

Equity in Perinatal Pathology for Stillbirths: Australian Perspective on reducing barriers

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AUSTRALIA



Custom Baby in Hands Sketch Stillborn Baby Loss Baby - Etsy Australia



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2024 Stillbirth Equity Symposium, Utah, USA

Outline

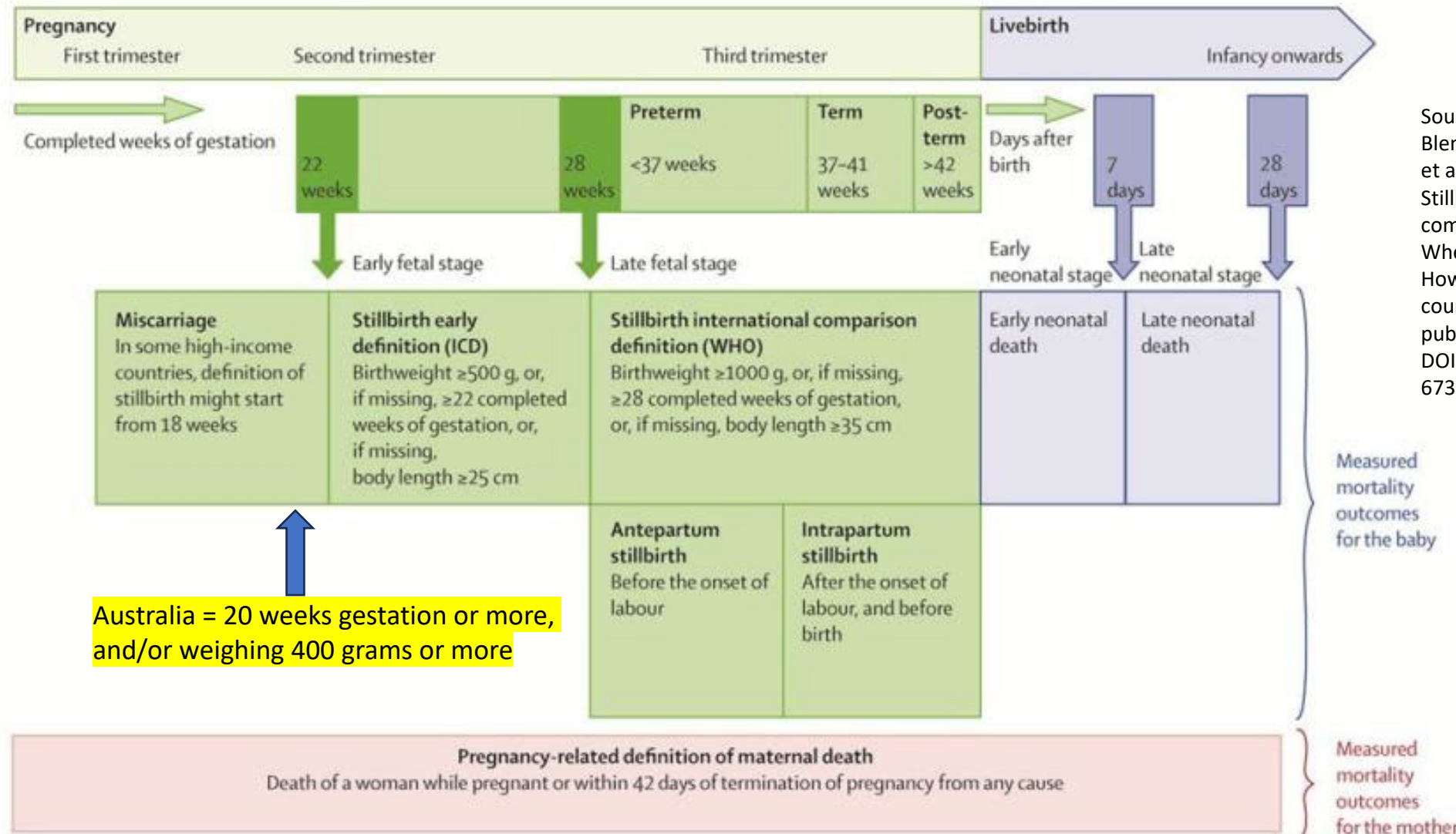
- Definitions and scene setting
- Ways we are addressing inequity in perinatal pathology in Australia
 - Active advocacy
 - Education
 - Funding/resources for services
 - Collection of data/ research



Talk will be available –internet links for more detailed information

<https://dworkenlaw.com/>

Definition: stillbirth



Australia = 20 weeks gestation or more, and/or weighing 400 grams or more

Background : stillbirth rates

2022: 300,684 registered births; 2357 stillbirths

2022: 7.9 stillbirths per 1,000 births

- 85% antepartum

(2022: Perinatal death rate of 10.2 deaths per 1,000 births)

On average day in Australia, 6 babies are stillborn ;1% of babies born

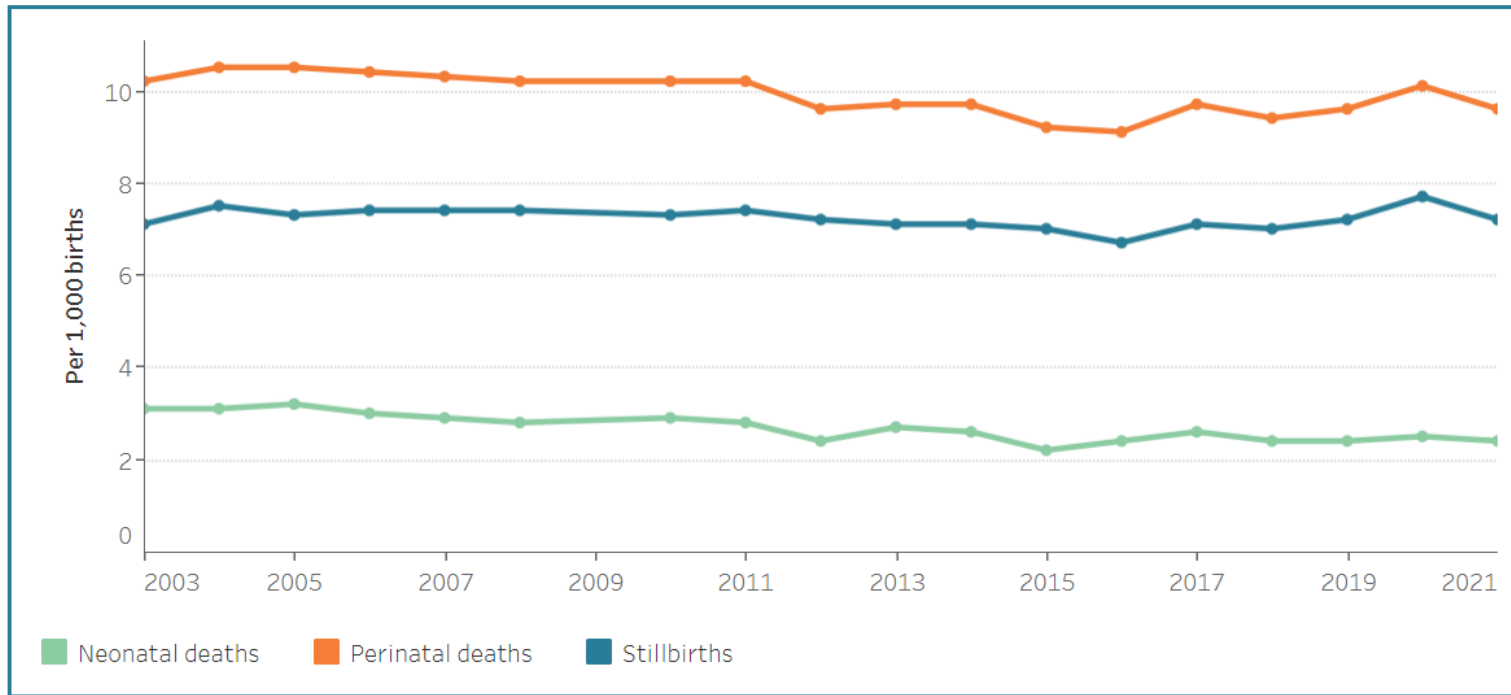
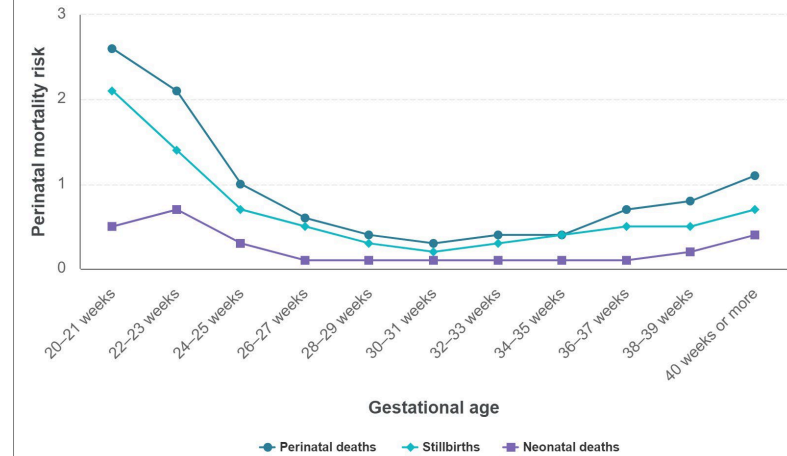


Figure 8: Gestational age-specific risk of perinatal mortality, 2021



<https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths> (accessed 28/9/2024)

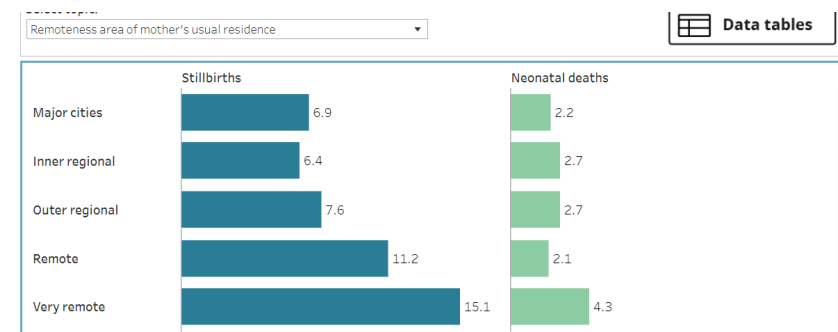
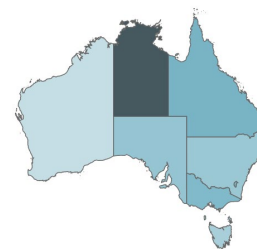
<https://www.abs.gov.au/statistics/people/population/births-australia/latest-release> (accessed 28/9/2024)

<https://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/data> (accessed 28/9/2024)

Background : stillbirth rates

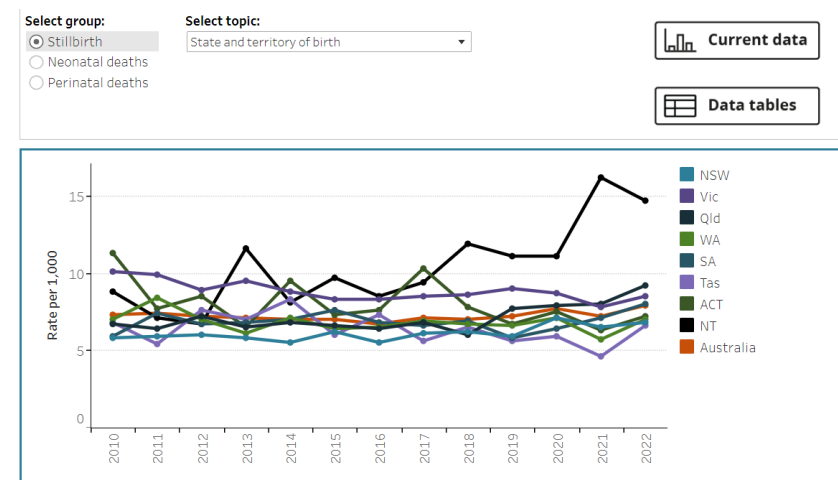
The overall rate of perinatal mortality in Australia in 2021 was 9.6 deaths per 1,000 births. Perinatal mortality rates were higher among babies born to:

- women who accessed 2 or fewer antenatal visits (96 perinatal deaths per 1,000 births)
- women with pre-existing diabetes mellitus (27 deaths per 1,000 births)
- women who have had a previous stillbirth (23 deaths per 1,000 births).
- women who were aged under 20 or 40 and over (21 and 14 deaths per 1,000 births, respectively)
- women who lived in *Very remote* areas (19 deaths per 1,000 births)
- women who have had four or more previous births (17 deaths per 1,000 births)
- First Nations women (17 deaths per 1,000 births)
- women who smoked throughout pregnancy (16 deaths per 1,000 births)
- women living in the most disadvantaged areas of Australia (12 deaths per 1,000 births for quintile



Notes:

1. The rate is the number of deaths per 1,000 births. Stillbirth and perinatal mortality rates were calculated using total births (live births and stillbirths). Neonatal mortality rates were calculated using live births.



<https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths> (accessed 28/9/2024)

Definition: Perinatal pathology

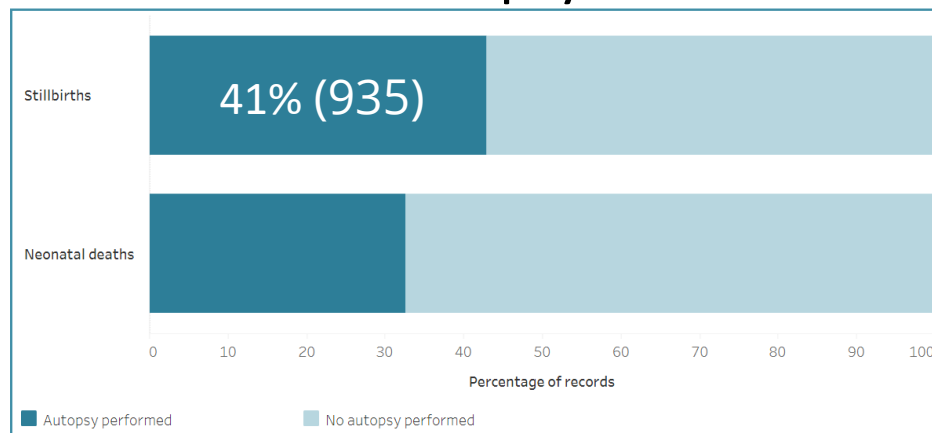
- Perinatal autopsy (examination of a baby after death) and placental examination
- The National Perinatal Mortality Data Collection

[FetalAndPerinatalPath-Jun01.pdf \(rcpath.org\)](#) (accessed 21/9/2024)



Families are approached – 95% in 2021 - issue more complex

Autopsy

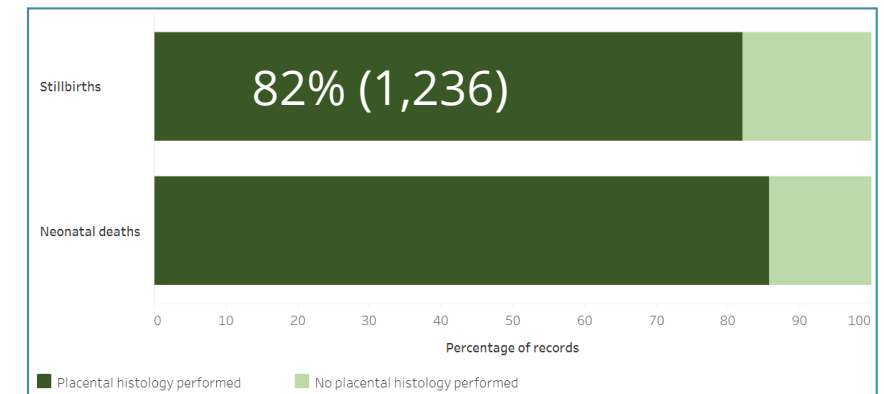


Notes:
1. Autopsy performed includes full and limited autopsies, external examinations and records where an autopsy was performed but type is unknown.

2017 31 % Queensland - 62 % WA

Autopsy performed in (50%) = 'Unexplained antepartum fetal death'

Placenta



Notes:
1. Data on whether placental histology was performed are not available for Qld and WA.
2. Percentages are calculated after excluding records where autopsy status was 'not stated'. Care must be taken when interpreting percentages.

34% of records

2017: Queensland (28.5 % Indigenous parents consent to autopsy following stillbirth compared to 38.9 % for non-Indigenous parents)

<https://www.health.gov.au/sites/default/files/response-stillbirth-research-and-education.pdf> (accessed 14/5/2023)

Improving equity in perinatal pathology in Australia 1: Advocacy

- Multi-pronged approach
 - Parents and community
 - Stillbirth support groups
 - Stillbirth Foundation Australia
 - Sands Australia
 - Global Stillbirth Advocacy Network
 - Red Nose
 - Health Consumers' Council
 - Professional medical organisations
 - Royal College of Pathologists of Australasia
 - The Royal Australian and New Zealand College of Obstetricians and Gynaecologists
 - Maternity Consumer Network
 - Australian
 - College of Midwives
 - Research and government organisations
 - Centre of Research Excellence in Stillbirth
 - Population Health Research Network
 - Health and Vital Statistics, Australian Bureau of Statistics

<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22chamber/hansards/0e1c9ae1-010d-4aea-a021-c8417644b139/0200%22> (accessed 14/5/2023)

Recent sentinel event



Kristina Keneally gives her first speech in the Senate on Tuesday. Photograph: Mike Bowers/The Guardian

Tuesday, 27 March 2018

"Six babies who die every day in Australia. Surely we can do better than this as a nation. On 18 June 1999, one of those babies was my daughter, Caroline."

Kristina Keneally announces Senate inquiry into stillbirths - as it happened

Select Committee on Stillbirth Research and Education



On 27 March 2018 the Senate established the Select Committee on Stillbirth Research and Education to inquire and report on the future of stillbirth research and education in Australia.

The closing date for submissions is 29 June 2018.

[Select Committee on Stillbirth Research and Education – Parliament of Australia \(aph.gov.au\)](#) (accessed 29/9/2024)

The Senate

Select Committee on
Stillbirth Research and Education

Report

think there are other options.¹⁰⁰

4.101 Professor Jane Hackett stated that examination of the placenta is an important part of stillbirth investigation and influences the quality of the data available. Professor Hackett also considered that such investigations should be undertaken by specialist perinatal pathologists, noting that: 'perinatal/placental pathologists are more likely to detect significant disease in a placenta associated with

98 Associate Professor Karen Ireland-Jenkin, Head of Unit, VPAS, Committee Hansard, 7 September 2018, pp. 14–15.

99 Ms Julie Matthews, Submission 100, [p. 3].

100 Dr Dana Payne, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australia (RCPA), Committee Hansard, 6 September 2018, p. 43.

101 Stillbirth CRE, Submission 56, p. 18.

102 Dr Gordon, RACP, Committee Hansard, 8 August 2018, p. 48.

56 stillbirth than a general anatomical pathologist.¹⁰² Associate Professor Ireland-Jenkin simply stated:

There are some of us who work in this area who feel that, if we—this is pathologists—were only allowed to do one test in the investigation of stillbirth and if you said to me, 'Would you like to examine the placenta or would you like to perform the autopsy?' I think I would choose the placental pathology, because I think it's incredibly important.¹⁰³

4.102 There is, however, a lack of funding to undertake stillbirth autopsies in some jurisdictions, and this is compounded by a shortage of skilled pathologists available to undertake autopsies on stillbirth babies—an issue for high-income countries more generally.¹⁰⁴

4.103 Dr Gordon noted that, in NSW where the autopsy rate is relatively low, the government has introduced a statewide perinatal pathology service that is available to all families, regardless of their geographical location. The service includes a coordinator and a central telephone number. 'It's all quite new. But I guess one solution to limited numbers of people is having some investment from the jurisdiction and a statewide service'.¹⁰⁵

4.104 Similarly, the Victorian government has introduced a coordinated perinatal autopsy service in public hospitals.¹⁰⁶ The VPAS stated that the perinatal autopsy rate in Victoria is approximately 40 per cent, although it considered the optimal rate to be 60 per cent, and considered that a centralised service was essential to achieving consistency in stillbirth reporting and improvements in a hospital's procedures.

[Final report \(aph.gov.au\)](#) (accessed 29/9/2024) - 187 pages

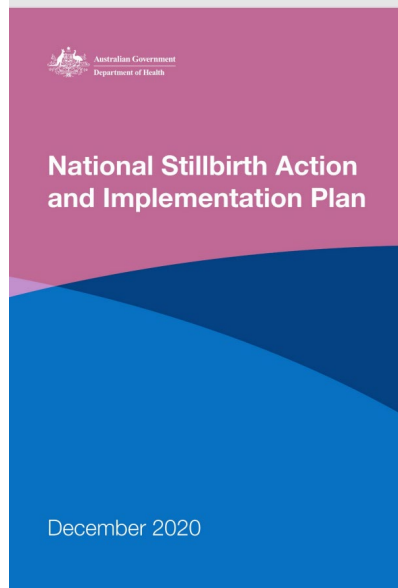
Improving equity : inquiry, report, recommendations, government investment and monitoring

On 27 March 2018, Senate established the Select Committee on Stillbirth Research and Education (the Committee) to inquire into and report on the future of stillbirth research and education in Australia (the Inquiry). The committee tabled its report (the Report), which includes **16 recommendations**, on 4 December 2018



Australian Government

\$52.4 million investment



Australian Government response to:

The Senate Select Committee on Stillbirth Research and Education Report

<https://www.health.gov.au/sites/default/files/response-stillbirth-research-and-education.pdf> (accessed 14/5/2023)



<https://www.health.gov.au/resources/publications/national-stillbirth-action-and-implementation-plan?language=en>
(accessed 21/9/2024)

Figure 1 Woman-centred care
The diagram above gives a visual representation of the purpose, values and principles outlined in Woman-centred care: strategic directions for Australian maternity services, with an additional outermost ring that includes additional principles of relevance to this Plan. The inner ring represents the purpose of the document and is surrounded by the values. The rays present the principles and the third ring represents the Respectful maternity charter: the universal rights of childbearing women.

July 2019

2024 Stillbirth Equity Symposium, Utah, USA

Improving equity: national inquiry - issues, report, recommendations, government investment and monitoring

Annual Monitoring Report Card: December 2021 to December 2022

Figure 2 provides a snapshot of implementation progress from December 2021 to December 2022. The Implementation Update has been filled out based on information and the implementation traffic light system from the First Evaluation Report.

Figure 2 | Annual Monitoring Report Card – Implementation update against action areas

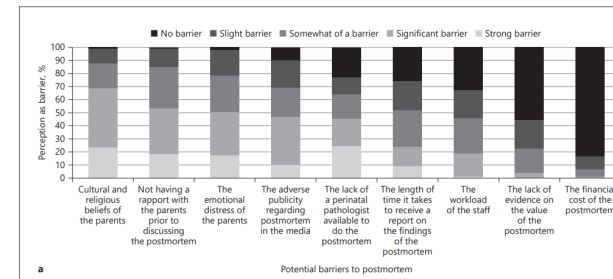
[The National Stillbirth Action and Implementation Plan Annual report 2, 2023 | Australian Government Department of Health and Aged Care](#) (accessed 30/9/2024)



Improving equity in perinatal pathology in Australia 2: Education

\$3 million for stillbirth education and awareness programs

- Funded partnership agreements between federal and state governments and educational institutions- delivery of education programs and resources especially around value of perinatal pathology and consent processes
 - Parents and community
 - Health professions
 - Health organisations



Spierson H, Kamupira S, Storey C, Heazell AEP. Professionals' Practices and Views regarding Neonatal Postmortem: Can We Improve Consent Rates by Improving Training? Neonatology. 2019;115(4):341-345

Recommendation 9

The committee recommends that the Department of Health, in consultation with local communities, develops national best practice guidelines for

hospitals and health centres on providing culturally appropriate support and information for bereaved families who have experienced stillbirth, drawing on successful models such as the Integrated Support After Infant Loss clinic. The guidelines should include provision for bereavement support and address the specific needs of:

- bereaved fathers, siblings, grandparents and other family members;
- families from rural and remote communities;
- Aboriginal and Torres Strait Islander families; and
- families from culturally and linguistically diverse backgrounds.

Table 1

Decision drivers: reasons for and against autopsy after stillbirth

| Decision driver | Reason for autopsy | Reason against autopsy |
|--------------------------------|---|---|
| Preparedness to make decisions | Certain of action to take | Feeling overwhelmed or unable to take things in |
| Parental responsibility | Confidence with scientific processes | |
| | Obligation to determine what went wrong | Desire to protect baby from unnecessary harm |
| | Consideration of needs of future children | |
| Possible consequences | Better peace of mind | Fear of blame for outcome |
| Role of health professionals | Supportive of autopsy | Unsupportive of autopsy |

Horey D, Flenady V, Conway L, McLeod E, Khong TY. Decision influences and aftermath: parents, stillbirth and autopsy. Health Expectations, 2014; 17: 534–544.

Table 1 Reasons for not offering a postmortem examination to all bereaved parents

| Reason | Respondents (%) |
|--|-----------------|
| Concern that the result might question your clinical judgement | 2 |
| Being uncomfortable with the postmortem examination process yourself | 4 |
| Recent cases of organ retention | 9 |
| The new consent form for postmortem examination | 15 |
| Concern that it might upset parents further | 20 |
| Availability of a perinatal pathologist | 35 |

Rose C, Evans M, Tooley J. Falling rates of perinatal postmortem examination: are we to blame? Arch Dis Child Fetal Neonatal Ed. 2006 Nov;91(6):F465.

Improving equity: nationally funded educational resources for families in perinatal pathology

Recommendation 10

The committee recommends that the Australian government develops and implements a national stillbirth public awareness campaign, similar to the successful SIDS campaign, which aims to demystify stillbirth, educates parents and the general public about the risks of stillbirth, and encourages public conversations about stillbirth as a public health issue.

Agreed.

Post mortem examination - an explanation for families

This information is for families whose baby has died at the Royal Women's Hospital. While some of the information will be relevant to families elsewhere, not all hospitals follow the same procedures.

- (ENGLISH) PDF (505 KB)
- (AMHARIC) PDF (98 KB)
- (ARABIC) PDF (89 KB)
- (BURMESE) PDF (601 KB)
- (CHINESE) PDF (238 KB)
- (HINDI) PDF (1 MB)
- (SOMALI) PDF (68 KB)
- (TURKISH) PDF (75 KB)
- (VIETNAMESE) PDF (80 KB)

[Obtaining informed consent for perinatal post-mortem | The Royal Women's Hospital \(thewomens.org.au\)](#)

First nations (culturally appropriate), multiple languages, written and visual resources

A range of resources to help you make an informed decision on your next steps.

These resources should not replace talking with your healthcare team. Ask them about any questions or concerns you have after reading the booklet and watching these videos. Take your time to watch these. You can pause or replay as many times as you need. There is also no rush to make your decision. Your support team will be able to tell you how much time you have. You can still spend time with your baby.

Options; cultural/religious concerns

Aim: reduce parental regret and decision conflict

Guiding Conversations

we are so sorry you are here

Parents of Loss

Autopsy & Investigation

Translated resources — by language

- Arabic
- Pre-admission (PDF 668KB) — معلومات تسبق النشوء التي تعاني من فقدان المولود في فترة الحمل
 - Stillbirth investigations (PDF 845KB) — استقصاءات الإلحاح (إلحاح طلق ممتلئ) معلومات للوالدين
 - Postnatal care (PDF 805KB) — الرعاية ما بعد الإلحاح (إلحاح طلق ممتلئ)
- Dari
- Pre-admission (PDF 669KB) — معلومات قبل الإلحاح (إلحاح طلق ممتلئ) معلومات للوالدين
 - Stillbirth investigations (PDF 1088KB) — تحقيقات في موت الجنين معلومات للوالدين
 - Postnatal care (PDF 1002KB) — الرعاية ما بعد الإلحاح (إلحاح طلق ممتلئ)
- Farsi
- Pre-admission (PDF 545KB) — معلومات قبل الإلحاح (إلحاح طلق ممتلئ) معلومات للوالدين
 - Stillbirth investigations (PDF 947KB) — تحقيقات في موت الجنين معلومات للوالدين
 - Postnatal care (PDF 920KB) — الرعاية ما بعد الإلحاح (إلحاح طلق ممتلئ)
- Hazaragi
- Pre-admission (PDF 691KB) — معلومات قبل الإلحاح (إلحاح طلق ممتلئ) معلومات للوالدين
 - Stillbirth investigations (PDF 1020KB) — تحقيقات في موت الجنين معلومات للوالدين
 - Postnatal care (PDF 777KB) — الرعاية ما بعد الإلحاح (إلحاح طلق ممتلئ)
- Simplified Chinese
- Pre-admission (PDF 1042KB) — 围产儿死亡家庭的人院前信息
 - Stillbirth investigations (PDF 1344KB) — 死产调查：给父母的信息
 - Postnatal care (PDF 524KB) — 死产产后护理
- Vietnamese
- Pre-admission (PDF 504KB) — Thông tin Trước khi Nhập viện cho các Gia đình bị Tử vong Chu Sinh
 - Stillbirth investigations (PDF 696KB) — Điều tra Thai chết non: Thông tin dành cho Cha Mẹ
 - Postnatal care (PDF 550KB) — Chăm sóc Sau sinh sau khi Thai chết non

<https://youtu.be/LLdruA7449Y>

[Stillbirth Parent Resources | Red Nose Australia \(accessed 17/6/2023\)](#)

Understanding what happened to your baby

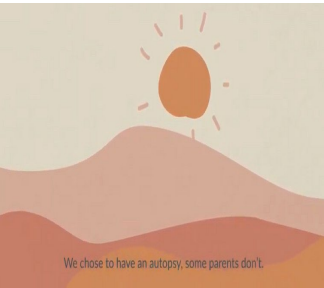
We are so sorry you are here

Understanding what happened to your baby

Translated Resources

We are so very sorry you are here right now watching this.

Follow the link below for translated resources to be found in Simplified Chinese, Traditional Chinese, Arabic, Vietnamese and Spanish.



Autopsy and Investigation - Spanish Subtitles

Your healthcare team is here for you at this very difficult time.

We are so sorry for your loss.

Understanding what happened to your baby

We are so sorry

This brochure has been designed to help you understand your options and outline some of the decisions you need to make.

When grieving making decisions can be very hard

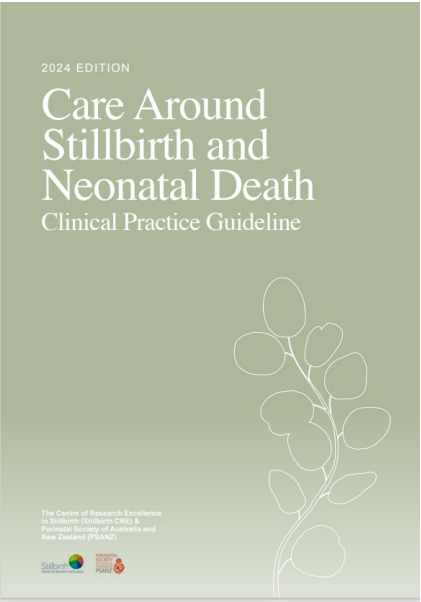
You may have been asked to think about investigations to look at what happened to your baby. You may not have heard of these things before. You might have lots of questions or worries – most families do. This is one of the hardest decisions you will make.

Not every stillbirth needs to be looked at in the same way. You can talk to your health team about what is best for you, your family and your baby.

Working with First Nations people we have created a brochure for Indigenous and Torres Strait Islander peoples.

These resources have also been translated into Spanish, Chinese, Simplified Chinese, Vietnamese and Arabic.

Improving equity: nationally endorsed evidenced guidelines for clinicians about stillbirth investigation



Recommendation 11

The committee recommends that the Australian government develops and implements a national best-practice, culturally appropriate education kit that equips current and future health professionals to:

- discuss risks and strategies for preventing stillbirth with pregnant women; and
- provide culturally and linguistically appropriate information about counselling and support services to assist them with emotional support whilst caring for parents following a stillbirth.

Agreed in principle.

[CAsaND-Guideline-2024-1.pdf \(stillbirthcre.org.au\)](#) (accessed 28/9/2024)

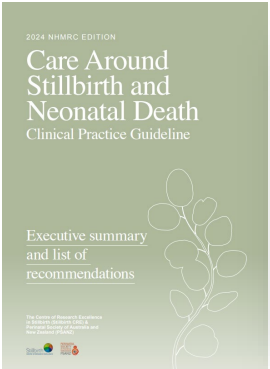
Resources

- **Appendix 6A Stillbirth investigations flowchart**
- **Appendix 6B Neonatal death investigations flowchart**
- **Appendix 6C Estimation of severity of foeto-maternal haemorrhage**
- **Appendix 6D Placental examination for healthcare professionals**
- **Appendix 6E Clinical examination of baby checklist**
- **Appendix 6F Instructions on taking clinical photographs**
- **Appendix 6G Autopsy clinical summary form**
- **Appendix 6H Birthweight centiles**
- **Appendix 6I Information for parents and healthcare professionals about perinatal death investigations**
- **Appendix 6J Information for healthcare professionals seeking parental consent for postmortem investigations of a baby**
- **Appendix 6K Exemplar placental histopathology request form**
- **Appendix 6L Indications for placental examination by the pathologist**

Stillbirth investigations flowchart



*Antiphospholipid antibody test includes antinuclear, lupus anticoagulant, anti-β2 glycoprotein-1 antibodies, DRV, Complement, LFTs, liver function tests, HbA1c, haemoglobin A1c, MRI, magnetic resonance imaging



Evidenced based test ordering, investigation options, costs, how to approach consent

Information for healthcare professionals seeking parental consent for postmortem investigations of a baby

Discussing postmortem investigations with parents

The death of a baby is devastating for parents and their family. Often the death is unexpected, and the parents are confronted with the shock of losing their baby, as well as the overwhelming emotions that follow. Sensitivity and compassion are critically important when providing information to parents around the death of a baby. This resource aims to provide guidance to healthcare professionals when approaching bereaved parents to discuss postmortem investigations. Each hospital should have its own policy and procedures regarding parental consent for autopsy and other investigations. This policy should ideally be consulted.

Why is it important to offer bereaved parents postmortem examinations?

Provision of information on why postmortem investigations are performed will help parents make the right decision for their baby. The primary reason for postmortem investigations is to understand why the baby has died. This investigation may confirm suspected reasons for the death or uncover new information, which may help parents to understand what happened and may be used in planning care for future pregnancies. Information from investigations after a perinatal death can also help healthcare services and researchers understand why babies sometimes die. A full investigation does not always provide an answer as to why a baby died, but it does offer the best opportunity to get this information, and may rule out some possible causes.

Non-invasive options include external examination of the baby by a specialist doctor or pathologist without surgical incisions. **Medical photographs** may help to identify possible causes of death and enable consultation with specialist expertise. **Full body X-ray** imaging of the baby (also known as a 'babygram'), helpful where skeletal abnormalities may be suspected.

Autopsy involves a specialist doctor or pathologist making a full autopsy. It is helpful to discuss these options with a perinatal pathologist to ensure the most appropriate investigation is undertaken. Less invasive options include **limited autopsy** which includes targeted examinations of organs or tissues (also known as minimally invasive tissue sampling) by the pathologist based on clinical suspicion of cause (e.g. the chest organs only, if a cardiac anomaly is suspected).

Placental examination is one of the most important investigations. Parents should be offered the option of taking the placenta home after examination. **Placental examination** is one of the most important investigations. Parents should be offered the option of taking the placenta home after examination.

Parents should be given time to consider the information before making their decision.

What are the options?

Explain to the parents that a full work up following antenatal or neonatal death and a full autopsy provides the highest likelihood of finding a cause of death along with placental examination.

As soon as possible after diagnosis of a fetal death in utero, a **fetal postmortem ultrasound** should be performed by a skilled healthcare professional, this may help to identify selected abnormalities.

Full autopsy involves a perinatal pathologist making a full autopsy and examines the baby's internal organs. Samples may be taken for examination under a microscope and medical photographs and X-rays may be taken.

Less invasive options may be offered if parents decline a full autopsy. It is helpful to discuss these options with a perinatal pathologist to ensure the most appropriate investigation is undertaken. Less invasive options include **limited autopsy** which includes targeted examinations of organs or tissues (also known as minimally invasive tissue sampling) by the pathologist based on clinical suspicion of cause (e.g. the chest organs only, if a cardiac anomaly is suspected).

Placental examination is one of the most important investigations. Parents should be offered the option of taking the placenta home after examination.

Parents should be given time to consider the information before making their decision.

Barriers to autopsy

The most common reason for parents to decline a full autopsy is concern about the invasiveness of the procedure. In addition, there are common misunderstandings around autopsy that may lead parents to decline. For example, parents may have concerns that they will not get to see their baby following the examination or that organs will not be returned. Sometimes autopsy is in conflict with religious or cultural practices around death. It is important to acknowledge parents' pre-conceived beliefs about their baby, address any unfounded concerns, and respond sensitively to questions. Other important factors are belief that the cause is already known. A lack of understanding by healthcare professionals about the value of autopsy can also be a barrier.

When is the best time to discuss autopsy?

The best time to discuss postmortem investigations varies. When a baby dies in utero, the parents should be given time to begin processing the information that their baby has died before discussing postmortem investigations. Discussing postmortem investigations prior to birth may be appropriate, particularly if parents are seeking information about why their baby has died. However, some parents can't comprehend that their unborn baby has really died until the baby is born, so mentioning postmortem investigations after the birth can be difficult in this circumstance. In addition, many parents as has discussed immediately following the birth to discuss autopsy and require time before making the decision. Each situation is different. The decision to have a postmortem investigation is time sensitive as it is usually possible to perform an autopsy within 72 hours of birth. However, the timing for initiating the decision needs to be as sensitive as possible.

Who should ask?

Due to the sensitive nature of the issue, the person most appropriate to initiate a discussion about postmortem investigations is the consultant obstetrician or paediatrician, or the healthcare professional with lead role or specialist bereavement care role, who has been established collaborating with the parents. In some cases, the healthcare professional may be better placed to discuss postmortem investigations with parents and be comfortable in answering questions relating to the procedures and

expectations about religious or cultural practices based on the parent stated or apparent religion or ethnicity. Cultural and religious requests should be accommodated where possible.

Information you need to have

- Types of postmortem investigations available and the advantages and disadvantages of these
- When the baby will go for the autopsy, when it is likely to occur, and when the baby will be returned to the parents
- Information regarding the preservation of the baby after autopsy, for example, where the remains will be made, and that they will be respectfully retained and covered with a dressing. Baby will be carefully retained and covered with a dressing.
- Confirmation that they will be able to see and hold their baby after the autopsy
- If any organs, including the placenta, are to be retained for longer, the parents can either return the organs, or have a separate burial or cremation of the organs
- Process for communicating the results, including contact details of who will arrange or support parents to discuss the results.
- Any associated costs for the autopsy or investigations

Reporting results

Explain to parents that the final report may not be available for several weeks or months. Although, postmortem results are likely to be available sooner. Advise parents of how the results will be communicated to them (e.g. meet by text message or by phone with no preparation). This will help to reduce anxiety in the parents as they wait for the final report. Ensure parents understand that sometimes an explanation is found for the cause of death.

Parents should be given time to consider the information before making their decision.

provision in a sensitive and informative manner. The **APPROVE** course is recommended for all healthcare professionals providing care for families around the time of a perinatal death. <https://stillbirthcre.org.au/resources/clinical-education-and-support/>

When should the discussion take place?

The most appropriate environment is a quiet, private room away from other patients, relatives, and hospital staff. It is not appropriate to have this discussion in a public area, such as a public waiting room. Some parents may prefer that discussions about postmortem investigations not take place in the presence of their baby.

How do I discuss postmortem investigations with parents?

The healthcare professional should approach the discussion with honesty, integrity, and respect. They should explain the options of the investigation options, their clinical indications, and why they recommend certain options. Sensitive, sensitive and calm, parents of investigation or termination, should be avoided. Although healthcare professionals should take their cues from the parents in terms of preferred language. If the baby has been given a name, refer to them using their name because this helps to validate the importance of the baby to the parents, as well as the significance of their loss.

Parents should be given time to consider the information before making their decision, and encouraged to discuss with others in their decision. The decision to have a postmortem investigation is time sensitive as it is usually possible to perform an autopsy within 72 hours of birth. However, the timing for initiating the decision needs to be as sensitive as possible.

Some parents may require information several times and shock and grief may limit the ability to take in and process new and unfamiliar information. Parents should be offered written and/or audiovisual information to take to the following discussion. However, some parents may prefer not to have detailed autopsy information, so check before providing this.

All parents should have any cultural, spiritual or religious needs around death and dying that are relevant to the discussion of autopsy. It is important not to make

Important things to keep in mind when discussing parents

- Treat parents with respect
- Always be honest
- Use the baby's name if this is the parent's preference
- Introduce details at the individual's pace and use language that parents understand
- Give parents time to make their decision
- Offer written and audiovisual material
- Hold a quiet visit to see the baby and what the parents say
- Avoid terms such as 'baby', 'products of conception', and 'termination' to refer to the baby unless parents use these terms first
- Be prepared for strong emotions. Do not get upset. Remember that parents may be having doubts and anger. These are not unusual and may help bereaved parents make a sense of control in an uncomfortable situation. These emotions must be acknowledged by you in an understanding and supportive manner.

Avoid terms such as 'fetus', 'products of conception', and 'termination' to refer to the baby unless parents use these terms first

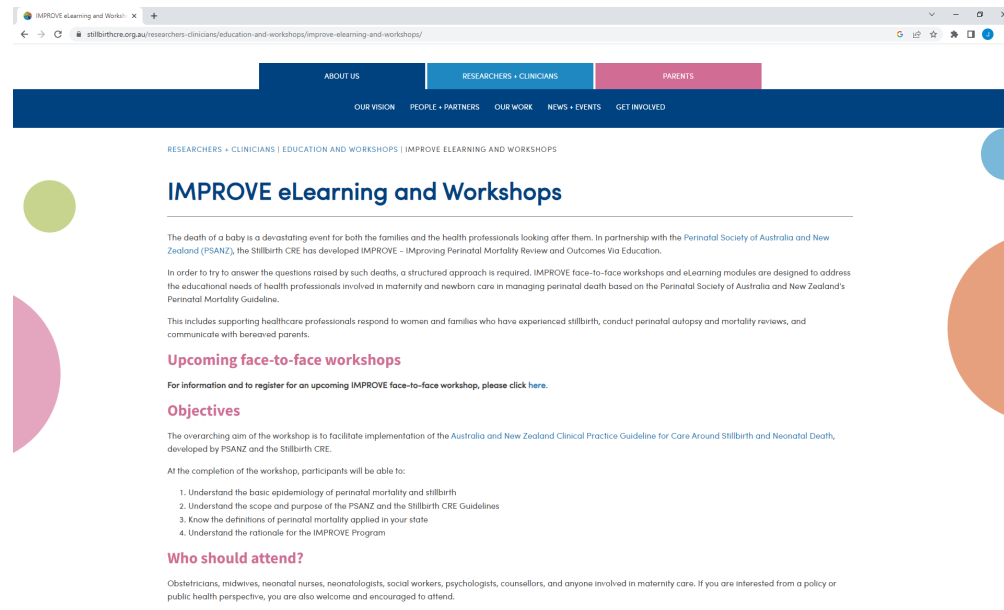
Improving equity: nationally funded education/training program for clinicians around perinatal pathology

Recommendation 11

The committee recommends that the Australian government develops and implements a national best-practice, culturally appropriate education kit that equips current and future health professionals to:

- discuss risks of and strategies for preventing stillbirth with pregnant women; and
- provide culturally and linguistically appropriate information about counselling and support services to assist them with emotional support whilst caring for parents following a stillbirth.

Agreed in principle.



[IMPROVE eLearning and Workshops | The Centre of Research Excellence in Stillbirth \(stillbirthcre.org.au\)](https://www.stillbirthcre.org.au) (accessed 28/9/2024)

Uniform messaging: understand the value and barriers for performing perinatal pathology; understand own bias

Station 2:

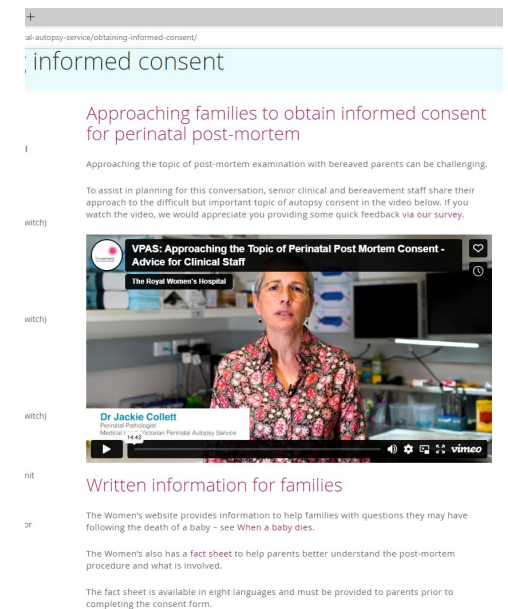
Autopsy and placental examination

Purpose: to inform participants of basics of autopsy and types of autopsy, investigations and processes as well as value of placental histology and examination

Learning Objectives

At the end of this station participants will be able to:

1. Understand why placental examination and autopsy (even an external only) are so important in understanding why a baby has died.
2. Describe the procedures involved in a perinatal autopsy and the appearance of a baby after an autopsy examination
3. Perform a delivery unit examination of the placenta and cord to identify important abnormal features.
4. Understand when placental histopathology should be undertaken and how to transport placentae to the pathology department.



[Obtaining informed consent for perinatal post-mortem | The Royal Women's Hospital \(thewomens.org.au\)](https://thewomens.org.au) (accessed 17/6/2023)

Improving equity: partnership between federal government and professional college (RCPA) increase public awareness of perinatal pathology services

\$750,000 has been allocated directly to pathology

PODCAST SERIES [RCPA - Perinatal pathology resources](#) (accessed 28/9/2024)

Four podcasts highlight the vital role perinatal pathologists play in determining the most likely causes of fetal death. In addition, the importance of multidisciplinary interactions with other prenatal professionals is discussed, providing greater insight as to the unique role of perinatal pathologists, as typically, most pathologists do not encounter these interactions.

The four podcasts are:

- **Where would we be without perinatal pathology?** Prof Jane Dahlstrom (anatomical pathologist) & Dr Farah Sethna (specialist obstetrician and gynaecologist) ACT [RCPA - S2 E7: Where would we be without perinatal pathology?](#)
- **The importance of clinical interactions when investigating perinatal loss** Dr Helen Harris (anatomical pathologist) & Serani Dodson (midwife) TAS
- **Redesign of the Victorian Perinatal Autopsy Service** Dr Jackie Collett (anatomical pathologist) & Ms Nicole vander Linden (perinatal loss coordinator)
- **The complementary role of radiology in pathology investigations in cases of perinatal loss** Dr Nick Manton (anatomical pathologist) & Dr Ajay Taranath (paediatric neuroradiologist)

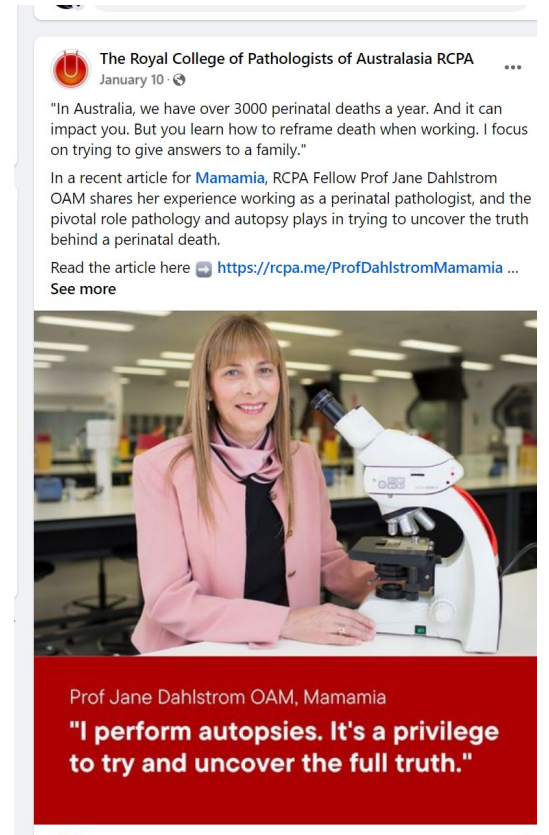


2024 Stillbirth Equity Symposium, Utah, USA

In this month's issue of PathWay:

- ['Holy grail' of cancer cures](#)
- [Pathology win shines light on neuropathology](#)
- [What is a perinatal pathologist?](#)

[RCPA – PathWay](#) (accessed 28/9/2024)



[How are autopsies done? All your questions answered. \(mamamia.com.au\)](#) (accessed 28/9/2024)

Organising interviews women's magazines

Improving equity in perinatal pathology in Australia 3: Investment in perinatal pathology services

- Funded partnership agreements between federal and state governments
 - Increase perinatal pathology workforce
 - Adequate federal funding for tests conducted in perinatal pathology
 - Adequate numbers of high quality well-resourced perinatal autopsy units
 - No costs to families for perinatal pathology services
 - Intentionally designing policies and programs to reach underserved women from poorer communities or ethnic minorities

Commitment to Equity and Accessibility of Services

The funding and services provided in each state/territory need to be consistent to safeguard equitable service delivery for all. Parents should not pay for perinatal autopsy or investigations required to thoroughly investigate and confirm the cause of death or anomaly of their fetus or baby and/or identify recurrence of antenatal risks.

- Funding must be equitable and available to all parents, public and private, in all Australian states and territories. Parents should not incur any expense for this service.
- Autopsies and investigations to be funded for all intact fetuses (no gestational age or weight limits) and neonates up to and including 28 days of life.
- All autopsy examination types and investigations must be available to bereaved parents in each state and territory, administered by specialised Perinatal autopsy service units with appropriately trained staff with suitable resources to provide equity of service.

[Guiding-Principles-for-Perinatal-Loss-Investigatio.aspx \(rcpa.edu.au\)](https://rcpa.edu.au/Guiding-Principles-for-Perinatal-Loss-Investigatio.aspx) (accessed 28/9/2024)

Pathologists Project Advisory Group in April 2022
- inclusive of all sites in Australia providing perinatal autopsy services – very collaborative

Improving equity: partnership agreements between federal and state governments to increase national perinatal pathology workforce – esp. perinatal pathologists

\$13. 576M allocated/ 3 years

Stillbirth autopsies and investigations
FEDERATION FUNDING AGREEMENT – HEALTH

Recommendation 4

The committee recommends that the Australian government consults with the Royal College of Pathologists of Australasia and relevant education and training authorities to identify strategies for increasing the number of perinatal pathologists available to undertake stillbirth investigations in Australia, including identifying costs and sources of funding.

Dear Minister

Thank you for affirming the Australian Capital Territory’s intention to partner with the Commonwealth on an initiative intended to increase the uptake of autopsies following a stillbirth (letter of 24 February 2023 refers). This activity will support the implementation of the National Stillbirth Action and Implementation Plan (Plan) which was released in 2020 following endorsement by all Health Ministers.

Funding according to need- stillbirth rates/ autopsy rates

| Table 1: Formalities and operation of schedule | |
|--|---|
| Parties | Commonwealth New South Wales Victoria Queensland Western Australia South Australia Tasmania Australian Capital Territory Northern Territory |
| Duration | This Schedule is expected to expire on 30 June 2026 or on completion of the projects, including final reporting. |
| Purpose | This Schedule will: deliver an increase in the perinatal loss workforce in each state and territory through the employment of perinatal pathologists, loss coordinators and related workforce, and address financial barriers parents face if travel is required for stillbirth autopsies / investigations. |
| Estimated financial | The Commonwealth will provide an estimated total financial contribution to the States of \$13.576m in respect of this Schedule. |



[Australian Government response to: The Senate Select Committee on Stillbirth Research and Education Report \(health.gov.au\)](https://health.gov.au) (accessed 23/9/2024)

Improving equity: partnership between federal government and professional college (RCPA) to recruit more perinatal pathologists

\$750,000 has been allocated directly to pathology

Increase resident awareness of perinatal pathology as a subspeciality

TRAINING, EDUCATION AND ASSESSMENT

INTRODUCTORY TRAINING/TRAINEE ROTATIONS TO PERINATAL SERVICE UNITS

States and territories offer introductory short-term training opportunities and visits to perinatal pathology service units.

State-based RCPA Anatomical Pathology Training Network Coordinators are well placed to coordinate and implement three- to five-day rotations with specialised perinatal pathology service units to provide anatomical pathology Trainees with an introduction to perinatal pathology as a career pathway.

By offering short-term training or rotations in perinatal service units, Trainees and interested anatomical pathologists will be introduced to a typical daily perinatal pathology workload, including time in both the laboratory and mortuary where they will be exposed to autopsy practices and reporting at the microscope, and will have the opportunity to attend multidisciplinary meetings.

TRAINEE ROTATIONS AT PERINATAL SERVICE UNITS (THREE MONTHS, SIX MONTHS OR 12 MONTHS)

Work with states and territories to identify longer-term training opportunities within perinatal pathology service units. Longer-term placements within specialised perinatal pathology service units will be determined based on-site rotation schedules and pathologist availability for supervision activities.

By offering longer-term training rotations in perinatal service units, Trainees and interested anatomical pathologists will be exposed to ongoing daily perinatal pathology workload, exposure to a greater variety of perinatal death presentations and the opportunity to gain knowledge by attend multidisciplinary meetings with haematologists, genetic pathologists, microbiologists and infectious disease specialists.

[RCPA - Training in perinatal pathology](#) (accessed 28/9/2024)

TRAINING IN PERINATAL PATHOLOGY

Every day in Australia, six babies are stillborn and two die within 28 days of birth. At least 60 lives are touched by each of these deaths, with over 175,000 people being affected by a perinatal death every year.

WHAT IS PERINATAL PATHOLOGY?

Perinatal pathology is a branch of anatomical pathology where tissues involving a pregnancy are examined, including the placenta, umbilical cord, embryos and fetuses. Perinatal pathologists are trained in performing autopsies and ascertaining which additional pathological and radiological investigations should be undertaken to determine the most likely cause of perinatal death.

It can also inform the provision of targeted counselling for patients for heritable disorders, and guide clinical care for maternal or environmental factors in future pregnancies. Perinatal pathology findings can be helpful not just for the affected family but also serve to broaden our knowledge and learning to help other patients with similar or associated risk factors.



WHAT DOES A PERINATAL PATHOLOGIST DO?

Perinatal pathologists work with multidisciplinary healthcare teams to collaborate on providing best patient care and support families affected by perinatal loss.

Perinatal pathologists provide answers for families to help give closure while also supporting healthcare professionals to better understand what may potentially have caused the death of a baby and work to reduce the risk of subsequent perinatal deaths.



Recommendation 4

The committee recommends that the Australian government consults with the Royal College of Pathologists of Australasia and relevant education and training authorities to identify strategies for increasing the number of perinatal pathologists available to undertake stillbirth investigations in Australia, including identifying costs and sources of funding.

RCPA SUPPORTS GOVERNMENT INVESTMENT IN PERINATAL PATHOLOGY TO REDUCE STILLBIRTHS

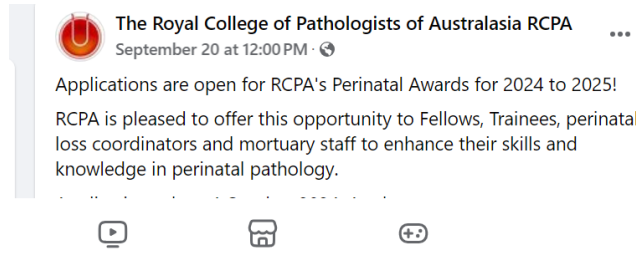
30 November 2022

[RCPA - RCPA supports Government investment in perinatal pathology to reduce stillbirth](#) (accessed 28/9/2024)

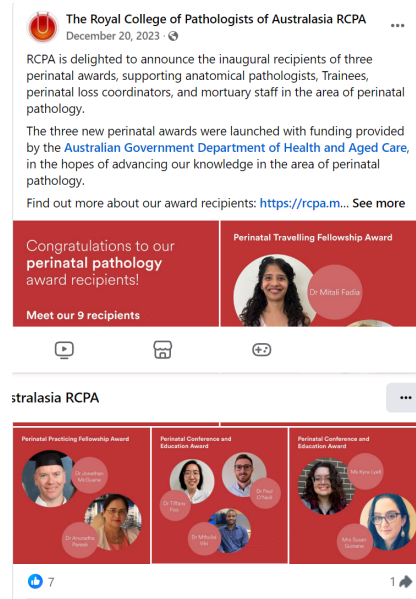
2024 Stillbirth Equity Symposium, Utah, USA

Improving equity: partnerships between federal government and professional college (RCPA) to recruit more perinatal pathologists

Increase educational resources and opportunities for pathologists to subspecialise in perinatal pathology



Australasia RCPA



(1) RCPA is... - The Royal College of Pathologists of Australasia RCPA | Facebook (accessed 14/5/2023)

CONFERENCES AND WORKSHOPS

RCPA Faculty of Post Mortem Imaging (FPMI) November 2023

Full day face-to-face workshop on 'Care of the infant following death: investigating the causes of stillbirth and neonatal death: Perinatal Pathologist Perspective' with Prof Jane Dahlstrom OAM. Annual FPMI workshops are expected to be held in the last half of each year.

RCPA Pathology Update 2025

A full day face-to-face program has been created for perinatal pathology, an inaugural promotional effort to attract interest in this subspecialty. Dr Amy Heerema McKenney, Staff Pathologist from the Cleveland Clinic Institute of Pathology and Laboratory Medicine, is confirmed to deliver the Perinatal Plenary Session on 22 February 2025. A total of nine speakers will present at this event. Although Pathology Update is now being presented in a hybrid format, due to the sensitive nature of most presentations, the majority will not be recorded.

PRACTICE SUPPORT RESOURCES

Australian and New Zealand Paediatric Pathology Group (ANZPPG) online resources

The RCPA Training Package hosts all ANZPPG material providing Trainees and Fellows with direct access to a range of perinatal and paediatric educational materials and resources.

The ANZPPG webpages contain content of an extremely sensitive nature (e.g. images of fetuses, babies and autopsy practices) and is therefore only available to RCPA Fellows and Trainees via Member login. The site includes:

- About us and contact information
- How to Join ANZPPG
- ANZPPG Paediatric & Perinatal Sessions
- Other Educational Resources (paediatric and perinatal eCases, national and international events, and links to international paediatric and perinatal websites)
- A series of perinatal autopsy teaching videos have been produced to demonstrate best practice procedures for performing the following:
 - Scalp incision
 - Open calvarium
 - Brain removal
 - Examination of the skull base
 - Heart dissection – second trimester
 - Heart dissection – third trimester
 - Skin incision
 - Chest wall opening
 - Peritoneal cavity.

Improving equity: lobbying by professional college (RCPA) of government for national funding for all perinatal pathology- no costs to families

Recommendation 3

The committee recommends that the Australian government seeks advice from the Medical Services Advisory Committee on the economic costs and benefits of adding stillbirth autopsies as a new item in the Medicare Benefits Schedule, and urges the government to consider funding the projected cost of this new item in the 2019–20 Federal Budget.

Agreed in principle.

The Government will refer this recommendation to the Medical Services Advisory Committee (MSAC) for advice.

The Committee is an independent body and will carry out its deliberations accordingly. As a matter of principle the Government will implement the recommendations of MSAC.

Costs born by state and territory public hospitals autopsy; Medicare for placenta assessment if performed in private sector

The funding model needs to accommodate these variables and allow for jurisdictions where autopsy referrals increase or decrease, with the ability to accommodate new ancillary tests, and include consumer price index (CPI) adjustments. Funding models to be considered include:

- Block Funding Model: the facility gets a fixed amount of funding to deliver perinatal services and is not flexible to account for service demand increases and decreases. Block funding will need to have provision for CPI increases. If considering a Block funding model, all core/traditional autopsy and investigation costs (see Appendix A) including staff and consumables are to be funded; Ancillary investigations (see Appendix C) as performed in a particular case would be billed separately and should also be funded. **Transportation costs must be funded separately to autopsy and investigations funding.**
- Fee For Service Funding Model: entire cost to be paid to the facility performing the autopsy. Includes a stratified or bespoke pricing schedule for post mortem examination types and additional investigations (fixed and variable costs). Fee For Service Models provide greater transparency, are easier to audit and produce reports. **Transportation costs must be funded separately to autopsy and investigations funding.**
- 50/50 Commonwealth/State Contributions Model: Federal DoHAC and jurisdictions with perinatal loss investigation services split all costs of providing this service equally. Includes a stratified or bespoke pricing schedule for post mortem examination types and additional investigations (fixed and variable costs). If considering a Block funding model, all core/traditional autopsy and investigation costs (see Appendix A) including staff and consumables are to be funded; Ancillary investigations (see Appendix C) as performed in a particular case would be billed separately and should also be funded. **Transportation costs must be funded separately to autopsy and investigations funding.**

Appendix B Core/traditional perinatal pathology investigations covered by Medicare Benefits Schedule

| Investigations covered by Medicare Benefits Schedule | MBS Item | MBS Rate | Proposed rate 2022 |
|--|----------|------------------------|---|
| Maternal, family & clinical history | 16401 | \$91.80 | Include with all autopsy complexities |
| Review of radiology (ANC screening) | 413 | \$130.65 | Include with all autopsy complexities |
| Review of ANC investigations | 413 | \$130.65 | Include with all autopsy complexities |
| Placenta and umbilical cord examination | 72823 | \$97.15 | Include with all autopsy complexities |
| | 72836 | \$417.20 | Bill separately when no autopsy consent given |
| +/- Microbiology studies/infection screening as indicated <ul style="list-style-type: none">Placenta surface swabs x 3 | 69321 | 3 @ \$48.15 = \$144.45 | Include with all autopsy complexities |

Appendix A Proposed rates for core/traditional perinatal pathology investigations

| Investigation | Proposed rate 2022 |
|---|---|
| Clinical photographs | N/A - Include with all autopsy complexities |
| Radiological examinations as indicated <ul style="list-style-type: none">MRISkeletal Survey (Babygram)XRayUltrasound | \$1,300 \$100.00 \$500.00 \$90.00 |
| External (limited) autopsy and examination only | \$1,600.00 |
| Autopsy (rate varies dependent upon complexity) | \$1,600 - \$4,200.00 |
| Internal organ examination + histology | N/A - Include with full autopsy |
| DNA extraction, storage and SNP microarray panel | \$700.00 |
| Clinicopathological correlation | N/A - Include with all autopsy complexities |
| PSANZ classification | N/A - Include with all autopsy complexities |
| Attendance at Multi-Disciplinary Team meetings (rate varies dependent upon pathologist pay level) | \$120.00 - \$260.00 per one hour case |
| +/- Metabolic studies as indicated | \$700.00 - \$2,500.00 - Include with complex full autopsy only as indicated |

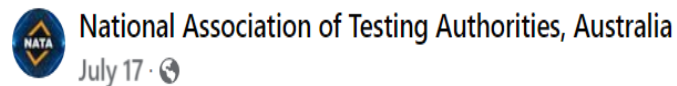
[Guiding-Principles-for-Perinatal-Loss-Investigatio.aspx](https://rcpa.edu.au/Guiding-Principles-for-Perinatal-Loss-Investigatio.aspx) (rcpa.edu.au) (accessed 28/09/2024)

RCPA Medical Services Advisory Committee (MSAC) is working toward increasing the MBS rebate for placentas, from Category 4 to Category 6, to better reflect the time and expertise required to properly examine placentas

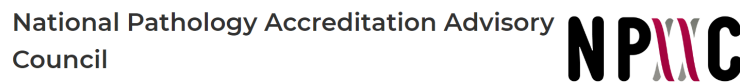
Improving equity: national approach to delivery of high quality well-resourced perinatal autopsy units accessible to all

- National (single) regulation/accreditation authority of perinatal autopsy services (NATA/RCPA) and national standards (NPAAC)
- National (single) medical registration (Medical Board of Australia) and continuing professional development program that enables perinatal pathologists to be able to work/ receive referrals across the country and babies/blocks/slides can be transported to any centre in country
- National laws in relation to consent process – although some state modifications of consent forms

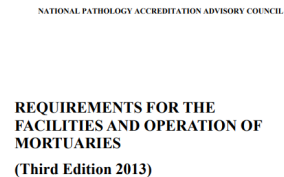
[Australian Health Practitioner Regulation Agency - About registration \(ahpra.gov.au\)](#) (accessed 28/9/2024)
[Medical Board of Australia – Home](#) (accessed 28/9/2024)



Celebrating 40 years of the first NATA/The Royal College of Pathologists of Australasia RCPA accredited laboratory!



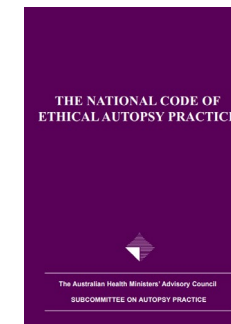
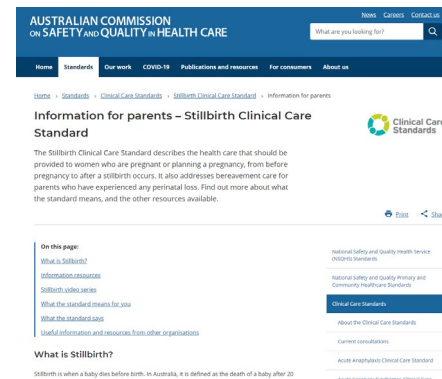
The National Pathology Accreditation Advisory Council (NPAAC) is responsible for developing and maintaining the accreditation standards for pathology laboratories in Australia.



Updated 2022

NPAAC Tier 4 Document

[tier 4 requirements for the facilities and operation of mortuaries third edition 2013.pdf \(safetyandquality.gov.au\)](#) (accessed 29/9/2024)



Part 4 of the [Transplantation and Anatomy Act 1983](#) (accessed 15/6/2023)

Improving equity in perinatal pathology in Australia 4: Data collection, review stillbirths and research

- State/territory based multidisciplinary team review perinatal deaths - classify stillbirths using national (PSANZ) system – highlight inequities - contributory factor assessment



PSANZ CLASSIFICATION SYSTEM FOR STILLBIRTHS AND NEONATAL DEATHS

Version 5.0, February 2024

[Perinatal post-mortem examination \(stillbirthcre.org.au\)](https://stillbirthcre.org.au) (accessed 23/9/2024)

- Implemented a national perinatal mortality audit
[National Perinatal Data Collection - Australian Institute of Health and Welfare \(aihw.gov.au\)](https://aihw.gov.au) (accessed 23/9/2024)
- Various federally funded research initiatives

\$6.7+ million for stillbirth research

Recommendation 2

The committee recommends that the Australian Health Ministers' Advisory Council agrees to prioritise the development of a comprehensive, standardised, national perinatal mortality data collection that:

- includes information on timing and cause of death, autopsy and termination of pregnancy; and
- links to the National Death Index and perinatal mortality data collections to utilise information on maternal health, pregnancy and birth risk factors.

Recommendation 6

The committee recommends that the Australian government reviews current research funding arrangements administered by the National Health and Medical Research Council, in consultation with a roundtable of relevant stakeholders, to examine options for longer-term funding cycles for targeted, large-scale, collaborative research partnerships, potentially through the Medical Research Future Fund.

Agreed in Principle.

Recommendation 13

The committee recommends that the Australian government creates an online register of current international and Australian research and clinical guidelines relating to stillbirth, accessible to all interested stakeholders including the public.

Agreed in principle.

Recommendation 7

The committee recommends that the Australian government gives urgent consideration to the allocation, through the Medical Research Future Fund, of long-term dedicated funding and support for the development of a national biobank for stillbirth placenta research.

Agreed in principle.

3.1 Purpose of the ACT Perinatal Mortality Committee

To provide advice to ACT Health, through the ACT Health Quality and Safety Committee (previously the ACT Clinical Audit Committee), on matters that relate to perinatal mortality in the ACT each year.

3.2 Terms of reference

This committee is a sub-committee of the ACT Maternal Perinatal Information Network Committee.

The membership should consist of:

- An obstetrician with involvement in high-risk pregnancy and fetal medicine;
- A pathologist with involvement in perinatal pathology;
- A neonatologist;
- Midwifery representatives from all delivery campuses;
- Epidemiology Section representative; and
- Any other members the committee feels are appropriate.

The role of the committee is to:

- Review all perinatal deaths within the ACT;
- Classify all deaths according to the PSANZ classification system;
- Provide an annual report to ACT Health Quality and Safety Committee; and
- Provide a five-year public health report for the ACT on perinatal mortality.

<https://stats.health.act.gov.au/sites/default/files/Number%2061%20-%20Perinatal%20Mortality%20in%20the%20ACT%202006-2010.pdf> (accessed 19/9/2018)

Recommendation 5

The committee recommends that, through the Australian Health Ministers' Advisory Council, the Australian government leads a process to establish a set of national stillbirth research funding priorities for the next 10 years, drawing on those developed by the Perinatal Society of Australia and New Zealand and Centre of Research Excellence in Stillbirth. This set of priorities should:

- draw on the experiences and knowledge of parents, parent-based support and advocacy organisations, international expert researchers, clinicians and other health professionals; and
- enable government, philanthropic and corporate funding bodies to identify, prioritise and coordinate efforts to produce the best and most cost-effective outcomes through collaborative research programs, including 'discovery projects' which explore new technologies that may prevent stillbirth.

Summary

Equity in Perinatal Pathology for Stillbirths is complex and multifactorial

Education key

Adequate funding for services crucial

More research to assist evidence-based decisions

