



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



sids and kids



Clinical Practice Guideline for Perinatal Mortality Audit

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, McCowan L, Kent A, Tudehope D, Richardson R, Conway L, Chan A, 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 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 Audit. 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

For further information about the guidelines, please contact:
*Coordinating Centre for the PSANZ Perinatal Mortality Group and
the Australian and New Zealand Stillbirth Alliance
Mater Mothers' Research Centre
Mater Health Services
Annerley Road
Woolloongabba
QLD 4102
Phone 61 7 3163 1592
Fax 61 7 3163 1588
www.psanznmsig.org ; www.stillbirthalliance.org/anz*



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

This document may be downloaded from the Perinatal Society of Australia and New Zealand Perinatal Mortality Group website at www.psanznmsig.org

TABLE OF CONTENTS

Section	Content	Page
Section 1	<i>Overview and summary of recommendations</i>	7-29
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
<i>Appendix 1</i>	Methods of guideline development	17
<i>Appendix 2</i>	Glossary of terms/abbreviations	27
Section 2	<i>Institutional perinatal mortality audit</i>	33-55
2.1	Introduction	34
2.2	Recommendations and rationale	34
2.2.1	Implementation of the guideline	34
2.2.2	Perinatal mortality review committees	34
2.2.3	Review of a perinatal death	36
2.2.4	Data collection, documentation and reporting	36
2.2.5	Communication and feedback	37
2.2.6	Definitions for registration of birth and perinatal deaths	38
2.3	References	39
<i>Appendices</i>		40-55
<i>Appendix 1</i>	Perinatal mortality audit package	41

<i>Appendix 2</i>	Instructions on taking clinical photographs	51
<i>Appendix 3</i>	Autopsy clinical summary form	54
<i>Appendix 4</i>	Perinatal mortality classifications – quick reference sheet	55
Section 3	<i>Psychological and social aspects of perinatal bereavement</i>	56-72
3.1	Introduction	57
3.2	Summary of key recommendations	58
3.3	References	67
<i>Appendices</i>		69-73
<i>Appendix 1</i>	Information for parents about autopsy	69
<i>Appendix 2</i>	Information for the health professional seeking consent	71
Section 4	<i>Perinatal post-mortem examination</i>	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
<i>Appendices</i>		85-89
<i>Appendix 1</i>	RCOP Guidelines for Autopsy Investigation of Fetal and Perinatal Death	85
<i>Appendix 2</i>	Suspected genetic metabolic disorders: Investigation and autopsy protocol	87
<i>Appendix 2a</i>	Screening for genetic metabolic disorders	88
<i>Appendix 2b</i>	Components of the genetic autopsy for investigation of metabolic disorders	89
Section 5	<i>Investigation of stillbirths</i>	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
<i>Appendices</i>		102-103
<i>Appendix 1</i>	Stillbirth investigations algorithm	102
<i>Appendix 2</i>	Estimation of severity of feto-maternal haemorrhage	103

Section 6	<i>Investigation of neonatal deaths</i>	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
<i>Appendices</i>		111-113
<i>Appendix 1</i>	High risk newborn investigation checklist	111
<i>Appendix 2a</i>	Screening for genetic metabolic disorders	112
<i>Appendix 2b</i>	Components of the genetic autopsy for investigation of metabolic disorders	113
Section 7	<i>Perinatal Mortality Classifications</i>	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
<i>Appendices</i>		138-154
<i>Appendix 1</i>	Changes in this version of the Classifications	138
<i>Appendix 2a</i>	Tables 1-4. Birthweight percentile values	146
<i>Appendix 2b</i>	Figures 1-4 Australian birthweight percentiles	150
<i>Appendix 3</i>	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

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 recommended 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 severe cardiorespiratory depression.
- 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 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 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 histopathology 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) Autopsy

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;
 - 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 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

1.8 References

1. PSANZ. Perinatal Society of Australia and New Zealand. <http://128.250.188.72/psanz/>. Australia and New Zealand; 2004 Contract No.: Document Number].
2. De Lange TE, Budde MP, Heard AR, Tucker G, Kennare R, Dekker GA. Avoidable risk factors in perinatal deaths: a perinatal audit in South Australia. *Aust N Z J Obstet Gynaecol*. 2008 Feb;48(1):50-7.
3. Saastad E, Vangen S, Froen JF. Suboptimal care in stillbirths - a retrospective audit study. *Acta Obstet Gynecol Scand*. 2007;86(4):444-50.
4. PSANZ PMN-SIG. Perinatal Society of Australia and New Zealand: Special Interest Group. http://128.250.188.72/PSANZ/SIG/sig_intro.htm. Australia and New Zealand: PSANZ; 2004 Contract No.: Document Number].
5. Chan A, King JF, Flenady V, Haslam R, Tudehope DI. Classification of perinatal deaths: Development of the Australian and New Zealand Classifications. In Print: *Paediatr Child Health*. 2004.
6. Laws P, Sullivan EA. Australia's mothers and babies 2002. Sydney: AIHW National Perinatal Statistics Unit (Perinatal Statistics Series no. 15); 2004 Contract No.: Document Number].
7. NZHIS. Report on Maternity: Maternal and Newborn Information 2002. <http://www.nzhis.govt.nz/publications/Fetal.html>. Manatu Hauora:: Ministry of Health, New Zealand Health Information Service (NZHIS); 2004.; 2004 Contract No.: Document Number].
8. AIHW NPSU 2003. Australian mothers and babies 2000. Canberra: AIHW National Perinatal Statistics Unit (Perinatal Statistics Series no. 12); 2003 Contract No.: Document Number].
9. Fretts RC, Boyd ME, Usher RH, Usher HA. The changing pattern of fetal death, 1961-1988. *Obstet Gynecol*. 1992 Jan;79(1):35-9.
10. Cernach MC, Patricio FR, Galera MF, Moron AF, Brunoni D. Evaluation of a protocol for postmortem examination of stillbirths and neonatal deaths with congenital anomalies. *Pediatr Dev Pathol*. 2004 Jul-Aug;7(4):335-41.
11. Dodd JM, Robinson JS, Crowther CA, Chan A. Stillbirth and neonatal outcomes in South Australia, 1991-2000. *Am J Obstet Gynecol*. 2003 Dec;189(6):1731-6.
12. Flenady V, Chan A, Haslam R, King JF, Tudehope DI, McCowan L. Cause specific perinatal mortality in Australia and New Zealand using a new clinical classification system (ANZACPM and ANZNDC). Perinatal Society of Australia and New Zealand 7th Annual Congress proceedings. Tasmania, Australia; 2003. p. A87.
13. CESDI - Confidential Enquiry into Stillbirths and Deaths in Infancy. 8th Annual Report. London: Maternal and Child Health Research Consortium; 2001 Contract No.: Document Number].
14. Bell R, Glinianaia SV, Rankin J, Wright C, Pearce MS, Parker L. Changing patterns of perinatal death, 1982-2000: a retrospective cohort study. *Arch Dis Child Fetal Neonatal Ed*. 2004 Nov;89(6):F531-6.
15. Flenady V. Causes and Risk Factors of Stillbirth in Australia. *Journal of Paediatrics & Child Health*. [Abstract]. 2008 April 2008;44(Supp. 1):A2.
16. CCOPMM. Annual Report for the Year 2000. Melbourne: The Consultative Council on Obstetric and Paediatric Mortality and Morbidity; 2003 Contract No.: Document Number].
17. CESDI - Confidential Enquiry into Stillbirths and Deaths in Infancy. 6th Annual Report. London: Maternal and Child Health Research Consortium, 1999 Contract No.: Document Number].
18. Richardus JH, Graafmans WC, Bergsjø P, Lloyd DJ, Bakketeig LS, Bannon EM, et al. Suboptimal care and perinatal mortality in ten European regions: methodology and evaluation of an international audit. *J Matern Fetal Neonatal Med*. 2003 Oct;14(4):267-76.
19. King Edward Memorial Hospital. Lessons from the enquiry into obstetrics and gynaecological services at King Edward Memorial Hospital: Australian Council for Safety and Quality in Healthcare; 2002 Contract No.: Document Number].
20. The Royal College of Pathologists. Guidelines on autopsy practice: Report of a working group of the Royal College of Pathologists. London: Royal College of Pathologists; 2002 [updated 2002; cited 2004]; Available from: http://www.rcpath.org/activities/publications/autopsy_practice_sept2002.html.
21. The Royal College of Pathologists. Guidelines for Post Mortem Reports. London: The Royal College of Pathologists; 1993 Contract No.: Document Number].
22. National Health and Medical Research Council. NHMRC handbook series on preparing clinical practice guidelines. <http://www.nhmrc.gov.au/publications/synopses/cp65syn.htm>. Canberra: Commonwealth of Australia; 1999 Contract No.: Document Number].
23. National Health and Medical Research Council. A guide to the development, implementation and evaluation of clinical practice guidelines. Canberra: Commonwealth of Australia; 1998 Contract No.: Document Number].

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 Audit 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, Newborn Intensive Care, Waikato Hospital	Classification 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, University of Sydney and RPA Newborn Care, Royal Prince Alfred Hospital, Sydney, NSW. NSW Regional Coordinator, Co-Chair Clinical Practice & Education Committee, ANZSA.	Overall consultation 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; fetal death, fetal 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 Neonatal Nurses	http://www.awhonn.org/awhonn
Australian Government, Department of Health & Ageing: Safety & Quality in Health Care	http://www.health.gov.au
Australian Government, National Health & Medical Research Council	http://www.nhmrc.gov.au
British Columbia Perinatal Care Program,, Canada	http://www.bcphp.ca/Perinatal%20Mortality%20Guidelines.htm
Canadian Paediatric Society	http://www.cps.ca/english/publications
Canadian Task Force On Preventive Health Care: Evidence-Based Clinical Prevention	http://www.ctfphc.org/
Confidential Enquiry into Maternal and Child Health (CEMACH)	http://www.cemach.org.uk/Publications.aspx
Department of Health, New South Wales	http://www.health.nsw.gov.au/
Department of Health, United Kingdom	http://www.dh.gov.uk/Home/fs/en
Department of Health, Western Australia	http://www.health.wa.gov.au/
Guideline Advisory Committee, Ontario, Canada	http://www.gacguidelines.ca/
HSTAT – Health Services/Technology Assessment Text	http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat
Human Tissue Authority, United Kingdom	http://www.hta.gov.uk/guidance/codes_of_practice.cfm
Institute of Clinical Systems Improvement	http://www.icsi.org/guidelines_and_more/
King Edward Memorial Hospital for Women, Subiaco, Western Australia	http://www.kemh.health.wa.gov.au/
National Guideline Clearinghouse	http://www.guideline.gov/
National Institute for Clinical Excellence, UK	http://www.nice.org.uk/
Neonatology on the Web	http://www.neonatology.org/
New Zealand Guidelines Group	http://www.nzgg.org.nz/index.cfm?screensize=1024&ScreenResSet=yes
Princess Margaret Hospital for Children, Subiaco, Western Australia	http://www.pmh.health.wa.gov.au/
Queensland Health, Australia	http://qheps.health.qld.gov.au/
Royal Children's Hospital, Melbourne, Australia	http://www.rch.org.au/clinicalguide/index.cfm?doc_id=5033
Royal College of Obstetricians and Gynaecologists, UK	http://www.rcog.org.uk/index.asp?PageID=8
Royal College of Pathologists	http://www.rcpath.org/
Royal Prince Alfred Hospital, Camperdown, New South Wales	http://www.cs.nsw.gov.au/rpa/
Scottish Intercollegiate Guidelines Network (SIGN)	http://www.sign.ac.uk/
Society of Obstetricians and Gynaecologists of Canada	http://www.sogc.org/index_e.asp
Three Centres Collaboration, Australia	http://www.3centres.com.au/
University of California and San Francisco, United States	http://medicine.ucsf.edu/resources/guidelines/
University of Manitoba, Canada	http://umanitoba.ca/
Wisconsin Stillbirth Service Program	http://www.wisc.edu/wissp/
Women's and Children's Hospital, Adelaide, Australia	http://www.wch.sa.gov.au/

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

Association	Guideline
Alberta Medical Association	Alberta Medical Association. Investigation of Stillborn Protocol. In: Alberta Medical Association; 1998 (updated 2005). http://www.albertadoctors.org/bcm/ama/ama-website.nsf/AllDoc/FB1F65D913EDB64787256E2A005E700E?OpenDocument accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 1: The Perinatal Mortality Review Process. British Columbia; 1999. http://www.bcrp.xplorex.com/sites/bcrp/files/Guidelines/Pmg/MasterPM1ReviewProcessApril99.pdf accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 2: Hospital Perinatal Mortality Review Committee: Terms of Reference. British Columbia; 1999. http://www.bcrp.xplorex.com/sites/bcrp/files/Guidelines/Pmg/MasterPM2TORHospReviewCommApril99.pdf accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 3: Classification of Perinatal Deaths. British Columbia; 1999. http://www.bcrp.xplorex.com/sites/bcrp/files/Guidelines/Pmg/MasterPM3ClassifDeathsApril99.pdf accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 4: Clinical Examination of the Placenta. British Columbia; 1999. http://www.bcrp.xplorex.com/sites/bcrp/files/Guidelines/Pmg/MasterPM4ExamPlacentaApril99.pdf accessed 2008
British Columbia Reproductive Care Program	British Columbia Reproductive Care Program. Perinatal Mortality Guideline 5: Investigation and Assessment of Stillbirths. British Columbia; 1999. http://www.bcrp.xplorex.com/sites/bcrp/files/Guidelines/Pmg/MasterPM5InvestAssesStillbirthsMay2000.pdf accessed 2008
Canadian Paediatric Society	Canadian Paediatric Society Statement. Guidelines for health care professionals supporting families experiencing a perinatal loss. Paediatric Child Health 2001;6(7):469-477. (Re-affirmed May 2007) http://www.cps.ca/english/statements/FN/FN01-02.pdf accessed 2008
South Australian Department of Human Services	Department of Human Services South Australia. Maternal, Perinatal and Infant Mortality in South Australia 2006. Including South Australian Protocol for investigation of stillbirths. In: Department of Human Services, South Australia; 2007. http://www.dh.sa.gov.au/pehs/PDF-files/0712-mortality-report-2006.pdf accessed 2008
Royal Prince Alfred Hospital, Sydney, NSW	Department of Neonatal Medicine RPAH. Stillbirths. In: Central Sydney Area Health Service. http://www.cs.nsw.gov.au/rpa/neonatal/default.htm accessed 2008
Department of Health, UK	DH Clinical Ethics and Human Tissue Branch. Families and post mortems - A code of practice. Best Practice Guideline. London: Department of Health; 2003 April 2003. http://www.dh.gov.uk/assetRoot/04/05/43/12/04054312.pdf accessed 2008
Department of Health, UK	DH Clinical Ethics and Human Tissue Branch. A guide to the post mortem examination procedure involving a baby or child. In: Department of Health; 2003. http://www.dh.gov.uk/assetRoot/04/08/39/60/04083960.pdf accessed 2004

Queensland Department of Health	Queensland Maternal and Perinatal Quality Council. Maternal and Perinatal Mortality Audit: Guidelines for Maternity Hospitals. Queensland: Queensland Government, Queensland Health; 2003.
Royal Children's Hospital, Melbourne, VIC	Kane H, Wilkinson G. Reproductive Loss: Pre 20 Week / Stillbirth / neonatal death / infant death, Melbourne. Melbourne: Royal Children's Hospital, Melbourne; 2003 19/05/2003. Report No.: 9W-04-1-002. http://www.rch.org.au/intranet/policy/9W041002.htm accessed 2004 Not able to be accessed March 2008
Royal Children's Hospital, Melbourne, VIC	Kane H, Wilkinson G. Reproductive Loss: Stillbirth 20 weeks and over, Melbourne. Electronic. Melbourne: Royal Children's Hospital, Melbourne; 2003 17/05/2003. Report No.: 9W-04-2-038. http://www.rch.org.au/intranet/policy/9W042038.htm accessed 2004 Not able to be accessed March 2008
Western Australia Department of Health	McLaughlin V. Non-Coronial Post-Mortem Examinations: Code of Practice 2007, WA: Health Department, WA; 2007. http://www.health.wa.gov.au/postmortem/docs/Non-Coronial_Post-Mortem_Examinations_Code_of_Practice_2007.pdf accessed March 2008
New South Wales Department of Health	NSW Health Department. Stillbirth: Management and Investigation.. Electronic/circular. Sydney: NSW Health Department; 1997 27/10/1997. Report No.: 97/107. http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007_025.pdf accessed March 2008
New South Wales Department of Health	NSW Health Department. Hospital Procedures for review and reporting of perinatal deaths. In; 2006. http://www.health.nsw.gov.au/policies/pd/2006/pdf/PD2006_006.pdf accessed March 2008
Royal College of Pathologists, UK	Royal College of Pathologists. Appendix 6: Guidelines for autopsy investigation of fetal and perinatal death. London: Royal College of Pathologists; 2002 Sept 2002. http://www.rcpath.org/resources/pdf/appendix_6.pdf accessed March 2008
Royal Children's Hospital, Melbourne, VIC	Ross J, Smith M, Dutton G. Reproductive Loss: Neonatal / Infant Death. Electronic. Melbourne: Royal Children's Hospital, Melbourne; 1999 18/11/99. Report No.: 9W-04-2-019. http://www.rch.org.au/intranet/policy/9W042019.htm accessed March 2008
King Edward Memorial Hospital, WA	Women's and Children's Health Services WA. Perinatal Death. In: King Edward Memorial Hospital; 2001. http://www.kemh.health.wa.gov.au/development/manuals/guidelines.htm accessed March 2008
Women's and Children's Hospital, Adelaide, SA	Women's and Children's Hospital Adelaide. Perinatal Protocols and Guidelines for Management; 1996. http://www.wch.sa.gov.au/services/az/divisions/wab/deliverysuite/ accessed 2004
Government of South Australia. Department of Health.	Directed to South Australian Government. (below) South Australian Perinatal Practice Guidelines http://www.health.sa.gov.au/PPG/Default.aspx?tabid=113 accessed March 2008.

Levels of evidence

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

ACNN

Australian College of Neonatal Nurses.

AETIOLOGY

The science of causes, especially of disease.

AMNION

A thin but tough extraembryonic membrane of reptiles, birds and mammals that lines the chorion and contains the foetus and the amniotic fluid around it, in mammals it is derived from trophoblast by folding or splitting.

AMNIOTIC FLUID

The fluid that surrounds the developing foetus within the amniotic sac. This environment cushions the baby from injury and plays an important role in foetal development

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-posterior 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.

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

Postero-anterior view.

PATHOLOGY

The branch of medicine concerned with disease, especially its structure and its functional effects on the body.

PCR

Polymerase Chain Reaction

PERINATAL MORTALITY RATE (PMR)

see Mortality Rates.

POST-MORTEM

After death. Hence a post-mortem examination may or may not include an autopsy.

POSTNEONATAL INFANT DEATH

Death occurring after 28 completed days up to 1 year following live birth.

PSANZ

Perinatal Society of Australia and New Zealand.

PSANZ-PDC

Perinatal Society of Australia and New Zealand – Perinatal Death Classification.

PSANZ-NDC

Perinatal Society of Australia and New Zealand – Neonatal Death Classification.

PSANZ-PMG

Perinatal Society of Australia and New Zealand Perinatal Mortality Group.

RANZCOG

Royal Australian and New Zealand College of Obstetricians and Gynaecologists.

RCP

Royal College of Pathologists.

RCPA

Royal College of Pathologists of Australasia.

RACP

Royal Australasian College of Physicians – Division of Paediatrics & Child

SAFDA

Support After Fetal Diagnosis of Abnormality.

SANDS

Stillbirth And Neonatal Death Support Group.

SGA

Small for gestational age – see *IUGR*.

SLE

Systemic lupus erythematosus.

STILLBIRTH (Fetal Death)

Death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 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.