

The Senate

Select Committee on
Stillbirth Research and Education

Report

December 2018

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Table of contents

The Committee	iii
Abbreviations	ix
Definition of terms	xiii
Recommendations	xv

Chapter 1

Introduction	1
Referral and conduct of the inquiry.....	1
Structure and scope of this report.....	2
Definitions	2
Acknowledgements	2
Notes on references	3

Chapter 2

Stillbirth in Australia—an overview.....	5
Stillbirth rates	5
Causes of stillbirth.....	9
Risk factors	10

Chapter 3

Quantifying the impacts of stillbirth.....	17
Direct and indirect costs	18
Impact on families	20
Intangible costs	22
Impact on healthcare providers	24
Employment-related costs	25
Best practice employment models.....	31
Committee view.....	33

Chapter 4

Stillbirth reporting and data collection	35
Quality and scope of data	35
Perinatal mortality audits.....	49
Autopsies and other post-mortem investigations	53
Committee view.....	60

Chapter 5

Stillbirth research in Australia.....	63
Government funding for stillbirth research	63
Other research funding	69
Research priorities	70
Innovative technology and coordinated research efforts.....	74
Corporate sector partnerships	78
Committee view.....	79

Chapter 6

Improving quality of care.....	83
Continuity of care	83
Culturally appropriate models of care	88
Support for bereaved families	93
Culturally appropriate bereavement care	100
Committee view.....	103

Chapter 7

Stillbirth education	107
A hidden tragedy	107
Public awareness campaigns	109
Education for families	111

Education for clinicians and other health professionals.....	114
Autopsies and other port-mortem investigations.....	120
Protocols for stillborn babies held in hospital morgues	126
Culturally appropriate education	127
Education for employers and work colleagues.....	128
Committee view.....	129
Chapter 8	
The future of stillbirth research and education in Australia.....	133
International policy context.....	133
Australia's policy framework.....	134
Towards a National Stillbirth Action Plan	135
Committee view.....	140
Appendix 1 - Submissions, answers to questions on notice, tabled documents and additional information.....	143
Appendix 2 - Public hearings and witnesses.....	155
Appendix 3 - Special Parental Leave provisions in selected Enterprise Agreements and Awards by jurisdiction	163

Abbreviations

ABS	Australian Bureau of Statistics
ACM	Australian College of Midwives
AFFIRM	(Can promoting) Awareness of Fetal movements and Focussing Interventions Reduce fetal Mortality
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
ALSWH	Australian Longitudinal Study on Women's Health
APS	Australian Public Service
BiOC	Birthing in Our Community
BoC	Birthing on Country
CALD	Culturally and linguistically diverse
CATSINaM	Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
COAG	Council of Australian Governments
CPSU NSW	Community and Public Sector Union New South Wales
DAPP	Dad and Partner Pay
FGR	Fetal growth restriction
GSAN	Global Stillbirth Advocacy Network
GROW	Customised antenatal growth
HIV	Human Immunodeficiency Virus
HMRI	Hunter Medical Research Institute
IMPROVE	Improving Perinatal Mortality Review and Outcomes Via Education
iSAIL	Integrated Support After Infant Loss
MBM	My Baby's Movements (app)

MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MBS	Medicare Benefits Schedule
MCCPD	Medical Certificate of Cause of Perinatal Death
MDG	Millennium Development Goal
MRFF	Medical Research Future Fund
MRI	Magnetic resonance imaging
NCLD	National Centre for Longitudinal Data
NES	National Employment Standards
NHMRC	National Health and Medical Research Council
NMDDP	National Maternity Data Development Project
NMDS	National Minimum Data Set
NPDC	National Perinatal Data Collection
NPESU	National Perinatal Epidemiology and Statistics Unit, University of New South Wales
NPMDC	National Perinatal Mortality Data Collection
NSAMS	National Strategic Approach to Maternity Services
NSW	New South Wales
PBS	Pharmaceutical Benefits Schedule
PDC	Perinatal Data Collections
PHAA	Public Health Association of Australia
PHRN	Population Health Research Network
PPL	Paid Parental Leave
PSA NSW	Public Service Association of New South Wales
PSANZ	Perinatal Society of Australia and New Zealand
PSANZ-PDC	Perinatal Society of Australia and New Zealand Perinatal Death Classification

PwC	PriceWaterhouseCoopers
RACP	Royal Australasian College of Physicians
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCPA	Royal College of Pathologists of Australasia
SA	South Australia
SANDA	Stillbirth and Neonatal Death Alliance
Sands	Stillbirth and Neonatal Death Support
SDG	Sustainable Development Goal
SIDS	Sudden Infant Death Syndrome
Stillbirth CRE	Centre of Research Excellence in Stillbirth
SUDI	Sudden Unexpected Death in Infancy
UK	United Kingdom
UN	United Nations
UNSW	University of New South Wales
USA	United States of America
UTS	University of Technology Sydney
VPAS	Victorian Perinatal Autopsy Service
WA	Western Australia
WHO	World Health Organisation

Definition of terms

Aetiology	The cause, set of causes, or manner of causation, of a disease or condition.
Antenatal	The period covering conception up to the time of birth.
Antepartum	Prior to labour.
Apgar Score	Numerical score used to indicate a baby's condition at 1 minute and at 5 minutes after birth, in relation to each of 5 characteristics: breathing, colour, heart rate, muscle tone and reflex irritability.
Apnea	Cessation of breathing.
Autopsy	An examination performed after the baby's death to determine the cause of death. A full autopsy involves a surgical cut or incision and x-ray. The placenta is also examined. A limited autopsy is subject to parental decision and may or may not include examination of the placenta.
Clinician	A physician involved in the diagnosis and treatment of patients, or who is skilled in clinical methods, as opposed to one who specialises in research.
Cultural safety	<p>The essential components of cultural safety include:</p> <ul style="list-style-type: none">• an understanding of one's own culture;• an acknowledgement of difference, and a requirement that caregivers are actively mindful and respectful of difference(s);• it is informed by the theory of power relations -any attempt to depoliticise cultural safety is to miss the point;• an appreciation of the historical context of colonisation, the practices of racism at individual and institutional levels, and their impact on First Nations People's lives and wellbeing – both in the past and the present; and• its presence or absence is determined by the experience of the recipient of care—it is not defined by the caregiver.¹

1 Congress of Aboriginal and Torres Strait Islander Nurses 2013, p. 7.

External examination	Involves x-ray and external examination of baby's body and placenta, but no examination of internal organs.
Fetal death	The death of a baby prior to birth (alternatively, stillbirth).
Gestation	The time between conception and birth during which the embryo or fetus is developing in the uterus.
Gestational age	Duration of a pregnancy in number of completed weeks.
Gravidity	The number of times that a woman has been pregnant.
Health practitioner	Someone qualified in the practice of a particular field of the health profession.
Hypertension	High blood pressure.
Hypoxic	A condition in which the body or a region of the body is deprived of adequate oxygen supply at the tissue level.
Intrapartum	Occurring during childbirth or during the birth process.
Neonatal	Pertaining to a newborn child.
Parity	The number of previous pregnancies experienced by a woman that have resulted in a live birth or a stillbirth.
Perinatal	Pertaining to, or occurring in, the period shortly before or after birth (usually up to 28 days after).
Placenta	A temporary organ that develops during pregnancy to nourish and maintain the fetus through the umbilical cord.
Postpartum	The period following labour and birth.
Stillbirth	Death before the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birthweight.
Term birth	Birth after 37 and before 42 completed weeks of gestation.
Vasa praevia	A rare but potentially serious condition in which blood vessels carrying blood between the placenta and the baby cross over the cervix. These vessels may bleed if the woman goes into labour, if the waters break, or if the cervix opens.

Recommendations

Recommendation 1

3.75 The committee recommends that the Australian government reviews and amends the *Fair Work Act 2009* (Cth) and provisions relating to stillbirth in the National Employment Standards (NES) to ensure that:

- provisions for stillbirth and miscarriage are clear and consistent across all employers, and meet international best practice such as those contained in the Ausgrid Enterprise Agreement; and
- legislative entitlements to paid parental leave are unambiguous in recognising and providing support for employees who have experienced stillbirth.

Recommendation 2

4.126 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 3

4.131 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.

Recommendation 4

4.133 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.

Recommendation 5

5.81 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.

Recommendation 6

5.83 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.

Recommendation 7

5.86 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.

Recommendation 8

6.85 The committee recommends that, through the Australian Health Ministers' Advisory Council, the Australian government leads a process to develop a national culturally and linguistically appropriate continuity of care model aimed at reducing the rate of stillbirths in Australia, particularly amongst groups identified as having a higher risk of stillbirth.

Recommendation 9

6.91 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.

Recommendation 10

7.97 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.

Recommendation 11

7.100 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.

Recommendation 12

7.104 The committee recommends that the Australian government develops and implements culturally and linguistically appropriate protocols for public hospitals and community health services in all jurisdictions, to guide them in:

- managing autopsies or other investigations into stillbirths;
- counselling for autopsy and other medical investigations;
- care of stillborn babies held in morgues; and
- communicating with bereaved parents.

Recommendation 13

7.107 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.

Recommendation 14

7.110 The committee recommends that the Australian government develops and implements a best-practice, culturally appropriate public education kit that assists families, friends, employers, work colleagues and people in the wider community to understand stillbirth and to offer support to a bereaved parent or family member following a stillbirth.

Recommendation 15

8.44 The committee recommends that, through the Australian Health Ministers' Advisory Council, the Australian government leads a process to develop and implement a National Stillbirth Action Plan aimed at reducing the rate of stillbirth in Australia by 20 per cent over the next three years (Budget forward estimates), and including:

- a nationally-coordinated and consistent framework for stillbirth reporting and data collection;

- **an online register of stillbirth research and data;**
- **national research priorities; and**
- **a public education campaign.**

Recommendation 16

8.48 The committee recommends that annual progress reports on the development and implementation of the National Stillbirth Action Plan to reduce the rate of stillbirth in Australia are provided to the Council of Australian Governments Health Council and made publicly available.

Chapter 1

Introduction

Referral and conduct of the inquiry

1.1 On 27 March 2018 the Senate established the Select Committee on Stillbirth Research and Education to inquire into and report on the future of stillbirth research and education in Australia, with particular reference to:

- (a) consistency and timeliness of data available to researchers across states, territories and federal jurisdictions;
- (b) coordination between Australian and international researchers;
- (c) partnerships with the corporate sector, including use of innovative new technology;
- (d) sustainability and propriety of current research funding into stillbirth, and future funding options, including government, philanthropic and corporate support;
- (e) research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education;
- (f) communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy;
- (g) quantifying the impact of stillbirths on the Australian economy; and
- (h) any related matters.¹

1.2 The committee indicated that it would consider individual cases and personal experiences where these addressed and were directly relevant to the terms of reference. The committee also indicated that it did not intend to accept personal records, such as medical records, coroners' reports and/or death certificates.

1.3 The committee received 269 submissions (listed at Appendix 1).

1.4 The committee took evidence over six days of public hearings in:

- Sydney on 8 August 2018;
- Melbourne on 9 August 2018;
- Adelaide on 10 August 2018;
- Katherine on 5 September 2018;
- Brisbane on 6 September 2018; and
- Canberra on 7 September 2018.

1 *Journals of the Senate*, No. 93, 27 March 2018, pp. 2949–2951.

1.5 The witnesses who appeared at these hearings are listed at Appendix 2.

Structure and scope of this report

1.6 This report comprises eight chapters:

- Chapter 1 outlines the conduct of the inquiry, and the definitions for stillbirth across jurisdictions;
- Chapter 2 outlines the numbers, rates, causes, and risk factors of stillbirth in Australia in comparison to other high-income countries;
- Chapter 3 discusses the economic and social impacts of stillbirth;
- Chapter 4 discusses stillbirth reporting and data collection;
- Chapter 5 discusses stillbirth research, innovative technology and corporate sector partnerships;
- Chapter 6 discusses quality of care in relation to stillbirth;
- Chapter 7 discusses stillbirth education and public awareness campaigns; and
- Chapter 8 considers stillbirth research and education in the context of international and policy frameworks, and strategies to reduce the rate of stillbirth in Australia.

Definitions

1.7 The standard definition of stillbirth in Australia is a birth (by 'expulsion or extraction') with no signs of life of at least 20 weeks' gestation or with a birthweight of at least 400 grams. This definition is used by both the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare (AIHW), the two entities collecting and publishing stillbirth data in Australia.

1.8 However, there are variations within this broad definition of stillbirth that make collation and comparison of data across Australian jurisdictions challenging.

1.9 Definitions of stillbirth also vary considerably around the world. High-income countries typically define stillbirth as a death occurring between 20 to 24 weeks and later, while the majority of low-income countries use 28 weeks' gestation or 1000 grams—the definition recommended for international comparison by the World Health Organisation (WHO).

1.10 The WHO definition is used by AIHW when reporting internationally and to enable international comparisons.

Acknowledgements

1.11 The committee thanks individuals and organisations that contributed to the inquiry, and takes this opportunity to express its gratitude to those individuals who took the time to share their personal stories with the committee.

1.12 The committee also thanks the Katherine Hospital for hosting the committee during a site visit on 5 September 2018.

1.13 The committee appreciates that, for some, sharing their personal experiences was difficult and upsetting. The committee was deeply moved by these stories and the inquiry has benefitted from their being shared.

Notes on references

1.14 References to *Committee Hansard* may be references to the proof transcript. Page numbers may differ between proof and official transcripts.

Chapter 2

Stillbirth in Australia—an overview

2.1 Australia is one of the safest places in the world to give birth, yet six babies are stillborn here every day, making it the most common form of child mortality in Australia.

2.2 Stillbirth affects over 2000 Australian families each year. For every 137 women who reach 20 weeks' pregnancy, one will experience a stillbirth. For women from Aboriginal and Torres Strait Islander backgrounds the rate is double that of other Australian women.¹

2.3 Furthermore, the rate of stillbirth in Australia has not changed over the past two decades, despite modern advances in medical practice and health care. According to the Centre of Research Excellence in Stillbirth (Stillbirth CRE), '[u]p to half of stillbirths at term in Australia are unexplained'.²

2.4 Stillbirth is one of the most devastating and profound events that any parent is ever likely to experience. It is 30 times more common than Sudden Infant Death Syndrome (SIDS), but stillbirth receives far less public or government attention than other infant and childhood deaths.³

2.5 Stillbirth is a hidden tragedy. The culture of silence around stillbirth means that parents and families who experience it are less likely to be prepared to deal with the personal, social and financial consequences. This failure to regard stillbirth as a public health issue also has significant consequences for the level of funding available for research and education, and for public awareness of the social and economic costs to the community as a whole.

The sorrow and sadness associated with a stillbirth has a profound rippling effect across communities that is long-lasting and is acknowledged to have significant social, emotional and economic impacts.⁴

2.6 This chapter outlines the numbers, rates, causes, and risk factors of stillbirth in Australia compared with other high-income countries.

Stillbirth rates

International trends

2.7 Internationally, the number of stillbirths occurring at or after 28 weeks' gestation declined by 19.4 per cent between 2000 and 2015, representing an annual reduction of two per cent. The World Health Organisation (WHO) estimated that, in 2015, there were 2.6 million stillbirths at or after 28 weeks' gestation worldwide. Most

1 Centre of Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, p. 4.

2 Stillbirth CRE, *Submission 56*, p. 4.

3 Stillbirth CRE, *Submission 56*, p. 4.

4 Stillbirth CRE, *Submission 56*, p. 4.

(98 per cent) stillbirths occur in low- and middle-income countries, and over half (60 per cent) occur in rural areas.⁵

2.8 The table below shows the rates and ranking of selected countries, including Australia, in 2009 and 2015, based on the WHO definition of stillbirth.

Table 2.1: Stillbirth rate (at or after 28 weeks' gestation) per 1000 births, and rank, by country, 2009 and 2015⁶

Country	2009		2015	
	Rate	Rank	Rate	Rank
Finland	2.0	1	1.8	4
New Zealand	3.5	34	2.3	11
Australia	2.9	15	2.7	17
UK & Northern Ireland	3.5	33	2.9	26
USA	3.0	17	3.0	29
Canada	3.3	26	3.1	30
Malaysia	5.9	55	5.8	55
China	9.8	82	7.2	68
India	22.1	154	23.0	165
Pakistan	46.7	193	43.1	194

High-income countries

2.9 Significant movement up the rankings occurred between 2009 and 2015 for the United Kingdom (UK) and Northern Ireland, and New Zealand; Australia slipped by two places; and the United States of America (USA), while having the same rate of stillbirth in both years, fell in ranking from 17 to 29.

2.10 Analyses of data in high-income countries show a decrease in the rate of stillbirth over the past 50 years, attributed largely to improvements in intrapartum care, but there has been little or no improvement over the past two decades and evidence of increases in some countries including Australia.⁷

2.11 In 2017 countries with the lowest stillbirth rates were Iceland (1.3 stillbirths per 1000), Denmark (1.7), and Finland (1.8).⁸

5 World Health Organisation (WHO), *Maternal, newborn, child and adolescent health*, http://www.who.int/maternal_child_adolescent/epidemiology/stillbirth/en/ (accessed 27 September 2018).

6 WHO, Global Health Observatory data repository, <http://apps.who.int/gho/data/view.main.GSWCAH06v> (accessed 24 July 2018).

7 I Ibiebele, M Coory, FM Boyle, et al, 'Stillbirth Rates Among Indigenous and Non-Indigenous Women in Queensland, Australia: Is the Gap Closing?', *British Journal of Obstetrics and Gynaecology*, vol. 122, no. 11, August 2014, p. 1476, <https://obgyn.onlinelibrary.wiley.com/doi/epdf/10.1111/1471-0528.13047> (accessed 19 September 2018).

8 H Reinebrant, 'Stillbirth is Not Just Stillbirth: More Information is Needed', The University of Queensland, 4 December 2017, <https://www.uq.edu.au/news/article/2017/12/stillbirth-not-just-stillbirth-more-information-needed> (accessed 19 September 2018).

2.12 Australia (2.7 stillbirths per 1000) lags well behind other high-income countries, with the stillbirth rate beyond 28 weeks of pregnancy 35 per cent higher than the best-performing countries.⁹

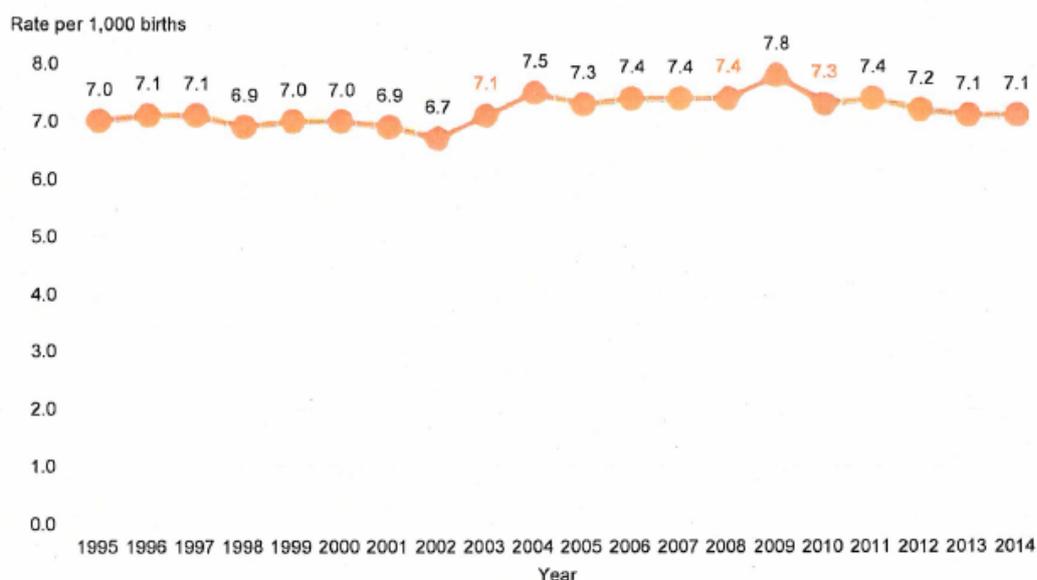
Australian trends

2.13 The rate of stillbirth in Australia is based on the Australian Institute of Health and Welfare (AIHW) definition of stillbirth as a fetal death occurring at 20 or more completed weeks of gestation or 400 grams or more birthweight.¹⁰

2.14 The AIHW uses this definition for the National Perinatal Data Collection (NPDC). This differs from the definition recommended by the World Health Organisation (a baby born with no signs of life at or after 28 weeks of gestation or 1000 gram birthweight) and the United Kingdom (24 weeks).¹¹

2.15 Between 1995 and 2014, there was an overall reduction in neonatal deaths (deaths occurring from birth to 28 days old), from 3.2 to 2.6 per 1000 births. However, the rate of stillbirth remained relatively unchanged, varying between 6.7 and 7.8 deaths per 1000 births over the same period (see Figure 2.1 below).

Figure 2.1: Stillbirth rate in Australia, 1995–2014¹²



The rate is the number of stillbirths per 1,000 total births (live births and stillbirths)

A stillbirth is defined as a fetal 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 grams or more birthweight.

Note: Victorian data was not included for 2009.

Source: AIHW. *Perinatal deaths in Australia 2013–2014*

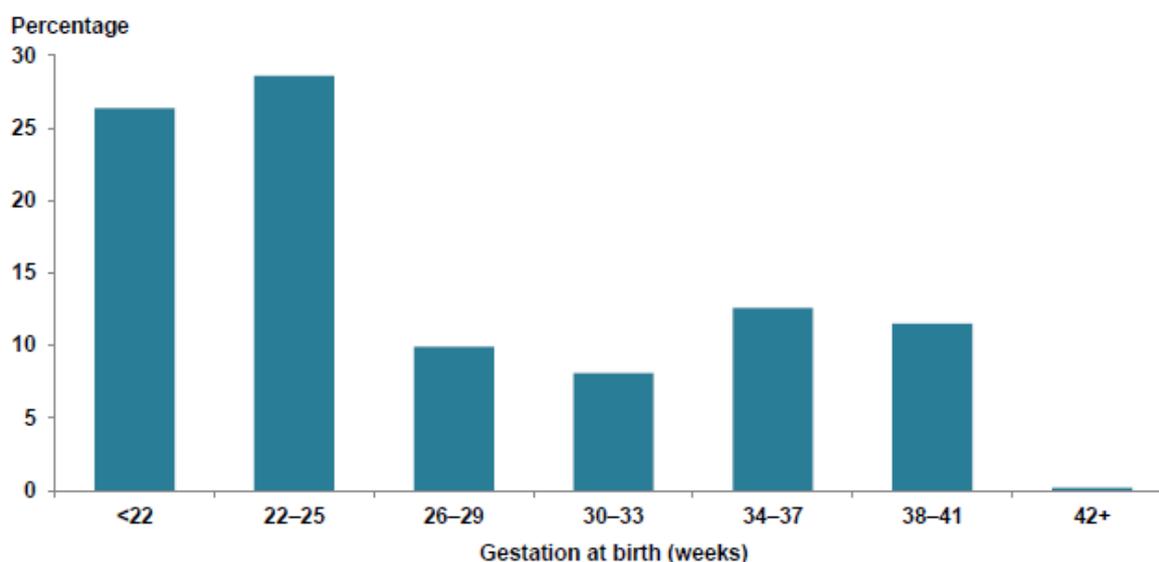
2.16 Figure 2.2 shows the percentage of stillbirths by gestation at birth in Australia over 2013 and 2014.

9 Stillbirth CRE, *Submission 56*, p. 4.

10 Australian Institute of Health and Welfare (AIHW), *National Health Data Dictionary*, version 16.2, 2015, p. 541.

11 AIHW, *Submission 26*, p. 3.

12 AIHW, *Submission 26*, p. 4.

Figure 2.2: Percentage of stillbirths by gestation at birth in Australia, 2013–14¹³

2.17 Table 2.2 presents the numbers of births, live births and stillbirths and the rate of stillbirths by jurisdiction between 2013 and 2014.

Table 2.2: Perinatal deaths by jurisdiction in Australia, 2013–14¹⁴

State or Territory	Total Births	Total Live Births	Stillbirths ^(a)		Neonatal Deaths ^(a)		Perinatal Deaths ^(a)	
			n	Rate	n	Rate	n	Rate
NSW	194,287	193,156	1,126	5.8	451	2.3	1,577	8.1
Vic ^(b)	157,496	156,054	1,436	9.1	473	3.0	1,909	12.1
Qld	126,968	126,125	843	6.6	380	3.0	1,223	9.6
WA ^(c)	69,609	69,150	459	6.6	109	1.6	568	8.2
SA	41,012	40,729	283	6.9	84	2.1	367	8.9
Tas	11,913	11,822	91	7.6	40	3.4	131	11.0
ACT ^(d)	12,716	12,614	102	8.0	36	2.9	138	10.9
NT	8,036	7,957	79	9.8	45	5.7	124	15.4
Australia	622,037	617,600	4,419	7.1	1,618	2.6	6,037	9.7

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

(b) Perinatal deaths in Victoria include terminations of pregnancy and fetus papyraceous. The majority of late terminations for psychosocial indications performed in Australia are undertaken in Victoria, and many women travel from interstate (and overseas) to Victoria to have the termination undertaken.

(c) For Western Australia, stillbirths and neonatal deaths include late termination of pregnancy.

(d) In 2013–2014, 14.4% of women who gave birth in the ACT were non-ACT residents. Care must be taken when interpreting rates. Rates by jurisdiction of mother's usual residence are shown in Table 2.5.

13 AIHW, *Perinatal Deaths in Australia 2013–2014*, May 2018, p. 23, <https://www.aihw.gov.au/getmedia/78784f2e-2f61-47ea-9908-84b34441ae0a/aihw-per-94.pdf.aspx?inline=true> (accessed 19 September 2018).

14 AIHW, *Perinatal Deaths in Australia 2013–2014*, p. 12.

Causes of stillbirth

2.18 A high proportion of stillbirths in Australia are unexplained. Many occur unexpectedly in late pregnancy, and many are related to undetected fetal growth restriction (FGR) and placental conditions.

Many of the predisposing factors for stillbirth are closely linked and overlap with those responsible for other serious perinatal outcomes including hypoxic [lack of oxygen to the brain] and traumatic injury to unborn babies.¹⁵

2.19 An AIHW study of the causes of stillbirths occurring between 1991 and 2009 showed the major causes of stillbirth in Australia as follows:

Table 2.3: Major causes of stillbirth in Australia, 1991–2009¹⁶

Cause of stillbirth	%	Number
Congenital abnormality	22.3	1891
Unexplained antepartum death	22.3	1896
Maternal Conditions	13.4	1141
Spontaneous pre-term (< 37 weeks gestation)	11.5	980
Specific perinatal condition	8.1	684
Fetal growth restriction (FGR)	7	593
Antepartum haemorrhage	6.9	589
Perinatal infection	3.5	251
Hypertension	3.1	265
Hypoxic peripartum death	1.9	159
No obstetric antecedent	0.5	41
Total	100	8490

2.20 AIHW data for 2013–14 showed the main causes of stillbirth as congenital anomaly (27 per cent), unexplained antepartum death (20 per cent) and maternal conditions (11 per cent).¹⁷

15 Stillbirth CRE, *Submission 56*, p. 10.

16 Stillbirth Foundation Australia, <https://stillbirthfoundation.org.au/cause-of-stillbirth/> (accessed 18 September 2018).

17 AIHW, *Perinatal Deaths in Australia 2013–2014*, p. 37.

Risk factors

High-income countries

2.21 According to recent international research, 90 per cent of stillbirths in high income countries occur in the antepartum period, and are frequently associated with placental dysfunction and FGR. Many stillbirths remain unexplained, while others are associated with preventable lifestyle factors.¹⁸

2.22 One international study of stillbirth summed up the situation in high-income countries:

The proportion of unexplained stillbirths is high and can be addressed through improvements in data collection, investigation, and classification, and with a better understanding of causal pathways. Substandard care contributes to 20–30% of all stillbirths and the contribution is even higher for late gestation intrapartum stillbirths. National perinatal mortality audit programmes need to be implemented in all high-income countries. The need to reduce stigma and fatalism related to stillbirth and to improve bereavement care are also clear, persisting priorities for action. In high-income countries, a woman living under adverse socioeconomic circumstances has twice the risk of having a stillborn child when compared to her more advantaged counterparts. Programmes at community and country level need to improve health in disadvantaged families to address these inequities.¹⁹

2.23 Potentially modifiable risk factors for stillbirth in high income countries include maternal overweight and obesity, advanced maternal age, placental abruption and pre-existing hypertension and diabetes.²⁰

Australia

2.24 Similarly, the major risk factors for stillbirth in Australia have been identified by the Royal Australian and New Zealand College of Obstetricians and

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- 18 SH Leisher, JE Lawn, MV Kinney, et al, 'Stillbirths: Investment in Ending Preventable Stillbirths by 2030 will Yield Multiple Returns and Help Achieve Multiple Sustainable Development Goals', *Brief for GSDR*, 2016, p. 2, https://sustainabledevelopment.un.org/content/documents/975137_Leisher%20et%20al._Stillbirths-Investment%20in%20ending%20preventable%20stillbirths%20by%202030%20will%20yield%20multiple%20returns%20and%20help%20achieve%20multiple%20Sustainable%20Development%20Goals.pdf (accessed 12 November 2018); V Flenady, L Koopmans, P Middleton, et al, 'Major Risk Factors for Stillbirth in High-Income Countries', *The Lancet*, vol. 377, 16 April 2011, pp. 1331–1340.
- 19 V Flenady, AM Wojcieszek, P Middleton, et al, 'Stillbirths: Recall to Action in High-Income Countries', *The Lancet*, vol. 387, no. 10019, 13 February 2016, p. 691, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)01020-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)01020-X/fulltext) (accessed 12 November 2018).
- 20 V Flenady, P Middleton, GC Smith, et al, 'Stillbirths: The Way Forward in High-Income Countries', *The Lancet*, vol. 377, no. 9778, 14 April 2011, p. 1703, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60064-0/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60064-0/fulltext) (accessed 12 November 2018).

Gynaecologists (RANZCOG) as obesity, advanced maternal age, smoking, first pregnancy and diabetes and hypertension.²¹

2.25 As in other high-income countries, there is also an elevated risk of stillbirth and other adverse pregnancy outcomes for women and women who live with social disadvantage.²²

2.26 In 2011–12, the stillbirth rate for babies of teenage mothers and mothers older than 45 was more than twice that for mothers aged 30–34 (13.9 and 17.1 versus 6.4 deaths per 1000 births).²³

2.27 In 2015, most stillborn babies were preterm (85 per cent) and the mean birthweight of stillborn babies (1125 grams) was far lower than for live-born babies (3342 grams). Four in five stillborn babies were low birthweight, and more than half (65 per cent) were extremely low birthweight (<1000 grams).²⁴

2.28 A study of stillbirths in New South Wales found additional risk factors, including small birthweight for gestation, low socioeconomic status, previous stillbirth or preterm birth, Aboriginality, and maternal country of birth.²⁵

2.29 However, studies have found that risk factors differ across gestational age and reflect different causes, with foetal anomalies and infection associated with stillbirth at early gestation; anomalies and antepartum haemorrhage across 26–33 weeks; vasa praevia,²⁶ infection and diabetes affecting late term stillbirths; and FGR being a strong predictor across all gestations.²⁷

2.30 Professor Craig Pennell, Senior Researcher at the Hunter Medical Research Institute, remarked that about half of the causes of stillbirth have a primary placental origin, but identifying those women whose placentas are not functioning well becomes increasingly difficult as a pregnancy progresses:

21 RANZCOG, *Submission 17*, [p. 3].

22 Professor Claire Roberts, Deputy Director, Robinson Research Institute, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 26; Flenady, Koopmans, Middleton, et al, 'Major Risk Factors for Stillbirth in High-Income Countries', p. 1332.

23 Australian Health Ministers' Advisory Council (AHMAC), *Developing a National Strategic Approach to Maternity Services*, Consultation Paper 1, Department of Health, 2018, additional information received 19 October 2018, p. 22.

24 AHMAC, *Developing a National Strategic Approach to Maternity Services*, p. 22.

25 JA Patterson, JB Ford, JM Morris, et al, 'Trends and Recurrence of Stillbirths in NSW', *Australian and New Zealand Journal of Public Health*, vol. 8, no. 20, 2014, p. 388, <https://onlinelibrary.wiley.com/doi/full/10.1111/1753-6405.12179> (accessed 11 October 2018).

26 Vasa praevia is a rare but potentially serious condition in which blood vessels carrying blood between the placenta and the baby cross over the cervix. These vessels may bleed if the woman goes into labour, if the waters break, or if the cervix opens. See RANZCOG, *Vasa Praevia*, 2016, p. 3, [https://www.ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Vasa-praevia-\(C-Obs-47\)-Review-July-2016_3.pdf?ext=.pdf](https://www.ranzcog.edu.au/RANZCOG_SITE/media/RANZCOG-MEDIA/Women%27s%20Health/Statement%20and%20guidelines/Clinical-Obstetrics/Vasa-praevia-(C-Obs-47)-Review-July-2016_3.pdf?ext=.pdf) (accessed 12 November 2018).

27 Flenady, Middleton, Smith, et al, 'Stillbirths: The Way Forward in High-Income Countries', pp. 1703–1717.

...we're relatively good at picking up the low-hanging fruit when it comes to pregnancies, but we're not very good at determining when a pregnancy that is going well starts to fall off. The simplest way to explain that is that the average placenta has about a 30 per cent reserve. So if I'm looking at a patient and her baby's growing normally and her blood flow studies are normal, all that tells me is that her placenta is functioning between 67 per cent and 100 per cent. It doesn't tell me where it is in that range.²⁸

Regional and remote communities

2.31 Around 33 per cent of all stillbirths in Australia are to women who live in regional and remote areas of Australia. According to AIHW data, the further away women are from a major city, the higher the rate of stillbirth, as shown in Table 2.4 below.

Table 2.4: Stillbirth deaths by maternal remoteness of residence, Australia, 2013–14²⁹

Remoteness of usual residence (ARIA+)	Total births ^(a)	Live births	Stillbirths	
			n	Rate ^(b)
Major cities	444,729	441,737	2,938	6.6
Inner regional	101,768	100,993	744	7.3
Outer regional	53,716	53,266	446	8.3
Remote	9,368	9,274	93	10.0
Very remote	6,204	6,141	64	10.2
Not stated	6,253	6,189	55	8.8
Total	622,037	617,600	4,419^(a)	7.1

(a) Total births comprise live births and stillbirths collected by the National Perinatal Data Collection. The sum of stillbirths and live births may not add up to total births. See Appendix C for further detail.

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

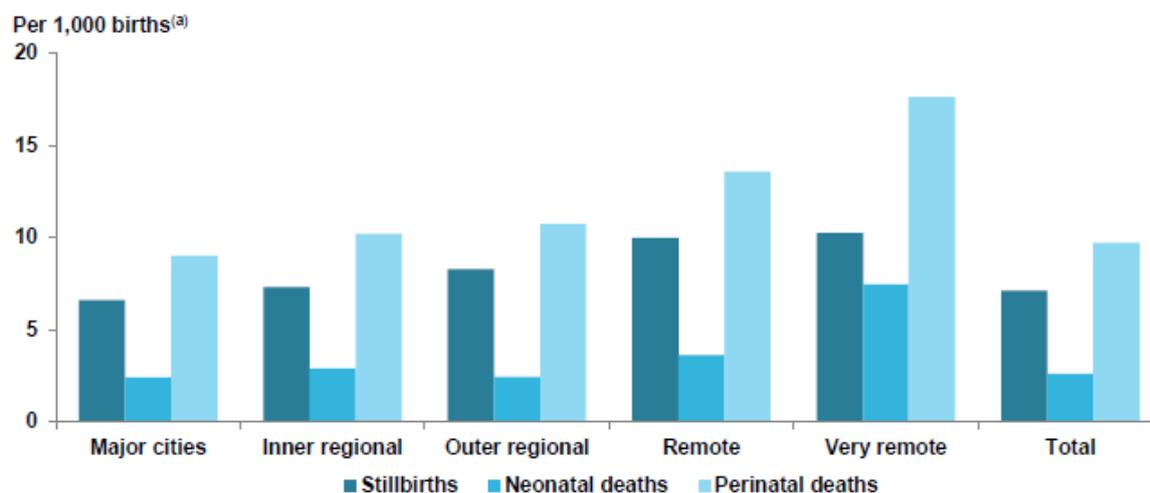
Source: AIHW 2018 - analysis of National Perinatal Mortality Data Collection and the National Perinatal Data Collection, Table A22: Perinatal deaths by maternal remoteness of residence (ARIA+), Australia, 2013–2014

2.32 The AIHW found that babies born to mothers living in remote and very remote areas were 65 per cent more likely to die during the perinatal period than babies born to mothers living in major cities or inner regional areas, as shown in Figure 2.3.

28 Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute, *Committee Hansard*, 8 August 2018, p. 20.

29 National Rural Health Alliance, *Submission 57*, [p. 4].

Figure 2.3: Perinatal mortality rates by remoteness of maternal residence in Australia, 2013–14³⁰



(a) Stillbirth and perinatal death rates were calculated using total births (live births and stillbirths). Neonatal rates were calculated using live births.

Note: Data for this figure are available in Supplementary Table A22 <<https://www.aihw.gov.au/reports/mothers-babies/perinatal-deaths-in-australia-2013-2014/data>>.

2.33 This trend may increase in the future as a result of the closure of small maternity units in rural and remote communities across Australia, where pregnant women are less likely to leave their community to seek antenatal care until late in their pregnancy.³¹

Aboriginal and Torres Strait Islander communities

2.34 The rate of stillbirth for Aboriginal and Torres Strait Islander babies is double that of other Australian women (13 in 1000 births compared to six in 1000 births).³²

2.35 Whilst there has been some progress in reducing the disparity for Indigenous women, this varies across jurisdictions. In Queensland, for example, rates are reducing, in Western Australia there has been no improvement, and in Victoria the rate amongst Aboriginal and Torres Strait Islander women has fallen to that of non-Indigenous women.³³

2.36 A recent study of stillbirth rates in Queensland found that Aboriginal and Torres Strait Islander women continued to be at increased risk of stillbirth as a result of potentially preventable factors including maternal conditions, perinatal infection, FGR and unexplained antepartum fetal death.³⁴

30 AIHW, *Perinatal Deaths in Australia 2013–2014*, p. 34.

31 National Rural Health Alliance, *Submission 57*, [p. 6]. See Chapter 6 for further discussion of the quality of care in rural and remote communities.

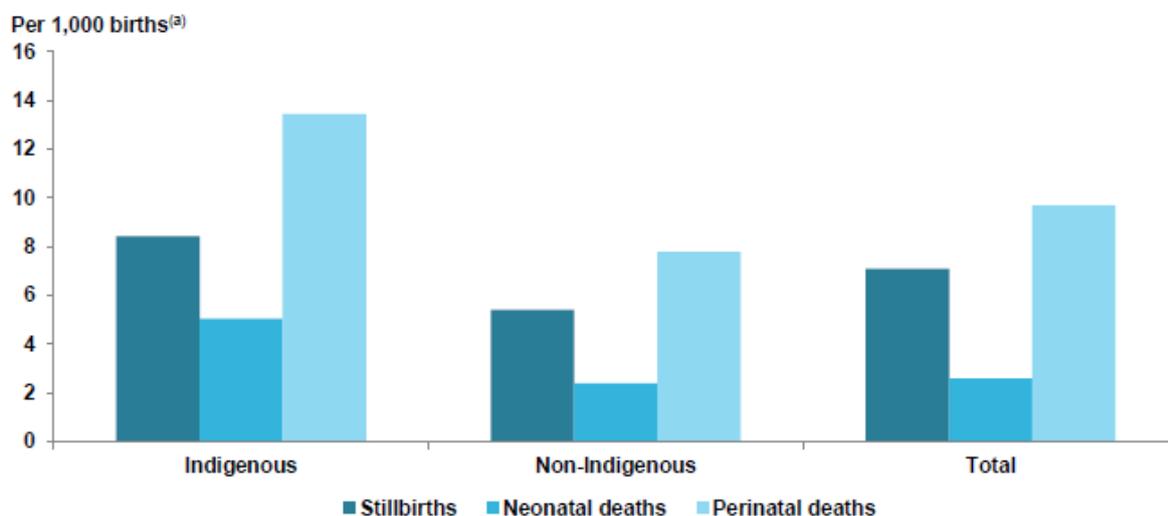
32 Stillbirth CRE, *Submission 56*, p. 12.

33 Stillbirth CRE, *Submission 56*, p. 12.

34 Ibiebele, Coory, Boyle, et al, 'Stillbirth Rates Among Indigenous and Non-Indigenous Women in Queensland, Australia', p. 1482.

2.37 Figure 2.4 shows the Aboriginal and Torres Strait Islander stillbirth rate by Indigenous status of the baby in Australia for the period 2013–14.

Figure 2.4: Perinatal mortality rates by Indigenous status of the baby in Australia, 2013–14³⁵



(a) Stillbirth and perinatal death rates were calculated using total births (live births and stillbirths). Neonatal rates were calculated using live births.

Note: Data for this figure are available in Supplementary Table A10 <<https://www.aihw.gov.au/reports/mothers-babies/perinatal-deaths-in-australia-2013-2014/data>>; similar data regarding the Indigenous status of the mother are in Figure 4.5 and Supplementary Table A11. Supplementary Table A12 cross-references the Indigenous status of the baby and the Indigenous status of the mother (incidence).

2.38 Table 2.5 compares the reported causes of stillbirth in 2013–14 between non-Aboriginal and Torres Strait Islander women and Aboriginal and Torres Strait Islander women.

Table 2.5: Perinatal Society of Australia and New Zealand Perinatal Death Classification (PSANZ-PDC) cause of stillbirth comparing non-Aboriginal and Torres Strait Islander women and Aboriginal and Torres Strait Islander women, 2013–14³⁶

Reported causes of stillbirth 2013-2014	non-Aboriginal and Torres Strait Islanders	Aboriginal and Torres Strait Islanders
congenital anomalies	27%	13.9%
unexplained antepartum death	20%	22%
spontaneous preterm birth	7.1%	12%
maternal conditions	10.8%	8.8%
specific perinatal conditions	8.6%	4%
antepartum haemorrhage	6.5%	10%
perinatal infection	6%	8%
fetal growth restriction	5.7%	8%
hypoxic peripartum death	3%	2%
maternal hypertension	2.5%	5%
no obstetric antecedent	0%	0%
Not stated	4.4%	6%
Total	100%	100%

2.39 Obesity is a major maternal risk factor for stillbirth in high income countries. The rate of obesity increases with remoteness, with rural and remote people 30 per cent more likely to be obese than those in major cities.

2.40 Maternal smoking is another risk factor for stillbirth in high income countries. In Australia, 45 per cent of Aboriginal and Torres Strait islander mothers smoke during pregnancy and are more likely to have pre-existing diabetes or hypertension.³⁷

2.41 There has been a significantly increased risk of stillbirth due to an outbreak of syphilis infection among Aboriginal and Torres Strait Islander women living in regional and rural areas.³⁸ The Australian government responded in 2018 by introducing rapid point-of-care testing across three high-risk regions in northern Australia, including a strong focus on expectant mothers and women considering pregnancy.³⁹

36 AIHW 2018 supplementary tables for perinatal deaths 2013–14, Tables A24 and A35, cited in National Rural Health Alliance, *Submission 57*, [p. 6].

37 AIHW data cited in National Rural Health Alliance, *Submission 57*, [p. 6].

38 Ibiebele, Coory, Boyle, et al, 'Stillbirth Rates Among Indigenous and Non-Indigenous Women in Queensland, Australia', pp. 1479 and 1482.

39 The Hon. Ken Wyatt, MP, Minister for Indigenous Health, 'Rapid response tests underway, aiming to halt syphilis spread', *Media release*, 8 August 2018, [http://www.health.gov.au/internet/ministers/publishing.nsf/Content/6CD2648BEBB4D34DCA2582E200780FF8/\\$File/KW113.pdf](http://www.health.gov.au/internet/ministers/publishing.nsf/Content/6CD2648BEBB4D34DCA2582E200780FF8/$File/KW113.pdf) (accessed 26 September 2018).

2.42 Such outbreaks have highlighted the need for infection prevention and control through improved antenatal screening, treatment and notification of partners as part of a broader stillbirth prevention strategy.⁴⁰

Culturally and linguistically diverse communities

2.43 There are higher stillbirth rates amongst culturally and linguistically diverse (CALD) communities in Australia. In 2013–14, 1531 (34.6 per cent) of the 4419 stillbirths that occurred in Australia were born to women who were themselves born in countries other than Australia.⁴¹

2.44 The percentage of women from CALD backgrounds in Victoria is slightly higher, with 38.5 per cent of women giving birth in 2016 born outside of Australia. However, information on ethnicity is not routinely collected for perinatal data collections, and has resulted in incomplete data.⁴²

40 Stillbirth CRE, *Submission 56*, p. 13.

41 Multicultural Centre for Women's Health, *Submission 70*, p. 2.

42 Parliament of Victoria, *Inquiry into Perinatal Services: Final Report*, Family and Community Development Committee, June 2018, p. 325.

Chapter 3

Quantifying the impacts of stillbirth

3.1 Stillbirth has far-reaching impacts on individuals, families, communities and Australian society. However, the economic and social costs of stillbirth are not widely recognised, and there has been limited attention to quantifying these costs in the Australian context.

3.2 International researchers found that the direct financial cost of care associated with a stillbirth was 10–70 per cent greater than the cost of care for a live birth, and that the costs were predominantly met by government.¹

3.3 Research conducted in the United States indicated that women whose babies were stillborn, particularly where the cause was unknown, had significantly higher hospital costs during labour and birth than women with live births, while in England and Wales there were increased costs for subsequent births as a result of more intensive surveillance of the pregnancy.²

3.4 More detailed research is required to guide national policymaking, funding decisions and future corporate investment, as well as to better target stillbirth research and education programs.³ According to the Centre of Research Excellence in Stillbirth (Stillbirth CRE):

The economic impact of stillbirth is significant and far reaching and extends further than just the direct costs to the healthcare sector. One important area in which major employer groups might see benefit from targeted stillbirth research is in the impact of pregnancy loss on women and their families in terms of time off work, altered work performance, and other employment-related impacts. Improving bereavement care and recovery after stillbirth has potential beneficial spin-offs for employers and the broader economy, and this could encourage investment from the corporate sector.⁴

1 Centre of Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, p. 14.

2 KJ Gold, A Sen and X Xu, 'Hospital Costs Associated with Stillbirth Delivery', *Maternal & Child Health Journal*, vol. 17, no. 10, 2012, pp. 1835–1841, https://www.researchgate.net/publication/233931011_Hospital_Costs_Associated_with_Stillbirth_Delivery (accessed 14 October 2018); Stillbirth CRE, *Submission 56*, p. 14.

3 Public Health Association of Australia, *Submission 66*, p. 6.

4 Stillbirth CRE, *Submission 56*, p. 8.

Direct and indirect costs

3.5 A study prepared by PriceWaterhouseCoopers (PwC) for Stillbirth Foundation Australia estimated the total projected direct and indirect costs of stillbirth to the Australian economy to be \$681.4 million for the five-year period from 2016 to 2020.⁵

3.6 The study analysed projected direct and indirect costs of stillbirth in Australia for the period 2016 to 2020 across 13 categories, as shown in Table 3.1 below.

Table 3.1: Cost of stillbirth in Australia for the five-year period 2016–20, in 2016 present value terms⁶

Cost category	Value (\$ millions)
Direct costs	
<i>Costs associated at the time of stillbirth</i>	
Cost of stillbirth investigations	33.3
Hospital fees	74.5
Cost of counselling	53.2
Cost of investigations 8-12 weeks postpartum	0.6
<i>Cost of a subsequent pregnancy</i>	
Cost of tests	5.6
Cost of counselling	4.9
Sub-total direct costs	172.1
Indirect costs	
Funeral costs	67.1
Absenteeism	129.4
Presenteeism	149.0
Lost productivity from exiting the labour force	70.6
Cost of divorce	37.4
Government subsidy	36.1
Absenteeism (family)	19.7
Sub-total indirect costs	509.3
Total cost	681.4

3.7 The PwC study projected that, if the 2016 stillbirth rate of 7.4 per 1000 births remained unchanged, and assuming an increase in the Australian population and

5 PriceWaterhouseCoopers (PwC), *The Economic Impacts of Stillbirth in Australia*, Stillbirth Foundation Australia, 2016, p.12, <https://stillbirthfoundation.org.au/wp-content/uploads/2016/10/Economic-Impacts-of-Stillbirth-2016-PwC.pdf> (accessed 27 September 2018).

6 PwC, *The Economic Impacts of Stillbirth in Australia*, p. iv. Costs are based on the 12-month period post-loss. They compare the additional costs of stillbirths with no stillbirths. Direct costs are primarily associated with the need for additional health care at the time of stillbirth, after the initial loss and in the case of a subsequent pregnancy. Indirect costs refer to those not directly associated with the stillbirth event including funeral costs, lost productivity associated with absenteeism and workers exiting the labour force, divorce, associated government subsidies and financial impacts on family members. Intangible costs may be associated with mental well-being, personal relationships, relationships with others, other children and financial loss.

number of births in this five-year period, the number of stillbirths would increase from approximately 2500 stillbirths in 2016 to 2700 stillbirths in 2020.⁷

3.8 In addition to the above projection, the study calculated the cost of lost future productivity of the stillborn child in 2016 as \$7.5 billion in 2016. PwC acknowledged that these costs were more difficult to quantify, but noted that they 'have serious impacts on people and society' and are no less important than the readily quantifiable costs included in the study.⁸

3.9 Stillbirth CRE noted that preliminary efforts to quantify stillbirth costs suggest that direct hospitalisation costs associated with the time of birth is \$9630 for women who had a stillbirth and \$6690 (30 per cent lower) for women who did not. This calculation did not take into account the ongoing costs of support, bereavement care and counselling, or the difficulty in returning to work.⁹

3.10 Other research projects are underway that focus on identifying and quantifying the costs of stillbirth to the nation, including a collaborative research project between the Australian Institute of Tropical Health and Medicine at James Cook University and the Stillbirth CRE.¹⁰

3.11 The Hunter Medical Research Institute (HMRI) also noted that there are significant costs to the community as a result of poor fetal health, even when a baby is born alive, and advocated that researchers should not solely focus on stillbirth, but also consider the ongoing risk of babies being born with long-lasting effects.

When the baby does not grow well in utero, the ongoing impact is great—the likelihood of doing well in school and securing a good job is reduced, the likelihood of a decreased life expectancy and developing of heart disease, diabetes and kidney failure is increased, particularly in vulnerable populations. The resulting impact to Australia's economic and social wellbeing is vast.¹¹

3.12 One witness advocated that a longitudinal study on the social and economic impacts of pregnancy loss be undertaken by the National Centre for Longitudinal Data (NCLD).¹²

3.13 The NCLD, funded by the Australian Department of Health, is a national population study examining the health of over 57 000 Australian women. The study includes data on the number who have experienced a miscarriage or stillbirth. However, it does not gather information about how experiencing stillbirth affects the

7 PwC, *The Economic Impacts of Stillbirth in Australia*, p. iii.

8 The study used the concept of 'value of statistical life year', which assumes a young adult to have at least 40 years of life ahead. See PwC, *The Economic Impacts of Stillbirth in Australia*, pp. 15–16.

9 Stillbirth CRE, *Submission 56*, p. 15.

10 Research Australia, *Submission 41*, p. 12.

11 Hunter Medical Research Institute (HMRI), *Submission 36*, [p. 7].

12 Name withheld, *Submission 145*, p. 3.

woman's future health. Professor Gita Mishra, Director, Australian Longitudinal Study on Women's Health, noted that this is an area that demands further research in order to identify women at risk of future health conditions.

I think that's so important—apart from her mental health. It could be an underlying condition that puts her at risk of maybe future cardiovascular diseases, as we've seen with other conditions. So, I think it's a big program that we really need to understand. If there are risk prediction models with accurate prevalence data, we can tell women what they're getting into and how we can avoid that situation for them. But, also, then what happens to her health and wellbeing in the future?¹³

Impact on families

3.14 Evidence presented to this inquiry clearly showed the significant financial impact that a stillbirth has on individual families. Some of the unexpected costs included:

- costs associated with the autopsy process including transporting the baby to the autopsy, travel and accommodation for the parents, and the cost of the autopsy itself;
- costs associated with a funeral, cemetery site and gravestone;
- the cost of grief counselling;
- extended periods of unpaid leave or part-time work;
- costs associated with an inability to return to work; and
- the cost of additional medical care associated with subsequent pregnancies.¹⁴

Autopsy costs

3.15 The Royal College of Pathologists of Australasia (RCPA) reported that costs of autopsies vary depending on complexity, and provided an example of one major public service charging \$2500 per autopsy.¹⁵

3.16 The Victorian Perinatal Autopsy Service reviewed the cost of a perinatal post-mortem examination in 2016, and found that the cost depended on the complexity of the examination, as follows:

- full post-mortem examination: \$1976–\$2673;
- limited post-mortem examination: \$1279–\$1859; and
- external post-mortem examination: \$654–\$866.¹⁶

13 Professor Gita Mishra, Director, Australian Longitudinal Study on Women's Health, *Committee Hansard*, 6 September 2018, p. 31.

14 See for example, Ms Robyn Wilson, *Submission 195*, [pp. 4–5]; Maurice Blackburn Lawyers, *Submission 69*, p. 14; Ms Julia Whitty, *Submission 194*, [pp. 3–4]; Ms Fiona Goss, *Submission 185*, [p. 2].

15 Royal College of Pathologists of Australasia (RCPA), answers to questions on notice, 6 September 2018 (received 18 October 2018).

3.17 Dr Diane Payton, Chair, Paediatric Advisory Committee, RCPA, pointed out that most autopsies are conducted on a voluntary basis due to the lack of funding.

This leads to virtually all of them being done in public hospitals, which for me is a good thing. But it also does mean that in a department, where the director is really looking after his budget and there is no funding for the perinatal autopsy, it really does get pushed to the bottom of the pile. Here is a departmental director who's looking at one of his pathologists maybe spending a whole day, when you add up the performance of the autopsy and the reporting, for which they could have been reporting 60 small biopsies, and they would have had money coming in, or medical benefits accrued—the sort of funding they count on their books—whereas for the autopsy there is nothing.¹⁷

Medicare and other healthcare benefits

3.18 Whilst Medicare benefits are available for standard medical care costs, there are a number of services for which benefits are not available. For example, pathology services performed on stillborn babies do not qualify for payment under the Medicare Benefits Schedule (MBS).¹⁸

3.19 Professor Hamish S Scott and Associate Professor Christopher Barnett noted that current MBS funding for perinatal autopsy only provides for anatomic analysis, and not genetic analysis. They argued that MBS funding processes need to become more flexible in order to deal with such rapid advances in medical research and technology, and estimated that MBS funding of \$4000 per autopsy would provide an answer for up to 50 per cent of cases involving stillbirth or congenital abnormalities leading to death.¹⁹

3.20 The *Parental Leave Act of 2010* (Cth) provides that a person is eligible for Paid Parental Leave or Dad and Partner Pay where the child is stillborn or dies. The welfare payment is linked to an entitlement to unpaid parental leave.²⁰

16 Victorian Perinatal Autopsy Service, answers to questions on notice, 7 September 2018 (received 5 October 2018).

17 Dr Diane Payton, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australasia (RCPA), *Committee Hansard*, 6 September 2018, pp. 39–40.

18 Royal College of Pathologists of Australasia (RCPA), *Submission 46*, p. 2. The Medicare Benefits Schedule (MBS) is a listing of Medicare services subsidised by the Australian government as part of the Medicare Benefits Scheme under the *Health Insurance Act 1973*; see Department of Health, *Medicare Benefits Schedule Book, Category 6*, Operating from 1 May 2018, p. 59, [http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/42A5C19503D6BE07CA25826C0009105B/\\$File/201805-Cat6.pdf](http://www.health.gov.au/internet/mbsonline/publishing.nsf/Content/42A5C19503D6BE07CA25826C0009105B/$File/201805-Cat6.pdf) (accessed 20 November 2018).

19 Professor Hamish S Scott and Associate Professor Christopher Barnett, *Submission 54*, [p. 2]. See Chapter 4 for further discussion about MBS funding for stillbirth autopsy.

20 Sections 277 and 277A, *Paid Parental Leave Act 2010*; Department of Human Services, *Dad and Partner Pay*, <https://www.humanservices.gov.au/individuals/services/centrelink/dad-and-partner-pay> (accessed 14 October 2018).

3.21 Parents of a stillborn child may also be able to access Centrelink benefits through the Stillborn Baby Payment, although there are time limits on applying and eligibility criteria in the form of income and/or work tests.²¹

3.22 Insurance policies may also have limitations in relation to health care claims resulting from stillbirth. One submitter discovered that her insurance policy excluded certain depressive and anxiety disorders, meaning that she was ineligible to make a claim as a result of seeking psychological support following stillbirth.²²

Families in rural and remote communities

3.23 As noted in Chapter 2, the closure of small maternity units in rural and remote communities across Australia has had an impact on maternity health outcomes for pregnant women living in those communities, including additional financial impacts as a result of having to travel long distances to receive maternity care, and a higher risk of stillbirth because women may be less likely to leave their community to seek antenatal care until late in their pregnancy.²³

Intangible costs

3.24 The intangible costs of stillbirth are more difficult to quantify, and as such have tended to receive less attention from policymakers. However, it is clear from research that they play a major role in families' circumstances and have a rippling effect across communities.

Stillbirth exacts an enormous psychological and social toll on mothers, fathers, families and society. It is estimated that 60–70% of affected women will experience grief-related depressive symptoms at clinically significant levels one year after their baby's death. These symptoms will endure for at least four years after the loss in about half of those women.²⁴

3.25 Researchers have noted that intangible costs contribute to the longer-term economic burden of stillbirth as a result of the higher level of anxiety and depression in families experiencing stillbirth compared to other families.²⁵

3.26 The PwC study analysed five intangible costs associated with stillbirth in Australia: the impact on mental well-being; relationship with partner; relationship with others (family and extended family); other children; and the effect of financial loss. It found that stillbirth had a profound psychological impact on parents.

21 *Stillborn Baby Payment*, <https://www.humanservices.gov.au/individuals/services/centrelink/stillborn-baby-payment> (all accessed 28 September 2018).

22 Elizabeth Luxford and Nathan Barker, *Submission 202*, [p. 2].

23 National Rural Health Alliance, *Submission 57*, [p. 6]. See Chapter 6 for further discussion of the quality of maternity care in rural and remote communities.

24 Stillbirth CRE, *Submission 56*, p. 5.

25 B Ogwulu Chidubern, LJ Jackson, AEP Heazell, et al, 'Exploring the Intangible Economic Costs of Stillbirth', *BMC Pregnancy and Childbirth*, vol. 15, no. 188, 2016, p. 2.

Many suffer from grief and anxiety, the effects often lasting long periods of time. Experiencing a stillbirth caused stress and anxiety in subsequent pregnancies and some parents received counselling to deal with this increased level of stress. Stillbirth put considerable strain on marital or partner relationships. Different grieving patterns between men and women, blame, anger and resentment were often cited. Some couples separated after the experience.²⁶

3.27 Other flow-on effects for families may include increased fear and anxiety amongst other children, and social isolation.²⁷ These psychological effects may adversely impact on their daily health, functioning, relationships and employment.²⁸

Costs can no doubt be attributed to each of the above issues by economists, but how do you quantify the impact of a stillborn baby on its family? Without wanting to be overly dramatic, Joshua's death traumatised me in ways I cannot always describe, and impacted on the mothering of my other two children. I was diagnosed with breast cancer six years after Joshua's birth, and although there is no evidence, I strongly believe the grief I experienced after Joshua, and the stress of my subsequent pregnancies played a role in this. I was 36 at the time of diagnosis.²⁹

3.28 In addition to the emotional grief and trauma of stillbirth, bereaved families are often faced with longer-term financial burdens that extend well beyond 12 months after the loss.³⁰

...I keep needing to see new specialists for things that we're still trying to find answers for. Now I'm struggling with infertility, so I'm going through IVF, which is partially Medicare rebated. Counselling is another thing that I've utilised. It has been very helpful to have access to the mental healthcare plan, but I don't think it's enough to subsidise 10 sessions a year for something that's as profound and ongoing as this.³¹

...

My husband and I were both self-employed. I was an IT consultant, and my husband has an electrical contracting business. He couldn't take time off. His staff tried to keep things going, but we had no such thing as paid leave, and ultimately we moved out of Sydney, partly for economics. That was an economic outcome of the death. I completely change[d] careers as a result. We went from a staff of five electricians down to just my husband.³²

26 PwC, *The Economic Impacts of Stillbirth in Australia*, p. iii.

27 PwC, *The Economic Impacts of Stillbirth in Australia*, p. iii.

28 Chidubern, Jackson, Heazell, et al, 'Exploring the Intangible Economic Costs of Stillbirth', p. 1.

29 Ms Wilson, *Submission 195*, [p. 5].

30 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 17.

31 Mrs Clare Rannard, *Committee Hansard*, 8 August 2018, p. 9.

32 Ms Natasha Donnelly, *Committee Hansard*, 8 August 2018, p. 9.

...

It's fair to say that my productivity was severely impacted by my loss experience. I struggled to concentrate, and I found it difficult to re-discover purpose in my work. I found group situations challenging, including leading meetings and presenting to groups. I had lost all confidence. This was my experience, despite my having accessed extensive bereavement counselling through (then) SIDS and Kids—both individual and support groups, and actively working hard to rediscover hope and happiness after loss.³³

...

...I now find myself mentally unprepared to re-join the workforce in the immediate future due to a lack of drive and mental capacity to be able to fulfil work obligations. Re-joining the workforce too soon may result [in] a phenomenon known as presenteeism, where an employee is physically present, but mentally absent. Further, the prolonged period of remaining at home without an active income will eventuate in financial burden, and potentially a strain on the relationships within the household.³⁴

Impact on healthcare providers

3.29 The College of Nursing and Health Sciences at Flinders University noted that some of the direct and indirect costs of stillbirth are borne directly by healthcare providers. These include increased medical and health care costs, costs associated with subsequent pregnancies which would be regarded as high-risk, and costs associated with stillbirth investigations and reporting.³⁵ As one bereaved parent explained:

Extended leave from the workforce, and impacted productivity are not the only impacts with respect to quantifying the impact of stillbirth on the Australian economy. It is important to also take account of the impact on the public health system of subsequent pregnancy care...This increased level of specialist care by an esteemed, senior medical professional, certainly came at a cost to the public health system. With this replicated more than 2000 times every single year, it is clear to see that we have an unacceptable and unsustainable situation on our hands.³⁶

3.30 The economic impact of stillbirth also extends to clinicians and other health professionals who care for those experiencing stillbirth, although this impact is not accounted for when quantifying the costs of stillbirth. As Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, explained:

Obstetricians, midwives and the nursing staff all feel this loss at the same time, and that wasn't taken into account. I'm sure there would be many workers who find it difficult to return to their jobs, having sat beside a

33 Ms Gillian Graham-Crowe, *Submission 4*, p. 6.

34 Ms Oi-Lai Leong, *Submission 147*, p. 6.

35 College of Nursing and Health Sciences, Flinders University, *Submission 39*, [p. 2].

36 Ms Graham-Crowe, *Submission 4*, p. 7.

family who've gone through this and held their hand and then had to go home and deal with that themselves. So, whilst we have this figure, it is much broader than it seems.³⁷

3.31 The 2018 Victorian parliamentary inquiry into perinatal services also heard evidence that short staffing combined with overtime and double shifts had led to workplace stresses for midwives, leading to increased sick leave, reduction in working hours, or even leaving the workforce.³⁸

3.32 Professor Craig Pennell, Senior Researcher, HMRI noted that, whilst considerable effort goes into training so that staff can deal with the emotional stress surrounding stillbirth, it takes a particular type of person to do so repeatedly. He noted that:

...there are staff who are involved, especially in the unexpected cases or cases that happen in labour, who would not attend work for a week or weeks. I know of staff who have left the profession because of stillbirths that were particularly unexpected, or where the management of those cases wasn't good, or where there was blame or the junior staff were blamed. But every case is, obviously, different.³⁹

3.33 The loss of skilled staff as a result of these pressures is therefore a significant issue that needs to be factored into the calculation of the economic impacts of stillbirth on hospitals and the healthcare system.

Employment-related costs

3.34 Stillbirth has a significant economic impact on employees, employers, and the labour force more generally. Bereaved parents may withdraw from normal social activities, including labour force participation, in the aftermath of stillbirth, with life-long implications for the economic status of women and their families.⁴⁰

3.35 Stillbirth CRE estimated that the annual cost of one mother missing from the labour force as a result of stillbirth was \$33 000 in Gross Domestic Product.⁴¹

3.36 PwC concluded that, even in cases where a bereaved mother has to return to work for financial reasons following a stillbirth, her productivity is estimated to be 26 per cent of her normal rate after 30 days.⁴²

37 Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 17.

38 Parliament of Victoria, *Inquiry into Perinatal Services: Final Report*, Family and Community Development Committee, June 2018, p. 221.

39 Professor Craig Pennell, Senior Researcher, HMRI, *Committee Hansard*, 8 August 2018, p. 26.

40 Stillbirth CRE, *Submission 56*, p. 14.

41 Stillbirth CRE, *Submission 56*, p. 14. The figure was based on Treasury's GDP formula.

42 PwC, *The Economic Impacts of Stillbirth in Australia*, p. 12. The study estimated the projected additional costs of stillbirth compared to no stillbirth.

Leave following stillbirth

3.37 A key issue raised by witness and submitters in relation to employment matters concerned leave entitlements for parents who experienced a stillbirth.

3.38 According to the International Labour Organisation, compulsory leave of six weeks should be provided to all women in the event of a stillborn child, as a health-related measure. However, only 12 of 170 countries with maternity benefit policies include any specific provision for stillbirth-related leave, while others have leave provisions that protect parents from discrimination based on maternity.⁴³

National Employment Standards

3.39 In Australia, the National Employment Standards (NES) of the *Fair Work Act 2009* (Cth) provide for minimum leave entitlements for all employees in the national workplace relations system. Other leave entitlements available under an award, registered agreement or contract of employment cannot be less than those contained in the NES.⁴⁴

3.40 Parental leave under the NES of the Fair Work Act is unpaid leave, although many employees are entitled to various degrees of paid parental leave under various industrial instruments, including enterprise agreements and some awards. These employees keep this paid entitlement as it is a benefit in excess of the NES entitlement.⁴⁵

3.41 The Fair Work Act provides for two days' compassionate or bereavement leave 'each time an immediate family or household member dies'.⁴⁶

3.42 The Fair Work Act provides for special maternity leave for a pregnant employee who is eligible for unpaid parental leave, where 'the pregnancy within 28 weeks of the expected date of birth of the child otherwise than by the birth of a living

43 Community and Public Sector Union New South Wales (CPSU NSW), answers to questions on notice, 14 September 2018, p. 6 (received 14 September 2018).

44 'Leave', Fair Work Ombudsman, <https://www.fairwork.gov.au/leave> (accessed 22 October 2018).

45 'Paid parental leave', FairWork Ombudsman, <https://www.fairwork.gov.au/leave/maternity-andparental-leave/paid-parental-leave> (accessed 21 November 2018); *Fair Work Act 2009*, section 22. Section 4 of the *Family Law Act 1975* defines the meaning of 'child' to include a stillborn child. A summary of special parental leave provisions in selected Enterprise Agreements and Awards across Australia is provided in Appendix 3.

46 'Compassionate and bereavement leave', Fair Work Ombudsman, <https://www.fairwork.gov.au/leave/compassionate-and-bereavement-leave> (accessed 21 November 2018); 'Maternity and parental leave', FairWork Ombudsman, <https://www.fairwork.gov.au/leave/maternity-and-parental-leave/pregnant-employee-entitlements> (accessed 20 September 2018).

child'. If an employee takes leave because of a stillbirth, the leave can continue until she is fit for work.⁴⁷

3.43 An eligible pregnant employee can reduce or cancel their period of unpaid birth-related parental leave if their pregnancy ends due to their child being stillborn, or if their child dies after birth.⁴⁸

3.44 State and territory parental leave provisions apply only to those employees not covered by the parental leave component of the NES (that is, employees who are award/agreement free). The majority of state and territory laws are generally consistent with the provisions provided for in the Fair Work Act. Only New South Wales, Queensland, Western Australia, South Australia and Tasmania have applicable laws, while the ACT, Northern Territory and Victoria are essentially governed by the Fair Work Act alone (with some exceptions regarding public service).⁴⁹

Parental Leave Pay

3.45 The Australian government's Paid Parental Leave Scheme, introduced on 1 January 2011, provides access to 18 weeks of parental leave pay for eligible working parents when they take time off from work to care for a newborn or recently adopted child. It is fully government-funded. Parental leave pay is not a leave entitlement, but a payment made to an eligible employee while that employee is on leave.

3.46 Parents of a stillborn child are eligible for parental leave pay, although the same income caps and activity tests apply as for paid parental leave which effectively excludes many employees.⁵⁰

Inconsistent leave provisions

3.47 The Community and Public Sector Union New South Wales (CPSU NSW) noted that the Fair Work Act appears to contradict the federal allowance provided under the Paid Parental Leave Scheme. Section 77A, for example, states that 'Pregnancy ends (other than by birth of a living child)', which appears to allow the employer to cancel unpaid leave in the instance of a stillbirth and require the worker to return to work. In other words the entitlement is removed.⁵¹

47 *Fair Work Act 2009*, section 80, http://www8.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol_act/fwa2009114/s80.html (accessed 21 November 2018).

48 'Applying for parental leave', FairWork Ombudsman, <https://www.fairwork.gov.au/leave/maternity-and-parental-leave/applying-for-parental-leave> (accessed 21 November 2018).

49 *Fair Work Act 2009*, sections 60 and 741–748.

50 Australian government, *Paid Parental Leave Guide*, 2.1.1 Eligibility differences between PLP & DAPP, <http://guides.dss.gov.au/paid-parental-leave-guide/2/1/1> (accessed 22 October 2018).

51 Community and Public Sector Union New South Wales (CPSU NSW), answers to questions on notice, 8 August 2018 (received 14 September 2018); also see Mr Andrew McBride, *Submission 102*, p. 3; *Fair Work Act 2009*, section 77A, http://www8.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol_act/fwa2009114/s77a.html (accessed 21 November 2018).

3.48 Mr Troy Wright, Branch Assistant Secretary, CPSU NSW, pointed out that the relevant provisions of the Fair Work Act (sections 77A and 80) are inadequate because they discriminate between mothers whose children are born full-term and mothers whose children are not.

Mothers who give birth to a child are recipients of the government's Paid Parental Leave scheme, whereas mothers experiencing a stillbirth or miscarriage are reliant upon unpaid parental leave [and] requires a series of medical certificates in the event of a miscarriage or stillbirth...somehow the issue of stillbirth and miscarriage is still treated as a medical issue industrially and is still reliant on medical certificates.⁵²

3.49 The CPSU NSW recommended that section 80 of the Fair Work Act be amended:

...to reduce the threshold from 12 weeks pregnancy and also to ensure that workers are paid special maternity leave at a rate equal to their pre miscarriage level regardless of the employment status of the worker.⁵³

Inadequate leave provisions

3.50 Even where bereavement or other types of paid leave were available to them, some bereaved parents found that the period of leave was not sufficient and were forced to take additional unpaid leave.⁵⁴ Tim and Leanne Smith explained that it took time to deal with the grief and trauma of a stillbirth:

I was not a functioning member of society or the workforce for at least 6 months. I believe that people need to be given sufficient time away from the workforce in the first instance to deal with the emotional and physical turmoil.⁵⁵

3.51 Mrs Jackie Barreau agreed, arguing that the two days' compassionate/bereavement leave provided under the Fair Work Act is not enough to manage the emotional, physical and mental impact of losing a child and planning for a funeral. She recommended that this leave should be extended to five days, and that flexible workplace arrangements in both public and private sectors should extend to stillbirth to allow for the bereavement of a family member.⁵⁶

3.52 Mrs Clare Rannard testified that, whilst she was able to access a combination of workplace maternity leave, paid parental leave and unpaid leave, she found it

52 Mr Troy Wright, Branch Assistant Secretary, CPSU NSW, *Committee Hansard*, 8 August 2018, p. 57.

53 CPSU NSW, *Submission 68*, [p. 5].

54 See for example, Britt Jacobsen and Samuel Haldane, *Submission 82*, [p. 4]; Mrs Rannard, *Committee Hansard*, 8 August 2018, p. 9; Mrs Megan Warren, *Submission 151*, [p. 5].

55 Tim and Leanne Smith, *Submission 77*, [p. 5].

56 Mrs Jackie Barreau, *Submission 215*, [p. 3].

difficult to work in a full-time capacity following her daughter's stillbirth, with implications for her employment security.⁵⁷

3.53 Ms Lisa Martin found that she was ineligible for parental leave because of strict provisions regarding the classification of 'stillborn'.

My son Carter Jake Martin was born at 19 weeks 6 days and 2 & half hours just making him a few hours shy of a classified stillborn, therefore not entitled to recognition of a birth or parental leave. Not only did I endure the birth I faced the cold hard reality of what was to come after that which was the effect on our family, my sons and friends, the impact on my job and the financial position we were in which may see us lose our home.⁵⁸

Employer discretion

3.54 The committee heard evidence about the difficulties and inconsistencies experienced by employees when seeking access to leave following a stillbirth, highlighting that employers may lack awareness of the trauma associated with stillbirth and exercise considerable discretion and control over access to parental leave entitlements.⁵⁹

3.55 Nick and Elena Xerakias noted that, while Ms Xerakias was not able to work full-time and could not commit to a full-time position, Mr Xerakias's employer and colleagues were supportive and, upon his return to work, he was provided with flexibility in his work hours.⁶⁰

3.56 Ms Naomi Herron was advised by her employer that she had been made redundant whilst on leave and that she would not receive a payout. She stated that she worked in a male-dominated industry and her employers seemed to be unaware of their responsibility to their employees.⁶¹

3.57 Sands Australia noted that '[s]tillbirth does not satisfy Centrelink/government maternity leave requirements and this is often the case for employer maternity leave entitlements'.⁶² Access to maternity leave may be granted at the discretion of the employer. One submitter stated that her employer had honoured their maternity leave policy 'even though I had no baby', and this had enabled her to work through her grief and not worry about losing her home.⁶³

57 Mrs Rannard, *Committee Hansard*, 8 August 2018, p. 9.

58 Ms Lisa Martin, *Submission 176*, [p. 1].

59 See for example, Mrs Clare Rannard, *Submission 179*; Tim and Leanne Smith, *Submission 77*; Flinders University, *Submission 28*.

60 Nick and Elena Xerakias, *Submission 193*, [p. 5].

61 Ms Naomi Herron, *Submission 204*, [p. 1].

62 Sands Australia, *Submission 59*, p. [11].

63 Ms Jana Hall, *Submission 216*, [p. 1].

3.58 Australian Public Service (APS) employees may be able to access accrued personal leave and paid maternity leave, but parental leave policies in the private sector are inconsistent and ambiguous.⁶⁴

3.59 Mr Andrew McBride stated that he and his wife were both in the APS at the time of their stillbirth, and were able to access paid personal and maternity leave. However, he recalls meeting a newly-grieving mother who had to return to work because she had no leave and could not afford to take time off and, when he was later employed in the private sector, he observed that corporate parental leave policies were often ambiguous as to whether parents of stillborn babies were entitled to paid parental leave, because they tended to mirror the provisions contained in the Fair Work Act.

3.60 Since then, he has been working with corporate leaders to ensure recognition of stillbirth in paid parental leave policies becomes the norm, and that parents of stillborn children are afforded the same rights as other parents.

Our ask of companies has been straightforward: a commitment to review company parental leave policies to ensure that employer funded paid parental leave is available in the circumstance of stillbirth.⁶⁵

3.61 Mr McBride recommended that the provisions for paid parental leave needed to be clarified in order to encourage private employers to ensure that employees who experience stillbirth have access to such leave.⁶⁶

I do not believe that the ambiguity in existing company parental leave policies was through ill-intent but simply neglect—companies have tended to take the mandated legislative provisions in the Fair Work Act of 2009 (that focus on unpaid parental leave) and overlay their own paid parental leave policies, which tend to be cast around the care-giving aspect of parental leave and just don't consider the circumstance of stillbirth. Consequently, clauses from the Fair Work Act, such as Section 80 on “Unpaid special maternity”, are confusingly included in policies that are addressing paid parental leave.⁶⁷

3.62 Annette Kacela and Christopher Lobo reported that, whilst they had access to some paid leave, their respective experiences of returning to work were starkly contrasting.

Following the stillbirth of our son Thomas, neither Christopher nor I were capable of immediately returning to work due to the sheer devastation, grief and crippling mental effects. We have since returned to our respective employers to different departments. Christopher's employer granted him paid leave for 2 months who was exceptionally supportive of the circumstances and even contacted him on multiple occasions to ensure his

64 Mr McBride, *Submission 102*, p. 2.

65 Mr McBride, *Committee Hansard*, 7 September 2018, p. 2.

66 Mr McBride, *Committee Hansard*, 7 September 2018, p. 6.

67 Mr McBride, *Submission 102*, p. 3.

and our family's wellbeing. My employer dealt with Thomas's passing in stark contrast, I was on leave for four months where I was required to use all of my personal and annual leave entitlements which I had been accumulating in preparation for Thomas live birth, the remainder of the time was un-paid...The non-supportive work culture demonstrated by my employer compounded the situation we were already in. I was also requested to complete my 'on-call' shifts over the Christmas period that I had to decline, this gesture clearly demonstrated the lack of awareness stillbirth has across various domains including the healthcare industry.⁶⁸

Best practice employment models

3.63 The Centre for Midwifery, Child and Family Health advocated a review of employment laws across Australian jurisdictions, using a 'stillbirth lens' to ensure that bereaved parents are protected and supported in legislation.⁶⁹

3.64 Stillbirth CRE recommended the following benefits to reduce the financial burden on parents of stillbirth:

- minimum paid period of time off work;
- respite child care if there are other children or care responsibilities;
- Medicare reimbursement for psychiatric or psychological referral; and
- equity of parental leave support post stillbirth for both mothers and fathers.⁷⁰

3.65 One submitter noted that 'parents of babies who die are subjected to a lot of misinformation on their rights and responsibilities in the workplace', and recommended that the Office of the Fair Work Ombudsman develop a best practice guide for employees and employers, and a national stillbirth in the workplace campaign to assist employers and employees to navigate the return to work after a stillbirth.⁷¹

3.66 In 2017 Stillbirth Foundation Australia called on private employers to review their parental policies to ensure that their company extended paid parental leave in the case of stillbirth. The Foundation listed the economic and social benefits including removing financial pressure from the bereaved family, recognising the birth of a child and allowing time for bereaved mothers to recover from the birth.⁷²

68 Annette Kacela and Christopher Lobo, *Submission 232*, [pp. 2–3].

69 Centre for Midwifery, Child and Family Health, *Submission 21*, p. 6.

70 Stillbirth CRE, *Submission 56*, p. 15.

71 Name withheld, *Submission 145*, p. 5.

72 Victoria Bowring, 'Paid parental leave should include the parents of stillborn children', *Huffington Post*, 15 October 2017, https://www.huffingtonpost.com.au/victoria-bowring/paid-parental-leave-should-include-the-parents-of-stillborn-children_a_23241984/ (accessed 27 September 2018). Stillbirth Foundation Australia hosts a register of companies that publicly support this initiative and have updated their corporate policies accordingly. See Stillbirth Foundation Australia, *Corporate Register*, <http://stillbirthfoundation.org.au/corporate-register/> (accessed 28 September 2018).

3.67 The committee identified two examples of best practice currently operating in Australia that contain specific provisions for employees who have experienced stillbirth.

Australian Public Service

3.68 The *Maternity Leave (Commonwealth Employees) Act 1973* (Cth) covers APS employees and ensures that mothers of stillborn children are entitled to the same maternity leave as mothers of children born live.

3.69 The Act provides for a maximum period of absence of 52 weeks. Under the Act, a person is required to commence maternity leave six weeks before the expected birth of the child. Where the child is born earlier than six weeks before the expected date of birth, the required absence commences on the date of birth and continues for six weeks. In this case, the 52 week period of maternity leave absence commences from the date of birth.

3.70 Eligible employees may access the Paid Parental Leave Scheme (PPL Scheme) or Dad and Partner Pay (DAPP) in addition to entitlements to paid and unpaid leave provided under individual agency Enterprise Agreements.

Ausgrid Enterprise Agreement

3.71 Maurice Blackburn Lawyers and the CPSU NSW advocated that the provisions for stillbirth and miscarriage in the Ausgrid Enterprise Agreement, as negotiated with the Electrical Trades Union, represented best practice and should be included in the NES. Section 30.8 of the Ausgrid Enterprise Agreement reads as follows:

30.8 Cessation of pregnancy - stillbirth and miscarriage

30.8.1 Where the pregnancy ceases by way of miscarriage between 12 and 20 weeks gestation then subject to providing a medical certificate:

(a) the birth parent will be entitled to six weeks paid special parental leave; and

(b) the non-birth parent will be entitled to compassionate leave in accordance with Clause 29 of this Agreement.

30.8.2 Where the pregnancy ceases by way of stillbirth after 20 weeks gestation to birth then subject to providing medical certificate:

(a) the birth parent will be eligible for 16 weeks paid special leave; and

(b) the non-birth parent will be eligible for one week of paid special leave.

30.8.3 The leave set out above in this Clause 30.8 may be added to with approved accrued leave including annual leave, personal carer's leave and accrued personal leave.⁷³

73 Maurice Blackburn Lawyers, answers to questions on notice, 9 August 2018, p. 4 (received 14 August 2018); see also CPSU NSW, *Submission 68*, [p. 5].

Committee view

3.72 Stillbirth has significant and far reaching economic effects for Australia that extend well beyond the direct costs to the healthcare sector. The committee acknowledges that further research and education is required to understand the full extent of these impacts and to inform public policymaking and awareness-raising, including:

- the impact on bereaved parents and their families, including additional financial pressures associated with additional health care, funeral costs and, for many, extended periods of unpaid leave, part-time employment or unemployment;
- the impact on employers and employees in relation to time off work, the process of returning to work, and altered work performance;
- the impact on society when skilled clinicians and health professionals leave the workforce as a result of the pressures of dealing with stillbirth;
- the potential benefits for employers and the Australian economy of improving bereavement care and recovery after stillbirth; and
- the potential for greater investment in innovative research and education from the corporate sector if the economic benefits of improved bereavement care and recovery are more widely recognised.

3.73 The committee recognises that providing protection and support for employees who have experienced stillbirth is a priority across Australia's jurisdictions. It urges the federal, state and territory governments to review employment laws and policies with a 'stillbirth lens' and make necessary changes to ensure that appropriate protection and support provisions are in place.

3.74 The committee acknowledges the success of the Stillbirth Foundation Australia campaign in urging private employers to formally recognise stillbirth in their corporate policies by ensuring that their company extends paid parental leave to employees who have experienced stillbirth. The committee agrees with the approach proposed by Mr McBride and the CPSU NSW, that the relevant provisions of the Fair Work Act should be clarified and strengthened to encourage private employers to review their workplace policies and afford employees who experience stillbirth the same access to paid parental leave as other parents.

Recommendation 1

3.75 The committee recommends that the Australian government reviews and amends the *Fair Work Act 2009* (Cth) and provisions relating to stillbirth in the National Employment Standards (NES) to ensure that:

- **provisions for stillbirth and miscarriage are clear and consistent across all employers, and meet international best practice such as those contained in the Ausgrid Enterprise Agreement; and**

- **legislative entitlements to paid parental leave are unambiguous in recognising and providing support for employees who have experienced stillbirth.**

Chapter 4

Stillbirth reporting and data collection

4.1 There is no systematic approach to reviewing and reporting stillbirths across Australia. This lack of standardisation and coordination has significant implications for research and education aimed at preventing future stillbirths.

4.2 The collection and analysis of data to determine trends in the rate, risk factors and underlying causes of stillbirth over time is important for understanding how stillbirth rates may be reduced, and provides direction for future research, education and preventive efforts. Data collection needs to encompass a wide range of factors in order to inform stillbirth prevention strategies.

4.3 The World Health Organisation (WHO) estimates that around 60 per cent of countries do not have adequate systems for counting births and deaths, and has produced *Making Every Baby Count*, a guide for the audit and review of stillbirths and neonatal deaths.

By counting the number of stillbirths and neonatal deaths, gathering information on where and why these deaths occurred and also by trying to understand the underlying contributing causes and avoidable factors, health-care providers, programme managers, administrators and policy-makers can help to prevent future deaths and grief for parents, and improve the quality of care provided throughout the health system.¹

4.4 The current process to develop a National Strategic Approach to Maternity Services, initiated by the Australian Health Ministers' Advisory Council (AHMAC), acknowledges that a national perinatal audit program is yet to be implemented.²

4.5 This chapter discusses the quality and scope of stillbirth reporting and data collection, and considers inconsistencies, gaps, costs, access and timeliness in Australia's stillbirth reporting and data collection system, as well as issues relating specifically to autopsies and other post-mortem investigations.

Quality and scope of data

4.6 The Department of Health funds the Australian Institute of Health and Welfare (AIHW) to collect data from each jurisdiction as part of the National Perinatal Data Collection (NPDC), undertake data analysis and prepare reports on perinatal deaths, including stillbirths. The AIHW has produced *Stillbirths in Australia*,

1 World Health Organisation (WHO), *Making Every Baby Count: Audit and Review of Stillbirths and Neonatal Deaths*, http://www.who.int/maternal_child_adolescent/documents/stillbirth-neonatal-death-review/en/ (accessed 11 October 2018).

2 Australian Health Ministers' Advisory Council (AHMAC), *Developing a National Strategic Approach to Maternity Services*, Consultation Paper 1, Department of Health, 2018, additional information received 19 October 2018, p. 23.

1991–2009, and publishes biennial reports on perinatal mortality. The most recent detailed data available is for 2013–14.³

4.7 The most recent consolidated report, *Perinatal Deaths in Australia 1993–2012*, provides an overview of the characteristics and causes of stillbirth and neonatal deaths in Australia at a population level, and identifies trends and changes in perinatal mortality over time.⁴

4.8 In its 2009 review of the Maternity Services Plan, the Department of Health identified that data gaps were a significant issue, and established the National Maternity Data Development Project (NMDDP) to develop a nationally consistent maternal and perinatal data collection. Stage 1 (2011–13) prioritised data gaps and inconsistencies in the existing NPDC, and included a National Perinatal Mortality Data Reporting Project to identify options for collecting and reporting national perinatal mortality data. Stages 3 and 4 of the NMDDP (2015–17) included the development of nationally consistent maternal and perinatal mortality data collection in Australia with standardised data specifications, annual reporting and data base development.⁵

4.9 However, a number of witnesses and submitters identified continuing problems affecting the quality, scope, timeliness and accessibility of stillbirth data.

Inconsistencies in perinatal data collection and reporting

4.10 The Centre of Research Excellence for Stillbirth (Stillbirth CRE) stated that the current national practice for stillbirth reporting data collection is 'suboptimal', with significant implications for the quality of research outcomes and policy decisions.

Major impediments to timely, quality data to inform effective prevention strategies for stillbirth include significant duplication of effort and disparate approaches across and within states and territories.⁶

4.11 The National Perinatal Epidemiology and Statistics Unit (NPESU) at the University of New South Wales (UNSW) reported on the difficulty of identifying

3 Australian Institute of Health and Welfare (AIHW), *Stillbirths in Australia 1991–2009*, Cat No PER 63, Canberra, 2014, <https://www.aihw.gov.au/reports/mothers-babies/stillbirths-in-australia-1991-2009/contents/table-of-contents>; AIHW, *Perinatal Deaths in Australia: 2013–2014*, Cat No PER 94, Canberra, 2018, <https://www.aihw.gov.au/reports/mothers-babies/perinatal-deaths-in-australia-2013-2014/contents/table-of-contents> (all accessed 17 October 2018).

4 AIHW, *Perinatal Deaths in Australia 1993–2012*, Cat No PER 86, Canberra, 2016, <https://www.aihw.gov.au/getmedia/7cd62505-c674-4926-8035-b879c009f5e3/19440.pdf.aspx?inline=true> (accessed 17 October 2018).

5 AIHW, 'Enhancing Maternity Data Collection and Reporting in Australia: National Maternity Data Development Project Stage 3 and 4', *APO*, 12 February 2018, <http://apo.org.au/node/132336> (accessed 1 November 2018).

6 Stillbirth CRE, *Submission 56*, p. 6.

research priorities when access to national data is 'highly constrained' and national reporting lacks detailed results.⁷

The lack of consistent ongoing funding for epidemiological research and reporting of stillbirth in Australia is hampering the ability to undertake this important research in Australia. The current restrictive processes for standardised national collection of data about pregnancy and birth have resulted in a national reporting system that is unresponsive to change, is delayed and lacks clinically meaningful and relevant information to assist clinicians in making changes to reduce the rate of preventable stillbirth. Improvements in the timeliness of and access to national data on pregnancy and birth are vital if we are to improve outcomes for mothers and babies and reduce the rate of preventable stillbirth in Australia.⁸

4.12 The NPESU also noted that it had prepared a report for AIHW in 2016, although this report has not been published. The report examined options for improving perinatal mortality data collection and reporting in Australia, including consultation with perinatal data custodians.⁹

Stillbirth datasets

4.13 Australia has two national datasets that record stillbirth in different ways and produce different results, as follows:

- (a) The AIHW is responsible for collating 'health' data on stillbirths in Australia. The AIHW collates data in the NPDC and the National Perinatal Mortality Data Collection (NPMDC), drawn from state and territory health authorities under individual data agreements between the AIHW and each state and territory.¹⁰
- (b) The Australian Bureau of Statistics (ABS) sources data from state and territory registries of Births, Deaths and Marriages and tabulates information on perinatal deaths, including stillbirths, as part of the Causes of Death, Australia (ABS Cat No. 3303.0) report, which is released annually.¹¹

4.14 In addition, the National Hospital Morbidity Database is a collection of electronic confidential summary records in public and private hospitals in Australia, compiled from data supplied by state and territory health authorities.¹²

7 National Perinatal Epidemiology and Statistics Unit (NPESU), University of New South Wales (UNSW), *Submission 37*, p. 7. The NPESU, established in 1979, was a formal collaborating unit of the AIHW until 2016.

8 NPESU, *Submission 37*, p. 8.

9 NPESU, *Submission 37*, p. 5.

10 AIHW, *Perinatal Deaths in Australia: 2013–2014*.

11 Australian Bureau of Statistics (ABS), Cat No 3303.0—Causes of Death, Australia, 2016.

12 AIHW, *Stillbirths in Australia 1991–2009*, p. 55.

4.15 These large population datasets are important for stillbirth research, particularly for undertaking large-scale epidemiological research using modern big-data analytics to determine why stillbirths occur and how to prevent them. However, data collected by the ABS generally shows lower rates of stillbirths than that collected by the AIHW, owing to the way that stillbirth is, or is not, accounted for in births and deaths in individual states and territories. For example, the ABS reported 23.8 per cent fewer stillbirths for 2013–14 than reported by AIHW.¹³ As NPESU noted:

Rates of stillbirth vary depending on which national source is used, with the ABS data known to significantly under-report the rate of stillbirth in Australia¹⁴

4.16 The under-reporting of stillbirths by the ABS is largely attributable to the two-step verification process required to fully register a stillbirth: the Medical Certificate of Cause of Perinatal Death issued by the attending clinician, and a statement from the parents. If only one notification is received, a partial registration is recorded.¹⁵ Mr James Eynstone-Hinkins, Director, Health and Vital Statistics, ABS, outlined the process as follows:

We collect information on all stillbirths registered through the registries of births, deaths and marriages in line with the same method used internationally for collecting information on perinatal deaths. The registration criteria in Australia for stillbirths are 20 weeks gestational age or 400 grams birth weight. That aligns with the Australian criteria and the ABS inclusion criteria. The causes of stillbirths and neonatal deaths are recorded on the medical certificate of cause of perinatal death. This captures the main condition in the infant and the main condition in the mother as well as any other relevant conditions. Causes are coded in accordance with the international classification of diseases, according to coding rules governed by the World Health Organization and used by WHO member states. The data that we capture is released approximately nine months after the end of a reference period, which roughly equates to a calendar year. That is released as aggregate data as part of the national causes of death data set.¹⁶

4.17 The statutory instruments and registration practices related to registration of births and perinatal deaths vary between jurisdictions. There are also variations in the reported causes of stillbirth. ABS data shows the number of unexplained stillbirths as three times that reported by AIHW (ABS, 64 per cent compared to AIHW, 20 per cent) as a result of ABS using information on the death certificate at the time of stillbirth and prior to the result of any investigation into the causes. AIHW data, on the

13 Australian Institute of Health and Welfare (AIHW), *Submission 26*, p. 4.

14 NPESU, *Submission 37*, p. 2.

15 AIHW, *National Perinatal Mortality Data Reporting Project: Issues paper, October 2012—Foundations for Enhanced Maternity Data Collection and Reporting in Australia*, National Maternity Data Development Project, Stage 1, 2014, p. 3.

16 Mr James Eynstone-Hinkins, Director, Health and Vital Statistics, ABS, *Committee Hansard*, 7 September 2018, p. 51.

other hand, is based on classification of causes following review of all available post-mortem investigations.¹⁷

Mandatory and voluntary items

4.18 Some data in the NPDC is mandated by the National Health Information Standards and Statistics Committee for collection under agreements between the Commonwealth and each state/territory as part of the National Minimum Data Set (NMDS).¹⁸

4.19 A national committee, the National Perinatal Data Development Committee, comprising the PDC custodians from each state and territory and the AIHW, manage what is included in the NPDC and which data items are mandated for collection in all jurisdictions. Each jurisdiction must agree to add a new item and commence collection and reporting otherwise data are collected on a voluntary basis and may differ between jurisdictions.

4.20 The AIHW noted that the Perinatal Mortality Committee uses data from jurisdictional perinatal mortality committees about the circumstances of a baby's death, the social history of the family and the professional care of the mother, and advised that it is working towards including this data in national reports 'as the quality of the data collected improves'. However, it also noted a high proportion of responses for certain items are 'not stated' because they are of a voluntary nature.¹⁹

4.21 Dr Fadwa Al-Yaman, Group Head, Indigenous and Maternal Health Group, AIHW, explained why there are delays in adding a new item to the national collection. The AIHW is required to determine what data are clinically relevant and appropriate by consulting with clinical experts, and defining the additional items based on national and international standards and guidelines. The AIHW then seeks agreement with the jurisdictions and clinical experts through a national committee. Once agreed, the new specifications are sent to the states and territories. In some jurisdictions, the new items are already collected. In other cases, the data may need to be collected 'from scratch', requiring changes to that jurisdiction's system of data collection. The AIHW allows six months for this new information to be collected, but delays in receiving the new data from the states and territories may lead to delayed publication of the national dataset.²⁰

17 Stillbirth CRE, *Submission 56*, p. 6.

18 NPESU, *Submission 37*, p. 3. Mandated items relating to the mother include demographic characteristics and factors relating to the pregnancy, labour and birth, and items relating to the baby include birth status, sex and birthweight.

19 AIHW, *Submission 26*, p. 5. For the 2013–14 data collection period, these included body mass index of mother, maternal antenatal care visits, Indigenous status of baby and timing of stillbirth.

20 Dr Fadwa Al-Yaman, Group Head, Indigenous and Maternal Health Group, AIHW, *Committee Hansard*, 7 September 2018, p. 54.

4.22 The NPESU argued that the information used for national stillbirth and neonatal death reporting 'is missing vital information to allow for comprehensive analysis, due to a lack of mandated standardised data items'.²¹

Inconsistent definitions

4.23 Within Australia, registration of stillbirths occurs at a state and territory level, and each jurisdiction has its own register of births and deaths and legislation defining what is registered as a birth or death in ABS data. There is, for example, no standardised definition of what constitutes a 'live birth' across the jurisdictions, making it difficult to distinguish between a termination of pregnancy, a stillbirth and a live birth.²²

4.24 All states and territories, except for Western Australia (WA), register stillbirths only as births. WA registers a stillbirth as both a birth and a death. South Australia (SA) does not include termination of pregnancy after 20 weeks in its legislative definition of 'birth'.²³

4.25 Victoria is the only state that offers access to late term termination between 20–24 weeks on request (without a referral or doctor's approval).²⁴ This means the rate of stillbirth for Victoria appears high in comparison to other jurisdictions (9.1 per 1000 births in 2013–14, compared to 7.1 per 1000 for the whole of Australia).²⁵

4.26 In addition, lower populations and smaller numbers of births and stillbirths can lead to significant variations in stillbirth rates over time, which may be misleading. This is particularly relevant in considering the higher rates of stillbirth in Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) populations in Australia.²⁶

4.27 There is also a lack of consistency in how risk factors are classified across different jurisdictions, suggesting that this may be the result of different data and evaluation processes being used.²⁷

21 NPESU, *Submission 37*, p. 5.

22 Associate Professor Georgina Chambers, Director, NPESU, Centre for Big Data Research in Health and School of Women's and Children's Health, Faculty of Medicine, University of New South Wales (UNSW), *Committee Hansard*, 8 August 2018, p. 30.

23 AIHW, *National Perinatal Mortality Data Reporting Project: Issues paper*, October 2012, p. 8.

24 Marie Stopes Australia, 'Late term abortions (20–24 weeks) and the law', <https://www.mariestopes.org.au/your-choices/abortion-laws-australia/> (accessed 24 July 2018). The Queensland government has recently passed legislation decriminalising pregnancy termination at up to 22 weeks' gestation. See Termination of Pregnancy Bill 2018 (Qld), <https://www.legislation.qld.gov.au/view/pdf/bill.first/bill-2018-089> (accessed 1 November 2018).

25 AIHW, *Perinatal Deaths in Australia 2013–2014*, p 12.

26 AIHW, *Perinatal Deaths in Australia 2013–2014*, p 11.

27 Mrs Ellana Iverach, *Submission 89*, [pp. 2–3].

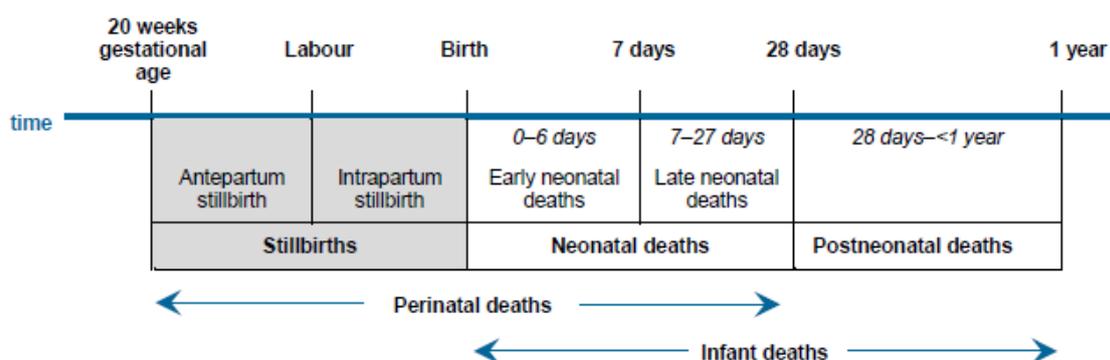
4.28 As a result, stillbirth data are recorded differently making it difficult to determine the rate of stillbirths across Australia. This is especially problematic where a woman moves from her place of residence in one jurisdiction in order to give birth in another jurisdiction.²⁸

4.29 This issue is noted in the Australian government's latest report on Sustainable Development Goals Indicators.

Various definitions are used for reporting and registering perinatal deaths in Australia. The National Perinatal Data Collection defines perinatal deaths as all fetal deaths (stillbirths) and neonatal deaths (deaths of liveborn babies aged less than 28 days) of at least 400 grams birthweight or at least 20 weeks' gestation. Fetal and neonatal deaths may include late termination of pregnancy (20 weeks or more gestation). Perinatal and fetal death rates are calculated using all live births and stillbirths in the denominator. Neonatal death rates are calculated using live births only. Neonatal deaths may not be included for babies transferred to another hospital, re-admitted to hospital after discharge or who died at home after discharge. The Australian Institute of Health and Welfare (AIHW) has established a separate National Perinatal Mortality Data Collection to capture complete information on these deaths.²⁹

4.30 The AIHW divides perinatal outcomes into three categories: stillbirths, live born neonatal survivors, and neonatal deaths, as follows:

Figure 4.1: Perinatal death periods for reporting in Australia³⁰



4.31 Stillbirth CRE argued that the lack of consistent definitions for many data items impacts on the accuracy of comparisons across jurisdictions and the capacity to identify key outcomes. It also leads to a time lag of two to three years between data collection and publishing in state/territory and national perinatal mortality reports.³¹

28 Associate Professor Chambers, UNSW, *Committee Hansard*, 8 August 2018, p. 30.

29 Department of Health, *Sustainable Development Goals*, Indicator 3.2.2: Neonatal mortality rate, 17 July 2018, <https://www.sdgdata.gov.au/goals/good-health-and-well-being/3.2.2> (accessed 11 October 2018).

30 AIHW, *Stillbirths in Australia 1991–2009*, p. 3.

31 Stillbirth CRE, *Submission 56*, p. 7.

Inadequate reporting standards

4.32 International studies have shown that inadequate information relating to the timing of the stillbirth and other details in relation to pregnancy and birth, maternal risk factors, obstetric and other conditions limits the value of data for evaluating and implementing preventive strategies.³²

4.33 According to Australian researchers, the data collected by the AIHW are not comprehensive, consistent nor detailed enough to enable the information to be used in meaningful ways to improve clinical care. This is due to a number of factors, including that a number of items in the data collections are voluntary (as noted above), which correlates with a higher rate of 'unknown' or 'unspecified' for those items.³³

4.34 Stillbirth Foundation Australia highlighted the need to break Australian stillbirth data down to a more granular level of analysis in order to understand trends, and to make this data available to the private sector, researchers and relevant organisations to encourage a more collaborative environment.³⁴

4.35 Having access to granular data is particularly important in giving a greater understanding of where research needs to be concentrated, particularly amongst rural and remote, Aboriginal and Torres Strait Islander and women from CALD backgrounds for whom there is an elevated risk of stillbirth and other adverse pregnancy outcomes.³⁵

4.36 Gestational age at birth, for example, is only reported nationally in completed weeks of gestation, which is an impediment to researching the impact of gestational age. '[M]ortality differences between 41.0 weeks' and 41.6 weeks' are of clinical significance but treated the same in a data collection that records only "completed weeks", that is, both are recorded in data collections as 41 weeks' gestation.³⁶

4.37 The NPESU noted that the lack of granular data has disguised the fact that there have been some improvements in stillbirth trends amongst particular age groups.

...national reporting indicates that there has been relatively little change in the overall stillbirth rate in Australia over the past 20 years...However, more in depth statistical analysis undertaken by the NPESU...has shown that improvements have been made in the risk of stillbirth at later

32 JE Hirst JE, J Villar, CG Victora, et al, 'The Antepartum Stillbirth Syndrome: Risk Factors and Pregnancy Conditions Identified from the INTERGROWTH-21st Project', *British Journal of Obstetrics and Gynaecology*, vol. 125, 2018, p. 1150.

33 AIHW, *Submission 26*, p. 5; NPESU, *Submission 37*, p. 5; Ms Natasha Donnelly, *Committee Hansard*, 8 August 2018, p. 10.

34 Stillbirth Foundation Australia, answers to questions on notice, 8 August 2018 (received 14 September 2018).

35 Stillbirth Foundation Australia, answers to questions on notice, 8 August 2018 (received 14 September 2018); Professor Claire Roberts, Deputy Director, Robinson Research Institute, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 26.

36 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Submission 17*, [p. 4].

gestational age groups, and the inclusion of terminations of pregnancy and reporting overall rates of stillbirth (rather than at different stages of pregnancy) in national statistics has masked some of the inroads gained.³⁷

4.38 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) considered that '[i]t is a serious deficiency of the national perinatal data set (and some state perinatal data sets), that maternal height and weight is not recorded'.³⁸ RANZCOG submitted that such customisation of data could be used to better predict the risk of fetal growth restriction, for example, and that 'not collecting critical data impairs important research'.³⁹

4.39 RANZCOG also noted, in relation to antenatal testing of fetal genetic, chromosomal and structural conditions, that there is an 'absence of national data collection in this critically important area of maternity care...[which] can assist in the prevention of mortality and long-term morbidity through measures being put in place around birth or early in the neonatal period'. Given that fetal growth restriction is the single largest cause of unexplained stillbirth, RANZCOG argued there was an urgent need to adopt 'severe intra-uterine growth restriction in a singleton pregnancy undelivered by 40 weeks' as a core maternity indicator in the National Core Maternity Indicators.⁴⁰

4.40 Professor Euan Wallace, Carl Wood Professor and Head of Department of Obstetrics and Gynaecology, Monash University, stated that women from migrant backgrounds are significantly under-represented in stillbirth data, including second generation South-East Asian women who migrated to Australia following warfare in their countries and who are recorded as Australian.

Those women are disproportionately represented in our stillbirth data, yet our data collection systems are blind to maternal and paternal ethnicity. We collect country-of-birth information of mothers but we don't collect ethnicity.⁴¹

4.41 Dr Jane Warland also noted that data collected on stillbirth generally omitted information about the father, even though he contributed half of the baby's DNA and his ethnicity and age are likely to be important.⁴²

Lack of data for rural, regional and remote Australia

4.42 There are almost seven million people living in rural, regional and remote Australia yet, as the AIHW review found, babies born to mothers living in these areas are 65 per cent more likely to die during the perinatal period than babies born to

37 NPESU, *Submission 37*, p. 7.

38 RANZCOG, *Submission 17*, [p. 4].

39 RANZCOG, *Submission 17*, [p. 4].

40 RANZCOG, *Submission 17*, [pp. 4–5].

41 Professor Euan Wallace, Carl Wood Professor and Head of Department of Obstetrics and Gynaecology, Monash University, *Committee Hansard*, 9 August 2018, p. 26.

42 Dr Jane Warland, *Committee Hansard*, 8 August 2018, p. 66.

mothers living in major cities or inner regional areas. Indeed, the further away women are from a major city, the higher the rate of stillbirth.⁴³

4.43 The National Rural Health Alliance called for improved data collection quality, consistency and dissemination so that it can be used to improve rural and remote maternal health outcomes and reduce perinatal deaths as well as improving quality and safety of care, identifying lessons learned and translating research into clinical practice and shared knowledge.⁴⁴

4.44 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, pointed to the need for more granular data in order to be able to concentrate research in areas where there is inadequate data. Rural and remote communities do not have access to the same level of health care as others, yet there is no data to establish the extent to which such communities are at higher risk of stillbirth.

It's one thing to submit a figure that is the sum total for a nation at the end of a five-year period, but, if we had access to where these are occurring—family history, background, location and all of those finer details—it gives a greater understanding of where the research needs to be concentrated.⁴⁵

Difficulty and cost of accessing data

4.45 The AIHW does not own the data contained in the NPDC, which is a collation of all the state and territory Perinatal Data Collections (PDC, also known as Midwives Data Collections). The data are therefore owned by the jurisdictions.⁴⁶

4.46 The NHMRC has an Open Access Policy which aims to 'mandate the open access sharing of publications and encourage innovative open access to research data'.⁴⁷ Recipients of NHMRC grants must comply with this policy.

4.47 However, given the relatively low numbers of stillbirth, researchers wishing to access stillbirth data on a national scale need to seek agreement from each jurisdiction each time they require it. This can be a lengthy and costly process that extends beyond the time available to researchers dependent upon three-year research funding cycles.⁴⁸

4.48 According to the NPESU, the cost of accessing data ranges from \$12 000 to \$25 000, depending on the nature of the data requested. In addition, it can take three to

43 AIHW, *Perinatal Deaths in Australia 2013–2014*, p. 34; National Rural Health Alliance, *Submission 57*, [p. 2]. See Chapter 2 for a breakdown of the data for rural and remote communities.

44 National Rural Health Alliance, *Submission 57*, [p. 2].

45 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 17.

46 Associate Professor Chambers, UNSW, *Committee Hansard*, 8 August 2018, p. 28.

47 National Health and Medical Research Council (NHMRC), *Submission 27*, p. 2.

48 Associate Professor Chambers, UNSW, *Committee Hansard*, 8 August 2018, p. 28.

five years just to obtain the necessary jurisdictional, national and ethical approvals required by AIHW to access national perinatal data.⁴⁹

4.49 Similarly, the Western Australian Perinatal Epidemiology Group noted that the 'costs of obtaining de-identified linked data from government are increasing and are approximately 10 per cent of a requested research budget...Preferably, provision of [this] data for research should be considered a core government service and therefore not cost recovered', as is the case in the United States of America (USA).⁵⁰

4.50 Mrs Ellana Iverach noted that the information derived from medical reviews and investigations of a stillbirth was difficult to locate, and that it should be more easily accessed so that it can be made available to researchers and other interested parties.⁵¹

4.51 The NPESU pointed to the Vital Statistics Online Data Portal used in the USA which offers a best-practice perinatal data collection model that is a far simpler and cheaper for researchers to access.

The tortuous process for accessing national perinatal data in this country stands in stark contrast to access to perinatal data in the USA where birth, cohort and period linked birth and infant death, cause of death and fetal death data are made available for independent research and analyses and can be downloaded free of charge. The level of detail exceeds that available in Australia.⁵²

Timeliness of data

4.52 Access to timely, high-quality data on causes and contributing factors to stillbirth are crucially important, not only for helping bereaved parents to understand what happened and to plan for future pregnancies, but also to inform the development of targeted prevention strategies.⁵³

4.53 However, several submitters raised the negative impact of delayed access to data on the ability of researchers to identify and address emerging issues relating to

49 NPESU, *Submission 37*, p. 6.

50 Western Australian Perinatal Epidemiology Group, *Submission 47*, [p. 3]; see also NPESU, *Submission 37*, p. 6.

51 Mrs Iverach, *Submission 89*, [p. 2].

52 NPESU, *Submission 37*, p. 6; National Center for Health Statistics, *Vital Statistics Online Data Portal*, https://www.cdc.gov/nchs/data_access/Vitalstatsonline.htm (accessed 24 October 2018); see also Associate Professor Chambers, UNSW, *Committee Hansard*, 8 August 2018, p. 30.

53 Stillbirth CRE, *Submission 56*, p. 5.

stillbirth.⁵⁴ The NPESU noted the long delays involved in adding new data items to the NPDC.

While having a NMDS is vital to ensuring consistency of reporting across the country, the process of adding new data items to the collection, gaining agreement from all jurisdictions and proceeding through the data development processes means it can take up to 5 years or longer before an item is mandated for collection and then a further 2 years before it might appear in a national report. This is very relevant to the issue of reporting of stillbirth data in Australia.⁵⁵

4.54 Based on information reported to the AIHW by states and territories, most stillbirths in Australian hospitals are reviewed by a hospital-level committee and then a jurisdiction-level perinatal mortality review committee.⁵⁶

4.55 However, the AIHW cited delays in provision of data by states and territories as the reason for the delay in reporting, and indicated that it would publish detailed data from 2015 by the end of the 2018 calendar year with the intention to update perinatal deaths data online annually from 2019.⁵⁷

4.56 In 2016, the NHMRC published Principles for Accessing and Using Publicly Funded Data for Health Research. The principles were developed to 'improve the consistency and timeliness of data available to researchers'.⁵⁸

4.57 Professor Wallace noted that, whilst Australia has a secure system in place for sharing sensitive data known as Secure Unified Research Environment (SURE), the timeliness of data is inhibited by a lack of resources available for collating and linking perinatal data.⁵⁹

4.58 Timely data are also considered crucial for identifying areas of substandard care that may contribute to stillbirth.

4.59 Stillbirth CRE reported that it had developed, in partnership with the Victorian Department of Health, an online system for national perinatal mortality audits designed to enhance investigation and reporting of stillbirths by providing timely data that will enable substandard care to be identified and addressed. 'In both

54 See for example, South Australian Health and Medical Research Institute, *Submission 19*; The Australian College of Nursing, *Submission 20*, p. 2; Stillbirth Foundation Australia, *Submission 33*, p. 14; Hunter Medical Research Institute, *Submission 36*, [p. 5]; College of Nursing and Health Sciences, Flinders University, *Submission 39*, [p. 1]; Global Stillbirth Advocacy Network, *Submission 40*, [p. 3].

55 NPESU, *Submission 37*, p. 3.

56 AIHW, answers to questions on notice, 7 September 2018 (received 5 October 2018).

57 AIHW, *Submission 26*, p. 6.

58 NHMRC, *Submission 27*, p. 1.

59 Professor Wallace, Monash University, *Committee Hansard*, 9 August 2018, p. 27; Dr Merran Smith, Chief Executive Officer, Population Health Research Network (PHRN), *Committee Hansard*, 9 August 2018, p. 49.

New Zealand and the United Kingdom (UK) national audit data and timely feedback has led to reduced perinatal deaths through quality improvement.⁶⁰

Linked datasets

4.60 Associate Professor Georgina Chambers, Director, NPESU, Centre for Big Data Research in Health and School of Women's and Children's Health, Faculty of Medicine, UNSW, noted that the NPESU has analysed stillbirth and neonatal data across jurisdictions and identified the discrepancies between the different datasets. She recommended that Council of Australian Governments should prioritise the harmonisation, sharing and centralisation of health data to establish comprehensive, standardised NPMDC.

Because Australia is a federation of states and territories, we understand it is challenging to bring together a standardised set of data items related to perinatal deaths that can be used not only by health systems but also by researchers. It takes five years for a new mandatory item to be added to the state perinatal data collections and at least another two for that item to be reported on. A comprehensive perinatal mortality data collection should routinely link to other datasets—such as the various registries of births, deaths and marriages—to improve surveillance and should be integrated with the national maternity mortality audit tool that was developed by the Mater Research Institute and PSANZ. The NPESU laid the basis for comprehensive data collection when we prepared the first perinatal mortality report in 2016. Creating such an important dataset would not be difficult; it just takes commitment and leadership from all involved.⁶¹

4.61 The AIHW noted that data gaps in the perinatal mortality collection could be addressed by linking data to established collections, such as linking Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS) and NPDC data.⁶²

4.62 The Population Health Research Network (PHRN), funded under the National Collaborative Research Infrastructure Strategy to build linkages between datasets in privacy-preserving ways, advised that seven of the eight states and territories routinely link perinatal and death data to other administrative data collections. These linked collections include MBS and PBS data, as well as clinical trial and other researcher datasets, and recommended that researchers should be made more aware of these linked, multi-jurisdictional resources.⁶³

4.63 The PHRN noted that a more detailed understanding of stillbirth could also be gained by linking death and perinatal data with data from other sources, such as hospital admissions and emergency department admission. However, several challenges remain in achieving coordinated datasets across jurisdictions as a result of different legislation and policies and reluctance by some jurisdictions to share

60 Stillbirth CRE, *Submission 56*, pp. 5–6.

61 Associate Professor Chambers, UNSW, *Committee Hansard*, 8 August 2018, p. 28.

62 AIHW, *Submission 26*, p. 6.

63 Population Health Research Network (PHRN), *Submission 31*, p. 1.

identifiers across borders. The PHRN noted that a project is underway that may address these issues and seeks to improve linkages between state/territory data collections and the Commonwealth data collections through the AIHW.⁶⁴

To get the full picture on health in Australia we need to be able to bring those together. Australia can already bring that data together, but it generally does it in a way that we would describe as create and destroy. Those linkages are not maintained. The good news is that we are making good progress with systematically linking that data, and I think it won't be too long before we have that data available to researchers.⁶⁵

4.64 Ms Belinda Jennings, Senior Midwifery Advisor, Policy and Practice, Katherine Hospital noted that, whilst midwives across Australia contribute to a minimum perinatal dataset, they also collect data on hundreds of other items during the course of a pregnancy. That dataset, however, is not linked to the NPDC.

The feedback from some midwives is that they don't want to be collecting data twice, but the benefit of the perinatal death data collection tool is that it is an all-encompassing one-stop shop which incorporates contributing factors, classifications and categorisations. So they sit parallel to one another, with equal importance in the arena of stillbirth,...It's a shame they're not going to talk to one another, because otherwise you could dump them there to export a lot of the information from midwives.⁶⁶

4.65 The Australian Longitudinal Study on Women's Health (ALSWH), a longitudinal population-based survey examining the health of over 58 000 Australian women, is funded by the Commonwealth Department of Health and managed by the universities of Newcastle and Queensland. The study includes a survey of women's experience of stillbirth throughout their reproductive years.

4.66 ALSWH links women's survey data to administrative datasets providing perinatal data (with provision for participants to opt out), and makes the data freely available to researchers. It also sources hospital admission and cancer registry data at the state/territory level and MBS and PBS data at the national level.⁶⁷

4.67 If made mandatory, linking the different datasets across states and territories, and integrating them with the perinatal data, PBS data, MBS data, and Perinatal Data Collections would yield important information including the financial impact of stillbirth on the public health system.⁶⁸

64 PHRN, *Submission 31*, pp. 1–2.

65 Dr Smith, PHRN, *Committee Hansard*, 9 August 2018, p. 46.

66 Ms Belinda Jennings, Senior Midwifery Advisor, Policy and Practice, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 15.

67 Australian Longitudinal Study on Women's Health (ALSWH), *Submission 60*, pp. 2–3. The ALSWH is funded until at least 2020.

68 Associate Professor Chambers, UNSW, *Committee Hansard*, 8 August 2018, pp. 30–31; ALSWH, *Submission 60*, p. 5.

Improving perinatal reporting and data collection

4.68 In order to address inconsistencies and delays in perinatal data reporting, and ensure that timely and consistent data are available to researchers and policymakers, Stillbirth CRE recommended the following strategies:

- introduction of a standardised national electronic reporting system to collect 'real-time' data of all births across Australia, including agreement on a single definition of stillbirth and the reporting systems to be used;
- annual reporting on perinatal deaths nationally, with a focus on stillbirths and including Indigenous and other high risk groups, to enable the impact of programs and policies to be monitored for effectiveness;
- inclusion of stillbirth rates as a key performance indicator in all state and territory annual perinatal outcomes reports; and
- hospital level audits of stillbirths and neonatal deaths to identify factors relating to care, to be included in national, state and territory reporting that informs improvements in clinical practice.⁶⁹

Perinatal mortality audits

4.69 In its report on perinatal deaths in 2013–14 the AIHW noted that, of the 6037 perinatal deaths that occurred, only 235 cases were reviewed by a jurisdictional perinatal review committee to consider possible contributing factors that would assist in identifying systemic issues affecting the perinatal mortality rate. Of the 235 cases reviewed, 99 were found to have contributing factors including professional care (58 per cent) or to the situation of the mother, her family or social situation (39 per cent), with 38 cases having factors likely to have significantly contributed to the adverse outcome.⁷⁰

4.70 Several submitters and witnesses called for a national policy on the conduct of stillbirth autopsies and perinatal mortality reviews as well as the collection and sharing of data.⁷¹

4.71 The *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*, developed by the Perinatal Society of Australia and New Zealand (PSANZ) and Stillbirth CRE, encourages clinicians in maternity services to standardise investigation, classification and reporting of stillbirths in order to improve the quality

69 Stillbirth CRE, *Submission 56*, p. 2.

70 AIHW, *Perinatal Deaths in Australia 2013–2014*, p. 54.

71 See for example, Mrs Dimitra Dubrow, Principal and Head of Medical Negligence, Maurice Blackburn Lawyers, *Committee Hansard*, 9 August 2018, p. 33; Ms Donnelly, *Committee Hansard*, 8 August 2018, p. 2; Mrs Clare Rannard, *Committee Hansard*, 8 August 2018, p. 7; Ms Donnelly, *Committee Hansard*, 8 August 2018, p. 3; Name withheld, *Submission 250*, [p. 2].

of data in Australia. However, Stillbirth CRE noted that application of this Guideline has been variable across Australia.⁷²

4.72 Ms Natasha Donnelly, who co-authored the first report on perinatal deaths in Australia, was critical of the lack of a national approach to perinatal mortality audits. She noted that, whilst there is now an electronic data collection tool available to jurisdictions, only Victoria has been active in this area.⁷³

4.73 Victoria has a long tradition of individual case review through the Consultative Council of Obstetric and Paediatric Mortality and Morbidity, an independent legislative body charged with reviewing all perinatal, child and adolescent deaths. Recommendations arising from these reviews are used to direct improvements in healthcare provision.

4.74 Victoria also undertakes annual reporting of *Victorian Perinatal Services Performance Indicators* which compares identifiable hospital data on outcomes for mothers and newborns against 10 safety and quality indicators. Making this information publicly available to clinicians and families has resulted in a 35 per cent improvement in the detection of fetal growth restriction.⁷⁴

4.75 Ms Donnelly noted that there has not been a state-wide audit of perinatal mortality in NSW, and it is therefore not possible to learn lessons about causes and prevention of stillbirth.

Other states have recently commenced piloting an electronic perinatal mortality audit tool but a national approach is urgently needed for consistency and for maximum benefit. Parents deserve to know that when they consent to post mortem examinations, that the information is contributing to a full investigation of their baby's death and that it will be used to the benefit of others as well as to find their own answers.⁷⁵

4.76 Several witnesses noted that New South Wales (NSW) public hospitals are required to prepare a 'root cause analysis' undertaken by a group of independent expert clinicians external to the hospital where a stillbirth has occurred. However, this is only undertaken by private hospitals on a voluntary basis. In addition in NSW, which has almost one-quarter of all stillbirths in Australia, the perinatal mortality review

72 Stillbirth CRE, *Submission 56*, pp. 6–7. See PSANZ Stillbirth and Neonatal Death Alliance, *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*, <https://sanda.psanz.com.au/clinical-practice/clinical-guidelines/> (accessed 14 November 2018).

73 Ms Donnelly, *Committee Hansard*, 8 August 2018, pp. 2–3. As noted above, this online tool was developed by Stillbirth CRE in partnership with the Victorian Department of Health.

74 Professor Wallace, Monash University, *Committee Hansard*, 9 August 2018, p. 28. See Department of Health and Human Services, *Victorian Perinatal Services Performance Indicators*, <https://www2.health.vic.gov.au/hospitals-and-health-services/safer-care-victoria/safer-care-publications/victorian-perinatal-services-performance-indicators-2016-17> (accessed 10 October 2018).

75 Ms Natasha Donnelly, *Submission 116*, p. 3.

committee has not undertaken a perinatal mortality review for more than four years, and its policy is more than seven years out of date.⁷⁶

4.77 The committee also heard evidence from bereaved parents that there was no standard information collected from them in relation to their experience of the pregnancy in the period immediately preceding the stillbirth, and no clarity as to how information obtained through a review of the stillbirth was compiled or subsequently used by researchers or clinicians.⁷⁷

4.78 One submitter proposed giving a survey to all parents after their child is stillborn which, when combined with data from the hospital, could be made widely available to researchers, medical professionals and families to help them better understand risks and methods of prevention.

It is not enough for research to be published in obstetric and midwifery journals. Women may see a whole range of medical professionals during their pregnancy, and each have a role to play in ensuring the safety of the woman and her baby.⁷⁸

Successful international models

4.79 Several witnesses commented on the success of overseas models of stillbirth data reporting and collection, with evidence indicating that they had contributed to a significant reduction in the rate of stillbirth in those countries.

4.80 Professor Jason Gardosi, Director of the Perinatal Institute in the UK, reported on the success of a stillbirth prevention program developed by the Perinatal Institute using detailed case reviews and analysis of regional maternity data.

4.81 The GAP program, which has now been implemented in over 80 per cent of UK hospitals in the National Health Service, is a comprehensive training and audit program drawing on data collected in relation to the mother's height, weight, previous pregnancies and ethnicity to produce a core dataset of maternal characteristics. It also enables the generation of customised antenatal growth charts (GROW) to assist obstetricians, midwives and ultrasonographers in undertaking antenatal assessments, and is credited with reducing stillbirth rates by 23 per cent over the last six years.⁷⁹

4.82 The Perinatal Institute has also been commissioned to roll out the GAP program in New Zealand, and it has produced an Australian version. The customised GROW chart and calculators are already being used by clinicians in some Australian states and territories, with evidence suggesting that they are helping to improve antenatal identification of babies at risk due to fetal growth restriction. The Perinatal Institute (UK) concluded that:

76 Mrs Rannard, *Committee Hansard*, 8 August 2018, p. 6; Ms Donnelly, *Committee Hansard*, 8 August 2018, pp. 7–8.

77 Ms Britt Jacobsen, *Committee Hansard*, 8 August 2018, pp. 8–9.

78 Ms Britt Jacobsen and Mr Samuel Haldane, *Submission 82*, [p. 3].

79 Professor Jason Gardosi, Director, Perinatal Institute, United Kingdom (UK), *Committee Hansard*, 7 September 2018, p. 70; Perinatal Institute (UK), *Submission 257*, p. 2.

...a significant and sustained impact on stillbirth prevention will require a co-ordinated, intensive yet affordable programme, modelled on experience elsewhere and adapted to Australian circumstances.⁸⁰

4.83 The MBRRACE-UK program is an initiative established in 2012 and administered by the Healthcare Quality Improvement Partnership to conduct surveillance and investigate causes of maternal deaths, stillbirths and infant deaths. The program involves confidential enquiries into aspects of perinatal death including stillbirths, and has a collaborative and multi-jurisdictional approach. In 2016 the rate of perinatal mortality had decreased overall, and the stillbirth rate for twins had nearly halved since 2014.⁸¹

4.84 The Netherlands has implemented a system of timely and consistent data collection and review, resulting in the rate of stillbirth being reduced by nearly 60 per cent.

The Netherlands system incorporates about seven different elements but it incorporates staff education, it incorporates patient education, it incorporates central recording systems with central reporting and it requires that to be monitored and for people to be accountable for it. So the hospitals are accountable for their own process issues, if they notice that there's something wrong with staffing or this or that. But, at a higher level, if they notice that a particular part of the Netherlands has more stillbirths, then they look at it. So there's a local level of accountability as well. They also have a higher doctor-patient ratio than other countries. That's been constant over the time, but the progressive improvement that they've demonstrated is incredible. It's very impressive.⁸²

4.85 The mortality review process used in the Netherlands has two steps. The first is a quick investigation to detect major patient safety or service issues, often in the form of a root cause analysis. The second step involves a more formal investigation between four and six weeks after the stillbirth and a formal perinatal mortality review meeting at which the case is discussed. Finally, the investigator meets with the bereaved family and outlines the review outcomes. Parents may also attend the review meeting.⁸³

...they took the aeroplane crash approach, which was to look at the systemic errors all the way along. What they found was that talking to the family within 48 hours of the loss to specifically identify what the parents' questions were meant that, when the case was investigated, those questions

80 Perinatal Institute (UK), *Submission 257*, p. 2.

81 Associate Professor Chambers, UNSW, *Committee Hansard*, 8 August 2018, p. 29. See MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK), <https://www.npeu.ox.ac.uk/mbrrace-uk> (accessed 9 October 2018). The program has been extended to run until 30 September 2021.

82 Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute (HMRI), *Committee Hansard*, 8 August 2018, p. 24

83 Professor Pennell, HMRI, *Committee Hansard*, 8 August 2018, p. 20.

could be answered. So the parents were engaged in the process in a way where every question they asked, whether it was important or not, was given an answer. These are often given in a written document. The family is then engaged again at the four-week point. They would speak to the families and do all of the appropriate bereavement care again at that stage and make sure that they were utilising the appropriate resources. Again, they would find out what the family wanted to know et cetera.⁸⁴

4.86 The Netherlands program also provided the basis for a successful Scottish education program, Maternity Care Quality Improvement Collaborative, implemented in 2011 and subsequently adopted in the UK (see Chapter 7).⁸⁵

Autopsies and other post-mortem investigations

4.87 As noted above, PSANZ and Stillbirth CRE have developed a Clinical Practice Guideline to improve maternity and newborn care for bereaved parents and families, and to improve the quality of data on causes of stillbirth and neonatal deaths through appropriate investigation, including autopsy, audit and classification.⁸⁶

4.88 The Guideline recommends that all parents be offered the option of a high quality autopsy following stillbirth or neonatal death. Stillbirth CRE considers autopsy to be the 'gold standard investigation' for perinatal deaths and should be offered to parents by trained health care professional.⁸⁷

4.89 The Guideline also recommends that, in the case of a stillbirth, neonatal death or birth of a high risk infant, the placenta, membranes and cord should be sent for examination by a perinatal/paediatric pathologist regardless of whether consent for an autopsy has been granted.⁸⁸

Low autopsy rates

4.90 Autopsy rates for perinatal death are low in Australia, despite advocacy over a long period for more autopsies to be performed and particularly where a cause of stillbirth has not been identified.⁸⁹

4.91 Autopsy is not a mandatory reporting item in state and territory perinatal data collections, and performance of an autopsy is not obligatory for stillbirths unless the death is referred to a coroner. The rates of autopsy therefore vary considerably across

84 Professor Pennell, HMRI, *Committee Hansard*, 8 August 2018, pp. 19–20.

85 Red Nose, *Submission 63*, p. 1.

86 AHMC, *Strategic Directions for Australian Maternity Services*, Consultation Paper 2, Department of Health, 2018, additional information received 19 October 2018, p. 22.

87 Stillbirth CRE, *Submission 56*, p. 18.

88 *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*, p. 12.

89 Ms Donnelly, *Committee Hansard*, 8 August 2018, p. 3; PriceWaterhouseCoopers (PwC), *The Economic Impacts of Stillbirth in Australia*, Stillbirth Foundation Australia, 2016, p. 2; ABC News, 'Call for Stillbirth Autopsies', 1 April 2006, <http://www.abc.net.au/news/2006-04-01/call-for-stillbirth-autopsies/1721680> (accessed 1 August 2018).

the states and territories, from 31 per cent in Queensland to 62 per cent in WA. The autopsy rates are even lower for Aboriginal and Torres Strait Islander stillbirths.⁹⁰

4.92 In 2011–12, for example, autopsies were conducted in 42.3 per cent of stillbirths in Victoria, Queensland, WA, SA, Tasmania and the Australian Capital Territory.⁹¹

4.93 According to Stillbirth CRE, autopsy rates are higher and unexplained stillbirth rates are lower in WA and SA, which may be explained by the existence of coordinated perinatal services in those jurisdictions.⁹²

4.94 Whilst the Clinical Practice Guideline has been in place for more than 10 years, it is not mandated.⁹³ Between 2004 and 2008 the number of unexplained antepartum deaths was 1949, but autopsies were undertaken for less than half of these (47 per cent). In addition, whilst 40 per cent of babies may have some type of post-mortem examination, only 20 per cent are given a full autopsy.⁹⁴

4.95 The AIHW reported that in 2013–14 full autopsies were performed in only 21 per cent of stillbirth cases in Australia compared to the UK (43.5 per cent) and New Zealand (42.5 per cent).⁹⁵

4.96 Research into the low rates of autopsy in perinatal death cases suggests that contributing factors include lengthy delays in finalising an autopsy, and poor counselling of parents about the option of having an autopsy performed.⁹⁶ Mr Haldane reported, for example, that he and his partner were told that a full autopsy report may take 18 months to be completed.⁹⁷

4.97 The length of time taken to complete an autopsy varies from state to state. In Victoria, the Victorian Perinatal Autopsy Service (VPAS) completes perinatal autopsies within eight weeks, as Associate Professor Kerryn Ireland-Jenkin, Head of Unit at VPAS, explained:

90 AHMAC, *Developing a National Strategic Approach to Maternity Services*, Consultation Paper 1, Department of Health, 2018, p. 23; Queensland Health, 'Stillbirth study aims to help close the gap', *Media release*, 14 August 2017.

91 AHMAC, *Developing a National Strategic Approach to Maternity Services*, p. 23.

92 Stillbirth CRE, *Submission 56*, p. 5.

93 Ms Bowring, *Committee Hansard*, 8 August 2018, p. 12.

94 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology, University of Melbourne, and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, *Committee Hansard*, 9 August 2018, pp. 27–28; Stillbirth CRE, *Submission 56*, p. 5; AIHW, *Stillbirths in Australia 1991–2009*, p. 32.

95 AIHW, *Submission 26*, p. 5.

96 Stillbirth CRE, *Submission 56*, p. 5; Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP), *Committee Hansard*, 8 August 2018, p. 48.

97 Mr Samuel Haldane, *Committee Hansard*, 8 August 2018, p. 1.

Within two business days of a perinatal autopsy being done, there should be what's called a preliminary report that goes back. The preliminary report doesn't really provide a lot of pathology data, but it basically says—this is important, because we have a service where people are referring to three hospitals in Victoria: 'Your baby came to hospital X. An autopsy was performed by Dr Y on this date. This is the list of investigations that we performed in that autopsy. We will be issuing a final report within eight weeks.' That fits with the requirement by NPAAC guidelines around autopsy turnaround time. Why do we say eight weeks? Could we turn them around a little quicker? It's often the ancillary investigations that take almost up to the eight weeks—maybe the genetics, sometimes radiology et cetera. We feel that, if we list that turnaround time, that's something that we think is absolutely achievable, and we'd rather say something that's realistic and fits within national guidelines than pretend we're offering something that is better than we can actually offer, and then people are disappointed and make appointments without data being available.⁹⁸

4.98 In contrast, in NSW, an autopsy report can take more than 12 months to be completed, forcing parents to wait for the information that may help them to avoid a future stillbirth or other pregnancy complications.⁹⁹ Queensland has been up to 18 months behind in its reporting, due to a lack of resources and funding.¹⁰⁰

4.99 Stillbirth CRE noted that lengthy waiting times and uncertainty around timeframes for the results of autopsies and other investigations are a source of distress for many bereaved parents.¹⁰¹

4.100 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP), noted that there are less invasive options available to families who do not wish to have a full autopsy conducted on their baby.

You can have a post-mortem MRI scan and you can request just an external examination of the baby by a skilled perinatal pathologist. Obviously, the placenta is key, so it's very important that, if a family do decline to have further examination with an autopsy, the placenta is still looked at. I do think there are other options.¹⁰²

4.101 Professor Jane Dahlstrom stated that examination of the placenta is an important part of stillbirth investigation and influences the quality of the data available. Professor Dahlstrom 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 Kerryn Ireland-Jenkin, Head of Unit, VPAS, *Committee Hansard*, 7 September 2018, pp. 14–15.

99 Ms Jodie Matthews, *Submission 100*, [p. 3].

100 Dr Diane Payton, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australasia (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.

stillbirth than a general anatomical pathologist'.¹⁰³ 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.¹⁰⁴

4.102 There is, however, a lack of funding to undertake stillborn autopsies in some jurisdictions, and this is compounded by a shortage of skilled pathologists available to undertake autopsies on stillborn babies—an issue for high-income countries more generally.¹⁰⁵

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'.¹⁰⁶

4.104 Similarly, the Victorian government has introduced a coordinated perinatal autopsy service in public hospitals.¹⁰⁷ 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.

The value of a high quality, centralised perinatal post-mortem service is that it provides high quality, consistent data regarding the findings (report) in a case of perinatal death...A high quality perinatal autopsy service reduces the rate at which cases of stillbirth are classified as Unexplained, which is an important outcome.¹⁰⁸

Autopsy costs and access

4.105 The committee heard that, since there is no funding available under the MBS to undertake a stillbirth autopsy, the costs must be met by state/territory health departments, hospitals or families.¹⁰⁹

103 Professor Jane Dahlstrom, *Submission 128*, p. 2.

104 Associate Professor Ireland-Jenkin, VPAS, *Committee Hansard*, 7 September 2018, p. 16.

105 Stillbirth CRE, *Submission 56*, p. 5; Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 48.

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

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

108 Victorian Perinatal Autopsy Service (VPAS), answers to questions on notice, 7 September 2018 (received 2 October 2018).

109 The Royal College of Pathologists of Australasia, *Submission 46*, p. 2. See Chapter 3 for more discussion of autopsy costs.

4.106 Associate Professor Ireland-Jenkin advised that the rebate levels for autopsy in Victoria are set by, and the costs allocated to, the state Department of Health and Human Services. She also explained:

There's no uniform rate of reimbursement across Australia. In some healthcare jurisdictions, the number that's been quoted to me—and I don't know the precise details—may be significantly higher than the current rates that are set in Victoria. We did engage in creating a business case when the service was set up at the start of 2016, when we looked at the number of hours of pathologist time, registrar time et cetera. We did a really robust business case.¹¹⁰

4.107 Other witnesses suggested that the cost of a perinatal autopsy is between \$3000 and \$5000, but Professor Flenady explained that '[m]ost parents, obviously, aren't charged. Even in the private system it will be absorbed.'¹¹¹ Dr Diane Payton, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australasia (RCPA) also discussed costs associated with transporting a baby from a regional or remote location to a major metropolitan hospital so that an autopsy can be performed.¹¹²

4.108 Research in other high-income countries identified similar problems, with resources being diverted away from stillbirth investigations.

Failure to offer autopsy denies parents a chance to understand the cause of their baby's death, increases the proportion of unexplained stillbirths, and hinders the effectiveness of subsequent audits. A crucial shortage of perinatal pathologists also hampers efforts. Such a shortage was shown in our surveys, where only 26% of care providers reported that autopsies were undertaken or supervised by perinatal or paediatric pathologists. Resources continue to be diverted away from perinatal pathology services, despite stillbirths and neonatal deaths outnumbering all deaths from cancer.¹¹³

4.109 Mrs Iverach stated that the available data for research is limited because families are not being given sufficient support following a stillbirth, resulting in the investigations of their baby's death not being completed.

The specialist reported to me that deaths are often listed as “cord accident” and this does not give an accurate cause or indication of factors involved...making this conclusion unhelpful in prevention or change. The specialist stated that “cord accident” is often used when no other data is

110 Associate Professor Ireland-Jenkin, VPAS, *Committee Hansard*, 7 September 2018, p. 12.

111 Professor Flenady, Stillbirth CRE, *Committee Hansard*, 6 September 2018, p. 19; also see Dr Payton, RCPA, *Committee Hansard*, 6 September 2018, p. 43.

112 Dr Payton, RCPA, *Committee Hansard*, 6 September 2018, p. 40.

113 V Flenady, AM Wojcieszek, P Middleton, et al, 'Stillbirths: Recall to Action in High-Income Countries', *The Lancet*, vol. 387, no. 10019, 13 February 2016, p. 693, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)01020-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)01020-X/fulltext) (accessed 12 November 2018).

available to make a full determination and this is the best conclusion they can make.¹¹⁴

4.110 Dr Warland recommended supplementing clinical data collection by introducing a standardised verbal autopsy from parents as soon as possible after the stillbirth.

This verbal autopsy should include questions about whether or not the mother noticed changes in her body and/or her unborn baby's behaviour in the days leading up to the stillbirth, what she did or didn't do about it and also what her maternity care provider did, or didn't do, about it.¹¹⁵

Coronial investigations

4.111 Traditionally, Australian coroners have jurisdiction to investigate the death 'of persons who at some stage have been alive after they have been born'.¹¹⁶ The committee heard evidence from several witnesses about the merits of extending coronial jurisdiction to cases of stillbirth.

4.112 Dr Warland noted that babies are not legal entities until they are born live, and therefore stillbirths fall outside of the jurisdiction of coroners. She argued that this is an anomaly that should be corrected, so that there is greater accountability for stillbirth deaths.¹¹⁷

4.113 Some researchers have argued that coronial inquests are not the most appropriate way of investigating stillbirths, and that autopsy and/or clinical audits would be preferred options, with the responsible health care service undertaking the audit, which would be reviewed by an independent external panel.¹¹⁸

4.114 The UK is currently considering widening its coronial jurisdiction to include certain cases of stillbirth, which is currently excluded on the basis that there has to have been an independent life prior to coronial investigation.¹¹⁹

114 Mrs Iverach, *Submission 89*, [p. 3].

115 Dr Jane Warland, *Submission 9*, [p. 1]; also see Ms Justine Reynolds, *Submission 73*, [p. 2].

116 Ian Freckleton, 'Stillbirth and the Law: Options for Law Reform and Issues for the Coronial Jurisdiction', *Journal of Law and Medicine*, September 2013, p.14, cited in Maurice Blackburn Lawyers, *Submission 69*, p. 3.

117 Dr Warland, *Submission 9*, [p. 2].

118 V Flenady, A Wojcieszek and D Ellwood, 'Better Care and Communication can Cut Stillbirth Rates and Avoid Unnecessary Trauma', *The Conversation*, 22 October 2015, <https://theconversation.com/better-care-and-communication-can-cut-stillbirth-rates-and-avoid-unnecessary-trauma-49435> (accessed 24 July 2018).

119 The UK Health Secretary announced in November 2017 that he would work with the Ministry of Justice to consider enabling full-term stillbirths to be covered by coronial law, as part of a new strategy to improve National Health Service maternity services. Catherine Fairbairn, Alex Bate and Oliver Hawkins, *The Investigation of Stillbirth*, Briefing paper 08167, House of Commons Library, 1 February 2018, pp. 3 and 12–13, <http://researchbriefings.files.parliament.uk/documents/CBP-8167/CBP-8167.pdf> (accessed 26 September 2018).

4.115 In Australia, coroners do not investigate stillbirth, as 'a coroner has jurisdiction not in respect of injuries or stillbirths but in respect of the deaths of persons who at some stage have been alive after they have been born'.¹²⁰

4.116 Mrs Dimitra Dubrow, Principal and Head of Medical Negligence, Maurice Blackburn Lawyers, noted that coronial findings often drive reforms in policies, procedures and standards, including increased awareness and management of risks, the need for ongoing training for locum obstetricians and a review of hospital procedures. She also noted that autopsy reports often contain statements that are unhelpful and arbitrary, and that a coronial investigation might yield significant new information about the circumstances of stillbirth. She argued that a similar reform in Australia would ensure a greater degree of independence, accountability and transparency in the process of determining why unexpected stillbirths occur. She noted that a coronial investigation should be used to determine the cause of stillbirth, rather than being a 'fault-finding exercise'.¹²¹

4.117 Dr Carrington Shepherd, Co-Lead, Western Australian Perinatal Epidemiology Group, considered that there is a need for a more systematic and independent approach to post-mortem investigations of stillbirths. He proposed that the National Coronial Information System, that includes information on perinatal loss, could be expanded to include stillbirth and autopsy findings.¹²²

4.118 Mrs Claire Foord, Chief Executive Officer and Founder of Still Aware, noted that there is generally a gap in autopsy reports where no cause of death could be determined, and called for the use of a coronial investigation in such cases to ensure that all the available evidence from both clinical and family perspectives is recorded and reviewed. Such an investigation would contribute to a better understanding of the circumstances surrounding the stillbirth.

There are gaping holes in autopsy reports that say 'there was no reason for anything to go wrong' or 'we have no understanding of any precursor to this'. But the fact is they're not going to know that unless they can go back and look at historical records and talk to all of the people involved in this child's life, and that's parents included. So, we're asking for the coroner to have jurisdiction not over every childhood death to stillbirth but rather those that are preventable deaths in the third trimester that can be reported, and as such it would be said, 'Okay the coroner should have jurisdiction over this'.¹²³

120 Maurice Blackburn Lawyers, *Submission 69*, p. 3.

121 Mrs Dubrow, Maurice Blackburn Lawyers, *Committee Hansard*, 9 August 2018, pp. 33 and 36; Maurice Blackburn Lawyers, *Submission 69*, pp. 4–5; see also Mrs Clare Rannard, *Submission 179.1*, [p. 3];

122 Dr Carrington Shepherd, Co-Lead, Western Australian Perinatal Epidemiology Group, *Committee Hansard*, 10 August 2018, p. 34.

123 Mrs Claire Foord, Chief Executive Officer and Founder, Still Aware, *Committee Hansard*, 8 August 2018, p. 43.

4.119 The National Perinatal Mortality Data Reporting Project noted that a requirement for a coronial investigation can delay jurisdictions submitting registration data to the ABS for inclusion in the national perinatal data collections.¹²⁴

Committee view

4.120 The lack of a consistent and coordinated approach to stillbirth at a national policy level has contributed to a fragmentation of stillbirth reporting and data collection, and is inhibiting efforts to undertake research that will assist in reducing the incidence of stillbirth in Australia.

4.121 The committee heard evidence from leading stillbirth research organisations that current national practice for stillbirth data collection in Australia is 'suboptimal', and is significantly impacting on their ability to answer important questions about the causes and prevention of stillbirth. Contributing factors include duplication of effort and disparate approaches across and within states and territories; fragmented data collections that do not link maternal health, pregnancy and birth risk factors; and a system that is fraught with delay and unresponsive to change.

4.122 The lack of progress in reducing stillbirth rates in Australia highlights the urgent need for a multi-jurisdictional commitment to systematic stillbirth reporting and data collection. This is crucial if governments are to provide researchers with reliable, timely and consistent data at a granular level necessary for the development of targeted, evidence-based prevention strategies.

4.123 The committee acknowledges the Australian government's proposed data sharing and release legislation that aims to enhance the integrity of the public sector data system and make it more accessible to researchers.¹²⁵ It urges the government to take into consideration, as part of its consultation, the need for Australian stillbirth researchers to have access to a NPMDC that is high-quality, timely, consistent, detailed, and cost-effective to access. It notes that the Vital Statistics Online Data Portal in the USA offers a best practice model that, if adopted in Australia, would ensure that stillbirth researchers are no longer hampered in their efforts to reduce the unacceptably high rate of stillbirth in Australia.

4.124 The committee also acknowledges the importance of the current PHRN-led project, being undertaken as part of the National Collaborative Research Strategy, which aims to improve linkages between state/territory data collections and the national data collections through the AIHW.

4.125 Whilst such initiatives are welcome, the paucity of timely, high-quality data on stillbirth remains a significant impediment to determining national research

124 AIHW, *National Perinatal Mortality Data Reporting Project: Issues paper*, October 2012, p. 9.

125 Department of the Prime Minister and Cabinet, *New Australian Government Data Sharing and Release Legislation: Issues paper for consultation*, 4 July 2018, <https://www.pmc.gov.au/resource-centre/public-data/issues-paper-data-sharing-release-legislation> (accessed 8 October 2018).

priorities, addressing substandard care, identifying causes and risk factors, and establishing evidence-based prevention strategies.

Recommendation 2

4.126 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.**

4.127 The committee urges the AHMAC to consider endorsing the strategies proposed by the Stillbirth CRE, as follows:

- adopting a single national definition for stillbirth to be used by all jurisdictions;
- implementing a standardised national electronic reporting system to collect 'real-time' data on births and deaths, including identification of Aboriginal and Torres Strait Islander and other high risk groups;
- including stillbirth rates as key performance indicators in annual perinatal outcomes reports; and
- undertaking hospital level audits to identify contributing factors relating to care in relation to stillbirths and neonatal deaths.

4.128 Determining the cause of a baby's death is one of the most significant questions surrounding stillbirth, and the lessons learned from reviews of medical data are important for improving research and education as well as clinical practice. Successful international programs such as MBRRACE-UK offer valuable models for a more collaborative, multi-jurisdictional approach to perinatal mortality review programs. However, the committee heard that the number of perinatal mortality audits in Australia is low and represents a significant barrier to reducing the rate of stillbirths in Australia.

4.129 The committee notes that there is no funding available under the MBS to undertake a stillbirth autopsy, and that the costs must be borne by state/territory health departments, hospitals or families. According to state and territory agencies responsible for data collection, it can take several years to implement a new mandatory reporting item.

4.130 The lack of funding is contributing to delays in the results being made available to bereaved parents as well as to researchers. In addition, the current process for extending MBS funding requires review in order to make it sufficiently flexible to accommodate breakthroughs in medical research and technology (see, for example, the discussion on genetic testing in Chapter 5).

Recommendation 3

4.131 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.

4.132 The committee acknowledges that Australia has a critical shortage of perinatal pathologists, severely restricting the number of autopsies and other pathology services being conducted following stillbirth. Unless more resources are provided for training and employing perinatal pathologists, efforts to reduce the rate of stillbirth will continue to be hampered by insufficient information and data about the causes of stillbirth. This shortage of skilled perinatal pathologists has significant implications for bereaved parents, clinicians, health professionals and researchers seeking to understand and address the causes of stillbirth.

Recommendation 4

4.133 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.

Chapter 5

Stillbirth research in Australia

5.1 Research plays a critical role in identifying the causes, risk factors and preventative measures for stillbirth and, together with innovation and education, holds the key to understanding the best ways to reduce the rate of stillbirth in Australia.

5.2 However, there is currently a lack of coordination and planning in determining national research priorities and appropriate funding for stillbirth research, as well as a lack of collaboration between the government, private sector and philanthropic supporters.¹

5.3 This issue is compounded by the stigma and silence that surrounds stillbirth in the community more generally. Mr Bruce McMillan stated that, whilst he had been aware of stillbirth prior to the stillbirth of his own baby, he was shocked to learn of the magnitude of the problem.

As we know, there are over 2,000 stillbirths a year. Our national road toll has not been over 2,000 since 1991. If governments of all persuasions had allowed the national road toll to carry on for 27 years with no reduction, there would be a national outcry at the failure of governments to act. Yet here we are, in 2018, with virtually no government money being spent on research into an area that impacts on so many lives and probably even less money being spent on supporting organisations who support those of us who have suffered the loss of a child.²

5.4 The impact of this lack of coordinated stillbirth research planning and funding has significant consequences for individual families who have experienced stillbirth. As Ms Lyndel Carbone stated, the lack of stillbirth research hampers efforts to determine the cause of death and 'leads to huge levels of stress and anxiety for subsequent pregnancies'.³

5.5 This chapter considers stillbirth research and funding issues, and opportunities for innovative technology and corporate sector partnerships.

Government funding for stillbirth research

National Health and Medical Research Council

5.6 The National Health and Medical Research Council (NHMRC) provides advice to the Australian government on health and medical research, including research into stillbirth, and approves clinical practice guidelines for use in Australian

1 Stillbirth Foundation Australia, *Submission 33*, p. 11; Hunter Medical Research Institute (HMRI), *Submission 36*, [pp. 2–3]; National Perinatal Epidemiology and Statistics Unit (NPESU), University of New South Wales (UNSW), *Submission 37*, p. 7.

2 Mr Bruce McMillan, *Committee Hansard*, 9 August 2018, p. 9.

3 Ms Lyndel Carbone, *Submission 171*, [p. 5].

health care settings. It also manages research support and funding, including grants for individual specific research projects and broad programs of research.⁴

5.7 Since 2007, the NHMRC has expended \$5.9 million for grants relating to stillbirth research, with a current commitment of grants of \$13.4 million.⁵ This funding commitment includes \$2.6 million over five years from 2016 for the NHMRC Centre of Research Excellence in Stillbirth (Stillbirth CRE) at the University of Queensland.⁶

5.8 The NHMRC has announced a new grant program which 'offers increased flexibility to invest in areas of particular research need'. The program includes Investigator Grant and Synergy Grant schemes, the latter of which encourages joint-funding of research, and the Targeted Call for Research scheme which 'focuses on research that has the potential to improve health outcomes for the community, reduce the burden of disease on the health system and Australian economy and contribute to the global research effort'.⁷

5.9 The NHMRC has also developed the NHMRC International Engagement Strategy 2016–2019 which outlines its approach to working with international partners.⁸

5.10 However, the NHMRC stated that applications for stillbirth research funding have been few in number and numbers fluctuate from year to year, with the level of funding for any particular disease dependent on 'the number and quality of the research proposals received by the NHMRC'.⁹

Medical Research Future Fund

5.11 The Medical Research Future Fund (MRFF), established in 2015–16, is administered by the Department of Health. It provides financial assistance to support health and medical research and innovation, although it is not clear whether funding has been provided for stillbirth research under this grant program.¹⁰

5.12 One of the MRFF priority areas, for which \$17.5 million in funding is being made available, is Maternal Health and First 2000 Days, which will provide

4 National Health and Medical Research Council (NHMRC), <https://www.nhmrc.gov.au/research>; Department of Health, answers to questions on notice, 28 February 2018 (received 14 May 2018).

5 NHMRC, *Submission 27*, pp. 1 and 3.

6 NHMRC, *Submission 27*, p. 3.

7 NHMRC, *Submission 27*, p. 4.

8 NHMRC, *Submission 27*, p. 2; Centre of Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, p. 7.

9 NHMRC, *Submission 27*, p. 3.

10 NHMRC, *Submission 27*, p. 4.

investment in research to improve health interventions between a woman's pregnancy and the first five years of a child's life.¹¹

5.13 The Australian Medical Research Advisory Board, which provides advice to the government on the MRFF, has been conducting public consultations to inform the development of the second round of MRFF priorities for 2018–2020, which help to inform the government's decisions around how the MRFF is allocated.¹²

5.14 The National Perinatal Epidemiology and Statistics Unit (NPESU), University of New South Wales (UNSW), recommended that targeted funding should be made available for collaborative research partnerships, potentially through the MRFF, which has the advantage of bringing together experts in perinatal epidemiology, academic units, clinicians, parents and governments.¹³

Government research funding issues

5.15 Government funding for stillbirth research was lagging well behind other areas of health research in Australia, even though stillbirth remains the greatest cause of infant mortality. For example, cancer research received \$187 million between 2006 and 2018, and mental health research has been allocated \$331.81 million over the next four years.¹⁴

5.16 Using Australian Institute of Health and Welfare (AIHW) data, Red Nose compared the number of deaths from breast cancer between 1994 and 2014 with stillbirths per 100 000 persons (see Figure 5.1). In 2014, there were 2844 deaths from breast cancer from the Australian population of 23.5 million, and 2225 stillbirths from 313 000 births.¹⁵

11 Department of Health, *Maternal Health and First 2000 Days*, <https://beta.health.gov.au/initiatives-and-programs/maternal-health-and-first-2000-days> (accessed 24 July 2018).

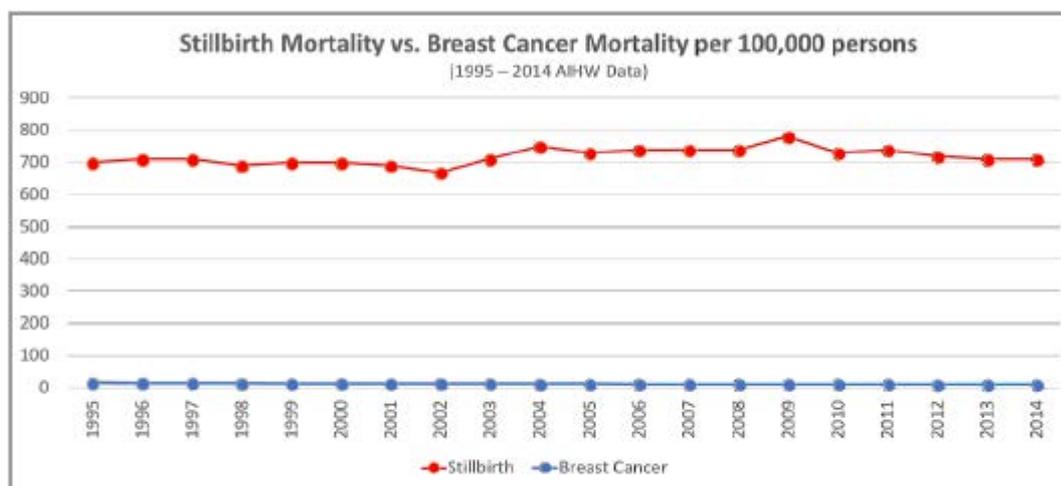
12 Consultations closed on 31 August 2018 to ensure that the second set of Priorities will take effect from the day the inaugural MRFF Priorities expire, on 8 November 2018. Australian Medical Research Advisory Board, *Medical Research Future Fund: 2018–2020 Priorities Consultation Discussion Paper*, Department of Health, 2018; MMRF, 'Medical Research Future Fund consultation to inform the second Australian Medical Research and Innovation Priorities 2018–2020', <https://consultations.health.gov.au/health-economics-and-research-division/medical-research-future-fund-consultation-for-the/> (accessed 31 October 2018).

13 Associate Professor Georgina Chambers, Director, NPESU, Centre for Big Data Research in Health and School of Women's and Children's Health, Faculty of Medicine, UNSW, *Committee Hansard*, 8 August 2018, p. 29.

14 Ms Danielle Pollock, Stillbirth researcher and bereaved parent representative, Global Stillbirth Advocacy Network (GSAN), *Committee Hansard*, 8 August 2018, p. 63.

15 Red Nose, *Submission 63*, p. 7. Red Nose is a charity established to eradicate Sudden Infant Death Syndrome (SIDS).

Figure 5.1: Stillbirth mortality vs. breast cancer mortality per 100 000 persons¹⁶



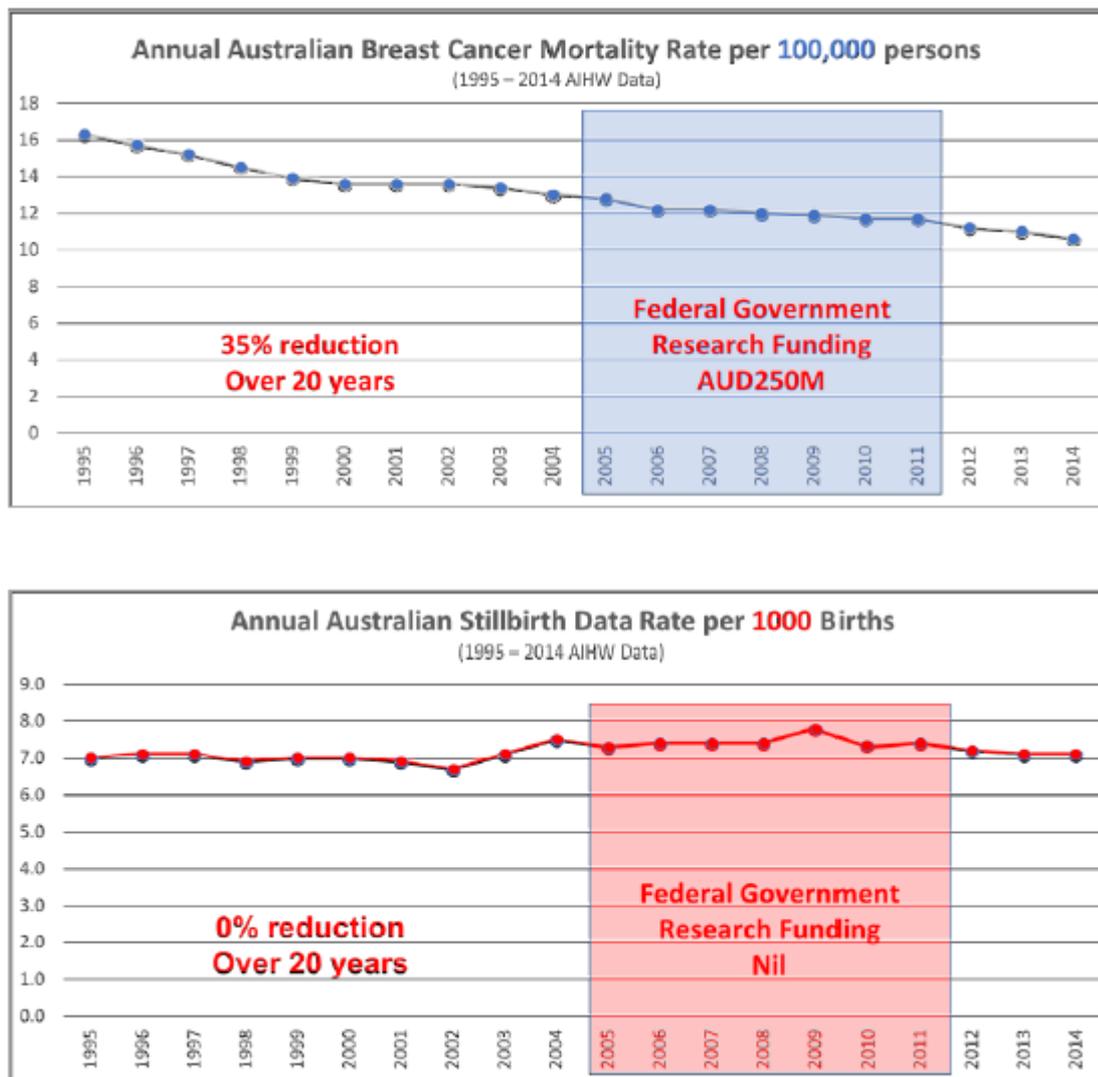
5.17 Red Nose noted that its investment of \$17 million into Sudden Infant Death Syndrome (SIDS) research had contributed to an 85 per cent reduction in the incidence of SIDS. It then compared the levels of federal government research funding in relation to the annual mortality rate for breast cancer (per 100 000 persons) and stillbirth (per 1000 births), based on AIHW data for 1995 to 2014 (see Figure 5.2).

5.18 Red Nose noted that funding provided from the NHMRC for stillbirth research has increased since 2012, totalling \$5.4 million over the last six years. It submitted, however, that a significant increase in funding is required for stillbirth research and for developing new diagnostic tools to prevent the 75 per cent of stillbirths that are most difficult to predict.¹⁷

¹⁶ Red Nose, *Submission 63*, p. 7.

¹⁷ Red Nose, *Submission 63*, p. 8.

Figure 5.2: Comparison of government research funding in relation to annual mortality rates for breast cancer and stillbirth¹⁸



5.19 The Global Stillbirth Advocacy Network observed that, in countries where national governments have taken action, the rate of stillbirth has been reduced. However, the limited amount of government funding available for stillbirth research and education in Australia has resulted in fragmented, short-term research efforts and a reliance on voluntary initiatives to provide public education and support for bereaved families.¹⁹

5.20 Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute, stated that one of the issues in research funding lies with the three-year research grant cycle that inhibits the longer-term investment needed to make inroads into stillbirth research and education.

¹⁸ Red Nose, *Submission 63*, p. 8.

¹⁹ Ms Pollock, GSAN, *Committee Hansard*, 8 August 2018, p. 63.

If you look at the amount of money that's invested into breast cancer research and then into stillbirth research, it's like a hundredth. What is required is an investment into research, but that research is discovery stuff and also implementation stuff. It needs to have a long-term element, because to educate Australian doctors, midwives and patients about something like this is going to take five years, realistically.²⁰

5.21 A submission from the Department of Obstetrics and Gynaecology at the University of Melbourne also noted the limitations of the cyclical nature of current research funding arrangements which are also often project-based. The intermittent and uncertain funding cycle reduces the capacity for large-scale research programs, although the MRFF does offer the potential for longer-term, multi-disciplinary and multi-faceted stillbirth research and education programs.²¹

5.22 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians, highlighted the benefits of having a greater diversity of expertise and interests amongst those allocated funding for stillbirth research, noting that funding for cancer research is provided through a range of organisations and that this approach has resulted in significant breakthroughs in the prevention and treatment of cancer.²²

5.23 Associate Professor Camille Raynes-Greenow of the School of Public Health, University of Sydney, proposed that a roundtable approach to coordinating research funding—involving relevant stakeholders including government, philanthropic and corporate representatives as well as researchers and care providers—would be preferable to the current piecemeal approach.²³

5.24 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, noted that NHMRC has traditionally allocated funding for 'clinical-style research' into stillbirth, but that there has been no significant reduction in the rate of stillbirth. She stated that there is currently no dedicated national stillbirth research fund administered by an independent organisation, and proposed that the Stillbirth Foundation Australia could provide such a service, in partnership with a government-led national organisation for stillbirth research and education.

We have a unique ability in being able to have insight into the family's experience around stillbirth, but also the understanding of the importance of particular types of research et cetera. We don't have a particular allegiance to any single institute or organisation. In this instance, because it is such a

20 Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute (HMRI), *Committee Hansard*, 8 August 2018, p. 25. Professor Pennell is a leading stillbirth researcher affiliated with the HMRI, part of a NHMRC-funded initiative to optimise the translation of cost-effective research outcomes into policy and practice.

21 Department of Obstetrics and Gynaecology, University of Melbourne, *Submission 45*, p. 16.

22 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians, *Committee Hansard*, 8 August 2018, p. 46.

23 Associate Professor Camille Raynes-Greenow, School of Public Health, University of Sydney, *Committee Hansard*, 8 August 2018, p. 52.

multifaceted issue, it needs to be dealt with in such a way that all of the stakeholders that are a part of the problem are also part of the solution, and not just one particular entity.²⁴

Other research funding

5.25 There are isolated examples of stillbirth research being undertaken in Australia without NHMRC funding.

5.26 The Australian Longitudinal Study on Women's Health (ALSWH), funded by the Commonwealth Department of Health, currently includes about 250 collaborative projects on women's health issues, including four investigating where stillbirth may be a factor.²⁵

5.27 Some funding for stillbirth research is provided by charitable organisations set up by and for families affected by stillbirth. Stillbirth Foundation Australia is the first Australian charity dedicated to stillbirth research, and has provided around \$1 million to research projects since 2009 through various research institutes, hospitals and parent advocacy organisations.²⁶

5.28 The Hunter Medical Research Institute (HMRI) noted that it had been the beneficiary of research funding from the philanthropic Haggarty Foundation. The HMRI suggested that any national coordination of research funding should recognise the potential for both community engagement and philanthropic support, and its research program and priorities should be oversighted by a high-calibre, multi-disciplinary scientific committee.²⁷

5.29 Stillbirth CRE partnered with the Stillbirth Foundation Australia to provide additional research funding which has largely been provided through community and corporate engagement, and noted that there is a need for greater government involvement in coordinating these activities.

As with other significant public health issues, a focussed effort is needed and investments that could bring a wider group under one umbrella would have significant benefits. The Stillbirth CRE has taken initial steps to coordinate activity and effort but a clear direction from governments to ensure that all research and public awareness campaigns are cost-effective and achieve maximum impact would be highly beneficial.²⁸

24 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 13.

25 Australian Longitudinal Study on Women's Health (ALSWH), *Submission 60*, pp. 2–3. The ALSWH, a collaborative project conducted by staff at the University of Newcastle and University of Queensland, is funded until at least 2020.

26 Stillbirth Foundation Australia, *Submission 33*, p. 11.

27 HMRI, *Submission 36*, [p. 6].

28 Stillbirth CRE, *Submission 56*, p. 9.

5.30 However, most research and investigation into stillbirth cause and prevention is still researcher-led, with minimal funding provided by government.²⁹ Stillbirth Foundation Australia argued that funding for researching what constitutes a national health crisis should not be borne only by those who have experienced stillbirth.³⁰

Research priorities

5.31 Up to 60 per cent of stillbirths at term in Australia are unexplained, highlighting the urgent need for further research into understanding why these deaths have occurred.³¹

5.32 In addition, for every one stillbirth there are another 99 births that narrowly avoid ending in stillbirth, making it imperative for research to identify not only why unexplained stillbirths occur but also the determinants of stillbirth in early fetal development.³²

Stillbirth is a little bit like the iceberg that you can see—underneath it you've got that 90 per cent of babies who were at risk but fortunately didn't die. By studying that group, you can learn a lot about the causes of stillbirth as well as optimising the outcome for a much larger number of people, improving...the ability to be educated and participate fully in our community and, almost certainly, having longer, healthier life expectancy.³³

5.33 The NHMRC determines research priorities based on current and emerging health issues in Australia and internationally, and identifies the National Health Priority Areas which receive a substantial proportion of NHMRC funding. Stillbirth is not identified as a National Health Priority Area.³⁴

5.34 The NPESU noted that research priority-setting had been undertaken by the Perinatal Society of Australia and New Zealand and members of the Stillbirth CRE, in consultation with all stakeholder groups including consumers, and recommended that these research priorities should inform future funding initiatives that encourage collaborative research between academia, governments, consumers and stillbirth organisations.³⁵

5.35 Ms Pip Brennan, Executive Director of the Health Consumers' Council (Western Australia) stated that the NHMRC had emphasised the need for research priorities to be driven by bereaved parents and families. She noted that the

29 Royal College of Pathologists of Australasia, *Submission 46*, p. 2.

30 Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 11.

31 Stillbirth CRE, *Submission 56*, p. 4; ALSWH, *Submission 60*, p. 3.

32 HMRI, *Submission 36*, [p. 6].

33 Laureate Professor Roger Smith, Director, Mothers & Babies Research Centre, HMRI, *Committee Hansard*, 8 August 2018, p. 26.

34 *National Health and Medical Research Council Corporate Plan 2017–2018*, August 2017, <https://nhmrc.gov.au/about-us/publications/nhmrc-corporate-plan-2017-2018> (accessed 11 October 2018).

35 NPESU, *Submission 37*, p. 7.

submissions to this inquiry from those who had experienced stillbirth suggested a range of excellent research questions, and argued that consumer generated research questions will help to ensure best practice in stillbirth research. Ms Brennan highlighted the need to:

- take verbal autopsies from parents and other key care providers who are not currently consulted in a stillbirth review;
- establish benchmarks for monitoring the rates of stillbirth across Australia;
- make research and data more accessible nationally; and
- translate stillbirth research into practice, for example by requiring customised fetal-growth charts to enable intrauterine growth retardation to be identified sooner.³⁶

5.36 Stillbirth CRE endorsed this approach.

Parents must remain at the centre of all future research as they inform research priorities and can provide invaluable advice on how to most effectively involve parents and families in appropriate ways.³⁷

5.37 Stillbirth CRE outlined its national research program, developed in consultation with parents, parent-based support and advocacy organisations, foremost international expert researchers and clinicians, and the Australian community. The program addresses four major priority areas:

- improving care and outcomes for women with risk factors for stillbirth;
- developing new approaches for identifying women at increased risk of stillbirth;
- implementing best practice in care after stillbirth and in subsequent pregnancies; and
- improving knowledge of causes and contributors to stillbirth.³⁸

5.38 Achieving meaningful and ongoing change requires additional government funding and policy support for a unified national priority driven approach building on the Stillbirth CRE model so that government, philanthropic and corporate funding bodies can work together to produce the best outcomes. According to Stillbirth CRE, the most important research priority is addressing the gap between '*what is known* and *what is done* in every day clinical care of women having a baby in Australia'.

Major gains can be made by simply doing better what is already known to be best practice, and although implementation projects may not be as

36 Ms Pip Brennan, Executive Director, Health Consumers' Council (Western Australia), *Committee Hansard*, 10 August 2018, pp. 14–15; see also Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 16.

37 Stillbirth CRE, *Submission 56*, p. 15.

38 Stillbirth CRE, *Submission 56*, p. 9.

attractive to funding bodies, it is vitally important that there is a rigorous approach to translating new ideas into practice.³⁹

5.39 The National Rural Health Alliance advised that research and education priorities to improve health outcomes and increase the quality of care to women in rural and remote Australia must include obesity prevention and management, and cultural safety and cultural competence.⁴⁰

5.40 Other suggestions included:

- introducing research performance as a key performance indicator for chief executives of tertiary hospitals across Australia;
- making a long-term investment in stillbirth research in order to allow time to properly implement research findings;
- implementing a centrally coordinated national process to enable pathologists to conduct collaborative investigations into stillbirth cases, similar to the research being conducted in relation to babies that have died from SIDS;⁴¹
- elucidating the causal pathways to stillbirth and neonatal death;
- examining stillbirth by location, cultural/ethnic background, and socioeconomic circumstances; and
- assessing the effectiveness of public health campaigns.⁴²

Identifying mothers at risk

5.41 As in other high-income countries, the risk of stillbirth for Aboriginal and Torres Strait Islander women and women who live with social disadvantage is far higher than other Australian women.⁴³

...statistics show that the rate of stillbirth increases the further away women are from an Australian major city. Stillbirth can have long term and economic consequences and adds to the inequitable health and social burden that people in rural and remote Australia already experience.⁴⁴

5.42 Contributing factors include perinatal infection, fetal growth restriction (FGR), unexplained antepartum fetal death, and maternal conditions (mainly

39 Stillbirth CRE, *Submission 56*, pp. 8–9; see also Ms Brennan, Health Consumers' Council (WA), *Committee Hansard*, 10 August 2018, p. 15; Centre for Midwifery, Child and Family Health, *Submission 21*, pp. 4–5; Australian College of Midwives, *Submission 24*, [p. 6].

40 National Rural Health Alliance, *Submission 57*, [p. 3].

41 Professor Pennell, HMRI, *Committee Hansard*, 8 August 2018, p. 25; Laureate Professor Roger Smith, HMRI, *Committee Hansard*, 8 August 2018, p. 25 in relation to Indigenous research.

42 Western Australian Perinatal Epidemiology Group, *Submission 47*, pp. 3–4.

43 Stillbirth CRE, *Submission 56*, p. 13; Department of Obstetrics and Gynaecology, University of Melbourne, *Submission 45*, p. 14; Department of Health, *Evidence Evaluation Report: Models for Aboriginal and Torres Strait Islander Women's Antenatal Care*, 16 May 2017, p. 5.

44 National Rural Health Alliance, *Submission 57*, [p. 3].

diabetes). However, there has been little reduction in the gap between Indigenous and non-Indigenous women in relation to stillbirth rates, indicating that this area is a priority for future research.⁴⁵

5.43 The Multicultural Centre for Women's Health drew attention to differences in the risk of stillbirth in relation to country of birth, and emphasised the need for more research to shed light on the causes and contributing factors to higher stillbirth rates amongst women from CALD backgrounds, including late presentation to antenatal care and disparity between rural and regional and metropolitan rates of stillbirth.⁴⁶

5.44 Submitters and witnesses also raised other risk factors that require further research, including FGR, ageing of placenta, and hypertensive disorders.

Fetal growth restriction

5.45 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) noted that FGR and intrapartum hypoxic death together contribute to about eight per cent of all stillbirths. As a strong risk factor, FGR screening, diagnosis and management are important to protect against stillbirth.⁴⁷

5.46 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology and Chair, Women's and Newborn Health Network at the Melbourne Academic Centre for Health agreed.

Fetal growth restriction is associated with a fourfold increase in the risk of stillbirth, is a common antecedent to stillbirth in labour and seems the likely mechanism linking factors such as obesity, medical conditions and increasing maternal age with stillbirth. Disappointingly, current care detects only 20 per cent of babies destined to be born small. Yet if we can discover better ways to identify small babies, we know we can halve their stillbirth risk. In conclusion, we suggest that by daring to connect, daring to inspire and daring to discover, we bring the day when families may be spared the tragedy of preventable stillbirth one day closer.⁴⁸

5.47 HMRI also pointed to the importance of conducting research into poor fetal development more generally, especially in vulnerable communities, noting that for every one stillbirth there are another 99 that narrowly avoid stillbirth.⁴⁹

45 I Ibiebele, M Coory, FM Boyle, et al, 'Stillbirth Rates Among Indigenous and Non-Indigenous Women in Queensland, Australia: Is the Gap Closing?', *British Journal of Obstetrics and Gynaecology*, vol. 122, no. 11, August 2014, p. 1482, <https://obgyn.onlinelibrary.wiley.com/doi/epdf/10.1111/1471-0528.13047> (accessed 19 September 2018).

46 Dr Jasmin Chen, Research and Executive Officer, Multicultural Centre for Women's Health, *Submission 70*, pp. 2–4.

47 Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Submission 17*, [p. 2].

48 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology and Chair, Women's and Newborn Health Network at the Melbourne Academic Centre for Health, *Committee Hansard*, 9 August 2018, p. 25; see also Dr Jonathon Hoy, *Submission 103*, [p. 1].

49 HMRI, *Submission 36*, [p. 7].

5.48 RANZCOG cited international studies showing that elective induction of labour at 39 weeks could reduce the risk of stillbirth and other adverse perinatal outcomes.⁵⁰ However, Professor Steve Robson stressed that RANZCOG was not advocating early induction for all pregnancies.

We're not saying for one second that everybody should be induced at 38 or 39 weeks or whatever. We're saying that the evidence around the world is coming down saying, 'If you're worried—if you have concerns about the condition of a baby, about how it's tolerating things—then a policy of having that low threshold, offering it to women and allowing them to make a choice, seems to be a safe thing. It doesn't seem to be associated with the other things that we worry about, like a rising caesarean section rate.'⁵¹

Placental insufficiency

5.49 Laureate Professor Roger Smith, Director, Mothers & Babies Research Centre, HMRI, drew attention to the recent discovery that stillbirths can be triggered by ageing of the placenta, and noted that the placenta is part of the baby not the mother.

So if the placenta ages prematurely, it may well have nothing to do with the mother, and I think that's important to think about. But it's also important for us to focus our research efforts on understanding this extraordinary organ on which the baby is dependent.⁵²

5.50 One submitter, who experienced a stillbirth despite having no known risk factors, considered that there needed to be better detection of placental insufficiency—an issue which is responsible for 24 per cent of stillbirths—as well as research into the effects of sleep apnea and sleep disordered-breathing on fetal health.⁵³

Hypertensive disorders

5.51 The Department of Obstetrics and Gynaecology at the University of Melbourne noted that preeclampsia is the most common and serious medical condition complicating pregnancy, responsible for 70 000 maternal deaths globally and over 500 000 perinatal deaths every year. It considered improved detection and management of hypertensive disorders of pregnancy to be a leading priority to reducing stillbirth risk.⁵⁴

Innovative technology and coordinated research efforts

5.52 There is an extensive international research community working together to address stillbirth. The NHMRC, recognising that no single country has the resources,

50 RANZCOG, *Submission 17*, [pp. 2–3].

51 Professor Steve Robson, President, RANZCOG, *Committee Hansard*, 9 August 2018, p. 40.

52 Laureate Professor Roger Smith, Director, Mothers & Babies Research Centre, HMRI, *Committee Hansard*, 8 August 2018, p. 23; HMRI, *Submission 36*, [p. 5].

53 Britt Jacobsen and Samuel Haldane, *Submission 82*, [p. 3].

54 Department of Obstetrics and Gynaecology, University of Melbourne, *Submission 45*, [p. 11]; see also Western Health, *Submission 48*, p. 3.

skills and capacity to address all health and medical research challenges, supports funding schemes that have provision for international collaborations.⁵⁵

5.53 Ms Stephanie Vowles cited recent financial modelling on the economic benefits of investing in medical research, noting that 'for every \$1 spent on research, at least \$2 was generated in additional economic output'.⁵⁶

5.54 Several submitters claimed that their stillbirth may have been prevented if their clinician had access to consistent and timely information, highlighting the potential role innovative new technology such as mobile phone apps offered in education, screening and delivering better health outcomes, especially for high risk births.⁵⁷

5.55 Ms Ellana Iverach submitted that most of the current research effort into stillbirth is focused on post-death and support requirements, and argued that more research needs to be done into stillbirth prevention. She pointed to recent technological advancements in fields such as neuroscience, which have allowed researchers to study the brain in new ways and gather data to build prevention and treatment strategies, and suggested that similar advancements may help to prevent stillbirth.⁵⁸

5.56 Stillbirth CRE reported that bereaved parents had identified the need for a 'cure' as their highest priority during consultative meetings, and expressed interest in partnering with the corporate sector and exploring opportunities for potential use of new technologies including:

- improving detection of the unborn baby who is at-risk;
- detailed evaluation of potential harms, including anxiety, of unnecessary intervention (such as preterm delivery); and
- prevention of spontaneous preterm birth (which contributes to around 15–20 per cent of stillbirths).⁵⁹

Mobile phone apps

5.57 New and relatively cheap technologies such as mobile phones can already deliver health messages, help lines and real-time monitoring and reporting of births and deaths. They also have the potential to increase communication and data-sharing amongst health providers and communities more generally.⁶⁰

55 NHMRC, *Submission 27*, p. 2; Stillbirth CRE, *Submission 56*, p. 7.

56 Ms Stephanie Vowles, *Submission 101*, [p. 6].

57 See for example, Name withheld, *Submission 250*, [p. 2]; Mrs Doshni Stewart, *Submission 229*, [p. 3]; Name withheld, *Submission 11*, [p. 1]; Dr Jonathon Hoy, *Submission 103*, [p. 1].

58 Mrs Ellana Iverach, *Submission 89*, [p. 3].

59 Stillbirth CRE, *Submission 56*, pp. 4 and 8.

60 World Health Organisation (WHO) and UNICEF, *Every Newborn: An Action Plan to End Preventable Deaths*, June 2014, pp. 33, 37 and 39.

5.58 Different countries have developed successful ways of educating women about the risks of stillbirth. A phone app developed in Finland, for example, provides a simple and effective tool for educating people about the risks of stillbirth, although it should also be coupled with a message that helps to alleviate any fear or guilt.⁶¹

5.59 Stillbirth CRE reported on the current Australian trial of a mobile phone app called 'My Baby's Movements' (MBM), developed by the Mater Research Institute, University of Queensland and funded by NHMRC. It aims to reduce late gestation stillbirth through earlier reporting and improved clinical care. The app is not yet available in multiple languages due to a lack of funding.⁶²

5.60 The trial forms part of a large research project being conducted in maternity hospitals across Australia and New Zealand, and led by experts from Australia, New Zealand, the Netherlands, the United Kingdom (UK) and Norway. Stillbirth CRE is collaborating with researchers in the UK to combine data from similar trials to explore the differential effects in higher risk groups.⁶³

5.61 An educational program has also been developed for clinicians on the MBM app's use and management of women reporting decreased fetal movement to reduce stillbirth in late gestation stillbirth.⁶⁴

Wearable technology for monitoring pregnancy

5.62 Opinions were divided over the merit of relying on wearable technology to monitor pregnancies.

5.63 Mrs Doshni Stewart recommended wider application of wearable technology for monitoring fetal movement. Mrs Stewart claimed that such technology offers a solution to the lack of resources in public hospitals, is not subject to human error, and has the potential to reduce the risk of stillbirth, especially for high-risk pregnancies.

With increasing high-risk pregnancies, the automation of certain processes within the health system is necessary not only to provide adequate health care to our growing population but also to drive efficiencies in our public hospitals. I recommend that more widespread use of fetal monitoring and other relevant technology be implemented. I believe there were elements of my antenatal care which could have been different and which could have changed what happened to Coralie. Our hope is that this inquiry will result in changes to the care of pregnant women that may reduce the incidence of

61 Professor Craig Pennell, Chair, National Scientific Advisory Group, Red Nose, *Committee Hansard*, 9 August 2018, pp. 23–24.

62 A similar app called 'Count the Kicks' is available in the United Kingdom; see <https://www.countthekicks.org/> (accessed 26 September 2018); Stillbirth CRE, *Submission 56*, p. 10; NHMRC, *Submission 27*, p. 2.

63 Australian College of Nursing, *Submission 20*, p. 4; Confidential, *Submission 156*, p. 3; Stillbirth CRE, *Submission 56*, p. 10.

64 NHMRC, *Submission 27*, p. 2.

stillbirth in this country, as has been achieved in other countries around the world.⁶⁵

5.64 One submitter argued that such technology may be particularly helpful for Aboriginal and Torres Strait Islander women in remote locations, where the rate of stillbirth is higher.⁶⁶

5.65 Dr Jane Warland warned against funding wearable devices at the expense of innovative technology to better support maternity care providers to detect and manage the fetus at risk.⁶⁷ Stillbirth CRE expressed similar reservations, noting that there are other methods of predicting at-risk pregnancies, although these require further research.

The current focus of innovation is on devices to detect changes in fetal movement, although it is unclear if this has real potential to change outcomes. There are other examples of new technology in which biomarkers might either predict the pregnancies 'at risk' or detect the vulnerable fetus late in gestation, but both of these require much more research.⁶⁸

5.66 Associate Professor Raynes-Greenow pointed out that some groups in Australia will be disadvantaged because of the cost of such technology.

We don't consider that technology will solve stillbirth, and it most likely would have unintended consequences, such as unnecessary interventions or causing anxiety, and it is most likely only ever going to be available at a personal level for people who can afford it.⁶⁹

5.67 The Centre for Midwifery, Child and Family Health cautioned that:

...technology is appropriately and carefully used and listening to women should be the first technology used. The risk is that clinicians tend to concentrate on the technology (the machines that say everyone is alright or that things are going wrong) and often forget to prioritise what the woman feels or is experiencing. Very often, women say that 'they knew something was wrong' but that all the tests they had showed no problems and she was sent home. Listening to women should be the first technology applied in this area.⁷⁰

5.68 Professor Caroline Homer, Distinguished Professor of Midwifery, representing the Centre for Midwifery, Child and Family Health, considered that

65 Mrs Doshni Stewart, *Committee Hansard*, 9 August 2018, p. 8.

66 Confidential, *Submission 156*, p. 4.

67 Dr Jane Warland, *Submission 9*, [p. 1].

68 Stillbirth CRE, *Submission 56*, p. 8.

69 Associate Professor Raynes-Greenow, University of Sydney, *Committee Hansard*, 8 August 2018, p. 52.

70 Centre for Midwifery, Child and Family Health, *Submission 21*, p. 3.

women are generally best at monitoring their own baby's movements, 'but if they don't know that they should be monitoring something they're going to miss out'.⁷¹

Genetic testing

5.69 The AIHW noted that, in 2013–14, 27 per cent of stillbirths were caused by a congenital anomaly, making it the leading cause of stillbirth death in Australia. It noted that work is commencing shortly to re-establish an Australian Congenital Anomaly Collection linked to the National Perinatal Mortality Data Collection.⁷²

5.70 Professor Hamish Scott, Head of Genetics and Molecular Pathology Laboratory, SA Pathology, and Associate Professor Christopher Barnett, Head, Paediatric and Reproductive Genetics Unit, The Women's and Children's Hospital, Adelaide, noted the limitations of standard autopsy in relation to stillbirth and reported on the success of their NHMRC-funded genomic autopsy study in identifying genetic causes of unexplained perinatal death, including stillbirth. The service is now available to all major perinatal centres in Australia.⁷³

5.71 Professors Scott and Barnett advised that they had also established a national and international network of collaborators across 10 countries.

Working closely with the Broad Institute of MIT and Harvard, world leaders in genomic technologies, we are delivering a world-class research service model to Australians to provide them with a genetic diagnosis of problems in pregnancy. Our model has been adopted nationally as part of this NHMRC-funded study and will involve all major women's and children's hospitals in Australia, including 37 clinicians and 20 researchers. We are also guiding two international groups in Boston, USA and Toronto, Canada to establish their own studies based on our model. We are also working with industry to develop the tools needed to help patients access IVF and genetic diagnosis of embryos if they are at risk of having a genetic condition in their next pregnancy.⁷⁴

Corporate sector partnerships

5.72 Stillbirth CRE noted that, with some notable exceptions such as the Stillbirth Foundation Australia and PriceWaterhouseCoopers (PwC) partnership, there has been little collaboration between stillbirth researchers and the corporate sector.⁷⁵

71 Professor Caroline Homer, Distinguished Professor of Midwifery, Centre for Midwifery, Child and Family Health, UTS, *Committee Hansard*, 8 August 2018, p. 37. The need to educate pregnant women to trust their instincts and express their concerns is discussed further in Chapter 7.

72 Australian Institute of Health and Welfare (AIHW), *Submission 26*, p. 6.

73 Professor Hamish Scott, Head of Genetics and Molecular Pathology Laboratory, SA Pathology, and Associate Professor Christopher Barnett, Head, Paediatric and Reproductive Genetics Unit, The Women's and Children's Hospital, Adelaide, *Committee Hansard*, 10 August 2018, pp. 17–18.

74 Professor Hamish S Scott and Associate Professor Christopher Barnett, *Submission 54*, [p. 2].

75 Stillbirth CRE, *Submission 56*, p. 8.

5.73 However, there is clearly a role for greater involvement of the private sector in developing innovative new technology and commercial products as well as non-commercial interventions that may help in stillbirth prevention, research and education.⁷⁶

5.74 The NHMRC highlighted the importance of private-public partnerships for delivering better health outcomes. Recent partnerships funded by the NHMRC have included:

- a universal blood test for all pregnant women to measure circulating proteins that are likely to be of placental origin and identify FGR, a major cause of stillbirth; and
- the biochemical processes within the placenta that lead to FGR and placental ageing.⁷⁷

5.75 The NHMRC also noted that Stillbirth CRE, in partnership with the Australian and New Zealand Placental Research Association, is establishing a national biobank to support ongoing placental research into the causes and predictors of stillbirth.⁷⁸

5.76 Several submitters highlighted the importance of a national biobank to improve research and clinical practice.⁷⁹ However Stillbirth CRE noted that, in the absence of any clinically useful tests for early predictors of stillbirth, longer-term research funding and changes to ethics approval processes are urgently needed to facilitate its development.

MRFF funding is one alternative to supporting long term initiatives that will have significant long-term benefits. While there has been support by individual families for research to be carried out where an adverse pregnancy outcome has arisen, Human Research Ethics Committee (HREC) requirements are restrictive particularly around sharing of data across centres. Such data are urgently needed if large scale collection of samples, amenable for later research, is to be permitted by HREC under a possible waiver of consent, or similar approach.⁸⁰

Committee view

5.77 There has been no reduction in the rate of stillbirth in Australia over the past two decades, despite modern advances in medical practice and health care, and stillbirth remains the greatest cause of infant mortality. Nevertheless, as international

76 Research Australia, *Submission 41*, p. 9.

77 NHMRC, *Submission 27*, p. 2.

78 NHMRC, *Submission 27*, p. 11.

79 See for example, Ms Natasha Donnelly, *Submission 116*, p. 5; Stillbirth CRE, *Submission 56*, p. 3; Robinson Research Institute, University of Adelaide. *Submission 158*, p. 6; Professor David Ellwood, Co-Director, Stillbirth CRE, *Committee Hansard*, 6 September 2018, p. 11.

80 Stillbirth CRE, *Submission 56*, p. 11.

studies have shown, when a national government takes action, the rate of stillbirth declines.

5.78 The committee acknowledges that the Australian government, through the NHMRC, has recently invested funds in a research project to investigate why the stillbirth rate is so high in Australia, particularly in rural and remote areas, and to seek strategies for prevention. The committee heard evidence, however, that funding for stillbirth research lags behind other areas of health research.

5.79 The committee recognises that Australian stillbirth researchers, clinicians, health professionals, advocacy groups and individuals have been working tirelessly to understand the causes of stillbirth and identify the strategies that will reduce the incidence of stillbirth. Such research is absolutely crucial, but much of this research and investigation into stillbirth cause and prevention is being undertaken with minimal funding provided by government.

5.80 The committee is concerned that stillbirth will continue to be a 'hidden tragedy' if it continues to be neglected as a national public health issue and is not prioritised in public health research funding.

Recommendation 5

5.81 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.**

5.82 Government research funding is currently restricted to three-year cycles. Stillbirth researchers are concerned that such arrangements limit stillbirth research which, because of the nature and complexity of the issue, requires longer-term funding in order to allow for large-scale, multi-disciplinary research to be undertaken and the results used to make improvements in clinical practice and stillbirth prevention strategies.

Recommendation 6

5.83 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.

5.84 One area of particular interest to the committee is the potential for new technologies to identify women at increased risk of stillbirth and other adverse pregnancy outcomes. The committee acknowledges that new wearable technologies may offer women a convenient tool for monitoring a pregnancy, but cautions that the use of such technologies should be balanced against the risk of downplaying the importance of a woman trusting her own instincts and experiences during pregnancy.

5.85 The committee supports the development of a national biobank to enable researchers to have access to a large-scale collection of samples in order to determine causes and early predictors of stillbirth. It considers that the Australian government should give urgent consideration to:

- provision of long-term dedicated funding and support through the MRFF; and
- a review of Human Research Ethics Committee requirements for access to the biobank and sharing of other large repositories of research data relevant to stillbirth research.

Recommendation 7

5.86 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.

Chapter 6

Improving quality of care

6.1 Recent Australian and international research on stillbirths, including inquiries into cases of substandard care, has shown that many stillbirths are preventable and that the number of deaths can be reduced through improved quality of care. According to the Centre of Research Excellence in Stillbirth (Stillbirth CRE), deficiencies in the quality of care in pregnancy and labour are implicated in 20–30 per cent of all stillbirths.¹

6.2 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) stated that the 'model of care directly influences the risk of perinatal death'. Antenatal care, for example, increases the probability that fetal growth restriction (FGR) will be identified before labour.² In 2013–14, women who accessed six or more antenatal visits were associated with a lower stillbirth rate than women who accessed fewer antenatal visits or had not accessed antenatal care at all.³

6.3 Nevertheless, there is no agreement amongst health professionals as to the most appropriate models of care in relation to stillbirth, and several submitters proposed that further research is needed in this area, particularly for women who may be at higher risk of stillbirth.⁴

6.4 This chapter examines quality of antenatal and bereavement care in relation to stillbirth, including culturally and linguistically appropriate models of care.

Continuity of care

6.5 There are different models of care for women in the perinatal period, including hospital clinic care, shared maternity care, team midwifery care, midwifery-led continuity of care, and planned homebirths.

6.6 Continuity of midwifery care is a strong traditional practice in parts of Europe including The Netherlands and Scandinavia. New Zealand has also adopted a midwifery care model, whereby about 80 per cent of women choose a midwife as their lead maternity carer and give birth at home, in a small midwifery-led unit or in a

1 Centre of Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, pp. 4–5.

2 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Submission 17*, [pp. 2–3].

3 Australian Institute of Health and Welfare, *Perinatal Deaths in Australia 2013-2014*, 31 May 2018, p. 30.

4 See for example Australian College of Midwives, *Submission 24*, [p. 10]; Hunter Medical Research Institute, *Submission 36*, [p. 3]; Professor Jane Dahlstrom, *Submission 128*, p. 3.

district or major hospital. Canada is also beginning to invest in employing midwives in hospitals to provide continuity of care.⁵

6.7 Professor Caroline Homer, Distinguished Professor of Midwifery, Centre for Midwifery, Child and Family Health, University of Technology Sydney, estimated that 10 per cent of Australian women receive continuity of midwifery care, while 25 per cent choose private obstetrician-led care. She noted that some hospitals are shifting to the continuity of care model, but these tend to be isolated examples.⁶

We now know from very good research from around the world, half of which was collected in Australia, that midwifery continuity of care will make a difference. If women see the same few midwives throughout their pregnancy, they will know those, usually, women during labour and birth, they will have fewer preterm births, they will be less likely to lose their babies, they will have a much more positive experience, and they will have fewer labour and birth interventions. It is not happening across the country. There are pockets of exemplary practice, but it is not widespread, despite policy at a state level. It is less so at a national level at the moment...I think there's a lack of political mandate, a lack of resourcing and a lack of understanding that continuity of care will save money in the long term.⁷

6.8 Therefore, health care for most pregnant women in Australia is fragmented, resulting in multiple caregivers throughout pregnancy. Ms Annie Butler, Federal Secretary, Australian Nursing and Midwifery Federation, noted that midwifery care models are known to be effective, particularly for women who experience stillbirth.

A 2016 Cochrane review conducted by Sandall et al highlighted that women were less likely to lose their baby before 24 weeks when they received models of midwife-led continuity of care. Midwifery continuity of care models have a strong evidence base in best supporting women with past trauma including stillbirth. Having a known midwife results in women experiencing greater support and decreasing their anxieties and unnecessary use of diagnostics and interventions.⁸

6.9 Some witnesses argued that continuity of care is important throughout pregnancy in building trust and understanding and enabling conversations that include the subject of stillbirth.⁹ The Australian College of Midwives cited research showing

5 Professor Caroline Homer, Distinguished Professor of Midwifery, Centre for Midwifery, Child and Family Health, University of Technology Sydney (UTS), *Committee Hansard*, 8 August 2018, p. 34.

6 Professor Homer, UTS, *Committee Hansard*, 8 August 2018, p. 33.

7 Professor Homer, UTS, *Committee Hansard*, 8 August 2018, pp. 33–34.

8 Ms Annie Butler, Federal Secretary, Australian Nursing and Midwifery Federation, *Committee Hansard*, 9 August 2018, p. 56; Australian Nursing and Midwifery Federation, *Submission 58*, p. 2.

9 For example, Ms Natasha Donnelly, *Committee Hansard*, 8 August 2018, p. 4; Australian College of Midwives, *Submission 24*, [p. 4]; Australian Nursing and Midwifery Federation, *Submission 58*, p. 2; Confidential, *Submission 261*, p. 5.

that a continuity of care model, delivered by midwives, can reduce the rate of stillbirths.¹⁰

6.10 Professor Michael Permezel, Immediate Past President, RANZCOG, considered that a collaborative model of care where midwives and obstetricians work together as a team, rather than 'obstetrician-led' care, is the most effective model for lowering perinatal risk.¹¹ Professor Homer suggested that such a model has been implemented in some places because of local will and enthusiasm as well as political leadership, but she noted that there are lingering issues that present barriers to continuity of care being introduced across Australia.

People always bring up the turf wars between midwives and obstetricians, and I think that's actually less of an issue in public services. Obstetricians generally want to look after complicated women in public services, not normal, straightforward women, and, when they've got complications, they want midwives with them because it enhances the whole care.¹²

6.11 Stillbirth CRE proposed that a review of maternity services should be undertaken, focusing on ensuring that all women have a continuity of care provider, whether a midwife, a GP obstetrician or a specialist obstetrician.¹³

6.12 In this context, Stillbirth CRE noted that it was developing a 'bundle of care' program for Australian hospitals, in partnership with the departments of health in New South Wales (NSW), Victoria and Queensland, Stillbirth Foundation, and Still Aware. The 'bundle of care' program is aimed at:

- improving detection and management of FGR;
- improving awareness and management of decreased fetal movement;
- reducing smoking in pregnancy;
- improving awareness of maternal safe sleeping position; and
- improving decision-making around timing of birth for women with risk.¹⁴

International models

6.13 The 'bundle of care' program is modelled on the United Kingdom National Health Service *Saving Babies Lives* bundle, which identified areas of substandard care and has resulted in a fall in stillbirth rates by one fifth in maternity units where the Care Bundle was implemented. It showed that, when the elements of care were

10 Australian College of Midwives, *Submission 24*, [p. 5].

11 Professor Michael Permezel, Immediate Past President, RANZCOG, *Committee Hansard*, 9 August 2018, pp. 38–39.

12 Professor Homer, UTS, *Committee Hansard*, 8 August 2018, p. 34.

13 Stillbirth CRE, *Submission 56*, p. 10.

14 Stillbirth CRE, "'Bundle of Care": A bundle of care to improve mothers' and babies' health', <https://www.stillbirthcre.org.au/resources/bundle-of-care/> (accessed 8 October 2018).

implemented as a package, greater benefits were achieved at a faster pace than if those improvements had been implemented individually.¹⁵

6.14 The Scottish AFFIRM study is assessing whether rates of stillbirth may be reduced by introducing an interventional package of care. It is aimed at increasing a pregnant woman's awareness of the need to promptly report decreased fetal movements, followed by a care management plan to identify possible placental issues, and timely delivery in confirmed cases.¹⁶

6.15 Whilst there are some good examples of continuity of care to be found, a lack of resourcing and understanding of the social and economic benefits of continuity of care inhibits wider acceptance of the model.

Public versus private health care

6.16 Mrs Doshni Stewart told the committee that a continuity of care model does not appear to be available in public hospitals and that, from the perspective of a pregnant woman, continuity of care is essential because the midwife knows her medical history and is able to implement a care plan taking account of risks.¹⁷

6.17 Dr Michael Gannon stated that many women do not have access to private maternity care, and that further work needs to be done in developing innovative public care models that seek to overcome the mortality gap.¹⁸

6.18 A recent study comparing perinatal mortality between public and private hospital care showed that mortality occurred more frequently in public care, although the disparity was not explained by population differences. Whilst differences in clinical practices seemed to be partly responsible, further research was needed to examine whether the private hospital obstetrician-led continuity of care model would improve outcomes in Australia.¹⁹

6.19 Dr Nisha Khot, a medical practitioner in the public health system, noted that appointments generally last for 15 minutes, and a pregnant woman will generally not

15 Australian Health Ministers' Advisory Council (AHMAC), *Strategic Directions for Australian Maternity Services*, Consultation Paper no. 2, 2018, p. 11.

16 AFFIRM: 'Can promoting Awareness of Fetal movements and Focussing Interventions Reduce fetal Mortality'; see J Norman, S Stock and A Heazell, 'The AFFIRM trial for prevention of stillbirth', <https://www.tommys.org/our-organisation/research-by-cause/stillbirth/affirm-trial-prevention-stillbirth> (accessed 22 October 2018).

17 Mrs Doshni Stewart, *Committee Hansard*, 9 August 2018, p. 15.

18 Dr Michael Gannon, *Committee Hansard*, 10 August 2018, p. 37.

19 N Adams, D Tudehope, KS Gibbons, et al, 'Perinatal Mortality Disparities Between Public Care and Private Obstetrician-led Care: A Propensity Score Analysis', *British Journal of Obstetrics and Gynaecology*, vol. 125, no. 2, January 2018, p. 156, <https://obgyn.onlinelibrary.wiley.com/doi/pdf/10.1111/1471-0528.14903> (accessed 22 October 2018).

see the same doctor for every appointment. She suggested that there should be a process for identifying those who need lengthier appointments.²⁰

6.20 Mrs Tiffany McIntosh considered that the approach to her care in the public system most likely contributed to her baby's stillbirth. When comparing her experience with private care in her two subsequent pregnancies, she concluded that continuity of care with the same doctor had been an important factor in their positive outcomes.

When you're seeing different doctors, you report that you're experiencing a symptom: 'Oh, okay. If it keeps happening, make sure you let us know.' But then, when you go to your next appointment, it's a different doctor.²¹

Rural and regional care

6.21 The burden of stillbirth is borne disproportionately by women in circumstances of socio-economic disadvantage, Aboriginal and Torres Strait Islander families, those living in rural and remote areas, and those who have difficulty in accessing antenatal care.²²

6.22 The lack of continuity of care is particularly acute for women in rural and regional centres, and has been exacerbated by the closure of small rural maternity services forcing pregnant women to travel long distances away from their family in order to receive care with negative impacts on their maternal health and wellbeing. The National Rural Health Alliance reported that:

...to avoid the family distress women in rural and remote areas...do not report pregnancy, avoid antenatal care so they will not be recognised by the system and then present late for care, consequently risks to maternal and fetal health can be missed.²³

6.23 Dr Khot suggested that a model could be introduced whereby a health expert in the city could liaise with local practitioners say, by teleconferencing, rather than the pregnant woman having to travel to a city for care not available in their own locality.²⁴

6.24 Whilst communicating with women via the internet or telephone may not be ideal for those living in rural and remote communities where community-based care and support is desirable, there are circumstances where it may be the best option.

...I think we need to have strong hub-and-spoke models for providing the tertiary care when it's needed. For example, we do telemedicine with Royal

20 Dr Nisha Khot, *Committee Hansard*, 9 August 2018, p. 16.

21 Mrs Tiffany McIntosh, *Committee Hansard*, 9 August 2018, p. 16.

22 Professor Euan Wallace, Carl Wood Professor and Head of Department of Obstetrics and Gynaecology, Monash University, *Committee Hansard*, 9 August 2018, p. 25.

23 National Rural Health Alliance, *Submission 57*, [p. 7].

24 Dr Khot, *Committee Hansard*, 9 August 2018, p. 16.

Darwin, and we're very cognisant of the huge burden that it is for women to travel for a suspected diagnosis of fetal abnormality. Yet if we can either make the diagnosis—or, in many cases, reassure them that there is no abnormality—it saves that family the enormous burden, financial and emotional, of having to travel to one of the major centres.²⁵

Culturally appropriate models of care

Aboriginal and Torres Strait Islander families

6.25 The Department of Health's evaluation of qualitative studies in Australia and Canada in 2017 found that the best continuity of care model for Aboriginal and Torres Strait Islander families was one where there were strong community links and control by Aboriginal and Torres Strait Islander communities. It recommended that mainstream services such as GPs and public hospitals should 'embed cultural competence into continuous quality improvement'.²⁶

6.26 The Stillbirth CRE reported that it has established an Indigenous Advisory Group which, while still finalising its terms of reference, aims to develop strategies to prevent stillbirth, provide better information about choices, and culturally appropriate models of care for Aboriginal and Torres Strait Islander women and families. The expectation is that it will have Indigenous leadership and work in a partnership model, build capacity amongst Aboriginal and Torres Strait Islander staff in maternity care, and advise on culturally appropriate models of care to prevent stillbirth.²⁷

Closing the gap in stillbirth rates

6.27 Stillbirth CRE noted that culturally relevant strategies needed to be developed in partnership with Aboriginal and Torres Strait Islander researchers and communities, recognising that pregnancy 'is a key window to address the intergenerational impacts of racism, trauma and disadvantage'. Specific areas highlighted for attention included early and adequate antenatal care for Aboriginal women to ensure health and social issues are addressed early and supported with appropriate models of care; infection prevention and control; smoking-cessation programs; and obesity (and nutrition) strategies.²⁸

6.28 A 2014 study of stillbirth rates amongst Aboriginal and Torres Strait Islander and non-Indigenous women in Queensland made similar findings.

25 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology; Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, *Committee Hansard*, 9 August 2018, p. 26.

26 Department of Health, *Evidence Evaluation Report: Models for Aboriginal and Torres Strait Islander Women's Antenatal Care*, 16 May 2017, p. 4.

27 Stillbirth CRE, *Submission 56.1*, [p. 1].

28 Stillbirth CRE, *Submission 56*, [p. 13].

High-quality antenatal care at all levels using culturally appropriate service delivery models that incorporate diabetes management, smoking cessation, STI screening and treatment, folic acid and fetal growth monitoring hold some promise of helping to improve pregnancy outcomes for Indigenous women.²⁹

6.29 Professor Craig Pennell, Chair of the Red Nose National Scientific Advisory Group, noted that Red Nose has invested \$17.6 million into research into stillbirth and Sudden Unexpected Death in Infancy (SUDI) over the past 40 years and, for the past decade, the organisation has had Indigenous representation on the advisory group and has been working to build relationships with Indigenous leaders and experts to create cultural change in relation to managing stillbirth and SUDI risks.³⁰

6.30 An evaluation of models undertaken for the Department of Health in relation to Aboriginal and Torres Strait Islander women's antenatal care concluded that a number of culturally appropriate care programs have been implemented around Australia, with positive outcomes.

6.31 The Aboriginal Maternal and Infant Health Service established in NSW to improve the health of Aboriginal women during pregnancy, for example, delivered a continuity of care model where midwives and Aboriginal health workers collaborated to provide a high-quality maternity service that is culturally sensitive, women-centred, and provided in partnership with Aboriginal people.³¹

6.32 The evaluation also found positive and cost-effective improvements to maternity care in a Northern Territory regional centre, where a midwifery group practice was introduced to provide continuity of care for women from remote communities who were transferred to the centre for antenatal care and birth. The practice resulted in women being more engaged with the health services through their midwives.³²

6.33 Ms Sara Potter, Clinical Nursing Midwife, Maternity Ward, Katherine Hospital, noted that many of the women who attend the Katherine Hospital to give birth can live up to 600 kilometres from Katherine, much of it on unsealed road. She stated that the hospital supports a collaborative care model for providing antenatal care.

29 I Ibiebele, M Coory, FM Boyle, et al, 'Stillbirth Rates Among Indigenous and Non-Indigenous Women in Queensland, Australia: Is the Gap Closing?', *British Journal of Obstetrics and Gynaecology*, vol. 122, no. 11, August 2014, p. 1481, <https://obgyn.onlinelibrary.wiley.com/doi/epdf/10.1111/1471-0528.13047> (accessed 19 September 2018).

30 Professor Craig Pennell, Chair, National Scientific Advisory Group, Red Nose, *Committee Hansard*, 9 August 2018, pp. 22–23.

31 Department of Health, *Evidence Evaluation Report*, pp. 3–4.

32 Department of Health, *Evidence Evaluation Report*, p. 4.

What we strive for is a seamless approach or, for the women, a seamless journey. That's looking at the origin of the antenatal care when they're coming in to us, and, when they go home back to their community or back to their local Aboriginal Medical Service that may well be a local service, that collaboration is then looking at the integration, coordination, and sharing of information between those health services.³³

6.34 Dr Megan Cope, Senior Medical Officer, Wurli-Wurlinjang Health Service, confirmed the value of this team approach to antenatal care provided in partnership with the Katherine Hospital.³⁴

Birthing on Country

6.35 *Birthing on Country* (BoC), a model of Indigenous maternity care operating in Canada for several decades, was first introduced in Australia in 2013. In 2016 a BoC maternity services program was launched as a partnership between the Australian College of Midwives, the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM), the University of Queensland and the University of Sydney. BoC is a community-driven solution to Closing the Gap, focusing on reducing the stillbirth rate and improving the general health and wellbeing of Aboriginal and Torres Strait Islander women.³⁵

6.36 BoC was tailored to an urban setting in Queensland known as *Birthing in Our Community* (BiOC). It is conducted by the Mater Mothers Hospital in Brisbane, in partnership with two local Aboriginal Community Controlled Health Services—the Institute for Urban Indigenous Health and Aboriginal and Torres Strait Islander Community Health Service, Brisbane Limited.

6.37 There is no specific training for stillbirth and bereavement care in the BiOC program, although this is currently being discussed with Stillbirth CRE. BiOC aims to bring birth back to community and country, and offer safe and culturally appropriate maternity services for Aboriginal and Torres Strait Islander mothers and babies.³⁶

33 Ms Sara Potter, Clinical Nursing Midwife, Maternity Ward, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 8.

34 Dr Megan Cope, Senior Medical Officer, Wurli-Wurlinjang Health Service, *Committee Hansard*, 5 September 2018, p. 2.

35 Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM), *Submission 263*, pp. 4–5; Australian College of Midwives, 'Ground breaking Indigenous maternity services program *Birthing on Country* launched, 8 November 2016, <https://www.midwives.org.au/news/ground-breaking-indigenous-maternity-services-program-birthing-country-launched> (accessed 23 October 2018).

36 Mater Mothers, *Closing the Gap: Birthing in Our Community*, <https://www.matermothers.org.au/mothers-news/news/february-2018/closing-the-gap-birthing-in-our-community>; Institute for Urban Indigenous Health, *Birthing in Our Community (BiOC) Partnership*, http://www.iuih.org.au/Services/Child_and_Maternal_Health#birthing (accessed 2 October 2018); see also Stillbirth CRE, *Submission 56*, p. 13; Mater Misericordiae Ltd, answers to questions on notice, 6 September 2018 (received 14 September 2018).

The BiOC model of care facilitates the development of trusting and respectful relationships with known members of the multi-disciplinary team (including social workers and psychologists) which supports individualised and responsive care.³⁷

6.38 Research amongst Aboriginal and Torres Strait Islander communities indicates that women believe birthing on country will improve maternal and perinatal health outcomes, even though this challenges the Western concept of health care which focuses on medical technologies and medico-legal liability. The researchers have concluded that there needs to be a better understanding of the social, cultural and spiritual risk of not birthing on country.

Indigenous women have stated that their relationship to the land is compromised by birthing in hospitals where many also feel culturally unsafe. Women also express a belief that the relationship between the new baby, siblings and father would be better if they were together for the birth. The health of Aboriginal and Torres Strait Islander Australians is integrally linked to their culture and the land, a link that is strengthened by birthing on their land. Enforced evacuation to distant hospital facilities breaks this link, precludes the presence of family and integration of traditional attendants and practices; and continues cultural disconnection into the next generation.³⁸

Culturally and linguistically diverse families

6.39 Most research and data related to stillbirth tends to focus on the mainstream population. However, 34.6 per cent of mothers who experienced stillbirth were born in countries other than Australia (see Chapter 2).

6.40 Some researchers raised the importance of culturally safe health care practices, whereby carers are required to reflect on how their own culture, history and biases might influence the care they deliver to culturally and linguistically diverse (CALD) families. However, it was acknowledged that few health professionals understand or receive specific training in this area.³⁹

37 Dr Michael Beckmann and Maree Reynolds, Mothers Babies & Women's Health Services, Mater Misericordiae Ltd, answers to questions on notice, 6 September 2018 (received 14 September 2018). Key aspects include an Indigenous governance framework and 24/7 midwifery care in pregnancy to six weeks postnatal care by a named midwife supported by Indigenous health workers and an Indigenous team coordinator.

38 S Kildea and V Van Wagner, *'Birthing on Country' Maternity Service Delivery Models: A Rapid Review*, Sax Institute, March 2013, p. 14.

39 See for example, Ms Karel Williams, Committee Member, Australian College of Midwives, *Committee Hansard*, 7 September 2018, p. 30; Dr Joanne Walker, Director Policy and Strategy Development, National Rural Health Alliance, *Committee Hansard*, 7 September 2018, p. 35; Angela Brown, 'Midwives' and Aboriginal and Torres Strait Islander women's experiences with cultural care in the birth suite: an interpretative phenomenological investigation', PhD thesis, University of South Australia, 6 May 2016, pp. 19–20.

6.41 The Multicultural Centre for Women's Health recommended culturally and linguistically appropriate health care, education and support that include bilingual health workers and culturally appropriate health education activities and participatory approaches.⁴⁰

6.42 Dr Jasmin Chen, Research and Executive Officer with the Multicultural Centre for Women's Health, argued that there is a need to listen to mothers and their families from non-English speaking countries to understand why pregnant women are less likely to access antenatal care in their first trimester.

...we also need to hear and amplify the voices of migrant and refugee women within research and education...we need to listen to mothers and families. We need to let people tell their stories.⁴¹

Mothers of South Asian origin

6.43 Professor Euan Wallace, Carl Wood Professor and Head of Department of Obstetrics and Gynaecology, Monash University, described how changes to clinical practice at Monash Health had helped to reduce stillbirth in women born in South Asia. The hospital observed a significant increase in pregnancies amongst women of South Asian origin from about 2009 corresponding to the increase in South Asian students studying at nearby Monash University. Importantly, they accounted for all the stillbirths at the hospital.

6.44 Researchers noted that the increase in stillbirth risk at the end of pregnancy happened much earlier in women of Indian or South Asian descent than in other Australian women. This finding resulted in the introduction of a new guideline of care in which the women at risk were offered an earlier intervention than was standard practice. There have been no stillbirths in South Asian women at term since then.⁴²

6.45 These findings suggest that care guidelines need to be tailored to particular women whose risks may differ from the majority, and points to the need for more research on stillbirth in relation to ethnicity.

What's fascinating about the work is that women of South-East Asian descent—so Chinese, Vietnamese, Cambodian—have a 40 per cent lower risk of stillbirth than white Australian women, and we don't know why. It goes to Sue's point that to solve stillbirth we need discovery research. We need to understand why Indian babies are at high risk of stillbirth and why Chinese babies are at lower risk of stillbirth. We don't know.⁴³

40 Dr Jasmin Chen, Research and Executive Officer, Multicultural Centre for Women's Health, *Submission 70*, pp. 2–4.

41 Dr Chen, Multicultural Centre for Women's Health, *Committee Hansard*, 9 August 2018, p. 50.

42 Professor Wallace, Monash University, *Committee Hansard*, 9 August 2018, p. 29.

43 Professor Wallace, Monash University, *Committee Hansard*, 9 August 2018, p. 30.

6.46 A more detailed understanding of specific risk factors, combined with more granular data and standardised collection of data across Australia, could help stillbirth researchers to create a tailored program of pregnancy care and timing of delivery in the same way that Monash has successfully done with ethnicity.⁴⁴

6.47 Mrs Stewart reported that, as a woman of South Asian background, her pregnancy was around two to three weeks shorter than that of Caucasian women and that the medical staff involved in her care seemed unaware of this prior to her stillbirth.

This has serious implications for the management of women and their unborn babies, with potentially dire consequences. With a huge influx of migrants in Australia, there should be adequate management of racially based health markers to identify groups at risk and to alter their care plan accordingly. My recommendation, firstly, is that there be a system to alert all those caring for pregnant women to any new research that may be relevant to their work. Secondly, I recommend that, very early in pregnancy assessment, mothers be placed in appropriate risk groups and their care plan be put in place so that decisions or recommendations are met strictly in conjunction with the associated known risks.⁴⁵

Support for bereaved families

6.48 Several voluntary services offer support for bereaved families following miscarriage, stillbirth or the loss of a baby, including Red Nose, Post and Antenatal Depression Association, and Stillbirth and Neonatal Death Support (Sands Australia). Sands Australia, for example, provides peer-to-peer bereavement support with different types of services provided to suit different needs, including in-hospital bereavement care.⁴⁶

6.49 Mrs Lyndy Bowden, Caretaker CEO of Sands Australia, emphasised the importance of timely and accurate data to ensure that bereavement services are targeted appropriately and available for bereaved families in the longer term, 'because when your baby dies you don't forget'.⁴⁷

We have an older-loss group. Sometimes we will have someone who is in their 70s and doesn't know where their baby is buried. Sometimes they don't

44 Professor Susan Walker, Melbourne Academic Centre for Health, *Committee Hansard*, 9 August 2018, p. 30. See above for discussion of the Stillbirth CRE 'bundle of care' program being developed for Australian hospitals.

45 Mrs Stewart, *Committee Hansard*, 9 August 2018, p. 8.

46 Mrs Janelle Marshall, General Manager Services, Sands Australia, *Committee Hansard*, 9 August 2018, p. 3; Sands: Miscarriage, stillbirth and newborn death support, <http://www.sands.org.au/>. See also The GroundSwell Project which aims to create a cultural shift in the way Australians respond to death and grief, <http://www.thegroundswellproject.com/> (all accessed 10 October 2018).

47 Mrs Lyndy Bowden, Caretaker CEO, Sands Australia, *Committee Hansard*, 9 August, p. 2.

even know what the sex of their baby was. We can walk them through how they can get that information. And they also look for that support. For some people it's the first time they've ever said the baby's name to someone. We're finding a lot of parents that are calling up or coming to the support group saying, 'I wish I'd known about you when our baby first died.' Because sometimes it's a couple of weeks, a couple of months or a couple of years. When they leave the hospital and go home, there's nothing in that space if they don't know about us.⁴⁸

Hospitals and health centres

6.50 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP), recalled working in a rural centre where there was more of a team approach to assisting bereaved families, noting that this is more difficult to achieve in busier hospitals and in a 'fractured health system' that does not provide coordinated health care for individuals.⁴⁹

6.51 Some hospitals have adopted strategies to ensure that hospital staff are aware of bereaved parents and families that have experienced a stillbirth so that they 'adjust their demeanour appropriately' when caring for them.⁵⁰ Strategies include flagging a stillbirth record in the hospital system, and placing a butterfly—the universal symbol of stillbirth—on the doors of suites where the baby has been stillborn, or on the cot of a surviving baby to indicate a multiple pregnancy where a sibling has been stillborn.⁵¹

6.52 Several witnesses and submitters reported significant differences in the standard of bereavement care received from their respective hospitals.

...the hospital staff were outstanding in their support and compassion. We had the best of care and were allowed as much time as needed to stay with Coralie. We were provided with a refrigerated cuddle cot and given a private room away from the maternity ward. They further supported us with pastoral care, bereavement support, memory boxes and keepsakes and provided crucial advice on funeral arrangements and Centrelink payments.⁵²

...

When my daughter was stillborn in 2002, the staff admitted they did not want to believe that she had died in utero, so convinced themselves that it was her heartbeat they were monitoring. The bereavement support we

48 Mrs Bowden, Sands Australia, *Committee Hansard*, 9 August, p. 4.

49 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP), *Committee Hansard*, 8 August 2018, p. 50.

50 Ms Terri Ryan, *Submission 124*, [p. 2].

51 Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 50.

52 Mrs Stewart, *Submission 229*, [p. 4].

received following her birth was terrible, the staff were uncomfortable and didn't know how to look after us.⁵³

...

We wanted to make special mention of the compassionate acts of the midwives who assisted with Magnus' birth, their kindness and professionalism was outstanding, I will never forget the midwife who stayed to support me even though her shift had finished. She just stayed to hold my hand. The hospital provided bereavement midwife was on leave when Magnus was born but she was helpful and supportive when she returned from leave and got in contact.⁵⁴

...

Three weeks after my daughter passed away, I received a call from the hospital saying that my daughter was due for a vaccination as she had not received it. I had to inform the person calling that I had a stillbirth and hence the call did not apply to me. This was not right. I should not need to have explained to the hospital that my daughter had died, the same hospital where I gave birth and where they registered my daughter's death.⁵⁵

6.53 Concern was also expressed about the lack of privacy in hospitals for those experiencing stillbirth. Parents about to knowingly experience stillbirth are likely to be further traumatised by being placed in a labour ward with mothers who have given birth to live babies. Ms Alex Lowe stated:

...I knew that I had to go to hospital to birth my daughter and was admitted along with mothers who had live babies. I could hear their labour cries and the babies crying. Our room was silent.⁵⁶

6.54 Some witnesses praised the support received from the Integrated Support After Infant Loss (iSAIL) clinic, which was established with private funding and offers coordinated meetings between the bereaved parents and clinicians or health professionals in the immediate period after stillbirth. Whilst that service is not available in many hospitals, it was considered a valuable model of care that should be available for everyone.⁵⁷

They were fantastic in coordinating people to meet with us if we wanted to see a particular specialist or ask questions. Anything that we requested we felt that we had that opportunity. So I do think that we were particularly

53 Ms Natasha Donnelly, *Submission 116*, p. 5.

54 Name withheld, *Submission 136*, [p. 4].

55 Name withheld, *Submission 12*, [p. 3].

56 Ms Alex Lowes, *Submission 78*, [p. 2].

57 Ms Britt Jacobsen, *Committee Hansard*, 8 August 2018, p. 8; Mr Samuel Haldane, *Committee Hansard*, 8 August 2018, p. 2; Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 50.

fortunate that we received very good care afterwards, but, from what I understand, that's not the norm.⁵⁸

6.55 Dr Gordon established the iSAIL clinic in the Sydney local health district. She stressed the importance of a custom-designed clinic providing continuity in care for bereaved parents so that they do not have to repeat their story to different people. She also highlighted the need to involve parents in the death review process.⁵⁹

6.56 Other submitters and witnesses offered a range of suggestions for improving the level of care and support in hospital for bereaved parents and their families following a stillbirth. These included:

- providing bereaved families with access to an appropriate private space in which to say goodbye to their baby and to receive support from a specially-trained person;⁶⁰
- providing a 'cuddle cot' (a cooling device placed into the cot), enabling parents to have more time with their deceased baby and giving them the opportunity to make necessary decisions regarding autopsy and test procedures;⁶¹
- providing bereaved families with the opportunity to discuss the stillbirth and related issues in a follow-up consultation with clinicians or other health professionals, including the results of any post-mortem investigation; and giving parents the opportunity to acknowledge the hospital staff involved;⁶² and
- ensuring that the information and terminology used when communicating with bereaved parents experiencing a stillbirth is accurate. In one case the bereaved parents were told they had lost a son and only discovered that their baby was a girl from the autopsy report. The invoice they received from the hospital was also insensitive, identifying the stillbirth as an 'abortion'.⁶³

Returning home from hospital

6.57 Hospitals also need to have strategies in place to care for bereaved families after they have returned home. Stillbirth CRE considered that there needs to be better integration of hospital and community services following stillbirth, so that bereaved

58 Ms Jacobsen, *Committee Hansard*, 8 August 2018, p. 8.

59 Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 50.

60 Ms Alex Lowes, *Submission 78*, [p. 2]; Ms Ryan, *Submission 124*, [p. 2].

61 Mr Haldane, *Committee Hansard*, 8 August 2018, p. 4; Ms Stephanie Vowles, *Submission 101*, [p. 3].

62 Mrs Leanne Smith, *Committee Hansard*, 8 August 2018, p. 62.

63 Tim and Leanne Smith, *Submission 77*, [p. 2].

parents receive appropriate support when they transition from hospital to community care.⁶⁴

6.58 Another witness expressed concern about the lack of follow up care from the hospital after they returned home. However, she was full of praise for the care she received whilst at the hospital, and highlighted the importance of bereaved parents receiving timely information and support.

We were given a beautiful memory box to take home which we will always treasure. The box also contained a book from Pregnancy Loss Australia, with lots of information about giving birth to a stillborn baby, creating memories, services like Heartfelt and information about online support groups. I wish this book would have been given to me earlier, before my daughter was born. I found out about lots of services and ways to create memories when it was already too late. The two only photos we have of our daughter, apart from the hand and feet ones the midwives took, are from the pathology in South Australia and I cannot express how grateful I am for those.⁶⁵

Listening to bereaved parents

6.59 One important facet of training for clinicians and other health professionals concerns how to listen to bereaved parents and encourage them to contribute their personal knowledge and experience following a stillbirth. As Mrs Clare Rannard explained:

...in the aftermath I feel a great sense of frustration that I knew the story best, it happened to my body, I lived through the days and hours leading up to this event and I remember it very clearly, yet I was never asked to tell my version of events...It's also quite intimidating to face up continually to specialist consultant doctors who have the experience and the knowledge to explain things away. You feel small and you feel alone and unsupported on the other side of the table against medical hierarchy.⁶⁶

6.60 Ms Terri Ryan pointed to the long-term consequences for women who do not raise their concerns and subsequently experience a stillbirth:

No person is more qualified to tell a woman what is going on with her body than the mother. Too often women are ignored when they raise concerns. We have full medical insurance. The question becomes what harm would it have done to place me under observation and monitor the baby for 24 hours? 12 hours? I will forever feel the weight of NOT speaking up, being too complicit and trusting, not asking for more to be done.⁶⁷

64 Stillbirth CRE, *Submission 56*, p. 11.

65 Julia and Debden Whaanga, *Submission 108*, pp. 2–3.

66 Mrs Clare Rannard, *Committee Hansard*, 8 August 2018, p. 8.

67 Ms Ryan, *Submission 124*, [p. 1].

6.61 The experience of a stillbirth commonly results in significant emotional stress in subsequent pregnancies and postnatal anxiety and depression. Indeed, research suggests that women who have experienced a stillbirth have a five-fold increased risk of stillbirth in subsequent pregnancies.⁶⁸ As one witness described it:

The stress and anxiety of the pregnancy took a severe physical and mental toll on me. I would lay awake at night monitoring Obie's movements, I would have panic attacks and late-night rushes to emergency because I thought something was wrong. It was exhausting and terrifying. I wouldn't buy baby items or set up a nursery—I was convinced I would lose another baby (it was all I'd ever known). I would see my doctor for fortnightly and then weekly ultrasounds and fought tooth and nail for an early induction.⁶⁹

Bereaved fathers

6.62 Several witnesses noted that bereaved fathers are often overlooked in the provision of advice, education and support. The implication is that they should be able to cope with the loss while providing support for their partner. As one submitter put it:

Although support for bereaved mothers needs improvement, there is barely any support for a bereaved father. Men need hand holding through this trauma too.⁷⁰

6.63 Sands Australia reported that bereaved fathers' grief responses may be quite different to those of bereaved mothers, in that they may feel that they need to be strong and supportive and put their own grief on hold. They may also feel that their grief is dismissed.⁷¹ One bereaved father explained the need for better education and care for fathers experiencing the stillbirth of their baby.

As a father, I have often felt left behind in this journey and it has often seemed that stillbirth is a women's issue. Listening to parts of yesterday's session in Sydney, I rarely heard about the impact on dads. I rarely hear dads mentioned and, invariably, we seem to get lumped in with families and partners. I am saddened to see, as I look at the committee, that there is no male presence either. One of the most important things that was said to me after the loss of our son was by our midwife, who came into our room and said, 'You won't understand this now, but you will in time: hello, mum and dad.' At the time, it seemed like a bizarre statement. As dads, we carry our own grief and, too often, we put this aside to support our partners. We are told to be strong for our wife, for our partner, for our families; we are usually asked how the wife is and rarely are we asked how we are. I can't recall the last time someone called me to see how I am doing. There is little research into the impact of stillbirth on dads, and dads seem to be resistant to attending support groups and seeking counselling. We need to find a way

68 Stillbirth CRE, *Submission 56*, p. 12.

69 Samantha and Aaron Isfahani, *Submission 121*, p. 4.

70 Ms Natasha Hulse, *Submission 211*, p. 9.

71 Mrs Marshall, Sands Australia, *Committee Hansard*, 9 August 2018, p. 5.

to engage dads in a way that will support them in our grief journey. Engaging in conversations around stillbirth that seem to imply that stillbirth is women's issue doesn't help; we have had our loss as well.⁷²

6.64 Ms Kate Obst, a researcher at the University of Adelaide, reported on recent studies into the psychological impact of pregnancy loss on men. She noted that bereaved fathers received variable levels of support, but a consistent theme was a lack of recognition of their experience, either by the healthcare system and workplaces upon return to work, or amongst family, friends and the community.⁷³ Ms Obst suggested a range of strategies for more male specific and informal support options, including male support workers in hospitals and 'more blokes on pamphlets' to normalise support for men affected by stillbirth.⁷⁴

6.65 Mr Adam Flanagan suggested that innovative approaches such as 'wilderness therapy' might help grieving fathers. He noted that a large proportion of couples break up after a loss, and that grieving men need ways to address their anger, regret and pain. He suggested that men may find it easier to interact and disclose their experiences and needs through shared activity, 'shoulder to shoulder rather than face to face'.⁷⁵

Bereaved siblings and grandparents

6.66 Antenatal education and post-stillbirth care tends to focus on the needs of the mother, but there has been little attention given to the experiences of bereaved siblings, grandparents and other family members. Emerging research suggests that educational programs about stillbirth are required and need to be tailored to their needs.⁷⁶

6.67 The PriceWaterhouseCoopers study found that there were significant flow-on effects of a stillbirth for other children, grandparents, extended family and friends (see Chapter 3).

Siblings and grandparents in particular were affected negatively by stillbirth. Some family members sought counselling to deal with the negative effects: 'My Father in law was very sad & depressed by the stillbirth of his first grandchild. So much so that he sought counselling'; 'My mum was highly affected by the loss...She was her first grandchild and she really struggled to be there for me as her grief was so intense...'; 'Parents on both sides were profoundly impacted and depressed, some had

72 Mr Bruce McMillan, *Committee Hansard*, 9 August 2018, p. 9.

73 Ms Kate Obst, PhD/Master of Psychology (Health) Candidate, School of Psychology, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 17.

74 Ms Obst, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 17.

75 Mr Adam Flanagan, *Submission 122*, p. 2.

76 Ms Kate Obst, Dr Clemence Due and Dr Melissa Oxlad, *Submission 28*, [pp. 1–2]; Ms Vowles, *Submission 101*, [p. 10].

to seek therapy...'; '...my best friend was put on anti-depressants. All my friends rallied around us and it had financial and mental impacts on many people'.⁷⁷

6.68 Studies conducted at the University of Adelaide have found that, whilst grandparents are very often the first people to be called upon to support the bereaved parents, most have no knowledge or experience of stillbirth. Researchers noted that many experienced a lack of recognition of the 'overwhelming and long-lasting' grief of stillbirth, and noted the lack of information about support services that may be available for bereaved grandparents.⁷⁸

6.69 Other children in the family are also likely to be deeply affected by the stillbirth of a sibling, and may need support and counselling to help them with their grief. Julia and Debden Whaanga described the long-lasting impact on their family.

Our two children are still grieving for their little sister and had lots of behavioural changes after the loss of our daughter. It would have been very helpful to have information about children and grief on hand from day one.⁷⁹

Culturally appropriate bereavement care

Aboriginal and Torres Strait Islander families

6.70 Aboriginal and Torres Strait Islander women in Australia experience twice the rate of stillbirth as non-Indigenous women (see Chapter 2), yet their experiences of stillbirth are often overlooked. CATSINaM noted that there are no specific guidelines or policies on bereavement care for Aboriginal and Torres Strait Islander Australians, and recommended that guidelines should be developed as part of culturally safe maternity care services, consistent with the BoC model of care.⁸⁰

6.71 Evidence suggests that bereavement support for Aboriginal and Torres Strait Islander women experiencing stillbirth needs to be tailored to their particular circumstances, given that they often come from different places and speak different languages.

They are absolutely suffering with the highest rates of stillbirth, yet they're overlooked, and I think that's a huge cry for help. So this issue needs funding, counselling services and, to repeat what Jane said, major reform of

77 PriceWaterhouseCoopers, *The Economic Impacts of Stillbirth in Australia*, September 2016, p. 15.

78 Dr Melissa Oxlad, Lecturer, School of Psychology, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 17.

79 Julia and Debden Whaanga, *Submission 108*, [p. 5].

80 CATSINaM, *Submission 263*, p. 5.

not just midwives but midwifery students, medical students and doctors—they don't do this well.⁸¹

6.72 For bereaved families there may be particular cultural or religious sensitivities in relation to autopsies and the timing of burial. Ms Potter pointed to a general lack of understanding in the health profession about how Aboriginal and Torres Strait Islander people view stillbirth, bereavement and care after their babies are born. She noted that particular care needs to be taken to provide stillbirth education that is for the whole community rather than focusing just on educating women.

As a health professional and from my experience, I'm not sure that we, as care providers, have a comprehensive understanding of what Aboriginal people see as a stillbirth, what their feelings are around stillbirth and, therefore, what their ideas would be around bereavement and care after their babies are born. To have knowledge around that would be invaluable. I don't think we do at the moment.⁸²

6.73 In 2017 the Townsville Hospital and Health Service and James Cook University commenced a study to address the gap in fetal autopsy rates for Aboriginal and Torres Strait Islander and non-Indigenous stillbirths. The study was undertaken in recognition of the higher rates of stillbirth for mothers in the Aboriginal and Torres Strait Islander population (13.3 stillbirths per 1000 compared to 7.1 deaths per 1000 for non-Indigenous mothers), and lower rates of fetal autopsy observed in Queensland (28.5 per cent of Indigenous parents consent to autopsy following stillbirth compared to 38.9 per cent for non-Indigenous parents). The aim was to explore culturally appropriate ways to approach Aboriginal and Torres Strait Islander families for consent to autopsy following stillbirth and develop guidelines for health care providers.⁸³

6.74 Preliminary results indicated an autopsy rate of 25 per cent for Aboriginal and Torres Strait Islander women in the study, which is well below the overall rates in Queensland and other states. It summarised the reasons women and families declined an autopsy as follows:

- not asked in a culturally appropriate manner;
- not enough time to think about giving permission; and
- not wanting baby 'cut up'.⁸⁴

81 Mrs Rachelle Martin, *Committee Hansard*, 10 August 2018, p. 10.

82 Ms Potter, *Committee Hansard*, 5 September 2018, p. 9.

83 Queensland Health, 'Stillbirth study aims to help close the gap', *Media release*, 14 August 2017; Department of Neonatology/Maternal Fetal Medicine, The Townsville Hospital and Health Services, *Submission 44*, [p. 2].

84 Townsville Hospital and Health Services, *Submission 44*, [p. 4].

Culturally and linguistically diverse families

6.75 Professor Pennell noted that one in three women who give birth in Australia are born outside of Australia while the rate of stillbirth amongst such women is double and even triple that of Australian-born women, depending on their background. He argued that stillbirth education needs to be better targeted to meet their particular needs.⁸⁵

6.76 Dr Clemence Due, Senior Lecturer, School of Psychology, University of Adelaide, noted that pregnancy loss and stillbirth impacts on a range of groups, but that there is very little research into the role of grief and support following stillbirth for men and women from CALD backgrounds in Australia.

In summary, while we know something of the needs of heterosexual women following stillbirth, there remain very large gaps in our knowledge concerning the psychological impact and support needs of nearly all other people impacted by a stillbirth, and we would advocate for further research for these groups to ensure that whole families are supported in the event of a stillbirth.⁸⁶

6.77 The 2018 Victorian Parliamentary Inquiry into Perinatal Services found that support for CALD communities is variable and dependent upon the availability of local services. It heard evidence about how women from CALD communities and refugee communities face particular disadvantages and barriers in accessing perinatal services as a result of:

- social isolation and vulnerability to developing mental health conditions during the perinatal period;
- difficulty in receiving support and services needed;
- difficulty communicating and navigating health and social services;
- inexperience of health professionals in working with CALD families; and
- insufficient use of interpreters to support women during consultations and in hospital.⁸⁷

6.78 Some programs in Australia are being designed to meet the needs of people from CALD backgrounds. For example Stillbirth CRE, in partnership with stillbirth research and advocacy groups, has begun a program which gives migrants and refugees access to face-to-face support visits with interpreters and information translated into community languages.⁸⁸

85 Professor Pennell, *Committee Hansard*, 9 August 2018, p. 19.

86 Dr Clemence Due, Senior Lecturer, School of Psychology, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 16.

87 Parliament of Victoria, *Inquiry into Perinatal Services: Final Report*, Family and Community Development Committee, June 2018, p. 321.

88 Australian College of Nursing, *Submission 20*, pp. 4–5.

6.79 Dr Chen reported that the Multicultural Centre for Women's Health specialises in providing bilingual outreach health education for women. She pointed out that the trauma of stillbirth is compounded for mothers and their partners whose primary language is not English, and who may not have the support networks of family and friends in Australia. Dr Chen highlighted that there is limited stillbirth education and advocacy available for them, in part because of the culture of silence surrounding stillbirth and the lack of funding for translating educational materials in culturally appropriate ways.

6.80 Dr Chen discussed the Centre's success in conducting bilingual outreach programs on other health issues, and argued that partnerships involving mothers and parents as co-researchers, leaders and experts are likely to deliver the most effective and meaningful stillbirth education campaigns and initiatives.⁸⁹

For example, in an unrelated project that I worked on, on palliative care, we went out and did focus group work with five different communities to try and understand more about their thoughts about grief and grieving, their ideas about health as well, and how that might affect the messages that we delivered to them and the approaches that we took. I think that probably goes a long way to explaining why this hasn't been really discussed through our service. It may be that it has been in other services but we're quite unique, in terms of the work that we do.

Committee view

6.81 Women experiencing socio-economic disadvantage, Aboriginal and Torres Strait Islander families, those living in rural and remote areas, and women from CALD backgrounds who may have difficulty in accessing antenatal care are more likely to experience stillbirth in Australia.

6.82 The rate of stillbirth for Aboriginal and Torres Strait Islander babies is unacceptably high, and requires a focused national effort to address the contributing factors. The committee acknowledges the importance of birthing on country in delivering community driven solutions. It is now widely recognised that the best continuity of care model for Aboriginal and Torres Strait Islander families is one where there are strong community links and control by Aboriginal and Torres Strait Islander communities. Providing culturally appropriate continuity of care for Aboriginal and Torres Strait Islander communities is therefore a high priority.

6.83 International initiatives, such as the mandatory government requirement in Scotland for clinicians to discuss fetal movement and stillbirth with all pregnant women at antenatal appointments from 20 weeks' gestation, have been successful in reducing stillbirths and provide a valuable model for creating a cultural change in relation to stillbirth in Australia (see Chapter 7).

89 Dr Chen, Multicultural Centre for Women's Health, *Committee Hansard*, 9 August 2018, pp. 50–51.

6.84 As part of this cultural change, mainstream health and hospital services should be encouraged to embed cultural competence in their protocols and training for clinicians and other health professionals.

Recommendation 8

6.85 The committee recommends that, through the Australian Health Ministers' Advisory Council, the Australian government leads a process to develop a national culturally and linguistically appropriate continuity of care model aimed at reducing the rate of stillbirths in Australia, particularly amongst groups identified as having a higher risk of stillbirth.

6.86 The Department of Health should contribute to this process by undertaking a review of Australian and international models of culturally and linguistically appropriate care, and identify examples of best practice that have successfully reduced the incidence of stillbirth amongst Aboriginal and Torres Strait Islander women, women from rural and remote regions, and women from CALD communities.

6.87 Given the high rate of stillbirth amongst women from Indigenous backgrounds, bereavement care guidelines need to be developed with public hospitals and health centres, in consultation with local communities, to ensure that they are culturally and linguistically appropriate and embedded within a cultural safety framework and consistent with the BoC model of care.

6.88 Successful programs of bereavement care are already available in some hospitals, such as the iSAIL clinic which offers coordinated meetings between the bereaved parents and clinicians or health professionals in the immediate period after stillbirth. However, culturally appropriate bereavement support services should be available for all parents who have experienced stillbirth, and such services should be better integrated with community services so that bereaved parents receive appropriate support when they transition from hospital to community care.

6.89 The preliminary findings of the 2017 study undertaken by Townsville Hospital and Health Service and James Cook University indicated reasons for low autopsy rates amongst Aboriginal and Torres Strait Islander families, and these findings should be taken into account when preparing guidelines for culturally appropriate bereavement support in hospitals and health centres.

6.90 The committee acknowledges that a lack of resources limits the capacity for hospitals to locate and work with Aboriginal and Torres Strait Islander parents who have experienced a stillbirth, and notes that some may be transient or live hundreds of kilometres from the health service.

Recommendation 9

6.91 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.**

Chapter 7

Stillbirth education

7.1 The committee received evidence from many parents and family members who described the devastating emotional impact of being told that their baby would be stillborn.

7.2 The pain and grief may last a lifetime, compounded by inadequate information about the risks, the personal and financial implications, and the social stigma that continues to keep the tragedy of stillbirth in the shadows.¹

7.3 This chapter discusses the need for better stillbirth education of families, clinicians and other health professionals, hospitals, workplaces and the community generally.

A hidden tragedy

7.4 Mr Gavin Youngman, Director, Stillbirth Foundation Australia, described the contrast between public perceptions of pregnancy and the reality of those who experience stillbirth.

...it's not discussed, so I don't understand how we think we can go from having that lack of conversation even in those intimate circles to all of a sudden—when you're told, you feel completely alone.²

7.5 Several witnesses described how societal attitudes to death underpin the silence and stigma surrounding stillbirth:

We're not very good at talking about deaths in general in Australia and so the taboo around speaking about the death of a baby is a whole other element. Babies dying is somehow treated differently in all of our society including that coroners don't get to look in on that because they're not really seen as real people yet.³

...

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- 1 Jessica Longbottom, 'Decades after stillbirths, long-grieving parents find answers in mass graves', *ABC News*, 7 October 2018, <http://www.abc.net.au/news/2018-10-07/parents-stillborns-mass-graves-melbourne/10344252> (accessed 16 October 2018); V Flenady, AM Wojcieszek, P Middleton, et al, 'Stillbirths: Recall to Action in High-Income Countries', *The Lancet*, vol. 387, no. 10019, 13 February 2016, p. 691, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)01020-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)01020-X/fulltext) (accessed 12 November 2018).
 - 2 Mr Gavin Youngman, Director, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 16.
 - 3 Mrs Jaime Yallup Farrant, *Committee Hansard*, 10 August 2018, p. 7.

Our society finds it very difficult to talk about death and finds it very difficult to talk about intense emotion, and the death of a little baby or a child is such a painful and confronting area for people.⁴

...

When I've spoken to friends of ours who are obstetricians and I've asked, 'Are you using the Still Aware stuff?' they have said, 'Well, you know, it doesn't happen that often.' That's not the answer we want to hear. How we get past that, how we deal with bereavement, how we deal with grief, how we deal with asking for help and how we deal with taking help on board is a stigma in Australia, and I think we need to look beyond it.⁵

7.6 One witness described how her stillbirth was met with silence and 'hushed condolences'.

Instead of feeling included, I felt a strong sense of being kept in the dark at arm's length. How can I trust a patriarchal healthcare system with a future pregnancy when it appears to prioritise silence over transparent communication?⁶

7.7 Ms Natasha Donnelly, a bereaved parent, researcher and advocate, argued that the 'paternalistic approach' to antenatal care contributes to a lack of awareness of stillbirth amongst women, and to feelings of shame and guilt amongst those who experience it. She urged clinicians and health professionals to be more open about stillbirth, citing the example of airline safety briefings that are presented to passengers on every flight, even though the risk of a crash occurring is extremely low.

Most passengers don't run off the plane screaming in fear that because it was discussed, it's going to happen. But we assume that women will do that if stillbirth is discussed. We desperately need a public awareness campaign and improvements to antenatal education to address this.⁷

7.8 One submitter expressed the importance of sharing the stories of families who have experienced stillbirth.

Learning how to be a mother to a child who never got to live is a horrible path to walk, but our children being acknowledged, and us being heard in the hope to help to make a change in their name and potentially save other babies and break the silence surrounding stillbirth is a small...piece of comfort.⁸

7.9 Dr Michael Gannon drew attention to the irony that women in developing countries with no organised maternity care are far more aware of the risk that they or their baby could die, whereas Australians tend to take their maternity care system for

4 Ms Deborah De Wilde, Volunteer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 15.

5 Mrs Rachele Martin, *Committee Hansard*, 10 August 2018, p. 9.

6 Mrs Clare Rannard, *Committee Hansard*, 8 August 2018, p. 3.

7 Ms Natasha Donnelly, *Committee Hansard*, 8 August 2018, p. 2.

8 Ms Zoe Marshall, *Submission 109*, [p. 8].

granted so that stillbirth or neonatal death is 'at least out of sight and potentially out of mind'.⁹

Public awareness campaigns

7.10 Public awareness campaigns such as Red Nose Day have been highly successful in raising public awareness, helping to reduce Sudden Infant Death Syndrome (SIDS) deaths by 85 per cent in Australia.¹⁰ However, even though stillbirth is statistically more common than SIDS, it is rarely discussed in public contexts.

7.11 Associate Professor Camille Raynes-Greenow, a public health specialist at the University of Sydney, cautioned that, whilst there is merit in a public awareness campaign, the emphasis should be on reducing the risk and not just providing information. She added that such a campaign should be evidence-based, inclusive, tailored to suit specific settings, and aimed at women who are likely to be at the greatest risk of stillbirth.¹¹

7.12 Nevertheless, as one bereaved parent noted, there is a widely-held perception that stillbirth only occurs in high-risk pregnancies, indicating that stillbirth education should be aimed at all women, regardless of risk.

Our naive understanding of stillbirth was that it was something that only happened in high-risk pregnancies, and that these families knew that there was a risk for their baby. We had researched many aspects of pregnancy and birth, but we had not researched stillbirth because we believed it was not a risk for us. As we have now learnt, many normal, healthy pregnancies like ours also end in stillbirth.¹²

7.13 Contrary to popular thinking, greater awareness is likely to reduce the incidence of stillbirth rather than create undue stress.

There is a feeling of not wanting to cause alarm or 'scare monger' women who are doing everything they can to bring a healthy child into the world. There is a feeling of not wanting to put too much responsibility on mothers since many cases are unavoidable. There is a fear of causing too much anxiety. My response to this is the example of SIDS. A terrifying thought for any new parent, however we are educated thoroughly and properly on the risk factors (from waiting room posters, to Parent Ed classes to midwife visits). The education on SIDS has not caused mass hysteria or anxiety, it has reduced rates.¹³

9 Dr Michael Gannon, *Committee Hansard*, 10 August 2018, p. 41.

10 Red Nose, *Submission 63*, p. 3.

11 Associate Professor Camille Raynes-Greenow, School of Public Health, University of Sydney, *Committee Hansard*, 8 August 2018, pp. 53–54.

12 Britt Jacobsen and Samuel Haldane, *Submission 82*, [p. 2].

13 Caroline Campbell and Kirk von Mollendorf, *Submission 80*, [p. 2].

7.14 Several witnesses and submitters called for a government-funded public campaign aimed at pregnant women so that they can be better educated about the risk of stillbirth and techniques for identifying and monitoring potential issues. Suggestions included:

- advice that pregnant women know their baby's movements, sleep on their side, trust their instincts and expect to be listened to when they have concerns;
- the distribution of pamphlets about stillbirth at antenatal appointments and classes such as the information provided by the organisation Still Aware, using clear, non-technical language in information and guidelines and avoiding medical terms such as 'fetal demise' and acronyms that most people will not understand; and
- information about mobile apps that enable pregnant mothers to monitor their babies' movements similar to the Australian government's 'Quit for You—Quit for Two' App released in 2013.¹⁴

7.15 Still Aware highlighted the importance of using clear terminology and language in educational materials, rather than acronyms and technical language which serve to perpetuate the lack of awareness and discussion about stillbirth.¹⁵

7.16 Mr Terry Slevin, Chief Executive Officer of the Public Health Association of Australia, drew on his extensive experience to outline the elements of conducting an effective national public health campaign but noted that, whilst Australia is internationally recognised for its public health campaigns, the financial investment in these programs is generally inadequate to meet the costs.¹⁶

7.17 Mr Slevin advised that such a campaign should be not only properly researched and implemented, but also appropriately funded over the longer term, in order to have a societal impact:

...if you think about any of those campaigns, whether in the skin cancer area, with Slip! Slop! Slap! or in HIV and the famous Grim Reaper campaign, those got attention to the issue; but there's been an awful lot of hard graft that's followed those things, and it's the hard graft that makes the difference.¹⁷

14 See for example, Ms Nerida Box, *Submission 105*, [p. 1]; Rebecca and Paul Dixon, *Submission 74*, [p. 2]; Name withheld, *Submission 252*, [p. 3]; Name withheld, *Submission 140*, [p. 1]; Meg and Shane Keating, *Submission 249*, [p. 2]; Mrs Rhonda Jeavons, *Submission 106*, [pp. 1–2]; Ms Kirsten Willis, *Submission 251*, [p. 2]; Ms Rebecca Barclay, *Submission 86*, [p. 2]; Ms Alex Lowes, *Submission 78*, [p. 1]; Ms Sarah Matheson, *Submission 237*, [p. 4]; Ms Caitlin Cvitkovic, *Submission 97*, [p. 2]; Mrs Claire Foord, Chief Executive Officer and Founder, Still Aware, *Committee Hansard*, 8 August 2018, p. 42; Mrs Bree Amer Wilkes, *Submission 22*, [p. 2].

15 Mrs Foord, Still Aware, *Committee Hansard*, 8 August 2018, p. 42.

16 Mr Terry Slevin, Chief Executive Officer, Public Health Association of Australia (PHAA), *Committee Hansard*, 7 September 2018, p. 46.

17 Mr Slevin, PHAA, *Committee Hansard*, 7 September 2018, p. 50.

7.18 Mr Slevin stressed that a public awareness campaign focusing on stillbirth is more likely to be effective if it not only identifies the problem but also offers the solution. It should also be delivered through different channels so that it will target particular audiences.

When it comes to issues of stillbirth, it is a really powerful and highly emotive issue. I think that with the right demographic it has the impact of having an emotional, and therefore likely, behavioural response that makes people more prepared to take up the practical advice you provide as to how they tackle obesity, or smoking cessation, or alcohol consumption or whatever it might be. So the issue gets embedded into the call for influencing people's behaviour in a healthy way.¹⁸

Education for families

7.19 Recent Australian and international research has shown that many stillbirths are preventable and that the number of deaths can be reduced through greater awareness and improved quality of care.¹⁹

7.20 Antenatal education is provided in a variety of ways and by a range of organisations and individuals, often on a fee-paying basis, and there is currently no standardised curriculum or content guidelines meaning that such education is generally not accessible to those without the means to pay.

7.21 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, described how the silence surrounding stillbirth during pregnancy poses challenges for educating families.

I would say it's probably the biggest hurdle that we face at the moment in regard to the issue. In the time that I've been with the Stillbirth Foundation, the very first thing that nine out of 10 families that come to us ask is, 'Why wasn't I ever told this was a possibility?' As was referred to before, we are told not to eat soft cheese and all of these different things, yet the issues arising from those particular behaviours are far less common than stillbirth. One in every 135 pregnancies in Australia will end in stillbirth. It's not spoken about. For nine out of 10 families to not even know that that is a possibility is astounding.²⁰

7.22 Ms Bowring estimated that the rate of stillbirth in Australia could be reduced by one-third if two of the biggest risk factors were common knowledge amongst pregnant women, clinicians and other health professionals.

Research indicates that, if two of the stillbirth risk factors that we are currently aware of—decreased fetal movement and maternal sleep position—were common knowledge among the pregnant population and health clinicians there is potential to reduce the number of stillbirths by up

18 Mr Slevin, PHAA, *Committee Hansard*, 7 September 2018, p. 50.

19 Centre of Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, p. 4.

20 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 13.

to 30 per cent...The sleep position, particularly, which we're working on at the moment through a public health campaign, has the potential to reduce that risk by up to 10 per cent, and just in Australia alone that's 200 babies a year.²¹

7.23 Dr Gannon, who reflected on his extensive experience in the area of stillbirth prevention, noted that he tended to avoid directly mentioning stillbirth to his patients, unless the discussion was 'remote from the delivery date'.

I will usually talk to them at 36 weeks about the increased frequency of visits, about the importance of reporting decreased fetal movements and the reasons why I will want them to give permission for them to be scheduled for induction of labour not long after 40 completed weeks or sometimes before 40 weeks. I will refer in bleak terms to it being safer for the baby. So even someone like myself who understands the issue and possibly should call [it] out is reluctant to use the word. There remains a taboo about it.²²

7.24 Similarly Professor Steve Robson, President, Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), found it difficult to discuss the issue of stillbirth with his patients.

There's an increasing recognition that perhaps people have been afraid to tell pregnant people certain things, and stillbirth would be key among them. Even I don't like directly bringing it up. If I'm seeing somebody and we're talking about things and they talk about movements or I do a scan, it's very difficult to say, 'I'm worried that your baby will die.' I often will phrase it: 'I'm anxious here. I would do something. I wouldn't want something to go wrong.' It's very difficult to say that.²³

7.25 Recent international research has shown the value of preconception care in improving pregnancy outcomes. Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute (HMRI) noted that the outcomes of a pregnancy are often good if conditions associated with adverse outcomes, such as low folate, Zinc, vitamin D and iron, are addressed before pregnancy. In the Hunter region, for example, the HMRI team meets each week with every family who has experienced a preterm birth or a stillbirth, and offers them an evaluation and assistance with planning for the future.

Also there is an offer available for preconception care for anyone who wants to have it in pregnancy through the referral system through GPs. That partly encourages GPs to do it, because they can do a lot of it, but for people with more complex issues they need to be referred in.²⁴

21 Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 12.

22 Dr Gannon, *Committee Hansard*, 10 August 2018, p. 41.

23 Professor Steve Robson, President, Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Committee Hansard*, 9 August 2018, pp. 41–42.

24 Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute (HMRI), *Committee Hansard*, 8 August 2018, p. 21.

7.26 Professor Robson also observed that every hospital has a different antenatal education program, and those that do operate do not necessarily provide for culturally and linguistically diverse families.²⁵

International models

7.27 Several witnesses and submitters drew attention to the success of the Scottish education program, Maternity Care Quality Improvement Collaborative, which has created a 'cultural change' in Scotland's medical system around the issue of stillbirth.²⁶ Scotland had one of the highest rates of stillbirth in Europe. In 2011 the Scottish government invested \$7.1 million over four years to implement a package that has seen a 22 per cent reduction in stillbirths in a population of 60 000 births.²⁷

7.28 Ms Danielle Pollock, Stillbirth Researcher and Bereaved Parent representative, Global Stillbirth Advocacy Network, summarised the reason for its success:

It actually seems so simple when you break it down. It was just educating pregnant women. It was not being afraid to mention the word 'stillbirth'. They got rid of the anxiety myth, which has absolutely no evidence for it.²⁸

7.29 The initiative was based on the successful program implemented in the Netherlands in 2001, which resulted in a 55 per cent reduction in stillbirths over 14 years. It is based on the concept that, whilst the risks of stillbirth are well known, 70 per cent of mothers of stillborn babies have no significant medical condition. The stillbirth prevention package includes five elements:

- a tailored patient education campaign with clear messaging that stillbirth can happen to anyone and some are preventable;
- implementation of a new package to reduce smoking in pregnancy across all maternity units in Scotland;
- raise awareness for reduced fetal movement;
- risk assessment and fetal surveillance for fetal growth restriction (FGR); and
- implementing a new Perinatal Mortality Review Tool.²⁹

7.30 Red Nose noted that it has been offered the new Perinatal Mortality Review Tool, developed for the Scottish Program and recently adopted by the United

25 Professor Robson, RANZCOG, *Committee Hansard*, 9 August 2018, p. 41.

26 Mrs Yallup Farrant, *Committee Hansard*, 10 August 2018, p. 7; Red Nose, *Submission 63*, p. 4; Ms Danielle Pollock, Stillbirth Researcher and Bereaved Parent representative, Global Stillbirth Advocacy Network (GSAN), *Committee Hansard*, 8 August 2018, pp. 63–64.

27 Red Nose, *Submission 63*, p. 1.

28 Ms Danielle Pollock, GSAN, *Committee Hansard*, 8 August 2018, pp. 63–64.

29 Red Nose, *Submission 63*, p. 4.

Kingdom (UK), for evaluation in a clinical setting as part of the Red Nose Stillbirth Prevention Program.³⁰

7.31 Red Nose estimated that the cost of rolling out the Scottish package in Australia would cost \$37 million over four years (\$9.3 million annually), resulting in 1218 fewer stillbirths during implementation, and 500 babies' lives saved per year thereafter.³¹

Education for clinicians and other health professionals

7.32 Ms Donnelly noted that clinicians are required to stay up-to-date on a wide range of issues, and may have limited time to discuss research on stillbirth with pregnant women during their appointments.³² However, while FGR is widely understood to be a major risk factor for stillbirth, there is still a need for clinicians to educate women in this area.

Most pregnant women can recite the foods they should avoid during pregnancy and that they should avoid alcohol but most women have no idea that their baby's movements shouldn't slow down at the end of pregnancy or that they should avoid sleeping on their back. Most women have no idea that their baby is far more likely to be stillborn than to die of SIDS, but most know to sleep their baby on their backs with no head covering or toys in the bed.³³

Antenatal monitoring

7.33 Several witnesses drew attention to the need for better education and training of sonographers to enable them to identify potential health issues during routine scans in pregnancy. Some reported discrepancies in the way that test results were reported by sonographers and clinicians.³⁴

7.34 Mrs Doshni Stewart, for example, received conflicting information about her baby's measurements from the sonographer and the obstetrician. She also noted that medical staff involved in her care seemed unaware of research from other countries that revealed how people from certain ethnic backgrounds had a shorter gestation period, even though the information was readily available on the internet.³⁵

7.35 Mrs Tiffany McIntosh experienced severe itchiness at 32 weeks, and was told that it was hormonal. After losing her baby, she discovered an online fact sheet about cholestasis of pregnancy identifying what action should have been taken. However,

30 Red Nose, *Submission 63*, p. 10.

31 Red Nose, *Submission 63*, p. 7.

32 Ms Donnelly, *Committee Hansard*, 8 August 2018, p. 6.

33 Ms Natasha Donnelly, *Submission 116*, p. 5.

34 See for example, Ms Jasmine Prowse, *Submission 256*, p. 4; Mrs Doshni Stewart, *Committee Hansard*, 9 August 2018, p. 11; Mrs Tiffany McIntosh, *Committee Hansard*, 9 August 2018, p. 12; Mrs Lyndy Bowden, Caretaker Chief Executive Officer, Sands Australia, *Committee Hansard*, 9 August 2018, p. 6.

35 Mrs Stewart, *Committee Hansard*, 9 August 2018, p. 11.

she claimed that the clinicians involved in her care were unaware of the diagnostic tests that were required at the time.

No medical professionals around me spoke about the fact that your baby could die before it's born. And even in the birthing class I attended they tell you to look out for symptoms like swelling, high blood pressure, reduced movement—nothing about itching, but furthermore, nothing about the fact that some of these symptoms can lead to stillbirth. So I think we still have a lot of people who haven't started a family yet that are simply unaware that that could happen to them, and when they're told about these symptoms in pregnancy have no idea of exactly what the adverse outcome can be.³⁶

7.36 One witness suggested that this problem could be addressed by establishing an online stillbirth research and education 'clearinghouse', bringing together domestic and international research in an accessible way for clinicians, health professionals and the general public.³⁷

7.37 The National Health and Medical Research Council (NHMRC) noted that the Centre of Research Excellence in Stillbirth (Stillbirth CRE) has been developing a Fetal Growth Restriction Program, a clinical face-to-face training program for health professionals designed to improve detection and management of women at risk.³⁸

7.38 The HMRI noted that Professor Craig Pennell is currently developing a pre-conception program in Newcastle for every pregnant woman, or a woman planning to have a baby. The program aims to reduce child mortality by improving the health of women before and during pregnancy.³⁹

Bereavement care

7.39 Witnesses who had experienced the trauma of stillbirth described responses from clinicians and other health professionals ranging from empathetic to unhelpful, and highlighted the need for better education about stillbirth amongst those who care for the bereaved parents and their families.⁴⁰

7.40 Ms Deborah De Wilde, Volunteer, Stillbirth Foundation Australia, stated that there are significant issues around the care of bereaved parents that need to be addressed, including the bedside manner and language used by clinicians and other health professionals at a time when bereaved parents are in a state of profound shock and disbelief.

We need to throw a ring of care and support around these people. We need to provide them with service providers who have a high level of communication. We need them to feel that we can give them, as we should, all the time in the world. We need to have people raise those important

36 Mrs McIntosh, *Committee Hansard*, 9 August 2018, p. 12.

37 Name withheld, *Submission 145*, pp. 3–4.

38 National Health and Medical Research Council (NHMRC), *Submission 27*, p. 3.

39 HMRI, *Submission 36*, [p. 7].

40 Ms Michelle Cullen, *Submission 111*, p. 5.

issues about seeing their baby, spending time with the baby, what delivering a baby who has died before it's birth might be like, how that little baby is going to feel in your arm, a parameter for how long you might be with your baby and who else might be invited into what, for me, becomes a sacred site.⁴¹

7.41 One witness noted an obvious lack of empathy and knowledge of basic administrative processes relating to stillbirth amongst some of the medical staff she encountered, both in hospital and at home following the stillbirth.⁴² Another highlighted the long-term impact of stillbirth when appropriate counselling is not provided:

In 14 hours from learning our baby was dead, we were never offered counselling. The midwife tried her best taking ink prints of Nina's hands and feet. She took photographs the best she could. But we needed more and should have been provided with much more. A grief counsellor should have supported us throughout those 14 hours. The guilt I carry with me for not picking her up could have been eased with a grief counsellor.⁴³

7.42 The review undertaken into the unusually high number of perinatal deaths at the Bacchus Marsh Hospital in 2013–14 found that death may have been preventable in seven of the 11 cases. The Wallace Report found that the workforce was inadequately skilled, and recommendations included improved staff education.⁴⁴

7.43 One witness, whose daughter was stillborn during a homebirth, expressed concern that homebirth midwives downplay the risks of stillbirth, and that parents do not have sufficient information about the stillbirth risks associated with homebirth.

Homebirth midwives need to be under stricter onus to correctly communicate the risks of stillbirth to their clients, as well as the limitations of their practice in the home. It is an absolute must, to counter-act the incredible amount of misinformation that is propagated by homebirth advocates.⁴⁵

7.44 Stillbirth CRE noted the need for more resources to support clinicians and other health professionals in caring for bereaved parents:

Providing care after stillbirth is a challenging area of practice for many health care professionals. Education, training, resources and support are critical enablers and organisational support and financial commitment are both required to create the conditions and structures for the implementation,

41 Ms De Wilde, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 15.

42 Ms Marshall, *Submission 109*, [p. 7].

43 Ms Terri Ryan, *Submission 124*, [p. 2].

44 Maurice Blackburn Lawyers, *Submission 69*, p. 7. The report was prepared by Professor Euan Wallace, Carl Wood Professor and Head, Department of Obstetrics and Gynaecology, Monash University.

45 Ms Willis, *Submission 251*, [p. 1].

monitoring and evaluation of best practice care. Training for clinicians in the care of women and families after stillbirth is urgently needed.⁴⁶

7.45 Stillbirth CRE drew attention to the Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) program developed by the Perinatal Society of Australia and New Zealand Stillbirth and Neonatal Death Alliance (PSANZ-SANDA) to provide clinicians and health professionals with appropriate training in managing a stillbirth or neonatal death including investigations, counselling for autopsy, and examining the baby.⁴⁷

7.46 Professor Vicki Flenady, Director of Stillbirth CRE, noted that the IMPROVE program has been well received by clinicians and midwives. The training comprises a half-day workshop conducted in hospitals, community centres or conference venues, and includes all aspects of care, including how to have a conversation about stillbirth. However, she noted that there is no funding provided for this training, and that the educators involved often provide it in their own time.

The only state that's actually putting in money for hospitals to avail themselves of this course is Queensland at the moment. We've had recurrent funding in Queensland for a few years to offset the cost for clinicians to attend. It's quite an expensive workshop, really, for hospitals with limited resources, but that's something we really need upscaled.⁴⁸

7.47 Dr Glenn Gardener, Director of Maternal Fetal Medicine, Mater Health endorsed the IMPROVE program, noting that it has been successful in increasing confidence and knowledge of participants and is being made available internationally.⁴⁹ Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP) proposed that the program could be expanded to provide practical guidance on communicating with bereaved families.⁵⁰

Clinical practice guidelines

7.48 The committee noted that there are currently multiple guidelines to guide clinical practice in relation to pregnancy, stillbirth and neonatal death. None of these guidelines are mandated, so their application is ad hoc and there is little information

46 Stillbirth CRE, *Submission 56*, p. 12.

47 Stillbirth CRE, *Submission 56*, p. 7. IMPROVE was developed to provide training for clinicians and health professionals in using the *Clinical Practice Guideline for Care around Stillbirth and Neonatal Death*.

48 Professor Vicki Flenady, Director, Stillbirth CRE, *Committee Hansard*, 6 September 2018, pp. 16–17.

49 Dr Glenn Gardener, Director of Maternal Fetal Medicine, Mater Health, *Committee Hansard*, 6 September 2018, p. 27.

50 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP), *Committee Hansard*, 8 August 2018, p. 49; see also Perinatal Society of Australia and New Zealand Stillbirth and Neonatal Death Alliance (PSANZ-SANDA), *IMPROVE*, <https://sanda.psanz.com.au/improve/> (accessed 9 October 2018).

on how to implement them.⁵¹ As one witness observed: 'some do it extremely well; others don't'.⁵²

7.49 As noted in Chapter 4, PSANZ-SANDA updated its *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death* in March 2018. It aims to:

...ensure best practice across Australia and New Zealand around the time of a perinatal death to improve maternity and newborn care for bereaved parents and families and to improve the quality of data on causes of stillbirth and neonatal deaths through appropriate investigation, audit and classification.⁵³

7.50 The PSANZ Guideline provides information for effective monitoring to reduce perinatal deaths; increased understanding of causes to further reduce perinatal deaths; better care and outcomes in future pregnancies; and improved psychosocial outcome for parents and families. There are also specific guidelines relating to aspects of antenatal care, including decreased fetal movement.

7.51 Professor David Ellwood, Co-Director of the Stillbirth CRE noted that, whilst there is 'a plethora of guidelines about everything', there are no nationally consistent guidelines.⁵⁴

Guidelines for antenatal care

7.52 In 2005 the Department of Health developed *Clinical Practice Guidelines: Pregnancy Care*, a series of national evidence-based antenatal care guidelines as one of four projects approved by the Australian Health Ministers Conference and Community and Disability Services Ministers Conference. The guidelines, updated in 2018, cover a range of topics including stillbirth, and are intended to assist health professionals who provide antenatal care to healthy pregnant women.⁵⁵

7.53 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne, reported on the success of live-streaming education events to 200 rural and remote sites to enable maternity care providers to be kept informed and connected with current practices and knowledge in relation to stillbirth risk and prevention.

51 Dr Warland, *Committee Hansard*, 8 August 2018, p. 41.

52 Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 12; also see Mrs Foord, Still Aware, *Committee Hansard*, 8 August 2018, p. 41.

53 PSANZ-SANDA, *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*, <https://sanda.psanz.com.au/clinical-practice/clinical-guidelines/> (accessed 14 November 2018).

54 Professor David Ellwood, Co-Director, Stillbirth CRE, *Committee Hansard*, 6 September 2018, p. 12.

55 NHMRC, *Clinical Practice Guidelines: Pregnancy Care*, 2018 Edition, updated 12 February 2018, <https://www.clinicalguidelines.gov.au/portal/2589/clinical-practice-guidelines-pregnancy-care-2018-edition> (accessed 17 October 2018).

They are the ones delivering prepregnancy care and, indeed, they're delivering much of the first half of antenatal care, as many of our public hospitals do not book patients until perhaps 16 to 18 weeks.⁵⁶

7.54 Some state jurisdictions have also produced clinical guidelines. Queensland Health, for example, has a guideline for 'Stillbirth care' as part of its *Maternity and Neonatal Clinical Guidelines*.⁵⁷

Guidelines for bereavement care

7.55 Stillbirth CRE noted that *Respectful and Supportive Perinatal Bereavement Care Guidelines* form part of the larger *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*, and are designed to improve the quality of bereavement care for parents who experience stillbirth or neonatal death.⁵⁸

7.56 Stillbirth CRE also drew attention to the 'Sands Australian Principles of Bereavement Care', and recommended that all major maternity hospitals should establish specialist bereavement care, with outreach services to smaller and regional/rural hospitals.⁵⁹

Support for health professionals

7.57 Several witnesses and submitters discussed the emotional impact that a stillbirth can have on the clinicians and other health professionals involved, noting that there is a need for strategies to care for health professionals and, where necessary, to guide them in handling their grief in the presence of the bereaved families.⁶⁰

7.58 Professor Pennell noted that staff might take leave, or occasionally even leave the profession, after having been involved in an unexpected stillbirth, and reflected on how he had developed his own ways of dealing with the situation.

If I feel like crying, I cry. I have no shame about giving the husbands hugs, sitting there holding their hand while their wife's pushing out their dead baby. But the implications are huge, and to do it repeatedly and see it repeatedly and not to see it change is frustrating, and it drives me into doing what we're doing.⁶¹

56 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne, *Committee Hansard*, 9 August 2018, p. 26. Also see Department of Obstetrics and Gynaecology, The University of Melbourne, *Submission 45*, p. 15.

57 'Stillbirth care', *Maternity and Neonatal Clinical Guidelines*, Queensland Health, March 2018, <https://www.health.qld.gov.au/qcg/publications#neonatal> (accessed 18 October 2018).

58 Stillbirth CRE, *Submission 56.1*, [p. 1].

59 Stillbirth CRE, *Submission 56*, pp. 2 and 12.

60 Mr Timothy Smith, Delegate, Public Service Association of New South Wales (PSA NSW), Community and Public Sector Union New South Wales (CPSU NSW), *Committee Hansard*, 8 August 2018, p. 61; Ms Marshall, *Submission 109*, pp. 2–3.

61 Professor Pennell, HMRI, *Committee Hansard*, 8 August 2018, p. 26.

7.59 Professor Caroline Homer, Distinguished Professor of Midwifery at the Centre for Midwifery, Child and Family Health, University of Technology Sydney, noted the stresses for those who care for a woman giving birth to a stillborn baby, and recommended education programs that help to build resilience in those involved.

One obstetrician told me about scars on his soul. He says, 'Every time something goes wrong, there's like a little scar on my soul. But I have to pick myself up and do it again tomorrow.' But how many scars can you do over time and still provide exemplary care? So I don't think we look after people well enough.⁶²

...

I know that as a midwife, standing outside a door going into a room where there is a woman who is going to give birth to a stillborn baby, you have to take a big breath and think, 'I've got to get this right.' That's quite stressful. You can't rewind it, really. So I think there is silence in the community and also in the professions, and we need to talk about it more, both at an undergraduate level and at the clinical coalface.⁶³

Autopsies and other port-mortem investigations

7.60 For bereaved parents, making a decision about whether to allow an autopsy following stillbirth is a harrowing and unexpected experience. A number of submissions pointed to the difficulties that face parents, families and healthcare providers in approaching the subject of autopsy.⁶⁴

Bereaved parents

7.61 Whilst information brochures are available that may help bereaved families decide whether or not to consent to an autopsy, many families will fear making such a decision or are unwilling to proceed with an autopsy for religious, cultural or other reasons. In one instance, the bereaved parents decided against an autopsy of their baby daughter because they were told it would 'rip her little body apart and probably never find out why'.⁶⁵ In some cases, a baby may need to be transferred to another hospital for the autopsy to be conducted, adding to the stress of the bereaved parents.⁶⁶

7.62 The bereaved parents may also be confronted with the cost of an autopsy or other post-mortem investigation costs associated with the autopsy process, including transporting the baby to the autopsy, travel and accommodation for the parents, and the cost of the autopsy itself (see Chapter 3 for further discussion of the financial

62 Professor Caroline Homer, Distinguished Professor of Midwifery, Centre for Midwifery, Child and Family Health, University of Technology Sydney (UTS), *Committee Hansard*, 8 August 2018, p. 35.

63 Professor Homer, UTS, *Committee Hansard*, 8 August 2018, p. 38.

64 Ms Britt Jacobsen, *Committee Hansard*, 8 August 2018, p. 4; Ms Donnelly, *Committee Hansard*, 8 August 2018, p. 2.

65 Ms Terri Ryan, *Submission 124*, [p. 2].

66 Ms Christine Prosser, *Submission 6*, p. 2.

implications of stillbirth for families). Stillbirth CRE recommended that all parents should have access to a high-quality autopsy service without charge.⁶⁷

7.63 The autopsy process itself can also add to the uncertainty and stress of bereaved parents, particularly where parents are given incomplete information.⁶⁸

Our experience with the autopsy process was also a nightmare. We continually had to chase up the progress and status of the results. Eventually a meeting was scheduled with one of the doctors at the hospital we delivered Evelyn (we had not had any interaction or involvement with this particular doctor until the meeting). The meeting was brief and brutal. The doctor basically said that there was no clear cause of death and then went on to say, “better luck next time”. I was an emotional mess—it was such a cold, quick and heartless delivery of results and I was left full of questions and fears for the future...A few weeks later we were left even more confused when we received a call from ANOTHER hospital to say our autopsy results were ready and they would like to schedule a meeting. Apparently the first meeting we had attended, and the results delivered were based on an incomplete report.⁶⁹

...

We had to go back to the hospital when the autopsy results were completed. It was horrible to sit there with my husband and the ob and a nurse while they talked to us about it. To be honest I wasn't expecting any answers. I think the results took about 7 weeks. I had googled hydrops a lot and there were a lot of causes. I was expecting them to say that it was my fault and I could have done something better. That was how I felt. I felt like it was my fault for whatever reason there was, it didn't matter what had happened but it was my fault. They told us that they found a valve in the heart that hadn't developed properly so the blood wasn't going back through, it was pooling in his heart. This is what caused the hydrops and that i[s] why he died. As much as I try, I can't remember the medical term, I think one day I will ask for records so I can find out what it was called. I did call the hospital to ask but it was really hard to get the information released so I gave up.⁷⁰

7.64 Professor Walker noted that the discussion with parents should not just be about the surgical procedure involved, but it should also convey the importance of obtaining as much information as possible about why the baby died.

I often ask those families, 'Can I spend a little bit of time to try to ascertain what I can about why your baby might have died?' If we had a minimum dataset that recorded biometry, amniotic fluid volume, whether there was any evidence of fetal hydrops—that is, excess fluid accumulation within the baby's body—if there were calcifications noted in the liver or the brain,

67 Stillbirth CRE, *Submission 56*, p. 3.

68 See for example, Ms Donnelly, *Submission 116*, pp. 1–2; Ms Julieanne Carmichael, *Submission 123*, [p. 1].

69 Samantha and Aaron Isfahani, *Submission 121*, p. 3.

70 Name withheld, *Submission 129*, [p. 4].

then these are things whereby, if a family does not have autopsy, at least we might have some signal of why the baby died.⁷¹

7.65 Nevertheless, even an autopsy may never provide an answer for bereaved families, as one witness explained:

Ultimately, it showed that they found nothing, which to me seemed unfathomable. I had given birth to a four-kilogram baby. He looked absolutely perfect. It seemed insane that nobody could tell me, after everything I'd been through—that this had all happened for no apparent reason. In the months that followed after that I think we tried to contact a pathologist to give us some sort of explanation as to what had gone wrong. At the end of the day they couldn't really find anything.⁷²

7.66 These issues highlight the need for bereaved families to be better informed about autopsies, and to be given the opportunity to meet the pathologist performing the autopsy. Nevertheless, parents should also have other options available to them.⁷³

Discussing autopsy after stillbirth

7.67 Educating clinicians and other health professionals about how to have a conversation about a stillbirth autopsy may help bereaved parents to make an informed decision.

7.68 Mr Brad Farrant highlighted the need for clinicians to be better trained to discuss the importance of an autopsy with bereaved parents. He reported that he and his wife were cared for by 'well trained and understanding midwives' who gave them time with their baby and information about the autopsy and review process.⁷⁴ Nevertheless, the cause of the stillbirth could not be determined, highlighting the need for more research. As Mrs Jaime Yallup Farrant observed:

...it's almost like there's an acceptance and a total toleration that this just happens sometimes. People even said that to us: 'It just happens sometimes, and we don't know why'—as if that's okay. And yet in our society we would never accept that for AIDS, for example, or for cancer. If people were dying of cancer and, as clinicians, politicians and a community, we just went, 'You know, it just kind of happens sometimes; sorry and all,' there'd be an uproar. I think that's part of what really needs to shift in this conversation: the toleration that it just happens. Life happens, yes. Death happens, yes. But lots of these cases are actually preventable if we do the work.⁷⁵

7.69 However, the trauma of an unexpected stillbirth may make it especially difficult for a clinician to discuss the issue of autopsy with the bereaved parents.

71 Professor Walker, The University of Melbourne, *Committee Hansard*, 9 August 2018, p. 28.

72 Mrs Martin, *Committee Hansard*, 10 August 2018, p. 7.

73 Professor Walker, The University of Melbourne, *Committee Hansard*, 9 August 2018, p. 28.

74 Mr Brad Farrant, *Committee Hansard*, 10 August 2018, p. 8.

75 Mrs Yallup Farrant, *Committee Hansard*, 10 August 2018, p. 8.

Deciding whether to undertake an autopsy is a harrowing decision for any parent to make at the time of their child's birth, and not something that any of us expected to be doing. So this decision is not made lightly, and it is made in the hope that answers can be found for the child's death, and in the hope that others may also benefit from information identified. It is therefore a travesty when this information is not used as part of perinatal mortality audit, and lessons are not being learnt about how maternity care can be improved to prevent stillbirth.⁷⁶

7.70 Even in cases where the bereaved parents consent to an autopsy, the decision may still be fraught with uncertainty or the results may leave parents with more questions than answers. This situation demonstrates the need for more research into unexplained stillbirths.

I cannot explain why she is dead and I have no way to prevent this from happening again in any future pregnancies. I don't know if anything more than the autopsy and placenta analysis could have been done to try and identify the causes of Hannah's death. I wish that more were done to find out about the causes of stillbirth, about understanding why it happens and about finding ways to prevent this happening to other families. It is inconceivable that for the last two decades there has been no improvement in the rate of stillborn babies, and that in more than 40% of cases the cause of death is unknown. I am not aware of anything I could have done to prevent Hannah's death. I would have done anything in my power to prevent my daughter's death. Had there been more research and investigation into stillbirths, she might still be alive today.⁷⁷

...

We owed it to ourselves, because we would have to live with not knowing, if we didn't pursue that, whether there was perhaps something genetic or something that could affect our future children. We felt not that we didn't have a choice, but that from a medical sense that was something important we needed to pursue. I know that we were very lucky that we did get an answer, but we had a six-week wait to receive that answer. I really struggled with that wait. I'm thinking medically: 'Oh my God; is it this? Is it that?' It was building my anxiety, because I just wanted to know why this had happened. It's also very difficult, when you put your child in their coffin, and you go to re-dress them, to see that they had been cut. Obviously that is done with the utmost respect, but it's very difficult to see your child like that, and I can understand that many parents just can't do it. But, in moving forward, we need to talk to parents about how important it is to do these post-mortems and to do more research. That way we can figure out why this is happening. There are so many people that just don't get an answer. There have to be answers out there; we just don't know what they are yet.⁷⁸

76 Ms Donnelly, *Committee Hansard*, 8 August 2018, pp. 2–3.

77 Name withheld, *Submission 12*, [p. 2].

78 Mrs Shannon Cook, *Committee Hansard*, 10 August 2018, pp. 7–8.

7.71 Bereaved parents need to be confident that the information gathered in an autopsy will be available to stillbirth researchers so that, ultimately, the results might help prevent future stillbirths.

[Had I] had more time to take every ounce of my experience into consideration, and to understand the real value in proceeding with an autopsy, my decision would have been different...it is absolutely necessary and paramount that medical professionals engaged in this type of scenario are equipped enough to navigate parents and families to really raise awareness as to why conducting autopsies and examinations is so important.⁷⁹

7.72 One witness expressed concern that bereaved parents were not asked for information about their own observations and experiences in the lead up to the stillbirth, noting that such information may help to inform the results of the investigation. In her own situation, Ms Britt Jacobsen and her partner had consented to an autopsy because they not only wanted answers but also hoped that the information yielded might help other families.⁸⁰

7.73 Professor Euan Wallace, Carl Wood Professor and Head, Department of Obstetrics and Gynaecology, Monash University noted that, following the inquiry into perinatal deaths at Bacchus Marsh, Victoria had established a dedicated perinatal autopsy service. However, he also noted that there are a limited number of sites where such autopsies are undertaken, meaning that a stillborn baby may have to be taken to another hospital for autopsy before being returned to the bereaved parents, adding to the trauma and cost for parents.⁸¹

7.74 Dr Gordon pointed out that a perinatal autopsy service in Victoria included a skilled coordinator as the first point of contact for a bereaved family in the hospital, and offered a useful model for how an autopsy might be discussed with bereaved families in a culturally and linguistically sensitive manner.⁸²

7.75 Still Aware, Australia's only not-for-profit organisation dedicated to raising awareness of stillbirth, provides information for clinicians and parents about stillbirth both online and at public events, promoting open dialogue about the realities of loss 'in order to break the silence and taboo surrounding stillbirth' and empowering parents to be actively involved in monitoring their pregnancy. Contrary to being confronted by autopsy information, Still Aware found that women and their partners were generally grateful to receive it.⁸³

They know that they will get a full report. They know will go through what happened. If we have done any sort of clinical investigations or root cause

79 Ms Michelle Cullen, *Submission 111*, p. 4.

80 Ms Jacobsen, *Committee Hansard*, 8 August 2018, p. 9.

81 Professor Euan Wallace, Monash University, *Committee Hansard*, 9 August 2018, p. 28.

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

83 Still Aware website, <http://stillaware.org/about-us/> (accessed 27 September 2018); Mrs Foord, Still Aware, *Committee Hansard*, 8 August 2018, p. 40.

analyses they know they'll get feedback from those. Our hope is that in the future we'll also be able to engage families in the review of their baby's death, as well as be feeding back the information about the review. That's one of the things that have happened in the UK. The Each Baby Counts program has very much tried to involve parents in the death review process—not just giving them the results in a coordinated fashion, but getting their story to add to the events that surrounded the baby's death. If that happens, that would be amazing.⁸⁴

7.76 Professor Flenady noted that the IMPROVE program includes a 'whole station...about how to have that conversation and the importance of the autopsy examination', although the lack of funding for the program has restricted its application.⁸⁵

7.77 Dr Gordon stated that there are other options available to clinicians and parents, apart from full autopsies. These include minimally invasive autopsies, a post-mortem MRI scan, an external examination by a skilled perinatal pathologist, in addition to a placental examination which is considered vital for every stillbirth.⁸⁶

7.78 Where an autopsy is not conducted, placental investigation can still yield important information about the stillbirth. As Dr Diane Payton, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australasia stated:

A detailed knowledge of placental pathology is also required, as the placenta is vital for the wellbeing of the infant during intrauterine life and placental pathology is being increasingly correlated with intrauterine deaths.⁸⁷

7.79 Associate Professor Kerry Ireland-Jenkin, Head of Unit, Victorian Perinatal Autopsy Service (VPAS) described the placenta as the 'black box flight recorder' of pregnancy. She argued that a placental examination should be undertaken in all perinatal autopsies following stillbirth, and noted that VPAS had recently conducted a course to update pathologists and pathology registrars from Australia and New Zealand on the guidelines for placental pathology.⁸⁸

84 Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 47.

85 Professor Flenady, Stillbirth CRE, *Committee Hansard*, 6 September 2018, p. 19.

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

87 Dr Diane Payton, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australasia, *Committee Hansard*, 6 September 2018, p. 38.

88 Associate Professor Kerry Ireland-Jenkin, Head of Unit, Victorian Perinatal Autopsy Service (VPAS), *Committee Hansard*, 7 September 2018, pp. 16–17.

Protocols for stillborn babies held in hospital morgues

7.80 The committee heard disturbing evidence about six stillborn babies of Aboriginal descent who had remained in the morgue at the Katherine Hospital, Northern Territory, for a number of years.⁸⁹

7.81 Ms Sara Potter, Clinical Nursing Midwife, Maternity Ward, Katherine Hospital, noted that the mothers may be transient or live hundreds of kilometres from the health service, and the difficulty for hospital staff in knowing how to manage these circumstances, even when the families were able to be contacted.⁹⁰

7.82 Ms Potter highlighted the lack of resources available for locating and working with bereaved Aboriginal and Torres Strait Islander parents, and noted that there may also be financial issues for the parents themselves. Until recently there was only one funeral service provider in the Katherine area, and they charged \$4000 for a service.⁹¹

7.83 However, the Stillborn Baby Payment was inadequate to cover the high cost of a funeral service in Katherine, and there were no other funeral services operating in the town at that time.⁹²

7.84 Ms Belinda Jennings, Senior Midwifery Advisor, Policy and Practice, Katherine Hospital, reported that a baby might remain in the morgue for several months while culturally appropriate arrangements are made for a funeral service. She described how a model of 'satellite care' can be used in cases of perinatal loss, where a midwife will arrange for care of the family to be transferred to a primary health care provider, although she acknowledged that this is difficult where the parents live in remote communities.⁹³

7.85 State and territory policies relating to babies held in morgues vary across jurisdictions. In the Australian Capital Territory and Queensland, for example, there is no legislation governing storage time for bodies held in a hospital morgue, although in the ACT a social worker is required to follow up with families if no communication has been received concerning the release of a body after three business days from the date of admission.⁹⁴ There is no time limit for holding a body in Tasmanian or South

89 Ms Sara Potter, Clinical Nursing Midwife, Maternity Ward, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 10.

90 Ms Potter, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 10.

91 Ms Potter, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 10. See Chapter 3 for further discussion of costs associated with bereavement services.

92 Ms Potter, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 10.

93 Ms Belinda Jennings, Senior Midwifery Advisor, Policy and Practice, Katherine Hospital, *Committee Hansard*, 5 September 2018, pp. 13–14.

94 Australian Capital Territory government, answers to written questions on notice, 24 September 2018 (received 22 October 2018); Queensland government, answers to written questions on notice, 21 September 2018 (received 19 November 2018).

Australian morgues, although provision is made in Tasmania for a basic funeral service under the Unclaimed Deceased Person Policy.⁹⁵

Culturally appropriate education

7.86 Inclusive, culturally appropriate education is important, particularly for families from culturally and linguistically diverse backgrounds including migrants and refugees. The NHMRC has stated that:

All Australians have the right to access health care that meets their needs. In our culturally and linguistically diverse society, this right can only be upheld if cultural issues are core business at every level of the health system-systemic, organisational, professional and individual.⁹⁶

7.87 Drawing on his experience as a member of the Western Australian (WA) Perinatal and Infant Mortality Committee, Dr Gannon noted that there was a need to address the particular circumstances of the diverse groups affected by stillbirth, and argued that the current PSANZ guidelines are inadequate and should be reviewed in the light of recent research into perinatal mortality.

Gaps do exist between women having their babies in rural areas and metropolitan areas. Gaps exist between Aboriginal and Torres Strait Islander women and non-Indigenous women. Gaps exist between culturally and linguistically diverse women and non-CALD women. And there are very real gaps between public and private hospitals. The greatest opportunity would be to construct a prospective study of women who have suffered a stillbirth and measure the perinatal maternal and psychological outcomes in their subsequent pregnancy.⁹⁷

7.88 The Multicultural Centre for Women's Health recommended that educational materials on stillbirth be delivered to migrant and refugee women via:

- bilingual peer support and education initiatives, particularly for newly-arrived women;
- culturally appropriate multilingual resources and education materials developed in consultation with communities and migrant women who have experienced stillbirth; and

95 Tasmanian government, answers to written questions on notice, 24 September 2018 (received 9 October 2018); South Australian government, answers to written questions on notice, 24 September 2018 (received 19 October 2018). See also Northern Territory government, answers to written questions on notice, 21 September 2018 (received 5 October 2018); Western Australian government, answers to written questions on notice, 24 September 2018 (received 26 October 2018); New South Wales government, answers to written questions on notice, 21 September 2018 (received 28 November 2018).

96 NHMRC, *Cultural Competence in Health: A Guide for Policy, Partnerships and Participation*, 2006, cited in Western Health, *Submission 48*, p. 2.

97 Dr Gannon, *Committee Hansard*, 10 August 2018, p. 37.

- referrals to antenatal care provided by an appropriately qualified workforce trained to deliver culturally responsive care.⁹⁸

Educational materials for Aboriginal and Torres Strait Islander communities

7.89 The WA Reducing the Risk of SIDS and Sleep Accidents in Aboriginal Communities program, introduced in 2005, is a culturally appropriate campaign in language. A similar pilot campaign has been undertaken in Victoria in English.⁹⁹

7.90 Red Nose made a decision not to translate its education materials into every First Nation language, on the basis that there are over 250 language groups in Australia. Instead, the organisation decided to translate them into the four most prevalent languages apart from English, and to develop education programs in more meaningful ways, in consultation with senior community health professionals and Indigenous elders who participated in the advisory group. The material is pictorial based and culturally appropriate.¹⁰⁰

7.91 Stillbirth Foundation Australia reported that it had moved to writing and distributing stillbirth research findings for Aboriginal and Torres Strait Islanders in a culturally appropriate manner and ensuring the correct use of language.¹⁰¹

Education for employers and work colleagues

7.92 Some submitters and witnesses drew attention to the need for better education designed for employers and work colleagues, particularly to provide information and guide them in supporting an employee who is returning to work after experiencing the trauma of stillbirth.¹⁰²

7.93 Mrs Jackie Barreau reported on her experience of returning to work, and noted a campaign being conducted by Sands (Stillbirth and Neonatal Death Charity) in the UK called *Finding the Words*, which seeks to assist employers to talk with a bereaved employee following a stillbirth.

My experience of workplace support by my employer was adequate and empathetic, but I was not prepared for the overwhelming grief that I experienced most days. My fellow work colleagues were supportive, although some were not sure what to say or what to do.¹⁰³

98 Multicultural Centre for Women's Health, *Submission 70*, pp. 4–5.

99 Mrs Jane Wiggill, Manager, Health and Advocacy, Red Nose, *Committee Hansard*, 9 August 2018, p. 23; Red Nose, *Keeping Bub Safe*, https://rednose.com.au/downloads/RROSIAC_brochure.pdf (accessed 2 October 2018).

100 Red Nose, answers to questions on notice, 9 August 2018 (received 14 September 2018).

101 Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 16.

102 See for example, Ms Alex Lowes, *Submission 78*, [p. 2]; Name withheld, *Submission 145*, p. 4; Ms Jennifer Thomas, *Submission 168*, [p. 2].

103 Mrs Jackie Barreau, *Submission 215*, [p. 2]; Sands (UK), *Finding the Words*, <https://www.sands.org.uk/get-involved/sands-campaigns/finding-words> (accessed 23 October 2018).

Committee view

7.94 Efforts to reduce the rate of stillbirth in Australia must begin with Australians being better informed about stillbirth and encouraged to acknowledge stillbirth in public conversations. There is no doubt that the culture of silence that surrounds stillbirth in Australia significantly adds to the emotional trauma experienced by bereaved families.

7.95 This silence reflects a broader lack of public awareness about the incidence and impact of stillbirth, and results in extended families, friends, work colleagues as well as people in the wider community being unprepared or unable to talk about stillbirth. In turn, this reinforces the profound grief and sense of social isolation experienced by bereaved parents. The issue is exacerbated by the fact that the current model of care for pregnancy and birth tends to normalise birth and seeks to reduce fears about the risks involved. Indeed, there appears to be a greater fear about stillbirth relative to other risk factors in pregnancy and birth that are, statistically, less likely to occur.

7.96 The committee agrees that better public education about stillbirth may reduce the rate of stillbirths in Australia by helping to demystify the risk of stillbirth and removing the stigma that inhibits clinicians and other health professionals from discussing the risk with pregnant women because they fear that it will cause them unnecessary anxiety.

Recommendation 10

7.97 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.

7.98 The committee commends the IMPROVE training workshops designed to assist clinicians and health professionals in managing a stillbirth or neonatal death including investigations, counselling for autopsy and examining the baby.

7.99 Stillbirth also exacts an emotional toll on clinicians and other health professionals who care for bereaved parents, and the committee recognises that they too should have access to counselling and support services when they need it during the course of their employment.¹⁰⁴

Recommendation 11

7.100 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:

104 Mr Smith, PSA NSW/CPSU NSW, *Committee Hansard*, 8 August 2018, p. 61; Ms Marshall, *Submission 109*, pp. 2–3.

- **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.**

7.101 The committee considers that protocols need to be developed to guide public hospitals and health centres in managing autopsies or other investigations into stillbirths and providing culturally appropriate counselling for autopsy and other medical investigations.

7.102 The committee is also concerned that there is no nationally consistent approach in public hospitals and community health services as to how they care for stillborn babies held in morgues; how they communicate with the parents of those babies, particularly for parents who may live long distances away from the hospital where their baby was stillborn; and how they assist those parents who may find the cost of a funeral service prohibitive and require advice on other options.

7.103 The committee sought data compiled by public health authorities in the states and territories relating to unclaimed stillborn babies left in morgues. Whilst not all jurisdictions responded within the committee's timeframe, it is clear to the committee that the situation varies across jurisdictions and requires a nationally consistent approach.

Recommendation 12

7.104 The committee recommends that the Australian government develops and implements culturally and linguistically appropriate protocols for public hospitals and community health services in all jurisdictions, to guide them in:

- **managing autopsies or other investigations into stillbirths;**
- **counselling for autopsy and other medical investigations;**
- **care of stillborn babies held in morgues; and**
- **communicating with bereaved parents.**

7.105 The success of public health education campaigns depends in part on being informed by high quality research. The committee is concerned that there is no central point of access to the growing body of research and clinical guidelines regarding stillbirth. As a result, this important resource is fragmented and difficult to access for researchers, clinicians and other health professionals, support and advocacy groups, and members of the general public.

7.106 As a starting point, the committee considers that an Australian online register, similar to the International Society for the Study and Prevention of Perinatal Infant Death, would help to reduce fragmentation and duplication of effort across the jurisdictions, and provide greater access and education for those involved in stillbirth

research as well as care providers and families who wish to undertake their own research.¹⁰⁵

Recommendation 13

7.107 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.

7.108 The committee recognises that better community education about stillbirth is a high priority, and urges the Australian government to develop culturally appropriate educational materials—informed by international best-practice models such as the UK program *Finding the Words*—that offer information about stillbirth, practical guidance on how to talk about stillbirth, and strategies for supporting a person who has experienced the trauma of stillbirth.

7.109 Such educational materials need to be culturally appropriate and aimed at a wide range of people in the community including extended family members, friends, employers, work colleagues, and anyone who may know or encounter a bereaved parent.

Recommendation 14

7.110 The committee recommends that the Australian government develops and implements a best-practice, culturally appropriate public education kit that assists families, friends, employers, work colleagues and people in the wider community to understand stillbirth and to offer support to a bereaved parent or family member following a stillbirth.

105 International Society for the Study and Prevention of Perinatal Infant Death, <https://www.ispid.org/index/> (accessed 18 October 2018).

Chapter 8

The future of stillbirth research and education in Australia

8.1 Stillbirth affects more than 2000 Australian families each year, and the economic and social costs are having significant effects on families, communities, the health system, and the Australian economy. The Centre for Research Excellence in Stillbirth (Stillbirth CRE) summarised the case for making stillbirth research and education a national priority.

Many stillbirths are preventable, and Australia is underperforming in the challenge to reduce deaths and improve care and support for those who experience stillbirth...Stillbirth is an issue of national significance that requires coordinated leadership and action across all levels of Australian government to improve the current and future wellbeing of Australian women, their families and our wider society.¹

8.2 This chapter considers the future of stillbirth research and education in the context of international and national policy frameworks, and strategies that could be implemented to reduce the rate of stillbirth in Australia.

International policy context

8.3 Stillbirth has not been high on the international health agenda, and was not listed as a priority area in either the United Nations' (UN) Millennium Development Goals (MDG) (covering the period 2000 to 2015), nor the Sustainable Development Goals (SDG) (covering the period 2016 to 2030) which have focused on other areas of maternal and child health.

8.4 However, evidence suggests that inclusion in high-level international agenda is having a significant impact on country level outcomes. For example, neonatal deaths and maternal deaths, both of which were targeted under the MDGs, have reduced significantly, while the stillbirth rate has not reduced by the same amount.²

8.5 The lack of progress in reducing stillbirth rates internationally has led to calls for its inclusion in international policy frameworks. The UN released its Global Strategy for Women's and Children's Health in 2010 and, in 2014, the World Health Organisation (WHO) launched *Every Newborn: An Action Plan to End Preventable*

1 Centre for Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, p. 2.

2 V Flenady, P Middleton, GC Smith, et al, 'Stillbirths: The Way Forward in High-Income Countries', *The Lancet*, vol. 377, no. 9778, 14 April 2011, pp. 1703–1717, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)60064-0/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60064-0/fulltext) (accessed 12 November 2018).

Deaths, providing a strategic framework aimed at ending preventable newborn deaths and stillbirths worldwide by 2035.³

8.6 In addition, the WHO Global Reference List of 100 Core Health Indicators was recently updated to include the rate of stillbirths (based on the WHO definition) as a core indicator for countries to measure the quality of health care services.⁴

Australia's policy framework

8.7 A range of national, state and territory governments, hospitals, research institutions and advocacy groups are engaged in research into the causes of stillbirth and education about the risk factors. However, there is no coordinated national policy framework that sets national targets for reducing stillbirth, nor consistent national standards for stillbirth reporting, research and education.⁵

8.8 State and territory governments are largely responsible for implementing laws and policies in relation to stillbirth, including health care services, registration of stillbirths, investigations, data collection, health and related policy and law.

8.9 As a result, stillbirth data collections, research initiatives and education strategies tend to be piecemeal, subject to different jurisdictional policies and clinical approaches and fragmented, short-term funding arrangements.

8.10 Whilst there have been attempts to coordinate policy at the national level, progress has been intermittent and there is still no coherent national policy framework that seeks to reduce the incidence of stillbirth in Australia.

National Strategic Approach to Maternity Services

8.11 The National Maternity Services Plan 2010–2015, developed under Commonwealth leadership, concluded on 30 June 2016.⁶ In April 2016, the Australian Health Ministers' Advisory Council (AHMAC) agreed to develop a National Framework for Maternity Services. This was discontinued and, in September 2017, the AHMAC agreed to start a new process to develop a National Strategic Approach to Maternity Services (NSAMS).

8.12 The final NSAMS is intended to provide an overarching national policy framework for maintaining Australia's high-quality maternity care system, and working towards further improvements in line with contemporary practice, research

3 World Health Organisation (WHO), *Every Newborn: An Action Plan to End Preventable Deaths*, June 2014, p. 5.

4 WHO, *Global Reference List of 100 Core Health Indicators (plus health-related SDGs)*, 2018 edition, <http://www.who.int/healthinfo/indicators/2018/en/> (accessed 23 July 2018), p. 26.

5 The United Kingdom, for example, has set a target to reduce stillbirths by 25 per cent by 2025.

6 Australian Health Ministers' Conference (AHMAC), *National Maternity Services Plan*, 2011, [http://www.health.gov.au/internet/main/publishing.nsf/content/8AF951CE492C799FCA257BF0001C1A4E/\\$File/maternityplan.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/8AF951CE492C799FCA257BF0001C1A4E/$File/maternityplan.pdf) (accessed 25 September 2018).

and international developments. The deadline for submissions in the first round of consultation on the NSAMS closed on 18 June 2018.⁷

8.13 A second round of face-to-face consultations was conducted in October–November 2018, with a deadline for submissions of 19 November 2018. The NSAMS is expected to be completed by July 2019.⁸

8.14 A second consultation paper outlined a set of draft strategic directions to 'provide an overarching national approach to maintaining Australia's high-quality maternity care system', and included a strategic direction that 'Service providers implement measure to reduce the rates of stillbirth', based on the success of the United Kingdom (UK) *Saving Babies Lives* Care Bundle and research being conducted by Stillbirth CRE. It also recommended access to bereavement care for women who experience stillbirth, neonatal death or whose babies have major congenital anomalies.⁹

Towards a National Stillbirth Action Plan

8.15 A number of submitters and witnesses called for the Council of Australian Governments (COAG) to make stillbirth research and education a national priority.¹⁰

8.16 Stillbirth CRE proposed a number of recommendations, developed in partnership with a number of institutions and organisations with expertise in research, policy and healthcare practice in Australia and internationally. It recommended that COAG provide coordinated leadership and action to use data to drive change; improve clinical practice; invest in research; increase public awareness; and improve perinatal pathology services.¹¹

8.17 Similarly, Stillbirth Foundation Australia called for a comprehensive and coordinated policy response led by the Commonwealth that is properly funded, sets clear targets and includes meaningful evaluation of implementation and progress.

Together, data, research and education, both at a community level and a medical practitioner level, and moving support and advice from a piecemeal

7 AHMAC, *Developing a National Strategic Approach to Maternity Services*, Consultation Paper 1, Department of Health, 2018, additional information received 19 October 2018, p. 15.

8 Department of Health, *National Strategic Approach to Maternity Services*, <https://consultations.health.gov.au/office-of-the-chief-nursing-and-midwifery-officer/national-strategic-approach-to-maternity-services/> (accessed 25 September 2018); Department of Health, answers to questions on notice, 21 September (received 8 October 2018).

9 AHMAC, *Strategic Directions for Australian Maternity Services*, Consultation Paper 2 (draft), Department of Health, 2018, additional information received 19 October 2018, pp. 3 and 11.

10 See for example, Stillbirth CRE, *Submission 56*, p. 2; Australian College of Nursing, *Submission 20*, p. 4; Australian College of Midwives, *Submission 24* [p. 6]; Hunter Medical Research Institute (HMRI), *Submission 36* [p. 3]; Ms Natasha Donnelly, *Submission 116*, p. 5.

11 Stillbirth CRE, *Submission 56*, pp. 2–3. The submission was prepared in partnership with the Perinatal Society of Australia and New Zealand, Australian College of Midwives, Women's Healthcare Australasia, Stillbirth and Neonatal Death Support (Sands Australia), Still Aware and the International Stillbirth Alliance.

approach to a coordinated strategy, holds the key to ensuring more healthy births and fewer stillbirth tragedies. If we can get the policy settings right, we believe we are on the cusp of dramatically reducing the rate of stillbirth in Australia...we need a plan that is developed by government, after consultation with many stakeholders, with measurable targets, a built-in review process and supported by a significant funding package that is proportionate, in line with precedent and will work.¹²

8.18 Stillbirth Foundation Australia suggested that it could be modelled on the recently-released National Action Plan for Endometriosis with strategies focused on:

- public education about preventing stillbirth;
- a dedicated research fund administered with clear priorities as part of a broader strategy;
- the harmonisation of data collection and management across jurisdictions, with regular public reporting periods; and
- improving the understanding and awareness of stillbirth among health professionals working at every stage of the clinical pathway.¹³

8.19 Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute (HMRI), similarly emphasised the need for national leadership to drive the establishment of a national reporting system and prevention initiatives, as well as a commitment to longer-term funding for stillbirth research.

This is not a short-term solution. This needs to be a long-term commitment over 10 years, to say, 'We can achieve this.' I think we can achieve a whole lot more than 25 per cent in certain pockets of Australia, but I think that there are going to be other pockets in Australia where it will be extremely difficult to bring about change.¹⁴

8.20 Professor Susan Walker, Department of Obstetrics and Gynaecology; and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne, emphasised the importance of coordinated and collaborative approaches to research, education and care, and the need to focus on reducing preventable stillbirth.

Our focus is on reducing preventable stillbirth. We suggest that reducing preventable stillbirth requires strong connections of women with high-quality and accessible pre-pregnancy, pregnancy and intrapartum care; of health services with research institutes; of policymakers with timely access to reliable data; of government, philanthropic and industry backers with

12 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 11.

13 Stillbirth Foundation Australia, *Submission 33*, pp. 15–16; see Department of Health, *National Action Plan for Endometriosis*, July 2018, <http://www.health.gov.au/internet/main/publishing.nsf/Content/endometriosis> (accessed 26 September 2018).

14 Professor Craig Pennell, Senior Researcher, HMRI, *Committee Hansard*, 9 August 2018, p. 21.

leaders in research; and of those researchers with their national and international counterparts.¹⁵

Red Nose Stillbirth Prevention Program

8.21 Red Nose stated that the organisation has set a goal of reducing the incidence of stillbirth in Australia, having achieved an 85 per cent reduction in Sudden Infant Death Syndrome (SIDS) through its public health campaign by adopting a simple formula:

...drive research and turn breakthroughs into education and advocacy, whilst continuing to provide bereavement support to families who have lost children, regardless of gestation or age, as they navigate the horrendous road of grief in front of them.¹⁶

8.22 Red Nose reported on the development of its Stillbirth Prevention Program, in collaboration with the Stillbirth CRE and the team that developed and implemented the successful Scottish Maternity Care Quality Improvement Collaborative initiative.¹⁷ The program aims to reduce the rate of stillbirth in Australia by 20 per cent in five years and contains five modules:

- (i) patient education campaign about stillbirth;
- (ii) implementation of a new package to reducing smoking in pregnancy;
- (iii) raising awareness for reduced fetal movement;
- (iv) risk assessment and fetal surveillance for fetal growth restriction; and
- (v) implementing a new Perinatal Mortality Review Tool.

8.23 Red Nose advised that it had secured matching funds from three partners (University of Newcastle, \$100 000; HMRI, \$100 000; and John Hunter Hospital, \$100 000), and is seeking to partner with government (\$300 000) to enable the modules to be developed, implemented (in the John Hunter Hospital) and evaluated.¹⁸

8.24 In addition, Red Nose has been offered the new Perinatal Mortality Review Tool, utilised in Scotland for several years and recently adopted in the UK, and will

15 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology; and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne, *Committee Hansard*, 9 August 2018, p. 25.

16 Mrs Jane Wiggill, Manager, Health and Advocacy, Red Nose, *Committee Hansard*, 9 August 2018, p. 18.

17 See Chapter 7 for details of the Maternity and Children Quality Improvement Collaborative, Healthcare Improvement Scotland, <https://ihub.scot/spsp/maternity-children-quality-improvement-collaborative-mcqc/> (accessed 10 October 2018); also see Professor Pennell, HMRI, *Committee Hansard*, 9 August 2018, p. 21.

18 Red Nose, *Submission 63*, p. 10. Red Nose, formerly SIDS and Kids, was formed 40 years ago by parents who had suffered loss.

evaluate the tool in a clinical setting for potential application in Australian hospitals as part of its vision to develop 'Red Nose Hospitals'.¹⁹

Possible strategies

8.25 The committee considered suggestions from submitters and witnesses for a range of possible actions on stillbirth reporting and data collection, research and education. It also considered suggestions for improved models of maternity care that may contribute to reducing the rate of stillbirth and providing culturally-appropriate care for families who have experienced stillbirth.

Strategy 1: Stillbirth reporting and data collection

8.26 Whilst Australia has the necessary expertise and a collaborative research environment, there is a lack of incentive for collecting agencies to link their data into a national system. As a result, there is a very long lead-time in collecting data, undertaking research and implementing the results of research. As Professor Pennell stated:

Until there is a unified approach to complex health issues across Australia, we're not going to achieve the solution, whether it be stillbirth or whether it be Indigenous health. Whilst we have meetings with seven groups coming together arguing about who's paying for what, where and how, there needs to be some degree of central control over elements of health.²⁰

8.27 Consideration could be given to linking national perinatal data collection to healthcare funding agreements, in order to provide an incentive to jurisdictions to increase the number of mandatory reporting items.²¹

Strategy 2: Stillbirth research

8.28 As discussed in Chapter 3, the lack of a nationally consistent set of research priorities is hampering stillbirth researchers.

8.29 The idea of a roundtable of relevant stakeholders to consider and advise on collaborative research partnerships and funding has merit.²² It would enable the government to draw on a range of expertise and perspectives on stillbirth, and provide a valuable vehicle for consultation between government, the philanthropic sector and the corporate sector, as well as experts, clinicians, academics, parents and stillbirth advocates.

8.30 A roundtable approach could also explore opportunities for longer-term funding arrangements that would enable the implementation of large-scale, multifaceted research projects into stillbirth causes and prevention.

19 A Red Nose Hospital will require implementation of all five modules and a site visit from an external review team.

20 Professor Pennell, HMRI, *Committee Hansard*, 8 August 2018, p. 25.

21 Ms Natasha Donnelly, *Committee Hansard*, 8 August 2018, p. 10.

22 Associate Professor Camille Raynes-Greenow, School of Public Health, University of Sydney, *Committee Hansard*, 8 August 2018, p. 52.

Strategy 3: Stillbirth education

8.31 The committee acknowledges that the risk of stillbirth is not widely known or discussed, and that a stillbirth education and awareness campaign is required to help overcome the stigma, misinformation and silence that currently surrounds stillbirth in Australia.

8.32 Stillbirth education programs are largely undertaken by voluntary and non-government organisations, who argued that it should be considered a national policy priority. As Ms Natasha Donnelly noted:

In summary, stillbirth needs to be a COAG-endorsed, high-priority research area. There needs to be a government funded public awareness campaign, and multidisciplinary education in how clinicians need to broach the subject of stillbirth during women's antenatal education. There needs to be better support for NGOs who provide care for families in this area. Our organisations, both in stillbirth prevention and bereavement support, are saving the government millions of dollars, and it's not much to ask for some of that back.²³

8.33 The committee commends the development of the Red Nose Stillbirth Prevention Program and the concept of Red Nose Hospitals as an important initiative aimed at reducing stillbirth in Australia. The committee notes that, by drawing on international models and collaborations, Red Nose has succeeded in reducing the costs of developing the program in Australia.²⁴

8.34 The committee considers that the Australian government should conduct a national stillbirth public awareness campaign, drawing inspiration from successful public health campaigns such as SIDS, Quit Smoking, and the Heart Foundation, aimed at:

- helping to raise awareness amongst pregnant women and their families about the known causes and risks of stillbirth, regardless of whether their pregnancy is considered high-risk;
- assisting clinicians and other health professionals to overcome the culture of silence surrounding stillbirth, and making it easier for them to have conversations about the causes and risks with pregnant women and their families;
- enabling employers and work colleagues to be better informed about stillbirth and equip them with the necessary skills to support bereaved parents returning to work following a stillbirth;
- increasing awareness of stillbirth amongst the broader Australian community; and
- providing flow-on effects for stillbirth research and education in the form of increased funding and opportunities to establish public-private partnerships.

23 Mrs Donnelly, *Committee Hansard*, 8 August 2018, p. 3.

24 Red Nose, *Submission 63*, p. 11.

Strategy 4: Models of care

8.35 The committee heard ample evidence about the merits of a continuity of maternity care model that can be adopted by hospitals, clinicians and other health professionals.

8.36 Professor Caroline Homer, Distinguished Professor of Midwifery, University of Technology Sydney, considered that the National Maternity Services Plan 2011 had understated the importance of continuity of care, and argued that a new national strategy was required to ensure consistency and continuity in maternity services for all Australian women.

Maternity services in hospitals are generally not on the top list of things to worry about, and so the impetus for change is not really there. Hospitals funded by the state governments are generally worried about their emergency room and their waiting lists. With maternity services, generally everything goes well and nicely and it just doesn't get political push and it doesn't get hospital mandate—'Actually it's terrible that 300 of our 6,000 women get what we consider evidence based practice but the rest just get ordinary care.' It sort of gets put on the side.²⁵

Committee view

8.37 There has never been a national target or federal government commitment to reducing the rate of stillbirth in Australia. However, the evidence suggests that, in countries like Scotland where such a commitment has been made, policies and practices have been changed and stillbirth rates have declined significantly as a result.

8.38 The committee acknowledges that the AHMAC is currently consulting stakeholders on the development of a National Strategic Approach to Maternity Services (NSAMS), with the aim of guiding national maternity services policy, aligning delivery of services with available evidence, and monitoring performance and outcomes so that progress can be measured and improvements identified.²⁶

8.39 The committee notes that submissions in the first consultation phase closed on 18 June 2018, and that a second round of face-to-face consultations is underway in October–November 2018 with the NSAMS due to be completed by July 2019.

8.40 Recognising that the outcomes of the NSAMS development process will not be available within the timeframe for this inquiry, the committee urges the Australian government to consider the information and recommendations arising from this inquiry when considering how stillbirth research and education will be addressed in the NSAMS.

25 Professor Caroline Homer, Distinguished Professor of Midwifery, University of Technology Sydney, *Committee Hansard*, 8 August 2018, p. 34.

26 The Hon. Greg Hunt, MP, Minister for Health, *Media release*, 2 March 2018, [http://www.health.gov.au/internet/ministers/publishing.nsf/Content/8FCA64944BFBB90CCA258243007CF802/\\$File/GH022.pdf](http://www.health.gov.au/internet/ministers/publishing.nsf/Content/8FCA64944BFBB90CCA258243007CF802/$File/GH022.pdf) (accessed 3 October 2018).

8.41 In addition, whilst acknowledging the current process to develop a national strategic approach for Australian maternity services, the committee strongly recommends that a National Stillbirth Action Plan should also be developed for specific consideration and endorsement by the AHMAC.

8.42 The committee recognises that a National Stillbirth Action Plan requires partnerships between governments, philanthropic organisations, academic institutions and health services, and that such partnerships should inform the development of the National Stillbirth Action Plan.

8.43 The committee considers that the Action Plan should form part of the NSAMS, and include the following elements:

- a national target of 20 per cent reduction in the rate of stillbirth in Australia over the next three years;
- guidelines for establishing nationally-coordinated and consistent stillbirth reporting standards and dataset;
- an online register of current research and data relating to stillbirth designed for researchers and health professionals and available to the general public;
- a set of national research priorities focused on reducing stillbirth, especially in relation to unexplained stillbirth; and
- an public education campaign drawing on successful public health campaigns such as SIDS and Quit Smoking.

Recommendation 15

8.44 The committee recommends that, through the Australian Health Ministers' Advisory Council, the Australian government leads a process to develop and implement a National Stillbirth Action Plan aimed at reducing the rate of stillbirth in Australia by 20 per cent over the next three years (Budget forward estimates), and including:

- **a nationally-coordinated and consistent framework for stillbirth reporting and data collection;**
- **an online register of stillbirth research and data;**
- **national research priorities; and**
- **a public education campaign.**

8.45 In addition, the committee considers that the Australian government should develop continuity of maternity care guidelines that encourage hospitals, clinicians and other health professionals to provide consistency and continuity in maternity services for all Australian women.

8.46 Details of each of these elements are discussed in previous chapters, but the committee considers that they represent the key strategic areas to be addressed in the National Stillbirth Action Plan.

8.47 The committee considers that annual progress reports on the development and implementation of the National Stillbirth Action Plan to reduce the rate of stillbirth in Australia should be provided to COAG's Health Council and made publicly available.

Recommendation 16

8.48 The committee recommends that annual progress reports on the development and implementation of the National Stillbirth Action Plan to reduce the rate of stillbirth in Australia are provided to the Council of Australian Governments Health Council and made publicly available.

**Senator Malarndirri McCarthy
Chair**

Appendix 1

Submissions, answers to questions on notice, tabled documents and additional information

Submissions

- 1 Mrs Jennie Klohs
- 2 Ms Chanel Forbes
- 3 Senator Janet Petersen
- 4 Ms Gillian Graham-Crowe
- 5 Ms Ashwini Rao
- 6 Ms Christine Prosser
- 7 Ms Marianne Cottle
- 8 Mrs Simone Balzer
- 9 Dr Jane Warland
- 10 Maternity Consumer Network
- 11 Name Withheld
- 12 Name Withheld
- 13 Name Withheld
- 14 Mr Phillip Youngman
- 15 Mrs Milena Vrankovic
- 16 Confidential
- 17 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
- 18 Dr Damien W Riggs & Dr Clemence Due
- 19 South Australian Health and Medical Research Institute (SAHMRI)
- 20 The Australian College of Nursing (ACN)
- 21 Centre for Midwifery, Child and Family Health
- 22 Mrs Bree Amer Wilkes
- 23 Ms Lauren Malcolm & Mr Shane Baggett
- 24 Australian College of Midwives
- 25 Minister for Health, Northern Territory Government
- 26 Australian Institute of Health and Welfare (AIHW)
- 27 National Health and Medical Research Council (NHMRC)

- 28 Ms Kate Obst, Dr Clemence Due and Dr Melissa Oxlad
- 29 Laureate Professor Roger Smith AM
- 30 Early Arrivals Special Interest Group (EASIG)
- 31 Population Health Research Network (PHRN)
- 32 Bears of Hope Pregnancy & Infant Loss Support
- 33 Stillbirth Foundation Australia
- 34 Queensland Maternal and Perinatal Quality Council
- 35 Australian Bureau of Statistics
- 36 Hunter Medical Research Institute
- 37 National Perinatal Epidemiology and Statistics Unit (NPESU), UNSW Sydney
- 38 Little Silk Wings
- 39 College of Nursing and Health Sciences, Flinders University
- 40 Global Stillbirth Advocacy Network
- 41 Research Australia
- 42 Still Aware
- 43 ACT Government
- 44 Departments of Neonatology/Maternal Fetal Medicine, The Townsville Hospital and Health Services
- 45 Department of Obstetrics and Gynaecology, University of Melbourne
- 46 The Royal College of Pathologists of Australasia
- 47 Western Australian Perinatal Epidemiology Group
- 48 Western Health
- 49 Mater Misericordiae Ltd
- 50 The Royal Australasian College of Physicians
- 51 Department of Obstetrics and Gynaecology, Monash University
- 52 Australian College of Nurse Practitioners
- 53 Mr Raymond Curro
- 54 Professor Hamish S. Scott and Associate Professor Christopher Barnett
- 55 Ramsay Health Care
- 56 Centre of Research Excellence in Stillbirth (Stillbirth CRE)
- 57 National Rural Health Alliance
- 58 Australian Nursing and Midwifery Federation
- 59 Sands Australia
- 60 Australian Longitudinal Study on Women's Health

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- 61 Health Consumers' Council (WA)
 - 62 WA Health
 - 63 Red Nose
 - 64 Baymatob Operations Pty Ltd
 - 65 University of Sydney, School of Public Health
 - 66 Public Health Association of Australia
 - 67 Caesarean Birth
 - 68 Community and Public Sector Union NSW
 - 69 Maurice Blackburn Lawyers
 - 70 Multicultural Centre for Women's Health
 - 71 Mrs Kaisi Siefert
 - 72 Bonnie and Stephen Carter
 - 73 Ms Justine Reynolds
 - 74 Rebecca and Paul Dixon
 - 75 Ms Emma Dalton
 - 76 Kirby & Daniel Channells
 - 77 Tim & Leanne Smith
 - 78 Ms Alex Lowes
 - 79 Ms Catherine Travers
 - 80 Caroline Campbell and Kirk von Mollendorf
 - 81 Bronwyn & Stewart White
 - 82 Britt Jacobsen and Samuel Haldane
 - 83 Erryn and Mathew Tharme
 - 84 Rebecca and Simon Scammell
 - 85 Ms Maryanne Lewis
 - 86 Ms Rebecca Barclay
 - 87 Ms Karen Fuser
 - 88 Ms Alexandra Tighe
 - 89 Mrs Ellana Iverach
 - 90 Ms Phillipa McGuinness
 - 91 Ms Jacqui Bruyn
 - 92 Jonathan Brabner & Karen Trovato
 - 93 Ms Muradiye Payir
 - 94 Ms Jennifer Nixon-Rennie

- 95 Ms Jacqueline Hoy
- 96 Mr David Balzer
- 97 Ms Caitlin Cvitkovic
- 98 Ms Sandra Dagher
- 99 Ms Bianca Dullens
- 100 Ms Jodie Matthews
- 101 Ms Stephanie Vowles
- 102 Mr Andrew McBride
- 103 Dr Jonathon Hoy
- 104 Ms Danielle Pollock
- 105 Ms Nerida Box
- 106 Mrs Rhonda Jeavons
- 107 Andrew and Renee Deuchar
- 108 Julia and Debden Whaanga
- 109 Ms Zoe Marshall
- 110 Ms Tarah Hau
- 111 Ms Michelle Cullen
- 112 Ms Kate Wynn
- 113 Richard and Amanda Johnston
- 114 Ms Jane Butler
- 115 Kate & Hugh FitzSimons
- 116 Ms Natasha Donnelly
- 117 Mr Bruce McMillan
- 118 Mrs Emma Stratton
- 119 Ms Donna Merigan
- 120 Ms Shannon Cook
- 121 Samantha and Aaron Isfahani
- 122 Mr Adam Flanagan
- 123 Ms Julieanne Carmichael
- 124 Ms Terri Ryan
- 125 Ms Sarah Shaw
- 126 Mrs Maria Curro
- 127 Dr Jason H. Collins MD. MSCR
- 128 Professor Jane Dahlstrom

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144	Name Withheld
145	Name Withheld
146	Name Withheld
147	Ms Oi-Lai Leong
148	Ms Maxine Baker
149	Ms Nicole Mitchell
150	Ms Belinda O'Dwyer
151	Mrs Megan Warren
152	Name Withheld
153	Ms Anita Selvam
154	Name Withheld
155	Confidential
156	Confidential
157	Confidential
158	Robinson Research Institute, The University of Adelaide
159	John & Kate De'Laney
160	Mrs Judith Rosewarne
161	Hayley Murphy
162	Ms Melissa Williams

- 163 Ms Katherine Sumaru
- 164 Ms Kellie French
- 165 Ms Sue-Anne Hunter
- 166 Ms Sara Gray
- 167 Hannah & Lachlan Bannon
- 168 Ms Jennifer Thomas
- 169 Mr Jeff Bourman MP
- 170 Ms Louise Alderman
- 171 Ms Lyndel Carbone
- 172 Ruth Steinbring and Adam Cowell
- 173 Ms Kristy Plisowsky
- 174 Mr Brad Heath
- 175 Ms Jo LeMass
- 176 Ms Lisa Martin
- 177 Ms Monica Williams
- 178 Mr James Price
- 179 Mrs Clare Rannard
- 180 Dr Wendy Bushby
- 181 Donna Penny & Bruce Bell
- 182 Ms Taryn Hayhurst
- 183 Ms Holly Ryan
- 184 Dr Nisha Khot
- 185 Ms Fiona Goss
- 186 Jaimi Mullins-Nutley
- 187 Ms Paula Dillon
- 188 Leah & Luc McKay
- 189 Ms Tennille Welsh
- 190 Ms Lisa Schmierer
- 191 Dallas and Kylie Smith
- 192 Ms Kylie Ashton
- 193 Nick and Elena Xerakias
- 194 Ms Julia Whitty
- 195 Ms Robyn Wilson
- 196 Dr Jane Wardell

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- 197 Ms Lauren Martyn-Jones
198 Ms Susannah Aumann
199 Ms Carmen Whittaker
200 Mr David Meade
201 Mrs Anna Omrod
202 Elizabeth Luxford and Nathan Barker
203 Ms Elsa Murray-White
204 Ms Naomi Herron
205 Ms Rebecca Lowis
206 Mr Joshua Ryan
207 Jessica and David Missio
208 Clare and Luke Chambers
209 Ms Marissa Lanyon
210 Ms Katie Thurlby
211 Ms Natasha Hulse
212 Ms Alison Webster
213 Ms Angelica Fricot
214 Ms Kim Mead
215 Mrs Jackie Barreau
216 Ms Jana Hall
217 Dr Jacqueline Mowbray
218 Jaime Yallup Farrant and Brad Farrant
219 Ms Georgia Hansen
220 Ms Victoria Hefford
221 Andrew Mooney & Karen Au
222 Mrs Linda Price
223 Ms Jacqui Hollier
224 Ms Jodie Roche-Jones
225 Dean and Ellen Brand
226 Ms Amanda Bollans
227 Alexandra and Scott Warren
228 Ms Lauren Hudson
229 Mrs Doshni Stewart
230 Ms Tracey Lovell

- 231 Ms Danielle Leal
- 232 Annette Kacela & Christopher Lobo
- 233 Ms Vicki Purnell
- 234 Ms Bronwyn Batten
- 235 Ms Tracey Simpson
- 236 Ms Amy Eldridge
- 237 Ms Sarah Matheson
- 238 Mr Trent Clark
- 239 Mrs Sue Bruyn
- 240 Mr Gerard Ryan
- 241 Mrs Lorraine Bolling
- 242 Dr Michael Gannon MBBS (WA) MRCPI FRANZCOG
- 243 Name Withheld
- 244 Name Withheld
- 245 Mrs Rachelle Martin
- 246 Mrs Tiffany McIntosh
- 247 Ms Jane Roeszler
- 248 Ms Jane McPherson
- 249 Meg & Shane Keating
- 250 Name Withheld
- 251 Ms Kirsten Willis
- 252 Name Withheld
- 253 Ms Laura Portch
- 254 Ms Georgia Findley
- 255 Mrs Sally Heppleston
- 256 Ms Jasmine Prowse
- 257 Perinatal Institute (UK)
- 258 Natalie and Michael Jonach
- 259 Confidential
- 260 Confidential
- 261 Confidential
- 262 Ms Jenna Suszko
- 263 Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
- 264 Wendy Allen

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- 265 Confidential
266 Ms Kate Campbell
267 Chantel and Joseph Murfet
268 Ms Gay Brummer
269 Group B Strep International (GBSI)

Answers to questions on notice

1. Multicultural Centre for Women's Health, Dr Jasmin Chen — answer to question on notice from 9 August 2018 (received 13 August 2018)
2. Stillbirth Foundation Australia — answer to question on notice from 8 August 2018 (received 14 September 2018)
3. Red Nose — answer to question on notice from 9 August 2018 (received 14 August 2018)
4. Maurice Blackburn — answers to questions on notice from 9 August 2018 (received 14 August 2018)
5. Community and Public Sector Union (CPSU) NSW — answers to questions on notice from 8 August 2018 (received 14 September 2018)
6. Mater Misericordiae Ltd — answers to questions on notice from 8 August 2018 (received 14 September 2018)
7. Centre of Research Excellence in Stillbirth — answers to questions on from 6 September 2018 (received 4 October 2018)
8. Centre of Research Excellence in Stillbirth — answers to questions on from 6 September 2018 (received 4 October 2018)
9. Australian Institute of Health and Welfare — answers to questions taken on notice on 7 September 2018 (received 5 October 2018)
10. Victorian Perinatal Autopsy Service — answers to questions taken on notice on 7 September 2018 (received 5 October 2018)
11. Australian College of Nursing — answers to questions taken on notice on 7 September 2018 (received 6 October 2018)

12. Department of Health (Cth) — answers to written questions on notice dated 24 September 2018 (received 8 October 2018)
13. Tasmanian Government — answers to written questions on notice dated 24 September 2018 (received 9 October 2018)
14. National Health and Medical Research Council — answers to questions taken on notice on 7 September 2018 (received 9 October 2018)
15. Ms Stevie Vowles — answer to question on notice from 6 September 2018 (received 7 September 2018)
16. Government of South Australia — answers to written questions on notice dated 24 September 2018 (received 19 October 2018)
17. ACT Government — answers to written questions on notice dated 24 September 2018 (received 22 October 2018)
18. Royal College of Pathologists of Australasia — answers to questions taken on notice on 6 September 2018 (received 18 October 2018)
19. WA Government — answers to written questions on notice dated 24 September 2018 (received 26 October 2018)
20. NT Government — answers to written questions on notice dated 21 September 2018 (received 5 October 2018)
21. Queensland Government — answers to written questions on notice dated 21 September 2018 (received 19 November 2018)
22. New South Wales Government — answers to written questions on notice dated 21 September 2018 (received 28 November 2018)

Tabled documents

1. Professor Caroline Homer AO — document tabled at Sydney hearing 8 August 2018 — Reducing Stillbirth in the Pacific: An opportunity for Australia to play a bigger role
2. Ms Claire Foord, Still Aware — document tabled at Sydney hearing 8 August 2018 — Call for change to stop preventable stillbirth

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3. Ms Claire Foord, Still Aware — document tabled at Sydney hearing 8 August 2018 — Safe pregnancy information pack
 4. Mr Bruce McMillian — document tabled at Melbourne hearing 9 August 2018 — Emerikus Land Foundation, Figures on cold cots within Australia
 5. The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) — document tabled at Melbourne hearing 9 August 2018 — RANZCOG Guidance on Stillbirth
 6. RANZCOG — document tabled at Melbourne hearing 9 August 2018 — World Journal of Clinical Pediatrics, Short and long term prognosis in perinatal asphyxia: An update
 7. RANZCOG — document tabled at Melbourne hearing 9 August 2018 — Resuscitation at birth and cognition at 8 years of age: a cohort study
 8. Dr Jane Warland — document tabled at Adelaide hearing 10 August 2018 — A triple risk model for unexplained late stillbirth
 9. Robinson Research Institute — document tabled at Adelaide hearing 10 August 2018 — Long-term trends in singleton preterm birth in South Australia from 1986 to 2014
 10. Professor Hamish Scott & Associate Professor Christopher Barnett — document tabled at Adelaide hearing 10 August 2018 — Genomic autopsy outline
 11. Public Health Association Australia — document tabled at Canberra hearing 7 September 2018 — Public Health Association of Australia submission on the Medical Research Future Fund

Additional information

1. Additional information from Ms Natasha Donnelly: N Javid et al, The experience of vasa praevia for Australian midwives: A qualitative study, *Women Birth* (2018), (received 14 August 2018)
2. Additional information from Australian Health Ministers' Advisory Council, *Developing a National Strategic Approach to Maternity Services, Consultation Paper*, Department of Health, 2018, (received 19 October 2018)

3. Additional information from Australian Health Ministers' Advisory Council, Strategic Directions for Australian Maternity Services, Consultation paper no. 2 (draft), Department of Health, 2018, (received 19 October 2018)
4. Additional information from Jason H Collins MD, MSCR: The Advanced Maternity Innovations, The Dutch Association of Hospitals 2017 Report (received 27 November 2018)
5. Additional information from Jason H Collins MD, MSCR: Fetal monitoring at home (received 27 November 2018)
6. Additional information from Jason H Collins MD, MSCR: Silent Risk, Issues about the Human Umbilical Cord (received 27 November 2018)
7. Additional information from Jason H Collins MD, MSCR: The Placenta: Basic Science and Clinical Practice (received 27 November 2018)

Correspondence

1. Sands Australia - Correction to evidence from public hearing 9 August 2018 (received 14 September 2018)

Appendix 2

Public hearings and witnesses

Wednesday, 8 August 2018—Sydney

BOWRING, Ms Victoria, Chief Executive Officer, Stillbirth Foundation Australia

CHAMBERS, Associate Professor Georgina, Director, National Perinatal Epidemiology and Statistics Unit, Centre for Big Data Research in Health and School of Women's and Children's Health, Faculty of Medicine, University of New South Wales Sydney

DE WILDE, Ms Deborah, Volunteer, Stillbirth Foundation Australia

DONNOLLEY, Ms Natasha, Private capacity

FOORD, Mrs Claire, Chief Executive Officer and Founder, Still Aware

GORDON, Dr Adrienne, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians

HALDANE, Mr Samuel, Private capacity

HOMER, Professor Caroline, Distinguished Professor of Midwifery, Centre for Midwifery, Child and Family Health, University of Technology Sydney

JACOBSEN, Ms Britt, Private capacity

McKELVIE, Ms Kylie, President, Public Service Association of New South Wales, Community and Public Sector Union New South Wales

PENNELL, Professor Craig, Senior Researcher, Hunter Medical Research Institute

POLLOCK, Ms Danielle, Stillbirth Researcher and Bereaved Parent Representative, Global Stillbirth Advocacy Network

RANNARD, Mrs Clare, Private capacity

RAYNES-GREENOW, Associate Professor Camille, University of Sydney School of Public Health

RICHARDS, Ms Sharon, Women's Industrial Officer, Community and Public Sector Union New South Wales

SMITH, Laureate Professor Roger, Director, Mothers & Babies Research Centre, Hunter Medical Research Institute

SMITH, Mr Timothy, Delegate, Public Service Association of New South Wales, Community and Public Sector Union New South Wales

SMITH, Mrs Leanne, Delegate, Community and Public Sector Union New South Wales

TAI-ROCHE, Mrs Meleseini, New South Wales Representative and Executive Volunteer, Still Aware

WARLAND, Dr Jane, Board Member, Still Aware

WARLAND, Dr Jane, Stillbirth Researcher and Bereaved Parent Representative, Global Stillbirth Advocacy Network

WRIGHT, Mr Tony, Assistant General-Secretary, Public Service Association of New South Wales, Community and Public Sector Union New South Wales

YOUNGMAN, Mr Gavin, Director, Stillbirth Foundation Australia

Thursday, 9 August 2018—Melbourne

BOWDEN, Mrs Lyndy, Caretaker Chief Executive Officer, Sands Australia

BUTLER, Ms Annie, Federal Secretary, Australian Nursing and Midwifery Federation

CHEN, Dr Jasmin, Research and Executive Officer, Multicultural Centre for Women's Health

DUBROW, Mrs Dimitra, Principal and Head of Medical Negligence, Maurice Blackburn Lawyers

KEARNEY, Professor Brendon, Chairman, Population Health Research Network

KHOT, Dr Nisha, Private capacity

MARSHALL, Mrs Janelle, General Manager, Services, Sands Australia

McINTOSH, Mrs Tiffany, Private capacity

McMILLAN, Mr Bruce, Private capacity

PENNELL, Professor Craig, Chair, National Scientific Advisory Group, Red Nose

PERMEZEL, Professor Michael, Immediate Past President, The Royal Australian and New Zealand College of Obstetricians and Gynaecologists

QUINLAN, Mrs Michele, Director, Practice and Advocacy, The Royal Australian and New Zealand College of Obstetricians and Gynaecologists

ROBSON, Professor Steve, President, The Royal Australian and New Zealand College of Obstetricians and Gynaecologists

SHARP, Ms Lori-Anne, Assistant Federal Secretary, Australian Nursing and Midwifery Federation

SMITH, Dr Merran, Chief Executive Officer, Population Health Research Network

SMITH, Ms Nicole, Acting Maternity Services Officer, Victorian Branch, Australian Nursing and Midwifery Federation

STEWART, Mrs Doshni, Private capacity

STRATTON, Mrs Emma, Private capacity

WALKER, Professor Susan, Head, Department of Obstetrics and Gynaecology; and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne

WALLACE, Professor Euan, Carl Wood Professor, Head, Department of Obstetrics and Gynaecology, Monash University

WIGGILL, Mrs Jane, Manager, Health and Advocacy, Red Nose

Friday, 10 August 2018—Adelaide

BARNETT, Associate Professor Christopher, Head, Paediatric and Reproductive Genetics Unit, The Women's and Children's Hospital

BRENNAN, Ms Pip, Executive Director, Health Consumers' Council (WA)

COOK, Mrs Shannon, Private capacity

DEKKER, Professor Gustaaf, Research Leader, Placental Development, Robinson Research Institute; Clinical Director of Women and Children's Division, Northern Adelaide Health Services; Professor in Obstetrics and Gynaecology, University of Adelaide

DUE, Dr Clemence, Senior Lecturer, School of Psychology, University of Adelaide

FARRANT, Mr Brad, Private capacity

GANNON, Dr Michael, Private capacity

LEONARD, Associate Professor Helen, Co-lead, Western Australian Perinatal Epidemiology Group

MARTIN, Mrs Rachelle, Private capacity

MIDDLETON, Associate Professor Philippa, Principal Research Fellow, South Australian Health and Medical Research Institute

OBST, Ms Kate, PhD/Master of Psychology (Health) Candidate, School of Psychology, University of Adelaide

OXLAD, Dr Melissa, Lecturer, School of Psychology, University of Adelaide

PEREIRA, Dr Gavin, Co-lead, Western Australian Perinatal Epidemiology Group

ROBERTS, Professor Claire, Deputy Director, Robinson Research Institute, University of Adelaide

SCOTT, Professor Hamish, Head of Genetics and Molecular Pathology Laboratory, SA Pathology

SHEPHERD, Dr Carrington, Co-lead, Western Australian Perinatal Epidemiology Group

SRINIVAS JOIS, Associate Professor Ravisha, Co-lead, Western Australian Perinatal Epidemiology Group

WARLAND, Dr Jane, Private capacity

YALLUP FARRANT, Mrs Jaime, Private capacity

Wednesday, 5 September 2018—Katherine

COPE, Dr Megan, Senior Medical Officer, Wurli Wurlinjang Health Service

JENNINGS, Ms Belinda, Senior Midwifery Advisor, Office of the Chief Nurse and Midwife, Department of Health, Northern Territory Government

POTTER, Ms Sara, Clinical Nurse and Midwife Manager, Department of Health, Northern Territory Government

Thursday, 6 September 2018—Brisbane

BECKMANN, Dr Michael, Director, Mothers, Babies and Women's Health Services, Mater Health

COWELL, Mr Adam, Private capacity

DILLON, Mrs Paula, Executive Volunteer, Queensland Educator, Still Aware

ELLWOOD, Professor David, Co-Director, Centre of Research Excellence in Stillbirth

FLENADY, Professor Vicki, Director, Centre of Research Excellence in Stillbirth

GARDENER, Dr Glenn, Director of Maternal Fetal Medicine, Mater Health

GORDON, Dr Adrienne, Neonatologist, Centre of Research Excellence in Stillbirth

KANDASAMY, Dr Yogavijayan, Senior Staff Specialist, Neonatology, Townsville Hospital and Health Service

MISHRA, Professor Gita, Director, Australian Longitudinal Study on Women's Health, University of Queensland

MULES, Ms Heidi, Parent representative, Centre of Research Excellence in Stillbirth

PAYTON, Dr Diane, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australasia

REYNOLDS, Ms Maree, Director of Nursing and Midwifery, Mater Health

STAINES, Ms Alecia, Director, Maternity Consumer Network

STEINBRING, Ms Ruth, Private capacity

VOWLES, Mrs Stephanie (Stevie), Private capacity

WATSON, Dr David, Senior Staff Specialist, Maternal and Fetal Medicine, Townsville Hospital and Health Service

WHAANGA, Mrs Julia, Private capacity

Friday, 7 September 2018—Canberra

AL-YAMAN, Dr Fadwa, Group Head, Indigenous and Maternal Health Group, Australian Institute of Health and Welfare

BELL, Mr Bruce, Private capacity

BELL, Ms Donna Penny, Private capacity

BOLAND, Ms Justine, Program Manager, Australian Bureau of Statistics

BUCHANAN-GREY, Ms Marina, Executive Director, Professional, Australian College of Nursing

CARTER, Mr Stephen, private capacity

CARTER, Mrs Bonnie, Private capacity

EYNSTONE-HINKINS, Mr James, Director, Health and Vital Statistics, Australian Bureau of Statistics

FLANAGAN, Mr Adam Private capacity

GARDOSI, Professor Jason, Executive Director, Perinatal Institute (UK)

GLOVER, Dr Julie, Executive Director, Research Foundations Branch, National Health and Medical Research Council

IRELAND-JENKIN, Associate Professor Kerry, Head of Unit, Victorian Perinatal Autopsy Service, The Royal Women's Hospital, Victoria

ISFAHANI, Mr Aaron, Private capacity

ISFAHANI, Mrs Samantha, Private capacity

JOHNSTON, Dr Ingrid, Senior Policy Officer, Public Health Association of Australia

KILDEA, Professor Sue, Director, Midwifery Research Unit, Mater Research Institute, The University of Queensland

KINGDON, Mr Antony, General Manager, National Health and Medical Research Council

KINNEAR, Ms Ann, Chief Executive Officer, Australian College of Midwives

MCBRIDE, Mr Andrew, Private capacity

REINTEN, Ms Tracie, Acting Unit Head, Maternal and Perinatal Health Unit, Australian Institute of Health and Welfare

SLEVIN, Mr Terry, Chief Executive Officer, Public Health Association of Australia

STAPLETON, Dr Carolyn, Manager, Policy and Advocacy, Australian College of Nursing

WALKER, Dr Joanne, Director Policy and Strategy Development, National Rural Health Alliance

WARD, Adjunct Professor Kylie, Chief Executive Officer, Australian College of Nursing

WILLIAMS, Ms Karel, Committee Member, Birthing on Country Project, Australian College of Midwives

Appendix 3

Special Parental Leave provisions in selected Enterprise Agreements and Awards by jurisdiction

Special Parental Leave in various - Enterprise Agreements (EA) and Awards – Australia

NSW/ACT

EA	Clause	Leave (weeks)	Still birth weeks gestation
Ausgrid	30.8 Cessation of pregnancy – stillbirth and miscarriage	12-20 – six weeks special Leave After 20 Weeks 16 weeks special leave Non- birth parent one All paid leave. Additional leave may be approved Medical certificates must be provided	12-20 weeks After 20 special leave** Non- birth parent one
University of Western Sydney 2017-2021	40.8	Up to 20 paid	Stillborn or dies shortly after birth**
University of Wollongong (General Staff) EA 2014	58.3 Unplanned Cessation of Maternity Leave		Stillborn or the child dies during paid maternity leave, a further 4 weeks of their paid maternity leave shall be able to be taken**
UWS College EA 2013	16.46 Special maternity leave 16.48		Within 28 weeks of expected birth date. Leave can continue for as long as 'she' is not fit for work.
Uni NSW	249	14	
Uni Syd 2018	249	14 weeks	
University of Technology, Sydney Professional Staff Agreement 2014	33.9 Cessation of pregnancy	20 days paid parental leave	
NSW Crown Employees NSW	75. Parental Leave 75.2.3	Available sick leave	Not specified
Australian Catholic University Staff EA	3.9.6 Unplanned Cessation of Parental leave	12 paid up to 14 unpaid	

	Paternity	Three weeks paid up to 14 unpaid	
Macquarie University Professional Staff EA 2015	4.1.50 b Premature birth, Still Birth, Miscarriage or Death of Child 4.1.50 c	14 weeks Person Leave and unpaid authorised absence	Four weeks Prior to 20 weeks
The University of Newcastle Professional Staff EA 2014	62.15 Entitlements (miscarriage , stillborn or life threatening)	Six weeks paid	After 20 weeks or within four weeks**
2013 Wollongong University Centre Ltd Administrative Employees EA	56.3 Unplanned Cessation of Maternity Leave		Stillborn or the child dies during paid maternity leave, a further 4 weeks of their paid maternity leave shall be able to be taken**

Western Sydney Universities currently in bargaining where miscarriage and stillbirth entitlements are being bargained over.

Victoria

Public Service EA	51.13 Special Maternity leave	51.3 <i>check</i>	After 20 weeks paid**
Australian Centre for the Moving Image EA 2012-2015	5.17.4 Personal/Carer's leave and special Maternity leave	Paid and/or unpaid personal/carers leave 14 weeks paid special maternity leave, then unpaid special maternity leave.	First 20 weeks After 20 weeks
AMES Australian Administrative Staff Agreement 2016	37.4 Entitlement to special paid parental leave	Miscarriage 14 weeks paid parental leave. Spouse or De Facto Partner 1 week paid parental leave.	At least 20 weeks
Emergency Service Superannuation Board EA 2016-2019	43.15 Special Parental Leave	Paid/unpaid personal/carers Paid special maternity not exceeding paid parental leave in this EA	First 20 weeks Completion of 20 weeks
Greyhound Racing Victoria EA 2016		Paid/unpaid personal/carers Paid special maternity not exceeding paid	First 20 weeks Completion of 20 weeks

		parental leave in this EA	
Parks Victoria EA 2016	6.13 Special Parental Leave	Paid/unpaid personal/carers Paid special maternity not exceeding paid parental leave in this EA	First 20 weeks Completion of 20 weeks
Parliament of Victoria EA 2016	1.13 Special Parental Leave	Paid/unpaid personal/carers Paid special maternity not exceeding paid parental leave in this EA	First 20 weeks Completion of 20 weeks

WA

Public Service and Government Officers CSA General Agreement 2017	25.6 Payment of Paid Maternity Leave	'entitled to remain on paid maternity leave if the pregnancy results in other than a live child'	
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SA

Flinders University EA 2014-2017	A21.1 Eligibility and entitlement	Six weeks paid and 46 weeks unpaid	Medically defined miscarriage or stillbirth
University of South Australia EA	4.5.22 Paid Maternity Leave on late pregnancy miscarriage or stillbirth	Seven weeks calculated from the date of miscarriage or stillbirth not inclusive of any maternity leave taken for the same pregnancy.	Six weeks leading up to expected birth date.**

Tasmania

University of Tasmania Staff Agreement 2013-2016	55.8 Where pregnancy does not result in the birth of a child	Entitled to paid and unpaid on the same basis as maternity leave (as per this agreement)	Not less than 20 weeks**
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Non CPSU NSW/PSA coverage

Independent Education Union of Australian NSW/ACT Branch (IEUA) EA NSW and ACT Catholic Systemic Schools	38.1 (g) Parental Leave (primary care –giver)	Where employee has commenced paid parental leave & subsequently the pregnancy results in a still birth.	Salary/wages for the period of parental leave taken by the employee.
UTS Student Association 2014 EA	33.9 6.8.2 6.8.3		20 days paid patently leave

*Universities - University agreements have the best provision relating to miscarriage and stillborn leave; also requiring medically definition. Many clauses refer to staff with more than 12 months continuous service.

** Clauses indicate late pregnancy i.e. after 20 weeks.

International

The International Labour Organisation's (ILO) Committee of Experts on the Application of Conventions and Recommendations (CEACR) has stated that postnatal compulsory leave of 6 weeks should be provided to all women in the event of a stillborn child, as a health-related measure.²

According to the ILO, only 12 of 170 countries with maternity benefit policies included specific provision for stillbirths; an average of 11 days leave for mothers and an average of 1 day off for fathers.³

Of those without specific provisions, a number of countries also have protections based on assisting parents via the provision of leave and protection from discrimination based on maternity⁴.

These include:

Denmark	13(1) Right to absence in special cases ⁵	14 weeks for mothers, 2 weeks for fathers	Unspecified in the Consolidation Act 2009; 21 Weeks onwards in the City of City of Copenhagen. ⁶
Iceland	20 The right to payment of a maternity/paternity grant in the event of	8-12 weeks	18-22 weeks

² International Labour Organisation (2014), *Maternity and paternity at work: Law and practice across the world*, Geneva.

³ The Lancet Ending Preventable Stillbirths investigator group (2016), 'Stillbirths: economic and psychological consequences', *Lancet*, Vol. 387, pp604-16

⁴ ILO, Maternity protection Resource Package, From Aspiration to Reality for All, Employment Protection and non discrimination <http://mprp.ilo.org/allegati/en/m9.pdf>

⁵ <https://bm.dk/media/7025/consolidation-act-on-entitlement-to-leave-and-benefits-in-the-event-of-childbirth.pdf>

⁶ <https://international.kk.dk/artikel/am-i-entitled-parental-leave-case-miscarriage>

	a stillbirth or a miscarriage ⁷		
Guinea-Bissau	ILO*	8 weeks	N/A
Uganda	ILO*	8 weeks	N/A
Indonesia	Article. 93 – (2)(C) and (4) (e) ⁸	6 weeks	N/A
India	ILO*	6 weeks	Compulsory for all women immediately following the day of their delivery or miscarriage.
South Africa **	Section 25 Amended Basic Conditions of Employment Act ⁹	6 weeks	(4) An employee who has a miscarriage during the third trimester of pregnancy or bears a stillborn child is entitled to maternity leave for six weeks after the miscarriage or stillbirth, whether or not the employee had commenced maternity leave at the time of the miscarriage or stillbirth.
Vietnam **	articles 34 and 35 of the Law on Social Insurance	20-50 days	The longer a female employee is pregnant, the more working days they are allotted to take off. One to three months of pregnancy will guarantee twenty working days off, three to six months is granted forty working days off, and a pregnancy over six months will be fifty working days off. In the case of a miscarriage or termination of pregnancy, women are granted leave as well.

⁷ Ministry of Welfare (2015), *Act on Maternity/Paternity Leave and Parental Leave*, Iceland.

⁸ State Gazette of the Republic of Indonesia (2003), *MANPOWER. Labour. Work Agreement. Employment Relations. Inspection. Termination of Employment. Workers' Institute. Wages. Central Government. Regional Governments.*, Jakarta Indonesia.

⁹ <http://www.labour.gov.za/DOL/legislation/acts/basic-conditions-of-employment/read-online/amended-basic-conditions-of-employment-act-21>

China**10		Varies province to province with following minima 15 days <3months >4months 6 weeks	Furthermore, no less than 15 days of maternity leave shall be offered in cases of abortion after a pregnancy shorter than four months, and no less than six weeks of maternity leave in cases of miscarriage/abortion after a pregnancy longer than four months.
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* Source: Compiled by United Nations Statistics Division based on information from ILO database: MATERNITY LEAVE - Duration of compulsory leave. Last accessed December 2015

**ILO except where indicated

¹⁰ China Briefing, Expecting in China: Employee Maternity Leave and Allowances

April 6, 2017

Source: Community and Public Sector Union New South Wales, answers to questions on notice, 8 August 2018 (received 14 September 2018).

