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

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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].

heath 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]

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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).

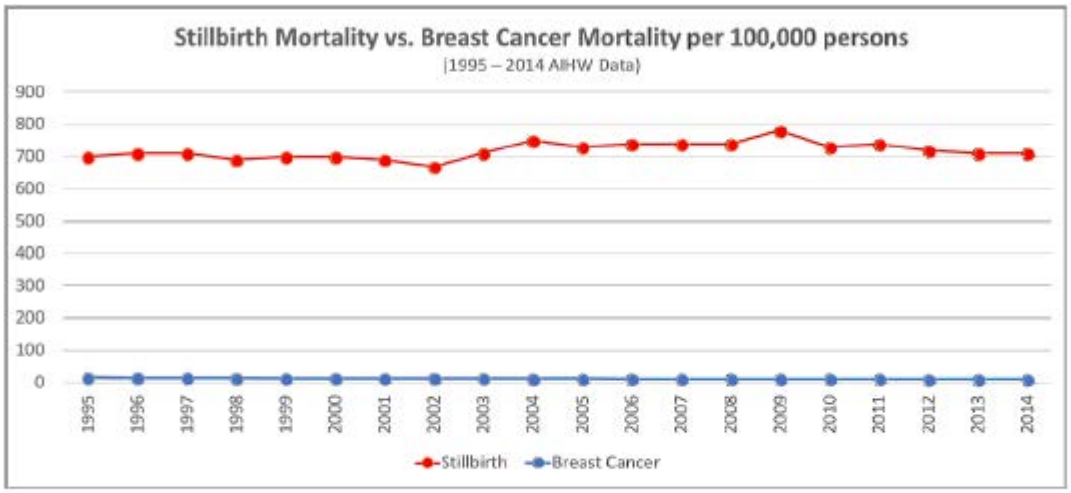
12 Consultations closed on 31 August 2018 to ensure that the second set of Priorities will take effect from the day the inaugural MRFF Priorities expire, on 8 November 2018. Australian Medical Research Advisory Board, *Medical Research Future Fund: 2018–2020 Priorities Consultation Discussion Paper*, 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 persons[16]



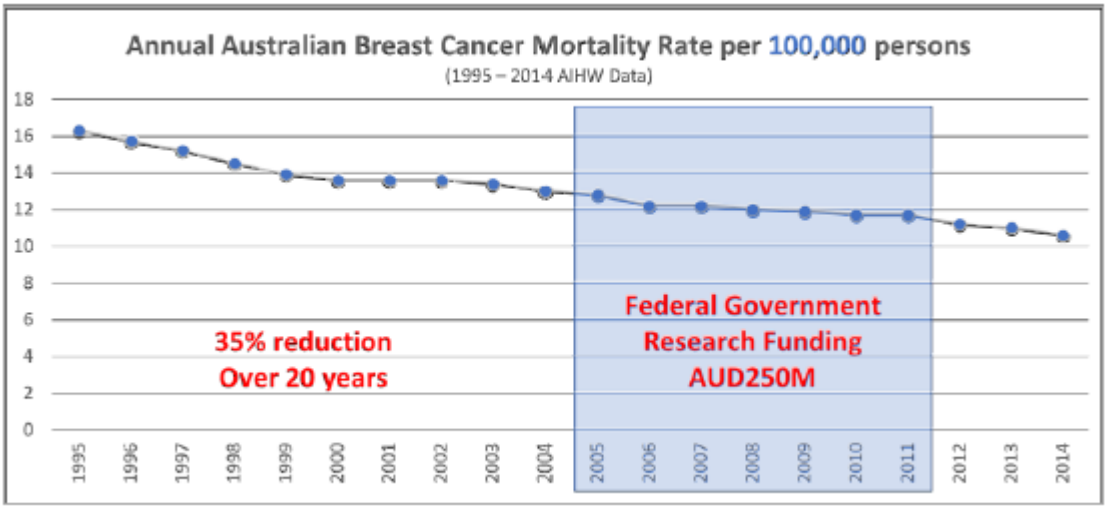
5.17 Red Nose noted that its investment of $17 million into Sudden Infant Death Syndrome (SIDS) research had contributed to an 85 per cent reduction in the incidence of SIDS. It then compared the levels of federal government research funding in relation to the annual mortality rate for breast cancer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

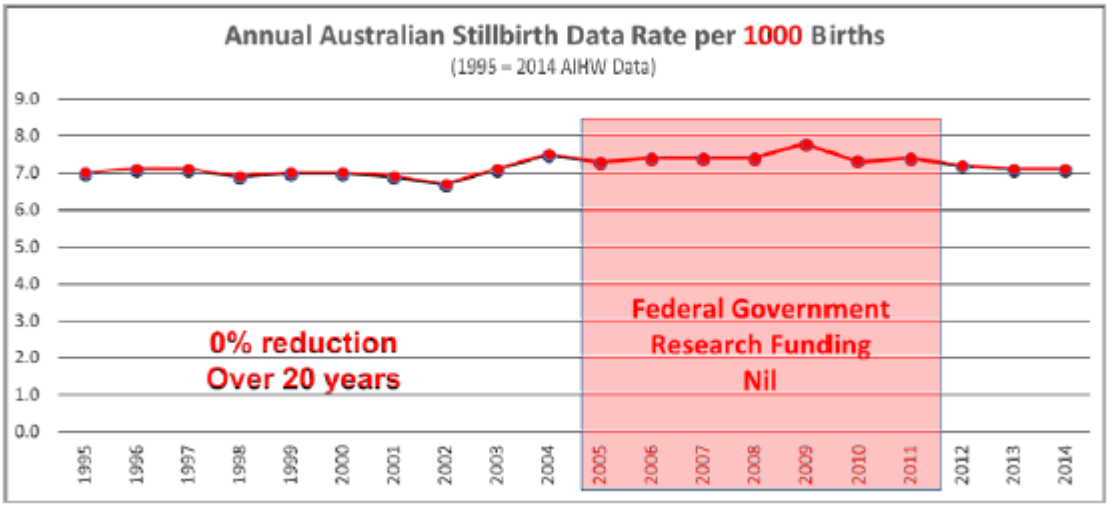
5.18 Red Nose noted that funding provided from the NHMRC for stillbirth research has increased since 2012, totalling $5.4 million over the last six years. It submitted, however, that a significant increase in funding is required for stillbirth research and for developing new diagnostic tools to prevent 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 stillbirth[18]





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

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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]

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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

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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 5*6, 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

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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 Heath 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]

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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 Heath 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,

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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]

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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

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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]

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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 Donnolley, *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.