

Clinical Practice Guideline for Perinatal Mortality

THE PERINATAL SOCIETY OF AUSTRALIA AND NEW ZEALAND

Perinatal Mortality Group http://www.psanzpnmsig.org.au Second edition, Version 2.2, April 2009









Clinical Practice Guideline for Perinatal Mortality

Produced by:

The Perinatal Mortality Group of the Perinatal Society of Australia and New Zealand in collaboration with the Australian and New Zealand Stillbirth Alliance.

Compiled by:

The Mater Mothers' Research Centre (previously Centre for Clinical Studies), Mater Health Services, Brisbane.

Supported by:

The Perinatal Society of Australia and New Zealand; Royal Australian and New Zealand College of Obstetricians and Gynaecologists; SIDS and Kids Queensland; Stillbirth and Neonatal Death Support Group (SANDS) Queensland (QLD); and Mater Health Services, Brisbane, Queensland.

Endorsed by:

Perinatal Society of Australia and New Zealand; Australian and New Zealand Stillbirth Alliance; Royal Australian and New Zealand College of Obstetricians and Gynaecologists; Australian College of Midwives Incorporated; SIDS and Kids; SANDS (QLD); Australian College of Neonatal Nursing (previously Australian Neonatal Nursing Association); Bonnie Babes Foundation; Stillbirth Foundation Australia.

Citation:

This guideline should be cited as:

Flenady V, King J, Charles A, Gardener G, Ellwood D, Day K, McGowan L, Kent A, Tudehope D, Richardson R, Conway L, Lynch K, Haslam R, Khong Y for the Perinatal Society of Australia and New Zealand (PSANZ) Perinatal Mortality Group. PSANZ Clinical Practice Guideline for Perinatal Mortality. Version 2.2, Brisbane April 2009. www.psanzpnmsig.org

IMPORTANT NOTICE

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.

This is the second edition of the PSANZ Clinical Practice Guideline for Perinatal Mortality. In preparation of this document input from many stakeholders was sought. The first edition was finalised in March 2005 following wide consultation and endorsement by the Perinatal Society of Australia and New Zealand; Royal Australian and New Zealand College of Obstetricians and Gynaecologists; Australian College of Midwives Incorporated; SIDS and Kids; SANDS (QLD); and the Australian Council of Neonatal Nurses (previously the Australian Neonatal Nurse Association). The guideline sections 1- 6 were reviewed and revised and made available in December 2008. Subsequently, Section 7 was revised and incorporated into this the second edition, Version 2.2, April 2009. This guideline will be reviewed and updated as required on or before April 2011. However, as the recommended data collection within Section 1 is currently being revised, it is anticipated that an update of this section will become available in late 2009.

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: vicki.flenady@mater.org.au with 'Perinatal Mortality Guideline' in the subject line.

SPECIAL THANKS

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), Stillbirth and Neonatal Death Support Group Qld (SANDS Qld Inc), and SIDS and Kids Qld for providing financial assistance for the first version of the guideline; SANDS Qld Inc. and SIDS and Kids NSW for leading the development of the psychological and social aspects of perinatal bereavement component of the guideline; and National SIDS and Kids, Australian College of Neonatal Nurses (ACNN); Australian College of Midwives Inc (ACMI) and Human Genetics Society Australasia (HGSA) for providing feedback on guideline drafts. We would like to acknowledge the contribution of the Stillbirth Foundation and also that of and Bonnie Babes as members of the Australian and New Zealand Stillbirth Alliance.

In addition to members of the Guideline Working Party, we would like to thank the following individuals for providing feedback on the draft guideline: Suellen Allen, NSW Department of Health; Denise Thomas, SIDS & Kids ACT; Belinda Jennings, King Edward Memorial Hospital; Dawn Elder, Dept Paediatrics, Wellington School of Medicine and Health Sciences, New Zealand; Dr Tony Bourne, Women's and Children's Hospital SA; Dr David Watson, The Townsville Hospital QLD, Tze Kin Lau, The Prince of Wales Hospital, The Chinese University of Hong Kong; Dr Tracy Dudding, Hunter Genetics NSW; Dr Kevin Carpenter, The Children's Hospital Westmead NSW; A/Prof Matthew Edwards, Hunter Genetics, University of Newcastle NSW; Prof Frank Bowling, Mater Health Services QLD; and Ann Robertson, Nuchal Translucency Quality Assurance Program; Dr Gabby Fennesey, RANZCOG; Sonia Herbert, SIDS and Kids QLD; Sue Jenkins-Manning, Mater Health Services, Brisbane QLD; Deborah Jessop, Mater Health Services, Brisbane QLD; Carlie Naylor, Public Health Officer NSW; Trish Wilson, Mater Health Services, Brisbane QLD; Lucy Cooke, Mater Health Services, Brisbane QLD; who provided comment on the first version of the guideline.

We would like to acknowledge the following people: Anne-Maree Stout and Sharon Egan for administrative support in editing and formatting the guidelines and Katie Welsh for literature searching, reference management and editing for version one. We would also like to thank Hattie Waters for providing the mannequin used for the guideline illustrations. For the second version of the guideline we would like to thank Elizabeth Flenady and Laura Koopmans for literature searching and editing and Tonia Graveson and Trish Smith for administrative support.

FURTHER INFORMATION

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Nater Health Services Brisbane Limited

We wish to acknowledge the Mater Health Services for generously providing accommodation for the ANZSA and PSANZ-PMG secretariats

This document may be downloaded from the Perinatal Society of Australia and New Zealand Perinatal Mortality Group website at <u>www.psanzpnmsig.org</u>

Section	Content	Page
Section 1	Overview and summary of recommendations	1-29
1.1	Introduction	7
1.2	Background and rationale	7
1.3	Purpose of the guideline	8
1.4	Intended audience	8
1.5	Methods	8
1.6	Changes in this update	9
1.7	Summary of key recommendations	9-15
1.7.1	Institutional perinatal mortality audit	9
1.7.2	Psychological and social aspects of perinatal bereavement	11
1.7.3	Perinatal post-mortem examination	12
1.7.4	Investigation of stillbirths	13
1.7.5	Investigation of neonatal deaths	15
1.7.6	Perinatal mortality classifications	15
1.8	References	16
Appendices		17-31
Appendix 1	Methods of guideline development	17
Appendix 2	Glossary of terms/abbreviations	26
Section 2	Institutional perinatal mortality audit	32-55
2.1	Introduction	33
2.2	Recommendations and rationale	33
2.2.1	Implementation of the guideline	33
2.2.2	Perinatal mortality review committees	33
2.2.3	Review of a perinatal death	35
2.2.4	Data collection, documentation and reporting	35
2.2.5	Communication and feedback	36
2.2.6	Definitions for registration of birth and perinatal deaths	37
2.3	References	38
Appendices		40-55
Appendix 1	Perinatal mortality audit package	40

TABLE OF CONTENTS

Appendix 2	Instructions on taking clinical photographs	51
Appendix 3	Autopsy clinical summary form	54
Appendix 4	Perinatal mortality classifications – quick reference sheet	55
Section 3	Psychological and social aspects of perinatal bereavement	56-72
3.1	Introduction	57
3.2	Summary of key recommendations	58
3.3	References	67
Appendices		69-73
Appendix 1	Information for parents about autopsy	69
Appendix 2	Information for the health professional seeking consent	71
Section 4	Perinatal post-mortem examination	73-89
4.1	Introduction	74
4.2	Recommendations and rationale	74
4.3	Coroner's post-mortem	79
4.4	Alternative investigations where permission for autopsy is not obtained	79
4.5	References	81
Appendices		85-89
Appendix 1	RCOP Guidelines for Autopsy Investigation of Fetal and Perinatal Death	85
Appendix 2	Suspected genetic metabolic disorders: Investigation and autopsy protocol	87
Appendix 2a	Screening for genetic metabolic disorders	88
Appendix 2b	Components of the genetic autopsy for investigation of metabolic disorder	89
Section 5	Investigation of stillbirths	90-103
5.1	Introduction	91
5.2	Recommendations and rationale	92
5.3	Alternative investigations where permission for autopsy is not obtained	97
5.4	Storage of plasma and amniotic fluid	98
5.5	References	99
Appendices		102-103
Appendix 1	Stillbirth investigations algorithm	102
Appendix 2	Estimation of severity of feto-maternal haemorrhage	98

Section 6	Investigation of neonatal deaths	104-113
6.1	Introduction	105
6.2	Recommended minimal investigations for all neonatal deaths	105
6.3	Recommended core investigations for high risk newborns	106
6.4	Further investigations for high risk newborns at the time of birth	106
6.5	Alternative investigations where permission for autopsy is not obtained	109
6.6	References	110
Appendices		111-113
Appendix 1	High risk newborn investigation checklist	111
Appendix 2a	Screening for genetic metabolic disorders	112
Appendix 2b	Components of the genetic autopsy for investigation of metabolic disorders	113
Section 7	Perinatal Mortality Classifications	114-154
7.1	Introduction	115
7.2	Purpose of the Classifications	115
7.3	Background	115
7.4	PSANZ Perinatal Mortality Classifications	117
7.5	PSANZ Classification Guide	122
7.6	References	137
Appendices		138-154
Appendix 1	Changes in this version of the Classifications	138
Appendix 2a	Tables 1-4. Birthweight percentile values	146
Appendix 2b	Figures 1-4 Australian birthweight percentiles	150
Appendix 3	Contact details/Regional Coordinators	154

SECTION 1 OVERVIEW AND SUMMARY OF RECOMMENDATIONS

1.1 Introduction

In acknowledging the importance of developing a systematic approach to the audit and review of perinatal deaths in Australia and New Zealand (ANZ) and the need to support audit and research activities aimed at reducing perinatal death, the Perinatal Society of Australia and New Zealand (PSANZ)⁽¹⁻³⁾ endorsed the establishment of the Perinatal Mortality Group (PSANZ-PMG)⁽⁴⁾ in March 2003. The establishment of this group was the culmination of collaborative efforts of members of the PSANZ over many years. The first major activity of the PSANZ-PMG was the development of a classification system for perinatal deaths. The PSANZ Perinatal Death and Neonatal Death Classifications⁽⁵⁾ have been developed and are in use across Australia and some jurisdictions in New Zealand (*Please see Section 7 Perinatal Mortality Classifications* of the guideline for further details). The development of this guideline is the second major activity of the PSANZ-PMG.

In 2007, the Department of Health and Ageing, Canberra provided seed funds to establish the Australian and New Zealand Stillbirth Alliance (ANZSA) to address the problem of stillbirth. One of the key objectives of ANZSA is to assist in the implementation of the PSANZ guidelines for perinatal mortality audit. ANZSA is working with the PSANZ-PMG to achieve this objective through the establishment of regional coordinators and conduct of educational programs for clinicians. For further information please go to the ANZSA website: www.stillbirthalliance.org/anz

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 post-mortem examination;
- Section 5 Investigation of stillbirths;
- Section 6 Investigation of neonatal deaths; and
- Section 7 Perinatal mortality classifications.

This first section contains an overview of the guideline including a summary of key recommendations.

A *Perinatal Mortality Audit Package*, which includes checklists and data collection forms, is provided to assist clinicians in implementation of the recommendations and to enhance the quality of information available for audit and research activities. This data collection tool is under revision and will be disseminated in late 2009. 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 PSANZ website: www.psanz.org.au.

1.2 Background and rationale

In Australia for the year 2006, based on data from the National Perinatal Statistics Unit (6) there were 282,619 births, and 2907 perinatal deaths giving a perinatal mortality rate (PMR) of 10.3 per 1000 births. The perinatal mortality comprised of 2091 fetal deaths, giving a fetal death rate (FDR) of 7.4 per 1000 births, and 816 neonatal deaths giving a neonatal death rate (NDR) of 3 per 1000 livebirths. Due to differences in reporting processes, the PMR calculated according to the Australian Bureau of Statistics (ABS), was 8.5 per 1000 (FDR 5.4, NDR 3.1) for the same year. In Australia in 2006, the PMR of babies born to Aboriginal or Torres Strait Islander mothers was approximately double that of babies born to other mothers (20.7 versus 10.1)(6). In New Zealand in 2004, there were 58,723 births and 666 perinatal deaths, giving a PMR of 11.2 per 1000 (8.5 and 3.4/1000 for fetal and neonatal death rates respectively) (7). Differences in definitions and reporting processes across regions within Australia and New Zealand (ANZ) make comparisons of perinatal mortality rates difficult, and it is hoped that these differences will be addressed by the various reporting agencies.

According to ABS data, the PMR in Australia declined by nearly two-thirds over the period from 1973 - 2000 from 23 per 1000 to the current rate of approximately 8 per 1000(8). The fall in the neonatal death component (a 75% reduction from 12.6 to 3 per 1000) was greater than the fetal death reduction which fell by 50% from 11 to 5 per 1000 births. Fetal death after the onset of labour has decreased by two-thirds. Antepartum deaths decreased to a lesser extent (46%)(8) and currently make up approximately 65% of all fetal deaths(6). This pattern is similar to other higher income countries where the reduction in the PMR is largely due to a decrease of deaths resulting from intrapartum asphyxia, birth trauma, and *Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Perinatal Mortality; Second Edition, Version 2.2, April* 72009. Section 1: Overview and summary of recommendations

isoimmunisation⁽⁹⁻¹¹⁾. Congenital abnormality, unexplained fetal death and spontaneous preterm births have now emerged as the leading causes of perinatal death^(10, 12-14). Using the PSANZ-PDC the leading categories of causes for perinatal death are Congenital anomaly and Spontaneous preterm. Approximately 20-30% of stillbirths are classified as unexplained ^(12, 15). These are therefore the categories where efforts to further reduce the PMR need to be focussed. Contributing factors relating to care (also called sub-optimal, avoidable or suspected preventable factors) have been reported in approximately 30-50% of perinatal deaths^(13, 16-18) and therefore also require consideration as part of routine review of perinatal deaths by hospital committees. The report of the inquiry into Obstetrics and Gynaecology Services at the King Edward Memorial Hospital⁽¹⁹⁾ highlighted the importance of clinical audit of perinatal deaths as part of ongoing clinical practice improvement.

The lack of comprehensive systematically collected information across ANZ hinders research and audit activities aimed at further reducing perinatal mortality. Inadequate investigation of a perinatal death limits the information available to health care providers and parents to assist with the understanding of the reasons for the death and also for planning future pregnancies.

It is hoped that systematic implementation of the recommendations included in this guideline through the planned educational programs of the PSANZ-PMG and ANZSA combined with local support from regional coordinators will enhance the quality of investigation and audit of perinatal deaths and care for parents following a perinatal death.

1.3 Purpose of the guideline

The main purposes of the guideline is to enable a high quality systematic approach to the provision of care around the time of a perinatal death including investigation and audit and bereavement care for parents across Australia and New Zealand (ANZ) to:

- enhance the accuracy of information about the causes of death and important contributing factors for stillbirth which will:
 - assist parents in gaining a better understanding of the cause of the death of their infant;
 - assist parents and clinicians in the planning and management of future pregnancies;
 - enhance the ability to undertake effective monitoring of strategies aimed at reducing perinatal deaths; and
 - contribute to the body of knowledge to further reduce perinatal death;
- enhance the quality of bereavement care for parents and families around the time of a stillbirth or neonatal death.

1.4 Intended audience

The intended audience for the guideline is clinicians providing maternity and newborn care in hospitals in ANZ, and all other parties with an interest in perinatal mortality audit, bereavement care and research.

1.5 Methods

The PSANZ-PMG commissioned the Mater Mothers' Research Centre (MMRC) (previously Centre for Clinical Studies), Mater Health Services, Brisbane to develop the guideline. The MMRC followed the National Health & Medical Research Council (NHMRC) recommended process for guideline development, which included the development of a multidisciplinary Working Party; searching for existing guidelines and a systematic literature search. Due to a lack of high quality evidence to guide the process of mortality audit, the recommendations are based on consensus by the Working Party after review of the available information; levels of evidence are therefore not referred to in the guideline. Subgroups of Working Party membership were formed to develop each section of the guideline prior to a wider distribution for comment. For this current update the Mater Mothers Research Centre (previously Centre for Clinical Studies) undertook a comprehensive literature review, screened all findings for relevance and incorporated new publications where relevant throughout.

(Please see Section 1; Appendix 1 Methods of guideline development for further details)

1.6 Changes in this update

The updated literature review did not identify any publications which have major implications for the current recommendations. Therefore only minor changes have been made to the guidelines. These changes are largely based on consensus of the Working Party. In brief, the main changes relate to:

- a) The title and citation of the guideline have been revised for clarity;
- b) Section 1. The Purpose of the Guideline (Item 1.3) has been revised to more clearly incorporate the bereavement aspects of the guideline;
- c) Sections 4, 5 & 6: the wording of the recommendation for seeking consent for a perinatal autopsy to ensure that autopsy is an option for parents and not mandated ("offering the option of the procedure" is now stated instead of "seeking consent for the procedure");
- d) Section 5: expansion of the recommended core investigations for stillbirths to include: Bile acids, thyroid function and Guthrie test. Further testing for thrombophilia has been expanded to include Antithrombin III and MTHFR testing for cases infants with cleft lip or palate and cardiac abnormalities. It is also suggested that the follow-up testing recommended at 8-12 weeks testing can be undertaken at birth where relevant with follow-up testing as required;
- e) Section 6: Addition of a CRP to the recommended investigations for high risk newborn infants presenting at birth with suspected infection or sever cardiorespiratory depression; and
- f) Section 7: Inclusion of an additional digit in the PSANZ-PDC classification to identify all terminations of pregnancy. Additional subcategories have been included in both the PSANZ PDC and NDC. Please see Section 7 for full details.

These changes are listed in detail in Section 1; Appendix 1. Further, the Working Party plan to collaborate with the New Zealand Maternal Perinatal Mortality and Morbidity Committee in revising the minimum dataset for perinatal death audit and reporting currently included within the Perinatal Mortality Audit Package in Section 2 of the guideline. Once finalised, the data collection tool will be disseminated to hospitals via the PSANZ-PMG/ANZSA regional coordinators. (For details of regional coordinators, please see Appendix 3).

1.7 Summary of key recommendations

1.7.1 Section 2: Institutional perinatal mortality audit

(i) Implementation of the guideline

The PSANZ Clinical Practice Guideline for Perinatal Mortality should be implemented in all institutions where births occur.

Strategies to assist in the uptake of the guideline into practice at the hospital level should be implemented. These strategies may include: identifying and addressing local barriers to uptake; ongoing structured and unstructured education for clinical staff including clinical leader advocacy; and implementing an audit and feedback mechanism on compliance with guideline recommendations.

(ii) Perinatal mortality review committees

Format

A format for review of perinatal deaths needs to be developed in each institution, taking into account principles of confidentiality and impartiality. All perinatal deaths should be reviewed by the Perinatal Mortality Committee, including deaths of infants born within the service but who died elsewhere. Maternity services (particularly smaller hospitals) may choose to combine the functions of the perinatal mortality review committee with another hospital committee or regional mortality review committee.

Purpose

The functions of the perinatal mortality committee should include:

- review of all stillbirths and neonatal deaths;
- classification of perinatal deaths according to the Perinatal Society of Australia and New Zealand (PSANZ)-Perinatal Death Classification (PDC) and Neonatal Death Classification (NDC);
- evaluation of the circumstances surrounding the death including a consideration of contributing factors; and
- on the basis of such considerations, the development of recommendations for improving processes of care, ensuring feedback to clinicians;

- implementation of action required based on these recommendations;
- provision of a confidential case summary to the relevant agency within the jurisdiction's Health Department; and
- coordination of care for parents following a perinatal death including follow-up.

Membership

The Perinatal Mortality Committee meetings should include multidisciplinary involvement, including those who are familiar with the circumstances of the death.

Membership of the Perinatal Mortality Committee should include representatives from: obstetrics, neonatology/paediatrics, pathology (preferably a perinatal/paediatric pathologist), midwifery, neonatal nursing, social workers, other relevant medical specialists, and allied health professionals.

It is the responsibility of each institution's management to ensure that committee members and their deliberations are indemnified while undertaking this kind of audit on their behalf.

(iii) Review of a perinatal death

The review should take place as soon as possible after the death, once results of core investigations are available.

The main cause of death and associated maternal/fetal/neonatal conditions, if present, should be classified according to PSANZ-PDC for all perinatal deaths and in addition for all neonatal deaths the PSANZ-NDC.

The review of each perinatal death should include consideration to the presence of potentially contributing factors in three main areas:

- maternal/social i.e. factors relating to the woman including her social situation;
- infrastructure/service organisation i.e. factors related to the setting in which the care was provided; and
- professional care delivery i.e. factors relating to the clinical care provided.

At the review of each perinatal death, consideration should be given to the adequacy of communication with parents and between health care professionals and the investigations undertaken.

(iv) Data collection, documentation and reporting

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.

The Medical Certificate of Perinatal Death should be completed by, or under the supervision of, the Consultant responsible for care with due consideration to presence and significance of all perinatal conditions and complications. A revised Medical Certificate of Perinatal Death should be submitted, following review by the Perinatal Mortality Committee, where required.

A comprehensive confidential clinical summary should be completed for every perinatal death to facilitate local audit and, if required, forwarded to the relevant agency within the jurisdiction's Health Department.

A standardised data set should be collected for all perinatal deaths. This data set includes all significant family, medical and obstetric history; all major pregnancy complications including whether the pregnancy was terminated; and investigations undertaken around the time of the death including placental histopatholgy and autopsy.

The PSANZ Perinatal Mortality Audit Package (Section 2; Appendix 1) is recommended for data collection and perinatal mortality review.

(v) Communication and feedback

Notification of the death to the General Practitioner and other relevant care providers should be undertaken as soon as possible after the death. This should be followed by a comprehensive clinical summary promptly after review of the death. A process of feedback to clinicians needs to be in place so that individual practices and hospital policy can be improved as a result of the review process. This includes standards in relation to perinatal mortality investigation, documentation and communication.

A follow-up consultation service should be provided for all parents following a perinatal death.

1.7.2 Section 3: Psychological and social aspects of perinatal bereavement

(i) Respect

For baby: deceased baby to be treated with same respect as live baby For parents: parents need to feel supported and in control; death validated Cultural/religious practices: different approaches to death and rituals respected

(ii) Provision of information

Timing of information: allow plenty of time to discuss issues at most appropriate time Delivery of information: clear, honest and sensitive. Repeat important information. Ensure both parents are present Mode of information: fact sheet/written information given for frequent reference Withdrawal of support: parents given prognostic information to reach decision Terminology: parent friendly language. Do not use terms such as fetus Post-mortem Examination: verbal and written information given. Allow time for discussion

(iii) Birth options

Timing: ascertain appropriate time to discuss birth options following determination of a fetal death in utero or abnormalities

Mode of delivery: benefits of birthing options given

(iv) Time

Parents are given time to make decisions Inform parents of how much time can be spent with baby

(v) Hospital stay

Environment: parents are given the option of a private room in surgical, maternity or gynaecological ward

Universal symbol placed outside room to alert all staff of death

(vi) Creating memories

Spending time with baby: no hurry to leave baby or hospital. Option to take baby home Parenting baby: inform parents that they can hold, undress, bath baby Mementos: helpful for long-term grief outcome. (*Please see Section 3.2.6*) Baptism/blessing: inform parents that this can be arranged through the hospital

(vii) Special circumstances

Multiple Pregnancies: special care is required in the circumstance where some infants in a multiple pregnancy survive Maternal illness: consideration given regarding access to baby/memory creation Previous perinatal/child death: consider impact of previous death/s on emotional response to and coping with current death

(viii) Aftercare

Maternal changes: advise on milk production and methods to manage supply Support services for parents and children: written information given regarding available support services for parents and children

Grief: inform parents of expectations of grief journey Follow up/Appropriate referral: expectations for 6 week check up – other babies present

(ix) Autospy

Parents given choice of funeral directors No urgency to organise funeral Continued access to baby if desired

(x) Health care professionals

Education: specific training in support skills given to relevant staff Access to support: debriefing/support services available to staff working with perinatal death

1.7.3 Section 4: Perinatal post-mortem examination

(i) Autopsy rates

Clinicians should discuss the value of an autopsy with the parents in all cases of a perinatal death and offer the option of the procedure.

To increase the rates of perinatal autopsy:

- Clinicians should collaborate with pathologists and parent groups such as Stillbirth and Neonatal Death Support (SANDS) and SIDS and Kids to raise public awareness of the value of perinatal autopsy and to advocate for high standards in perinatal autopsy at the 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.

(ii) Placenta, membrane and cord histopathology

Following a stillbirth, neonatal death in the delivery room or birth of a high risk infant, the placenta, membrane and cord should be sent fresh and unfixed for examination by the perinatal/paediatric pathologist regardless of whether consent for an autopsy has been gained.

(iii) Quality and minimum standards

The Guidelines on Autopsy Practice produced by the Royal College of Pathologists⁽²⁰⁾ should be used for guidance on minimum standards until guidelines for Australia and New Zealand are developed.

Specific protocols developed for post-mortem examination in the circumstance of Sudden Unexpected Death in Infancy and deaths with suspected genetic metabolic disorders should be followed (*Please see Section 4 for further details*).

A perinatal/paediatric pathologist should perform or supervise all perinatal post-mortems. Clinicians should request autopsies from the service providing the highest quality.

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.

A comprehensive maternal history should accompany the baby for a post-mortem examination including:

- clinical/obstetric history including relevant previous obstetric history (Please see Section 2; Appendix 3);
- copy of the death certificate;
- copies of all antenatal ultrasound reports; and
- copy of amniocentesis report if available.

(iv) Post-mortem reporting

Guidelines for post-mortem reports produced by the Royal College of Pathologists⁽²¹⁾ should be used as a guide for reporting of perinatal post-mortem examinations.

Ideally, a preliminary post-mortem report should be forwarded to the referring clinician within 3 working days of the post-mortem. The final report should be forwarded to the referring clinician within 8 weeks of the post-mortem.

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.

A Plain Language Report (PLR) should be available to parents on request.

A request for the General Practitioner to receive a copy of report (including the PLR if available) should be explicit on the request form, as they are the main care provider on discharge.

(v) Communication and consent for post-mortem examination

Where possible, a senior clinician who has established a rapport and understanding with the parents and who has a clear understanding of the autopsy procedure should discuss the value of a post-mortem examination and offer the option of the procedure. The clinician should have a high level of communication skills and knowledge of the post-mortem examination, preferably having witnessed several perinatal post-mortem examinations.

The clinician approaching for autopsy consent should discuss the options for a full, limited or stepwise post-mortem examination; the issue of retained tissues; the value of the autopsy and the possibility that the information gained may not benefit them but may be of benefit to others. Parents should be given written information explaining the post-mortem examination.

When consent has been obtained for specific organ/s to be retained for further examination, the parents should be offered the choice of either delaying the funeral until the organs can be returned to the body or specifying their preferred method of organ disposal.

Consent for the autopsy which clearly outlines the extent of the investigation should be recorded on an approved consent form, relevant to the jurisdiction.

The pathologist should be available to discuss the autopsy with the parents before and/or after the procedure and, where possible, the requesting clinician should attend the autopsy and provide the parents with a preliminary report immediately after the examination.

(vi) Costs of a post-mortem examination and transport

Clinicians need to be aware of costs associated with transfer of an infant from non-metropolitan areas to the tertiary centre for post-mortem within their region and to inform parents of any personal cost implications.

1.7.4 Section 5: Investigation of stillbirths

A post-mortem examination, including examination of the placenta, by a perinatal/paediatric pathologist should be offered to all parents following stillbirth.

Following a stillbirth, the placenta, membranes and cord should be sent to the perinatal pathologist fresh and unfixed for macroscopic and histological examination regardless of whether consent for autopsy has been gained.

(Please refer to Section 4 Perinatal post-mortem examination for further details, including rationale, on autopsy and placental pathology.)

A non-selective approach according to a list of recommended Core Investigations should be adopted for all stillbirths. This non-selective approach is defined as investigations which should be undertaken as the standard approach for all stillbirths, debating the relative merits of not following this approach on an individual case basis.

Further investigations should be undertaken according to the particular clinical problem (See Item 5.2.2).

(i) Core Investigations for all stillbirths

At diagnosis of a fetal death

- Comprehensive maternal and family history;
- Ultrasound scan to detect possible fetal abnormalities and to assess amniotic fluid volume;
- Amniocentesis (where available) for cytogenetic and infection investigation;
- Low vaginal and peri-anal swab to culture for anaerobic and aerobic organisms;
- Blood tests:
 - Full blood examination;
 - Serology for Cytomegalovirus, Toxoplasma, Parvovirus B19;
 - o Rubella and Syphilis if not already undertaken in this pregnancy;
 - o Blood group and antibody screen if not already undertaken in this pregnancy;
 - Kleihauer-Betke test;
 - Renal Function Tests including Uric Acid;
 - Liver Function Tests including Bile acid:
 - Thyroid Function Tests;
 - HbA_{1c};
 - Anticardiolipin antibodies;
 - Lupus anticoagulant; and
 - Activated protein C (APC) resistance.

Following birth

- External examination of the baby (by a perinatal pathologist, neonatologist or paediatrician where possible);
- Clinical photographs;
- Surface swabs (ear and throat) for microbiological cultures;
- Post-mortem examination;
- Blood samples from the cord or cardiac puncture for investigation of infection;
- Blood samples for chromosomal analysis and Guthrie test;
- Detailed macroscopic examination of the placenta and cord;
- Placental microbiological cultures;
- Placental and amnion biopsy for chromosomal analysis; and
- Placental histopathology.

(ii) Further investigations for thrombophilia

Further investigation for thrombophilia should be undertaken 8-12 weeks postnatally where a fetal death is associated with fetal growth restriction, pre-eclampsia, maternal thrombosis and/or maternal family history of thrombosis, remains unexplained following the core investigations or where tests for thrombophilia were positive at the time of the intrauterine fetal death (IUFD) as follows:

- Anticardiolipin antibodies; and Lupus anticoagulant repeated if positive at the time of the IUFD or initial testing if not previously undertaken;
- APC resistance if not undertaken at birth;
- Factor V Leiden mutation if APC resistance was positive at birth;
- Fasting Homocysteine and if positive test for *MTHFR gene mutation;
- Protein C and S deficiency; and
- Prothrombin gene mutation 20210A; and
- Anti-thrombin III

These additional thrombophilia tests may be performed at birth where the above specific conditions eg fetal growth restriction are known. MTHFR mutation testing should be performed when the following fetal anomalies are identified: cleft lip/palate, neural tube defects or congenital cardiac defects.

1.7.5 Section 6: Investigation of neonatal deaths

(i) Neonatal deaths

Clinicians should discuss the value of an autopsy with the parents in all cases of a neonatal death and offer the option of the procedure.

A newborn screening blood sample should be performed for all neonatal deaths if not undertaken before the death occurred.

A detailed external examination including recommended photographs of the baby should be performed by a perinatal pathologist or an experienced Neonatologist or paediatrician where possible.

(ii) High risk infant

Close collaboration between the obstetric/midwifery and neonatal care teams is required to ensure that relevant maternal and neonatal factors are considered in the investigation of the neonate.

The following core investigations are recommended at the birth of high risk infants:

- detailed external examination of the baby by a neonatologist or paediatrician (where possible) with clear documentation of the findings in the medical record;
- A comprehensive maternal medical, social and antenatal history including the results of investigations should be documented in the medical record by the obstetric staff;
- Cord blood gas analysis including both arterial and venous samples;
- A detailed macroscopic examination of the placenta and cord and documentation of the findings in the medical record by the obstetric staff; and
- Placenta, cord and membranes sent fresh and unfixed to pathology for histopathological examination.

Further investigations are recommended for particular clinical scenarios (*Please see Section 6 Investigation of neonatal deaths for further details*).

1.7.6 Section 7: Perinatal Mortality Classification

Please See Section 7

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Section 1; Appendix 1 Methods of guideline development

The guideline has been developed by the Perinatal Society of Australia and New Zealand Perinatal Mortality (PSANZ-PMG)⁽⁴⁾. The Centre for Clinical Studies (CCS) (now Mater Mothers' Research Centre), 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 this second revision (2008/2009), the PSANZ-PMG collaborated with Australia and New Zealand Stillbirth Alliance (ANZSA) with funds made available by PSANZ and ANZSA.

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 ANZ;
- 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 1999⁽²²⁾. 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. The revisions to Section 7 were 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 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
	Bonnie Babes Foundation
	The Stillbirth Foundation Australia

SBF Stillbirth Foundation Australia

BBF Bonnie Babes Foundation

*second edition of the Guideline only.

Working Party Membership

Member	Profession & Organisation	WP Sub-group
Dr Susan Arbuckle	Paediatric and Perinatal Pathologist, The New Children's Hospital, NSW.	Perinatal post-mortem examination
Dr David Cartwright	Director Neonatal Intensive Care Unit, Royal Women's Hospital, Brisbane, QLD.	Investigation of neonatal deaths
Dr Annabelle Chan	Epidemiologist, Women's and Children's Hospital, Adelaide, SA.	Perinatal mortality classification
Dr Adrian Charles	Consultant Paediatric and Perinatal Pathologist, Women's and Children's Health Service, WA. WA Regional Coordinator, Member of Clinical Practice & Education Committee, ANZSA.	Perinatal post-mortem examination
Dr Yogesh Chadha	Obstetric Consultant, Royal Women's and Brisbane Hospital, QLD	Investigation of a stillbirth infant
Vicki Culling	SANDS, NZ. NZ Regional Coordinator, Co-Chair Public Awareness & Health Promotion Committee, ANZSA.	Second version consultation
A/Prof Jane Dahlstrom	Anatomical Pathologist, ACT Pathology; A/Prof Canberra Clinical School, Australian National University and University of Sydney	Investigation of neonatal deaths Perinatal post-mortem examination
Liz Davis	State Coordinator, SANDS (QLD). Member of Public Awareness & Health Promotion Committee, ANZSA.	Psychological and social aspects of perinatal bereavement
Katie Day (nee Waters) (Project Officer, first version)	Research Midwife, Centre for Clinical Studies, Mater Health Services, QLD.	Investigation of a stillborn infant
Dawn Elder	Senior Lecturer, Department of Paediatrics, Wellington School of Medicine and Health Sciences, New Zealand.	Neonatal death classification
		Investigation of neonatal deaths
A/Prof Vicki Flenady (Coordinator)	Perinatal Researcher; Acting Director, Mater Mothers' Research Centre, Mater Health Services, QLD. QLD Regional Coordinator, Co-chair Clinical Practice & Education Committee, ANZSA.	All sections
Dr Adrienne Gordon	Neonatologist, RPA Newborn Care, Royal Prince Alfred Hospital. Research Committee, ANZSA.	Overall consultation Neonatal Death Classification Investigation of neonatal deaths

Member	Profession & Organisation	WP Sub-group
Dr Glenn Gardener	Maternal Fetal Medicine Specialist, Mater Mothers' Hospital, Mater Health Services, QLD. Research and Clinical Practice & Education Committees, ANZSA.	Investigation of a stillborn infant
Deborah Harris	Nurse Practitioner, Neonatology,	Classification
	Newborn Intensive Care, Waikato Hospital	Investigation of neonatal deaths
Dr Ross Haslam	Director, Neonatal Intensive Care Unit, Women's and Children's Hospital, SA	Investigation of neonatal deaths
Dell Horey	Editor, Cochrane Consumers & Communication Group, Carlton, VIC	Psychological and social aspects of perinatal bereavement Perinatal post-mortem examination
Heather Jeffery	Professor International Maternal and Child Health, School of Public Health,	Overall consultation
	University of Sydney and RPA Newborn Care, Royal Prince Alfred Hospital, Sydney, NSW. NSW Regional Coordinator, Co-Chair Clinical Practice & Education Committee, ANZSA.	Neonatal Death Classification
Belinda Jennings	Midwifery, King Edward Memorial Hospital, Bagot Road, SUBIACO, WA. Clinical Practice & Education Committee, ANZSA. Board Member, ISA.	Overall consultation
Alison Kent	Neonatalologist, Dept of Neonatology, Centre for Newborn Care, The Canberra Hospital, ACT	Investigation of neonatal deaths
James King (Chair)	Clinical Perinatal Epidemiologist, Royal Women's Hospital, Melbourne, VIC. Founding Chair, ANZSA.	All sections
Prof Lesley McCowan	Maternal Fetal Medicine Specialist, National Women's Hospital, Auckland, New Zealand. Research Committee, ANZSA.	Investigation of a stillborn infant
Kassam Mahomed	Senior Staff Specialist, Obstetrics, Ipswich Hospital, QLD. Clinical Practice & Education Committee, ANZSA.	Overall consultation
Dr Diane Payton	Paediatric and Perinatal Pathologist, Royal Brisbane and Women's Hospital, QLD.	Perinatal post-mortem examination

Member	Profession & Organisation	WP Sub-group
Ros Richardson	Health Promotion Manager, SIDS and Kids, NSW. Co-Chair Public Awareness & Health Promotion Committee, ANZSA.	Psychological and social aspects of perinatal bereavement
		Perinatal post-mortem examination
Dr Christine Roberts	Epidemiologist, Research Director, Centre for Perinatal Health Services Research, Sydney, NSW	Perinatal mortality classification
Prof. David Tudehope	Neonatologist, Director of Neonatology, Mater Mothers' Hospital, Mater Health Services, QLD.	Investigation of neonatal deaths
Trish Wilson	Clinical Midwife - Perinatal Bereavement Support Program. Clinical Practice & Education Committee, ANZSA.	Second version consultation
Dr Jane Zuccollo	Senior Lecturer, Obstetrics & Gynaecology, Wellington School of Medicine & Health Sciences; Perinatal Pathologist, Wellington Hospital, Wellington, New Zealand	Investigation of a stillborn infant Perinatal post-mortem examination

Search strategy

A comprehensive search strategy was developed based on the initial discussions of the Working Party and those of the Working Party's sub-groups. The search strategy included an electronic database search and guideline web site 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 as follows:

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	http://www.awhonn.org/awhonn
Neonatal Nurses	
Australian Government, Department of Health &	http://www.health.gov.au
Ageing: Safety & Quality in Health Care	
Australian Government, National Health &	http://www.nhmrc.gov.au
Medical Research Council	
British Columbia Perinatal Care Program,, Canada	http://www.bcphp.ca/Perinatal%20Mortality%20Gui delines.htm
Canadian Paediatric Society	http://www.cps.ca/english/publications
Canadian Task Force On Preventive Health Care:	http://www.ctfphc.org/
Evidence-Based Clinical Prevention	
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	http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat
Assessment Text	
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, Subjaco Western Australia	http://www.kemh.health.wa.gov.au/
National Guideline Clearinghouse	http://www.auideline.aov/
National Institute for Clinical Excellence LIK	http://www.galdeine.gov/
Neonatology on the Web	http://www.neonatology.org/
New Zealand Guidelines Group	http://www.nzgg.org.nz/index.cfm?screensize=1024
	&ScreenResSet=ves
Princess Margaret Hospital for Children, Subjaco,	http://www.pmh.health.wa.gov.au/
Western Australia	
Queensland Health, Australia	http://gheps.health.gld.gov.au/
Royal Children's Hospital, Melbourne, Australia	http://www.rch.org.au/clinicalguide/index.cfm?doc_i d=5033
Roval College of Obstetricians and	http://www.rcog.org.uk/index.asp?PageID=8
Gynaecologists, UK	····· ································
Royal College of Pathologists	http://www.rcpath.org/
Royal Prince Alfred Hospital, Camperdown, New	http://www.cs.nsw.gov.au/rpa/
South Wales	
Scottish Intercollegiate Guidelines Network	http://www.sign.ac.uk/
(SIGN)	
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,	http://www.wch.sa.gov.au/
Australia	

The guideline web site search yielded the following 22 guidelines on aspects of perinatal mortality audit:

Association	Guideline
	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?OpenD
British Columbia Reproductive Care Program	ocument accessed 2008 British Columbia Reproductive Care Program. Perinatal Mortality Guideline 1: The Perinatal Mortality Review Process. British Columbia; 1999.
	http://www.bcrcp.xplorex.com//sites/bcrcp/files/Guidelines/Pmg/Master PM1ReviewProcessApril99.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.bcrcp.xplorex.com//sites/bcrcp/files/Guidelines/Pmg/Master PM2TORHospReviewCommApril99.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.bcrcp.xplorex.com//sites/bcrcp/files/Guidelines/Pmg/Master PM3ClassifDeathsApril99.pdf accessed 2008
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	http://www.bcrcp.xplorex.com//sites/bcrcp/files/Guidelines/Pmg/Master PM4ExamPlacentaApril99.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.bcrcp.xplorex.com//sites/bcrcp/files/Guidelines/Pmg/Master
Canadian Paediatric Society	Canadian Paediatric Society Statement. Guidelines for health care
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Royal Prince Alfred Hospital, Sydney, NSW	Department of Neonatal Medicine RPAH. Stillbirths. In: Central Sydney Area Health Service.
Department of Health, UK	http://www.cs.nsw.gov.au/rpa/neonatal/default.htm accessed 2008 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. <u>http://www.rch.org.au/intranet/policy/9W042038.htm accessed 2004</u> Not able to be accessed March 2008
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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.ht m 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 <u>http://www.health.sa.gov.au/PPG/Default.aspx?tabid=113</u> accessed March 2008.

Levels of evidence

As defined by "A guide to the development, implementation and evaluation of clinical practice guidelines"⁽²³⁾ 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.

Section 1; Appendix 2 Glossary of terms / abbreviations

ABS Australian Bureau of Statistics.

ACMI Australian College of Midwifes 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

ANTEPARTUM 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.

AP View Anterio-posteria view.

ANZSA

Australia and New Zealand Stillbirth Alliance.

AUTOPSY

A surgical procedure postmortem, which involves the examination of body tissues (including internal organs), often to determine cause of death.

CARDIOTOCOGRAPH (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.

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.

Gardosi, J., M. Mongelli, M. Wilcox, and A. Chang. 1995. An adjustable fetal weight standard. Ultrasound Obstet Gynecol 6 (3):168-74.

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.

DENOMINATORS

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 10th 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 10th 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 TEST

A test for diagnosing diabetes, where blood glucose is measured in intervals after a glucose-rich meal is taken.

GP General Practitioner.

GROWTH RESTRICTION See also FETAL GROWTH RESTRICTION

Birthweight below the 10th 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

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. Perinatal Society of Australia and New Zealand Perinatal Mortality Audit Guideline. Second Edition, Version 2.2, April 2009. Section 1: 29 Overview and summary of recommendations; Appendix 2 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 365th day of life (366th 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)

MORTALITY RATES

Perinatal mortality rate The number of stillbirths and neonatal deaths per 1000 births.

NEONATAL DEATH RATE

The number of neonatal deaths (those occurring within the first 28 days of life) per 1000 livebirths.

STILLBIRTH RATE

The number of stillbirths per 1000 births.

MRI Magnetic Resonance Imaging. NECROPSY Rarely used term for autopsy.

MTHFR Methylenetetrahydrofolate reductase.

NHMRC National Health & Medical Research Council.

NEONATAL DEATH Death before the age of 28 completed days following livebirth.

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 Posterio-anteria 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.

RANZCOG Royal Australian and New Zealand College of Obstetricians and Gynaecologists.

RCP Royal College of Pathologists.

SAFDA

RCPA Royal College of Pathologists of Australasia.

RACP Royal Australasian College of Physicians – Division of Paediatrics & Child

Support After Fetal Diagnosis of Abnormality. Perinatal Society of Australia and New Zealand Perinatal Mortality Audit Guideline. Second Edition, Version 2.2, April 2009. Section 1: 31 Overview and summary of recommendations; Appendix 2

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 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.

SUDDEN INFANT DEATH SYNDROME (SIDS)

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. *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.*

SIDS AND KIDS

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.



Section 2 of 7 - Institutional Perinatal Mortality Audit

2.1	Introduction	333
2.2	Recommendations and rationale	333
2.2.1	Implementation of the guideline	333
2.2.2	Perinatal mortality review committees	333
2.2.3	Review of a perinatal death	35
2.2.4	Data collection, documentation and reporting	35
2.2.5	Communication and feedback	36
2.2.6	Definitions for registration of births and perinatal deaths	37
2.3	References	38
Appe	ndix 1 Perinatal Mortaility Audit Package	40
Appe	ndix 2 Instructions on taking clinical photographs	51
Appe	ndix 3 Autopsy clinical summary form	54
Appe	ndix 4 Perinatal Mortality Classifications - quick reference sheet	55

SECTION 2 INSTITUTIONAL PERINATAL MORTALITY AUDIT

2.1 Introduction

The purpose of this section is to provide guidance for clinicians at maternity hospitals in the conduct of high quality audit of perinatal deaths to determine an accurate cause of death and issues surrounding the death for the purposes of discussion with the parents; planning of future pregnancies; practice improvement; and to improve the quality of data available for monitoring and research activities aimed at reducing perinatal death. Practice recommendations are supplemented by data collection forms and checklists in the Perinatal Mortality Audit Package (*Appendix 1*) to assist clinicians in implementing the guideline recommendations.

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; 2003⁽¹⁾.
- 2. NSW Health Department. Hospital Procedures for review and reporting of perinatal deaths. In; 2000⁽²⁾.
- 3. Perinatal Mortality Guidelines in British Columbia. Vital Statistics. In. Victoria, British Columbia; 1998⁽³⁾.

2.2 Recommendations and rationale

2.2.1 Implementation of the guideline

The PSANZ Clinical Practice Guideline for Perinatal Mortality Audit should be implemented in all institutions where births occur.

Strategies to assist in the uptake of the guideline into practice at the hospital level should be implemented. These strategies may include: identifying and addressing local barriers to uptake; ongoing structured and unstructured education for clinical staff including clinical leader advocacy; and implementing an audit and feedback mechanism on compliance with guideline reccommendations..

The implementation of best practice is often not simple and the lack of evidence for optimal approach to assist in this process remains elusive⁽⁴⁾. Although clinical practice guidelines are a promising tool in improving the quality of care, it is important for guidelines to be accompanied by a program for implementation and dissemination to ensure their use in clinical practice⁽⁵⁾. Although the evidence is unclear, interventions which may assist in the uptake of guidelines into practice include: professional education, audit and feedback, reminders and a multidisciplinary teams approach^(6, 7). The development of evidence-based practice support units within hospitals and clinical research implementation networks have been proposed as a means of effecting change to improve clinical care across the healthcare system⁽⁸⁾.

A recent survey of maternity hospitals in ANZ indicated less than optimal awareness and use of the guidelines⁽⁹⁾. The Australian and New Zealand Stillbirth Alliance and the PSANZ Perinatal Mortality Group have developed an educational program to aid in the implementation of the guidelines across Australia and New Zealand (www.stillbirthalliance.org/anz). It is hoped that this program will be used widely to address the problem of implementation.

2.2.2 Perinatal mortality review committees

(i) Format

A format for review of perinatal deaths needs to be developed in each institution, taking into account principles of confidentiality and impartiality. All perinatal deaths should be reviewed by the Perinatal Mortality Committee, including deaths of infants born within the service but who died elsewhere. Maternity services (particularly smaller hospitals) may choose to combine the functions of the perinatal mortality review committee with another hospital committee or regional mortality review committee.

(ii) Purpose

The functions of the Perinatal Mortality Committee should include:

- the review of all stillbirths and neonatal deaths;
- the classification of perinatal deaths according to the Perinatal Society of Australia and New Zealand (PSANZ)-Perinatal Death Classification (PDC) and Neonatal Death Classification (NDC);
- evaluation of the circumstances surrounding the death including a consideration of contributing factors; and
- on the basis of such considerations, the development of recommendations for improving the processes of care, ensuring feedback to clinicians;
- implementation of action required based on these recommendations;
- provision of a confidential case summary to the relevant agency within the jurisdiction's Health Department; and
- coordination of care for parents following a perinatal death, including follow-up.

(10) Membership:

The Perinatal Mortality Committee meetings should include multidisciplinary involvement, including those who are familiar with the circumstances of the perinatal death.

Membership of the Perinatal Mortality Committee should include representatives from: obstetrics, neonatology/paediatrics, pathology (preferably a perinatal/paediatric pathologist), midwifery, neonatal nursing, social workers, and other relevant medical specialists and allied health professionals.

Review by a multidisciplinary team has been shown to increase the yield from mortality review⁽¹¹⁾. 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 strategies for care improvement where necessary. Multidisciplinary perinatal death review is advocated by international groups⁽¹²⁾ and is incorporated in most Health Departments perinatal mortality review in Australia. Some Health Departments in Australia currently recommend multidisciplinary review by hospital committees^(1, 2) with some evidence of implementation⁽¹³⁾.

(iv) Protection for committee members

It is the responsibility of each institution's management to ensure that committee members and their deliberations are indemnified while undertaking this kind of audit on their behalf.

The aim of the perinatal mortality committee is to provide an atmosphere of confidence and security that will encourage health care providers and managers to communicate openly and honestly with their colleagues⁽¹⁴⁾. In order to do this, assurance should be sought by the administration of the institution that the information and discussion arising from the formal review cannot be used in legal proceedings. As mechanisms for establishing perinatal mortality committees with the appropriate protection differs across Australia and New Zealand (ANZ), committees should seek advice from their respective Health Departments.

(v) Timing of the review

The review should take place as soon as possible after the death, once results of core investigations are available.

The review should be undertaken in a timely manner so that it is within recent memory of those involved and also to enable information from the review to be incorporated into the discussion with the parents at the follow-up visit. The review should take place as soon as results are available from the 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 assist in providing counselling and support for staff.

2.2.3 Review of a perinatal death

(i) Cause of death and associated factors

The review should take place as soon as possible after the death, once results of core investigations are available.

The main cause of death and associated maternal/fetal/neonatal conditions, if present, should be classified according to the PSANZ-PDC for all perinatal deaths and in addition for all neonatal deaths and the PSANZ-NDC⁽¹⁵⁾.

(Please see Section 7 Perinatal Mortality Classifications for full details of the classifications and also Section 2; Appendix 4 for the Classification Quick Reference sheet.)

(ii) Potential contributing factors

The review of each perinatal death should include consideration to the presence of contributing factors in three main areas:

- maternal/social i.e. factors relating to the woman including her social situation;
- infrastructure/service organisation i.e. factors relating to the setting in which the care was provided; and
- professional care delivery i.e. factors relating to the clinical care provided.

The determination that contributing factors (also referred to as sub-optimal or avoidable factors) were present does not imply that the death could have been prevented if these factors were not present, rather that the risk of death may have been reduced.

Contributing factors can be classified by the type of factor: maternal/social; infrastructure/service organisation; and professional care delivery and may be further classified by timing: antenatal; intrapartum; and neonatal. This system is based on that described by the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI)⁽¹²⁾ and later adapted for use in the EuroNatal study⁽¹⁶⁾. Sub-optimal care factors have been identified in approximately 30- 50% of stillbirths(17-20). Similarly, the EuroNatal study involving ten European countries showed sub-optimal factors were possibly or likely to have contributed to the death in about half of the 1619 perinatal deaths reviewed. Although there is limited information available in Australia on the contribution of sub-optimal care to perinatal death, the Consultative Council on Obstetric and Paediatric Mortality and Morbidity in Victoria reported the presence of *Suspected preventable factors in perinatal deaths* in approximately 30% of perinatal deaths⁽²¹⁾.

(Please see Section 2 Appendix 1.5 for a recommended format for review of contributing factors)

(iii) Other aspects of care - Communication and investigation

At review of each perinatal death, consideration should be given to the adequacy of communication with parents and between health care professionals and the investigations undertaken.

To ensure ongoing practice improvement, a review of the adequacy of communication around the time of death and investigations undertaken should be undertaken at the time of committee review of the death. CESDI identified sub-optimal care around the time of stillbirth in the following areas relating to communication and investigation: incomplete investigation of a stillbirth; staff not discussing the possibility of a post-mortem with parents, or not presenting adequate information about the different levels of examination which could be carried out; discussion about the post-mortem often undertaken by junior staff; not undertaking a post-mortem when consent was obtained and incompleteness of post-mortem reports. Bereavement support was also criticised. The report identified several cases where bereavement support was not provided and where written communication was described by the panel members as insensitive⁽¹²⁾.

2.2.4 Data collection, documentation and reporting

(i) Medical record

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.

(ii) Death certificate
The Medical Certificate of Perinatal Death should be completed by, or under the supervision of, the Consultant responsible for care with due consideration to presence and significance of all perinatal conditions and complications. A revised Medical Certificate of Perinatal Death should be submitted, following review by the Perinatal Mortality Committee, where required.

The Royal College of Pathologists Australasia (RCPA) recommend that the death certificate be issued by the senior clinician responsible for care⁽²²⁾. As Perinatal Death Certificates are often issued prior to the results of an autopsy becoming available and, as perinatal autopsy may identify significant information about the cause of death⁽²³⁾, the completion of death certificates without consideration of autopsy findings may result in significant error in cause of death data⁽²⁴⁻²⁶⁾. Review by a multidisciplinary clinical group has also been shown to increase the value of post-mortem examination in determining an accurate cause of death. Therefore, it is essential that for all perinatal deaths the details on the death certificate are reviewed by the perinatal mortality committee including the full results of the autopsy when available⁽¹¹⁾.

As the process of revising the death certificate may differ across regions, it is recommended that all perinatal mortality committees become familiar with the process within their region and that a process is implemented to ensure that a revised death certificate is submitted when required.

(iii) Confidential clinical summary

A comprehensive confidential clinical summary should be completed for every perinatal death to facilitate local audit and, if required, forwarded to the relevant agency within the jurisdiction's Health Department.

A standardised data set should be collected for all perinatal deaths. This data set includes all significant family, medical and obstetric history; all major pregnancy complications including whether the pregnancy was terminated; and investigations undertaken around the time of the death including placental histopatholgy and autopsy.

The PSANZ Perinatal Mortality Audit Package (Section 2; Appendix 1) is recommended for data collection and perinatal mortality review.

2.2.5 Communication and feedback

(i) Feedback to clinicians

Notification of the death to the General Practitioner and other relevant care providers should be undertaken as soon as possible after the death. This should be followed by a comprehensive clinical summary promptly after review of the death.

A process of feedback to clinicians needs to be in place so that individual practices and hospital policy can be improved as a result of the review process. This includes standards in relation to perinatal mortality investigation, documentation and communication.

(ii) Follow-up consultation for parents

A follow-up consultation service should be provided for all parents following a perinatal death.

The follow-up meeting should involve the senior clinician who provided care and be scheduled at a suitable time after all relevant test results are available and following hospital perinatal mortality committee review where possible.

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 such as investigations for thrombophilia.

(Please see Section 5 Investigation of stillbirths and Section 6 Investigation of neonatal deaths for further details.)

2.2.6 Definitions for registration of births and perinatal deaths

The following definitions and examples are provided for clarification of the requirements for registration of births and perinatal deaths.

(i) 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 gms 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.

A Perinatal Death Certificate 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.

Example 1: Fetus papyraceus

In the case of a birth after 20 weeks gestation where the birth weight is less than 400 gms and where the Intrauterine Fetal Death (IUFD) may have occurred some time before the birth, the birth is considered a stillbirth except in the case of fetus papyraceus where the fetus is not readily recognisable.

Example 2: Multiple pregnancy

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

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

(ii) Neonatal death

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 liveborn⁽⁽²⁷⁾⁾.

Neonatal death: is defined as death of a liveborn baby within 28 days of life.

A Perinatal Death Certificate 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 heart beat 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.

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Perinatal Mortality Audit Package



THE PERINATAL SOCIETY OF AUSTRALIA AND NEW ZEALAND

> Perinatal Mortality Group http://www.psanz.org.au

- 1.1 Stillbirth investigations
- 1.2 Neonatal death investigations
- 1.3 Accoucheur placental examination and preparation for pathology
- 1.4 Clinical examination of baby checklist
- 1.5 Perinatal mortality confidential case summary
 - Part a Perinatal death clinical summary
 - Part b Perinatal Mortality Committee review

1.1 Stillbirth investigations

CORE INVE		
Performed Comments/Results At diagnosis of IUFD Yes/No Comments/Results Please place √(Yes) or X (No) in boxes provided Mother Medical & obstetric history □ See Appendix 1.5	Performed At birth Yes/No Comments/Results Please place √ (Yes) or X (No) in boxes provided	Maternal Sticker (Inc Name, DOB, UR, Address, Telephone Number)
Ultrasound L	Clinical examination Abnormal See Appendix 1.4 Clinical photographs	
Performed Image: Constraint of the second secon	Babygram Swabs of ear & throat	
Sample for chromosomes	Not approached	Singleton Multiple Baby number (e.g. Twin 1)
Vaginal culture Low vaginal/Peri-anal	Refused	FURTHER INVESTIGATIONS
culture Image: Culture c	PartialFullGenetic autopsy Results	PerformedDate/8-12 weeks PostpartumYes/NoResultsPlease place \sqrt{Yes} or X (No) in boxes provided
Group & antibody screen	Cord/Cardiac blood samples Full blood count with smear (nucleated red count)	Thrombophilia Anticardiolipin antibodies Lupus anticoagulant APC resistance Fasting homocysteine Protein C deficiency Protein S deficiency Prothrombin G20210A Factor V Leiden mutation MTHFR
Other	Other	Comments
Date//	Date/	

Perinatal Society of Australia and New Zealand Perinatal Mortality Audit Guideline; Second Edition, Version 2.2, April 2009. Section 2: Institutional Perinatal Mortality Data; Appendix 1.1

1.2 Neonatal death investigations

AT BIRTH OF HIG		
Performed Yes/NoComments/ResultsPlease place $\sqrt{(Yes)}$ or X (No) in boxes provided	Performed Yes/NoComments/ResultsPlease place $\sqrt{(Yes)}$ or X (No) in boxes provided	Maternal Sticker
Mother Medical & obstetric history See Appendix 1.5 Vaginal culture Low vaginal/Peri-anal culture	Baby Clinical examination Clinical photographs Baby gram Swabs of ear & throat	(Inc Name, DOB, UR, Address, Telephone Number)
Blood tests Full blood exam		Singleton Multiple Baby number (e.g. Twin 1)
Kleihauer	Not approached	FURTHER INVESTIGATIONS
Renal function	Refused Partial Full Genetic autopsy Results	8-12 weeks Postpartum Performed Yes/No Comments/ Results Please place √(Yes) or X (No) in boxes provided
CMV	Cord blood sample Full blood count with smear (nucleated red count)	Thrombophilia Anticardiolipin antibodies Lupus anticoagulant APC resistance Fasting homocysteine Protein C deficiency Protein S deficiency
Other Placenta, membranes and cord Macroscopic examination See Appendix 1.3	Group DCT	Prothrombin G20210A
Placental swabs for microbiology	C Reactive Protein	Other
Placental histopathology	Other	Comments
Other		
- Date/	Signature	Signature
	Date/	Date//

Perinatal Society of Australia and New Zealand Perinatal Mortality Audit Guideline; Second Edition, Version 2.2, April 2009. Section 2: Institutional Perinatal Mortality Audit; Appendix 1.2

1.3 Accoucheur placental examination and preparation for pathology

Please complete details as required

Maternal Sticker

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

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

Step 1

Placental cultures

Using aseptic technique and being careful not to cross contaminate, swab in between the amnion and chorion.

Step 2	Accoucheur examination of the placenta, membranes and cord using sterile gloves					
Cord insertion (Circle)	Eccentric / Cen	tral / Marginal / Velamentous / Other				
Cord appearance (Circle)	Thin / Thick / M	leconium Stained / Other				
No of cord vessels		Total cord length	cm	Cord knots (Circle)	Yes / No	
Placental dimensions	cm	Placental weight	gms	Placental odour		
Maternal surface (Circle all	that apply)	Intact / Incomplete / Gritty / Fatty Infarc	cts / Retroplacent	al Clot / Succenturiate /		
		Circumvallate / Bipartite				

Step 3

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 twin number if appropriate.

Step 4 Send Placenta, Membrane and Cord to the Pathology fresh and unfixed for histopathological examination

1.4 Clinical examination of baby checklist

Please tick appropriate box and complete details as required

Maternal Sticker

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

Baby measurements 1. Crown – heel (stretched) 2. Head circumference		
If Stillbirth Estimated date of IUFD:// Maceration degree	Singleton Multiple Baby number	
Slight; focal minimal skin slippage	Normal Mass	Limbs Length Normal Short If Short, what segments seem short
no secondary comprehensive changes or decomposition	CHEST Long & narrow	Form Normal Asymmetric Missing parts If other, describe:
HEAD AND FACE Head Relatively normal Collapsed	Short & broad Other	HANDS <u>Length</u> Appearance: Normal Abnormal
Anencephalic Hydrocephalic Abnormal shape I If abnormally shaped, describe:	ABDOMEN Normal Flattened Distended Hemia Omphalocele Gastroschisis	If abnormal, describe: Fingers Number present: If not 4 + 4 describe
Eyes Normal Prominent Sunken Straight Far apart Close together Upslanting Downslanting	BACK Normal Spina bifida If Spina bifida, describe:	Unusual form of fingers
Globes normal Absent Eyes very small Very large Lens opacity Corneal opacity	Scoliosis Kyphosis Other If other, describe:	If abnormal, describe
Eyelids fused Other If other, describe:	GENITALIA Anus Normal I Imperforate Other I If other, describe:	If not 1+ 1 describe Unusual position
Normal Abnormally small Asymmetric Abnormally large Nostrils Apparently patent Obstructed	Gender Male Female Ambiguous Male	Finger nails All present If not describe
If other, describe:	Penis Normal Very small Hypospadias Chordee Hypospadias, level of opening	FEET Appearance Normal Abnormal I If abnormal, describe
Normal size Large Small	Scrotum Normal Abnormal I If abnormal, describe	Toes Number present: If not 5+ 5 describe
Left Right Bilateral Midline Palate Intact Cleft	Testes Descended Undescended Other If other, describe:	Spacing: Normal Abnormal I If abnormal, describe
Mandible Normal Large Small Other	Female Urethral opening Present Absent/unidentifiable	All present
Ears	Vaginal introitus Present Absent/unidentifiable Clitoris	Revised gestational age Based on
Normai Preauricular tags Lowset Preauricular pits Other Posteriorly rotated If other, describe; If other	Present Unidentifiable Enlarged Other If other, describe:	Date:
	Ambiguous sex	

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1.5 Perinatal mortality confidential case summary										
Part A - Clinical summary Form to be completed by Hospital of birth Please tick appropriate box and complete details as required						Maternal Sticker (Inc Name, DOB, UR, Address, Telephone Number)				
Maternal de	<u>tails</u>									
Country of birt	h:		Ethn	icity:		Singleton	Multiple	Baby nu	ı mber (e	e.g. Twin 1)
Education: <	High school		gn school	complete				-		-
Occupation: N	Nother		·····		- <i>c</i> · D · · · · ·	Husband/Partne	er			
Marital Status:	Never marrie	ed 🗳	Marr	ried 🗳	De facto 🖵 Widowed	L Divor	ced 🔲	Separated		
Medical and	l obstetric	: histo	ory		(Details)			_	(Details)	
Family history Venous thromboembolism Image: mail isotropy constraints Congenital abnormalities Image: mail isotropy constraints Image: mail isotropy constraints Other relevant Image: mail isotropy constraints Image: mail isotropy constraints							Hyperte Diabete	ension 🗆 es 🛛		
Maternal mec	dical history	Ci O	ervical sur ther 🔲	gery 🗖 Details	Venous thromboembolism	Uterine abr	normality 🗖			
Previous pre	gnancy outc	omes (numbers)	Miscarria	ges Terminations S	tillbirths Li	ive births	Neonatal deat	hs Postnatal d	eaths
Obstetric his	tory									
DOB	Baby number	Sex	GA	Birth weight	Delivery Ba method ou	by tcome Co	omplications	(Include detail abnormalities	s of congenital and cause of death)	
Current pre	egnancy	_			M	aternal transfer:				
Diurality	Gravio	la hon Г	Parit	ty	(Numbor)	tonatal 🗖	During Jahou			
Charge statu	s Public	IUN L		ate 🗖		ate and time of tra	ansfer / /	 		
Adverse soci	ial factors	-			Ha	ospital transferrec	d from			
Type of anter	natal care	No ant Home	enatal care birth midw	e □ ife □	Hospital clinic Obstetrician/Midwife (Private)	General GP/Midv	l practitioner (G wife	P) 🔲	Birth centre	
Intended plac	ce of birth		Mator	 	ht at booking visit	DMI				
Antonatal mo	dications		Water	nai weigi						
Corticosteroid	s		То	colvtics	Normal E	J Vegetaria	an 🗖 Ve	aan 🗖		
- Not stated	•	[] Fol	ic acid	Dietary suppl	ement 🛛 Ple	ease state	<u> </u>		
- None		[☐ Ant	tibiotics						
- < 24 hrs prio	r to baby's bi	rth 🛛	Me	thadone						
- Complete			- - C	osing	_					
- > 7 days bef	ore baby's bi	rth [_ Oth	ner	Please state					
Substance us Tobacco Si	se moking				Alcohol		Other			
At first visit		Ave	rage numb	ber of cigs) –	-			.	-
- Never sm	oked		 	م مام ز		L	L Cannal	bis 📙	Amphetamines	
- Quit in last	t i∠ months I		iumper pei	r day	Units per	uay	Heroin		Cocaine	
- Quit DelOfe - Smoker	ธาอเขอไป		Inknown	SHUKEI (WGGN	i talluci Comm	ents	LUSIASY	
- Unknown	i	s	Smoking at	time of b	irth Yes 🛛 No 🖾 Unkno	own 🗖				

1.5 Perinatal mortality confidentia	al case summary	Maternal Sticker			
Part A - Clinical summary continued		(Inc Name, DOB, UR, /	Address, Telephone Number)		
Please place $\sqrt{(Yes)}$ or X (No) in boxes provide	ed				
Antenatal (AN) EDC by USS/ EDC by LMP/ Assisted conception Type Gestation at 1st antenatal visit Screening/Diagnostics/Monitoring	 Morphology USS □ Total No. of antenatal visits	Gest D Total No.	uss 🗖		
 Chorionic villus sampling C Nuchal translucency Amniocentesis G Cordocentesis Vation of the second s	TG Image: Description of the studies poppler studies Image: Description of the strep screen aginal culture (HVS) Image: Description of the strep screen	Glucose screen Cervical suture Other diagnostics/proc	D cedures		
Medical conditions and pregnancy complicate Diabetes Hypertension - Pre-existing - Chronic hypertension - Gestational - Chronic hypertension SLE - Chronic hypertension Cardiac disease - Gestational hypertensia Renal disease - Pre-eclampsia Asthma - Pre-eclampsia supering Maternal injury - Unspecified hypertension Cervical surgery - Max systolic Mage	tions Antepartum h : essential - Placental abr : secondary - Placenta prae : unspecified - Vasa praevia sion - Other APH - APH or undet mposed Cervical incom ision Bleeding <20 w sion Prelabour ROW x diastolic Duration MR V Hrs Unknow	aemorrhage Twin t uption Threa evia Oligot Polyh Anaer ermined origin Urinar petence Asym /ks GBS M Fetal Vks Days Other vn	twin transfusion		
Labour and Delivery Labour onset Spont Induced No labour Induction reason Induction method Oxytocin Prostaglandis Induction method Oxytocin Prostaglandis Method of delivery Spont vag Vacuum Spont vag Forceps C.S. emerg C.S. elect. Reason for Operative Delivery Spont Comparison Spont Comparison Presentation Cephalic Breech Other Analgesia None Nitrous oxide IMI narcotice	Labour duration (hrs/mins) 1st s Amniotic fluid Clear Med a ARM Other Image: Second sec	stage/ 2nd stage/ conium Nil Nil Norioamnionitis Clinical signs Placental pathol	Fetal monitoring Intermittent auscultation Cardiotocography - On admission - Intermittent intrapartum - Continuous External Intermal Fetal scalp pH Lowest record Date and time Other		
Anaesthesia None LI General LI Spinal L	I Epidural 🖵 Pudendal 🖵	Other 📙			
Date Gestation		Event			

1.5 Perinatal mortality confidential case summary	Maternal Sticker							
Part A - Clinical summary continued	(Inc Name, DOB, UR, Address, Telephone Number)							
Please complete Clinical Examination of Baby Form (Appendix 1.4)								
Baby Details								
UR number: Birth order Gestational age wk days Birthweight Place of birth	Sex Male Female Undetermined							
Type of death: Fetal □ Antepartum death Unknown □ No Yes Neonatal (NND) □ → NND d	If yes estimated date of death/							
Resuscitation: Apgars 1 min Resuscitation 5 min Resuscitation None Suction Oxygen therapy IPPV - bag and max Who performed resuscitation? Not done Neonatal Registrar Paediatric Registrar Resuscitation medications None Narcotic antagonist Sodium bicar	Resuscitation: Apgars 1 min							
Neonatal death: Admitted to SCN Yes No Admitted to NICU Yes Image: Science of Sc	No Mech. Vent Yes No Image: Constraint of the state of th							
Active life supporting measures withdrawn Yes I No I	If yes, date &t time of withdrawal:/;;							
<u>Relevant neonatal events summary</u>								
Date Time Postnatal Event age								
······								

1.5 Perinatal mortality confidential case summary

Part B - Perinatal Mortality Committee review

Please tick appropriate box and complete details as required

1. Classification of Cause of Death

(i)	PSAN a. b.	IZ Perinatal Mortality Classification cause of death Perinatal Death Classification (PSANZ-PDC) Category No. Category Description: Neonatal Death Classification (PSANZ-PDC) Category No.
(ii)	Cause a.	Category description: e of death recorded on Medical Certificate Main disease or condition in fetus or infant:
	b.	Other diseases or conditions in fetus or infant:
	C.	Main maternal disease or condition affecting fetus or infant:
	a. e.	Other relevant circumstances

2. Classification of associated conditions

(i)	Peri a.	inatal Mortality Classifications associated conditions 1 Perinatal Death Classification (PSANZ-PDC) Category No Category description:	(ii) Pe a.	inatal Mortality Classifications associated conditions 2 Perinatal Death Classification (PSANZ-PDC) Category No Category description:		
	b.	Neonatal Death Classification (PSANZ-NDC) Category No Category description	b.	Neonatal Death Classification (PSANZ-NDC) Category No. Category description		
3.	Co Was If ye	ngenital abnormality s congenital abnormality present? Yes □ No □ Unknown □ es, please state abnormality:	lf unkno If yes, p	wn, are results of investigations pending? Yes □ No □ blease state tests awaiting:		
4.	Fet Did	tal / Neonatal infection infection contribute to the death? Yes □ No □ If C	yes state o Culture site	organism Date & time:/;;		
5.	Ter Was	rmination of pregnancy s the pregnancy terminated? Yes □ No □ Fetal abnormality □ Maternal psychosocial reasons (pre-viable)	lf yes, w	as the pregnancy terminated due to: Maternal medical condition (pre-viable)		

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

1.5	Per	inatal mortality confidential case summary						
Part	B - P	Perinatal Mortality Committee review continued		Ма	ternal Sticker			
Plea	se tick	appropriate box and complete details as required		(Inc	Name, DOB, UR, Addre	ss, Telephone	e Number)	
6.	Fa	ctors relating to care						
(i)	Pot Wei If ye	rentially contributing factors: re any potentially contributing factors relating to care access or provisions, pes, please complete below:	No 🗖	No 🗖				
		Factor					Timing	
	(a)	Factors relating to the woman/ her family/ social situation: Yes D]	No		Antenatal	Intrapartum	Postnatal
		Factor 2:						
	(b)	Factors relating to access to care: Yes Factor 1:]	No				
		Factor 2:						
	(c)	Factors relating to professional care: Yes Factor 1:]	No				
		Factor 2:						
(ii)	<i>Oth</i> Wei If Ye	ner factors (e.g. counselling, communication, investigation) re any other factors present relating to care? Yes □ No □ es, please state factors:						
7.	Pra Wei If ye	actice improvement recommendations: re any areas identified for practice improvement es, please complete <i>Practice Improvement Recommendations</i> below.	Yes		No 🗖			
	Acti Acti	on required:	on respo	onsible	Ð:			
	Rec	commendation 2:						
	Acti Acti	on required:on to be reviewed by (date): / / / Perso	on respo	onsible	ə:			
	<u>Rec</u>	commendation 3:						
	Acti Acti	on required: on to be reviewed by (date): / / / Perso	on respo	onsible	9:			

8. Other discussion relevant to practice improvement or educational aspects

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1.5	Perinatal	mortality	confidential	case summary
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Part B - Perinatal Mortality Committee review continued

Please tick appropriate box and complete details as required

Maternal Sticker

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

9. Follow-up visits for parents

Obstetrician:			Date arranged: / /
			Date arranged: / /
			Date arranged: / /
GP notified of the death?	Yes 🗖	No 🗖	Date General Practitioner was notified
Genetic counselling required?	Yes 🗖	No 🗖	Date arranged: / /
Further investigations required?	Yes 🗖	No 🗖	If yes, please state

10. Administrative Details

Hospital of birth name:
Date of committee review / /
Review finalised: No 🔲 Yes 🗖
If no, specify outstanding areas for finalisation of this review:
If yes, date finalised: / /
Name of person completing this form:
Contact person for additional information:
Phone number:
Signed

endix 2 Instructions on taking clinical photographs

High quality medical photographs are preferred; however, Polaroid pictures are better than no pictures at all. Ideally digital photographs should be taken which will allow the clinician to check each photograph after it is taken. These photographs should be taken in addition to bereavement photographs.

Consent:

Parental consent is necessary prior to taking clinical photographs. Due to their clinical nature it is strongly recommended that the parents are not offered copies, but specific bereavement photographs are taken instead.

Background:

Plain white or surgical drapes (other backgrounds may create glare or alter skin tone).

Scale:

- Place a paper tape measure next to the baby (a plastic ruler will create glare)
- Ensure zero is aligned at the base of the foot or crown of the head.
- Use sticky tape to ensure the tape is straight; and
- Measure should be on the bottom of the frame or the left.

Identification:

Write the baby's UR number on the paper tape measure for identification. Don't write any other identifying information in case the photographs are ever mislaid.

Setting:

Photographs should be taken in a private area away from the parents.

Technique:

The photographs should be taken from directly above the baby. Consequently it is best to place the baby on the floor, in order to get sufficient height above the baby.

Magnification:

Use a 50 mm lens/magnification for the whole body photographs, and maintain a consistent distance. Use a 100 mm lens/magnification (except for digital) for the facial photographs, filling the whole frame.

Baby:

The baby should be naked for all the photographs.

Position:

- AP view whole body frontal including limbs
- 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



- Tape measure to the left
- Palms facing up



- Keep the baby in this position for the minimum time possible.
- Tape measure to the left
- Palms facing down

Sect ion 2; App endi x 2 Instr ucti ons on takin g clini cal phot ogra phs conti nued

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

Page 2 of 3

Section 2 Appendix 2 Instructions on taking clinical photographs continued



Lateral views of the face

• Keep tape measure to the left of the frame to aid easy identification of the side being viewed.

If there are any specific abnormalities these should be photographed individually, with a scale in view and the photograph labelled with the baby's UR number.

Section 2; Appendix 3 Autopsy clinical summar Please attach the following: • copy of the death certificate; • copies of all antenatal ultrasound reports; and • copy of amniocentesis report if available	y form Maternal Sticker (Inc Name, DOB, UR, Address, Telephone Number)
Baby Details	Singleton Multiple Baby number (e.g. Twin 1)
UR number:Sex Male Female Undetermined Gestational age wks days Birthweight gms Date & Time Place of birth	of birth:/;
Type of death: Fetal Antepartum death Unknown No Yes	□ → If yes estimated date of death
Death Certificate completed Yes No	date & time of death:/;;
Treatment or condition likely to cause hazard at autopsy Hepatitis B Pos Tuberculosis Specify Specify	HIV (Aids Virus) Other
Provisional clinical diagnosis (to be completed by physician reque	sting autopsy)
2	
3	
4	
Please list doctors to receive report Name Add	Iress
Consultant	ephonePager
Signature (person completing this form) Print name	Date / /

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Section 2: Appendix 4 Perinatal Mortality Classifications - quick reference sheet

		-			-
		PS/	ANZ-PDC	6	Spe 6.1
1	Cong cong 1.1 1.2	genital enital a Centra Cardio	Abnormality (including terminations for abnormalities) al nervous system ovascular system		6.2 6.3
	1.3	Urinar	y system		6.4
	1.5	Chron	nosomal		6.5
	1.6 1.7	Metab Multip	oolic le/non chromosomal syndromes		6.6
	1.9 Pleas death inclus digit o	1.81 1.82 1.83 1.84 1.85 1.88 Unspese note as with sion of a codes	Musculoskeletal Respiratory Diaphragmatic hernia Haematological Tumours Other specified congenital abnormality ecified congenital abnormality et hat terminations of pregnancy for perinatal in this category should be identified by the an "09" for two-digit codes and a "9" for the three		6.7 6.8
2	2.1	natal In Bacte	fection rial		6.9
		2.11 2.12 2.13 2.14 2.18 2.19	Group B Streptococcus E coli Listeria monocytogenes Spirochaetal eg Syphilis Other bacterial Unspecified bacterial	7	Hyp ges 7.1
	2.2	Viral 2.21 2.22 2.23	Cytomegalovirus Parvovirus Herpes simplex virus		7.2

- 2.24 Rubella virus
- 2.28 Other viral
- 2.29 Unspecified viral 2.3 Protozoal eg Toxoplasma
- 25 Fungal
- 2.8
- Other specified organism Other unspecified organism 2.9

Hypertension 3

- 3.1 Chronic hypertension: essential
- Chronic hypertension: secondary, eq renal disease 3.2
- Chronic hypertension: unspecified 3.3
- 3.4 Gestational hypertension
- 3.5 Pre-eclampsia
- 3.51 With laboratory evidence of thrombophilia Pre-eclampsia superimposed on chronic hypertension 3.6
- 3.61 With laboratory evidence of thrombophilia
- Unspecified hypertension 3.9

4 Antepartum Haemorrhage (APH)

- 4.1 Placental abruption
- 4.11 With laboratory evidence of thrombophilia
- Placenta praevia 42
- 43 Vasa praevia
- 4.8 Other APH
- 4.9 APH of undetermined origin

Maternal Conditions

5

- Termination of pregnancy for maternal psychosocial 5.1 indications Diabetes / Gestational diabetes 5.2
- 5.3 Maternal injury 5.31 Accidental
- 5.32 Non-accidental
- Maternal sepsis 5.4
- Antiphospholipid syndrome 5.5
- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions

- Specific Perinatal Conditions
 - 6.1 Twin-twin transfusion
 - Fetomaternal haemorrhage 6.2 63
 - Antepartum cord complications 6.31 Cord haemorrhade
 - 6.32 True knot with evidence of occlusion
 - 6.38 Other
 - 6.39 Unspecified
 - 6.4 Uterine abnormalities, eg 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
 - Idiopathic hydrops
 - 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
 - 6.9 Unspecified

Hypoxic Peripartum Death (typically infants of >24 weeks gestation or >600g birthweight) With intrapartum complications 7.1

- 7.11 Uterine rupture
- 7.12 Cord prolapse
- 7.13 Shoulder dystocia
- 7.18 Other
- Evidence of non-reassuring fetal status in a normally grown 7.2 infant (eg abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intrapartum complications)
- No intrapartum complications and no evidence of non-7.3 reassuring fetal status.
- Unspecified hypoxic peripartum death 7.9

Fetal Growth Restriction (FGR) 8

- 8.1 With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (eg significant infarction, acute atherosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)
- With chronic villitis 82
- No placental pathology 83

9

- No examination of placenta 8.4
- Other specified placental pathology 8.8
- Unspecified or not known whether placenta examined 8.9

Spontaneous Preterm (<37 weeks gestation)

- Spontaneous preterm with intact membranes, or
 - membrane rupture <24 hours before delivery 9.11 With chorioamnionitis on placental histopathology
 - 9.12 Without chorioamnionitis on placental
 - histopathology 9.13 With clinical evidence of chorioamnionitis, no
 - examination of placenta No clinical signs of chorioamnionitis, no 9 1 7 examination of placenta
 - 9.19 Unspecified or not known whether placenta examined
- 9.2 Spontaneous preterm with membrane rupture ≥24 hours before delivery
 - With chorioamnionitis on placental histopathology 9.21
 - 9.22 Without chorioamnionitis on placental histopathology
 - 9 23 With clinical evidence of chorioamnionitis, no examination of placenta
 - No clinical signs of chorioamnionitis, no 9.27 examination of placenta
- 9.29 Unspecified or not known whether placenta examined Perinatal Society of Australia and New Zealand Perinatal Mortality Audit Guideline; Second Edition, Version 2.2, April 2009. Section 2: Institutional Perinatal Mortality Audit; Appendix 4

- 9.3 Spontaneous preterm with membrane rupture of unknown duration before delivery
 - 9.31 With chorioamnionitis on placental histopathology

4

Infection

4.2 Viral

4.3

4.5 Fungal 4.8 Other specified organism

5.2

5.8 Other

Other

7.2

7.3

74

78

79

Gastrointestinal

6.8 Other

5

6

7

Bacterial

4.11 Congenital bacterial

4.112 E coli

4.12 Acquired bacterial

4.122 E coli

coli)

4.21 Congenital viral

4.22 Acquired viral

4.9 Unspecified organism

>600g birthweight)

6.1 Necrotising enterocolitis

Multisystem failure

7.31 Accidental

7.39 Unspecified

7.41 Surgical

7.42 Medical

Other specified

7.32 Non accidental

Treatment complications

Unknown/Undetermined

7.91 Unclassified Sudden Infant Death

7.92 Other Unknown/Undetermined

Trauma

7.28 Other specified

trigger event

Intracranial haemorrhage

Neurological

4.111 Group B Streptococcus

4.113 Lysteria monocytogenes

4.114 Spirochaetal, eq syphilis

4.119 Unspecified bacterial

4.121 Group B Streptococcus

4.126 Staphylococcus aureus

4.128 Other specified bacterial

4.129 Unspecified bacterial

4.213 Herpes simplex virus

4.218 Other specified viral

4.219 Unspecified viral

4.221 Cytomegalovirus

4.224 Rubella virus

Protozoal e.g. Toxoplasma

4.223 Herpes simplex virus

4.228 Other specified viral

5.1 Hypoxic ischaemic encephalopathy / Perinatal

5.21 Intraventricular Haemorrhage

5.23 Subarachnoid Haemorrhage

7.1 Sudden Infant Death Syndrome (SIDS)

5.28 Other Intracranial Haemorrhage

5.22 Subgaleal Haemorrhage

5.24 Subdural Haemorrhage

asphyxia (typically infants of >24 weeks gestation or

7.11 SIDS Category IA: Classic features of SIDS

present and completely documented. 7.12 SIDS Category IB: Classic features of SIDS

present but incompletely documented.

category I except for one or more features.

55

7.13 SIDS Category II : Infant deaths that meet

7.21 Secondary to intrauterine growth restriction

7.29 Unspecified/undetermined primary cause or

4.229 Unspecified viral

4.211 Cytomegalovirus

4.214 Rubella virus

4.125 Other Gram negative bacilli (other than E

4.127 Coagulase negative Staphylococcus

4.118 Other bacterial

41

- 9.32 Without chorioamnionitis on placental histopathology
- 9.33 With clinical evidence of chorioamnionitis, no examination of placenta
- 9.37 No clinical signs of chorioamnionitis, no examination of placenta
- 9.39 Unspecified or not known whether placenta examined

Unexplained Antepartum Death 10

- 10.1 With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (eg significant infarction, acute atherosis, maternal and/or fetal vascular thrombosis or maternal floor infarction) 10.2 With chronic villitis
- 10.3 No placental pathology 10.4 No examination of placenta

11.2 Postnatally acquired infection

11.3 Accidental asphyxiation

11.9 Unknown/Undetermined

congenital abnormalities)

Urinary system

Chromosomal

Metabolic

1.82

1.83

1.84

1.85

1.88

2.1 Not resuscitated

attempted

1.1 Central nervous system

Cardiovascular system

Gastrointestinal system

Other congenital abnormality

1.81 Musculoskeletal

Tumours

gestation or <=600g birthweight)

2.2 Unsuccessful resuscitation

Cardio-Respiratory Disorders

syndrome (RDS)

Pneumothorax

Pulmonary hypoplasia

Pulmonary haemorrhage

Meconium aspiration syndrome

bronchopulmonary dysplasia)

Respiratory

Haematological

11.8 Other specified

1

1.2

1.3

1.4

1.5

1.6

1.7

1.8

1.9

2.9

3.1

3.2

33

3.4

3.5

3.6

37

3.8 Other

2

3

- 10.8 Other specified placental pathology
- 10.9 Unspecified or not known whether placenta examined

11 No Obstetric Antecedent

- 11.1 Sudden Infant Death Syndrome (SIDS) 11.11 SIDS Category IA: Classic features of SIDS
 - present and completely documented. 11.12 SIDS Category IB: Classic features of SIDS
 - present but incompletely documented. 11.13 SIDS Category II : Infant deaths that meet Category I except for one or more features.

11.4 Other accident, poisoning or violence (postnatal)

11.91 Unclassified Sudden Infant Death

PSANZ-NDC

Congenital Abnormality (including terminations for

Multiple/non chromosomal syndromes

Diaphragmatic hernia

Unspecified congenital abnormality

Extreme Prematurity (typically infants of <=24 weeks

Unspecified or not known whether resuscitation

Hyaline membrane disease / Respiratory distress

Primary persistent pulmonary hypertension

Chronic neonatal lung disease (typically,

Other specified congenital abnormality

11.92 Other Unknown/Undetermined



Section 3 of 7 – Psychological and Social Aspects of Perinatal Bereavement

3.1	Introduction	. 577
3.2	Summary of key recommendations	. 588
3.2.1	Respect	59
3.2.2	Provision of information	60
3.2.3	Birth options	61
3.2.4	Time	62
3.2.5	Hospital stay	62
3.2.6	Creating memories	62
3.2.7	Special circumstances	63
3.2.8	Aftercare	64
3.2.9	Funeral arrangements	64
3.2.10	Health care professionals	66
3.3	References	67
Appen	dices	

Appendix 1; Information for parents about autopsy	69
Appendix 2; Information for the health professional seeking consent	71

SECTION 3 PSYCHOLOGICAL AND SOCIAL ASPECTS OF PERINATAL BEREAVEMENT

3.1 Introduction

Health professionals are typically involved with bereaved parents during and immediately following the death of their baby. Despite this, the training of health professionals in the care of parents following the death of a child has been reported to be one of the most neglected areas of education^{((1, 2)}. In the absence of such training, professional, cultural and societal assumptions of how patients should respond to perinatal loss influence the quality of emotional care provided to patients by health professionals. Health professionals may themselves find it difficult to provide sympathetic and compassionate care due to a lack of knowledge and understanding of how best to approach this difficult situation.

Research has suggested that the role of practitioners in the handling of death and their interaction with the bereaved person following a loved one's death influences the intensity of $grief^{(1, 2)}$. One study found that grief levels in bereaved persons were significantly reduced when the practitioners involved them in medical decisions and decisions relating to the deceased person's care⁽³⁾. It is proposed that skilled, sensitive and caring treatment in the time surrounding pregnancy loss positively impacts on the grief experience of bereaved parents^(1, 3). Disempowerment, an absence of acknowledgement and validation for their physical and emotional experience and lack of information^(1, 3, 4) and insensitive and unsympathetic care⁽¹⁾ may result in intense feelings of guilt, misunderstanding and rumination in the bereaved parent^(1, 4).

A number of studies have examined the factors considered to be important to bereaved parents following the death of their child, as well as aspects of care that they considered to be lacking⁽¹⁻⁶⁾. These findings implicate the importance of validation and acknowledgement of the physical and emotional aspects of their experience; empowerment and safety; collaborative decision-making; the sharing of knowledge; creation of memories; and sensitive care. One study⁽⁴⁾ found that parents reported higher levels of sensitive care when the clinician associated the death with a similar event in his or her own life experience rather than an experience in their training. Further, it is important that clinicians accept the range of responses given by bereaved parents and that they do not project their own values or expectations upon those in their care. The Cochrane systematic review on the topic of support concluded that there is insufficient information available from randomised trials to indicate whether there is or is not a benefit from interventions which aim to provide psychological support or counselling for mothers, fathers or families after perinatal death and recommended that methodologically rigorous trials are undertaken ^{(27).}

Based on these findings, the following information is provided as a guide to assist clinicians in providing positive treatment for the bereaved parents and their baby.

A subgroup of the working party (Kylie Lynch, Liz Davis, Sonia Herbert, Ros Richardson, Dell Horey and Vicki Flenady) worked collaboratively in the development of the first edition of this section of the guideline. The review and minor updating of this section for this second edition was undertaken by Liz Davis, Ros Richardson and Vicki Flenady.

3.2 Summary of key recommendations

Respect	
For baby	Deceased baby to be treated with same respect as live baby
For parents	Parents need to feel supported and in control; death validated
Cultural/religious practices	Different approaches to death and rituals respected
Provision of Information	
Timing of information	Allow plenty of time to discuss issues at most appropriate time
Delivery of information	Clear, honest and sensitive. Repeat important information. Ensure both parents are present.
Mode of information	Fact sheet/written information given for frequent reference
Withdrawal of support	Parents given prognostic information to reach decision
Terminology	Parent friendly language. Do not use terms such as fetus
Post-mortem examination	Verbal and written information given. Allow time for discussion
	Ensure both parents present when discussing autopsy – the parents may also be assisted by having a support person (family, friend) present
Birth Options	
Timing	Ascertain appropriate time to discuss birth options following determination of a fetal death in utero or abnormalities
Mode of delivery	Benefits of birthing options given
Time	
	Parents are given time to make decisions Inform parents of how much time can be spent with baby
Hospital Stay	
Environment	Parents are given the option of a private room in surgical, maternity or gynaecological ward Universal symbol placed outside room to alert all staff of death
Creating Memories	
Spending time with baby	No hurry to leave baby or hospital. Option to take baby home
Parenting baby	Inform parents that they can hold, undress, bath baby
Mementos	Helpful for long-term grief outcome. See Section 3.2.6
Baptism/blessing	Inform parents that this can be arranged through the hospital
Special Circumstances	
Multiple pregnancies	Special care is required in the circumstance where some infants in a multiple pregnancy survive.
Maternal illness	Consideration given regarding access to baby/memory creation
Previous perinatal/child death	Consider impact of previous death/s on emotional response to and coping with current death
Aftercare	
Maternal changes	Advise on milk production and methods to manage supply
Support services for parents	Written information given regarding available support services
Support services for children	Written information provided for children's support services
Grief	Inform parents of expectations of grief journey
Follow up/Appropriate referral	Expectations for 6 week check up – other babies present

Funeral Arrangements

Parents given choice of funeral directors No urgency to organise funeral Continued access to baby if desired

Health Care Professionals

Education	Specific training in support skills given to relevant staff
Access to support	Debriefing/support services available to staff working with perinatal death

3.2.1 Respect

For baby

The baby should be respected, just as if a live baby. This includes the way in which the baby is handled. Use of the baby's name (where applicable and culturally appropriate) is recommended. This suggests to the parents that you recognise the baby's individuality and helps to validate their loss. Parents need to know that their baby will be cared for with dignity and respect at all times.

For parents

Parents should be supported to enable them to feel that they have some control. They should be provided with enough support to enable them to reach their own decisions regarding their care and the care of their baby. The provision of care needs to be responsive to their individual needs and feelings.

The depth of their loss needs to be recognised and validated. The death of a baby through stillbirth and neonatal death can be isolating for parents due to the assumption that the death is less significant than that of an older child⁽⁷⁾. Many parents also face a shattering of worldview, as the death of a baby violates the natural order of life, where it is expected that the old will die before the young⁽⁷⁻¹¹⁾.

For cultural and religious practices

People of different cultures approach death in different ways. This belief system may vary both across and within their culture. They may also have rituals that they traditionally perform following the death of a loved one. These rituals should be respected in instances where they comply with state regulations. Sufficient information is also provided to enable the ritual to be carried out. It is important for practitioners to gain a general working knowledge of cultural practices to avoid offending the bereaved parent. For example, the stillborn baby of a Muslim woman may be bathed by a same sex relative; questioning and eye contact may be considered to be offensive by an Aboriginal woman.

3.2.2 Provision of information

Timing of information

Health care professionals need to be sensitive to the needs of bereaved parents and aware of appropriate times to deliver information. Parents should be assisted to understand and appreciate the issues on their own terms and understand the important aspects of diagnosis, treatment, consequences and outcome. Provision of information should allow parents the time for consideration. Allow time for questions and allow time for silent grieving also. It is therefore necessary to allow adequate time to spend with the bereaved parents. Be flexible and repeat the information as required. Ensure that both parents are present when information is to be given. This is particularly relevant when an IUFD has been diagnosed. If the mother is on her own, her partner or other support person should be contacted. It should be recommended that she not drive home on her own.

Delivery of information

Communication needs to be clear and honest and delivered in a sensitive manner. There may be a requirement to provide parents with the same information many times over due to information processing deficits caused by shock and/or grief. It is important to ensure that both parents process the information that is given and that both achieve the same understanding of the information to enable the parents to make accurate and informed decisions. If the baby has been named and it is culturally appropriate to do so, always use the baby's name during discussions.

Information should be delivered in a quiet, private room, away from other patients, relatives and hospital staff.

Parents understanding of the issues should be actively assessed by reflective listening while communicating with parents. Where the situation requires (e.g. Giving of consent for intervention), it is important that decision-making is based on a fully informed appreciation of the issues. Take the opportunity to ensure that parents' understanding of the situation is accurate in terms of the facts and up to date in terms of the clinical progress. Many parents will be more in tune to the issues than staff anticipate; however it is important to constantly assess that parents understanding is based on correct information and not on false hopes. Where possible, ask specific questions to confirm parents understand, particularly when discussing possible new interventions or changes to treatment plans. Parents may appear to understand the information being given but may in fact not be able to recall the conversation at a later time.

Competent interpreters should be used in cases where the parents are not fluent in English.

The National Health and Medical Research Council has recently produced guidelines to assist clinicians to communicate more effectively and provide information to patients^(12, 13) (*Please refer to these documents for full details.*)

Mode of information

Parents generally have difficulty absorbing and retaining information during and following the death of their baby. It is therefore useful to reinforce verbally delivered information with a fact sheet or written information about issues relevant to the parents, their baby and their loss.

Offer parents Stillbirth And Neonatal Death Support (SANDS), SIDS and Kids and/or Support After Fetal Diagnosis of Abnormality (SADFA) support group brochures – whichever is applicable to their circumstances.

Withdrawal of support (14, 15)

Parents need to be provided with all information regarding their baby's condition and prognosis to enable them to reach the decision of withdrawal of support themselves or in conjunction with the Neonatologist. Parental decision to withdraw support on the grounds of compassionate care reduces the risk of parents blaming practitioners for their baby's death. It is natural for parents to want to protect their baby and the withdrawal of support may be considered to contravene this innate quality. To assist parents thinking about withdrawal of care from their baby, parents need to be provided with full and honest information regarding their baby's prognosis. This information needs to be delivered compassionately and sensitively and preferably from one Neonatologist in order to avoid discrepancies in information and/or prognosis, although parents should be offered the opportunity to seek a second opinion. Where possible, concrete evidence regarding the poor prognosis should be given. It is essential that all aspects of the baby's condition and prognosis be discussed to avoid the perception that a different agenda exists for the recommendation of withdrawal of support. Encourage parents to speak to others (family, friends, and social worker) about the decision to withdraw support. Speaking to others may allow them to express their fears and anxieties and assist them to make an informed decision.

Staff caring for the baby should provide parents with the opportunity to hold their baby prior to death. Parents are generally guided by staff during this time and all efforts should be made to make the experience as compassionate, sensitive and meaningful as it can possibly be. Privacy is essential at this time and can be provided by offering a private room (where possible) or screen (if in Neonatal Intensive Care Unit). Staff should be guided at these times by the principles of compassionate, supportive and empathic care. Respect for the baby and his/her life and respect for the intensity of parental grief are crucial.

Parents need to be informed that it is often difficult to predict how soon a baby will die following the withdrawal of support. Many parents may expect this to be a quick process and may become distressed when their baby continues to live for some time following the withdrawal of support. This may create a situation where some parents question their decision and may feel anger and uncertainty with the advice and recommendations of staff. It can be helpful for parents and staff to agree on how the baby will be cared for after the withdrawal of support until the baby dies. However, some babies may die very quickly after support has been withdrawn – it may be necessary to ensure parents are on hand at the start of the process.

Terminology

Parent friendly language should be used when discussing issues pertaining to the death of their baby. Where possible, establish the parents' level of understanding. Some parents may have spent days or weeks with their baby and have a detailed and sophisticated understanding of the problems and the treatment plan. However, in many cases, there will be no antenatal diagnosis and post-natal problems may occur very

rapidly, leaving very little time to provide detailed technical examinations of what is going on. Medical terminology should be avoided as many parents have minimal understanding of these terms and have a limited capacity to understand during this traumatic time.

It is imperative that health care practitioners avoid the use of terms such as fetus and products of conception. These terms dehumanise the baby and take away his or her individuality. The use of the baby's name (where culturally appropriate) in place of any term helps to validate the importance of the baby and the depth of loss for the parent. Health care professionals need to be clear in their communication with parents when discussing procedures around labour and delivery.

Autopsy

Parents should be provided with verbal and written communication regarding their options for post-mortem examination. Sufficient time should be allocated to explain the options available and to answer any questions that the parents may have. Parents should be informed that a decision is not required immediately and have access to information and support. A follow up appointment may be required if the parents are unable to decide during the initial meeting. It may be beneficial to the parents to have a support person present when the discussion is being held. It is important that the person requesting permission understands the process of autopsy and be able to answer, within their knowledge, questions the parents will have. The health care professional who is to speak to the parents should already have developed a rapport or relationship with them. Options for autopsy, such as a partial autopsy, need to be discussed.

Parents should be given the opportunity, where possible, to meet with the pathologist who will perform the examination. Assurance that their baby will be treated with respect needs to be given. Parents need to be given the option to see and hold their baby after the autopsy has been performed, either in the hospital or at the funeral home. The pathologist will need to understand that parents may see and hold their baby after the autopsy. It is important that the person taking their baby to the autopsy be known to the parents. The discussion regarding autopsy should be in a quiet, private place away from others. It is not appropriate

The discussion regarding autopsy should be in a quiet, private place away from others. It is not appropriate to discuss autopsy in a corridor, shared room or other public place.

Parents need to know that it may take several months for the results to become available to them. It is also important to inform the parents that there is a chance that nothing adverse will be discovered.

(Please see Section 3; Appendix 1 Information for parents when your baby has died, and Section 3, Appendix 2 Information for the health professional seeking consent.)

3.2.3 Birth options

Timing

In the event of a diagnosis of fetal death in utero or fetal abnormalities that are incompatible with life, parents are faced with both the reality that their baby has died (or will die) as well as the need to deliver the baby. Parents should be informed of factors relating to delivery, e.g. when to deliver, how to deliver, and the impact that waiting to deliver will have on accuracy of post-mortem examination results, etc. Parents may be experiencing a range of emotions such as shock, disbelief and grief, and have difficulty processing information. The timing of delivery of information is important to provide parents with the opportunity to make appropriate decisions relating to the birth of their baby. The health care professional who is most closely involved with the parents would be the most appropriate person to determine the best time to discuss these issues, although parents should be offered an alternative person with whom to discuss their options. In the event that no particular person has been involved in their care, the practitioner who is most experienced in discussing these issues should approach the matter. Amniocentesis before delivery, if appropriate should be discussed with parents – the health care professional working with the parents should have knowledge of current practices.

Mode of delivery

Where possible, parents should be offered a choice in birthing options. Many mothers find the concept of delivering their stillborn baby naturally to be overwhelming. However, some mothers report satisfaction and a sense of accomplishment with natural delivery following the determination of a fetal death in utero⁽¹⁶⁾.

In the event of interruption of pregnancy due to abnormalities, the benefits of delivering naturally or by caesarean versus dilatation and curettage should be explained. Seeing and holding the baby and creating memories is an important part of the grief process for many, but not all, women. Women and their partners need to be informed that if their baby is delivered (removed) by a dilatation and curettage procedure, their baby's body will not remain intact.

In all circumstances where options are available, natural delivery vs. delivery by caesarean section and the benefits of each mode should be explained to the parents. For example, a baby may be born alive if delivered by caesarean and may not survive a natural birth. Consequences of caesarean delivery on future pregnancies/births should be discussed.

Ensure that the parents are fully informed before commencing any procedure. Where possible, offer parents the option of returning home prior to induction/delivery. Going home before delivery can give parents time to consider the information they have received and gather their support people around them. They will also have time to think about memory creation – camera, video camera etc. It is important to remember that it may not always be appropriate to ask the father to return home on his own immediately after a fetal death has been diagnosed. Parent safety is paramount. It may be helpful for the mother and father to stay together while a friend or family member brings necessary items to the hospital.

The primary caregiver is favoured to present the parents with available options as rapport and trust is already established. In the event that this is not possible, a person experienced in perinatal bereavement would be appropriate.

3.2.4 Time

Parents need to be given time to make decisions. Where fetal death in utero or fetal abnormalities have been determined, parents should be given a choice between remaining in hospital and returning home prior to induction. Information needs to be reinforced or in written form, if possible, to enable parents to prepare, discuss and decide between options⁽¹⁶⁾.

Practitioners should allow ample time to deliver information about the hospital stay, creating memories and consent for an autopsy and discuss issues and concerns, which may be raised repetitively.

3.2.5 Hospital stay

Environment

For some bereaved parents, it can be very distressing to return to or remain in the maternity ward. The sound of crying babies may add to their distress. Other parents may find it more upsetting if they are moved to the surgical or gynaecological ward and interpret this as meaning that they are no longer considered to be parents. It is therefore important to ask the parents if they would prefer a room in the maternity or surgical ward while they remain in hospital. Time with their baby should be available and they should be informed that there is no urgency to leave the hospital. It is important that clinicians do not impose their own preferences on parents and that they understand that not all parents want to hold or see their baby at this time. In these circumstances it is important that mementoes such as photographs are collected (see below).

Bereaved parents should be provided with a private room, away from the busiest part of the ward and a symbol placed on door to alert all staff to the situation. This needs to be a universal symbol with which all hospital staff is familiar, to help to ensure the continuity of sensitive care.

Continuity of care is recommended. A staff member should be available at all times to collect or return the baby at the parent's request.

Referral to a social worker must be made to provide support, counselling and information pertaining to support groups and funeral options. If it is established that the baby has a congenital abnormality or a genetic condition, a Genetic Counsellor, if available, can assist with bereavement care, provision of information and support.

3.2.6 Creating memories

Spending time with baby

Validating the death of the baby assists in facilitating a healthy grieving process and is enhanced by the encouragement of the creation of memories^(5, 15, 17, 18). Providing suitable clothing, blankets, cots and baskets and seeing, holding and naming their baby assists the parents in creating memories, which may aid in the grief process. ^(1, 7, 15).

Parents may initially be reluctant or afraid to see their baby. While some research in the area of parental bereavement recommends encouraging parents to see and/or hold their baby⁽¹⁶⁾, others do not⁽¹⁹⁾. Therefore, it is important that the parents be encouraged to explore what is the best option for them in regard to seeing and holding their baby and their wishes respected. This is of particular importance when caring for parents of *Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Perinatal Mortality; Second Edition, Version 2.2, April 2009.* 62 *Section 3: Psychological and social aspects of perinatal bereavement*

different cultural backgrounds. Parents may need guidance from the doctor or midwife in how to approach their baby⁽¹⁶⁾. Parents will often take their cues from the staff caring for them and their baby and will sense if a staff member is not comfortable caring for a baby who has died. Some mothers may like the baby delivered onto their chest so they experience the warmth of their baby.

Parents choosing to spend time with their baby should be informed about the length of time that they are able to spend with their baby. It is important to inform them that there is no urgency to arrange a funeral or leave their baby Parents need to be informed of the option of placing the baby in the hospital morgue from time to time to preserve the baby's body.

Options need to be offered regarding staying at the hospital versus taking the baby home. Factors relating to climate need to be discussed, as time spent with baby in the home may be limited in hotter climates.

It is important that parents are prepared for the appearance of the baby, particularly when the baby is extremely premature or has a congenital disability^(15, 18). Providing a photograph or describing the baby's appearance can be helpful for the family. In circumstances where abnormalities are present, parents may prefer that their baby is presented in such a way that the abnormalities are less evident (for example, covered with blanket, bonnet or other clothes).

Parenting baby

Parents should be provided with the opportunity to bath their baby if they so desire. They should be informed that it is quite acceptable to hold and undress their baby. Options may need to be offered several times, as parents may not initially process the information. It can be helpful if staff offer to assist the family. Siblings may also wish to be involved in this care.

Parents should be informed of what to expect when the baby has abnormalities or is extremely premature. Staff should have this knowledge so they can better inform parents.

Inform parents of the option to provide clothes from home for their baby if they so wish.

Mementos

Although some parents may be reluctant to see their baby, there are a number of things that should automatically occur following the death of a baby. These include the compilation of memories that may be kept until the parents are ready to accept them. For some, it may be culturally appropriate to explain and obtain permission for procedures, such as taking photographs.

Parents may take days, months or years to decide that they would like these mementos; therefore no time provision should be made regarding storage. Some families may choose to never receive these items.

As a minimum, items included should be:

- hand and footprints
- ID bracelet
- measuring tape
- cot card
- digital photographs
- lock of hair (where possible and only after permission of the parents has been given)

Suggestions to parents for the creation of memories may include:

- photographs of baby and with family
 - taken professionally if a death is one of a multiple pregnancy, a photo of all the babies together.
 - without clothes
 - o abnormalities special attention given
 - photos during birth
 - photos on disc
 - video taping of the birth and afterwards
- hand and foot moulds
- blanket used to wrap baby
- clothes worn by baby
- Baptism clothes and service notes

Baptism/Blessing

Parents should be informed that this can be arranged with the hospital chaplain or a religious representative of their choice. In the event of stillbirth, parents should be informed that the service would be a 'Baptism of *Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Perinatal Mortality; Second Edition, Version 2.2, April 2009.* 63 *Section 3: Psychological and social aspects of perinatal bereavement*

Desire' as opposed to a traditional Baptism. Some families may choose to baptise or name their baby themselves, or have a relative or friend do this for them.

Where a baby is in the Intensive Care Nursery, parents should be given the option of a baptism prior to their baby's death. Parents may be reluctant to consider this option as they may feel that permitting a baptism is giving up hope that their baby might survive. It is important to inform the parents that a formal ceremony can take place at a later time.

3.2.7 Special circumstances

Multiple pregnancies

Parents of twins, triplets or quads 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 the deceased baby/ies, or for not devoting enough time to the surviving baby/ies because they are grieving;
- blame of self or others; and
- grief for deceased baby/ies while trying to bond with live baby/ies.

Parents may respond to the death of one or more of their babies by withdrawing from their surviving baby/ies through fear of them also dying. They may also feel torn between their surviving and deceased babies. It is important for additional support and information to be provided during this time. Parents may benefit from referral to support groups such as SANDS and SIDS and Kids for support and discussion with parents who have experienced similar losses.

Information should be provided to allow parents to make decisions such as:

- funeral arrangements delaying funeral until the surviving baby/ies condition/s is/are determined; and
- possible benefits of autopsy for the surviving child/ren.

Maternal illness

Provisions should be made in the event that the mother is unwell following the birth (e.g. septicemia, admission to Intensive Care Unit, located in another hospital). Where possible, efforts should be made to provide an opportunity for access to baby during and/or after maternal recovery.

In the event of perinatal death, the baby should remain in the hospital (if possible) until the mother recovers. If the mother's illness is expected to exceed the time that the baby is able to be kept at the hospital, staff should recommend to fathers/family members the importance of creating as many memories as possible. Staff may discuss with the father or relevant family member the option of embalming the baby if it is expected that the maternal illness will be for a considerable time. This provides the mother with the opportunity to spend time with the baby following her recovery. Taking photos or video taping the baby with family members may be beneficial to the mother.

If the baby is going to be kept for some time, care needs to be taken with the placement of the baby so that unnecessary deterioration does not occur.

Mothers who have experienced prenatal illness or disease may feel intense guilt following the death of their baby. This may be a perception only as the baby may not have died as a result of maternal factors. This issue may need to be addressed by the staff member/s caring for the mother and detailed explanation given regarding the cause of death.

Previous perinatal/child death

Parental response to the death of their baby may be intensified by a previous perinatal or child death. Parents may experience a reliving of the previous death, which may significantly impede on their ability to effectively cope with the subsequent death. Other parents may have clear ideas regarding the way in which they chose to manage the death of their baby due to their experience. This may include the creation of memories and the way in which they chose to parent their baby. It is important for the practitioner to provide appropriate support and information and to be guided by the response of the parent.

3.2.8 Aftercare

Maternal changes

Many mothers are not aware that their milk will still come in. Mothers should be informed of this. This experience alone can be both physically and emotionally painful. The option of a consultation with a lactation

consultant should be offered to discuss ways to manage and decrease milk production. Mothers also need to know about other post-pregnancy changes such as bleeding. They need to be informed that an early check up with their General Practitioner (GP) or obstetrician is required at 6 weeks post birth and suggestions regarding timing of the appointment should be discussed (e.g. Other pregnant women in waiting room – suggest making last appointment for the day). When the appointment is made, suggest that the receptionist be told about the death of the baby so an appropriate appointment can be made.

Support services for parents and children

Written information provided regarding support services available for parents and children can be found on the PSANZ website: <u>www.psanz.org.au</u>, under Perinatal Mortality Group.

While high quality research on the effects of support interventions which aim to provide psychological support or counselling for mothers, fathers or families is lacking ⁽²⁷⁾, from the currently available research and from understanding and experience in grief and loss be the developers of this guideline, the following information and advice is provided to assist clinicians in providing appropriate care for parents after a perinatal death.

Grief

Bereaved mothers have been found to experience more intense grief reactions and depression than do bereaved spouses, siblings or adult children⁽²⁰⁾. Parental grief is often protracted and intense^(9, 10, 21, 22). What is normal in parental bereavement often would seem exaggerated or abnormal in other types of bereavement⁽²²⁾.

Bereaved parents respond to grief in a number of ways. Denying the importance of their loss leaves bereaved parents vulnerable to delayed or complicated grief reactions^(22, 23). For many, the death of their baby is their first experience with the loss of a loved one. It may be useful to inform parents that their grief is a normal response to death.

Numerous studies have found that gender differences exist in the grieving styles of mothers and fathers following the death of an infant^(3, 6, 9, 10, 21, 23-25). Common trends in grief behaviours of women include:

- more likely than fathers to cry with others
- more likely to openly seek support both within and outside of the home
- a desire to speak tirelessly about the baby
- a constant preoccupation with their loss

Common trends in grief behaviours of men include:

- a preference to seek solitude
- reports of grief being a private concern
- disappointment in questions relating to their loss generally focussing upon how the mother is coping
- avoiding discussing the baby in social or work environments

Parent's long term adjustment may improve if given expectations of the grief journey and the different responses that may arise for mothers, fathers and children^(11, 25).

Medical care is generally centred on the mother in the time surrounding perinatal loss. This may apply also to emotional care. A father's grief is often overlooked during this time. It may be important for the bereaved father's long-term adjustment that his grief is also acknowledged⁽²³⁾.

Follow up

A follow-up appointment with the senior obstetrician and/or Neonatologist is required within two months of the baby's death⁽¹⁵⁾. This appointment should be made in rooms away from the hospital where possible, or the first or last appointment for the day should be offered, so that the parents can avoid coming into contact with newborn babies or pregnant women. During this appointment it can be helpful for parents to talk over their experience with the doctor. They may find it valuable to prepare questions in advance.

All efforts should be made to enquire after the parents' welfare and to explain the circumstances surrounding their baby's death. Autopsy results (if available) are given. If autopsy results are not yet available, an anticipated date that they will be available should be provided as well as information regarding how the family will be informed. Implications for future pregnancies, if known, should be discussed.

Where possible and if culturally appropriate, use baby's name. Do not use impersonal terms such as fetus when referring to the baby, and avoid unnecessary medical terminology, except where this is necessary to accurately describe the situation.

Appropriate referral

Referral to relevant health care professionals for different treatment options should be offered. For example, genetic counsellor (if needed), obstetrician (to discuss future birth options), support groups such as SANDS (Stillbirth And Neonatal Death Support Group), SIDS and Kids, and SAFDA (Support After Fetal Diagnosis of Abnormality), social worker, pastoral care worker.

To date, no evidence from randomised control trials exists to suggest greater advantages of specialised psychological support or counselling over sensitive routine perinatal care following perinatal loss^(26,27). It may therefore be necessary to offer the parents an external referral to an appropriate treating professional, e.g. psychiatrist, psychologist, bereavement counsellor, if the practitioner is of the opinion that this intervention is required.

3.2.9 Funeral arrangements

Parents should be informed of their options in relation to funeral arrangements. It is a legislative requirement to arrange a funeral for a baby whose gestation is 20 weeks or greater. Parents should be informed of this, as they may not be aware of this requirement.

It is useful to provide the parents with written information regarding funeral directors and to include several options. Funeral companies vary widely in the range of services they provide. Some funeral homes offer free or reduced funeral costs to families whose baby has been stillborn or died in the newborn period. There is also the availability of government funded funerals in some circumstances. Information regarding this and other benefits is available from Centrelink.

The funeral director should advise parents that they have access to their baby while their baby is in the funeral home. The options of bathing and dressing their baby, placing the baby in the coffin or spending time together before the funeral are also often available. It should be reinforced that there is no urgency for the funeral.

3.2.10 Health care professionals

Staff working with bereaved parents should be provided with an opportunity to develop their knowledge and understanding of perinatal loss, together with development of skills in working in this area^{(1),(9)}. Encouragement and support of medical and midwifery staff in their professional development, specifically with regard to bereavement care, is vital to ensure provision of skilled assistance to women and their partners under their care.

Imaging staff may also benefit from professional development in bereavement care. They are often the first practitioners to discover abnormalities that are incompatible with life or that a baby has died in utero. This training should focus on the role of non-verbal communication in perinatal loss. It is also important to recognise the importance of "being" with the bereaved family and providing gentle, quiet reassurance and support without the need to "do" or say a lot.

Sonographers and other imaging staff who provide services to pregnant women should develop policies and procedures for staff to follow in the event of a diagnosis of fetal abnormality, FDIU or pregnancy loss. These policies and procedures should focus on responsive care for all front of house staff and imaging staff caring for women who are shocked and distressed about the findings on their ultrasound scan. Policies and procedures should incorporate care for parents after the delivery of bad news, ensuring parents are not sent home in a state of shock.

Access to support

Staff working with bereaved parents should have access to support to avoid burnout. Check hospital policy regarding Employee Assistance Programs or provide access to appropriate professional (e.g. social worker, midwife experienced in perinatal loss and staff debriefing).

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EXPLAINING AUTOPSY

INFORMATION FOR PARENTS WHEN YOUR BABY HAS DIED

The death of a baby is devastating. It is a time when you may have to consider issues such as a postmortem examination for your baby. The following information is provided to assist parents in making a decision about a post-mortem examination.

What is an autopsy?

An autopsy examination is performed after death to find out as much as possible about why your baby died. The examination is performed by a pathologist, a medical practitioner who specialises in this field.

Why consent to an autopsy?

There are a number of reasons why you may decide to consent to an autopsy. These may depend on the age of your baby and the circumstances of his or her death. While it is difficult at such a time to think about future pregnancies, an autopsy may help in the management of a future pregnancy.

Autopsy may help to tell us:

- Cause of death or what to exclude as cause of death
- Gestational age
- Time of death
- Impact of genetic or physical problems
- Whether obstetric and/or paediatric care was appropriate
- Information important to the health of other children

Your doctor may suggest other reasons as to why you might consent to a post-mortem examination of your baby's body.

Where will the examination occur?

The autopsy will be performed at a centre specialising in perinatal autopsies. This may be within the hospital where your baby was born.

What happens during an autopsy?

There are several types of autopsy, all of which require your consent. The following provides a brief description of each examination:

1. Full autopsy – this allows the pathologist to look at possible external and internal anomalies, structural defects and organ growth. 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. The face, hands and limbs are never cut. Like all surgical procedures all incisions are stitched up and are normally not visible once your baby is dressed. Pathologists adhere to standards set by the

2. Limited autopsy – this is an examination that you have placed restrictions upon. For example, you may decide to have the abdominal organs examined only and not have incisions in the head or chest, as well as external, placental and x-ray examinations.

3. External examination only – you may decide to consent to 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.

4. Step-wise examination – in this examination, restrictions are placed and further investigation is conducted only if initial findings suggest that there may be irregularities elsewhere. For example, if you permit a step-wise examination of the abdomen due to a condition affecting this area and the pathologist finds clear indications that the condition has also affected the chest, the chest will then be examined.

The level of information obtained by a post-mortem examination depends upon how complete the examination is, and the actual cause of death. The greater the information, the better your doctor or caregiver may explain how your baby died and if this will affect future pregnancies or the health of your other children. However, even in a full autopsy the cause of death may not be able to be determined.

What happens to my baby's organs?

In most cases during an autopsy in which a baby's organs are examined, the organs are replaced intact following investigation. However, in some circumstances, it is considered necessary to take a small tissue sample to examine the cells and tissue under a microscope. This part of the examination is called a histological analysis and will be included in the autopsy report. The tissue sample is approximately one cubic centimetre, or the size of a small pea. If a problem is found with the tissue sample, a more detailed investigation may be required.

Some organs, such as the brain, are unable to be examined properly without 'fixation', which is a chemical treatment that increases the amount of information that can found. If you give permission for fixation, the organ may be retained for up to a week. This may affect funeral arrangements for your baby. In these circumstances you may either:

- a) delay cremation or burial until the examination is complete and your baby's body is completely restored.
- *b)* continue with funeral arrangements and have a separate burial or return of cremated organs at a later time.

All decisions are entirely up to you, although your doctor, pathologist or caregiver may be able to

assist, providing information and support through this difficult process.

What can I expect after the examination?

It is usually possible for you to see and hold your baby after an autopsy. Usual changes occur once a baby has died, such as a change in skin colour and body temperature, however there are also some changes due to the examination. The changes will depend on which procedures have been conducted. Where internal organs have been examined, you can expect to see the presence of stitches (or sutures), which are usually under the baby's clothing. You may also notice that the balance of your baby's head and body has changed. You may get more information about seeing and holding your baby following a autopsy from nursing staff, the hospital social worker, or your funeral director. They may also be able to describe your baby's appearance to you, or dress your baby to cover any sutured lines if you prefer.

When can I expect the results from the autopsy?

After any autopsy, the pathologist writes a report, which details all of his or her findings. This report is then sent to the doctor who cared for your baby.

Generally a preliminary report will be available within two to three weeks. Once all test results are known, a final report is forwarded to your doctor. This may take several months following a baby's death.

The information in the post-mortem report may assist your doctor in providing the cause of your baby's death, implications for future pregnancies or the health of existing children and assist in appropriate referral to relevant professionals, such as a Genetic Counsellor. Parents need to be aware that in some instances the autopsy results will not be able to explain the cause of your baby's death.

How do I know if I am making the right decision?

There is no right or wrong decision regarding consent to a autopsy of your baby's body. For many parents it is a very difficult and personal decision which takes into account many factors and considerations, including religious, cultural and personal beliefs.

Family and friends may offer their advice and opinions about autopsy, or be opposed to your decision. It is important to remember that, although their perspective is suitable for them, the decision is yours.

Do I need to make any decisions right now?

No. You may prefer to keep this brochure and discuss the options with your doctor or with the pathologist before making a decision. It may take time before you decide. Delaying an autopsy may result in less accurate information being obtained, however this may not be the case. Further information regarding timeframes can be obtained from your doctor or from the nursing staff.

Who can I contact for further information?

For further information and/or support in your decision, please contact:

- SANDS/SIDS & Kids (whichever is relevant for each state)
- Your General Practitioner or Obstetrician.

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 postmortem 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 autopsywith 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 www.psanz.org.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, SIDS and Kids information – whichever is relevant in each state.

*See PSANZ Perinatal Mortality Audit Guideline, Section 3 for list of references. More Brochures are available at www.psanz.org.au under Perinatal Mortality Special Interest Group.

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.



Section 4 of 7 - Perinatal post-mortem examination

4.1	Introduction	744
4.2	Recommendations and rationale	744
4.2.1	Autopsy rate	744
4.2.2	Placenta, membranes and cord histopathology	766
4.2.3	Quality and minimum standards	766
4.2.4	Post-mortem reporting	777
4.2.5	Communication and consent for post-mortem examination	788
4.2.6	Costs of a post-mortem examination and transport	799
4.3	Coroner's post-mortem	799
4.4	Alternative investigations where permission for autopsy is not obtained	799
4.4.1	External examination by a perinatal/paediatric pathologist, clinical geneticists or	
	paediatrician	799
4.4.2	Babygram	799
4.4.3	Ultrasound scan	
4.4.4	Magnetic Resonance Imaging (MRI)	
4.4.5	Clinical photographs	
4.4.6	Other alternatives to a full post-mortem	
4.5	References	

Appendices

Appendix 1	RCOP Guidelines for Autopsy Investigation of Fetal and Perinatal Death	85
Appendix 2	Suspected genetic metabolic disorders: Investigation and autopsy protocol	87
Appendix 2a	Screening for genetic metabolic disorders	88
Appendix 2b	Components of the genetic autopsy for investigation of metabolic disorders	89

SECTION 4 PERINATAL POST-MORTEM EXAMINATION

4.1 Introduction

The perinatal autopsy remains the gold standard in diagnostic evaluation of the causes of perinatal death^(1, 2). Information gained from an autopsy can assist in the understanding of events surrounding the death and in future pregnancy planning by enabling consideration of the recurrence risk and different management strategies. Despite this, perinatal autopsy rates have declined over the last decade to a concerning low level and the quality of many perinatal autopsies may be inadequate. The PSANZ perinatal Mortality Group in collaboration with the member organisations of the Australian and New Zealand Stillbirth Alliance are working closely to improve the standards for perinatal post-mortem examinations⁽³⁾⁽⁶⁸⁾.

The purpose of this section is to assist clinicians in improving standards for perinatal post-mortem investigation including communication with the parents. For further information regarding communication with parents, please also refer to Section 3 Psychological and social aspects of perinatal bereavement.

This section was 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:

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4.2 Recommendations and rationale

4.2.1 Autopsy rate

Clinicians should discuss the value of an autopsy with the parents in all cases of a perinatal death and offer the option of the procedure.

To increase the rates of perinatal autopsy:

- clinicians should collaborate with pathologists and parent groups such as Stillbirth and Neonatal Death Support (SANDS) and SIDS and Kids to raise public awareness of the value of perinatal autopsy and to advocate for high standards in perinatal autopsy at the local and government level.
- clinical leaders should promote formal and informal educational opportunities for clinicians on: postmortem 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.

(i) Purpose of a perinatal autopsy

The purpose of an autopsy examination extends beyond diagnosis of the cause of death, and the clinician needs to address these purposes with parents at the time of the discussion and approach for consent⁽⁴⁻⁹⁾.

The main purposes of an autopsy are:

- identification of an accurate cause of death^(4, 5, 7, 9);
- exclude some causes of death⁽¹⁰⁾;
- identification of disorders with implications for counselling and monitoring for future pregnancies⁽¹⁰⁻¹⁶⁾;
- to assist in the grieving process by enhancing the parents understanding of the events surrounding the death^(2, 11, 16, 17);
- for research purposes e.g. recognition of new disease entities and expansion of the body of knowledge on known diseases^(14, 15, 18-23);
- to inform clinical audit of perinatal deaths including deaths due to iatrogenic conditions⁽²¹⁾ and confirmation of antenatally diagnosed or suspected fetal pathology^(22, 23);
- teaching of pathologists and medical students^(10, 11, 24); and
- medicolegal reasons for example in a coronial investigation or providing information in cases of litigation^(10, 16).

(ii) Value of an autopsy

The autopsy examination remains the gold standard for identification of the cause of perinatal death^(1, 2). An accurate cause of death assists in the parents grieving process by providing an explanation for the death and other information on the circumstances surrounding the death which may alleviate feelings of guilt^(2, 8, 9, 11, 16). The quality of research and audit activities and subsequent public health policy based on findings may be compromised due to inaccuracies in causes of death data without an autopsy⁽²⁵⁻²⁸⁾.

Several studies have demonstrated the value of a perinatal autopsy in providing information resulting in a change of diagnosis or important additional findings^(17, 22, 29-34). A review of 27 studies found that perinatal autopsy revealed a change in diagnosis or additional findings in 22% to 76% of cases⁽²⁹⁾. 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 that some decrease in error rate had occurred over time however the rate remained sufficiently high, that encouraging ongoing use of the autopsy appeared warranted⁽³⁵⁾. The value of adequate numbers of perinatal autopsies in ensuring standards in perinatal pathology has also been suggested⁽³⁶⁾.

(iii) Declining rates of autopsy

An optimal rate of 75% for perinatal autopsy examination has been recommended by the Working Party of the Royal College of Pathologists⁽⁵⁾. However, the perinatal autopsy rate has steadily declined over recent years to rates much lower than this recommendation in many regions. A 2.8% per year decline over the last decade (1990-1999) was reported by one tertiary setting in the United Kingdom⁽¹⁷⁾. Reports of current perinatal autopsy rates range from 33% to 67%^(17, 37, 38). An analysis of perinatal deaths from three states in Australia showed variation in overall perinatal autopsy rates (39%, 48% and 70%) and, for unexplained antepartum deaths, 96% compared with 59% and 62%⁽³⁹⁾.

(iv) Why the decline?

Consent is the major limiting factor in achieving adequate autopsy rates^(16, 40). Consent for autopsy is difficult for clinicians and parents. Parents are confronted by a process that appears intrusive, and are required to understand detailed consent procedures while in a state of grief⁽¹⁰⁾ and clinicians are reluctant to place further burden on the parents^{(41).}

The adverse publicity generated from the inquiries into autopsy practices in the United Kingdom over retained organs^(18, 42, 43) and the enquiry at the NSW Institute of Forensic Pathology⁽⁴⁴⁾ are thought to have made a major impact on clinicians willingness to seek consent and parents acceptance of the procedure^(45, 46). Although improvements in practices have resulted from the enquiry, increased complexity in the consent process which followed may be a deterrent to

clinicians⁽⁸⁾. Clinician reluctance to seek consent due to the burden placed on the family may be misplaced as a recent survey of parents indicated that over 80% would agree to a post-mortem examination⁽⁴⁶⁾. The low autopsy rate may also indicate that clinicians are ambivalent about the value of an autopsy^(10, 47).

Other factors which may affect a clinician's willingness to approach parents for consent include lower gestation at death^(17, 48), and discipline and seniority of clinicians^(16, 48). Khong et al reported, in a recent survey, that while obstetricians and Neonatologist were not averse to seeking consent for perinatal autopsies, midwives and neonatal nurses were influenced by factors which may negatively impact on the consent rate⁽¹⁶⁾. In this survey, obstetricians and Neonatologist rated nurses and midwives as influential in parents decision about consenting to an autopsy⁽¹⁶⁾.

Provision of educational opportunities for clinicians, 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. Workforce shortages is also a limiting factor in adequate autopsy rates ⁽⁸⁾.

4.2.2 Placenta, membranes and cord histopathology

Following a stillbirth, neonatal death in the delivery room or birth of a high risk infant, the placenta should be sent for examination by the perinatal/paediatric pathologist regardless of whether consent for an autopsy has been gained.

The placenta is an integral part of the post-mortem examination and, ideally, all placentas should be retained for a few days after birth to allow subsequent retrieval should an infant deteriorate, such as may happen with sepsis, or a metabolic disorder⁽¹⁰⁾. 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 examination⁽⁴⁹⁾. A recent series of publications in Seminars of Neonatology has highlighted the importance of placental histopathology in identifying causal and associated factors in neonatal morbidity and mortality including: congenital abnormality; 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^(13, 14, 45, 50).

Placental examination by a perinatal/paediatric pathologist should be performed for all high risk neonates including the following:

- infants admitted to neonatal intensive care
- infants failing to respond to resuscitation;
- spontaneous preterm labour and birth
- planned delivery for fetal compromise including growth restriction
- severe cardiorespiratory depression at birth including resuscitated stillborn babies
- signs consistent with congenital infection
- severe growth restriction;
- hydropic infants
- suspected severe anaemia
- suspected or known major congenital abnormalities
- other circumstances where a liveborn infant dies shortly after birth in the delivery room.

4.2.3 Quality and minimum standards

- The Guidelines on Autopsy Practice produced by the Royal College of Pathologists⁽⁵⁾ should be used for guidance on minimum standards until guidelines for Australia and New Zealand are developed.
- Specific protocols developed for post-mortem examination in the circumstance of Sudden Unexpected Deaths in Infancy and death with suspected genetic metabolic disorders should be followed.
- A perinatal/paediatric pathologist should perform or supervise all perinatal post-mortems. Clinicians should request autopsies from the service providing the highest quality.
- 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.

- A comprehensive maternal history should accompany the baby for a post-mortem examination including:
 - o clinical/obstetric history including relevant previous obstetric history;
 - copy of the death certificate;
 - o copies of all antenatal ultrasound reports; and
 - o copy of amniocentesis report if available.

There is limited research on the quality of perinatal autopsies however, the available data suggests that approximately half may not reach minimum standards^(47, 51). The ethics of approaching parents for consent where a quality post-mortem service is not available has been questioned⁽¹⁾.

The post-mortem examination of an infant is very different to that performed on an adult^(5, 52-54), and ideally should be performed by a paediatric pathologist. Pathologists with paediatric training find a higher incidence of causes of death in infants⁽⁵⁵⁾, provide a much higher proportion of adequate reports^(56, 57), and the causes of death based on perinatal/paediatric pathologists reports are infrequently revised by the CESDI review panel⁽⁵⁸⁾. There are currently no guidelines for ANZ on guality and minimum standards for perinatal autopsies. The Royal College of Pathologists Australasia⁽⁸⁾ and SIDS and Kids⁽³⁾ have expressed an intention to support their development. Until the availability of such guidelines, the Guidelines on Autopsy Practice produced by the Royal College of Pathologists should be used for guidance⁽⁴⁾.

Specific autopsy protocols for examination for suspected genetic metabolic disorders⁽⁵⁹⁾ (*Please see Section 4; Appendix 2 Suspected genetic metabolic disorders: Investigation and autopsy protocol for details on peri-mortem investigations and autopsy for suspected genetic metabolic disease investigations*) and in the circumstance of a Sudden Unexpected Deaths in Infancy⁽⁶⁰⁾ have been developed. Please refer to these protocols for full details.

(Please see:

- Section 4; Appendix 1 RCOP Guidelines for Autopsy Investigation of Fetal and Perinatal Death
- Section 4; Appendix 2 Suspected genetic metabolic disorders: Investigation and autopsy protocol for details on peri-mortem investigations and autopsy for suspected genetic metabolic disease investigations
- Section 2; Appendix 3 Autopsy clinical summary form.)

4.2.4 Post-mortem reporting

- Guidelines for post-mortem reports produced by the Royal College of Pathologists⁽⁴⁾ should be used as a guide for reporting of perinatal post-mortem examinations.
- Ideally, a preliminary post-mortem report should be forwarded to the referring clinician within 3 working days of the post-mortem. The final report should be forwarded to the referring clinician within 8 weeks of the post-mortem.
- 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.
- A Plain Language Report (PLR) should be available to parents on request.
- 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.

A preliminary report is usually available within 2 days of the examination, and should include a summary of the clinical history, samples taken, and macroscopic findings. The final report may take up to six weeks with more complex genetic or metabolic workups taking up to 6 -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 imposed⁽¹⁰⁾. A PLR may be helpful to parents⁽⁸⁾. A copy of the PLR, if available, and full autopsy report should also be sent to the GP.

4.2.5 Communication and consent for post-mortem examination

Where possible, a senior clinician who has established a rapport and understanding with the parents should discuss the value of a post-mortem examination and offer the option of the procedure. The clinician should have a high level of communication skills and knowledge of the post-mortem examination, preferably having witnessed several perinatal post-mortem examinations.

The clinician approaching for autopsy consent should discuss the options for a full, limited or stepwise post-mortem examination; the issue of retained tissues; the value of the autopsy and the possibility that the information gained may not benefit them but may be of benefit to others. Parents should be given written information explaining the post-mortem examination.

When consent has been obtained for specific organ/s to be retained for further examination, the parents should be offered the choice of either delaying the funeral until the organs can be returned to the body or specifying their preferred method of organ disposal.

Consent for the autopsy which clearly outlines the extent of the investigation should be recorded on an approved consent form, relevant to the jurisdiction.

The pathologist should be available to discuss the autopsy with the parents before and/or after the procedure and, where possible, the requesting clinician should attend the autopsy and provide the parents with a preliminary report immediately after the examination.

All hospital perinatal autopsy examinations require written consent from the parent following informed discussion⁽⁴¹⁾. The extent of the examination including retention of organs needs to be clearly explained and documented in the consent form. Options for a full, limited or stepwise autopsy should be explained. 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 which may provide valuable information⁽⁶¹⁾.

Parents want to know why their baby has died and consent to an autopsy to find out the reasons. Therefore, parents may be very disappointed and regret their decision about autopsy when a cause of death is not found⁽³⁾. Informed discussion with the parents should include the possibility that a cause of death may not be found, however that the information obtained may benefit other babies in the future. Clinicians need to be aware of religious beliefs which may be an influencing factor in a parent's decision^(8, 11).

(i) Who should seek consent?

Seeking of parental consent is best done by an experienced clinician who has a rapport and understanding with the parents. While the responsibility for informed consent lies with the primary attending physician^(1, 10) and in most cases the consultant clinician will approach the parents, this may be delegated to another attending clinician (e.g. midwife, nurse)⁽⁶²⁾. Clinicians seeking consent should be prepared to answer questions about what actually happens to the baby during the procedure and how the baby will look after the examination⁽⁶²⁾. Therefore, all clinicians seeking consent should have an in-depth understanding of post-mortem procedures and preferably have witnessed several autopsy examinations. Discussion with parents about consent for post-mortem examination needs to take into account the importance of partnerships in decision making⁽⁶³⁾.

(Please refer to Section 3 Psychological and social aspects of perinatal bereavement for further discussion and information sheets for parents and professionals)

4.2.6 Costs of a post-mortem examination and transport

Clinicians need to be aware of costs associated with transfer of an infant from non-metropolitan areas to the tertiary centre for post-mortem within their region and to inform parents of any personal cost implications.

Diverse arrangements exist across Australia regarding payment for autopsy⁽⁸⁾. The SIDS Focussing On Stillbirth initiative (SOS)⁽³⁾ costed the perinatal autopsy at \$2,608.25. Currently the post-mortem examination of a stillborn infant is not covered under Medicare and consequently the costs for the post-mortem examination need to be covered either by the institution, requesting clinician or billed to the family.

4.3 Coroner's post-mortem

The purpose of the coroner's post-mortem is to determine the cause of death, and specifically whether it is natural or unnatural. Examples of cases which should be referred to the coroner are:

- babies dead on arrival at hospital, or within 24 hours of admission;
- unattended stillbirth;
- deaths within 24 hours of 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 not;
- 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; and
- unexpected death on the ward⁽¹⁰⁾.

If there is any doubt, discussion with an experienced coronial officer or with the coroner is advised. Coroners should ideally arrange for paediatric pathologists rather than general or forensic pathologists to perform the post-mortem⁴, and provide results to relevant clinicians.

4.4 Alternative investigations where permission for autopsy is not obtained

If permission for an autopsy is not obtained, other less invasive testing may assist in establishing whether any important abnormalities have been missed. These alternatives permit detailed investigation of the fetus or infant while still respecting the wishes of the parents⁽⁶⁴⁾. However, a Working Group of the Royal College of Paediatrics and Child Health found little evidence for valid alternatives to the paediatric post-mortem⁽⁵²⁾. 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.

4.4.1 External examination by a perinatal/paediatric pathologist, clinical geneticists or paediatrician

An examination by an experienced clinician is of particular importance where an autopsy examination is declined⁽⁶⁵⁾. Clinicians should discuss the importance of this examination with the parents and arrange for an appropriately skilled clinican to undertake the examination.

4.4.2 Babygram

Parents who decline an autopsy should be asked for consent to undertake a full body X-ray (Babygram). 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 stillborns will have abnormalities which are detectable on X-Ray⁽⁶⁵⁾.

4.4.3 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 which may not be identified by an external examination⁽⁶⁶⁾.

4.4.4 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 supply tissue samples and therefore important information may be missed.

A recent comprehensive overview presented the advantages and disadvantages of the post-mortem MRI⁽²⁾. 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 declined.

4.4.5 Clinical photographs

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. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality should be considered.

4.4.6 Other alternatives to a full post-mortem

Post-mortem needle biopsy; laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected abnomalities.

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Section 4; Appendix 1 RCOP Guidelines for Autopsy Investigation of Fetal and Perinatal Death⁽⁶⁷⁾

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
- Foot length
- Apparent gestation
- Maceration (if baby is born dead)
- Meconium staining
- Full description to include, 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.

- Dimensions
- Trimmed weight
- Umbilical cord (length, vessels, abnormalities)
- Membranes (complete, incomplete, colour, abnormalities)
- Fetal, maternal and cut surfaces.

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. Special procedures and investigations

- X-ray mandatory 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
- Karyotype, 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.

6. 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
- Attendance of clinician
- 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 incorporated into a final report when available
- Timely dispatch to clinicians with particular reference to the timing of postnatal appointments.

Section 4; Appendix 2 Suspected genetic metabolic disorders: Investigation and autopsy protocol

Recommendations

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.

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.

All tissue samples should be stored and transported to a Specialist Metabolic Laboratory for investigation as convenient.

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

- Prior to death:
 - Seek consent from the parents for a metabolic autopsy;
 - o 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 futher details of collection.
- Immediately following the death:
 - Obtain blood sample by cardiac puncture if blood sample not already taken and only if parental consent has been obtained.
 - 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.
 - 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⁽⁵⁹⁾ 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 malformations⁽⁵⁹⁾.

Section 4; Appendix 2 a Screening for genetic metabolic disorders

Extract from: Christodoulou J, Wilcken B. Perimortem laboratory investigation of genetic metabolic disorders. Seminars in Neonatology 2004;9(4):275-280⁽⁵⁹⁾.

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
- ß 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.

Section 4; Appendix 2 b 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⁽⁵⁹⁾.

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.



Section 5 of 7 - Investigation of Stillbirths

5.1	Introduction	91
5.2	Recommendations and rationale	92
5.2.2	Further investigations for Thrombophilia	96
5.3	Alternative investigations where permission for autopsy is not obtained	97
5.3.1	External examination by a perinatal/paediatric pathologist, clinical geneticists or paediatrician	97
5.3.2	Babygram	98
5.3.3	Ultrasound scan	98
5.3.4	Magnetic Resonance Imaging (MRI)	98
5.3.5	Instructions for taking clinical photographs	98
5.3.6	Other alternatives to a full post-mortem	98
5.4	Storage of plasma and amniotic fluid	98
5.5	References	

Appendices

Appendix 1	Stillbirth investigations algorithm	102
Appendix 2	Estimation of severity of feto-maternal haemorrhage	103

SECTION 5 INVESTIGATION OF STILLBIRTHS

5.1 Introduction

This section recommends investigations to be undertaken for stillbirths. The investigations are presented according to those which should be considered routine for all stillbirths (Core investigations) and those which may be required depending on results of Core investigations and in particular clinical conditions (Further investigations). The Core investigations are grouped by the timing of the investigation in relation to the death, i.e. at the time of confirmation of an intrauterine fetal death (IUFD) and following the birth. The guideline includes checklists and data collection forms included in the appendices in Section 2 Institutional Perinatal Mortality Audit to assist clinicians in undertaking uniform investigation and reporting of stillbirths.

There will be situations where the cause of fetal death has already been clearly established (e.g. when karyotyping has already been undertaken in the pregnancy) or previous investigation clearly negates the need for certain tests e.g. no requirement to include HbA1C in patients with normal GCT 2 weeks earlier. However, as using a selective investigative approach may result in missed important diagnoses ⁽¹⁾, clinicians should use the non-selective approach as the standard (i.e. Core investigations for all stillbirths) and debate the relative merits of not following this approach on an individual case basis. Depending on particular circumstances of the death (e.g. family wishes and access to services) it may not be possible for some investigations to be carried out.

The recommendations have been developed to provide a comprehensive approach to the investigation of stillbirths with the aim of providing better information to assist in discussion with the parents and in the planning of future pregnancies, and to contribute to the body of knowledge in the understanding of factors associated with stillbirth which may help in reducing future pregnancy loss. It is hoped that, with the support of clinicians across Australia and New Zealand (ANZ) with implementation of these recommendations, a high quality comprehensive data set will be available to enhance the value of surveillance and research activities aimed at reducing the risk of stillbirth. Inevitably, given the lack of high quality studies, some contentious issues remain. The Working Party welcomes comments which will assist with further refinement of the recommendations for stillbirth investigation.

A subgroup of the Working Party (Glenn Gardener, Lesley McCowan, James King, Jane Zucculo, Katie Day (nee Waters) Gus Dekker, and Vicki Flenady) drew on existing national and international protocols for stillbirth investigation and the findings of a comprehensive literature search in the development of this section of the guideline.

The main 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. NSW Health Department. Hospital Procedures for review and reporting of perinatal deaths. Electronic source http://www.health.nsw.gov.au/fcsd/rmc/cib/circulars/2002/cir2002-6.pdf; 2002 January.
- 3. 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.
- 4. Wisconsin Stillbirth Service Program UoW. Guide to etiologic evaluation of the stillborn infant: The WiSSP Protocol. In. Wisconsin: Wisconsin Stillbirth Service Program.
- 5. British Columbia Reproductive Care Program. Perinatal Mortality Guideline 5: Investigation and Assessment of Stillbirths. British Columbia; 1999.

5.2 Recommendations and rationale

A post-mortem examination, including examination of the placenta, by a perinatal/paediatric pathologist should be offered to all parents following stillbirth.

Following a stillbirth, the placenta, membranes and cord should be sent to the perinatal pathologist fresh and unfixed for macroscopic and histological examination regardless of whether consent for autopsy has been gained.

(Please refer to Section 4 Perinatal post-mortem examination for further details, including rationale, on autopsy and placental pathology.)

A non-selective approach according to a list of recommended Core Investigations should be adopted for all stillbirths. This non-selective approach is defined as investigations which should be undertaken as the standard approach for all stillbirths, debating the relative merits of not following this approach on an individual case basis.

Further investigations should be undertaken according to the particular clinical problem (See Item 5.2.2).

(Please see Section 5; Appendix 1 Stillbirth investigations algorithm.)

5.2.1 Core Investigations for all stillbirths

(i) At diagnosis of a fetal death

- Comprehensive maternal and family history;
- Ultrasound scan to detect possible fetal abnormalities and to assess amniotic fluid volume;
- Amniocentesis (where available) for cytogenetic and infection investigation;
- Low vaginal and peri-anal swab to culture for anaerobic and aerobic organisms;
- Blood tests:
 - Full Blood Examination;
 - Serology for Cytomegalovirus, Toxoplasma, Parvovirus B19;
 - Rubella and Syphilis if not already undertaken in this pregnancy;
 - Blood group and antibody screen if not already undertaken in this pregnancy;
 - Kleihauer-Betke test;
 - Renal Function Tests including Uric Acid;
 - Liver Function Tests and Bile Acid;
 - Thyroid Function Tests
 - HbA1c
 - Anticardiolipin antibodies;
 - Lupus anticoagulant; and
 - Activated protein C (APC) resistance.

Ultrasound scan

At the time of ultrasound confirmation of an IUFD, the ultrasound should include examination for possible fetal abnormalities, fetal biometry and assessment of amniotic fluid volume.

This assessment may be helpful in identifying a cause for the death particularly where an autopsy examination is not performed.

Maternal history

A comprehensive maternal medical and social history should be taken following all perinatal deaths.

(Please refer to Section 2 Institutional Perinatal Mortality Audit, Appendix 1 Perinatal Mortality Audit Package, 1.5 Perinatal mortality confidential case summary for a maternal history proforma.)

Amniocentesis for cytogenetic and infection investigation

Where possible, an amniocentesis should be performed for cytogenetic and infection investigation following diagnosis of an IUFD. It is estimated that 6.9%–20% of stillbirths have a fetal chromosomal abnormality, including a wide range of lethal conditions⁽¹⁻³⁾. Caution should be exercised in utilising a selective approach for cytogenetic assessment as important diagnoses may be missed^(1, 4). Tissue samples of the amnion as well as placental villi may maximise the

likelihood of a result if the fetus is macerated (personal communication with Mark Pertile; Head Scientist, Murdoch Institute, Prenatal Diagnosis, Laboratory)⁽⁵⁾.

The rate of successful chromosome analysis using amniocentesis in cases of fetal death ranges from 82%-92%^(2, 4). In contrast, the success rate for placental chromosome analysis is approximately 60% and approximately 30% for skin⁽²⁾. The total time elapsed from fetal death until biopsies can be processed is often long, and the chances of succeeding with a chromosomal analysis diminishes progressively with time⁽²⁾. The Wisconsin Stillbirth Protocol Program (WiSSP) ⁽⁶⁾ study series indicates that the success of karyotyping ranges from 80% in stillbirths without maceration to 30% in stillbirths with mild to advanced maceration⁽⁶⁾. Amniocentesis reduces the elapsed time between fetal death and sample collection, and the samples are easier to handle and for the laboratory to process⁽⁷⁾.

Amniotic fluid collected by amniocentesis prior to the onset of labour can provide an uncontaminated specimen for microbiological assessment. It is the only sample where the detection of pathogens such as E-coli will be of value, especially if no autopsy is performed. This is due to potential contamination during vaginal birth where findings from cultures of natural orifices and the placenta/membranes are often discredited⁽⁷⁾.

Vaginal cultures: Low vaginal peri-anal culture for anaerobic and aerobic organisms.

McDonald et al identified that although 70% of women with mid-gestation spontaneous abortions were asymptomatic for infection, micro-organisms were identified from the placenta and/or fetus in 62% of women studied and histological chorioamnionitis was present in 69%. Among 51 women with intact membranes, 28 were culture-positive, with the most frequent isolate being Group B Streptococcus (GBS). In this study, GBS was the most significant pathogen associated with the fetal deaths, and was often the sole pathogen recovered⁽⁸⁾. The detection of GBS is optimised with the use of a peri-anal swab in conjunction with a low vaginal swab and the use of specific culture media⁽⁹⁾.

Method for GBS culture: Using one single dry swab stick, first take a culture from the introitus and with the same swab stick, take a culture from the anorectal region. Place the swab in Stuarts transport medium and send to laboratory clearly labelled. Swabs may be self collected by the patient⁽¹⁰⁾.

Full blood examination

A full blood examination can assist in detection of: infection as a cause of the fetal death⁽¹¹⁾; maternal anaemia which may indicate conditions such as thalassemia; low platelet levels - a marker for pre-eclampsia; autoimmune diseases such as systemic lupus erythematosus (SLE) and Idiopathic Thrombocytopenia Purpura (ITP)⁽¹²⁾; and elevated platelet levels may indicate thrombocythemia.

Serology for Cytomegalovirus, Toxoplasma, Parvovirus B19, Rubella and Syphilis

Serology for Cytomegalovirus, Toxoplasma and Parvovirus B19 should be undertaken following an IUFD. Rubella and Syphilis should also be included if they have not already been undertaken during the antenatal period. Where test results are positive, a microbiologist or infectious disease specialist should be consulted regarding further testing and treatment required.

Toxoplasmosis

Maternal-fetal transmission of Toxoplasmosis is dependent on the time of maternal infection. The earlier the fetus acquires the infection the more severe the consequences, however maternal-fetal transmission is more likely to occur later in pregnancy. Disseminated Toxoplasma may cause fetal death⁽¹³⁾.

Parvovirus (B19)

Parvovirus (B19) causes severe fetal anaemia, nonimmune hydrops and fetal death^(13, 14). It was found to be the cause of death in 10% of all non-malformed fetal deaths occurring between 10 and 24 weeks of gestation referred for pathological examination⁽¹⁵⁾. 1%-3% of susceptible pregnant women will develop serologic evidence of infection in pregnancy, of which the transmission rate to the fetus is 17%-33%⁽¹⁶⁻¹⁸⁾. The spontaneous loss rate of fetuses affected by Parvovirus B19 after 20 weeks gestation is 2.3%^(16, 18-20).

Rubella

Rubella is associated with a wide variety of fetal abnormalities and also infects the placenta, enhancing the risk of stillbirth^(21, 22). However due to widespread vaccination, congenital rubella infection in developed countries is extremely rare⁽¹³⁾.

Cytomegalovirus (CMV)

Whether CMV actually causes stillbirth and, if so, the mechanism by which it does so is not clear⁽¹³⁾. However, a prospective study of more than 10,000 women found an increase in fetal loss associated with infection in early pregnancy⁽²³⁾.

Blood group and antibody screen

A blood group and antibody screen should be performed to exclude haemolytic disease due to maternal sensitisation to red cell antigens, for example Rh D and Kell⁽²⁴⁾.

Kleihauer-Betke test

A Kleihauer-Betke test to detect feto-maternal haemorrhage should be performed following the diagnosis of an intrauterine fetal death (IUFD) preferably prior to delivery^(25, 26). Limited evidence suggests that post delivery Kleihauer may still be useful⁽²⁷⁾.

The incidence of massive feto-maternal haemorrhage is $<0.1\%^{(28)}$. However the incidence in otherwise unexplained cases of fetal death has been estimated to be as high as $14\%^{(29)}$. The diagnosis of a significant feto-maternal haemorrhage is confirmed by quantification of fetal erythrocytes in maternal blood performed by the Kleihauer test. The general consensus is that 50ml constitutes a significant haemorrhage, with various studies using limits ranging from 30-150ml^(29, 30). However, as the impact of a haemorrhage of a given volume will be dependent on the fetal age, weight and total blood volume, individual assessments need to be calculated^(7, 31).

The time period over which the haemorrhage occurs will have a direct impact upon the mortality associated with it, according to whether the fetus was able to compensate for the loss in blood volume. However, as it is not currently possible to assess this, a loss of 20% of total fetal blood volume should be considered severe enough to cause fetal mortality⁽⁶⁾.

(Please refer to Section 5; Appendix 2 Estimation of severity of feto-maternal haemorrhage for the calculation of significant haemorrhage.)

Renal Function Tests including Uric Acid

Elevated uric acid levels early in the third trimester in pre-eclamptic women have been associated with perinatal death and it is therefore recommended to evaluate the contribution of pre-eclampsia to the death. Abnormal renal function is an indicator of possible SLE⁽³²⁾ which is associated with a significant increase in fetal morbidity and mortality⁽³³⁾. Uric acid is the most sensitive laboratory indicator of pre-eclampsia⁽³⁴⁾ and is a better predictor of perinatal outcome than blood pressure⁽³⁵⁾.

Liver Function Tests and Bile acid

Mild liver test abnormalities are a possible marker for obstetric cholestasis. Obstetric cholestasis is associated with a significant increase in the perinatal mortality rate, ranging from 3%-20% as well as a five-fold increased incidence intrapartum fetal distress and pre-term labour^(36, 37). Abnormalities in liver function are also a marker for viral hepatitis, cytomegalovirus, and toxoplasmosis. Abnormal liver function has also been associated with acute fatty liver of pregnancy and HELLP syndrome (Haemolysis, Elevated Liver function, Low Platelets)⁽³⁸⁾.

Thyroid Function Test

Pregnancy is associated with physiological changes in the thyroid function which may result in thyroid disorders. Thyroid disorders during pregnancy have been associated with adverse health outcomes for both the mother and child, including increased risk of miscarriage, gestational hypertension, low birth weight and fetal death.⁽³⁹⁾

HbA_{1c}

The increased risk of fetal morbidity and mortality with maternal diabetes is well known. A stillbirth rate of 35 per 1000 births to type 2 diabetic mothers has been reported⁽⁴⁰⁾. Gestational diabetes mellitus (GdM) is defined as carbohydrate intolerance of variable severity with the onset or first recognition during pregnancy. There is some evidence to indicate that uncontrolled GDM is associated with increased perinatal mortality⁽⁴¹⁾. *HbA_{1c}* monitors glycaemia over the previous 3

months by reflecting the average glucose concentration over the life of the red cells⁽⁴²⁾ and therefore may provide information to aid in the consideration of the contribution of diabetes to the fetal death. 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. Please refer to the Australasian Diabetes in Pregnancy Society GDM management guidelines for further details^(41, 43).

Investigation for Thrombophilia

Anticardiolipin antibodies, Lupus anticoagulant and APC resistance are recommended for all women at the time of IUFD. (*Please see Item 5.2.2 (ii) Further Investigation for further details.*)

(ii) Following birth

- External examination of the baby (by a perinatal pathologist, Neonatologist or paediatrician where possible);
- Clinical photographs;
- Surface swabs (ear and throat) for microbiological cultures;
- Post-mortem examination;
- Blood samples from the cord or cardiac puncture for investigation of infection;
- Blood samples for chromosomal analysis;
- Routine Guthrie test
- Detailed macroscopic examination of the placenta and cord;
- Placental microbiological cultures;
- Placental and amnion biopsy for chromosomal analysis; and
- Placental histopathology

External examination of the baby

A detailed external examination of the baby should be performed by a perinatal pathologist, neonatologist or paediatrician where possible.

A comprehensive external examination of the baby is an essential component of the investigation of a stillbirth^(25, 44-52). A report on a large case series from the 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 missed⁽⁶⁾.

A detailed external examination of the baby is a component of a full post-mortem. As the perinatal pathologist is the most appropriate person to carry out the external examination, parents who have declined a full post-mortem should be asked to consent for the baby to be examined by a pathologist. In the circumstance where it is not possible for a pathologist to perform the examination, then a neonatologist or paediatrician should conduct the examination. If neither are available, a proforma (Section 2 Institutional Perinatal Mortality Audit, Appendix 1 Perinatal Mortality Audit Package) is provided to assist the midwife/doctor in carrying out the procedure.

Clinical photographs

Clinical photographs should accompany the detailed external examination of the stillborn.

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 stillborns have observable abnormalities identifiable on photographs and photographs were critical in establishing a diagnosis in approximately 5% of cases⁽⁶⁾. Consent from the parents for clinical photographs should be clearly documented in the medical record.

(Please refer to Section 2 Institutional Perinatal Mortality Audit, Appendix 2 Instructions for taking clinical photographs.)

Infant surface swabs for microbiological cultures

Surface swabs for microbiological cultures should be taken from the ear and throat of all stillbirths.

Intrauterine infections have been reported to represent the cause of death in 15%-24% of cases of stillbirths when premature rupture of membranes are included. Infection may be subclinical in the mother, hence the importance of investigating all incidences of fetal death where a cause is not obvious. Swabs should be taken from the ear and throat of the stillborn and sent for aerobic and anaerobic bacterial culture.

Infant blood samples for investigation of infection, chromosomal analysis and Guthrie test screening

A blood sample should be collected from the infant for investigation of the presence of infection, to assess other haematological parameters for karyotyping (if not already performed) and a routine Guthrie test.

A cord blood sample should be collected after delivery where possible; if this is not possible, cardiac puncture can be performed. This blood sample will provide a potentially uncontaminated sample for microbiological culture and assessment of fetal inflammatory response. If a sample of blood is obtained it should also be sent for chromosomal analysis, and haematological assessment (full blood count, nucleated red cell count, group and antibody screen). If the fetus is macerated samples form the amnion and placenta should also be sent to cytogenetics for chromosomal analysis.

Post-mortem examination

A post-mortem examination by a perinatal pathologist should be recommended to all parents following stillbirth.

The following should accompany the infant for post-mortem examination:

- Post-mortem consent form;
- Placenta;
- Clinical/obstetric history including relevant previous obstetric history;
- Copies of the death certificate;
- Copies of all antenatal ultrasound reports; and
- Copy of prenatal karyotyping results if available

Placenta, membrane and cord histopathology

Following a stillbirth, the placenta, membrane and cord should be sent to the perinatal pathologist fresh and unfixed for macroscopic and histological examination.

(Please refer to Section 4 Perinatal post-mortem examination for further details on the postmortem examination and Section 3 Psychological and social aspects of perinatal bereavement, Appendices 1 and 2 for information brochures for parents and professionals about post-mortem examinations.)

Placental and cord investigations by clinician

At time of delivery, the clinician should undertake:

- A detailed macroscopic examination of the placenta and cord and document the findings;
- Placental swabs between the amnion and chorion using aseptic technique for aerobic and anaerobic bacterial cultures; and
- Sampling of amnion and placental tissue for karyotyping if required.

If a prenatal karyotype has already been performed, a placental sample for karyotyping is not required.

(Please refer to Section 2 Institutional Perinatal Mortality Audit, Appendix 1 Perinatal Mortality Audit Package for instructions on placental examination and preparation for pathology.)

5.2.2 Further investigations for Thrombophilia

Further investigation for thrombophilia should be undertaken 8-12 weeks postnatally where a fetal death is associated with fetal growth restriction, pre-eclampsia, maternal thrombosis and/or maternal family history of thrombosis, remains unexplained following the core investigations or where tests for thrombophilia were positive at the time of the IUFD as follows:

- Anticardiolipin antibodies; and Lupus anticoagulant repeated if positive at the time of the IUFD or initial testing if not previously undertaken;
- APC resistance if not undertaken at birth;
- Factor V Leiden mutation if APC resistance was positive at birth;
- Fasting Homocysteine and if positive test for *methylenetetrahydrofolate reductase (MTHFR) gene mutation;

- Protein C and S deficiency
- Prothrombin gene mutation 20210A; and
 - Anti-thrombin III

These additional thrombophilia tests may be performed at birth where the above specific conditions eg fetal growth restriction are known. MTHFR mutation testing should be performed when the following fetal anomalies are identified: cleft lip/palate, neural tube defects or congenital cardiac defects(53).

Testing for thrombophilia at 8-12 weeks postnatal should be undertaken where a fetal death is associated with fetal growth restriction, pre-eclampsia, maternal thrombosis and/or maternal family history of thrombosis, if the stillbirth remains unexplained following the core investigations, or thrombophilia tests performed at the time of birth were positive (i.e. Anticardiolipin antibodies, lupus anticoagulant).While the value of screening for inherited thrombophilia remains unclear⁽⁵⁴⁾, the Working Party has recommended the following investigations based on the strength of association of many thrombophilic conditions and fetal death(55). It is hoped the implementation of these recommendations for investigation of thrombophilic disorders will not only assist in informing management strategies for future pregnancies, but that this will also enable the establishment of robust prospective data collections across ANZ for research and audit to assist in the understanding of the contribution of thrombophilia to adverse pregnancy outcome and enable monitoring of the effects of interventions to reduce the risk of fetal death.

Thrombophilia is a multigenic disorder caused by inherited and acquired (including a combination of both) defects resulting in a predisposition to thrombosis⁽⁵⁶⁾. Antiphospholipid antibodies are the most important causes of acquired thrombophilias. In pregnancy, thrombophilic disorders are associated with an increased risk of venous thromboembolism (VTE), pre-eclampsia, placental abruption, early and late fetal demise, recurrent pregnancy loss and fetal growth restriction^(57, 58). Women with inherited combined thrombophilias are at high risk of VTE and poor obstetric outcome as are women with a personal or family history of VTE⁽⁵⁸⁾.

Accurate estimates of strength of the associations for adverse pregnancy outcome and inherited thrombophilic disorders are problematic due to small numbers and heterogeneity of the available studies on this broad topic. However, recent systematic reviews have demonstrated a statistically significant increase in the risk of stillbirth associated with: APC resistance^(57, 59); Factor V Leiden mutation^(57, 59-61); Protein C deficiency⁽⁵⁹⁾; Protein S deficiency^(57, 59, 60); Prothrombin G20210 mutation^(59, 60); and MTHFR ⁽⁵⁹⁾. One review also demonstrated statistically significant associations with these thrombophilic conditions and pre-eclampsia which was strengthened in the analysis for severe pre-eclampsia⁽⁵⁹⁾.

The pathogenesis of unexplained fetal loss in women with thrombophilia is thought to involve uteroplacental insufficiency, thrombosis and infarction. Ideally the identification of thrombophilia following an apparently unexplained stillbirth would result in intervention in future pregnancies to reduce the risk. Although the evidence is unclear, there is emerging data from randomised controlled trials that antithrombotic therapy may reduce adverse pregnancy outcome for women with thrombophilia^(62, 63). Therefore, screening for thrombophilic disorders following fetal death may be helpful in assisting parents and clinicians in understanding the cause of the death and in the planning of future pregnancies including consideration of the balance of risks and benefits for antithrombotic therapy⁽⁶⁴⁾.

5.3 Alternative investigations where permission for autopsy is not obtained

If permission for an autopsy is not obtained, other less invasive testing may assist in establishing whether any important abnormalities have been missed. These alternatives permit detailed investigation of the fetus or infant while still respecting the wishes of the parents⁽⁶⁵⁾. However, a Working Group of the Royal College of Paediatrics and Child Health found little evidence for valid alternatives to the paediatric post-mortem⁽⁶⁶⁾. 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.

5.3.1 External examination by a perinatal/paediatric pathologist, clinical geneticists or paediatrician

An examination by an experienced clinician is of particular importance where an autopsy examination is declined⁽⁶⁾. Clinicians should discuss the importance of this examination with the parents and arrange for an appropriately skilled clinican to undertake the examination.

5.3.2 Babygram

Parents who decline an autopsy should be asked for consent to undertake a full body X-ray (Babygram). 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 stillborns will have abnormalities which are detectable on X-Ray⁽⁶⁾.

5.3.3 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 which may not be identified by an external examination⁽⁴⁸⁾.

5.3.4 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 supply tissue samples and therefore important information may be missed.

A recent comprehensive overview presented the advantages and disadvantages of the post-mortem MRI⁽⁶⁷⁾. 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 declined.

5.3.5 Instrucitons for taking clinical photographs

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. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality should be considered.

5.3.6 Other alternatives to a full post-mortem

Post-mortem needle biopsy; laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected abnomalities.

5.4 Storage of plasma and amniotic fluid

Unexplained fetal death is currently the subject of extensive research. Storage of maternal and fetal plasma and amniotic fluid will allow testing for other potential factors in the future, which are currently unidentified, when new discoveries have been made. Therefore, even if it is not possible initially to provide an explanation as to the cause of death, parents and siblings may benefit from research findings in the future. It is essential that informed consent is obtained prior to storage of human samples.

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Stillbirth investigations algorithm



Section 5; Appendix 2 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 = <u>Fetal Cells x</u> 1800 x 1.22 x <u>100</u> Volume Lost Maternal Cells 92 x 2 x <u>100</u> 150 x fetal wt in kg

Or, to simplify,

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

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 x 3200 ÷ 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://www.wisc.edu./wissp/wisspers/93940001.ht



Section 6 of 7 - Investigation of neonatal deaths

6.1	Introduction	1055
6.2	Recommended minimal investigations for all neonatal deaths	1055
6.3	Recommended core investigations for high risk newborns	1066
6.4	Further investigations for high risk newborns at the time of birth	1066
6.4.1	Suspected congenital infection including birth after clinical chorioamnionitis and	i
	spontaneous preterm labour and delivery	1066
6.4.2	Suspected congenital abnormalities, hydropic and severely growth restricted infa	ants1066
6.4.3	Severe cardiorespiratory depression	1077
6.4.4	Suspected thrombophilic disorders: pre-eclampsia, fetal growth restriction	1077
6.4.5	Macrosomic infant	1077
6.4.6	Suspected genetic metabolic disorders	1088
6.4.7	Sudden unexpected neonatal death	1088
6.5	Alternative investigations where permission for autopsy is not obtained	1099
6.5.1	External examination by a perinatal/paediatric pathologist, clinical geneticists or	
	paediatrician	1099
6.5.2	Babygram	1099
6.5.3	Magnetic Resonance Imaging (MRI)	1099
6.5.4	Clinical photographs	11010
6.5.5	Other alternatives to a full post-mortem	11010
6.6	References	110
Appendi	lices	
Appendi	lix 1 High risk newborn investigation checklist	11111

Appendix 1	High risk newborn investigation checklist	11111
Appendix 2a	Screening for genetic metabolic disorders	11212
Appendix 2b	Components of the genetic autopsy for investigation of metabolic disorders	11313

SECTION 6 INVESTIGATION OF NEONATAL DEATHS

6.1 Introduction

Neonatal deaths can result from disorders of the neonate, placenta or mother. The majority of neonatal deaths are due to major congenital abnormalities 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, a comprehensive standardised protocol on investigation of neonatal deaths accommodating all scenarios is not feasible or appropriate. The decisions regarding appropriate investigations should be made by the clinical team providing care based on the individual circumstances accessing additional specialist expertise as required, such as a Neonatologist (if the death occurs outside a tertiary centre), clinical geneticist and metabolic physician.

However, the importance of a high quality autopsy in accurately determining 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.)

Investigation to identify the cause of neonatal death should ideally commence at the birth of all high risk infants. In this section of the guideline, a list of core investigations is provided, based on a consensus of the Working Party, which should be undertaken at the birth of high risk newborns. Investigations which may be considered in certain clinical scenarios are also provided. Investigations at the time of birth are particularly important for infants who survive for only a short time and where an autopsy examination is not undertaken.

High risk newborns include the following:

- Admissions to neonatal intensive care;
- Preterm birth less than 32 weeks gestation;
- Suspected fetal compromise including growth restriction;
- Severe cardiorespiratory depression at birth;
- Signs consistent with congenital infection;
- Severe growth restriction;
- Hydropic infants;
- Suspected severe anaemia;
- Suspected or known major congenital abnormalities; and
- Other circumstances where a liveborn infant dies shortly after birth in the delivery room.

A subgroup of the Guideline Working Party have worked collaboratively in the development of this Section, the members were: Alison Kent, David Tudehope, Ross Haslam, David Cartwright, Sue Jenkins-Manning, Vicki Flenady and Jane Dahlstrom.

6.2 Recommended minimal investigations for all neonatal deaths

Clinicians should discuss the value of an autopsy with the parents in all cases of a neonatal death and offer the option of the procedure.

(Please see Section 4: Perinatal postmortem examination.)

A newborn screening blood sample should be performed for all neonatal deaths if not undertaken before the death occurred.

A detailed external examination of the baby should be performed by a perinatal pathologist or an experienced Neonatologist or paediatrician where possible.

(Please see Section 2; Appendix 1.4 Clinical examination of baby checklist)

6.3 Recommended core investigations for high risk newborns

Close collaboration between the obstetric and neonatal care teams is required to ensure that relevant maternal and neonatal factors are considered in the investigation of the neonate.

The following core investigations are recommended at the birth of high risk infants::

- A detailed external examination of the baby by a Neonatologist or Paediatrician (where possible) with clear documentation of the findings in the medical record;
- A comprehensive maternal medical, social and antenatal history including the results of investigations should be documented in the medical record by the obstetric staff;
- Cord blood gas analysis including both arterial and venous samples;
- A detailed macroscopic examination of the placenta and cord and documentation of the findings in the medical record by the obstetric staff; and
- Placenta, cord and membranes sent fresh and unfixed to pathology for histopathological examination.

6.4 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, particularly in the event of neonatal death, where consent for autopsy is not obtained.

These scenarios and investigations include:

6.4.1 Suspected congenital infection including birth after clinical chorioamnionitis and spontaneous preterm labour and delivery

- 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 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), 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; and
- If viral infection is supected a placental biopsy should be sent for appropriate PCR or viral culture.

6.4.2 Suspected congenital abnormalities, hydropic and severely growth restricted infants

- 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), blood group, DCT and antibody screen and microbiological culture and CRP;
- Infant surface swabs from the ear and throat for microbiological cultures;
- Placental swabs between the amnion and chorion using aseptic technique for aerobic and anaerobic bacterial cultures;
- If viral infection is suspected a placental biopsy should be sent for appropriate PCR or viral culture;
- Infant cord or peripheral blood sample for chromosomal analysis;
- Clinical photographs; and
- For hydropic infants blood test for Transferrin Isoforms for Carbohydrate deficient glycoprotein disorders (CDG)

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. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality should be considered.

6.4.3 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);
- 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); blood group, DCT and antibody screen and microbiological culture;
- Infant surface swabs from the ear and throat for microbiological cultures;
- Placental swabs between the amnion 1 and chorion using aseptic technique for aerobic and anaerobic bacterial and fungal cultures. (See Section 2 Institutional Perinatal Mortality Audit, Appendix 1 Perinatal Mortality Audit Package for instructions on taking a placental culture); and
- Consider investigation for genetic metabolic disorder and blood sample for chromosomal analysis.

6.4.4 Suspected thrombophilic disorders: pre-eclampsia, 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^(1, 2). These should include initial testing followed by further testing at 8-12 weeks postpartum as required. Selective screening for thrombophilic disorders following birth of high risk neonate or a neonatal death may be helpful in assisting parents and clinicians in understanding the cause of death, planning future pregnancies giving consideration to the risks and benefits of antithrombotic therapy^{(3).}

Screening:

- At birth: Anticardiolipin antibodies; Lupus anticoagulant; Activated protein C (APC) resistance. These tests are recommended at birth as antiphospholipid antibodies may become negative one to two months after pregnancy, and more importantly a number of women may not return for follow-up;
- 8 to 12 weeks postpartum: If antiphospholipid antibodies were present at birth, the test should be repeated, also a fasting Homocysteine and test for Protein C and S deficiency and Prothrombin mutation G20210A and Anti-thrombin III should be undertaken;
- If the APC resistance is positive testing for factor V Leiden gene mutation should be undertaken;
- If the homocysteine test is positive testing for Methylenetetrahydrofolate reductase (MTHFR) should be undertaken.
- MTHFR3 mutation testing should also be performed when the following fetal anomalies are identified cleft lip/palate, neural tube defects and cardiac defects.

*NB the recommended testing for 8 to 12 weeks postpartum may be performed at birth where the above specific conditions eg fetal growth restriction are known.

(See Section 4 Investigation of a stillbirth for further discussion on Thrombophilia.)

6.4.5 Macrosomic infant

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.

The increased risk of perinatal morbidity and mortality with maternal diabetes is well known. 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. HbA1_C monitors glycaemia over the previous 3 months by reflecting the average glucose concentration over the life of the red cells.
6.4.6 Suspected genetic metabolic disorders

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.

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.

All tissue samples should be stored and transported to a Specialist Metabolic Laboratory for investigation as convenient.

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

- Prior to death (Section 6; Appendix 2a Screening for genetic metabolic disorders)
 - 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); and
 - 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 Appendix 2b Components of the Genetic Autopsy for futher details of collection.
- Immediately following the death:
 - Obtain blood sample by cardiac puncture if blood sample not already taken and only if parental consent has been obtained;
 - 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; and
 - 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⁽⁴⁾ 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 6; 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, 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 malformations⁽⁴⁾.

(Please see Section 6; Appendix 1 High risk newborn investigation checklist for the investigations checklist; Section 2 Institutional Perinatal Mortality Audit, Appendix 1 Perinatal Mortality Audit Package 1.3 for instructions on placental examination and culture technique and Section 2 Institutional Perinatal Mortality Audit, Appendix 2 Instructions for taking clinical photographs for instructions on taking clinical photographs.)

6.4.7 Sudden unexpected neonatal death

The investigation of a sudden unexpected neonatal death should include, as a minimum, a thorough maternal and infant medical history; and a full autopsy examination by a forensic pathologist skilled in perinatal autopsy or a forensic pathologist in conjunction with a perinatal pathologist. An investigation of the various scenes where incidents leading to the death might have occurred including the infants sleeping environment.

For all sudden unexpected neonatal deaths, investigation for genetic metabolic disorders should be undertaken.

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^(4, 5). It is important that all unexpected deaths are investigated fully prior to designation to the category of SIDS. Recently a new classification, based on epidemiologial and population characteristics, has been developed⁽⁵⁾ and incorporated in the PSANZ classification systems⁽⁶⁾. 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 recently published a comprehensive protocol for care and investigation for sudden unexpected deaths in infancy. Please refer to this document for further details^{(7).}

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

6.5 Alternative investigations where permission for autopsy is not obtained

If permission for an autopsy is not obtained, other less invasive testing may assist in establishing whether any important abnormalities have been missed. These alternatives permit detailed investigation of the fetus or infant while still respecting the wishes of the parents⁽⁸⁾. However, a Working Group of the Royal College of Paediatrics and Child Health found little evidence for valid alternatives to the paediatric post-mortem⁽⁹⁾. 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.

6.5.1 External examination by a perinatal/paediatric pathologist, clinical geneticists or paediatrician

An examination by an experienced clinician is of particular importance where an autopsy examination is declined^{(10).} Clinicians should discuss the importance of this examination with the parents and arrange for an appropriately skilled clinican to undertake the examination.

6.5.2 Babygram

Parents who decline an autopsy should be asked for consent to undertake a full body X-ray (Babygram). 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 stillborns will have abnormalities which are detectable on X-Ray⁽¹⁰⁾.

6.5.3 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 recent comprehensive overview presented the advantages and disadvantages of the post-mortem MRI⁽¹¹⁾. 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 declined.

6.5.4 Clinical photographs

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. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality should be considered.

6.5.5 Other alternatives to a full post-mortem

Post-mortem needle biopsy; laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected abnomalities.

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Section 6; Appendix 1

		Risk criteria at birth								
Investigations at birth		Preterm	Suspected Infection	Suspected Congenital Abnorm- alities	Hydropic Infant	Cardio- respiratory depression	Pre- eclampsia Hypertension	FGR	Macrosomia	Suspected Metabolic Disorder
	Maternal History	+	+	+	+	+	+	+	+	+
	External exam of neonate	+	+	+	+	+	+	+	+	+
Core	Exam. of placenta and cord	+	+	+	+	+	+	+	+	+
	Placental Pathology	+	+	+	+	+	+	+	+	+
	Cord Gas	+	+	+	+	+	+	+	+	+
	Placental Culture	+	+	+	+/-	+		+		
	Placental Cytogenetics			+/-		+/-		+/-		+
	Ear, Throat Swabs	+	+	+	+/-	+		+/-		
	FBC	+	+	+	+	+	+	+		+
	CRP		+			+				
lby	Group DCT	+	+/-	+/-	+	+/-	+/-	+/-		+
B	Blood Culture	+	+	+/-	+	+		+/-		
	Clinical photos	+/-	+	+	+	+/-	+/-	+/-	+/-	+/-
	Baby Gram	+/-		+/-	+/-	+/-		+/-	+/-	+/-
	Blood Chromosomes			+	+	+/-		+/-		
	Genetic Autopsy			+/-	+/-	+/-		+/-		+
	Urine									+/-
	Vag Culture	+	+		+	+		+		
her	Torch Serology	+	+	+	+	+		+		
Mot	Thrombophilic Screen				+/-		+	+		
	HbA1c			+/-	+				+	

Section 6; Appendix 2a Screening for genetic metabolic disorders

Extract from: Christodoulou J, Wilcken B. Perimortem laboratory investigation of genetic metabolic disorders. Seminars in Neonatology 2004;9(4):275-280. (4)

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
- ß 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.

Section 6; Appendix 2b 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. (4)

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 for fibroblast culture and storage. 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.



Section 7of 7- Perinatal Mortality Classifications

7.1	Introdu	uction	11515			
7.2	Purpo	se of the Classifications	11515			
7.3	Background11515					
7.4	PSANZ	Z Perinatal Mortality Classification	11717			
7.4.1	PSANZ	Z Perinatal Death Classification (PSANZ-PDC)	11717			
7.4.2	PSANZ	Z Neonatal Death Classification (PSANZ-NDC)	12020			
7.5	PSANZ	Z Classification Guide	12222			
7.5.1	PSANZ	Z-PDC Classification Guide	12222			
7.5.2	PSANZ	Z-NDC Classification Guide	13232			
7.6	Refere	ences:	13737			
Append	ix 1:	Changes - July 2008	13838			
1.1. PSA	NZ Per	rinatal Death Classification (PSANZ-PDC)	13838			
1.1. PSA	NZ Nec	onatal Death Classification (PSANZ-NDC)	13839			
Append	ix 2a:	Table 1. Birthweight percentile values (g) for live singleton males, Australia,				
	1991-1	1994	14646			
Append	ix 2a:	Table 2. Birthweight percentile values (g) for live singleton females, Australia,				
	1991-1	1994	14747			
Append	ix 2a:	Table 3. Birthweight percentile values (g) for male twins, Australia, 1991-19-94				
		14848				
Append	ix 2a:	Table 4. Birthweight percentile values (g) for female twins, Australia, 1991-199	4			
		14949				
Append	ix 2b:	Figure 1 Australian birthweight percentiles for singleton boys	15050			
Append	ix 2b:	Figure 2 Australian birthweight percentiles for singleton girls	15151			
Append	ix 2b:	Figure 3 Birthweight percentiles for male twins, Australia	15252			
Append	ix 2b:	Figure 4 Birthweight percentiles for female twins, Australia	15353			
-						

SECTION 7 PERINATAL MORTALITY CLASSIFICATIONS

7.1 Introduction

This document presents the third revision of the Perinatal Society of Australia and New Zealand (PSANZ) classifications for perinatal death (Perinatal Death and Neonatal Death Classifications) and the accompanying Classification Guide (which provides a detailed description of the classification and case examples) which was first released in May 2003. The PSANZ Classifications and Guide for use are a result of the collaborative efforts of members of the PSANZ over many years. This activity has been focused on development of a uniform classification system for Australia and New Zealand, of perinatal mortality by antecedent cause using the PSANZ Perinatal Death Classification and, in addition for neonatal deaths, by conditions in the neonatal period, or prior to discharge home, leading to the death using the PSANZ Neonatal Death Classification.

The November 2004 revision included the ability to classify 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 can 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).

The changes made in this update are not considered to be major and are summarized in Appendix 1.

In addition to application of the classification, the PSANZ PMG recommends collection of a standardised data set included in a comprehensive confidential clinical summary to facilitate local audit and, if required, forwarded to the relevant agency within the jurisdiction's Health Department. The *PSANZ Perinatal Mortality Audit Package* (Section 2; Appendix 1) is recommended for this purpose. This data set includes all significant family, medical and obstetric history; all major pregnancy complications including whether the pregnancy was terminated; and investigations undertaken around the time of the death including placental histopatholgy and autopsy. A different data collection tool is currently being used across New Zealand. A working party is being established to review this data collection with the aim of reaching agreeement on a minimum data set for use in Australia and New Zealand.

7.2 Purpose of the Classifications

The purpose of the PSANZ Perinatal Death Classification (PSANZ-PDC) is to identify the single most important factor which led to the chain of events which resulted in the death.

The purpose of the PSANZ Neonatal Death Classification (PSANZ-NDC) is in addition to the PSANZ-PDC to identify the single most important factor in the neonatal period which caused the death.

7.3 Background

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 classification⁽¹⁾ 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 *Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Perinatal Mortality; Second Edition, Version 2.2, April* 116

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-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⁾.

The PSANZ-PDC is intended for use in a hierarchical manner in relation to its major categories, but not within subcategories. This is reflected in the numbering system used. Thus Category 1 *Congenital Abnormality*, if present, would take precedence over other categories. However, in some situations, this hierarchical system may not apply, as in the relationship between Category 3 *Hypertension* or Category 4 *Antepartum Haemorrhage* and Category 5 *Maternal Conditions*, and each case may need to be coded according to its own particular clinical circumstances.

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. PSANZ-PDC is a 4 digit coding system. If data are entered with a decimal point, a subcategory such as 'Central nervous system' (Category 1 *Congenital Abnormality*) 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, while subcategory Consistent with SIDS (Category 11, *No Obstetric Antecedent*) would be 11.11 or 1111.

PSANZ-NDC is not intended for use in a hierarchical manner. However, its Category 1 is also *Congenital Abnormality*, in keeping with PSANZ-PDC, which takes precedence over other categories. It is a 3 digit coding system.

7.4 PSANZ Perinatal Mortality Classification

7.4.1 **PSANZ** Perinatal Death Classification (PSANZ-PDC)

Congenital abnormality (including terminations for congenital abnormalities) 1

- Central nervous system 1.1
- Cardiovascular system 1.2
- 1.3 Urinary system
- 1.4 Gastrointestinal system
- 1.5 Chromosomal
- 1.6 Metabolic
- Multiple/non chromosomal syndromes 1.7 1.8
 - Other congenital abnormality
 - Musculoskeletal 1.81
 - Respiratory 1.82
 - 1.83 Diaphragmatic hernia
 - 1.84 Haematological
 - 1.85 Tumours
 - 1.88 Other specified congenital abnormality
- 1.9 Unspecified congenital abnormality

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

2 **Perinatal infection**

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

Hypertension 3

4.1

- 3.1 Chronic hypertension: essential
- 3.2 Chronic hypertension: secondary, e.g. renal disease
- Chronic hypertension: unspecified 3.3
- Gestational hypertension 3.4
- 3.5 Pre-eclampsia
 - With laboratory evidence of thrombophilia 3.51
- Pre-eclampsia superimposed on chronic hypertension 3.6
 - 3.61 With laboratory evidence of thrombophilia
- 3.9 Unspecified hypertension

Antepartum haemorrhage (APH) 4

- **Placental abruption**
 - With laboratory evidence of thrombophilia 4.11
- 4.2 Placenta praevia
- 4.3 Vasa praevia
- 4.8 Other APH
- 4.9 APH of undetermined origin

5 Maternal conditions

- 5.1 Termination of pregnancy for maternal psychosocial indications
- Diabetes / Gestational diabetes 5.2
- 5.3 Maternal injury
 - 5.31 Accidental
 - 5.32 Non-accidental
- 5.4 Maternal sepsis
- Antiphospholipid syndrome 5.5
- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions

Specific perinatal conditions 6

- Twin-twin transfusion 6.1
- Fetomaternal haemorrhage 6.2
- 6.3 Antepartum cord complications
 - 6.31 Cord haemorrhage
 - 6.32 True knot with evidence of occlusion
 - 6.38 Other
 - Unspecified 6.39
- 6.4 Uterine abnormalities, eg bicornuate uterus, cervical incompetence
- Birth trauma (typically infants of >24 weeks gestation or >600g birthweight) 6.5
- 6.6 Alloimmune disease
 - 6.61 Rhesus
 - 6.62 ABO
 - 6.63 Kell
 - 6.64 Alloimmune thrombocytopenia
 - 6.68 Other

6.7

- 6.69 Unspecified
- Idiopathic hydrops
- 6.8 Other specific perinatal conditions
 - 6.81 Rupture of membranes after amniocentesis
 - Termination of pregnancy for suspected but unconfirmed congenital 6.82 abnormality.
 - 6.83 Fetal subdural haematoma
 - Other 6.88
 - Unspecified 6.89

Hypoxic peripartum death (typically infants of >24 weeks gestation or >600g birthweight) 7 7.1

- With intrapartum complications
 - 7.11 Uterine rupture
 - 7.12 Cord prolapse
 - 7.13 Shoulder dystocia
 - 7.18 Other
- 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)
- 7.3 No intrapartum complications and no evidence of non-reassuring fetal status.
- 7.9 Unspecified hypoxic peripartum death

Fetal Growth Restriction (FGR) 8

- With evidence of reduced vascular perfusion on Doppler studies and /or placental 8.1 histopathology (e.g. significant infarction, acute atherosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)
- With chronic villitis 8.2
- No placental pathology 8.3
- 8.4 No examination of placenta
- 8.8 Other specified placental pathology
- 8.9 Unspecified or not known whether placenta examined

9 Spontaneous preterm (<37 weeks gestation)

- 9.1 Spontaneous preterm with intact membranes, or membrane rupture <24 hours before delivery
 - 9.11 With chorioamnionitis on placental histopathology
 - 9.12 Without chorioamnionitis on placental histopathology
 - 9.13 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.17 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.19 Unspecified or not known whether placenta examined
- 9.2 Spontaneous preterm with membrane rupture ≥24 hours before delivery
 - 9.21 With chorioamnionitis on placental histopathology
 - 9.22 Without chorioamnionitis on placental histopathology
 - 9.23 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.27 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.29 Unspecified or not known whether placenta examined
- 9.3 Spontaneous preterm with membrane rupture of unknown duration before delivery
 - 9.31 With chorioamnionitis on placental histopathology
 - 9.32 Without chorioamnionitis on placental histopathology
 - 9.33 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.37 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.39 Unspecified or not known whether placenta examined

10 Unexplained antepartum death

- 10.1 With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (e.g. significant infarction, acute atherosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)
- 10.2 With chronic villitis
- 10.3 No placental pathology
- 10.4 No examination of placenta
- 10.8 Other specified placental pathology
- 10.9 Unspecified or not known whether placenta examined

11 No obstetric antecedent

- 11.1 Sudden Infant Death Syndrome (SIDS)
 - 11.11 SIDS Category IA: Classic features of SIDS present and completely documented.
 - 11.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.
 - 11.13 SIDS Category II : Infant deaths that meet Category I except for one or more features.
- 11.2 Postnatally acquired infection
- 11.3 Accidental asphyxiation
- 11.4 Other accident, poisoning or violence (postnatal)
- 11.8 Other specified
- 11.9 Unknown/Undetermined
 - 11.91 Unclassified Sudden Infant Death
 - 11.92 Other Unknown/Undetermined

7.4.2 PSANZ Neonatal Death Classification (PSANZ-NDC)

1. Congenital abnormality (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 abnormality
 - 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

2. Extreme prematurity (typically infants of ≤24 weeks gestation or ≤600g birthweight)

- 2.1 Not resuscitated
- 2.2 Unsuccessful resuscitation
- 2.9 Unspecified or not known whether resuscitation attempted

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

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, eg 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

5. Neurological

- 5.1 Hypoxic ischaemic encephalopathy / Perinatal asphyxia (typically infants of >24 weeks gestation or >600g birthweight)
- 5.2 Intracranial haemorrhage
 - 5.21 Intraventricular Haemorrhage
 - 5.22 Subgaleal Haemorrhage
 - 5.23 Subarachnoid Haemorrhage
 - 5,24 Subdural Haemorrhage
 - 5.28 Other Intracranial Haemorrhage
- 5.8 Other

6. Gastrointestinal

- 6.1 Necrotising enterocolitis
- 6.8 Other

7. Other

- 7.1 Sudden Infant Death Syndrome (SIDS)
 - 7.11 SIDS Category IA: Classic features of SIDS present and completely documented.
 - 7.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.
 - 7.13 SIDS Category II : Infant deaths that meet category I except for one or more features.
- 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
- 7.8 Other specified
- 7.9 Unknown/Undetermined
 - 7.91 Unclassified Sudden Infant Death
 - 7.92 Other Unknown/Undetermined

7.5 PSANZ Classification Guide

7.5.1 PSANZ-PDC Classification Guide

1. Congenital abnormality (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 abnormality
 - 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

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

This category includes deaths in which a congenital abnormality, whether structural, functional or chromosomal, is considered to have made a major contribution, even though the abnormality may not always be lethal. It includes terminations of pregnancy \geq 20 weeks undertaken because of congenital abnormalities, even if they are not considered to be lethal abnormalities.

If fetal hydrops is associated with congenital abnormalities, e.g. with pulmonary hypoplasia or multiple abnormalities, it is classified here under subcategory 1.7 *Multiple/non chromosomal syndromes*. If fetal hydrops is the result of cardiac failure from congenital heart disease, it is classified here under subcategory 1.2 *Cardiovascular system*. If it occurs in isolation and the cause is unknown, classify under *Specific Perinatal Conditions*, subcategory 6.7 *Idiopathic hydrops*.

Category 1.84 *Haematological* includes deaths due to congenital haematological abnormalities, such as thalassemia; Category 1.85 *Tumours* includes congenital tumours including cystic hygroma; and Category 1.88 *Other specified congenital abnormality* is used to classify identified abnormalities which are not included in Categories 1.1 to 1.85. Category 1.9 *Unspecified congenital abnormality* includes cases where there is an obvious abnormality but the investigation is incomplete and is therefore unknown or unspecified.

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
 - 2.28 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

This category includes (i) primary infections occurring in term and preterm neonatal and fetal deaths and (ii) secondary infections e.g. following \geq 24 hours of membrane rupture before delivery, resulting in neonatal early onset infection (within 48 hours of birth) in term infants. Deaths in preterm infants from

such secondary infection would be classified under the *Spontaneous Preterm* group, subcategory 9.2, and in this situation, the hierarchical system for categories would not apply. 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.

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

Examples:

Classify here: Term prelabour rupture of the membranes, delivery following \geq 24 hours of membrane rupture, neonatal pneumonia identified within 48 hours of birth, subsequent neonatal death, group B Streptococcus identified on vaginal culture and in gastric aspirate. Classify as subcategory 2.11.

Do not classify here: Neonatal death from late onset (≥48 hrs of age) Group B Streptococcal disease. Classify under No Obstetric Antecedent (subcategory 11.2).

Classify here: Spontaneous rupture of membranes, followed by spontaneous labour at 26 weeks and delivery of a stillborn baby. Membranes were ruptured for 12 hours prior to delivery. Fetal pneumonia was detected at autopsy and growth of E Coli from the lungs. Classify 2.12.

Do not classify here:

Spontaneous rupture of the membranes at 24 weeks gestation. Clinical chorioamnionitis ensued after 4 days of membrane rupture. Induction of labour was undertaken resulting in a vaginal delivery of a liveborn infant. Birthweight was 650gms and Apgars scores were 2 at 1 minute and at 5 mins. Despite active resuscitation the infant died at 15 minutes of age. No autopsy or placental pathology was undertaken. Cord blood cultures grew E coli. Classify as PSANZ-PDC 9.23 and PSANZ-NDC 4.11.

DEATH TYPE	CRITERIA OF INFECTION
Fetal	 Histological confirmation of infection 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
Neonatal	 Congenital infection 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 3a – 3d 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. NB: Some congenital viral infections may have onset later than 48 hours after birth. For neonatal deaths occurring within a few hours of birth, especially those for which resuscitation was not attempted, where infection is presumed to be the cause of death, the infection criteria for fetal death may be used.

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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
 - 3.51 With laboratory evidence of thrombophilia
- 3.6 Pre-eclampsia superimposed on chronic hypertension
 - 3.61 With laboratory evidence of thrombophilia
- 3.9 Unspecified hypertension

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. 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.

Thus, although the numbering of main groups of causes of death is in a hierarchical order in general, in some cases, as in the relationship between *Maternal Conditions* and *Hypertension* or *APH*, this hierarchy may not always apply, and each case needs to be classified according to its own particular circumstances.

The classification of *Hypertension* follows that of the Australasian Society for the Study of Hypertension in Pregnancy⁽³⁾ with the exceptions that unspecified subcategories have been included. The definitions also follow those in the consensus statement, which should be referred to whenever any classification difficulties arise:

<u>Hypertension is diagnosed</u> when the systolic blood pressure is \geq 140 mm Hg and /or diastolic blood pressure (Korotkoff V) is \geq 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.

<u>Gestational hypertension</u> 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.

<u>Pre-eclampsia</u> 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.

With recent increasing interest in thrombophilic conditions, the 4th digit or second decimal point is used for associations of thrombophilia with pre-eclampsia, i.e. subcategories 3.51 and 3.61. There should be laboratory (biochemical or haematological) evidence of thrombophilia to warrant inclusion. Due to the rapidly unfolding area of thrombophilia in pregnancy, the Special Interest Group had some difficulty developing a definition for laboratory (biochemical or haematological) evidence of thrombophilia. A working party of the SIG has been formed to develop a definition appropriate for inclusion in the classification guide in the future.

4. Antepartum Haemorrhage (APH)

- 4.1 Placental abruption
 - 4.11 With laboratory evidence of thrombophilia
- 4.2 Placenta praevia
- 4.3 Vasa praevia
- 4.8 Other APH
- 4.9 APH of undetermined origin

This category includes all perinatal deaths where the primary factor leading to the death was an APH. If abruption occurs as a complication of a hypertensive disorder, the death is attributed to the hypertensive disorder (Category 3).

With recent increasing interest in thrombophilic conditions, the 4th digit or second decimal point can be used to identify associations of thrombophilia with antepartum haemorrhage, i.e. subcategory 4.11. There should be laboratory (biochemical or haematological) evidence of thrombophilia to warrant inclusion.

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

This category includes deaths attributed to any medical or surgical disorder in the mother, or to its complications or treatment, excluding hypertensive disorders. The subcategory 5.1 includes terminations of pregnancy undertaken for any other indication than congenital abnormality; a termination of pregnancy undertaken because of congenital abnormality would be classified under *Congenital Abnormality*, Category 1.

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. Substance abuse may also be included under subcategory 5.8 *Other specific maternal condition* if there is a significant history of abuse and the fetal or neonatal death is believed to have been caused by the abuse.

Example:

Classify here: Fetal death as a result of severe uncontrolled Type I Diabetes with mild pre-eclampsia classify as subcategory 5.2, rather than *Hypertension* Category 3.

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
- 6.9 Unspecified

This category includes deaths of normally formed, appropriately grown babies in which the specific perinatal condition made a major contribution. Cord complications during labour should be categorised under *Hypoxic Peripartum Death*, subcategory 7.1.

As preterm rupture of the membranes and preterm labour are often preceded by premature cervical dilatation as a result of subclinical infection, the subcategory of cervical incompetence should be reserved for those rare circumstances where the clinical history and ultrasound scanning unequivocally point to pre-existing damage to the cervix from a surgical procedure or to congenital structural abnormality (as in some cases of DES exposure). Thus, there should be convincing evidence from the previous obstetric history and/or the state of the cervix, whether or not a cervical suture has been inserted.

Category 6.3.2 True knot with evidence of 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 of 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.

Category 6.5: *Birth trauma* includes infants with evidence of significant trauma at autopsy (e.g. tentorial tears, skull fracture), typically those of >24 weeks gestation or >600g birthweight.

Example:

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 9 as the cord complication occurred as a result of the preterm ROM.

7. Hypoxic peripartum death (typically infants of >24 weeks gestation or >600g birthweight) 71

- With intrapartum complications
 - 7.11 Uterine rupture
 - 7.12 Cord prolapse
 - 7.13 Shoulder dystocia
 - 7.18 Other
- 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)
- 7.3 No intrapartum complications and no evidence of non-reassuring fetal status
- 7.9 Unspecified hypoxic peripartum death.

This category includes deaths from acute or chronic hypoxia of normally formed babies, typically of >24 weeks gestation or >600g birthweight. For subcategories 7.2 to 7.9, the presence of fetal growth restriction (FGR) overrides this classification and, if present, the death should be classified under FGR, Category 8.

This category includes deaths where the fetus was alive at the onset of labour, during which there may have been intrapartum complications (subcategory 7.1), or no intrapartum complications but with evidence of non-reassuring fetal status in a normally grown infant (subcategory 7.2), or no intrapartum complications or evidence of non-reassuring fetal status (subcategory 7.3). If there was no labour, and there were no apparent complications, the death would be classified in either subcategory 7.2 or 7.3. A specific major intrapartum complication, such as uterine rupture, cord prolapse or shoulder dystocia, is required for inclusion as subcategory 7.1. However, if there were no apparent intrapartum complications (as defined in category 7.1) but there was fetal growth restriction (FGR), then the death should be attributed to FGR, Category 8.

If there is insufficient information about fetal wellbeing or intrapartum complications, classify as subcategory 7.9 Unspecified hypoxic peripartum death.

Neonatal deaths as a result of hypoxic ischaemic encephalopathy^(4, 5) 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.

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^(3, 4).

Examples:

Classify here: No known problems prior to labour at gestation 38 weeks. Severe fetal heart rate decelerations in second stage of labour. Baby is born with no signs of life with a birthweight of 3500gm. Classify as subcategory 7.2.

Classify here: No known problems prior to labour at 36 weeks. No FGR. No evidence of intrapartum fetal distress. At delivery, the baby shows signs of severe respiratory depression and hypoxia. Subsequently develops encephalopathy and multiorgan failure and dies on Day 10 of life. Classify as subcategory 7.3.

8. Fetal Growth Restriction (FGR)

- 8.1 With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (e.g. significant infarction, acute atherosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)
- 8.2 With chronic villitis
- 8.3 No placental pathology
- 8.4 No examination of placenta
- 8.8 Other specified placental pathology
- 8.9 Unspecified or not known whether placenta examined

This category includes deaths of babies with birthweight <10th percentile for gestational age for livebirths or non macerated stillbirths, or for all perinatal deaths where repeated antenatal ultrasound measurements have already shown growth restriction or growth arrest before death. This category excludes perinatal deaths with FGR as a result of an identified maternal or fetal condition where the death is classified according to the condition.

In the situation of a macerated stillbirth with suspected Small for Gestational Age (SGA) but without prior antenatal ultrasound evidence of FGR, a brain:liver ratio equal to or greater than 4:1 at autopsy is required for classification 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 10), as the weight discrepancy may be a post mortem effect.

Customised birthweight centiles (CBW) are being increasingly used to more accurately determine the presence of FGR. ⁽⁶⁻⁸⁾ 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 calculation of FGR according to CBW centiles. 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 subcategory 8.8 Other specified placental pathology is used when placental pathology other than that described in the subcategories 8.1 or 8.2 is present. The subcategory 8.9 Unspecified or not known whether placenta examined is used when information is not available on whether placental pathology was undertaken or where there is insufficient information about the placental pathology to categorise elsewhere.

Examples:

Do not classify here: A woman with an uncomplicated pregnancy presents with no fetal movements for 2 days at 34 weeks gestation, with no labour and intact membranes. An ultrasound scan confirms an intrauterine fetal death. Labour begins spontaneously after 4 days and a macerated female infant is born 12 hours later weighing 1500gms (<5th centile for 34 weeks). An autopsy is undertaken which did not reveal a cause for the death, a brain:liver ratio was not available. The histopathological report on the placenta stated that small areas of infarction were present but were not considered to be an explanation for the death. Further maternal investigations failed to identify a cause for the death. Classify as *Unexplained Antepartum Death: Other placental pathology* subcategory 10.8.

9. Spontaneous preterm (<37 weeks gestation)

- 9.1 Spontaneous preterm with intact membranes, or membrane rupture <24 hours before delivery
 - 9.11 With chorioamnionitis on placental histopathology
 - 9.12 Without chorioamnionitis on placental histopathology
 - 9.13 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.17 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.19 Unspecified or not known whether placenta examined
- 9.2 Spontaneous preterm with membrane rupture \geq 24 hours before delivery
 - 9.21 With chorioamnionitis on placental histopathology
 - 9.22 Without chorioamnionitis on placental histopathology
 - 9.23 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.27 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.29 Unspecified or not known whether placenta examined
- 9.3 Spontaneous preterm with membrane rupture of unknown duration before delivery
 - 9.31 With chorioamnionitis on placental histopathology
 - 9.32 Without chorioamnionitis on placental histopathology
 - 9.33 With clinical evidence of chorioamnionitis, no examination of placenta
 - 9.37 No clinical signs of chorioamnionitis, no examination of placenta
 - 9.39 Unspecified or not known whether placenta examined

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 <u>Table 1 Determination of perinatal infection</u>) among those with membranes ruptured less than 24 hours, otherwise classify under Category 2 *Perinatal Infection*. Careful examination of the placenta macroscopically and microscopically is recommended. The diagnosis of placental evidence of chorioamnionitis should only be made when there is histological or microbiological evidence of inflammation or infection of the placenta and membranes.

In cases where there is placental evidence of chorioamnionitis with or without evidence of clinical chorioamnionitis classify as subcategory 9.11, 9.21 or 9.31 as appropriate. Clinical evidence of chorioamnionitis is defined as maternal fever (\geq 38 $^{\circ}$ 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^{(9-11).} 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 9.13, 9.23 or 9.33 as appropriate.

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.

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 9.12 *Without chorioamnionitis on placental histopathology.*

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 on placental histology, no organism identified. Classify here as subcategory 9.21.

10. Unexplained antepartum death

- 10.1 With evidence of reduced vascular perfusion on Doppler studies and /or placental histopathology (e.g. significant infarction, acute atherosis, maternal and/or fetal vascular thrombosis or maternal floor infarction)
- 10.2 With chronic villitis
- 10.3 No placental pathology
- 10.4 No examination of placenta
- 10.8 Other specified placental pathology
- 10.9 Unspecified or not known whether placenta examined

This category includes deaths of normally formed fetuses prior to the onset of labour where no predisposing factors are considered likely to have caused the death e.g. Fetal Growth Restriction or any other primary complication such as spontaneous preterm rupture of the membranes. The subcategory 10.8 *Other specified placental pathology* is used when other placental pathology is present. other than that included elsewhere (categories 10.1, 10.2). Subcategory 10.9 *Unspecified or not known whether placenta examined* is used to classify deaths fulfilling the criteria for this category where it is not known *either* whether the placenta was examined *or* if the placenta was examined, the results of this examination.

Examples:

Classify here: Intrauterine Fetal Death (IUFD) at 27 weeks, with membranes intact, before onset of labour, no explanation. No autopsy or examination of placenta. Classify as *Unexplained Antepartum Death*, subcategory 10.4.

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 9.32 *Spontaneous Preterm.*

11. No obstetric antecedent

- 11.1 Sudden Infant Death Syndrome (SIDS) (See appendix p130)
 - 11.11 SIDS Category IA: Classic features of SIDS present and completely documented.
 - 11.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.
 - 11.13 SIDS Category II : Infant deaths that meet Category I except for one or more features.
- 11.2 Postnatally acquired infection
- 11.3 Accidental asphyxiation
- 11.4 Other accident, poisoning or violence (postnatal)
- 11.8 Other specified
- 11.9 Unknown/Undetermined
 - 11.91 Unclassified Sudden Infant Death
 - 11.92 Other Unknown/Undetermined

Subcategories 11.1 *SIDS* and 11.91 *Unclassified Sudden Infant Death* are defined according to the new SIDS classification system by Krous et al⁽¹²⁾. 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 11.91.

Subcategory 11.4 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 11.8 Other specified is used to classify other identified conditions which are not included in subcategories 11.1 to 11.4.

Definitional approach to Sudden Infant Death⁽¹²⁾

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 determination that they do not provide an explanation for the death.

Found in a safe sleeping environment, with no evidence of accidental death.

Autopsy

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. No evidence of unexplained trauma, abuse, neglect, or unintentional injury.

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. Negative results of toxicologic, microbiologic, radiologic, vitreous chemistry, and metabolic screening studies.

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.

7.5.2 PSANZ-NDC Classification Guide

The Neonatal Death Classification has been developed for use in conjunction with the PSANZ Classification of Perinatal Death in order to provide more comprehensive information on the factors in the neonatal period associated with neonatal deaths.

For example, a mother who has an antepartum haemorrhage at 32 weeks gestation delivers a 1500g infant which thrives in the neonatal nursery but subsequently acquires a lethal nosocomial infection: the obstetric antecedent is antepartum haemorrhage, but neonatal death classification is subcategory 4.12 *Acquired Bacteria.* Neonatal nosocomial infection is an important potentially preventable condition and its contribution to perinatal deaths may not be identified by applying the antecedent classification alone.

1. Congenital abnormality (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 abnormality
 - 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

2. Extreme prematurity (typically infants of \leq 24 weeks gestation or \leq 600g birthweight)

- 2.1 Not resuscitated
- 2.2 Unsuccessful resuscitation
- 2.9 Unspecified or unknown whether resuscitation attempted

This group includes infants deemed too immature for resuscitation or continued life support beyond the delivery room, typically infants of gestational age \leq 24 weeks or birthweight \leq 600g. 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 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia (BPD))
- 3.6 Pulmonary haemorrhage
- 3.7 Pneumothorax
- 3.8 Other

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 or pneumothorax.

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. For example, a non-ventilated neonate who dies of sepsis, is classified as Category 4 *Infection*.

Examples

 A 26 week gestation infant with RDS receives mechanical ventilation (SIPPV R50, P20/5, Fi0₂ 0.4) develops complications of pneumothorax requiring drainage followed by a patent ductus arteriosus is classified as Category 3.1. 2. 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 is successfully weaned to CPAP on Day 7. He requires re-ventilation for sepsis on Day 10 and on Day 21 has developing BPD and post hemorrhagic hydrocephalus (PHH) and ventilation is withdrawn. Classification is dependent on the major reason for withdrawal of support. In this case PHH. Classify as 3.5.

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.

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, eg 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

Determination of 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
- 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.

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

B. Acquired

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

5. Neurological

- 5.1 Hypoxic ischaemic encephalopathy / Perinatal asphyxia (typically infants of >24 weeks gestation or >600g birthweight)
- 5.2 Intracranial haemorrhage
 - 5.21 Intraventricular Haemorrhage
 - 5.22 Subgaleal Haemorrhage
 - 5.23 Subarachnoid Haemorrhage
 - 5.24 Subdural Haemorrhage
 - 5.28 Other Intracranial Haemorrhage
- 5.8 Other

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

Examples of sentinel events (this would apply to infants typically of >24 weeks gestation or of >600g birthweight).

Massive antepartum haemorrhage from abruption, placenta praevia or ruptured vasa praevia, breech presentation or delivery with complications, e.g. cervical constriction ring or difficult delivery, feto-maternal haemorrhage, twin-twin transfusion.

Where possible, evidence for perinatal asphyxia 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. On the absence of a sentinel asphyxial event every effort must be undertaken to exclude alternative diagnosis.

6. Gastrointestinal

- 6.1 Necrotising enterocolitis
- 6.8 Other

- 7. Other
 - 7.1 Sudden Infant Death Syndrome (SIDS)
 - 7.11 SIDS Category IA: Classic features of SIDS present and completely documented.
 - 7.12 SIDS Category IB: Classic features of SIDS present but incompletely documented.
 - 7.13 SIDS Category II : Infant deaths that meet category I except for one or more features.
 - 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
 - 7.8 Other specified
 - 7.9 Unknown/Undetermined
 - 7.91 Unclassified Sudden Infant Death
 - 7.92 Other Unknown/Undetermined

The new classification for SIDS, by Krous et al¹¹, has been adopted as follows:

Definitional approach to Sudden Infant Death

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 \geq 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 determination that they do not provide an explanation for the death.

Found in a safe sleeping environment, with no evidence of accidental death.

Autopsy

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. No evidence of unexplained trauma, abuse, neglect, or unintentional injury.

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. Negative results of toxicologic, microbiologic, radiologic, vitreous chemistry, and metabolic screening studies.

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.

Postresuscitation 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.

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Appendix 1: Changes - April 2009

The previous version of the classification is dated October 2004. This revision incorporates amendments to the PSANZ-PDC and 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.

1. Changes made in the March 2009 revision

1.1. PSANZ Perinatal Death Classification (PSANZ-PDC)

1.1.1 The inclusion of a code to identify terminations of pregnancy for congenital abnormality

PSANZ-PDC version October 2004		PSANZ-PDC version April 2009		
1	Congenital Abnormality (including terminations	1	Congenital Abnormality (including	
	for congenital abnormalities)		terminations for congenital abnormalities)	
1.1	Central nervous system	1.1	Central nervous system	
1.2	Cardiovascular system	1.2	Cardiovascular system	
1.3	Urinary system	1.3	Urinary system	
1.4	Gastrointestinal system	1.4	Gastrointestinal system	
1.5	Chromosomal	1.5	Chromosomal	
1.6	Metabolic	1.6	Metabolic	
1.7	Multiple/non chromosomal syndromes	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	
	1.84 Haematological		1.84 Haematological	
	1.85 Tumours		1.85 Tumours	
	1.88 Other specified congenital abnormality		1.88 Other specified congenital abnormality	
1.9	Unspecified congenital abnormality	1.9	Unspecified congenital abnormality	
		Plea deat inclu three	use note that terminations of pregnancy for perinatal ths within this category should be identified by the usion of an "09" for two-digit codes and a "9" for the e digit codes	

1.1.2 Change of wording for Category 5.5

PS/	ANZ-PDC version October 2004	PSANZ-PDC version April 2009		
5	Maternal conditions	5 Maternal conditions		
5.1	Termination of pregnancy for maternal	5.1 Termination of pregnancy for maternal		
	psychosocial indications	psychosocial indications		
5.2	Diabetes / Gestational diabetes	5.2 Diabetes / Gestational diabetes		
5.3	Maternal injury	5.3 Maternal injury		
	5.31 Accidental	5.31 Accidental		
	5.32 Non-accidental	5.32 Non-accidental		
5.4	Maternal sepsis	5.4 Maternal sepsis		
5.5	Lupus obstetric syndrome	5.5 Antiphospholipid syndrome		
5.6	Obstetric cholestasis	5.6 Obstetric cholestasis		
5.8	Other specified maternal conditions	5.8 Other specified maternal conditions		

1.1.3 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	Specific perinatal conditions		
6.1	Twin-twin transfusion	6.1	Twin-twin transfusion		
6.2	Fetomaternal haemorrhage	6.2	Fetomaternal haemorrhage		
6.3	Antepartum cord complications (e.g. cord	6.3	Antepartum cord complications		
	haemorrhage; true knot with evidence of occlusion)		6.31 Cord haemorrhage		
6.4	Uterine abnormalities, e.g. bicornuate		6.32 True knot with evidence of occlusion		
	uterus, cervical incompetence		6.38 Other		
6.5	Birth trauma (typically infants of >24		6.39 Unspecified		
	weeks gestation or >600g birthweight)	6.4	Uterine abnormalities, e.g. bicornuate uterus,		
6.6	Alloimmune disease	cerv	ical incompetence		
	6.61 Rhesus	6.5	Birth trauma (typically infants of >24 weeks		
	6.62 ABO	gest	ation or >600g birthweight)		
	6.63 Kell	6.6	Alloimmune disease		
	6.64 Alloimmune thrombocytopenia		6.61 Rhesus		
	6.68 Other		6.62 ABO		
	6.69 Unspecified		6.63 Kell		
6.7	Idiopathic hydrops		6.64 Alloimmune thrombocytopenia		
6.8	Other specific perinatal conditions (includes		6.68 Other		
	iatrogenic conditions such as rupture of		6.69 Unspecified		
	membranes after amniocentesis, termination of	6.7	Idiopathic hydrops		
	pregnancy for suspected but unconfirmed	6.8	Other specific perinatal conditions		
	congenital abnormality).		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		

1.1.4 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.)

1.2 PSANZ Neonatal Death Classification (PSANZ-NDC)

1.2.1 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	Cardio-respiratory disorders		
3.1	Hyaline membrane disease /	3.1	Hyaline membrane disease / Respiratory distress		
	Respiratory Distress Syndrome (RDS)		syndrome (RDS)		
3.2	Meconium aspiration syndrome	3.2	Meconium aspiration syndrome		
3.3	Primary persistent pulmonary hypertension	3.3	Primary persistent pulmonary hypertension		
3.4	Pulmonary hypoplasia	3.4	Pulmonary hypoplasia		
3.5	Chronic neonatal lung disease (typically,	3.5	Chronic neonatal lung disease (typically,		
	bronchopulmonary dysplasia)		bronchopulmonary dysplasia)		
3.8	Other	3.6	Pulmonary haemorrhage		
		3.7	Pneumothorax		
		3.8	Other		

1.2.1 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	Infection	
4.1	Bacterial	4.1	Bacterial	
	4.11 Congenital bacterial		4.11 Congenital bacterial	
	4.12 Acquired bacterial		4.111 Group B Streptococcus	
4.2	Viral		4.112 E coli	
	4.21 Congenital viral		4.113 Lysteria monocytogenes	
	4.22 Acquired viral		4.114 Spirochaetal, eg syphilis	
4.3	Protozoal e.g. Toxoplasma		4.118 Other bacterial	
4.4	Spirochaetal e.g. Syphilis		4.119 Unspecified bacterial	
4.5	Fungal		4.12 Acquired bacterial	
4.8	Other		4.121 Group B Streptococcus	
4.9	Unspecified organism		4.122 E coli	
			4.125 Other Gram negative bacilli (other	

Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Perinatal Mortality; Second Edition, Version 2.2, April 140 2009. Section 7: Perinatal Mortality Classifications; Appendix 1

than E coli)
4.126 Staphylococcus aureus
4 127 Coagulase negative Staphylococcus
1.127 Obligation hogative etaphylococous
4.120 Other specified bacterial
4.129 Unspecified bacterial
4.2 Viral
4.21 Congenital viral
4.211 Cytomegalovirus
4 213 Hernes simplex virus
4 214 Pubelle virue
4.214 Rubella VIIUS
4.218 Other specified viral
4.219 Unspecified viral
4.22 Acquired viral
4.221 Cytomegalovirus
4 223 Hernes simplex virus
A 224 Pubella virus
4.224 Rubella VIIUS
4.228 Other specified viral
4.229 Unspecified viral
4.3 Protozoal e.g. Toxoplasma
4.5 Fungal
4.8 Other specified organism
4.0 Unspecified organism
4.9 Unspecified Organisill

1.2.2Additional subcategories under Category 5.2 Intracranial haemorrhage

PSANZ-NDC version October 2004	PSANZ-NDC version February 2009		
5. Neurological	5. Neurological		
 5.1 Hypoxic ischaemic encephalopathy / Perinatal asphyxia (typically infants of >24 weeks gestation or >600g birthweight) 5.2 Intracranial haemorrhage 5.8 Other 	 5.1 Hypoxic ischaemic encephalopathy / Perinatal asphyxia (typically infants of >24 weeks gestation or >600g birthweight) 5.2 Intracranial haemorrhage 5.21 Intraventricular Haemorrhage 5.22 Subgaleal Haemorrhage 5.23 Subarachnoid Haemorrhage 5.24 Subdural Haemorrhage 5.28 Other Intracranial Haemorrhage 5.8 Other 		

1.2.3 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
7 Other	7 Other
 7. Other 7.1 Sudden Infant Death Syndrome (SIDS) 7.11 SIDS Category IA: Classic features of SIDS present and completely documented. 7.12 SIDS Category IB: Classic features of SIDS present but incompletely documented. 7.13 SIDS Category II : Infant deaths that meet category I except for one or more features. 7.2 Multisystem failure-only if unknown primary cause or trigger event 7.3 Trauma 7.8 Other specified 7.9 Unknown/Undetermined 7.92 Other Unknown/Undetermined 	 7 Other 7.1 Sudden Infant Death Syndrome (SIDS) 7.11 SIDS Category IA: Classic features of SIDS present and completely documented. 7.12 SIDS Category IB: Classic features of SIDS present but incompletely documented. 7.13 SIDS Category II : Infant deaths that meet category I except for one or more features. 7.2 Multisystem failure 7.21 Secondary to intrauterine growth restriction 7.28 Other specified 7.29 Unspecified/undertemined primary cause or trigger event 7.3 Trauma 7.31 Accidental 7.32 Non accidental 7.39 Unspecified 7.41 Surgical 7.42 Medical 7.8 Other specified 7.9 Unknown/Undetermined 7.91 Unclassified Sudden Infant Death 7.02 Other Linknown/Undetermined
	1.52 Guier Ghidiown/Ghidelennined

2. Changes made in the October 2004 revision

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).

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. 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.

4. Changes to the Perinatal Death Classification Categories

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.

PSAI	IZ-PDC version May 23 rd 2003	PSAN	IZ-PDC version October 2004
1.	Congenital Abnormality (including	1.	Congenital Abnormality (including
	terminations for congenital abnormalities)		terminations for congenital abnormalities)
1.1	Central nervous system	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
			· · ·

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
2.2	 2.11 Group B Streptococcus 2.12 E coli 2.13 Listeria monocytogenes 2.18 Other bacterial 2.19 Unspecified bacterial Viral 		 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
2.3 2.4 2.5 2.8	 2.21 Cytomegalovirus 2.22 Parvovirus 2.23 Herpes simplex virus 2.24 Rubella virus 2.28 Other viral 2.29 Unspecified viral Protozoal e.g. Toxoplasma Spirochaetal e.g. Syphilis Fungal Other 	2.2 2.3 2.5	Viral 2.21 Cytomegalovirus 2.22 Parvovirus 2.23 Herpes simplex virus 2.24 Rubella virus 2.28 Other viral 2.29 Unspecified viral Protozoal e.g. Toxoplasma Fungal
2.9	Unspecified organism	2.8 2.9	Other specified organism Other unspecified organism

4.3 Hypertension: Category 3

Two subcategories have been included to identify laboratory evidence of thrombophilia with preeclampsia (Subcategories 3.51 and 3.61). These categories were included in the previous version of the guideline in the Addendum for Special Interest Groups.

PSA	PSANZ-PDC version May 23 rd 2003		PSANZ-PDC version October 2004	
3.	Hypertension	3.	Hypertension	
3.1	Chronic hypertension: essential	3.1	Chronic hypertension: essential	
3.2	Chronic hypertension: secondary, e.g. renal	3.2	Chronic hypertension: secondary, e.g. renal	
	disease		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		3.51 With laboratory evidence of thrombophilia	
	hypertension	3.6	Pre-eclampsia superimposed on chronic	
3.9	Unspecified hypertension		hypertension	
			3.61 With laboratory evidence of thrombophilia	
		3.9	Unspecified hypertension	

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	
4.	Antepartum Haemorrhage (APH)	4.	Antepartum Haemorrhage (APH)
4.1	Placental abruption	4.1	Placental abruption
4.2	Placenta praevia		4.11 With laboratory evidence of thrombophilia
4.3	Vasa praevia	4.2	Placenta praevia
4.8	Other APH	4.3	Vasa praevia
4.9	APH of undetermined origin	4.8	Other APH
	-	4.9	APH of undetermined origin
			-

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*).
PSA	NZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004				
5.	Maternal Conditions	5.	Maternal Conditions			
5.1	Termination of pregnancy (other than for congenital	5.1	Termination of pregnancy for maternal			
	(fetal) abnormality)		psychosocial indications			
5.2	Diabetes / Gestational diabetes	5.2	Diabetes / Gestational diabetes			
5.3	Maternal injury	5.3	Maternal injury			
	5.31 Accidental		5.31 Accidental			
	5.32 Non-Accidental		5.32 Non-accidental			
5.4	Maternal sepsis	5.4	Maternal sepsis			
5.8	Other maternal conditions, e.g. Lupus obstetric	5.5	Lupus obstetric syndrome			
	syndrome.	5.6	Obstetric cholestasis			
		5.8	Other specified maternal conditions			

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.*

PSA	NZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004					
7.	Hypoxic Peripartum Death (typically infants of	7.	Hypoxic Peripartum Death (typically infants of				
	>24 weeks gestation or >600g birthweight)		>24 weeks gestation or >600g birthweight)				
7.1	With intrapartum complications	7.1	With intrapartum complications				
	7.11 Uterine rupture		7.11 Uterine rupture				
	7.12 Cord prolapse		7.12 Cord prolapse				
	7.13 Shoulder dystocia		7.13 Shoulder dystocia				
	7.18 Other		7.18 Other				
7.2	No apparent complications	7.2	Evidence of non-reassuring fetal status in a				
7.9	Unspecified hypoxic peripartum death		normally grown infant (e.g. abnormal fetal heart				
			rate, fetal scalp pH/lactate, fetal pulse oximetry				
			without intrapartum complications)				
		7.3	No intrapartum complications and no evidence of				
			non-reassuring fetal status.				
		7.9	Unspecified hypoxic peripartum death				

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.

PSAN	IZ-PDC version May 23 rd 2003	PSANZ-PDC version October 2004					
8.	Fetal Growth Restriction (FGR)	8.	Fetal Growth Restriction (FGR)				
8.1	With evidence of uteroplacental insufficiency e.g.	8.1	With evidence of reduced vascular perfusion on				
	significant infarction, acute atherosis, maternal		Doppler studies and /or placental histopathology				
	and/or fetal vascular thrombosis or maternal floor		(e.g. significant infarction, acute atherosis,				
	infarction		maternal and/or fetal vascular thrombosis or				
8.2	With chronic villitis		maternal floor infarction)				
8.3	Without the above placental pathology	8.2	With chronic villitis				
8.4	No examination of placenta	8.3	No placental pathology				
8.9	Unspecified FGR or not known whether placenta	8.4	No examination of placenta				
	examined	8.8	Other specified placental pathology				
		8.9	Unspecified or not known whether placenta				
			examined				

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 ⁰C) 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.

PSA	NZ-PDC version May 23 rd 2003	PSA	NZ-PDC version October 2004
9.	Spontaneous Preterm (<37 weeks gestation)	9.	Spontaneous Preterm (<37 weeks gestation)
9.1	Spontaneous preterm with intact membranes, or	9.1	Spontaneous preterm with intact membranes, or
	membrane rupture <24 hours before delivery		membrane rupture <24 hours before delivery
	9.11 With chorioamnionitis		9.11 With chorioamnionitis on placental
	9.12 Without chorioamnionitis		histopathology
	9.13 No examination of placenta		9.12 Without chorioamnionitis on placental
	9.19 Unspecified or not known whether		histopathology
	placenta examined		9.13 With clinical evidence of chorioamnionitis, no
9.2	Spontaneous preterm with membrane rupture		examination of placenta
	≥24 hours before delivery		9.17 No clinical signs of chorioamnionitis, no
	9.21 With chorioamnionitis,		examination of placenta
	9.22 Without chorioamnionitis,		9.19 Unspecified or not known whether placenta
	9.23 No examination of placenta		examined
9.3	Spontaneous preterm with membrane rupture of	9.2	Spontaneous preterm with membrane rupture ≥24
	unknown duration before delivery,		hours before delivery
	9.31 With chorioamnionitis		9.21 With chorioamnionitis on placental
	9.32 Without chorioamnionitis		histopathology
	9.33 No examination of placenta		9.22 Without chorioamnionitis on placental
			histopathology
			9.23 With clinical evidence of chorioamnionitis, no
			examination of placenta
			9.27 No clinical signs of chorioamnionitis, no
			examination of placenta
			9.29 Unspecified or not known whether placenta
			examined
		9.3	Spontaneous preterm with membrane rupture of
			unknown duration before delivery
			9.31 With chorioamnionitis on placental
			histopathology
			9.32 Without chorioamnionitis on placental
			histopathology
			9.33 With clinical evidence of chorioamnionitis, no
			examination of placenta
			9.37 No clinical signs of chorioamnionitis, no
			examination of placenta
			9.39 Unspecified or not known whether placenta
			examined

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.

PSAN	Z-PDC version May 23 rd 2003	PSANZ-PDC version October 2004					
10.	Unexplained Antepartum Death	10.	Unexplained Antepartum Death				
10.1	With evidence of uteroplacental insufficiency, e.g.	10.1	With evidence of reduced vascular perfusion				
	significant infarction, acute atherosis, maternal		on Doppler studies and /or placental				
	and/or fetal vascular thrombosis or maternal floor		histopathology (e.g. significant infarction, acute				
	infarction		atherosis, maternal and/or fetal vascular				
10.2	With chronic villitis		thrombosis or maternal floor infarction)				
10.3	Without the above placental pathology	10.2	With chronic villitis				
10.4	No examination of placenta	10.3	No placental pathology				
10.9	Unspecified unexplained antepartum death or not	10.4	No examination of placenta				
	known whether placenta examined	10.8	Other specified placental pathology				
		10.9	Unspecified or not known whether placenta				
			examined				

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.

PSAN	Z-PDC version May 23 rd 2003	PSAN	Z-PDC version October 2004
11.	No Obstetric Antecedent	11.	No Obstetric Antecedent
11.1	SIDS	11.1	Sudden Infant Death Syndrome (SIDS)
	11.11 Consistent with SIDS		11.11 SIDS Category IA: Classic features of
	11.12 Possible SIDS		SIDS present and completely
11.2	Postnatally acquired infection		documented.
11.3	Accidental asphyxiation		11.12 SIDS Category IB: Classic features of
11.4	Other accident, poisoning or violence (postnatal)		SIDS present but incompletely
11.8	Other		documented.
11.9	Unknown / Unexplained		11.13 SIDS Category II : Infant deaths that
			meet Category I except for one or more
			features.
		11.2	Postnatally acquired infection
		11.3	Accidental asphyxiation
		11.4	Other accident, poisoning or violence
			(postnatal)
		11.8	Other specified
		11.9	Unknown/Undetermined
			11.91 Unclassified Sudden Infant Death
			11.92 Other Unknown/Undetermined

5. Changes to the Neonatal Death Classification Categories

5.1 Congenital abnormality: Category 1.

Changes to subcategories have been made as for the Perinatal Death Classification.

5.2 Other: Category 7.

Changes to the classification of SIDS have been made as for the Perinatal Death Classification.

Gestation	No. births	Mean	Standard	Percent	ile (gm)									
(weeks)		(gm)	Deviation	1st	3rd	5th	10th	25th	50th	75th	90th	95th	97th	99th
20	27	385	76					330	380	430				
21	43	447	66					410	440	490				
22	74	495	80				400	440	490	540	600			
23	95	607	92			470	500	550	610	660	710	780		
24	135	690	129		470	480	520	610	680	780	860	930	990	
25	180	791	132		560	580	620	700	785	870	980	1000	1030	
26	235	921	158		610	620	720	840	920	1020	1130	1160	1170	
27	284	1017	209		610	650	740	900	1000	1140	1280	1350	1440	
28	361	1157	240	570	670	720	850	1000	1170	1300	1440	1550	1600	1790
29	397	1316	261	670	760	840	950	1170	1340	1480	1640	1740	1810	1900
30	571	1477	313	730	860	960	1080	1270	1490	1680	1860	1950	2050	2270
31	743	1682	311	910	1070	1130	1310	1490	1670	1870	2070	2170	2280	2450
32	1117	1875	378	1020	1150	1230	1400	1640	1890	2100	2320	2470	2690	2980
33	1471	2142	415	1210	1360	1450	1640	1900	2120	2370	2650	2920	3060	3300
34	2657	2358	418	1310	1560	1670	1840	2100	2350	2600	2870	3080	3250	3530
35	4092	2610	413	1600	1830	1960	2110	2360	2590	2850	3140	3330	3490	3770
36	8788	2835	432	1780	2020	2150	2320	2560	2820	3100	3380	3570	3730	3960
37	18660	3089	442	2030	2270	2380	2550	2800	3080	3370	3660	3840	3960	4200
38	51404	3317	431	2310	2520	2620	2780	3030	3310	3600	3870	4050	4160	4390
39	72871	3471	426	2500	2690	2790	2940	3180	3460	3750	4020	4200	4310	4520
40	141553	3610	432	2630	2830	2920	3070	3320	3600	3890	4170	4340	4460	4680
41	55946	3739	443	2730	2930	3030	3180	3440	3730	4030	4310	4490	4600	4820
42	14781	3787	463	2730	2950	3040	3210	3470	3780	4090	4390	4570	4680	4910
43	1267	3698	501	2510	2770	2910	3080	3360	3680	4000	4360	4580	4670	4970
44	409	3612	474	2620	2720	2850	3050	3290	3590	3900	4270	4440	4530	4790

Appendix 2a: Table 1. Birthweight percentile values (g) for live singleton males, Australia, 1991-1994

From: Roberts CL & Lancaster PAL. Australian national birthweight percentiles by gestational age. MJA 1999; 170: 114-118.

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Gestation	No. births	Mean	Standard	Percent	ile (gm)									
(weeks)		(gm)	Deviation	1st	3rd	5th	10th	25th	50th	75th	90th	95th	97th	99th
20	12	418	184						345					
21	25	414	55					400	420	440				
22	71	485	85				400	430	480	540	600			
23	79	591	103				470	520	580	640	740			
24	115	661	95		490	500	540	600	660	720	780	830	850	
25	136	760	116		510	560	620	700	750	840	900	960	980	
26	188	865	158		540	550	680	780	865	960	1040	1130	1180	
27	231	944	183		600	620	730	830	950	1070	1180	1250	1280	
28	287	1060	228		610	700	760	900	1070	1200	1340	1400	1440	
29	325	1233	247	630	720	810	890	1070	1250	1400	1510	1580	1660	1820
30	440	1403	275	740	860	945	1045	1220	1420	1560	1730	1885	1950	2100
31	548	1581	336	800	990	1050	1140	1360	1590	1765	2000	2130	2330	2560
32	877	1797	383	920	1070	1170	1340	1560	1780	2000	2230	2470	2640	2970
33	1200	2038	403	1135	1280	1385	1520	1790	2040	2265	2515	2755	2955	3150
34	2086	2282	439	1260	1440	1570	1760	2010	2260	2530	2810	3090	3290	3510
35	3418	2523	433	1520	1740	1840	2030	2260	2490	2760	3100	3340	3500	3710
36	7320	2738	433	1740	1950	2060	2220	2450	2720	3000	3300	3505	3650	3860
37	16105	2967	432	1940	2170	2280	2430	2680	2960	3240	3520	3700	3830	4050
38	47809	3187	419	2220	2420	2520	2660	2900	3170	3460	3730	3900	4020	4220
39	68846	3329	412	2390	2580	2670	2820	3050	3320	3600	3860	4030	4140	4340
40	137570	3463	414	2530	2720	2810	2950	3180	3450	3730	4000	4170	4280	4490
41	53260	3577	421	2630	2820	2910	3050	3290	3560	3850	4130	4300	4410	4620
42	13318	3627	442	2630	2830	2930	3080	3320	3610	3920	4210	4370	4500	4700
43	1285	3539	463	2460	2710	2770	2950	3240	3540	3840	4120	4320	4430	4620
44	433	3490	448	2420	2590	2720	2930	3180	3490	3800	4070	4230	4320	4470

Appendix 2a: Table 2. Birthweight percentile values (g) for live singleton females, Australia, 1991-1994

From: Roberts CL & Lancaster PAL. Australian national birthweight percentiles by gestational age. MJA 1999: 170: 114-118.

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Gestation	No.	Mean	Standard	Percentile ((g)									
(weeks)	Births	(g)	Deviation	1st	3rd	5th	10th	25th	50th	75th	90th	95th	97th	99th
20	5	354	72						370					
21	17	479	202						420					
22	33	475	76					410	480	530				
23	37	549	119					460	560	630				
24	34	653	149					520	675	770				
25	67	764	125				580	690	770	840	920)		
26	57	853	142				690	750	860	940	1000)		
27	80	990	159			750	780	885	995	1080	1170	1245	5	
28	93	1168	224			760	850	1060	1170	1310	1400	1590)	
29	54	1304	230		860	930	1010	1160	1310	1450	1590	1670) 17	90
30	171	1459	238		1000	1070	1170	1300	1460	1620	1760	1830) 18	60
31	191	1622	283		1020	1060	1250	1460	1640	1810	1980	2090) 21-	40
32	331	1782	273	1100	1250	1330	1450	1620	1780	1960	2100	2240) 23	00 2480
33	384	1977	295	1340	1420	1500	1600) 1780	1980	2170	2360	2480) 25	30 2630
34	699	2141	315	1350	1460	1600	1730) 1960	2150	2350	2540	2630) 27	20 2910
35	928	2365	333	1530	1710	1800	1960	2150	2365	2575	2780	2930) 304	40 3180
36	1384	2526	369	1590	1810	1900	2080	2300	2520	2780	2990	3120) 32	10 3380
37	1926	2731	364	1860	2000	2100	2260	2500	2730	2980	3200	3320) 33	80 3520
38	2260	2863	381	1910	2120	2230	2380	2610	2870	3110	3340	3490) 35	60 3760
39	749	2963	379	2130	2300	2360	2480	2700	2960	3190	3440	3600) 37:	50 3920
40	399	3071	441	2090	2310	2350	2490	2780	3060	3340	3650	3820) 39	60 4160
41	52	2951	508				2120	2650	3035	3285	3550)		
42	10	2889	362						2685					
43	4	2695	559						2670					
44	4	2490	833						2415					

Appendix 2a: Table 3.	Birthweight I	percentile values	(a) for	male twins.	Australia.	1991-1994
			(3)			

From Roberts, C, & Lancaster, P., "National birthweight percentiles by gestational age for twins born in Australia", *Journal of Paediatrics and Child Health*, (1999) Vol 35, pp 278-282; tables 4 and 5, fig 2 and 3., Reproduced with permission.

Gestation	No.	Mean	Standard	Percentile (g)									
(weeks)	births	(g)	Deviation	1st 3	Brd	5th	10th	25th	50th	75th	90th	95th	97th	99th
20	8	314	48						310					
21	19	517	401						410					
22	14	441	85						455					
23	30	552	93					490) 550	620				
24	40	606	126					530) 570	680				
25	46	689	100					620) 680	740				
26	67	838	140				680) 750) 830	910	1030)		
27	70	894	205				575	5 790) 940	1020	1135			
28	111	1092	161			780	860	1000) 1110	1200	1280	131	0	
29	86	1171	206			710	870	1080) 1175	1310	1430	150	0	
30	137	1386	225		960	970	1080	1250) 1410	1530	1620	172	18	320
31	207	1507	242		1000	1030	1170	1380) 1520	1630	1800	189	0 19	000
32	322	1673	273	980	1130	1200	1340	1520) 1680	1850	2010	209	0 21	70 2370
33	400	1869	330	1020	1195	1300	1440) 1675	5 1865	2080	2280	240	0 24	55 2705
34	625	2058	307	1240	1440	1530	1660) 1870) 2060	2260	2440	255	0 26	640 2810
35	907	2270	335	1520	1620	1710	1860	2050) 2270	2470	2720	284	0 29	040 3070
36	1463	2430	348	1550	1760	1870	2010) 2200) 2430	2670	2860	298	30 30	90 3320
37	1910	2602	343	1790	1950	2050	2170	2380) 2600	2820	3050	317	0 32	.60 3430
38	2165	2731	359	1860	2050	2140	2270) 2490) 2740	2960	3190	331	0 34	00 3600
39	715	2850	373	2020	2130	2200	2380	2600) 2850	3110	3340	344	0 35	50 3700
40	359	2920	410	2000	2100	2220	2390	2660) 2920	3200	3420	359	0 37	⁷ 50 3860
41	41	2826	469					2540) 2880	3090				
42	14	2684	277						2660					
43	2	2830	0						2830					
44	2	2665	290						2665					

Appendix 2a: Table 4. Birthweight percentile values (g) for female twins, Australia, 1991-1994

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From Roberts, C, & Lancaster, P., "National birthweight percentiles by gestational age for twins born in Australia", *Journal of Paediatrics and Child Health*, (1999) Vol 35, pp 278-282; tables 4 and 5, fig 2 and 3., Reproduced with permission.



Appendix 2b: Figure 1 Australian birthweight percentiles for singleton boys

Gestational age (weeks)

From: Roberts CL & Lancaster PAL. Australian national birthweight percentiles by gestational age. MJA 1999;170: 114-118. ©Copyright 1999. *The Medical Journal of Australia* - reproduced with permission

Appendix 2b: Figure 2 Australian birthweight percentiles for singleton girls

Weight (grams)

Percentile



From: Roberts CL & Lancaster PAL. **Australian national birthweight percentiles by gestational age**. MJA 1999;170: 114-118. ©Copyright 1999. *The Medical Journal of Australia* - reproduced with permission

Appendix 2b: Figure 3 Birthweight percentiles for male twins, Australia



From Roberts, C, & Lancaster, P., "**National birthweight percentiles by gestational age for twins born in Australia**", *Journal of Paediatrics and Child Health*, (1999) Vol 35, pp 278-282; Reproduced with permission



Appendix 2b: Figure 4 Birthweight percentiles for female twins, Australia

From Roberts, C, & Lancaster, P., "National birthweight percentiles by gestational age for twins born in Australia", Journal of Paediatrics and Child Health, (1999) Vol 35, pp 278-282; Reproduced with permission

Appendix 3: Contact details

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