤22 gestation | <input type="checkbox"/> | <i>(If "Yes")</i> How many scans? <input type="text"/> |
| 1 st trimester screening (MSS1) | <input type="checkbox"/> | |
| 2 nd trimester screening (MSS2) | <input type="checkbox"/> | |
| Anatomy scan | <input type="checkbox"/> | <i>(If "Yes")</i> Gestation of 1 st anatomy scan <input type="text"/> weeks <input type="text"/> days
<i>(If repeated)</i> gestation of 2 nd anatomy scan <input type="text"/> weeks <input type="text"/> days |
| Chorionic villus sampling | <input type="checkbox"/> | |
| Cervical suture | <input type="checkbox"/> | |
| Amniocentesis | <input type="checkbox"/> | |
| Doppler studies | <input type="checkbox"/> | |
| Growth scan | <input type="checkbox"/> | |
| External cephalic version | <input type="checkbox"/> | |
| Fetocide | <input type="checkbox"/> | |
| Amnioreduction | <input type="checkbox"/> | |
| Fetoscopic laser treatment | <input type="checkbox"/> | |
| Traditional massage | <input type="checkbox"/> | |
| Other | <input type="checkbox"/> | If other please state: <input type="text"/> |
| No antenatal procedures | <input type="checkbox"/> | |
| Unknown | <input type="checkbox"/> | |

18. a. Smoking at 1st registration with a LMC (cigarettes)?

Yes

No

Unknown

b. Smoking status at birth (cigarettes)?

Never smoked

Current non-smoker

Stopped before this pregnancy

Stopped < 16 weeks gestation

Stopped ≥16 weeks gestation

Previous status unknown

Current smoker

How many cigarettes per day Unknown

Smoking status unknown

c. Smoking cessation support?

No

Yes – by LMC/clinician only

Yes – referred to external agent

Offered but declined

Unknown

19. Maternal use of alcohol and other drugs:

Yes

No

Unknown

(If “Yes” select all drugs used by mother during this pregnancy)

	during 1st trimester	month prior to birth	Describe
Alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Amphetamine/P	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Cocaine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Ecstasy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Hallucinogens	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
“Herbal highs”	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Synthetic cannabis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Marijuana	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Opiates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Methadone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Petrol/paint/glue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

If other please state:

20. Antenatal visits before fetal death/or delivery:

a. Total number of visits from antenatal record

Unknown

b. Gestation at first antenatal visit with LMC:

weeks

Unknown

c. Gestation at first antenatal visit with any health provider:

weeks

Unknown

21. Mother's clinical history (including any diagnoses made in this pregnancy)

(Please answer all questions)

	Yes	No	Unknown
a. Asthma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(If "Yes" answered for part b answer the below)

- Type 1 diabetes
- Type 2 diabetes
- Impaired glucose tolerance

c. Epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Heart condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(If "Yes" selected for part d answer the below)

- Congenital heart condition
- Rheumatic heart disease
- Coronary artery disease
- Other cardiac condition - if other please state:

e. Thyroid abnormality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-------------------------------	--------------------------	--------------------------	--------------------------

(If "Yes" answered for part e answer the below)

- Hypothyroidism
- Hyperthyroidism
- Other - if other please state:

f. Inflammatory bowel disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Systemic lupus erythematosus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Other autoimmune disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Mental health disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(If "Yes" answered for part i answer the below)

- Depression
- Psychotic disorder
- Other - if other please state:

j. Renal disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Venous thromboembolism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Blood disorders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(If "Yes" answered for part l answer the below)

- Anaemia
- Thalassaemia trait
- Thrombophilia
- Other - if other please state:

m. Hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
------------------------	--------------------------	--------------------------	--------------------------

(If "Yes" answered for part m answer the below)

- Chronic/essential hypertension
- Secondary hypertension

Mother's clinical history *continued*

	Yes	No	Unknown
n. Cervical surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Urinary tract infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Uterine abnormality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. Uterine surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Other	<input type="checkbox"/>		

If other please state:

22. a. Screening for diabetes in pregnancy:

Yes	No	Unknown	Declined
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

b. Gestational Diabetes confirmed

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

c. Laboratory results

i) HbA1c at booking

Result: _____ mmol/mol Date __/__/__

ii) HbA1c (≥ 20 weeks) *(record highest result)*

Result: _____ mmol/mol Date __/__/__

iii) Polycose *(record highest result)*

Result: mmol/L Date __/__/__

iv) Glucose Tolerance Test *(record highest result)*

Result: Fasting: mmol/L 2hour: mmol/L Date __/__/__

23. Was this a multiple pregnancy?

Yes	No	Unknown
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(If "Yes" is answered for Question 23 answer the below)

1. Number of fetuses/babies at first ultrasound in pregnancy:

2. Number total number of babies born in this delivery, including stillbirths?

3. Was a fetal reduction performed? If YES, please describe:

4. What type of multiple:

Dichorionic diamniotic

Monochorionic diamniotic

Monoamniotic

Other Multiple – please describe chorionicity

Unknown

(If "Yes" selected in Question 23 answer Question 24)

24. If multiple pregnancy, please note NHI of all fetuses/babies:

First **NHI**

Second **NHI**

If more than two babies in this pregnancy please state other NHI:

25. Was there any vaginal bleeding related to this pregnancy? (Please complete both)

	Yes	No	Unknown
Before 20 weeks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
After 20 weeks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26. Obstetric conditions

Did the mother have any of these conditions in this pregnancy? (Select all relevant)

	Yes	No	Unknown
a. Hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(If "Yes" answered part "a" answer one of the below)

- Gestational hypertension
- Pre-eclampsia
- Pre-eclampsia with chronic hypertension
- Eclampsia
- Chronic hypertension
- Unspecified

b. Preterm labour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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c. Prolonged rupture of membranes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-----------------------------------	--------------------------	--------------------------	--------------------------

(If "Yes" answered to part "c" answer one of the below)

- Preterm - rupture < 37 weeks gestation
- Term - rupture ≥ 37 weeks gestation

d. Cholestasis of pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-----------------------------	--------------------------	--------------------------	--------------------------

e. Confirmed maternal infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
---------------------------------	--------------------------	--------------------------	--------------------------

(If "Yes" answered to part "e" answer the below)

Kind of infection:

- Pyelonephritis
- Lower urinary tract infection
- Other infection

If other please state:

f. Trauma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-----------	--------------------------	--------------------------	--------------------------

(If "Yes" answered to part "f" answer one of the below)

Kind of trauma:

- Vehicular
- Violent personal injury or assault
- Other (e.g. falls)

If other please state:

g. Other obstetric condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
------------------------------	--------------------------	--------------------------	--------------------------

If other please state:

h. Surgery in pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
-------------------------	--------------------------	--------------------------	--------------------------

Please state type of surgery:

27. Fetal growth restriction was suspected before fetal demise: (Select one)

- No
 Yes but no scan performed
 Yes and confirmed by scan
 Unknown
 Yes but normal growth on scan

a. Was a customised growth chart generated for this woman antenatally? **Yes** **No** **Unknown**

28. Folic Acid taken in this pregnancy? (Please complete both)

Yes **No** **Unknown**
 Folic Acid taken pre-pregnancy?
 Folic Acid taken first trimester?

29. Was there consultation with an obstetrician during pregnancy?

- Obstetrician was lead maternity carer
 Yes (If "Yes" please - select all relevant below)
 No
 Unknown

What was/were the reason(s) for the obstetrician consultation?

- Prolonged pregnancy (>41 weeks)
- Age of mother
- Breech
- Recurrent miscarriage
- Mother's request
- Stillbirth (this pregnancy)
- Previous Stillbirth
- Suspected size of fetus (If "Yes") large fetus small fetus
- Previous intrauterine growth restriction
- Previous Caesarean section
- Renal
- Cardiac
- Hypertension
- Prolonged rupture of membranes
- Cholestasis
- Other medical Please specify: _____
- Surgery in pregnancy
- Significant infection
- Multiple pregnancy
- Antepartum haemorrhage
- Diabetes
- Unstable lie
- Fetal Abnormality
- Raised BMI
- Other reason

If other please state:

30. Was the mother referred to any other healthcare services (apart from midwifery & obstetrics) during pregnancy?

Yes No Unknown

(If "Yes" answered to Question 30 answer the below – select all relevant)

Medical (includes MFM, non-obstetric specialists)

Mental health

Drug and alcohol

Social

Other service

If other please state:

31. Induction Yes No Unknown

(If "Yes", please select all that apply)

a) Medication/method used

Balloon PG gel 1 mg

Cervidil PG gel 2 mg

Misoprostol – if yes dose: mcg PGE2 tablets

Mifegyne Oxytocin

Artificial rupture of membranes Time: :: 24 hour clock Date __/__/__

Other, please specify: _____

b) Reason for induction:

Post dates Intrauterine fetal death

Pre-eclampsia Intrauterine growth restriction

APH Fetal Abnormality

Diabetes Prolonged rupture of membranes

Maternal request

Other, please specify: _____

32. Augmentation: Yes No Unknown

(If "Yes", please select all that apply)

Medication/Method:

Artificial rupture of membranes Time: :: 24 hour clock Date __/__/__

Oxytocin

Other, please specify: _____

33. Analgesia in labour Yes No Unknown

(If "Yes" answer the below, select all relevant)

Opiate

Nitrous oxide

Epidural

TENS* *Transcutaneous electrical nerve stimulation

Unknown

Other Please specify: _____

b. Type of caesarean section

If the baby born by caesarean section, please state the type of caesarean section

Planned - no labour

Unplanned - no labour

Planned - during labour

Unplanned - during labour

c. Was an anaesthetic administered? Yes No Unknown

(If "Yes", please select one)

General

Local

Spinal

Other

Epidural

If other please state:

36. Maternal outcome:

Alive and generally well

Alive but with serious morbidity e.g. admitted to ICU, hysterectomy or stroke.

Dead *(Please add further details if morbidity or mortality has occurred)*

37. Placenta:

a) Placenta weight: gm or placenta not weighed Unknown

b) Placental examination: Not examined Normal Some abnormalities

(If "Some abnormalities" select all relevant)

Retroplacental clot

Gritty/ calcified

Circumvallate placenta

Other If other please state:

38. Umbilical cord examined? Yes No Unknown

(If "Yes" selected answer the below)

Any problems with cord? (Select all relevant) Yes No Unknown

True knot *(If selected answer)* tight knot loose knot

Cord round neck *(If selected answer)* tight around loose around

Cord round limbs or body *(If selected answer)* tight around loose around

Torsion/spring-like cord (e.g. hypercoiled)

Marginal/ velamentous insertion

Abnormal cord thickness *(If selected answer)* thin cord thick cord

Meconium stained

Tear in cord

2 vessels

Other abnormality If other please state:

39. Summary

Please provide any information you think relevant that was not covered in the previous questions, which you consider may have contributed to the outcome. *(Please continue over page)*

Form completed by:

Name:

Designation:

**Contact details: Phone-
Email-**

Date:

**LMC name and address if different to clinician
completing the form**

Please send (mail or fax) the completed form to:

National Coordination Service
Perinatal and Maternal Mortality Review Committee (PMMRC)
Department of Obstetrics and Gynaecology
University of Auckland
Private Bag 92019
Auckland
Phone 09 923 4440
Fax 09 303 5969

APPENDIX H

INSTRUCTIONS ON TAKING CLINICAL PHOTOGRAPHS

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

Purpose

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

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

Consent

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

Bereavement photographs may require verbal agreement that they are taken and provided (see local unit policy).

Identification

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

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

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

Setting

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

The setting should comply with Occupations Safety and Health regulations, such as Infection Control Guidelines, Work Place design, etc.

Scale

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

Technique

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

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

Magnification

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

Baby

The baby should be naked for all the photographs.

Position

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

General Comments

Additionally, staff should

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

AP View – Whole body frontal including limbs



- Tape measure to the left
- Palms facing up

PA View – Whole body back including limbs



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

Lateral view of the body



To stabilise:

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

Frontal view of the face



- Ensure tape measure is in the frame.

Right lateral views of the face



Left lateral views of the face



- Keep tape measure to the left of the frame to aid easy identification of the side being viewed.

Note: If there are any specific abnormalities these should be photographed individually, with a scale in view and the photograph labelled with the baby's identification.

APPENDIX I AUTOPSY CLINICAL SUMMARY FORM

Maternal Sticker

(Inc Name, DOB, UR, Address, Telephone Number)

Please attach the following:

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

Baby Details

Singleton **Multiple** **Baby number.....** (e.g. Twin 1)

UR number: **Sex** Male Female Undetermined

Gestational age wks days Birthweight gms Date & Time of birth:/...../.....;

Place of birth

Type of death: Fetal **Antepartum death** Unknown No Yes If yes estimated date of death/...../.....

Neonatal (NND) → NND date & time of death:/...../.....;

Death Certificate completed Yes No

Treatment or condition likely to cause hazard at autopsy

Hepatitis B Pos Tuberculosis HIV (Aids Virus) Other

Specify.....

Clinical summary (including details to be clarified at autopsy)

.....

.....

.....

.....

Provisional clinical diagnosis (to be completed by physician requesting autopsy)

1

2

3

4

Please list doctors to receive report

Name	Address
1
2

Consultant

Clinical contact **Telephone** **Pager**

(Please print)

Signature (person completing this form) **Date** / /

Print name

APPENDIX J - PERINATAL MORTALITY CLASSIFICATIONS – QUICK REFERENCE SHEET

PSANZ-PDC		
<p>1 Congenital Anomaly</p> <p>1.1 Structural anomaly</p> <p>1.11 Nervous system</p> <p>1.12 Cardiovascular system</p> <p>1.13 Genitourinary system</p> <p>1.14 Gastrointestinal system</p> <p>1.15 Musculoskeletal</p> <p>1.151 Congenital diaphragmatic hernia</p> <p>1.152 Gastroschisis/omphalocele</p> <p>1.16 Respiratory system (include congenital pulmonary airway malformation (CPAM))</p> <p>1.17 Haematological</p> <p>1.18 Multiple Congenital anomaly (no chromosomal/genetic cause or not tested)</p> <p>1.19 Other congenital abnormality</p> <p>1.192 Idiopathic hydrops fetalis</p> <p>1.193 Fetal tumour (include sacro-coccygeal teratoma)</p> <p>1.198 Other specified</p> <p>1.199 Congenital anomaly, unspecified</p> <p>1.2 Chromosomal anomaly</p> <p>1.21 Down syndrome (trisomy 21)</p> <p>1.22 Edward syndrome and Patau syndrome (trisomy 18, trisomy 13)</p> <p>1.23 Other trisomies and partial trisomies of the autosomes, not elsewhere classified (includes pathogenic duplications, unbalanced translocations and insertions)</p> <p>1.24 Monosomies and deletions from the autosomes, not elsewhere classified (includes pathogenic deletions e.g. 22q11.2 deletion syndrome (diGeorge syndrome), Wolff-Hirschorn syndrome, Cri-du-chat syndrome)</p> <p>1.25 Turner syndrome (monosomy X)</p> <p>1.26 Other sex chromosome abnormalities (e.g. Klinefelter syndrome)</p> <p>1.28 Other chromosomal abnormalities, not elsewhere specified (includes Fragile X syndrome, imprinting syndromes, triploidy)</p> <p>1.29 Unspecified</p> <p>1.3 Genetic anomaly</p> <p>1.31 Genetic condition, specified (e.g. Tay-Sachs disease; includes inborn errors of metabolism)</p> <p>1.32 Syndrome/association with demonstrated chromosomal/gene anomaly.</p> <p>1.39 Genetic condition, unspecified</p> <p>2 Perinatal Infection</p> <p>2.1 Bacterial</p> <p>2.11 Group B Streptococcus</p> <p>2.12 E coli</p> <p>2.13 Listeria monocytogenes</p> <p>2.14 Spirochaetal e.g. Syphilis</p> <p>2.18 Other bacterial</p> <p>2.19 Unspecified bacterial</p> <p>2.2 Viral</p> <p>2.21 Cytomegalovirus</p> <p>2.22 Parvovirus</p> <p>2.23 Herpes simplex virus</p> <p>2.24 Rubella virus</p> <p>2.25 Zika virus</p> <p>2.28 Other viral</p> <p>2.29 Unspecified viral</p> <p>2.3 Protozoal e.g. Toxoplasma</p> <p>2.5 Fungal</p> <p>2.8 Other specified organism</p> <p>2.9 Other unspecified organism</p> <p>3 Hypertension</p> <p>3.1 Chronic hypertension: essential</p>	<p>3.2 Chronic hypertension: secondary, e.g. renal disease</p> <p>3.3 Chronic hypertension: unspecified</p> <p>3.4 Gestational hypertension</p> <p>3.5 Pre-eclampsia</p> <p>3.6 Pre-eclampsia superimposed on chronic hypertension</p> <p>3.9 Unspecified hypertension</p> <p>4 Antepartum Haemorrhage (APH)</p> <p>4.1 Placental abruption</p> <p>4.2 Placenta praevia</p> <p>4.3 Vasa praevia</p> <p>4.9 APH of undetermined origin</p> <p>5 Maternal Conditions</p> <p>5.1 Termination of pregnancy for maternal psychosocial indications</p> <p>5.2 Diabetes</p> <p>5.21 Gestational diabetes</p> <p>5.22 Pre-existing diabetes</p> <p>5.3 Maternal injury</p> <p>5.31 Accidental</p> <p>5.32 Non-accidental</p> <p>5.4 Maternal sepsis</p> <p>5.5 Antiphospholipid syndrome</p> <p>5.6 Obstetric cholestasis</p> <p>5.8 Other specified maternal conditions</p> <p>5.81 Maternal suicide</p> <p>5.82 Other specified maternal medical or surgical conditions</p> <p>6 Complications of multiple pregnancy</p> <p>6.1 Monochorionic twins</p> <p>6.11 Twin to twin transfusion syndrome (TTTS)</p> <p>6.12 Selective fetal growth restriction (FGR) (i.e. affecting only one twin)</p> <p>6.13 Monoamniotic twins (including cord entanglement)</p> <p>6.18 Other</p> <p>6.19 Unknown or unspecified</p> <p>6.2 Dichorionic twins</p> <p>6.21 Early fetal death in a multiple pregnancy (<20 weeks gestation)</p> <p>6.22 Selective fetal growth restriction (FGR)</p> <p>6.28 Other</p> <p>6.29 Unknown or unspecified</p> <p>6.3 Complications of higher order multiples (3 or more fetuses)</p> <p>6.31 Twin to twin transfusion syndrome (TTTS)</p> <p>6.32 Selective fetal growth restriction (FGR)</p> <p>6.33 Monoamniotic multiples (including cord entanglement)</p> <p>6.34 Early fetal death in a multiple pregnancy (<20 weeks gestation)</p> <p>6.38 Other</p> <p>6.39 Unknown or unspecified</p> <p>6.4 Complications where chorionicity is unknown</p> <p>6.8 Other</p> <p>6.9 Unspecified</p> <p>7 Specific perinatal conditions</p> <p>7.1 Fetomaternal haemorrhage</p> <p>7.2 Antepartum cord or fetal vessel complications (excludes monochorionic twins or higher order multiples)</p> <p>7.21 Cord vessel haemorrhage</p> <p>7.22 Cord occlusion (True knot with evidence of occlusion or other)</p> <p>7.28 Other cord complications</p> <p>7.29 Unspecified cord complications</p> <p>7.3 Uterine abnormalities</p> <p>7.31 Developmental anatomical abnormalities (e.g. bicornuate uterus)</p> <p>7.38 Other</p> <p>7.39 Unspecified</p> <p>7.4 Alloimmune disease</p> <p>7.41 Rhesus isoimmunisation</p> <p>7.42 Other red cell antibody</p>	<p>7.43 Alloimmune thrombocytopenia</p> <p>7.48 Other</p> <p>7.49 Unspecified</p> <p>7.5 Fetal antenatal intracranial injury</p> <p>7.51 Subdural haematoma</p> <p>7.52 Fetal antenatal ischaemic brain injury</p> <p>7.53 Fetal antenatal haemorrhagic brain injury</p> <p>7.6 Other specific perinatal conditions</p> <p>7.61 Complications of antenatal, diagnostic or therapeutic procedures:</p> <p>7.611 Complications of prenatal diagnostic procedures (e.g. amniocentesis, chorionic villus sampling,) (e.g. rupture of membranes after amniocentesis)</p> <p>7.612 Complications of fetal ultrasound guided needle interventions (e.g. FBS/fetal transfusion, thoracocentesis, vesicocentesis, fetal cardiac valvoplasty, division of amniotic bands, fetal skin biopsy, unipolar/bipolar diathermy, RFA procedures)</p> <p>7.613 Complications of fetal shunt interventions (e.g. pleuroamniotic shunt, vesicoamniotic shunt)</p> <p>7.614 Complications of minimally invasive fetoscopic interventions (e.g. fetoscopic laser surgery for TTTS, FETO for CDH, laser ablation of posterior urethral valves)</p> <p>7.615 Complications of open maternal fetal surgery (e.g. open maternal fetal surgery for spina bifida)</p> <p>7.618 Other</p> <p>7.62 Termination of pregnancy for suspected but unconfirmed congenital anomaly.</p> <p>7.63 Amniotic band</p> <p>7.68 Other</p> <p>7.9 Unspecified</p> <p>8 Hypoxic peripartum death</p> <p>8.1 With intrapartum complications (sentinel events)</p> <p>8.11 Uterine rupture</p> <p>8.12 Cord prolapse</p> <p>8.13 Shoulder dystocia</p> <p>8.14 Complications of breech presentation</p> <p>8.15 Birth trauma</p> <p>8.16 Intrapartum haemorrhage</p> <p>8.18 Other</p> <p>8.2 Evidence of significant fetal compromise (excluding other complications)</p> <p>8.3 No intrapartum complications recognised and no evidence of significant fetal compromise identified</p> <p>8.9 Unspecified hypoxic peripartum death</p> <p>9 Placental dysfunction or causative placental pathology</p> <p>9.1 Maternal vascular malperfusion</p> <p>9.2 Fetal vascular malperfusion</p> <p>9.3 High grade villitis of unknown etiology (VUE)</p> <p>9.4 Massive perivillous fibrin deposition/maternal floor infarction</p> <p>9.5 Severe chronic intervillitis (Histiocytic intervillitis)</p> <p>9.6 Placental hypoplasia</p> <p>9.7 No causal placental pathology demonstrated, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)</p> <p>9.8 Placental pathological examination was not performed, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)</p> <p>9.9 Other placental pathology (e.g. multiple pathologies with evidence of loss of placental function leading to death)</p> <p>10 Spontaneous preterm labour or rupture of membranes (<37 weeks gestation)</p> <p>10.1 Spontaneous preterm</p> <p>10.11 With histological chorioamnionitis</p> <p>10.12 Without histological chorioamnionitis</p> <p>10.13 With clinical evidence of chorioamnionitis, no examination of placenta</p> <p>10.17 No clinical signs of chorioamnionitis, no examination of placenta</p> <p>10.19 Unspecified or not known whether placenta examined</p>

APPENDIX J - PERINATAL MORTALITY CLASSIFICATIONS – QUICK REFERENCE SHEET

<p>10.2 Spontaneous preterm preceded by premature cervical shortening</p> <p>11 Unexplained antepartum fetal death</p> <p>11.1 Unexplained antepartum fetal death despite full investigation</p> <p>11.2 Unclassifiable antepartum fetal death with incomplete investigation</p> <p>11.3 Unclassifiable antepartum fetal death due to unknown level of investigation</p> <p>12 Neonatal death without obstetric antecedent</p> <p>12.1 Neonatal death with no obstetric antecedent factors despite full investigation</p> <p>12.2 Neonatal death unclassifiable as to obstetric antecedent with incomplete investigation</p> <p>12.3 Neonatal death unclassifiable as to obstetric antecedent due to unknown level of investigation</p> <p style="text-align: center;">PSANZ-NDC</p> <p>1 Congenital Anomaly (Please refer to PSANZ PDC)</p> <p>2 Periviable infants (typically <24 weeks)</p> <p>2.1 Not resuscitated (including infants where there is an antenatal plan for no resuscitation at birth or in the circumstance of re-directed care)</p> <p>2.2 Unsuccessful resuscitation</p> <p>2.9 Unspecified or not known whether resuscitation attempted</p> <p>3 Cardio-respiratory disorders</p> <p>3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)</p> <p>3.2 Meconium aspiration syndrome</p> <p>3.3 Primary persistent pulmonary hypertension</p> <p>3.4 Pulmonary hypoplasia</p> <p>3.5 Pulmonary haemorrhage</p> <p>3.6 Air leak syndromes</p> <p>3.61 Pneumothorax</p> <p>3.62 Pulmonary interstitial emphysema</p> <p>3.68 Other</p> <p>3.7 Patent ductus arteriosus</p> <p>3.8 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)</p> <p>3.9 Other</p> <p>3.91 Neonatal anaemia/hypovolaemia</p> <p>4 Neonatal infection</p> <p>4.1 Congenital/Perinatal bacterial infection (early onset<48 hrs)</p> <p>4.11 Blood stream infection/septicaemia</p> <p>4.111 Positive culture of a pathogen</p> <p>4.112 Clinical signs of sepsis + ancillary evidence but culture negative</p> <p>4.12 Bacterial meningitis</p> <p>4.13 Bacterial pneumonia</p> <p>4.15 Multiple site bacterial infection</p> <p>4.18 Other congenital bacterial infection e.g. gastroenteritis, osteomyelitis, cerebral abscess</p> <p>4.19 Unspecified congenital infection</p> <p>4.2 Congenital/Perinatal viral infection</p> <p>4.3 Congenital fungal, protozoan, parasitic infection</p> <p>4.4 Acquired bacterial infection (late onset>48hrs).</p> <p>4.41 Blood stream infection/septicaemia</p> <p>4.411 Positive culture of a pathogen</p> <p>4.412 Clinical signs of sepsis + ancillary evidence but culture negative</p> <p>4.42 Bacterial meningitis</p> <p>4.43 Bacterial pneumonia</p> <p>4.48 Other acquired bacterial infection e.g. gastroenteritis, osteomyelitis</p> <p>4.49 Unspecified acquired infection</p> <p>4.5 Acquired viral infection</p> <p>4.6 Acquired fungal, protozoan, parasitic infection</p>	<p>5 Neurological</p> <p>5.1 Hypoxic ischaemic encephalopathy/Perinatal asphyxia</p> <p>5.2 Cranial haemorrhage</p> <p>5.21 Intraventricular Haemorrhage</p> <p>5.22 Subgaleal Haemorrhage</p> <p>5.23 Subarachnoid Haemorrhage</p> <p>5.24 Subdural Haemorrhage</p> <p>5.28 Other intracranial haemorrhage</p> <p>5.3 Post haemorrhagic hydrocephalus</p> <p>5.4 Periventricular leukomalacia</p> <p>5.8 Other</p> <p>6 Gastrointestinal</p> <p>6.1 Necrotising enterocolitis (NEC)</p> <p>6.2 Short gut syndrome</p> <p>6.3 Gastric or intestinal perforation (excluding NEC)</p> <p>6.4 Gastrointestinal haemorrhage</p> <p>6.8 Other</p> <p>7 Other</p> <p>7.1 Sudden unexpected death in infancy (SUDI)</p> <p>7.11 Sudden Infant Death Syndrome (SIDS)</p> <p>7.112 SIDS Category IA: Classic features of SIDS present and completely documented.</p> <p>7.113 SIDS Category IB: Classic features of SIDS present but incompletely documented.</p> <p>7.114 SIDS Category II: Infant deaths that meet category I except for one or more features.</p> <p>7.12 Unclassified Sudden Infant Death in the neonatal period</p> <p>7.121 Bed sharing</p> <p>7.122 Not bed sharing</p> <p>7.19 Unknown/Undetermined</p> <p>7.2 Multisystem failure</p> <p>7.21 Secondary to intrauterine growth restriction</p> <p>7.28 Other specified</p> <p>7.29 Unspecified/undetermined primary cause or trigger event</p> <p>7.3 Trauma</p> <p>7.31 Accidental</p> <p>7.32 Non accidental</p> <p>7.39 Unspecified</p> <p>7.4 Treatment complications</p> <p>7.41 Surgical</p> <p>7.42 Medical</p> <p>7.5 Unsuccessful resuscitation in infants of 28 weeks gestation or more without an obvious sentinel event</p> <p>7.8 Other specified</p> <p style="text-align: center;">PSANZ ASSOCIATED CONDITIONS Associated conditions for both stillbirths and neonatal deaths</p> <p>Categories 1 -11 PSANZ PDC</p> <p>13 Genetic testing results not diagnostic</p> <p>13.1 Copy number variant of unknown or uncertain significance</p> <p>13.2 No mutation identified matching phenotype</p> <p>13.3 Tested for genetic mutations but failed</p> <p>13.4 Not tested or not known if tested for genetic mutations</p> <p>14 Associated placental pathology</p> <p>14.1 Delayed villous maturation</p> <p>14.2 Large chorioangioma</p> <p>14.3 Early bleeding often leading to preterm prelabour ROM</p> <p>14.8 Other associated placental pathology</p> <p>15 Associated cord pathology</p> <p>15.1 True knot (excluding histological evidence of causation)</p>	<p>15.2 Hypercoiled cord</p> <p>15.3 Tethered cord</p> <p>15.4 Velamentous insertion</p> <p>15.8 Other cord associated cord pathology</p> <p>16 Fetal Growth Restriction</p> <p>16.1 Autopsy evidence (brain:liver ratio equal to or greater than 4:1)</p> <p>16.2 Antenatal ultrasound evidence of FGR</p> <p>16.3 Clinical examination of the baby (by paediatrician, pathologist)</p> <p>16.4 Birthweight (less than 10th centile for gestational age)</p> <p>16.41 Customised centiles</p> <p>16.42 Population centiles</p> <p>17 Maternal risk factors (optional category)</p> <p>17.1 Smoking</p> <p>17.2 Substance use</p> <p>17.3 High BMI</p> <p>17.4 Maternal mental health disorder</p> <p>17.5 Socioeconomic deprivation</p> <p>17.6 Refugee or asylum seeker</p> <p style="text-align: center;">Associated conditions for neonatal deaths only</p> <p>NDC Categories 1- 6</p> <p>In addition to the above for associated maternal/fetal conditions the NDC Categories 1- 6 can be used to assign associated neonatal conditions</p>
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APPENDIX K

MORTALITY AUDIT MEETING CODE OF PRACTICE DECLARATION (WHO)¹

In order to foster an environment of collaboration rather than blame, a written and agreed to code of practice may be helpful to establish by the Perinatal Mortality Audit Steering Committee, in discussion with facility staff and management. Having wording specific to each team is encouraged, but here is suggested short text that can be signed by each individual before each review meeting.

An attendance sheet could also be signed at the end of the meeting, to credit those who stayed and participate throughout the meeting.

To show respect for the babies and families we are responsible to look after, we, the staff of _____ **(name of facility)**, agree to respect the rules of good conduct during meetings reviewing death cases in our facility. We understand and appreciate that the results of these meetings will not result in punitive measures. The rules of our mortality audit meetings include:

- Participate actively in discussions
- Respect everyone's ideas and ways of expressing these
- Accept discussion and disagreement without verbal violence
- Respect the confidentiality of the discussions in the group
- Agree not to hide useful information or falsify information which could allow the understanding of the case under review
- Try (as much as possible as it is not easy) to accept that your own actions can be questioned
- Arrive on time to the audit meeting

Signed: _____ Date: _____

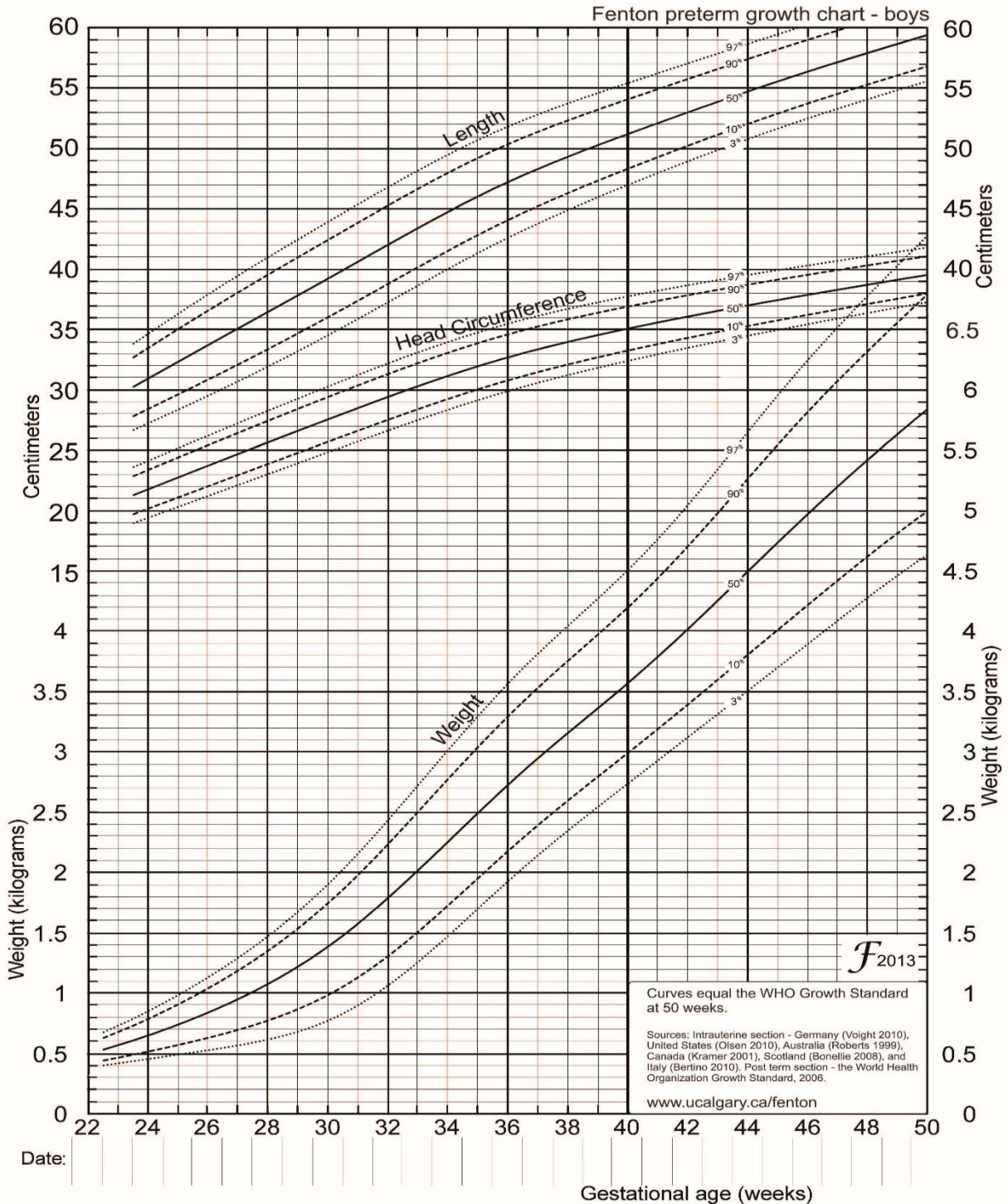
Signed: _____ Date: _____

Signed: _____ Date: _____

APPENDIX L

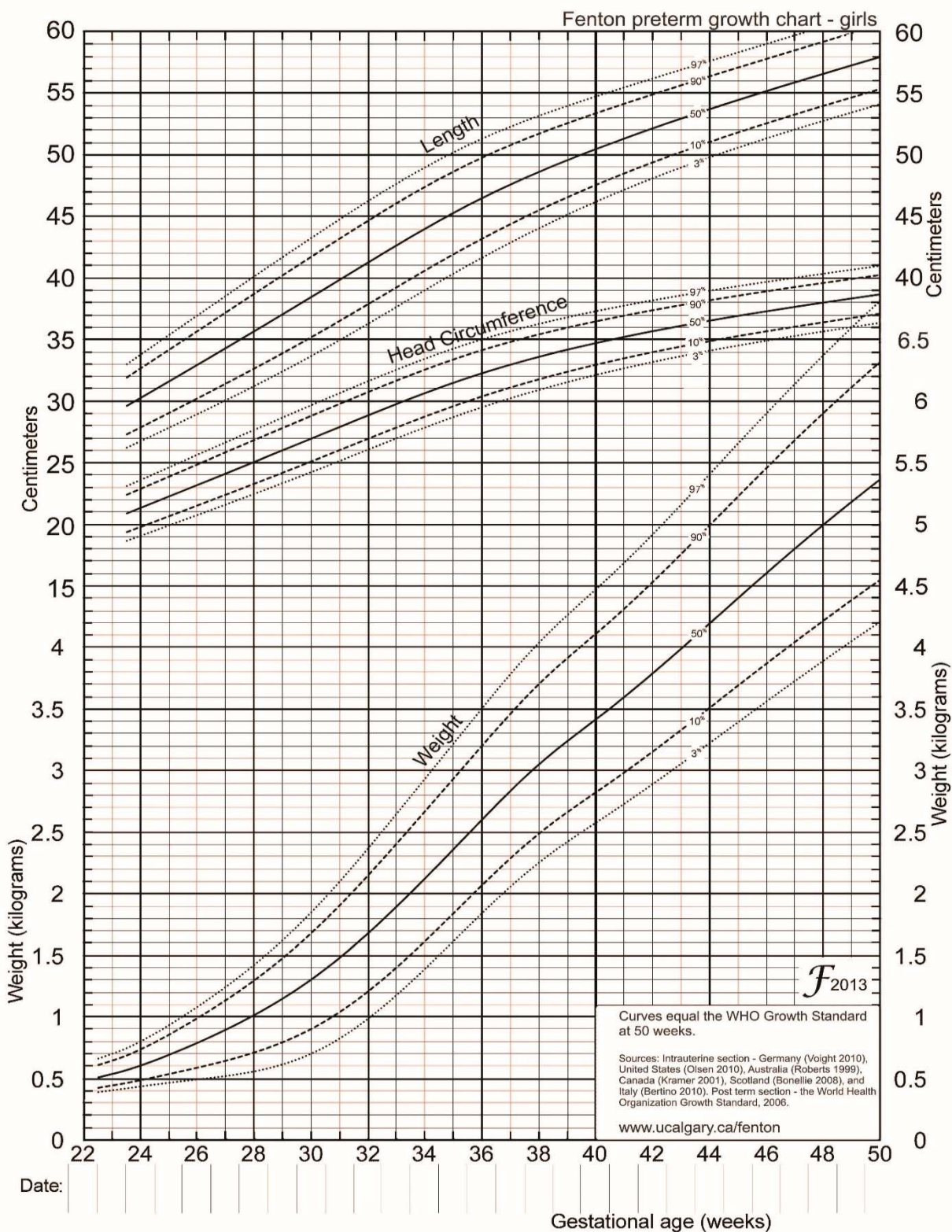
BIRTHWEIGHT PERCENTILES

Figure 1. Australian birthweight percentiles for boys



From: Fenton TR, Kim JH. A systematic review and meta-analysis to revise the Fenton growth chart for preterm infants. *BMC Pediatrics* 2013; **13**(1): 59

Figure 2. Fenton birthweight chart for girls



From: Fenton TR, Kim JH. A systematic review and meta-analysis to revise the Fenton growth chart for preterm infants. *BMC Pediatrics* 2013; **13**(1): 59 –check multiple /singletons

Autopsy

Trying to find answers
when your baby has died



Thinking about an autopsy

The death of your child is devastating. You might have known this was coming, or you might not have expected it at all, but nothing could have prepared you for how you would feel.

Unfortunately, at a time of great loss, you have to think about an autopsy, for your sake, for the sake of others and for the sake of your baby.

What is an autopsy?

An autopsy is an examination performed after your baby's death. It is done to find out as much as possible about why your baby died.

All autopsies are carried out by pathologists – doctors who specialise in this field.

Do I have a choice?

In some cases, no, your doctor will explain that an autopsy is essential.

But some people do have a choice. Some parents are able to decide whether or not they agree to their baby having an autopsy. These parents will also be able to decide what type of autopsy their child will have.

Why agree to an autopsy?

An autopsy may help you understand:

- why the baby died
- whether there were any genetic or physical problems
- whether the medical care was appropriate
- when the baby died and how many weeks along he or she was if your baby was stillborn.

An autopsy might also provide information that is important for the health and wellbeing of any other children you have now, or may have in the future.

Does an autopsy guarantee I'll find out why my baby died?

No. Unfortunately, there are no guarantees. But it does give you the best chance of finding out. And it can help to rule out possibilities, so you are not left wondering.

Where does an autopsy take place?

All autopsies are performed at a centre specialising in perinatal autopsies. This may be within the hospital where your baby was born, or it may be somewhere else. Your doctor or hospital staff should be able to tell you where your local centre is.

What happens during an autopsy?

There are different types of autopsy. The more thorough the autopsy, the better the chance of getting good information, and the greater the chance of helping you and others.

Full autopsy

A surgical cut (or incision) is made from the shoulder blade to just below the naval, which allows an examination of chest and abdominal organs. A small incision is also made at the back of the head to examine the brain. These cuts are similar to those used in surgery. Your baby's face, arms, legs, hands and feet will not be cut.

Your baby will be x-rayed, and the placenta will be examined.

Once the autopsy is over, all the wounds will be stitched up carefully. Once your baby is dressed, you will not be able to see the wounds.

Limited autopsy

If you have a choice, you can set limits on what can be examined. For example, you may decide to have only the abdominal organs examined, and not have incisions in the head or chest. Or you may decide that you don't want the placenta examined. It's up to you.

External examination only

If you have a choice, you may decide you want only an x-ray and external examination of your baby's body and the placenta, and not allow any incisions. This means that the pathologist would not be able to examine any internal organs.

Step-wise examination

If you have a choice, you may decide on a step-wise examination. You and the pathologist would agree on how the autopsy would be carried out.

The pathologist would carry out an initial examination. If the pathologist finds something that he or she thinks may give an answer as to why your baby died, they will continue. But if not, the autopsy will stop at the initial examination.

If you are interested in this option, talk to the pathologist.

What happens to my baby's organs?

Most babies have their organs replaced intact after an autopsy.

In some babies, a small sample of tissue is removed. This is about the size of a 10 cent piece, but round. It is examined under a microscope to give you further information, and is not replaced.

If your baby's brain needs to be examined closely, it will have to be removed and treated with chemicals to allow the proper examination. This takes about a week. If this happens, you can:

- delay burial or cremation until the brain is returned to your baby's body
- go ahead with the burial and cremation, and have a separate burial or cremation for your baby's organs later.

These are important decisions, and they are entirely up to you. Your doctor, pathologist or caregiver may be able to help you through this difficult process. It is a good idea to record your decisions and give them to your doctor, pathologist or caregiver in writing.

What can I expect after the examination?

Most people get to see and hold their baby after an autopsy if they want.

Your baby's colour will have changed – that happens to all babies after they have died. Your baby might feel different to hold. Your baby will be cold. There may be other changes as well – these depend on what examination has taken place. You may be able to see some stitches, although these can be covered by clothing if you wish.

You can get more information about seeing and holding your baby after an autopsy from nursing staff, the hospital social worker, or your funeral director.

When can I expect the results from the autopsy?

The doctor who cared for your baby will usually get a preliminary report in two to three weeks. It may take a few months to get the final report.

Sometimes, the results of an autopsy means the cause of death on your baby's death certificate will need to be changed. Although pathologists would want you to know if this happens, that might not happen.

How do I know if I am making the right decision?

It is a difficult decision, and there is no right or wrong answer. You must decide based on what feels right for you

Other people may have their opinions, but whatever decision you make it must be the right decision for you.

When do I need to decide?

In some cases, a delay may mean you get less accurate information, but not always. You need to decide when you are ready to decide and that may take some time.

Is there someone else I can talk to?

Yes. For further information and support, please contact:

- Sands/Rednose - *we will list phone numbers and websites for each jurisdiction*
- your general practitioner, obstetrician or midwife.





This brochure was produced by PSANZ SANDA
<https://psanz.com.au/>
Contact: stillbirthcre@mater.uq.edu.au

Bereavement services are available from:

Red Nose, a national not for profit organisation.
To access services in your State or Territory call their 24 hour
bereavement support line on 1300 308 307
For more information go to <https://rednose.com.au>

SANDS, a self-help support group comprised of parents who have
experienced the death of a baby. SANDS provides miscarriage,
stillbirth and newborn death support.
If you need support you can call 1300 0 SANDS (1300 0 72637).
For more information go to <https://www.sands.org.au>

APPENDIX N

INFORMATION FOR HEALTH PROFESSIONALS SEEKING CONSENT – OBTAINING PARENTAL CONSENT FOR THE AUTOPSY OF A BABY

OBTAINING PARENTAL CONSENT FOR THE AUTOPSY OF A BABY

IMPORTANT INFORMATION FOR THE HEALTH PROFESSIONAL SEEKING CONSENT

The death of a baby is a devastating time for parents and their family. In many situations the death is unexpected and the parent is confronted with both the shock of losing their baby, as well as the overwhelming emotions that follow. Research has indicated the importance of compassionate care and provision of information in the time surrounding the death of a baby*. One aspect of this is approaching bereaved parents to discuss the autopsy. The purpose of this pamphlet is to provide guidance to the health care professional in discussing stillbirth and neonatal autopsy with bereaved parents.

Each hospital should have its own policy and procedures regarding obtaining autopsy consent. This policy should initially be consulted.

Why is it important to seek parental permission for post-mortem examinations?

There are a number of common misunderstandings within the community regarding autopsy. Parents may be unwilling to give consent, due to concerns about organ retention or that they will not be able to see their baby following the examination.

Provision of information regarding the reasons why autopsies are performed may make it easier for parents to consent to its request.

When is the best time to ask?

The best time to request parental consent for a autopsy varies significantly from parent to parent and may also be dependent upon the circumstances surrounding the baby's death. For instance, if a baby dies in utero, the request may be made once the parent has processed the information that their baby has died and prior to delivery. In this instance, some parents may be too distressed immediately following the delivery, while others may not consent after a significant period of time due to protective instincts toward their baby. It is also commonplace for women to not comprehend that their unborn baby has really died until their baby is delivered, so mentioning autopsy prior to the birth of the baby could be very difficult in this circumstance.

Who should ask?

The person who may be best at judging the most suitable time to request consent is the health professional who knows the parents best. If this is not an option, consultation should be sought from a professional experienced in requesting autopsy.

Due to the sensitive nature of the issue, the person most appropriate to approach the parents would be the most senior doctor, consultant obstetrician or paediatrician, or the health professional that has an established relationship with the parents. In all cases, the health professional must be familiar with the process of seeking parental consent for post-mortem examination, and be competent in answering all of the parents'

questions relating to the procedure. Excellent interpersonal communication skills are essential to ensure that the request is delivered in a sensitive and informative manner.

Where should the discussion be held?

The most appropriate environment is in a quiet, private room away from other patients, relatives and hospital staff. It is not appropriate to request permission in a corridor, shared room or public waiting room.

How do I ask parents for permission for an autopsy?

The treating consultant should explain to the parents the clinical indications for conducting an autopsy. It is appropriate for the consultant to recommend that an autopsy be performed.

In seeking consent, the health professional should approach the discussion with honesty, integrity and respect.

Do not use terms such as fetus, products of conception or termination, or any words that may take away the humanity or individuality of the baby. Always try to use the baby's name, if culturally appropriate as this helps to validate the importance of the baby to the parents, as well as the significance of the loss.

Parents may require some time to make their decision, during which they may formulate several questions. It is important that these questions are accurately addressed. Parents may prefer that discussions about

autopsy are not conducted in the presence of their baby. Be aware of any cultural or religious beliefs concerning death and dying and show sensitivity to these beliefs when discussing autopsy with parents. On the other hand, do not assume to know what is required of religions with which you are unfamiliar. If you are uncertain, or do not know, it is reasonable to ask the parents what is required.

Be prepared to give parents written information on the autopsy procedure, but be aware of how much detail the parents wish to know before presenting this information. Few people are familiar with autopsy procedures. It is important to know that parents may require information several times due to deficits in information processing as the result of shock and grief.

Information you need to know

- Know where the baby will be taken for the autopsy and when s/he will be returned and available to the parents. Inform them that they will be able to see and hold their baby afterwards if they wish.
- Be able to give advice regarding the presentation of their baby after autopsy, for example, where the incisions will be made, their approximate size and that they will be stitched as in other surgical procedures. Parents should also be told that the baby's body may be more fragile than prior to the autopsy.
- Explain to the parents that the baby will still be returned to them for burial. You will need to explain that if an organ is to be retained, the parents can either delay the funeral, have a separate burial or return of cremated organs at a later time.
- Know, if possible, when the results of the autopsy will be available and if appropriate, make an appointment to see the parents to discuss these results. Give parents the contact details of who will

be able to keep them advised about the progress of the report.

The amount of information you give to parents will depend on their need for details. Prompts may be helpful as many parents feel that their questions may be too simple or trivial.

Parents should be provided with written information regarding post-mortem examinations to allow frequent reference. Please refer to the pamphlet: Explaining Autopsy: Information for Parents When Your Baby Has Died"

Before consenting, some parents may like the opportunity to discuss their feelings with other bereaved parents. Please refer to the PSANZ website on <http://www.psanz.com.au> for a list of relevant support groups for each state.

Discussing results

It is important to explain to parents that results may not be available for several weeks or months and that provisional results may be available sooner. In some cases, final results may not be available for up to 6 months or longer. This will help to reduce anxiety in the parent as they wait for the final report.

Ensure that when the results are discussed with parents, they are fully explained without the use of medical terminology. Allow time to answer all questions and concerns about the results. Do not edit or withhold information from parents.

Summary – Do's and Don'ts

- allow plenty of time with parents
- always be honest
- use the baby's name

- not use terms such as fetus, products of conception, termination, or any words that take away the individuality of the baby
- use a quiet, private place to conduct discussions with parents
- introduce details at the individual's pace and use language that parents understand
- provide written material

- make a note of what you say and of what the parents say
- give parents time to make their decision
- treat parents with respect.
- Do not get defensive. Parents may be looking to blame doctors and they may be feeling hostile and angry. These are real emotions that may help the bereaved parent to maintain a sense of control in an uncontrollable situation. These emotions must be acknowledged by you in an understanding and supportive manner.

Who Can Parents Contact if They Wish to Discuss Their Feelings with Other Bereaved Parents?

Provide SANDS and Red Nose information – whichever is relevant in each state.

*See PSANZ Perinatal Mortality Audit Guideline, Section 3 for list of references.

Acknowledgement: This brochure has been adapted from the original version written by Medical Students of the Graduate Medical Course, University of Queensland in conjunction with bereaved parents of the Stillbirth And Neonatal Death Support Group (Qld) Inc. including Miscarriage Support in May 1999.

APPENDIX O

RCOP GUIDELINES FOR AUTOPSY INVESTIGATION OF FETAL AND PERINATAL DEATH

All hospital post-mortem procedures are subject to parental consent that must not be exceeded. The following guidelines apply to an unrestricted post-mortem examination.

1. External examination

- body weight (to nearest gram, if less than 5kg)
- head circumference
- crown-heel and crown-rump lengths
- abdominal circumference
- foot length
- maceration (if baby is born dead)
- meconium staining
- full description (e.g. fontanelles, eyes, ears, nose, mouth and palate, digits, palmar creases, umbilicus and state of cord, genitalia, anus etc).
- dysmorphic features, congenital malformations and deformities
- other abnormalities

2. Internal examination

- comment on cranial, thoracic and abdominal cavities
- retention and fixation of the brain where practicable, subject to informed consent
- systematic description of major organs and tissues
- specific reference to ductus arteriosus and umbilical vessels
- weights of all major organs in digital balance (to 0.1g)
- comment on muscle and skeleton

3. Placenta

Placenta to be examined in all cases. A convenient method of ensuring the placenta is available in each case may be to send all placentas from babies admitted to the special care baby unit/neonatal intensive care unit to the pathology department. Whilst these need not be examined unless the baby dies, many departments would, in any case, consider it good practise to examine them.

- 3 dimensions
- trimmed weight
- umbilical cord (length, vessels, abnormalities)
- membranes (complete, incomplete, colour, abnormalities)
- fetal, maternal and cut surfaces

For further reference, please see: <http://www.rcpa.edu.au/Library/Practising-Pathology/Macroscopic-Cut-Up/Specimen/Gynaecology-and-perinatal/Placenta>

4. Histology

- at least one block of all major thoracic and abdominal organs (right and left lungs, heart, liver, kidney, thymus, adrenals and pancreas)
- costochondral junction (over 24 weeks' gestation)
- adequate sampling of brain (varies with case: minimum of one block from hind brain and one from cerebral hemispheres)
- adequate sampling of placenta (cord, membranes, focal lesions, grossly normal parenchyma to include amnion and decidua)

5. Chromosome analysis and genetic testing of the stillborn infant and placenta

If not previously performed antenatally via amniocentesis or other diagnostic fetal sample, a molecular karyotype (i.e. chromosomal microarray, CMA) should be performed for all stillborn infants¹⁻³. CMA is preferred over routine conventional G-banded karyotype for two main reasons: (i) high success rate with CMA as cell culture is not required (87.4% successful analysis with CMA vs. 70.5% with karyotype)²; (ii) better diagnostic yield with CMA compared with conventional karyotype (8.8% vs. 6.5% detection rate for genetic abnormalities for antepartum stillbirths respectively)². If additional DNA testing for single gene disorders (including metabolic conditions) is being considered, then a request for DNA storage can be made to the cytogenetic laboratory.

Suitable samples for CMA evaluation of the fetus include:

(i) **Fetal tissue** (e.g. cartilage from the patella or costochondral junction)

(ii) If consent for autopsy or fetal tissue collection has not been given, but cytogenetic testing is desired, then an **umbilical cord** sample (1cm segment taken from the placental end) or **placental biopsy** (1cm³ block of tissue taken from the fetal side of the placenta) would be suitable.

6. Other special procedures and investigations

- X-ray ideally should be undertaken for suspected skeletal dysplasia and multiple malformations
- photography mandatory for dysmorphic fetuses and babies without ante-mortem diagnosis; advised for other gross abnormalities
- bacteriology (blood/spleen/lung/CSF), if clinically indicated
- virology, if clinically indicated
- storage of fibroblasts/frozen tissue/DNA, if clinically indicated
- biochemistry, if clinically indicated
- haematology, if clinically indicated
- neuropathology, if clinical or radiological evidence of CNS pathology or the brain appears abnormal on external examination

7. Autopsy reports

- demographic details
- date of autopsy
- details of consent and any restrictions

- availability of clinical records at time of post-mortem, including anomaly scans if relevant
- clinical history
- systematic description of external, internal and placental examination and results of X-rays and other ancillary investigations
- summary of major findings including sex and apparent gestation, estimated timing of death in babies born dead, adequacy of growth and nutrition, presence/absence of congenital abnormalities, major pathological lesions, evidence of chronic stress or disease prior to death, placental examination
- commentary addressing the clinical questions and significance of pathological findings
- mode/cause of death
- record of photographs and any samples retained
- record of disposal of any tissues or samples
- a provisional report on the macroscopic findings should be issued within 24-48 hours of the autopsy, with histology and further investigations including chromosome analysis incorporated into a final report when available
- timely dispatch to clinicians with particular reference to the timing of postnatal appointments

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APPENDIX P

PLACENTA HISTOPATHOLOGY REPORTING FORM

This is a singleton or twin (monochorionic/dichorionic; monoamniotic/diamniotic) placenta with the following features:

Placental maturity: This is a mature/premature/immature placenta in keeping with ____ weeks gestation. There is placental dysmaturity (Yes/No)

Placental weight: _____g (____centile)

Fetoplacental weight ratio:

Placental cord diameter: _____mm

Placental hypoplasia (weight <10th centile for gestation and/or cord diameter <10th centile for gestation or <8 mm diameter at term): Present/Not identified

Placentomegaly (weight >90th centile for gestation): Present/Not identified

Placental vascular processes:

Maternal stromal-vascular lesions: Present/Not identified

Developmental changes: Superficial implantation: Present/Not identified

Changes of maternal malperfusion: Present/Not identified

Global changes:

Early (distal villous hypoplasia): Present/Not identified

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

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

Late (accelerated villous maturation): Present/Not identified

Increased syncytial knots (>30% villi): Present/Not identified

Segmental changes:

Villous infarct(s): Present/Not identified

Number:

Site:

Size:

Age:

Recent Established Variable:

Placental involvement: _____ %

Decidual arteriopathy: (Present/Not identified)

Site: Placental bed/Parietal membranes/Not Identified

Acute atherosclerosis: Present/Not identified

Fibrinoid necrosis: Present/Not Identified

Spiral artery remodelling: Present/Not Identified

Parietal mural hypertrophy: Present/Not Identified

Intramural trophoblast: third trimester: Present/Not Identified

Chronic perivasculitis: Present/Not Identified

Increased immature extravillous trophoblast: Present/Not Identified

Loss of maternal vascular integrity:

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

Retroplacental haemorrhage: Present/Not identified

Indentation: Present/Not identified.

Size:

Weight of separate blood clot: _____g

Compression of overlying placenta: Present/Not identified

Villous congestion/haemorrhage: Present/Not identified

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

Fetal stromal-vascular lesions:

Developmental:

Villous capillary lesions: Present/Not identified

Chorangioma: Present/Not identified

Delayed villous maturation (maturation defect; >34 weeks gestation, monotonous villous population, >10 villi >30% 1 slide): Present/Not Identified/Not Applicable (gestational age <34 weeks :

Grade: Focal (1 slide)/Diffuse (>/= 2slides)

Diabetes related

Idiopathic

Dysmorphic villi: Present/Not Identified

Villous oedema: Present/Not Identified

Changes of fetal malperfusion:

Global/partial:

Obstructive lesions of umbilical cord: Present/Not identified.

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

Small foci of avascular or karyorhectic villi: Present/Not Identified

Segmental/complete:

Chorionic plate or stem villous thrombi: Present/Not Identified
Large foci of avascular or karyorhectic villi: Present/Not Identified

Loss of vascular integrity:

Large vessel rupture (fetal haemorrhage): Present/Not Identified
Small vessel rupture (fetomaternal haemorrhage): Present/Not Identified

Placental inflammatory-immune processes:

Acute maternal inflammatory response: Present/Not Identified

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

Subacute/chronic maternal: Present/Not Identified

Mixed neutrophilic - histiocytic chorioamnionitis (weeks)

Acute fetal inflammatory response: Present/Not Identified

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

Subacute/chronic fetal response: Present/Not Identified

Subnecrotising or necrotising funistis/prevasculitis (weeks)

Chronic maternal/fetal inflammatory response:

Villitis: Present/Not Identified
Infectious lesions: Present/Not Identified
Viral inclusions: Present/Not Identified
Other organisms: Present/Not Identified
Immune/idiopathic inflammatory lesions: Present/Not Identified
Villitis of unknown etiology: Present/Not Identified

Location:

Basal: Yes/No

Parabasal: Yes/No

Paraseptal: Yes/No

Random parenchyma: Yes/No

Subchorionic: Yes/No

Type: Lymphocytic villitis/Lymphoplasmacytic villitis/Lymphohistocytic villitis.

Giant cells: Present/Not Identified

Grade:

Focal low grade (<10 contiguous villi any one focus, on a single slide)

Multi-focal low grade (<10 contiguous villi any one focus, on multiple slides)

Patchy high grade (at least one focus <10 contiguous villi on multiple slides)

Diffuse high grade (at least one focus >10 contiguous villi, 30% terminal villi involved).

Ungradable, possible low grade, villitis (one focus < 10 contiguous villi).

Ungradable, possible high grade, villitis (one focus >10 contiguous villi)

Obliterative fetal vascular changes: Present. Not identified.

Chronic chorioamnionitis: Present/Not Identified

Lymphoplasmacytic deciduitis: Present/Not Identified

Eosinophil T-cell fetal vasculitis: Present/Not Identified

Intervillositis:

Chronic histiocytic intervillositis: Present/Not Identified

Acute intervillositis: Present/Not Identified

Fibrin deposition: Present/Not Identified

Other placental pathology:

Massive perivillous fibrinoid deposition (maternal floor infarction) Present/Not Identified

Abnormal placental shape or umbilical insertion site: Present/Not Identified

Morbidly adherent placentas (accrete): Present/Not Identified

Meconium-associated changes: Present/Not Identified

Increased circulating nucleated red blood cells: Present/Not Identified

Changes of fetal death in utero: Present/Not Identified

Changes suggestive of aneuploidy: Present/Not Identified

Changes suggestive of polyploidy: Present/Not Identified

Comments:

CONCLUSION:

APPENDIX Q

SUSPECTED GENETIC METABOLIC DISORDERS: INVESTIGATION AND AUTOPSY PROTOCOL

Peri-mortem investigation by the clinician should include the following

- Prior to death:
 - seek consent from the parents for a metabolic autopsy;
 - consult metabolic physician or histopathologist before collection of samples;
 - blood sample (0.8ml) in a lithium heparin tube and refrigerate;
 - urine sample (5-10 ml);
 - skin biopsy (3 x 2 mm punch biopsies): It is not necessary for the baby to be taken from the nursery for this procedure. The process, which can be undertaken by a registrar, should only take 15-20 minutes, is minimally invasive, with the sites being covered by a small dressing. See Section 4; Appendix 2a Screening for genetic metabolic disorders for further details of collection.
- Immediately following the death after consultation with the metabolic team and pathologist:
 - Obtain blood sample by cardiac puncture if blood sample not already taken and only if parental consent has been obtained, or establish a fibroblast culture from the baby.
 - Liver and muscle biopsies (for electron microscopy, histopathology and enzymology (for the latter wrap in aluminium foil, snap freeze and store at -70 °C). These should ideally be taken prior to death, the yield is very low after death.
 - Contact the laboratory to request that all unused portions of blood or urine specimens are retained. If neonatal screening test has been performed, any unused portions of the blood spots can be requested from the state laboratory. Tandem mass spectrometry can identify selected disorders of fatty acid oxidation and amino acid metabolism in dried blood samples.

A recent publication by Christodoulou and Wilcken in *Seminars in Neonatology*⁶¹ highlighted the need for an increased index of suspicion for genetic metabolic disorders (inborn errors of metabolism) in neonatal care. The authors describe predominant clinical or biochemical presentations of genetic metabolic disorders in the neonatal period and recommend a protocol for screening for these disorders and also for a genetic autopsy. *Please see Section 4; Appendix 2b, Components of the Genetic Autopsy* for details of a genetic autopsy.

The predominant clinical or biochemical presentations of genetic metabolic disorders are as follows: Acute encephalopathy: hypoglycaemia, hyperammonemia, ketosis, disorders of acid-base balance, seizures as an early predominant feature; Acute hepatocellular disease; sudden death; severe hypotonia; non-immune hydrops fetalis; facial dysmorphism, with or without congenital malformations⁶¹.

Appendix K Recommendations

- 1** | To ensure a precise diagnosis, peri-mortem evaluation of infants suspected of having genetic metabolic disorders is required. Parental consent is required for a post-mortem examination and for tissue and blood samples to be taken prior to the death. Clinicians need to counsel parents sensitively about the importance of an accurate diagnosis for future genetic risks in this very distressing time.

- 2** | Due to the complexity and number of different possible diseases, it is strongly recommended that clinicians discuss each individual case with the regional referral Laboratory to identify the optimum tests to request. Should more expert guidance be required a clinical metabolic specialist should be consulted.

- 3** | All tissue samples should be stored and transported to a Specialist Metabolic Laboratory for investigation as convenient. The current development of genetic testing has altered the investigation pathway of metabolic disorders. Antemortem samples are better than post mortem, and post mortem electron microscopy has limited value and low yield. A fibroblast culture which can be established after death, but again is better taken before death can be invaluable.

APPENDIX R

SCREENING FOR GENETIC METABOLIC DISORDERS

Extract from: Christodoulou J, Wilcken B. Perimortem laboratory investigation of genetic metabolic disorders. *Seminars in Neonatology* 2004;9(4):275-280¹.

Screening investigations that should be performed in an acutely ill neonate suspected of having a genetic metabolic disorder

Urine

- Odour
- Dipstick tests for ketones, pH, sulphite (a)
- Reducing substances (testing for both glucose and non-glucose reducing substances)
- Amino, organic acid screens (including acylglycines)

Blood

- Full blood count/film
- Urea, electrolytes, anion gap, creatinine
- Glucose
- Calcium
- Blood gases
- Liver enzymes
- Uric acid
- Ammonium
- Lactate and pyruvate
- Amino acids (b)
- Carnitine and acylcarnitines (b)

Cerebrospinal Fluid

- Lactate and pyruvate
- Glucose
- Amino acids (b)

In the case of hypoglycaemia collect blood for the following when the child is hypoglycaemic

- Growth hormone
- Cortisol
- Insulin
- Free fatty acids
- β – Hydroxybutyrate
- Acylcarnitine profile
- Urine should always be collected at the time of hypoglycaemia

(a) Sulphite is very labile. A negative test result does not exclude sulphite oxidase deficiency or the molybdenum cofactor defect.

(b) These tests should only be ordered after consultation with a biomedical geneticist or metabolic physician.

1. Christodoulou J, Wilcken B. Perimortem laboratory investigation of genetic metabolic disorders. *Semin Neonatol* 2004; **9**(4): 275-80.

APPENDIX S

COMPONENTS OF THE GENETIC AUTOPSY FOR INVESTIGATION OF METABOLIC DISORDERS

Extract from: Christodoulou J, Wilcken B. Perimortem laboratory investigation of genetic metabolic disorders. *Seminars in Neonatology* 2004;9(4):275-280.

Dedicated examination of the stillborn infant for a metabolic disorder should only be performed after consultation with a clinical geneticist and/or metabolic physician. Where there is no specific suspicion of a metabolic disorder, routine chromosome evaluation with microarray using umbilical cord tissue sample or placental sample would constitute appropriate genetic evaluation of a stillborn infant (see Appendix K). If in doubt, DNA can be stored from the umbilical cord/placental samples if additional genetic testing is being considered.

Components of the Genetic Autopsy

- Careful family history, including three generation pedigree
- Invite a clinical geneticist with expertise in dysmorphic syndromes to inspect the infant
- Clinical photographs
- Full skeletal survey
- Parental investigations for a haemoglobinopathy
- Maternal investigations for a thrombophilic disorder

Samples to collect from the baby

Blood

- Dried blood spots on filter paper (newborn screening cards, at least two to three cards stored at room temperature but NOT in a plastic bag (for acylcarnitine profile analysis and is a source of DNA))
- Whole blood (5ml in lithium heparin tube (for carnitine, quantitative amino acids, very long chain fatty acids; separated within 20 mins of collection and stored at -70 °c); AND 5ml in EDTA tube (for DNA extraction; can be stored at 4 °c for 48 h) AND 5ml in lithium heparin tube (for chromosome analysis; must be commenced within 4 h of sample collection))

Urine

- Freeze and store (5ml or more if possible, stored at -70 °c; (for amino acid and organic acid profiles, acylglycines, orotic acid))

Cerebrospinal Fluid

- Freeze and store (1ml stored at -70 °c (for amino acid profile))

Skin

- Biopsy (3x2mm full thickness collected under sterile conditions (DO NOT use iodine-containing preparations) into culture or viral transport, or saline soaked gauze. Store at 4 °c. Best collected within 12 h of death. Cartilage may be taken for culture if there has been a prolonged period after death before biopsies can be taken. Send as soon as possible to a cytogenetics laboratory. To be cultured for archiving in liquid nitrogen)

Other biopsies

- Liver and muscle biopsies (for electron microscopy, histopathology and enzymology (for the latter wrap in aluminium foil, snap freeze and store at -70 °c). Collect within 4 h (preferably 2 h) of death. Consult metabolic physician or histopathologist before collection of samples)
- Other tissue biopsies if specific diagnoses are under consideration

APPENDIX T – AUSTRALIA AND NEW ZEALAND PERINATAL MORTALITY DEFINITIONS

Terms of Reference					
	Stillbirth		Fetal Death	Neonatal Death	Perinatal Death
	<i>Births, Deaths and Marriages Act</i>	<i>State Perinatal Mortality Council</i>			
NZ^(1, 2)	<p>A dead foetus that;</p> <p>(a) weighed 400 grams or more when it issued from its mother; or</p> <p>(b) issued from its mother after the 20th week of pregnancy</p> <p>Death is indicated by the fact that, after such separation, the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles</p>	<p>Not defined however the PMMRC does not include terminations of pregnancy in this definition</p>	<p>Fetal death is the death of a fetus at 20 weeks gestation or beyond (≥ 20 weeks) or weighing at least 400g if gestation is unknown.</p> <p>Fetal death includes stillbirth and termination of pregnancy.</p>	<p>Death of any baby showing signs of life at 20 weeks gestation or beyond or weighing at least 400 g if gestation is unknown. Early neonatal death is a death that occurs up until midnight of the sixth day of life. Late neonatal death is a death that occurs between the seventh day and midnight of the 27th day of life</p>	<p>Perinatal death is fetal and early neonatal death from 20 weeks gestation (or weighting at least 400g if gestation is unknown) until less than 7 days of age.</p> <p>Perinatal related mortality is fetal deaths and neonatal deaths (up to 28 days) at 20 weeks or beyond, or weighing at least 400g if gestation was unknown.</p>
Australia⁽³⁾	n/a	<p>Death, before the complete expulsion or extraction from its mother, of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birthweight.</p> <p>Death is indicated by the fact that, after such separation, the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles</p>	See Stillbirth	<p>Death of a live born baby within 28 days of birth. Early neonatal death is death of a live born baby within 7 days of birth. Late neonatal death is death of a live born baby after 7 is completed days and before 28 completed days.</p>	<p>A fetal or neonatal death of at least 20 weeks gestation or at least 400 grams birthweight.</p>

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<p>QLD^(4, 5)</p>	<p>A child who has shown no sign of respiration or heartbeat, or other sign of life, after completely leaving the child's mother; and who;</p> <p>(a) has been gestated for 20 weeks or more; or</p> <p>(b) weighs 400g or more.</p>	<p>Defined by the Registration of Births, Deaths and Marriages Act as a child who has shown no sign of respiration or heartbeat, or other sign of life, after completely leaving the child's mother; and</p> <p>a) who has be gestated for 20 weeks or more; or</p> <p>b) weights 400g or more</p>	<p>See Stillbirth</p>	<p>Neonatal deaths are those occurring in live births within the first 28 days of life.</p>	<p>A fetal or neonatal death of at least 20 weeks gestation or at least 400 grams birthweight.</p> <p>QLD legislation also includes live born babies where the birthweight is less than 400 grams and/or the gestation is less than 20 weeks, and deaths of liveborn babies when the birthweight and gestational age are unknown</p>
<p>SA^(6, 7)</p>	<p>A child of</p> <p>(a) at least 20 weeks' gestation, or</p> <p>(b) if it cannot be reliably established whether the period of gestation is more or less than 20 weeks, with a body mass of at least 400 grams at birth, that exhibits no sign of respiration or heartbeat, or other sign of life, after birth but</p> <p>c) does not include the product of a procedure for the termination of pregnancy</p>	<p>The birth of a fetus</p> <p>a) at or after 20 weeks gestation and/or with a birthweight of</p> <p>b) 400g or more, with no signs of life at birth</p>	<p>Not specified</p>	<p>The death of a liveborn infant within 28 days of birth</p>	<p>Includes stillbirth and neonatal death.</p>
<p>NT^(8, 9)</p>	<p>A child of;</p> <p>(a) at least 20 weeks' gestation or</p> <p>(b) with a body mass of at least 400 grams at birth that exhibits no sign of respiration or heartbeat, or other sign of life, after birth</p>	<p>A child of;</p> <p>(a) at least 20 weeks' gestation or</p> <p>(b) with a body mass of at least 400 grams at birth that exhibits no sign of respiration or heartbeat, or other sign of life, after birth</p>	<p>See Stillbirth</p>	<p>The death of a live born baby within 28 days of birth</p>	<p>A fetal or neonatal death.</p>

APPENDIX T – AUSTRALIA AND NEW ZEALAND PERINATAL MORTALITY DEFINITIONS

<p>WA^(10, 11)</p>	<p>Still born child means a child;</p> <p>a) of at least 20 weeks' gestation, or</p> <p>b) if it cannot be reliably established whether the child's period of gestation is more or less than 20 weeks, with a body mass of at least 400 grams at birth,</p> <p>that exhibits no sign of respiration or heartbeat, or other sign of life, immediately after birth.</p>	<p>The complete expulsion or extraction from its mother of an infant weighing</p> <p>a) at least 400 grams birthweight or</p> <p>b) at least 20 weeks gestation,</p> <p>which shows no sign of life from the time of birth.</p>	<p>See Stillbirth</p>	<p>The death of a liveborn infant within 28 days of birth</p>	<p>A stillbirth (fetal death) or neonatal death.</p>
<p>ACT⁽¹²⁾</p>	<p>A child of;</p> <p>a) at least 20 weeks gestation, or</p> <p>(b) if it cannot be established reliably whether the period of gestation is more or less than 20 weeks—a child with a body mass of at least 400g at birth, who shows no sign of respiration or heartbeat, or other sign of life, immediately after birth.</p>	<p>Refers to death prior to the complete expulsion or extraction from its mother of a product of conception</p> <p>a) of 20 or more completed weeks of gestation or</p> <p>b) of 400g or more of birthweight; the death is indicated by the fact that after separation the fetus does not breathe or show any other evidence of life, such as the beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles</p>	<p>See Stillbirth</p>	<p>The death of an infant within 28 days of birth</p>	<p>A fetal death or a neonatal death</p>
<p>TAS⁽¹³⁻¹⁵⁾</p>	<p>A child of</p> <p>(a) at least 20 weeks' gestation or,</p> <p>(b) if it cannot be reliably established whether the period of gestation is more or less than 20 weeks, with a body mass of at least 400 grams at birth, that</p>	<p>A foetal death prior to the complete expulsion or extraction from its mother of a product of conception of</p> <p>a) 20 or more completed weeks of gestation or</p>	<p>See Stillbirth</p>	<p>A death occurring within 28 days of birth in an infant whose birthweight was at least 400 grams, or if the weight was not known, an infant born after at least 20 weeks of gestation</p>	<p>Perinatal deaths means;</p> <p>(a) the death of a viable foetus at any time up to the moment of its complete expulsion or extraction from its mother; and</p>

APPENDIX T – AUSTRALIA AND NEW ZEALAND PERINATAL MORTALITY DEFINITIONS

	exhibits no sign of respiration or heartbeat or other sign of life after birth.	b) 400 grams or more birthweight; the death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles			(b) the death of a child born alive where the death occurs before the twenty-ninth day after the date of the birth;
NSW ⁽¹⁶⁻¹⁸⁾	A child that exhibits no sign of respiration or heartbeat, or other sign of life, after birth and that: (a) is of at least 20 weeks' gestation, or (b) if it cannot be reliably established whether the period of gestation is more or less than 20 weeks, has a body mass of at least 400 grams at birth.	The complete expulsion or extraction from its mother of a product of conception of a) at least 20 weeks gestation or b) 400 grams birth weight who did not, at any time after birth, breathe, or show any evidence of life such as a heartbeat	Not specified	Not specified	Perinatal death comprises all deaths of liveborn babies within 28 days of birth, regardless of gestational age at birth, and stillbirths of at least 20 weeks gestation or 400 grams birth weight.
VIC ^(19, 20)	A child of; a) at least 20 weeks' gestation or; b) if it cannot be reliably established whether the period of gestation is more or less than 20 weeks, with a body mass of at least 400 grams at birth, that exhibits no sign of respiration or heartbeat, or other sign of life, after birth	A stillbirth is defined as the birth of an infant of a) at least 20 weeks gestation or, if gestation is unknown, b) weighing at least 400g, who shows no signs of life at birth	See Stillbirth	Defined as a subcategory of infant death . Neonatal death refers to the death of a live-born infant less than 28 days after birth, of at least 20 weeks gestation or, if gestation is unknown, weighing at least 400g	Perinatal death included stillbirth and neonatal deaths within 28 days of birth of infants of gestation ≥ 20 weeks or if gestation is unknown of birth weight $\geq 400g$

APPENDIX T – AUSTRALIA AND NEW ZEALAND PERINATAL MORTALITY DEFINITIONS

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APPENDIX T – AUSTRALIA AND NEW ZEALAND PERINATAL MORTALITY DEFINITIONS

APPENDIX U

CHANGES TO PSANZ PERINATAL DEATH CLASSIFICATION AND PSANZ NEONATAL DEATH CLASSIFICATION

1. Changes – This revision

1.1 PSANZ Perinatal Death Classification (PSANZ-PDC)

1.1.1 Category 1 – PDC. Addition of new subcategories

PSANZ-PDC version 2009	PSANZ-PDC version 2017
1 Congenital Anomaly (including terminations for congenital abnormalities) 1.1 Central nervous system 1.2 Cardiovascular system 1.3 Urinary system 1.4 Gastrointestinal system 1.5 Chromosomal 1.6 Metabolic 1.7 Multiple/non chromosomal syndromes 1.8 Other congenital anomaly 1.81 Musculoskeletal 1.82 Respiratory 1.83 Diaphragmatic hernia 1.84 Haematological 1.85 Tumours 1.88 Other specified congenital anomaly 1.9 Unspecified congenital anomaly	1 Congenital Anomaly 1.1 Structural anomaly 1.11 Nervous system 1.12 Cardiovascular system 1.13 Genitourinary system 1.14 Gastrointestinal system 1.15 Musculoskeletal 1.151 Congenital diaphragmatic hernia 1.152 Gastroschisis/omphalocele 1.16 Respiratory system (include congenital pulmonary airway malformation (CPAM)) 1.17 Haematological 1.18 Multiple Congenital anomaly (no chromosomal/genetic cause or not tested) 1.19 Other congenital abnormality 1.192 Idiopathic hydrops fetalis 1.193 Fetal tumour (include sacro-coccygeal teratoma) 1.198 Other specified 1.199 Congenital anomaly, unspecified 1.2 Chromosomal anomaly 1.21 Down syndrome (trisomy 21) 1.22 Edward syndrome and Patau syndrome (trisomy 18, trisomy 13) 1.23 Other trisomies and partial trisomies of the autosomes, not elsewhere classified (includes pathogenic duplications, unbalanced translocations and insertions) 1.24 Monosomies and deletions from the autosomes, not elsewhere classified (includes pathogenic deletions e.g. 22q11.2 deletion syndrome (diGeorge syndrome), Wolff-Hirschorn syndrome, Cri-du-chat syndrome) 1.25 Turner syndrome (monosomy X) 1.26 Other sex chromosome abnormalities (e.g. Klinefelter syndrome) 1.28 Other chromosomal abnormalities, not elsewhere specified (includes Fragile X syndrome, imprinting syndromes, triploidy) 1.29 Unspecified 1.3 Genetic anomaly 1.31 Genetic condition, specified (e.g. Tay-Sachs disease; includes inborn errors of metabolism) 1.32 Syndrome/association with demonstrated chromosomal/gene anomaly. 1.39 Genetic condition, unspecified

1.1.2 Category 2 – PDC. Addition of new subcategories

PSANZ-PDC version 2009		PSANZ-PDC version 2017	
2	Perinatal infection	2	Perinatal infection
2.1	Bacterial	2.1	Bacterial
	2.11 Group B Streptococcus		2.11 Group B Streptococcus
	2.12 E coli		2.12 E coli
	2.13 Listeria monocytogenes		2.13 Listeria monocytogenes
	2.14 Spirochaetal e.g. Syphilis		2.14 Spirochaetal e.g. Syphilis
	2.18 Other bacterial		2.18 Other bacterial
	2.19 Unspecified bacterial		2.19 Unspecified bacterial
2.2	Viral	2.2	Viral
	2.21 Cytomegalovirus		2.21 Cytomegalovirus
	2.22 Parvovirus		2.22 Parvovirus
	2.23 Herpes simplex virus		2.23 Herpes simplex virus
	2.24 Rubella virus		2.24 Rubella virus
	2.28 Other viral		2.25 Zika virus
	2.29 Unspecified viral		2.28 Other viral
2.3	Protozoal e.g. Toxoplasma		2.29 Unspecified viral
2.5	Fungal	2.3	Protozoal e.g. Toxoplasma
2.8	Other specified organism	2.5	Fungal
2.9	Other unspecified organism	2.8	Other specified organism
		2.9	Other unspecified organism

1.1.3 Category 3 – PDC. Removal of subcategories 3.51 and 3.61

PSANZ- PSANZ-PDC version February 2009		PSANZ-PDC version 2017	
3. Hypertension		3	Hypertension
3.1	Chronic hypertension: essential	3.1	Chronic hypertension: essential
3.2	Chronic hypertension: secondary, e.g. renal disease	3.2	Chronic hypertension: secondary, e.g. renal disease
3.3	Chronic hypertension: unspecified	3.3	Chronic hypertension: unspecified
3.4	Gestational hypertension	3.4	Gestational hypertension
3.5	Pre-eclampsia	3.5	Pre-eclampsia
3.6	Pre-eclampsia superimposed on chronic hypertension	3.6	Pre-eclampsia superimposed on chronic hypertension
	3.61 With laboratory evidence of thrombophilia	3.9	Unspecified hypertension
3.9	Unspecified hypertension		

1.1.4 Category 4 – PDC. Addition of new category and removal of subcategory 4.11.

PSANZ- PSANZ-PDC version February 2009		PSANZ-PDC version 2017	
4. Antepartum haemorrhage (APH)		4	Antepartum haemorrhage (APH)
4.1	Placental abruption	4.1	Placental abruption
	4.11 With laboratory evidence of thrombophilia	4.2	Placenta praevia
4.2	Placenta praevia	4.3	Vasa praevia
4.3	Vasa praevia	4.9	APH of undetermined origin

4.8	Other APH
4.9	APH of undetermined origin

1.1.5 Category 5 – PDC. Addition of subcategories

PSANZ- PSANZ-PDC version February 2009	PSANZ-PDC version 2017
<p>5. Maternal conditions</p> <p>5.1 Termination of pregnancy for maternal psychosocial indications</p> <p>5.2 Diabetes / Gestational diabetes</p> <p>5.3 Maternal injury</p> <p>5.31 Accidental</p> <p>5.32 Non-accidental</p> <p>5.4 Maternal sepsis</p> <p>5.5 Antiphospholipid Syndrome</p> <p>5.6 Obstetric cholestasis</p> <p>5.8 Other specified maternal conditions</p>	<p>5 Maternal Conditions</p> <p>5.1 Termination of pregnancy for maternal psychosocial indications</p> <p>5.2 Diabetes</p> <p>5.21 Gestational diabetes</p> <p>5.22 Pre-existing diabetes</p> <p>5.3 Maternal injury</p> <p>5.31 Accidental</p> <p>5.32 Non-accidental</p> <p>5.4 Maternal sepsis</p> <p>5.5 Antiphospholipid syndrome</p> <p>5.6 Obstetric cholestasis</p> <p>5.8 Other specified maternal conditions</p> <p>5.81 Maternal suicide</p> <p>5.88 Other specified maternal medical or surgical conditions</p>

1.1.6 Category 6 – PDC. Restructure with separation of two Categories

PSANZ- PSANZ-PDC version February 2009	PSANZ-PDC version 2017
<p>6. Specific perinatal conditions</p> <p>6.1 Twin-twin transfusion</p> <p>6.2 Fetomaternal haemorrhage</p> <p>6.3 Antepartum cord complications</p> <p>6.31 Cord haemorrhage</p> <p>6.32 True knot with evidence of occlusion</p> <p>6.38 Other</p> <p>6.39 Unspecified</p> <p>6.4 Uterine abnormalities, e.g. bicornuate uterus, cervical incompetence</p> <p>6.5 Birth trauma (typically infants of >24 weeks gestation or >600g birthweight)</p> <p>6. Alloimmune disease</p> <p>6.61 Rhesus</p> <p>6.62 ABO</p> <p>6.63 Kell</p> <p>6.64 Alloimmune thrombocytopenia</p> <p>6.68 Other</p> <p>6.69 Unspecified</p> <p>6.7 Idiopathic hydrops</p> <p>6.8 Other specific perinatal conditions</p> <p>6.81 Rupture of membranes after amniocentesis</p> <p>6.82 Termination of pregnancy for suspected but unconfirmed congenital anomaly,</p> <p>6.83 Fetal subdural haematoma</p> <p>6.88 Other</p> <p>6.9 Unspecified</p>	<p>6 Complications of multiple pregnancy</p> <p>6.1 Monochorionic twins</p> <p>6.11 Twin to twin transfusion syndrome (TTTS)</p> <p>6.12 Selective fetal growth restriction (FGR) (i.e. affecting only one twin)</p> <p>6.13 Monoamniotic twins (including cord entanglement)</p> <p>6.18 Other</p> <p>6.19 Unknown or unspecified</p> <p>6.2 Dichorionic twins</p> <p>6. 21 Early fetal death in a multiple pregnancy (<20 weeks gestation)</p> <p>6.22 Selective FGR</p> <p>6.23 Other</p> <p>6.29 Unknown or unspecified</p> <p>6. 3 Complications of higher order multiples (3 or more fetuses)</p> <p>6.31 Twin to twin transfusion syndrome (TTTS)</p> <p>6.32 Selective fetal growth restriction (FGR)</p> <p>6.33 Monoamniotic multiples (including cord entanglement)</p> <p>6.34 Early fetal death in a multiple pregnancy (<20 weeks gestation)</p> <p>6.38 Other</p> <p>6.39 Unknown or unspecified</p> <p>6.4 Complications where chorionicity is unknown</p> <p>6.8 Other</p> <p>6.9 Unspecified</p> <p>7 Specific perinatal conditions</p> <p>7.1 Fetomaternal haemorrhage</p> <p>7.2 Antepartum cord or fetal vessel complications (excludes monochorionic twins or triplets)</p> <p>7.21 Cord vessel haemorrhage</p> <p>7.22 Cord occlusion (True knot with evidence of occlusion or other)</p> <p>7.23 Other cord complications</p> <p>7.29 Unspecified cord complications</p> <p>7.3 Uterine/cervical abnormalities</p> <p>7.31 Developmental anatomical abnormalities (e.g. bicornuate uterus)</p> <p>7.38 Other</p> <p>7.39 Unspecified</p> <p>7.4 Alloimmune disease</p> <p>7.41 Rhesus isoimmunisation</p> <p>7.42 Other red cell antibody</p> <p>7.43 Alloimmune thrombocytopenia</p> <p>7.48 Other</p> <p>7.49 Unspecified</p> <p>7.5 Fetal antenatal intracranial injury</p> <p>7.51 Subdural haematoma</p> <p>7.52 Fetal antenatal ischaemic brain injury</p> <p>7.53 Fetal antenatal haemorrhagic brain injury</p> <p>7.6 Other specific perinatal conditions</p> <p>7.61 Complications of prenatal diagnostic or therapeutic procedures</p>

	<p>7.611 Complications of prenatal diagnostic procedures (e.g. amniocentesis, chorionic villus sampling,) (e.g. rupture of membranes after amniocentesis)</p> <p>7.612 Complications of fetal ultrasound guided needle interventions (e.g. FBS/fetal transfusion, thoracocentesis, vesicocentesis, fetal cardiac valvoplasty, division of amniotic bands, fetal skin biopsy, unipolar/bipolar diathermy, RFA procedures)</p> <p>7.613 Complications of fetal shunt interventions (e.g. pleuroamniotic shunt, vesicoamniotic shunt)</p> <p>7.614 Complications of minimally invasive fetoscopic interventions (e.g. fetoscopic laser surgery for TTTS, FETO for CDH, laser ablation of posterior urethral valves)</p> <p>7.615 Complications of open maternal fetal surgery (e.g. open maternal fetal surgery for spina bifida)</p> <p>7.618 Other</p> <p>7.62 Termination of pregnancy for suspected but unconfirmed congenital anomaly.</p> <p>7.63 Amniotic band</p> <p>7.68 Other</p> <p>7.9 Unspecified</p>
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1.1.7 Category 7– PDC. Restructured and addition of subcategory

PSANZ- PSANZ-PDC version February 2009	PSANZ-PDC version 2017
<p>7. Hypoxic peripartum death (typically infants of >24 weeks gestation or >600g birthweight)</p> <p>7.1 With intrapartum complications</p> <p>7.11 Uterine rupture</p> <p>7.12 Cord prolapse</p> <p>7.13 Shoulder dystocia</p> <p>7.18 Other</p> <p>7.2 Evidence of non-reassuring fetal status in a normally grown infant (e.g. abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intrapartum complications)</p> <p>7.3 No intrapartum complications and no evidence of non-reassuring fetal status</p> <p>7.9 Unspecified hypoxic peripartum death</p>	<p>8 Hypoxic peripartum death</p> <p>8.1 With intrapartum complications (sentinel events)</p> <p>8.11 Uterine rupture</p> <p>8.12 Cord prolapse</p> <p>8.13 Shoulder dystocia</p> <p>8.14 Complications of breech presentation</p> <p>8.15 Birth trauma</p> <p>8.16 Intrapartum haemorrhage</p> <p>8.18 Other</p> <p>8.2 Evidence of significant fetal compromise (excluding other complications)</p> <p>8.3 No intrapartum complications recognised and no evidence of significant compromise identified.</p> <p>8.9 Unspecified hypoxic peripartum death</p>

1.1.8 Category 8 – PDC. Restructured

PSANZ- PSANZ-PDC version February 2009	PSANZ-PDC version 2017
8. Fetal Growth Restriction (FGR)	9. Placental dysfunction or causative placental pathology

8.1	With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (e.g. significant infarction, acute atherosclerosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)	9.1	Maternal vascular malperfusion
8.2	With chronic villitis	9.2	Fetal vascular malperfusion
8.3	No placental pathology	9.3	High grade villitis of unknown etiology (VUE)
8.4	No examination of placenta	9.4	Massive perivillous fibrin deposition/maternal floor infarction
8.8	Other specified placental pathology	9.5	Severe chronic intervillitis (Histiocytic intervillitis)
8.9	Unspecified or not known whether placenta examined	9.6	Placental hypoplasia
		9.7	No causal placental pathology demonstrated, with antenatal evidence of poor placental function identified (such as abnormal umbilical artery Doppler)
		9.7	Placental pathological examination was not performed, with antenatal evidence of poor placental function identified (such as abnormal umbilical artery Doppler)
		9.8	Other placental pathology (e.g. multiple pathologies with evidence of loss of placental function leading to death)

1.1.9 Category 9 – PDC. Restructured including changes to subcategories

PSANZ- PSANZ-PDC version February 2009	PSANZ-PDC version 2017
<p>9. Spontaneous preterm labour (<37 weeks gestation)</p> <p>9.1 Spontaneous preterm with intact membranes, or membrane rupture <24 hours before deliver</p> <p>9.11 With chorioamnionitis on placental histopathology</p> <p>9.12 Without chorioamnionitis on placental histopathology</p> <p>9.13 With clinical evidence of chorioamnionitis, no examination of placenta</p> <p>9.17 No clinical signs of chorioamnionitis, no examination of placenta</p> <p>9.19 Unspecified or not known whether placenta examined</p> <p>9.2 Spontaneous preterm with membrane rupture ≥24 hours before delivery</p> <p>9.21 With chorioamnionitis on placental histopathology</p> <p>9.22 Without chorioamnionitis on placental histopathology</p> <p>9.23 With clinical evidence of chorioamnionitis, no examination of placenta</p> <p>9.27 No clinical signs of chorioamnionitis, no examination of placenta</p> <p>9.29 Unspecified or not known whether placenta examined</p> <p>9.3 Spontaneous preterm with membrane rupture of unknown duration before delivery</p> <p>9.31 With chorioamnionitis on placental histopathology</p> <p>9.32 Without chorioamnionitis on placental histopathology</p> <p>9.33 With clinical evidence of chorioamnionitis, no examination of placenta.</p> <p>9.37 No clinical signs of chorioamnionitis, no examination of placenta</p> <p>9.39 Unspecified or not known whether placenta examined</p>	<p>10 Spontaneous preterm labour or rupture of membranes (ROM (<37 weeks gestation)</p> <p>10.1 Spontaneous preterm</p> <p>10.11 With histological chorioamnionitis</p> <p>10.12 Without histological chorioamnionitis</p> <p>10.13 With clinical evidence of chorioamnionitis, no examination of placenta</p> <p>10.17 No clinical signs of chorioamnionitis, no examination of placenta</p> <p>10.19 Unspecified or not known whether placenta examined</p> <p>10.2 Spontaneous preterm preceded by premature cervical shortening</p>

1.1.10 Category 10 – Restructured

PSANZ- PSANZ-PDC version February 2009	PSANZ-PDC version 2017
<p>10 Unexplained antepartum death</p> <p>10.1 With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (e.g. significant infarction, acute atherosclerosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)</p> <p>10.2 With chronic villitis</p> <p>10.3 No placental pathology</p> <p>10.4 No examination of placenta</p> <p>10.8 Other specified placental pathology</p> <p>10.9 Unspecified or not known whether placenta examined</p>	<p>11 Unexplained antepartum fetal death</p> <p>11.1 Unexplained antepartum fetal death despite full investigation</p> <p>11.2 Unclassifiable antepartum fetal death with incomplete investigation</p> <p>11.3 Unclassifiable antepartum fetal death due to unknown level of investigation</p>

1.1.11 Category 10 – PDC. Restructured

PSANZ- PSANZ-PDC version February 2009	PSANZ-PDC version 2017
<p>11. No obstetric antecedent</p> <p>11.1 Sudden Infant Death Syndrome (SIDS) (See appendix p130)</p> <p>11.11 SIDS Category IA: Classic features of SIDS present and completely documented.</p> <p>11.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.</p> <p>11.13 SIDS Category II: Infant deaths that meet Category I except for one or more features.</p> <p>11.2 Postnatally acquired infection</p> <p>11.3 Accidental asphyxiation</p> <p>11.4 Other accident, poisoning or violence (postnatal)</p> <p>11.8 Other specified</p> <p>11.9 Unknown/Undetermined</p> <p>11.91 Unclassified Sudden Infant Death</p> <p>11.92 Other Unknown/Undetermined</p>	<p>12 Neonatal death without obstetric antecedent</p> <p>12.1 Neonatal death with no obstetric antecedent factors despite full investigation</p> <p>12.2 Neonatal death unclassifiable as to obstetric antecedent with incomplete investigation</p> <p>12.3 Neonatal death unclassifiable as to obstetric antecedent due to unknown level of investigation</p>

1.2 PSANZ Neonatal Death Classification (PSANZ-NDC)

1.2.1 Category 2 – NDC. Name change

PSANZ-NDC version 2009	PSANZ-NDC version 2017
<p>2. Extreme prematurity (typically infants of gestational age ≤ 24 weeks or birthweight ≤ 600g)</p> <p>2.1 Not resuscitated</p> <p>2.2 Unsuccessful resuscitation</p> <p>2.9 Unspecified or not known whether resuscitation attempted</p> <p>This group includes infants deemed too immature for resuscitation or continued life support beyond the delivery room, typically infants of gestational age ≤ 24 weeks or birthweight ≤ 600g. Resuscitation in this context means the use of positive pressure ventilation.</p>	<p>2 Periviable infants (typically <24 weeks)</p> <p>2.1 Not resuscitated (including infants where there is an antenatal plan for no resuscitation at birth or in the circumstance of re-directed care)</p> <p>2.2 Unsuccessful resuscitation</p> <p>2.9 Unspecified or not known whether resuscitation attempted</p>

1.2.2 Category 3 - NDC. Change to subcategories

PSANZ-NDC version 2009	PSANZ-NDC version 2017
<p>3. Cardio-respiratory disorders</p> <p>3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)</p> <p>3.2 Meconium aspiration syndrome</p> <p>3.3 Primary persistent pulmonary hypertension</p> <p>3.4 Pulmonary hypoplasia</p> <p>3.5 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)</p> <p>3.6 Pulmonary haemorrhage</p>	<p>3 Cardio-respiratory disorders</p> <p>3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)</p> <p>3.2 Meconium aspiration syndrome</p> <p>3.3 Primary persistent pulmonary hypertension</p> <p>3.4 Pulmonary hypoplasia</p> <p>3.5 Pulmonary haemorrhage</p> <p>3.6 Air leak syndromes</p> <p>3.61 Pneumothorax</p>

3.7 Pneumothorax	3.62 Pulmonary interstitial emphysema
3.8 Other	3.63 Other
	3.7 Patent ductus arteriosus
	3.8 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)
	3.9 Other
	3.91 Neonatal anaemia/hypovolaemia

1.2.3 Category 4 - NDC. Addition of subcategories

PSANZ-NDC version 2009		PSANZ-NDC version 2017	
4	Infection	4	Neonatal infection
4.1	Bacterial	4.1	Congenital/Perinatal bacterial infection (early onset<48 hrs)
	4.11 Congenital bacterial		4.11 Blood stream infection/septicaemia
	4.111 Group B Streptococcus		4.111 Positive culture of a pathogen
	4.112 E coli		4.112 Clinical signs of sepsis + ancillary evidence but culture negative
	4.113 Listeria monocytogenes		4.12 Bacterial meningitis
	4.114 Spirochaetal, e.g. syphilis		4.13 Bacterial pneumonia
	4.118 Other bacterial		4.15 Multiple site bacterial infection
	4.119 Unspecified bacterial		4.18 Other congenital bacterial infection e.g. gastroenteritis, osteomyelitis, cerebral abscess
	4.12 Acquired bacterial		4.19 Unspecified congenital infection
	4.121 Group B Streptococcus	4.2	Congenital/Perinatal viral infection
	4.122 E coli	4.3	Congenital fungal, protozoan, parasitic infection
	4.125 Other Gram negative bacilli (other than E coli)	4.4	Acquired bacterial infection (late onset>48hrs)
	4.126 Staphylococcus aureus		4.41 Blood stream infection/septicaemia
	4.127 Coagulase negative Staphylococcus		4.411 Positive culture of a pathogen
	4.128 Other specified bacterial		4.412 Clinical signs of sepsis + ancillary evidence but culture negative
	4.129 Unspecified bacterial		4.42 Bacterial meningitis
4.2	Viral		4.43 Bacterial pneumonia
	4.21 Congenital viral		4.48 Other acquired bacterial infection e.g. gastroenteritis, osteomyelitis
	4.211 Cytomegalovirus		4.49 Unspecified acquired infection
	4.213 Herpes simplex virus	4.5	Acquired viral infection
	4.214 Rubella virus	4.6	Acquired fungal, protozoan, parasitic infection
	4.218 Other specified viral		
	4.219 Unspecified viral		
	4.22 Acquired viral		
	4.221 Cytomegalovirus		
	4.223 Herpes simplex virus		
	4.224 Rubella virus		
	4.228 Other specified viral		
	4.229 Unspecified viral		

1.2.4 Category 5 - NDC. Addition of subcategories

PSANZ-NDC version 2009		PSANZ-NDC version 2017	
5.	Neurological	5	Neurological
5.1	Hypoxic ischaemic encephalopathy / Perinatal asphyxia (typically infants of >24 weeks gestation or >600g birthweight)	5.1	Hypoxic ischaemic encephalopathy/Perinatal asphyxia
5.2	Intracranial haemorrhage	5.2	Cranial haemorrhage
	5.21 Intraventricular Haemorrhage		5.21 Intraventricular Haemorrhage
			5.22 Subgaleal Haemorrhage

5.22 Subgaleal Haemorrhage	5.23 Subarachnoid Haemorrhage	5.23 Subarachnoid Haemorrhage	5.24 Subdural Haemorrhage
5.23 Subarachnoid Haemorrhage	5.24 Subdural Haemorrhage	5.28 Other Intracranial Haemorrhage	5.3 Post haemorrhagic hydrocephalus
5.24 Subdural Haemorrhage	5.28 Other Intracranial Haemorrhage	5.4 Periventricular leukomalacia	5.8 Other
5.28 Other Intracranial Haemorrhage			
5.8 Other			

1.2.5 Category 6 - NDC. Addition of subcategories

PSANZ-NDC version 2009		PSANZ-NDC version 2017	
6.	Gastrointestinal	6	Gastrointestinal
6.1	Necrotising enterocolitis	6.1	Necrotising enterocolitis (NEC)
6.8	Other	6.2	Short gut syndrome
		6.3	Gastric or intestinal perforation (excluding NEC)
		6.4	Gastrointestinal haemorrhage
		6.8	Other

1.2.6 Category 7 - NDC. Addition of subcategories

PSANZ-NDC version 2009		PSANZ-NDC version 2017	
7. Other		7	Other
7.1	Sudden Infant Death Syndrome (SIDS)	7.1	Sudden unexpected death in infancy (SUDI)
	7.11 SIDS Category IA: Classic features of SIDS present and completely documented.		7.11 Sudden Infant Death Syndrome (SIDS)
	7.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.		7.112 SIDS Category IA: Classic features of SIDS present and completely documented.
	7.13 SIDS Category II : Infant deaths that meet category I except for one or more features.		7.113 SIDS Category IB: Classic features of SIDS present but incompletely documented.
7.2	Multisystem failure		7.114 SIDS Category II: Infant deaths that meet category I except for one or more features.
	7.21 Secondary to intrauterine growth restriction	7.12	Unclassified Sudden Infant Death in the neonatal period
	7.28 Other specified		7.121 Bed sharing
	7.29 Unspecified/undetermined primary cause or trigger event		7.122 Not bed sharing
7.3	Trauma	7.19	Unknown/Undetermined
	7.31 Accidental	7.2	Multisystem failure
	7.32 Non accidental		7.21 Secondary to intrauterine growth restriction
	7.39 Unspecified		7.28 Other specified
7.4	Treatment complications		7.29 Unspecified/undetermined primary cause or trigger event
	7.41 Surgical	7.3	Trauma
	7.42 Medical		7.31 Accidental
7.8	Other specified		7.32 Non accidental
7.9	Unknown/Undetermined		7.39 Unspecified
	7.91 Unclassified Sudden Infant Death	7.4	Treatment complications
	7.92 Other Unknown/Undetermined		7.41 Surgical
			7.42 Medical
		7.5	Unsuccessful resuscitation in infants of 28 weeks gestation or more without an obvious sentinel event

	7.8	Other specified to unknown level of
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1.2.7 Addition of PSANZ Associated Conditions for both stillbirths and neonatal deaths

2. Changes made in the 2009 revision

The 2009 revision incorporates amendments to the PSANZ Perinatal Death Classification (PSANZ-PDC) and PSANZ Neonatal Death Classification (PSANZ-NDC) based on feedback received from users and discussion with the guideline working party which includes developers of the classification systems. The changes to previous version dated October 2004 are listed here. Previous changes made are listed at the end of this appendix.

2.1 PSANZ Perinatal Death Classification (PSANZ-PDC)

2.1.1 The inclusion of a code to identify terminations of pregnancy for congenital abnormality

PSANZ-PDC version October 2004	PSANZ-PDC version April 2009
<p>1 Congenital Abnormality (including terminations for congenital abnormalities)</p> <ul style="list-style-type: none"> 1.1 Central nervous system 1.2 Cardiovascular system 1.3 Urinary system 1.4 Gastrointestinal system 1.5 Chromosomal 1.6 Metabolic 1.7 Multiple/non chromosomal syndromes 1.8 Other congenital abnormality <ul style="list-style-type: none"> 1.81 Musculoskeletal 1.82 Respiratory 1.83 Diaphragmatic hernia 1.84 Haematological 1.85 Tumours 1.88 Other specified congenital abnormality 1.9 Unspecified congenital abnormality 	<p>1 Congenital Abnormality (including terminations for congenital abnormalities)</p> <ul style="list-style-type: none"> 1.1 Central nervous system 1.2 Cardiovascular system 1.3 Urinary system 1.4 Gastrointestinal system 1.5 Chromosomal 1.6 Metabolic 1.7 Multiple/non chromosomal syndromes 1.8 Other congenital abnormality <ul style="list-style-type: none"> 1.81 Musculoskeletal 1.82 Respiratory 1.83 Diaphragmatic hernia 1.84 Haematological 1.85 Tumours 1.88 Other specified congenital abnormality 1.9 Unspecified congenital abnormality <p>Please note that terminations of pregnancy for perinatal deaths within this category should be identified by the inclusion of an "09" for two-digit codes and a "9" for the three digit codes</p>

2.1.2 Change of wording for Category 5.5

PSANZ-PDC version October 2004**PSANZ-PDC version April 2009****5 Maternal conditions**

- 5.1 Termination of pregnancy for maternal psychosocial indications
- 5.2 Diabetes / Gestational diabetes
- 5.3 Maternal injury
 - 5.31 Accidental
 - 5.32 Non-accidental
- 5.4 Maternal sepsis
- 5.5 Lupus obstetric syndrome
- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions

5 Maternal conditions

- 5.1 Termination of pregnancy for maternal psychosocial indications
- 5.2 Diabetes / Gestational diabetes
- 5.3 Maternal injury
 - 5.31 Accidental
 - 5.32 Non-accidental
- 5.4 Maternal sepsis
- 5.5 Antiphospholipid syndrome
- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions

2.1.3 Addition of subcategories under Categories 6.3 and 6.8**PSANZ-PDC version October 2004****PSANZ-PDC version February 2009****6 Specific perinatal conditions**

- 6.1 Twin-twin transfusion
- 6.2 Fetomaternal haemorrhage
- 6.3 Antepartum cord complications (e.g. cord haemorrhage; true knot with evidence of occlusion)
- 6.4 Uterine abnormalities, e.g. bicornuate uterus, cervical incompetence
- 6.5 Birth trauma (typically infants of >24 weeks gestation or >600g birthweight)
- 6.6 Alloimmune disease
 - 6.61 Rhesus
 - 6.62 ABO
 - 6.63 Kell
 - 6.64 Alloimmune thrombocytopenia
 - 6.68 Other
 - 6.69 Unspecified
- 6.7 Idiopathic hydrops
- 6.8 Other specific perinatal conditions (includes iatrogenic conditions such as rupture of membranes after amniocentesis, termination of pregnancy for suspected but unconfirmed congenital abnormality).

6 Specific perinatal conditions

- 6.1 Twin-twin transfusion
- 6.2 Fetomaternal haemorrhage
- 6.3 Antepartum cord complications
 - 6.31 Cord haemorrhage
 - 6.32 True knot with evidence of occlusion
 - 6.38 Other
 - 6.39 Unspecified
- 6.4 Uterine abnormalities, e.g. bicornuate uterus, cervical incompetence
- 6.5 Birth trauma (typically infants of >24 weeks gestation or >600g birthweight)
- 6.6 Alloimmune disease
 - 6.61 Rhesus
 - 6.62 ABO
 - 6.63 Kell
 - 6.64 Alloimmune thrombocytopenia
 - 6.68 Other
 - 6.69 Unspecified
- 6.7 Idiopathic hydrops
- 6.8 Other specific perinatal conditions
 - 6.81 Rupture of membranes after amniocentesis
 - 6.82 Termination of pregnancy for suspected but unconfirmed congenital abnormality,
 - 6.83 Fetal subdural haematoma
 - 6.88 Other
 - 6.89 Unspecified

2.1.4 Fetal growth restriction (FGR) Category 8 - customised birthweight centiles

A recommendation for the collection of data to determine FGR according to Customised birthweight centiles.(please see item 7.5.1.)

2.2 PSANZ Neonatal Death Classification (PSANZ-NDC)

2.2.1 Addition of new categories: 3.6 Pulmonary haemorrhage and 3.7 Pneumothorax

PSANZ-NDC version October 2004	PSANZ-NDC version February 2009
3 Cardio-respiratory disorders 3.1 Hyaline membrane disease / Respiratory Distress Syndrome (RDS) 3.2 Meconium aspiration syndrome 3.3 Primary persistent pulmonary hypertension 3.4 Pulmonary hypoplasia 3.5 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia) 3.8 Other	3 Cardio-respiratory disorders 3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS) 3.2 Meconium aspiration syndrome 3.3 Primary persistent pulmonary hypertension 3.4 Pulmonary hypoplasia 3.5 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia) 3.6 Pulmonary haemorrhage 3.7 Pneumothorax 3.8 Other

2.2.2 Addition of new categories: 4.1 Congenital and 4.2 Acquired; Additional subcategories under Categories 4.1 and 4.2

PSANZ-NDC version October 2004	PSANZ-NDC version February 2009
4 Infection 4.1 Bacterial 4.11 Congenital bacterial 4.12 Acquired bacterial 4.2 Viral 4.21 Congenital viral 4.22 Acquired viral 4.3 Protozoal e.g. Toxoplasma 4.4 Spirochaetal e.g. Syphilis 4.5 Fungal 4.8 Other 4.9 Unspecified organism	4 Infection 4.1 Bacterial 4.11 Congenital bacterial 4.111 Group B Streptococcus 4.112 E coli 4.113 Lysteria monocytogenes 4.114 Spirochaetal, e.g. syphilis 4.118 Other bacterial 4.119 Unspecified bacterial 4.12 Acquired bacterial 4.121 Group B Streptococcus 4.122 E coli 4.125 Other Gram negative bacilli (other than E coli) 4.126 Staphylococcus aureus 4.127 Coagulase negative Staphylococcus 4.128 Other specified bacterial 4.129 Unspecified bacterial 4.2 Viral 4.21 Congenital viral 4.211 Cytomegalovirus 4.213 Herpes simplex virus 4.214 Rubella virus 4.218 Other specified viral 4.219 Unspecified viral 4.22 Acquired viral 4.221 Cytomegalovirus 4.223 Herpes simplex virus 4.224 Rubella virus 4.228 Other specified viral 4.229 Unspecified viral 4.3 Protozoal e.g. Toxoplasma 4.5 Fungal

- 4.8 Other specified organism
- 4.9 Unspecified organism

2.2.3 Additional subcategories under Category 5.2 Intracranial haemorrhage

PSANZ-NDC version October 2004	PSANZ-NDC version February 2009
<p>5. Neurological</p> <p>5.1 Hypoxic ischaemic encephalopathy / Perinatal asphyxia (typically infants of >24 weeks gestation or >600g birthweight)</p> <p>5.2 Intracranial haemorrhage</p> <p>5.8 Other</p>	<p>5. Neurological</p> <p>5.1 Hypoxic ischaemic encephalopathy / Perinatal asphyxia (typically infants of >24 weeks gestation or >600g birthweight)</p> <p>5.2 Intracranial haemorrhage</p> <p>5.21 Intraventricular Haemorrhage</p> <p>5.22 Subgaleal Haemorrhage</p> <p>5.23 Subarachnoid Haemorrhage</p> <p>5.24 Subdural Haemorrhage</p> <p>5.28 Other Intracranial Haemorrhage</p> <p>5.8 Other</p>

2.2.4 Addition of a new category – 7.4 Treatment complications; Additional subcategories under 7.2 and 7.3.

PSANZ-NDC version October 2004	PSANZ-NDC version February 2009
<p>7 Other</p> <p>7.1 Sudden Infant Death Syndrome (SIDS)</p> <p>7.11 SIDS Category IA: Classic features of SIDS present and completely documented.</p> <p>7.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.</p> <p>7.13 SIDS Category II : Infant deaths that meet category I except for one or more features.</p> <p>7.2 Multisystem failure-only if unknown primary cause or trigger event</p> <p>7.3 Trauma</p> <p>7.8 Other specified</p> <p>7.9 Unknown/Undetermined</p> <p>7.91 Unclassified Sudden Infant Death</p> <p>7.92 Other Unknown/Undetermined</p>	<p>7 Other</p> <p>7.1 Sudden Infant Death Syndrome (SIDS)</p> <p>7.11 SIDS Category IA: Classic features of SIDS present and completely documented.</p> <p>7.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.</p> <p>7.13 SIDS Category II : Infant deaths that meet category I except for one or more features.</p> <p>7.2 Multisystem failure</p> <p>7.21 Secondary to intrauterine growth restriction</p> <p>7.28 Other specified</p> <p>7.29 Unspecified/undetermined primary cause or trigger event</p> <p>7.3 Trauma</p> <p>7.31 Accidental</p> <p>7.32 Non accidental</p> <p>7.39 Unspecified</p> <p>7.4 Treatment complications</p> <p>7.41Surgical</p> <p>7.42 Medical</p> <p>7.8 Other specified</p> <p>7.9 Unknown/Undetermined</p> <p>7.91 Unclassified Sudden Infant Death</p> <p>7.92 Other Unknown/Undetermined</p>

3. Changes made in the October 2004 revision

3.1 Classification of associated factors

To enable consideration of factors associated with perinatal death, following classification of the main obstetric antecedent factor according to the PSANZ-PDC, and in addition for neonatal deaths the neonatal factor according to the PSANZ-NDC, it is now recommended that up to two associated factors, where present, be recorded using the classifications.

For example, when the death was due to placental abruption which was preceded by pre-eclampsia, according to the PSANZ-PDC, the death is classified as *Hypertension - Pre-eclampsia* (subcategory 3.5) and the associated factor is classified as *Antepartum Haemorrhage Placental Abruption* (subcategory 4.1).

3.2 Subcategories for Special Interest Groups: PDC and NDC

The subcategories in Addendums 1 and 2 for Special Interest Groups in the PSANZ-PDC and PSANZ-NDC version May 23rd 2003 have been removed from the guideline. These subcategories have been superseded by the incorporation of classifying associated factors as discussed in 1 above and the additional of subcategories within the classification (*Please see Hypertension Category 3 and APH Category 4*).

3.3 Minimum data set for perinatal deaths

The SIG has developed a recommended core dataset for the purpose of classification and reporting of perinatal deaths (see *PSANZ Perinatal Mortality Audit Package* Section 2; Appendix 1) is recommended for this purpose. It is hoped that the use of this core dataset will enhance the quality of perinatal audit and thus the value of analyses of perinatal mortality audit and research activities across ANZ.

3.4 Changes to the Perinatal Death Classification Categories

3.4.1 Congenital abnormality: Category 1.

Additional subcategories have been included under Category 1.8 *Other congenital abnormality*. These are: Category 1.84 *Haematological* for classification of deaths due to haematological abnormalities such as thalassemia; and Category 1.85 *Tumours* for classification of tumours which includes cystic hygroma. Subcategory 1.7 has been renamed to *Multiple/non chromosomal syndromes*. In addition, clarification of Categories 1.8 *Other congenital abnormality* and 1.9 *Unspecified congenital abnormality* has been included in the Classification Guide. Categories 1.3 *Urinary tract* and 1.4 *Gastrointestinal tract* have been renamed to Urinary system and Gastrointestinal system.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
1 Congenital Abnormality (including terminations for congenital abnormalities) 1.1 Central nervous system	1 Congenital Abnormality (including terminations for congenital abnormalities) 1.1 Central nervous system

1.2 Cardiovascular system	1.2 Cardiovascular system
1.3 Urinary tract	1.3 Urinary system
1.4 Gastrointestinal tract	1.4 Gastrointestinal system
1.5 Chromosomal	1.5 Chromosomal
1.6 Metabolic	1.6 Metabolic
1.7 Multiple	1.7 Multiple/non chromosomal syndromes
1.8 Other congenital abnormality	1.8 Other congenital abnormality
1.81 Musculoskeletal	1.81 Musculoskeletal
1.82 Respiratory	1.82 Respiratory
1.83 Diaphragmatic hernia	1.83 Diaphragmatic hernia
1.88 Other specified congenital abnormality	1.84 Haematological
1.9 Unspecified congenital abnormality	1.85 Tumours
	1.88 Other specified congenital abnormality
	1.9 Unspecified congenital abnormality

3.4.2 Perinatal infection: Category 2.

Subcategory 2.4 *Spirochaetal e.g. Syphilis* has been moved to 2.14. Category 2.8 has been renamed *Other specified organism* and 2.9 *Other unspecified organism*. In addition, clarification of the use of subcategories 2.8 and 2.9 has been included in the Classification Guide.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
2 Perinatal infection	2 Perinatal infection
2.1 Bacterial	2.1 Bacterial
2.11 Group B Streptococcus	2.11 Group B Streptococcus
2.12 E coli	2.12 E coli
2.13 Listeria monocytogenes	2.13 Listeria monocytogenes
2.18 Other bacterial	2.14 Spirochaetal e.g. Syphilis
2.19 Unspecified bacterial	2.18 Other bacterial
2.2 Viral	2.19 Unspecified bacterial
2.21 Cytomegalovirus	2.2 Viral
2.22 Parvovirus	2.21 Cytomegalovirus
2.23 Herpes simplex virus	2.22 Parvovirus
2.24 Rubella virus	2.23 Herpes simplex virus
2.28 Other viral	2.24 Rubella virus
2.29 Unspecified viral	2.28 Other vira
2.3 Protozoal e.g. Toxoplasma	2.29 Unspecified viral
2.4 Spirochaetal e.g. Syphilis	2.3 Protozoal e.g. Toxoplasma
2.5 Fungal	2.5 Fungal
2.8 Other	2.8 Other specified organism
2.9 Unspecified organism	2.9 Other unspecified organism

3.4.3 Hypertension: Category 3

Two subcategories have been included to identify laboratory evidence of thrombophilia with pre-eclampsia (Subcategories 3.51 and 3.61). These categories were included in the previous version of the guideline in the Addendum for Special Interest Groups.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
<p>3 Hypertension</p> <p>3.1 Chronic hypertension: essential</p> <p>3.2 Chronic hypertension: secondary, e.g. renal disease</p> <p>3.3 Chronic hypertension: unspecified</p> <p>3.4 Gestational hypertension</p> <p>3.5 Pre-eclampsia</p> <p>3.6 Pre-eclampsia superimposed on chronic hypertension</p> <p>3.9 Unspecified hypertension</p>	<p>3. Hypertension</p> <p>3.1 Chronic hypertension: essential</p> <p>3.2 Chronic hypertension: secondary, e.g. renal disease</p> <p>3.3 Chronic hypertension: unspecified</p> <p>3.4 Gestational hypertension</p> <p>3.5 Pre-eclampsia</p> <p> 3.51 With laboratory evidence of thrombophilia</p> <p>3.6 Pre-eclampsia superimposed on chronic hypertension</p> <p> 3.61 With laboratory evidence of thrombophilia</p> <p>3.9 Unspecified hypertension</p>

3.4.4 Antepartum haemorrhage Category 4

An additional subcategory 4.11 has been included to identify laboratory evidence of thrombophilia with placental abruption. This category was previously included in the Addendum for Special Interest Groups.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
<p>4 Antepartum Haemorrhage (APH)</p> <p>4.1 Placental abruption</p> <p>4.2 Placenta praevia</p> <p>4.3 Vasa praevia</p> <p>4.8 Other APH</p> <p>4.9 APH of undetermined origin</p>	<p>4 Antepartum Haemorrhage (APH)</p> <p>4.1 Placental abruption</p> <p> 4.11 With laboratory evidence of thrombophilia</p> <p>4.2 Placenta praevia</p> <p>4.3 Vasa praevia</p> <p>4.8 Other APH</p> <p>4.9 APH of undetermined origin</p>

3.4.5 Maternal conditions: Category 5.

Category 5.1 has been renamed to *Termination of pregnancy for maternal psychosocial indications*. Additional subcategories have been included as follows: 5.5 *Lupus obstetric syndrome* and 5.6 *Obstetric cholestasis* (previously classified under 5.8 *Other maternal conditions*).

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
<p>5 Maternal Conditions</p> <p>5.1 Termination of pregnancy (other than for congenital (fetal) abnormality)</p> <p>5.2 Diabetes / Gestational diabetes</p> <p>5.3 Maternal injury</p> <p> 5.31 Accidental</p> <p> 5.32 Non-Accidental</p> <p>5.4 Maternal sepsis</p> <p>5.8 Other maternal conditions, e.g. Lupus obstetric syndrome</p>	<p>5 Maternal Conditions</p> <p>5.1 Termination of pregnancy for maternal psychosocial indications</p> <p>5.2 Diabetes / Gestational diabetes</p> <p>5.3 Maternal injury</p> <p> 5.31 Accidental</p> <p> 5.32 Non-accidental</p> <p>5.4 Maternal sepsis</p> <p>5.5 Lupus obstetric syndrome</p>

- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions

3.4.6 Hypoxic peripartum death: Category 7

An additional subcategory has been included: 7.2 Evidence of non-reassuring fetal status in a normally grown infant (e.g. abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intrapartum complications). This category identifies hypoxic peripartum deaths where there was evidence of fetal distress in a normally grown infant without apparent intrapartum complications as defined in 7.1. A new subcategory 7.3 has been included to identify deaths where there are no apparent complications as defined in 7.1 and no evidence of non-reassuring fetal status as defined in 7.2.

In the circumstance of a growth restricted infant fulfilling the criteria for this category, the death should be classified as *Category 8 Fetal Growth Restriction* with the exception of deaths due to an intrapartum obstetric complication where the death should be classified as Category 7.1. The Classification Guide has been updated to incorporate these changes and also to clarify the application of Category 7.9 *Unspecified hypoxic peripartum death*.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
<p>7 Hypoxic Peripartum Death (typically infants of >24 weeks gestation or >600g birthweight)</p> <p>7.1 With intrapartum complications</p> <ul style="list-style-type: none"> 7.11 Uterine rupture 7.12 Cord prolapse 7.13 Shoulder dystocia 7.18 Other <p>7.2 No apparent complications</p> <p>7.9 Unspecified hypoxic peripartum death</p>	<p>7 Hypoxic Peripartum Death (typically infants of >24 weeks gestation or >600g birthweight)</p> <p>7.1 With intrapartum complications</p> <ul style="list-style-type: none"> 7.11 Uterine rupture 7.12 Cord prolapse 7.13 Shoulder dystocia 7.18 Other <p>7.2 Evidence of non-reassuring fetal status in a normally grown infant (e.g. abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intrapartum complications)</p> <p>7.3 No intrapartum complications and no evidence of non-reassuring fetal status.</p> <p>7.9 Unspecified hypoxic peripartum death</p>

3.4.7 Fetal Growth Restriction (FGR): Category 8

Revised definition

The definition of FGR in the case of a macerated stillborn infant with suspected Small for Gestational Age (SGA) and without prior antenatal ultrasound evidence of FGR has been revised to include infants with a brain:liver ratio of 4:1 at autopsy. Suspected Small for Gestational Age (SGA) macerated stillbirths without prior ultrasound evidence of FGR or brain:liver ratio of 4:1 at autopsy should be classified as *Unexplained Antepartum Death* (Category 10), as the weight discrepancy may be a post mortem effect. Customised centiles⁽²⁾ should be used in determining the presence of FGR, however, as yet data are not available to recommend their routine use in ANZ. It is also recommended that for fetal deaths, where possible, the date of death and not date of birth be used to define the presence of FGR.

The changes to subcategories are as follows:

Subcategory 8.1 description changed to include Doppler evidence; subcategory 8.3 new wording: *No placental pathology*; new subcategory 8.8 *Other placental pathology* is used when placental pathology as described in the subcategories 8.1 or 8.2 is not present.

Clarification of the use of subcategory 8.9 *Unspecified or not known whether placenta examined* has been included in the Classification Guide.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
<p>8 Fetal Growth Restriction (FGR)</p> <p>8.1 With evidence of uteroplacental insufficiency e.g. significant infarction, acute atherosclerosis, maternal and/or fetal vascular thrombosis or maternal floor infarction</p> <p>8.2 With chronic villitis</p> <p>8.3 Without the above placental pathology</p> <p>8.4 No examination of placenta</p> <p>8.9 Unspecified FGR or not known whether placenta examined</p>	<p>8 Fetal Growth Restriction (FGR)</p> <p>8.1 With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (e.g. significant infarction, acute atherosclerosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)</p> <p>8.2 With chronic villitis</p> <p>8.3 No placental pathology</p> <p>8.4 No examination of placenta</p> <p>8.8 Other specified placental pathology</p> <p>8.9 Unspecified or not known whether placenta examined</p>

3.4.8 Spontaneous preterm: Category 9

Description change for subcategories 9.11, 9.21 and 9.31 to *With chorioamnionitis confirmed on placental histopathology* to clarify the need for placental confirmation of chorioamnionitis for this category; new subcategories 9.13, 9.23 or 9.33 for clinical chorioamnionitis where no placental histopathology is available; new subcategories 9.17, 9.27 and 9.37 *No clinical signs of chorioamnionitis, no examination of placenta*.

Clinical chorioamnionitis is defined as maternal fever ($\geq 38^{\circ}\text{C}$) associated with one or more of the following symptoms or signs: maternal or fetal tachycardia, uterine tenderness, malodorous amniotic fluid, and maternal leukocytosis or raised C-reactive protein. Clarification on the use of subcategory 9.39 has been included in the Classification Guide.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
<p>9 Spontaneous Preterm (<37 weeks gestation)</p> <p>9.1 Spontaneous preterm with intact membranes, or membrane rupture <24 hours before delivery</p> <p>9.11 With chorioamnionitis</p> <p>9.12 Without chorioamnionitis</p> <p>9.13 No examination of placenta</p> <p>9.19 Unspecified or not known whether placenta examined</p> <p>9.2 Spontaneous preterm with membrane rupture ≥ 24 hours before delivery</p> <p>9.21 With chorioamnionitis,</p> <p>9.22 Without chorioamnionitis,</p>	<p>9 Spontaneous Preterm (<37 weeks gestation)</p> <p>9.1 Spontaneous preterm with intact membranes, or membrane rupture <24 hours before delivery</p> <p>9.11 With chorioamnionitis on placental histopathology</p> <p>9.12 Without chorioamnionitis on placental histopathology</p> <p>9.13 With clinical evidence of chorioamnionitis, no examination of placenta</p> <p>9.17 No clinical signs of chorioamnionitis, no examination of placenta</p> <p>9.19 Unspecified or not known whether placenta</p>

<p>9.23 No examination of placenta whether placenta examined</p> <p>9.3 Spontaneous preterm with membrane rupture of unknown duration before delivery,</p> <p>9.31 With chorioamnionitis</p> <p>9.32 Without chorioamnionitis</p> <p>9.33 No examination of placenta</p> <p>9.39 Unspecified or not known whether placenta examined</p>	<p>9.29 Unspecified or not known whether placenta examined</p> <p>9.2 Spontaneous preterm with membrane rupture ³24 hours before delivery</p> <p>9.21 With chorioamnionitis on placental histopathology</p> <p>9.22 Without chorioamnionitis on placental histopathology</p> <p>9.23 With clinical evidence of chorioamnionitis, no examination of placenta</p> <p>9.27 No clinical signs of chorioamnionitis, no examination of placenta</p> <p>9.29 Unspecified or not known whether placenta examined</p> <p>9.3 Spontaneous preterm with membrane rupture of unknown duration before delivery</p> <p>9.31 With chorioamnionitis on placental histopathology</p> <p>9.32 Without chorioamnionitis on placental histopathology</p> <p>9.33 With clinical evidence of chorioamnionitis, no examination of placenta</p> <p>9.37 No clinical signs of chorioamnionitis, no examination of placenta</p> <p>9.39 Unspecified or not known whether placenta examined</p>
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3.4.9 Unexplained antepartum death: Category 10

Description change to subcategory 10.1 to include Doppler evidence of reduced vascular perfusion; subcategory 10.3 has been reworded; new subcategory 10.8 *Other placental pathology* is used when placental pathology as described in the subcategories 10.1 or 10.2 is not present; Category 10.9 description changed for clarity. Clarification of the use of subcategory 10.9 *Unspecified or not known whether placenta examined* has been included in the Classification Guide.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
<p>10 Unexplained Antepartum Death</p> <p>10.1 With evidence of uteroplacental insufficiency, e.g. significant infarction, acute atherosclerosis, maternal and/or fetal vascular thrombosis or maternal floor infarction</p> <p>10.2 With chronic villitis</p> <p>10.3 Without the above placental pathology</p> <p>10.4 No examination of placenta</p> <p>10.9 Unspecified unexplained antepartum death or not known whether placenta examined</p>	<p>10 Unexplained Antepartum Death</p> <p>10.1 With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (e.g. significant infarction, acute atherosclerosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)</p> <p>10.2 With chronic villitis</p> <p>10.3 No placental pathology</p> <p>10.4 No examination of placenta</p> <p>10.8 Other specified placental pathology</p> <p>10.9 Unspecified or not known whether placenta examined</p>

3.4.10 No obstetric antecedent: Category 11.

Subcategories 11.1 *SIDS* and 11.91 *Unclassified Sudden Infant Death* are defined according to the new SIDS classification system by Krous et al⁽¹¹⁾. This classification system provides a broad overall definition of SIDS which is then subcategorised on the basis of specific epidemiological features and the amount of information available (*Please see below*). Subcategory 11.92 *Other*

Unknown/Undetermined has been included to identify unknown causes of death which do not fulfil the criteria of Category 11.92.

An explanation of the categories is included in the Classification Guide.

In addition, subcategory 11.8 has been renamed to *Other specified* for clarity and includes classification of conditions which are not included in subcategories.

PSANZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004
<p>11 No Obstetric Antecedent</p> <p>11.1 SIDS</p> <p> 11.11 Consistent with SIDS</p> <p> 11.12 Possible SIDS</p> <p>11.2 Postnatally acquired infection</p> <p>11.3 Accidental asphyxiation</p> <p>11.4 Other accident, poisoning or violence (postnatal)</p> <p>11.8 Other</p> <p>11.9 Unknown / Unexplained</p>	<p>11 No Obstetric Antecedent</p> <p>11.1 Sudden Infant Death Syndrome (SIDS)</p> <p> 11.11 SIDS Category IA: Classic features of SIDS present and completely documented.</p> <p> 11.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.</p> <p> 11.13 SIDS Category II : Infant deaths that meet Category I except for one or more features.</p> <p>11.2 Postnatally acquired infection</p> <p>11.3 Accidental asphyxiation</p> <p>11.4 Other accident, poisoning or violence (postnatal)</p> <p>11.8 Other specified</p> <p>11.9 Unknown/Undetermined</p> <p> 11.91 Unclassified Sudden Infant Death</p> <p> 11.92 Other Unknown/Undetermined</p>

3.5 Changes to the Neonatal Death Classification Categories

3.5.1 Congenital abnormality: Category 1.

Changes to subcategories have been made as for the Perinatal Death Classification.

3.5.2 Other: Category 7.

Changes to the classification of SIDS have been made as for the Perinatal Death Classification.

APPENDIX V

DEVELOPMENT OF PSANZ PERINATAL DEATH CLASSIFICATION AND PSANZ NEONATAL DEATH CLASSIFICATION

Since 1986, clinicians in some Australian States and Territory Perinatal Committees (notably South Australia and Queensland) and the Perinatal Mortality Committee at the National Women's Hospital in Auckland, have been considering ways of classifying fetal and neonatal deaths beyond standard ICD (International Classification of Diseases) coding, with a view to better assessing aetiology (in order to consider preventable factors) and to more accurately determine specific factors leading to neonatal death.

Experience with the Whitfield obstetric antecedent classification¹ led to realisation that there were shortcomings with this system - it was not hierarchical and did not accommodate more recent knowledge about the causation of some perinatal deaths. Modifications of the Whitfield system were made and published independently by the South Australian and Queensland committees and in the National Women's Hospital report. In 1999, the National Perinatal Data Development Committee (NPDDC) recommended that the topic be further considered at a workshop to be held about the time of the 4th Annual Conference of the Perinatal Society of Australia and New Zealand, held in Brisbane on the 16th March 2000, attended by representatives of most jurisdictions. This was the third such workshop, the two previous being in Brisbane 1996 and Alice Springs 1998. At this workshop it was agreed to attempt to develop uniform classification systems for use throughout Australia and New Zealand. It was agreed that drafts be developed by the Queensland and South Australian representatives, and circulated for comment and discussion, to representatives from the other Australian States and Territories and from New Zealand, with a view to presenting a consensus to the NPDDC in July 2000. Consensus was reached and the finalised classifications were accepted by the NPDDC.

The classifications systems were originally named the Australian and New Zealand Antecedent Classification of Perinatal Mortality (ANZACPM), and the Australian and New Zealand Neonatal Death Classification (ANZNDC). Following endorsement of this activity as a Special Interest Group of the PSANZ in March 2003, the classifications have been renamed to the Perinatal Society of Australia and New Zealand Perinatal Death Classification (PSANZ-PDC) and the Perinatal Society of Australia and New Zealand Neonatal Death Classification (PSANZ-NDC). A description of the classification development in the context of other classification systems was recently published in the *Journal of Paediatrics and Child Health* ².

References

1. Whitfield CR, Smith NC, Cockburn F, Gibson AA. Perinatally related wastage – a proposed classification of primary obstetric factors. *Br J Obstet Gynaecol* 1986; **93**.
2. Chan A, King JF, Flenady V, Haslam RH, Tudehope DI. Classification of perinatal deaths: development of the Australian and New Zealand classifications. *J Paediatr Child Health* 2004; **40**.

APPENDIX W

METHODS OF GUIDELINE DEVELOPMENT AND REVISION

The guideline has been developed by the Perinatal Society of Australia and New Zealand Perinatal Mortality (PSANZ-PMG)¹ The Centre for Clinical Studies (CCS) (now Mater Mothers' Research Centre - MMRC), Mater Health Services, Brisbane was originally commissioned by the PSANZ-PMG (through funding made available by the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, SANDS Queensland and SIDS and Kids) to coordinate the development of the guidelines. The MMRC conducted the literature search and collated the review and assembled the draft guidelines in consultation with Working Party members. In the second revision (2008/2009), the PSANZ-PMG collaborated with Australia and New Zealand Stillbirth Alliance (ANZSA) with funds made available by PSANZ and ANZSA. In the third revision of the guideline in 2017, the PSANZ Stillbirth and Neonatal Death Alliance (previously PSANZ PMG) worked in partnership with NHMRC Centre of Research Excellence (previously ANZSA) following the methods of the original version of the guidelines. Literature searches were updated to Dec 2015.

Perinatal Mortality Guidelines Working Party

The Working Party was originally convened in March 2004 to:

- Produce a guideline on Perinatal Mortality Audit for use in Australia and New Zealand;
- Identify gaps in current information and data for the ongoing refinement and evaluation of the above guideline; and
- Collaborate with local and national bodies in the development, implementation and evaluation of the guideline including the impact on health outcomes

In fulfilling this task, the Working Party followed the procedures recommended in the NHMRC documents: Handbook series on preparing clinical practice guidelines, endorsed November 1999² and 2011³ for subsequent updates. This process included attention to the following steps:

- Define the scope of the guidelines in order to: ensure clinical relevance; identify further questions, target groups and relevant health outcomes to be addressed by the guidelines;
- Assess any existing guidelines;
- Undertake (or commission) a systematic review of the literature and evaluate the extent and strength of the scientific evidence relating to the effectiveness and appropriateness of the relevant interventions;
- Refine the evidence-based guidelines and other materials to explain guidelines to consumers and other defined target groups;
- Undertake wider consultation;
- Disseminate and implement guidelines; and
- Evaluate and maintain guidelines.

The Working Party was re-convened in February 2008 to review and update the guideline. A one-day meeting was held in Sydney to discuss the required changes on the basis of which amendments were made and finalised through email communication. Section 7 was finalised in April 2009.

Consultation process

For the first version of the guideline, two meetings were held in March 2004 at the PSANZ 8th Annual Congress, Sydney, Australia; one meeting involved the whole Working Party; the other, the perinatal pathologists. Subsequently, subgroups of the Working Party were set up for each of the major sections of the guideline based on the interests of the members. Consultation was undertaken with the subgroup members by email and telephone to produce a final draft for consultation.

Organisations included in the wider consultation up to and including the 2008/9 update were as follows:

ACMI	Australian College of Midwives Incorporated
ACNN	Australian College of Neonatal Nurses
HGSA	Human Genetics Society Australasia
PSANZ	Perinatal Society of Australia and New Zealand
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
SANDS (Qld)	Stillbirth and Neonatal Death Support Group (Qld)
SIDS & Kids	Sudden Infant Death & Stillbirth and Kids
ANZNN	Australian and New Zealand Neonatal Network
BBF	Bonnie Babes Foundation*
SBF	The Stillbirth Foundation Australia*

*second edition of the Guideline only.

Organisations included in the wider consultation for the 2017 update are as follows:

Australian College of Midwives

Australian College of Neonatal Nurses

Human Genetics Society Australasia

Perinatal Society of Australia and New Zealand

Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Women's Healthcare Australasia

Stillbirth and Neonatal Death Support National

Red Nose

Australian and New Zealand Neonatal Network

The Stillbirth Foundation Australia

Still Aware

Bears of Hope

Queensland Maternal Perinatal Quality Council

Consultative Council on Obstetric and Paediatric Morbidity and Mortality, Victoria

Maternal and Perinatal Mortality Committee, South Australia

Council on Obstetric and Paediatric Mortality, Tasmania

Perinatal and Infant Mortality Committee of Western Australia

Perinatal Mortality and Morbidity Review Committee, New Zealand

Search strategy

A comprehensive search strategy was developed based on the initial discussions of the Working Party and those of the Working Party's subgroups. The search strategy included an electronic database search and guideline website search. In addition, the CCS and members of the Working Party searched previous reviews including cross references and contacted experts in the field for additional information.

The search strategy for the first edition included searches of the following electronic databases: The Cochrane Library (Issue 2, 2004); MEDLINE (1966-2004); and CINAHL (1982-2004). Generic terms were used throughout the guideline, with additional terms included in the section specific searches.

Generic search terms included: text terms; f?etal death, f?etal wastage, perinatal mortality, perinatal death, stillb*, neonatal mortality, neonatal death, NND and MeSH terms; fetal death and perinatal death.

The generic search terms were combined with section specific terms, including the following: review, audit, classification, investigat*, guideline, protocol, test*, explor* rural, non-metropolitan, outreach, isolat*, info*, brochure*, pamphlet*, parent*, mother*, father*, profession*, nurs*, midwi*, doctor*, p?ediatric*, neonatolog*, bereave*, grief, emotion*, care, psycho*, funeral, social*, suboptimal, substandard, standard*, inadequate, compliance, manage*, HBA1c, glucose tolerance test, GTT, Fasting blood glucose.

This search was updated and expanded in February 2008, searching the years 2004 to March 2008.

The following guideline web sites were searched in March 2008 for existing perinatal mortality audit guidelines.

Web site name/Organisation name	Web site address/URL
Alberta Medical Association, Canada	http://www.albertadoctors.org/home
American College of Obstetrics and Gynecology	http://www.acog.com/
Association of Women's Health, Obstetric and Neonatal Nurses	http://www.awhonn.org/awhonn
Australian Government, Department of Health & Ageing: Safety & Quality in Health Care	http://www.health.gov.au
Australian Government, National Health & Medical Research Council	http://www.nhmrc.gov.au
British Columbia Perinatal Care Program,, Canada	http://www.bcphp.ca/Perinatal%20Mortality%20Guidelines.htm
Canadian Paediatric Society	http://www.cps.ca/english/publications
Canadian Task Force On Preventive Health Care: Evidence-Based Clinical Prevention	http://www.ctfphc.org/
Confidential Enquiry into Maternal and Child Health (CEMACH)	http://www.cemach.org.uk/Publications.aspx
Department of Health, New South Wales	http://www.health.nsw.gov.au/

Department of Health, United Kingdom	http://www.dh.gov.uk/Home/fs/en
Department of Health, Western Australia	http://www.health.wa.gov.au/
Guideline Advisory Committee, Ontario, Canada	http://www.gacguidelines.ca/
HSTAT – Health Services/Technology Assessment Text	http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat
Human Tissue Authority, United Kingdom	http://www.hta.gov.uk/guidance/codes_of_practice.cfm
Institute of Clinical Systems Improvement	http://www.icsi.org/guidelines_and_more/
King Edward Memorial Hospital for Women, Subiaco, Western Australia	http://www.kemh.health.wa.gov.au/
National Guideline Clearinghouse	http://www.guideline.gov/
National Institute for Clinical Excellence, UK	http://www.nice.org.uk/
Neonatology on the Web	http://www.neonatology.org/
New Zealand Guidelines Group	http://www.nzgg.org.nz/index.cfm?screenize=1024&ScreenResSet=yes
Princess Margaret Hospital for Children, Subiaco, Western Australia	http://www.pmh.health.wa.gov.au/
Queensland Health, Australia	http://qhps.health.qld.gov.au/
Royal Children’s Hospital, Melbourne, Australia	http://www.rch.org.au/clinicalguide/index.cfm?doc_id=5033
Royal College of Obstetricians and Gynaecologists, UK	http://www.rcog.org.uk/index.asp?PageID=8
Royal College of Pathologists	http://www.rcpath.org/
Royal Prince Alfred Hospital, Camperdown, New South Wales	http://www.cs.nsw.gov.au/rpa/
Scottish Intercollegiate Guidelines Network (SIGN)	http://www.sign.ac.uk/
Society of Obstetricians and Gynaecologists of Canada	http://www.sogc.org/index_e.asp
Three Centres Collaboration, Australia	http://www.3centres.com.au/
University of California and San Francisco, United States	http://medicine.ucsf.edu/resources/guidelines/
University of Manitoba, Canada	http://umanitoba.ca/

Wisconsin Stillbirth Service Program	http://www.wisc.edu/wissp/
Women's and Children's Hospital, Adelaide, Australia	http://www.wch.sa.gov.au/

The guideline web site search yielded the following 22 guidelines on aspects of perinatal mortality audit:

Association	Guideline
Alberta Medical Association	Alberta Medical Association. Investigation of Stillborn Protocol. In: Alberta Medical Association; 1998 (updated 2005). http://www.albertadoctors.org/bcm/ama/ama-website.nsf/AllDoc/FB1F65D913EDB64787256E2A005E700E?OpenDocument accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 1: The Perinatal Mortality Review Process. British Columbia; 1999. http://www.bccrcp.xplorex.com//sites/bccrcp/files/Guidelines/Pmg/MasterPM1ReviewProcessApril99.pdf accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 2: Hospital Perinatal Mortality Review Committee: Terms of Reference. British Columbia; 1999. http://www.bccrcp.xplorex.com//sites/bccrcp/files/Guidelines/Pmg/MasterPM2TORHospReviewCommApril99.pdf accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 3: Classification of Perinatal Deaths. British Columbia; 1999. http://www.bccrcp.xplorex.com//sites/bccrcp/files/Guidelines/Pmg/MasterPM3ClassifDeathsApril99.pdf accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 4: Clinical Examination of the Placenta. British Columbia; 1999. http://www.bccrcp.xplorex.com//sites/bccrcp/files/Guidelines/Pmg/MasterPM4ExamPlacentaApril99.pdf accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 5: Investigation and Assessment of Stillbirths. British Columbia; 1999. http://www.bccrcp.xplorex.com//sites/bccrcp/files/Guidelines/Pmg/MasterPM5InvestAssesStillbirthsMay2000.pdf accessed 2008
Canadian Paediatric Society	Canadian Paediatric Society Statement. Guidelines for health care professionals supporting families experiencing a perinatal loss. Paediatric Child Health 2001;6(7):469-477. (Re-affirmed May 2007) http://www.cps.ca/english/statements/FN/FN01-02.pdf accessed 2008
South Australian Department of Human Services	Department of Human Services South Australia. Maternal, Perinatal and Infant Mortality in South Australia 2006. Including South Australian Protocol for investigation of stillbirths. In: Department of Human Services, South Australia; 2007. http://www.dh.sa.gov.au/pehs/PDF-files/0712-mortality-report-2006.pdf accessed 2008
Royal Prince Alfred Hospital, Sydney, NSW	Department of Neonatal Medicine RPAH. Stillbirths. In: Central Sydney Area Health Service. http://www.cs.nsw.gov.au/rpa/neonatal/default.htm accessed 2008

Department of Health, UK	DH Clinical Ethics and Human Tissue Branch. Families and post mortems - A code of practice. Best Practice Guideline. London: Department of Health; 2003 April 2003. http://www.dh.gov.uk/assetRoot/04/05/43/12/04054312.pdf accessed 2008
Department of Health, UK	DH Clinical Ethics and Human Tissue Branch. A guide to the post mortem examination procedure involving a baby or child. In: Department of Health; 2003. http://www.dh.gov.uk/assetRoot/04/08/39/60/04083960.pdf accessed 2004
Queensland Department of Health	Queensland Maternal and Perinatal Quality Council. Maternal and Perinatal Mortality Audit: Guidelines for Maternity Hospitals. Queensland: Queensland Government, Queensland Health; 2003.
Royal Children's Hospital, Melbourne, VIC	Kane H, Wilkinson G. Reproductive Loss: Pre 20 Week / Stillbirth / neonatal death / infant death, Melbourne. Melbourne: Royal Children's Hospital, Melbourne; 2003 19/05/2003. Report No.: 9W-04-1-002. http://www.rch.org.au/intranet/policy/9W041002.htm accessed 2004 Not able to be accessed March 2008
Royal Children's Hospital, Melbourne, VIC	Kane H, Wilkinson G. Reproductive Loss: Stillbirth 20 weeks and over, Melbourne. Electronic. Melbourne: Royal Children's Hospital, Melbourne; 2003 17/05/2003. Report No.: 9W-04-2-038. http://www.rch.org.au/intranet/policy/9W042038.htm accessed 2004 Not able to be accessed March 2008
Western Australia Department of Health	McLaughlin V. Non-Coronial Post-Mortem Examinations: Code of Practice 2007, WA: Health Department, WA; 2007. http://www.health.wa.gov.au/postmortem/docs/Non-Coronial_Post-Mortem_Examinations_Code_of_Practice_2007.pdf accessed March 2008
New South Wales Department of Health	NSW Health Department. Stillbirth: Management and Investigation.. Electronic/circular. Sydney: NSW Health Department; 1997 27/10/1997. Report No.: 97/107. http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007_025.pdf accessed March 2008
New South Wales Department of Health	NSW Health Department. Hospital Procedures for review and reporting of perinatal deaths. In; 2006. http://www.health.nsw.gov.au/policies/pd/2006/pdf/PD2006_006.pdf accessed March 2008
Royal College of Pathologists, UK	Royal College of Pathologists. Appendix 6: Guidelines for autopsy investigation of fetal and perinatal death. London: Royal College of Pathologists; 2002 Sept 2002. http://www.rcpath.org/resources/pdf/appendix_6.pdf accessed March 2008
Royal Children's Hospital, Melbourne, VIC	Ross J, Smith M, Dutton G. Reproductive Loss: Neonatal / Infant Death. Electronic. Melbourne: Royal Children's Hospital, Melbourne; 1999 18/11/99. Report No.: 9W-04-2-019. http://www.rch.org.au/intranet/policy/9W042019.htm accessed March 2008
King Edward Memorial Hospital, WA	Women's and Children's Health Services WA. Perinatal Death. In: King Edward Memorial Hospital; 2001. http://www.kemh.health.wa.gov.au/development/manuals/guidelines.htm accessed March 2008

Women's and Children's Hospital, Adelaide, SA	Women's and Children's Hospital Adelaide. Perinatal Protocols and Guidelines for Management; 1996. http://www.wch.sa.gov.au/services/az/divisions/wab/deliverysuite/ accessed 2004 Directed to South Australian Government. (below)
Government of South Australia. Department of Health.	South Australian Perinatal Practice Guidelines http://www.health.sa.gov.au/PPG/Default.aspx?tabid=113 accessed March 2008.

Levels of evidence

As defined by "A guide to the development, implementation and evaluation of clinical practice guidelines"⁴, <http://www.nhmrc.gov.au/publications/synopses/cp30syn.htm>

Level I evidence obtained from a systematic review of all relevant randomised controlled trials.

Level II evidence obtained from at least one properly designed randomised controlled trial.

Level III-1 evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method).

Level III-2 evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case control studies, or interrupted time series with a control group.

Level III-3 evidence obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group.

Level IV evidence obtained from case series, either post-test or pre-test and post-test.

Although an attempt was initially made to apply the above quality ratings to the available literature, due to limited resources available for development of the guideline combined with the apparent paucity of high quality evidence, it was decided not to continue with this activity. Therefore, recommendations are based on consensus by the Working Party after review of the available information and levels of evidence are not referred to in the guideline.

2. Section notes

Section 2

In the development of this section an attempt was made to obtain all existing national and international guidelines and protocols on perinatal mortality review. The following guideline/policy statements were used as a basis for development of this guideline:

1. Queensland Maternal and Perinatal Quality Council. Maternal and Perinatal Mortality Audit: Guidelines for Maternity Hospitals. Queensland: Queensland Government, Queensland Health; 2003⁵.
2. Centre for Epidemiology and Evidence. Deaths - Review and Reporting of Perinatal Deaths. North Sydney: Ministry of Health, NSW; 2011.
3. Perinatal Mortality Guidelines in British Columbia. Vital Statistics. In. Victoria, British Columbia; 1998⁶.

Section 3

We would like to acknowledge those who have significantly contributed to the review and update of this section of the guidelines.

First edition: Kylie Lynch, Liz Davis, Sonia Herbert, Ros Richardson, Dell Horey, Vicki Flenady

Second edition: (minor review): Liz Davis, Ros Richardson and Vicki Flenady

Third edition: (major review): Trish Wilson, Belinda Jennings, Diana Bond, Paula Dillon, Fran Boyle

Section 4

This section was first developed by Adrian Charles, Susan Arbuckle, Diane Payton, Vicki Flenady, Jane Dahlstrom, Jane Zuccolo, Yee Khong and Nick Smith.

The main resource documents used in the development of this section were:

1. The Royal College of Pathologists of Australasia Autopsy Working Party. The decline of the hospital autopsy: a safety and quality issue for healthcare in Australia. *Med J Aust* 2004;180(6):281-5.
2. The Royal College of Pathologists of Australasia. Autopsies and the use of tissues removed from autopsies. In. Sydney: Royal College of Pathologists of Australasia; 2002.
3. The Royal College of Pathologists. Guidelines for Post Mortem Reports. London: The Royal College of Pathologists; 1993.
4. The Royal College of Pathologists. Guidelines on autopsy practice: Report of a working group of the Royal College of Pathologists. In. London: Royal College of Pathologists; 2002.
5. AHMAC Subcommittee on Autopsy Practice. The national code of ethical autopsy practice. Adelaide: SA Department of Human Services; 2002 5 April.
6. SIDS & Kids Australia. SIDS Focussing on Stillbirth: Investigation and Prevention of Stillbirth: Setting the Policy and Research Agenda: SIDS and Kids Australia; 2001 29/11/2001.
7. SIDS & Kids Australia. SIDS and Kids Focussing On Stillbirth: Report from the SOS Pathology Workshop. Sydney: SIDS & Kids Australia; 2002 22 Nov.
8. Royal College of Paediatrics and Child Health. The future of paediatric pathology services: fetal, perinatal and paediatric pathology; a critical future. Report of a working group to restore and develop specialist paediatric pathology: a critically important specialty, essential for the best quality care of children. London: Royal College of Paediatrics and Child Health; 2002 March.

Section 5

A subgroup of the Working Party (Glenn Gardener, Lesley McCowan, James King, Jane Zuccolo, Katie Day (nee Waters), Gus Dekker, Hanna Reinebrant, Kimberly Abussi and Vicki Flenady) drew on existing national and international protocols for stillbirth investigation and the findings of a comprehensive literature search in the initial development of this section of the guideline.

The main initial resource documents used in the development of this section were:

1. Queensland Maternal and Perinatal Quality Council. Maternal and perinatal mortality audit: Guidelines for maternity hospitals. Queensland: Queensland Government, Queensland Health; 2003.

2. Department of Human Services South Australia. Maternal, Perinatal and Infant Mortality in South Australia 2002. Including South Australian Protocol for investigation of stillbirths. In: Department of Human Services, South Australia; 2002.
3. Wisconsin Stillbirth Service Program. Guide to etiologic evaluation of the stillborn infant: The WiSSP Protocol. In. Wisconsin: Wisconsin Stillbirth Service Program.
4. British Columbia Reproductive Care Program. Perinatal Mortality Guideline 5: Investigation and Assessment of Stillbirths. British Columbia; 1999.
5. The American College of Obstetricians and Gynecologists. Management of Stillbirth. In: ACOG Practice Bulletin: Clinical management for Obstetricians and Gynaecologists; 2009.
6. Alberta Perinatal Health Program. Stillborn Protocol: Investigation of Stillborn protocol. In Alberta Medical Association, Alberta; 1998.
7. Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland. Investigation and Management of Late Fetal Intrauterine Death and Stillbirth Clinical Practice Guideline; 2011
8. Iowa Department of Public Health. Fetal Death Evaluation Protocol. Iowa State Health; 2011
9. Royal College of Obstetricians and Gynaecologists. Late intrauterine Fetal Death and Stillbirth. In Greentop Guideline No. 55; 2010
10. Maternal Fetal Medicine Committee of Society of Obstetricians and Gynecologists of Canada. Stillbirth and Bereavement: Guidelines for investigation. In: SOGC Clinical Practice Guidelines; 2006

Section 6

A subgroup of the Guideline Working Party worked collaboratively in the development of this Section, the members were: Alison Kent, Lucy Cooke, David Tudehope, Ross Haslam, Jane Dahlstrom and Adrienne Gordon.

Section 7

A subgroup of the Guideline Working Party worked collaboratively in the development of this Section. We wish to acknowledge and Annabelle Chan and James King for their leadership in reaching consensus on the initial PDC system and Ross Haslam and Andy McPhee for development of the NDC. All revisions will be summarized in the Appendix of Section 7.

5. References

1. PSANZ PMN-SIG. Perinatal Society of Australia and New Zealand: Special Interest Group. Australia and New Zealand: PSANZ, 2004.
2. National Health and Medical Research Council. How to present the evidence for consumers: Preparation of consumer publications. Canberra: NHMRC, 1999.
3. National Health and Medical Research Council. 2011. Melbourne: National Health and Medical Research Council; Procedures and requirements for meeting the 2011 NHMRC standard for clinical practice guidelines
4. National Health and Medical Research Council. A guide to the development, implementation and evaluation of clinical practice guidelines. Canberra: Commonwealth of Australia, 1998.
5. Queensland Maternal and Perinatal Quality Council. Maternal and perinatal mortality audit: Guidelines for maternity hospitals. Queensland: Queensland Government, Queensland Health, 2003.
6. British Columbia vital statistics agency. Vital Statistics. Victoria; 1998
<http://www.vs.gov.bc.ca/>.

APPENDIX X

GLOSSARY OF TERMS AND ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACMI	Australian College of Midwives Incorporated
ACNN	Australian College of Neonatal Nurses
aetiology	The science of causes, especially of disease
amnion	A thin but tough extraembryonic membrane of reptiles, birds and mammals that lines the chorion and contains the foetus and the amniotic fluid around it, in mammals it is derived from trophoblast by folding or splitting.
amniotic fluid	The fluid that surrounds the developing foetus within the amniotic sac. This environment cushions the baby from injury and plays an important role in foetal development.
anteartum death	Death of a baby before the onset of labour
ANZNN	Australian and New Zealand Neonatal Network
ANZSA	Australian and New Zealand Stillbirth Alliance
APC resistance	Activated protein C resistance
Apgar score	A system to assess the status of the infant after birth. The Apgar score is based on the following five variables: heart rate, respiratory effort, muscle tone, reflex irritability and colour. Maximum score is 10. It is recorded at one minute and five minutes after birth.
APS	Antiphospholipid syndrome
AP view	Anterio-posteria view
autopsy	A surgical procedure postmortem, which involves the examination of body tissues (including internal organs), often to determine cause of death.
cardiotocography (CTG)	The electronic monitoring of the fetal heart rate and of uterine contractions. The fetal heart rate is recorded by means of either an external ultrasonic abdominal transducer or a fetal scalp electrode. Uterine contractions are recorded by means of an abdominal pressure transducer. The recordings are graphically represented on a continuous paper printout (trace).

case control studies	Case control studies are used to evaluate multiple risk factors associated with a particular disease or outcome. They are particularly useful when the condition is rare.
chorion	Extraembryonic membrane surrounding the embryo of amniote vertebrates. The outer epithelial layer of the chorion is derived from the trophoblast.
chromosome analysis (karyotype)	A picture of the chromosomes of an individual arranged in a standard manner so that abnormalities of chromosome number or form can be identified.
confidential enquiry	Enquiry by peer groups, including experts in the field, into the cause of, and the factors surrounding, a death, where strict confidentiality is observed at all stages of the process. It is a form of clinical audit, with the important difference that the feedback or 'closing of the audit loop' is via reports on the general findings, and not direct feedback to those involved with the individual cases subjected to enquiry.
CESDI	Confidential Enquiry into Stillbirths and Deaths in Infancy
CMA	Chromosomal microarray
CMV	cytomegalovirus
confidence intervals (95% CI)	A range of values about which there is a 95% chance that it includes the true value. For example, if the stillbirth rate is 5.4 per 1000 total births and the 95% confidence intervals are 5.3 to 5.5 per 1000 total births, then there is a 95% chance that the actual stillbirth rate lies between 5.3 and 5.5 per 1000 total births.
congenital anomaly	A physical malformation, chromosomal disorder or metabolic abnormality which is present at birth.
control	As used in a case control study, 'control' means person(s) in a comparison group that differ only in their experience of the disease or condition in question. If matched controls are used they are selected so that they are similar to the study group, or cases, in specific characteristics, eg age, sex, weight.
customised birthweight	The principle that the weight reference for the fetus should be individualised (customised), and not based on population averages. Factors shown to be predictive of birthweight are maternal height, weight at booking for the first antenatal visit, ethnicity and fetal gender and gestational age. The customised birthweight is an adjusted standard for the individual infant. <i>Gardosi, J., M. Mongelli, M. Wilcox, and A. Chang. 1995. An adjustable fetal weight standard. Ultrasound Obstet Gynecol 6 (3):168-74.</i>

cytogenetics	The study of the structure of chromosomes; cytogenetic tests are carried out to detect any chromosomal abnormalities associated with a disease; these help in the diagnosis and selection of optimal treatment.
denominator	The population at risk in the calculation of a rate or ratio. An example relevant to CESDI is the number of all live births as the denominator for neonatal mortality rate.
DIC	Disseminated intravascular coagulation is an acquired disorder of clotting characterised by intravascular fibrin formation which occurs in the course of a variety of conditions including sepsis and pre-eclampsia.
DCT	direct Coombs test
early neonatal death	Death of a liveborn infant occurring less than 7 completed days (168 hours) from the time of birth.
EFM	electronic fetal monitoring
fasting blood glucose	A method for finding out how much glucose (sugar) is in the blood. The test can show if a person has diabetes.
FBS	Fetal blood sampling. This is a test performed in labour to obtain a capillary blood sample from the baby to check for well-being.
fetal growth restriction (FGR)	This is a term often used interchangeably with the term 'small for gestational age' (SGA). SGA is defined as a baby/fetus with antenatal ultrasound biometry assessment less than the 10 th centile for gestational age according to National birthweight centiles. FGR strictly refers to babies that have failed to reach their growth potential during pregnancy. They are frequently but not always SGA. FGR is defined antenatally by an estimated fetal weight or serial antenatal ultrasound evidence of growth restriction or growth arrest and at birth a birthweight below the 10 th centile using the National birthweight centiles. Ideally FGR should be defined according to the infant's individual growth potential using customised birthweight centiles. See customised birthweight.
fetal death	See stillbirth.
FHR	fetal heart rate
GBS	group B streptococcus
gestation	The time from conception to birth. The duration of gestation is measured from the first day of the last normal menstrual period.
gestational diabetes	A carbohydrate intolerance of variable severity with onset, or first recognition during pregnancy.
glucose tolerance	A test for diagnosing diabetes, where blood glucose is measured in

test	intervals after a glucose-rich meal is taken.
GP	General practitioner
growth restriction	See also fetal growth restriction. Birthweight below the 10 th centile for gestational age according to National birthweight centiles. Ideally FGR should be defined according to the infant's individual growth potential using customised birthweight centiles.
GTT	Glucose tolerance test. This is a test for diagnosing diabetes, where blood glucose is measured at specific intervals after a glucose-rich meal is taken.
haemoglobin A1c (Hba1c)	The substance of red blood cells that carries oxygen to the cells and sometimes joins with glucose. Because the glucose stays attached for the life of the cell (about 4 months), a test to measure haemoglobin A1C shows what the person's average blood glucose level was for that period of time.
HELLP syndrome	haemolysis, elevated liver function, low platelets
histology	The study of cells and tissue on the microscopic level.
histopathology	This is the science concerned with the study of microscopic changes in diseased tissues.
infant death	Death in the first year following live birth; on or before the 365 th day of life (366 th in a leap year).
infant mortality rate	See mortality rates.
intermittent auscultation	Listening to the fetal heart at regular intervals between contractions.
intrapartum death	Fetal death during labour. If a baby is born without signs of life, but also without maceration (the skin and other changes that occur at varying lengths of time after death in the womb), there is a strong presumption that death occurred during labour. There are exceptions in both directions, which require judgement on the timing of death in relation to the presumed onset of labour.
intrauterine fetal death (IUFD)	Death of a fetus in utero after 20 weeks gestation or at birth weighing at least 400gms. See stillbirth.
ITP	idiopathic thrombocytopenia purpura
IUFD	See intrauterine fetal death

intra-uterine growth restriction (IUGR)	See fetal growth restriction.
karyotype	The complete set of chromosomes of a cell or organism; used especially for the display prepared from photographs of mitotic chromosomes arranged in homologous pairs
Kleihauer-Betke	A blood test performed on the mother's blood to identify whether substantial bleeding has occurred from the fetus into the mother's circulation.
live birth	A livebirth is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered liveborn.
methylenetetrahydrofolate reductase (MTHFR) gene	The MTHFR gene provides instructions for making an enzyme called methylenetetrahydrofolate reductase. This enzyme plays a role in processing amino acids (the building blocks of proteins).
MIA	Minimally-invasive autopsy
mortality rates	Perinatal mortality rate. The number of stillbirths and neonatal deaths per 1000 births.
MRI	magnetic resonance imaging
MTHFR	methylenetetrahydrofolate reductase
necropsy	Rarely used term for autopsy.
neonatal death	Death before the age of 28 completed days following livebirth.
neonatal death rate	The number of neonatal deaths (those occurring within the first 28 days of life) per 1000 livebirths.
NHMRC	National Health & Medical Research Council
NIA	Non-invasive autopsy
odds ratio (OR)	This is a measure of the excess risk or degree of protection given by exposure to a certain factor. An odds ratio of greater than one shows an increased risk and less than one shows a protective effect.

PA view	Posterior-anterior view
pathology	The branch of medicine concerned with disease, especially its structure and its functional effects on the body.
PCR	polymerase chain reaction
Perinatal mortality rate (PMR)	See mortality rates.
post-mortem	After death. Hence a post-mortem examination may or may not include an autopsy.
Postneonatal infant death	Death occurring after 28 completed days up to 1 year following live birth.
PSANZ	Perinatal Society of Australia and New Zealand
PSANZ-PDC	Perinatal Society of Australia and New Zealand – Perinatal Death Classification
PSANZ-NDC	Perinatal Society of Australia and New Zealand – Neonatal Death Classification
PSANZ-PMG	Perinatal Society of Australia and New Zealand Perinatal Mortality Group
RACP	Royal Australasian College of Physicians – Division of Paediatrics & Child
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCP	Royal College of Pathologists
RCPA	Royal College of Pathologists of Australasia
SAFDA	Support After Fetal Diagnosis of Abnormality
SANDS	Stillbirth And Neonatal Death Support Group
SGA	Small for gestational age – see IUGR.
SLE	systemic lupus erythematosus
Stillbirth (fetal death)	Death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400g or more birthweight where gestation is not known. The death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary

	muscles.
stillbirth rate	The number of stillbirths per 1000 births.
sudden infant death syndrome (SIDS)	<p>General Definition of SIDS</p> <p>SIDS is defined as the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.</p> <p><i>Krous HF, Beckwith JB, Byard RW, Rognum TO, Bajanowski T, Corey T, et al. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. Pediatrics 2004;114(1):234-8.</i></p>
SIDS AND KIDS	An organisation striving to eliminate sudden and unexpected infant deaths, supporting bereaved families and funding research.
termination of pregnancy	This is the term used to describe deliberate ending of a pregnancy with the intention that the fetus will not survive.
VTE	venous thromboembolism
WISSP	The Wisconsin Stillbirth Protocol Program

APPENDIX Y

CONTACT DETAILS AND REGIONAL COORDINATORS

PSANZ – SANDA Coordinating Centre

NHMRC Centre of Research Excellence in Stillbirth
Mater Research Institute-The University of Queensland
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PSANZ - SANDA Regional Coordinators

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