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,*

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[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

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[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]

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[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 Australia[14]

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

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[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]

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[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]

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[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].

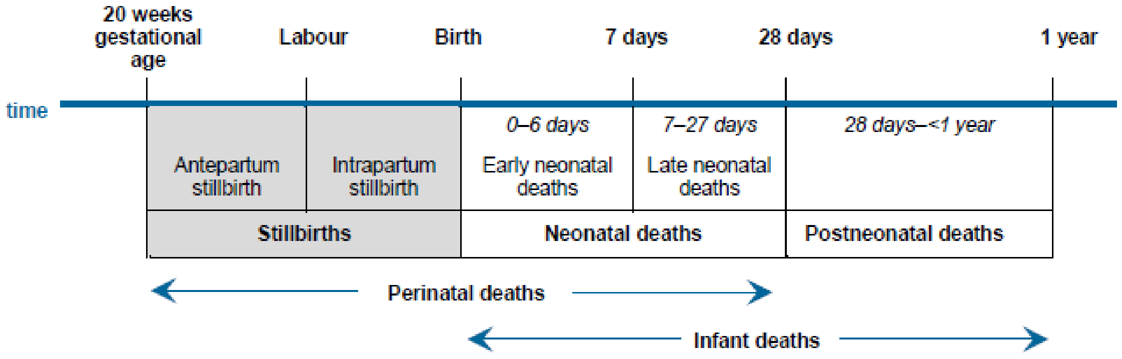
4.28 As a result, stillbirth data are recorded differently making it difficult to determine the rate of stillbirths across Australia. This is especially problematic where a woman moves from her place of residence in one jurisdiction in order to give birth in another jurisdiction.[28]

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 Australia[30]



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]

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[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

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[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 Donnolley, *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

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[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

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[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

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[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

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[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

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[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]

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[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

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[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 Donnolley, *Committee Hansard*, 8 August 2018, p. 2; Mrs Clare Rannard, *Committee Hansard*, 8 August 2018, p. 7; Ms Donnolley, *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 Donnolley, 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 Donnolley 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

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[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 Donnolley, *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 Donnolley, *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:

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[76] Mrs Rannard, *Committee Hansard*, 8 August 2018, p. 6; Ms Donnolley, *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

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[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

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[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 Donnolley, *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:

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[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

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[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]

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[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

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[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 (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]

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[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 port-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]

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[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

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[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 Shoring 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 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.