Chapter 8

The future of stillbirth research and education in Australia

8.1 Stillbirth affects more than 2000 Australian families each year, and the economic and social costs are having significant effects on families, communities, the health system, and the Australian economy. The Centre for Research Excellence in Stillbirth (Stillbirth CRE) summarised the case for making stillbirth research and education a national priority.

> Many stillbirths are preventable, and Australia is underperforming in the challenge to reduce deaths and improve care and support for those who experience stillbirth…Stillbirth is an issue of national significance that requires coordinated leadership and action across all levels of Australian government to improve the current and future wellbeing of Australian women, their families and our wider society.[1]

8.2 This chapter considers the future of stillbirth research and education in the context of international and national policy frameworks, and strategies that could be implemented to reduce the rate of stillbirth in Australia.

International policy context

8.3 Stillbirth has not been high on the international health agenda, and was not listed as a priority area in either the United Nations' (UN) Millennium Development Goals (MDG) (covering the period 2000 to 2015), nor the Sustainable Development Goals (SDG) (covering the period 2016 to 2030) which have focused on other areas of maternal and child health.

8.4 However, evidence suggests that inclusion in high-level international agenda is having a significant impact on country level outcomes. For example, neonatal deaths and maternal deaths, both of which were targeted under the MDGs, have reduced significantly, while the stillbirth rate has not reduced by the same amount.[2]

8.5 The lack of progress in reducing stillbirth rates internationally has led to calls for its inclusion in international policy frameworks. The UN released its Global Strategy for Women's and Children's Health in 2010 and, in 2014, the World Health Organisation (WHO) launched *Every Newborn: An Action Plan to End Preventable*

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1 Centre for Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, p. 2.

2 V Flenady, P Middleton, GC Smith, et al, 'Stillbirths: The Way Forward in High-Income Countries', *The Lancet*, vol. 377, no. 9778, 14 April 2011, pp. 1703−1717, https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)60064-0/fulltext (accessed 12 November 2018).

Deaths, providing a strategic framework aimed at ending preventable newborn deaths and stillbirths worldwide by 2035.[3]

8.6 In addition, the WHO Global Reference List of 100 Core Health Indicators was recently updated to include the rate of stillbirths (based on the WHO definition) as a core indicator for countries to measure the quality of health care services.[4]

Australia's policy framework

8.7 A range of national, state and territory governments, hospitals, research institutions and advocacy groups are engaged in research into the causes of stillbirth and education about the risk factors. However, there is no coordinated national policy framework that sets national targets for reducing stillbirth, nor consistent national standards for stillbirth reporting, research and education.[5]

8.8 State and territory governments are largely responsible for implementing laws and policies in relation to stillbirth, including health care services, registration of stillbirths, investigations, data collection, health and related policy and law.

8.9 As a result, stillbirth data collections, research initiatives and education strategies tend to be piecemeal, subject to different jurisdictional policies and clinical approaches and fragmented, short-term funding arrangements.

8.10 Whilst there have been attempts to coordinate policy at the national level, progress has been intermittent and there is still no coherent national policy framework that seeks to reduce the incidence of stillbirth in Australia.

National Strategic Approach to Maternity Services

8.11 The National Maternity Services Plan 2010−2015, developed under Commonwealth leadership, concluded on 30 June 2016.[6] In April 2016, the Australian Health Ministers' Advisory Council (AHMAC) agreed to develop a National Framework for Maternity Services. This was discontinued and, in September 2017, the AHMAC agreed to start a new process to develop a National Strategic Approach to Maternity Services (NSAMS).

8.12 The final NSAMS is intended to provide an overarching national policy framework for maintaining Australia’s high-quality maternity care system, and working towards further improvements in line with contemporary practice, research

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3 World Health Organisation (WHO), *Every Newborn: An Action Plan to End Preventable Deaths*, June 2014, p. 5.

4 WHO, *Global Reference List of 100 Core Health Indicators (plus health-related SDGs)*, 2018 edition, http://www.who.int/healthinfo/indicators/2018/en/ (accessed 23 July 2018), p. 26.

5 The United Kingdom, for example, has set a target to reduce stillbirths by 25 per cent by 2025.

6 Australian Health Ministers' Conference (AHMAC), *National Maternity Services Plan*, 2011, http://www.health.gov.au/internet/main/publishing.nsf/content/8AF951CE492C799FCA257BF0001C1A4E/$File/maternityplan.pdf (accessed 25 September 2018).

and international developments. The deadline for submissions in the first round of consultation on the NSAMS closed on 18 June 2018.[7]

8.13 A second round of face-to-face consultations was conducted in October−November 2018, with a deadline for submissions of 19 November 2018. The NSAMS is expected to be completed by July 2019.[8]

8.14 A second consultation paper outlined a set of draft strategic directions to 'provide an overarching national approach to maintaining Australia's high-quality maternity care system', and included a strategic direction that 'Service providers implement measure to reduce the rates of stillbirth', based on the success of the United Kingdom (UK) *Saving Babies Lives* Care Bundle and research being conducted by Stillbirth CRE. It also recommended access to bereavement care for women who experience stillbirth, neonatal death or whose babies have major congenital anomalies.[9]

Towards a National Stillbirth Action Plan

8.15 A number of submitters and witnesses called for the Council of Australian Governments (COAG) to make stillbirth research and education a national priority.[10]

8.16 Stillbirth CRE proposed a number of recommendations, developed in partnership with a number of institutions and organisations with expertise in research, policy and healthcare practice in Australia and internationally. It recommended that COAG provide coordinated leadership and action to use data to drive change; improve clinical practice; invest in research; increase public awareness; and improve perinatal pathology services.[11]

8.17 Similarly, Stillbirth Foundation Australia called for a comprehensive and coordinated policy response led by the Commonwealth that is properly funded, sets clear targets and includes meaningful evaluation of implementation and progress.

> Together, data, research and education, both at a community level and a medical practitioner level, and moving support and advice from a piecemeal

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7 AHMAC, *Developing a National Strategic Approach to Maternity Services*, Consultation Paper 1, Department of Health, 2018, additional information received 19 October 2018, p. 15.

8 Department of Health, *National Strategic Approach to Maternity Services*, https://consultations.health.gov.au/office-of-the-chief-nursing-and-midwifery-officer/national-strategic-approach-to-maternity-services/ (accessed 25 September 2018); Department of Health, answers to questions on notice, 21 September (received 8 October 2018).

9 AHMAC, *Strategic Directions for Australian Maternity Services*, Consultation Paper 2 (draft), Department of Health, 2018, additional information received 19 October 2018, pp. 3 and 11.

10 See for example, Stillbirth CRE, *Submission 56*, p. 2; Australian College of Nursing, *Submission 20*, p. 4; Australian College of Midwives, *Submission 24* [p. 6]; Hunter Medical Research Institute (HMRI), *Submission 36* [p. 3]; Ms Natasha Donnolley, *Submission 116*, p. 5.

11 Stillbirth CRE, *Submission 56*, pp. 2−3. The submission was prepared in partnership with the Perinatal Society of Australia and New Zealand, Australian College of Midwives, Women's Healthcare Australasia, Stillbirth and Neonatal Death Support (Sands Australia), Still Aware and the International Stillbirth Alliance.

> approach to a coordinated strategy, holds the key to ensuring more healthy births and fewer stillbirth tragedies. If we can get the policy settings right, we believe we are on the cusp of dramatically reducing the rate of stillbirth in Australia...we need a plan that is developed by government, after consultation with many stakeholders, with measureable targets, a built-in review process and supported by a significant funding package that is proportionate, in line with precedent and will work.[12]

8.18 Stillbirth Foundation Australia suggested that it could be modelled on the recently-released National Action Plan for Endometriosis with strategies focused on:

- public education about preventing stillbirth;
- a dedicated research fund administered with clear priorities as part of a broader strategy;
- the harmonisation of data collection and management across jurisdictions, with regular public reporting periods; and
- improving the understanding and awareness of stillbirth among health professionals working at every stage of the clinical pathway.[13]

8.19 Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute (HMRI), similarly emphasised the need for national leadership to drive the establishment of a national reporting system and prevention initiatives, as well as a commitment to longer-term funding for stillbirth research.

> This is not a short-term solution. This needs to be a long-term commitment over 10 years, to say, 'We can achieve this.' I think we can achieve a whole lot more than 25 per cent in certain pockets of Australia, but I think that there are going to be other pockets in Australia where it will be extremely difficult to bring about change.[14]

8.20 Professor Susan Walker, Department of Obstetrics and Gynaecology; and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne, emphasised the importance of coordinated and collaborative approaches to research, education and care, and the need to focus on reducing preventable stillbirth.

> Our focus is on reducing preventable stillbirth. We suggest that reducing preventable stillbirth requires strong connections of women with high-quality and accessible pre-pregnancy, pregnancy and intrapartum care; of health services with research institutes; of policymakers with timely access to reliable data; of government, philanthropic and industry backers with

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12 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 11.

13 Stillbirth Foundation Australia, *Submission 33*, pp. 15−16; see Department of Health, *National Action Plan for Endometriosis*, July 2018, http://www.health.gov.au/internet/main/publishing.nsf/Content/endometriosis (accessed 26 September 2018).

14 Professor Craig Pennell, Senior Researcher, HMRI, *Committee Hansard*, 9 August 2018, p. 21.

> leaders in research; and of those researchers with their national and international counterparts.[15]

Red Nose Stillbirth Prevention Program

8.21 Red Nose stated that the organisation has set a goal of reducing the incidence of stillbirth in Australia, having achieved an 85 per cent reduction in Sudden Infant Death Syndrome (SIDS) through its public health campaign by adopting a simple formula:

> …drive research and turn breakthroughs into education and advocacy, whilst continuing to provide bereavement support to families who have lost children, regardless of gestation or age, as they navigate the horrendous road of grief in front of them.[16]

8.22 Red Nose reported on the development of its Stillbirth Prevention Program, in collaboration with the Stillbirth CRE and the team that developed and implemented the successful Scottish Maternity Care Quality Improvement Collaborative initiative.[17] The program aims to reduce the rate of stillbirth in Australia by 20 per cent in five years and contains five modules:

(i) patient education campaign about stillbirth;

(ii) implementation of a new package to reducing smoking in pregnancy;

(iii) raising awareness for reduced fetal movement;

(iv) risk assessment and fetal surveillance for fetal growth restriction; and

(v) implementing a new Perinatal Mortality Review Tool.

8.23 Red Nose advised that it had secured matching funds from three partners (University of Newcastle, $100 000; HMRI, $100 000; and John Hunter Hospital, $100 000), and is seeking to partner with government ($300 000) to enable the modules to be developed, implemented (in the John Hunter Hospital) and evaluated.[18]

8.24 In addition, Red Nose has been offered the new Perinatal Mortality Review Tool, utilised in Scotland for several years and recently adopted in the UK, and will

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15 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology; and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne, *Committee Hansard*, 9 August 2018, p. 25.

16 Mrs Jane Wiggill, Manager, Health and Advocacy, Red Nose, *Committee Hansard*, 9 August 2018, p. 18.

17 See Chapter 7 for details of the Maternity and Children Quality Improvement Collaborative, Healthcare Improvement Scotland, https://ihub.scot/spsp/maternity-children-quality-improvement-collaborative-mcqic/ (accessed 10 October 2018); also see Professor Pennell, HMRI, *Committee Hansard*, 9 August 2018, p. 21.

18 Red Nose, *Submission 63*, p. 10. Red Nose, formerly SIDS and Kids, was formed 40 years ago by parents who had suffered loss.

evaluate the tool in a clinical setting for potential application in Australian hospitals as part of its vision to develop 'Red Nose Hospitals'.[19]

Possible strategies

8.25 The committee considered suggestions from submitters and witnesses for a range of possible actions on stillbirth reporting and data collection, research and education. It also considered suggestions for improved models of maternity care that may contribute to reducing the rate of stillbirth and providing culturally-appropriate care for families who have experienced stillbirth.

Strategy 1: Stillbirth reporting and data collection

8.26 Whilst Australia has the necessary expertise and a collaborative research environment, there is a lack of incentive for collecting agencies to link their data into a national system. As a result, there is a very long lead-time in collecting data, undertaking research and implementing the results of research. As Professor Pennell stated:

> Until there is a unified approach to complex health issues across Australia, we're not going to achieve the solution, whether it be stillbirth or whether it be Indigenous health. Whilst we have meetings with seven groups coming together arguing about who's paying for what, where and how, there needs to be some degree of central control over elements of health.[20]

8.27 Consideration could be given to linking national perinatal data collection to healthcare funding agreements, in order to provide an incentive to jurisdictions to increase the number of mandatory reporting items.[21]

Strategy 2: Stillbirth research

8.28 As discussed in Chapter 3, the lack of a nationally consistent set of research priorities is hampering stillbirth researchers.

8.29 The idea of a roundtable of relevant stakeholders to consider and advise on collaborative research partnerships and funding has merit.[22] It would enable the government to draw on a range of expertise and perspectives on stillbirth, and provide a valuable vehicle for consultation between government, the philanthropic sector and the corporate sector, as well as experts, clinicians, academics, parents and stillbirth advocates.

8.30 A roundtable approach could also explore opportunities for longer-term funding arrangements that would enable the implementation of large-scale, multifaceted research projects into stillbirth causes and prevention.

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19 A Red Nose Hospital will require implementation of all five modules and a site visit from an external review team.

20 Professor Pennell, HMRI, *Committee Hansard*, 8 August 2018, p. 25.

21 Ms Natasha Donnolley, *Committee Hansard*, 8 August 2018, p. 10.

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

Strategy 3: Stillbirth education

8.31 The committee acknowledges that the risk of stillbirth is not widely known or discussed, and that a stillbirth education and awareness campaign is required to help overcome the stigma, misinformation and silence that currently surrounds stillbirth in Australia.

8.32 Stillbirth education programs are largely undertaken by voluntary and non-government organisations, who argued that it should be considered a national policy priority. As Ms Natasha Donnolley noted:

> In summary, stillbirth needs to be a COAG-endorsed, high-priority research area. There needs to be a government funded public awareness campaign, and multidisciplinary education in how clinicians need to broach the subject of stillbirth during women's antenatal education. There needs to be better support for NGOs who provide care for families in this area. Our organisations, both in stillbirth prevention and bereavement support, are saving the government millions of dollars, and it's not much to ask for some of that back.[23]

8.33 The committee commends the development of the Red Nose Stillbirth Prevention Program and the concept of Red Nose Hospitals as an important initiative aimed at reducing stillbirth in Australia. The committee notes that, by drawing on international models and collaborations, Red Nose has succeeded in reducing the costs of developing the program in Australia.[24]

8.34 The committee considers that the Australian government should conduct a national stillbirth public awareness campaign, drawing inspiration from successful public health campaigns such as SIDS, Quit Smoking, and the Heart Foundation, aimed at:

- helping to raise awareness amongst pregnant women and their families about the known causes and risks of stillbirth, regardless of whether their pregnancy is considered high-risk;
- assisting clinicians and other health professionals to overcome the culture of silence surrounding stillbirth, and making it easier for them to have conversations about the causes and risks with pregnant women and their families;
- enabling employers and work colleagues to be better informed about stillbirth and equip them with the necessary skills to support bereaved parents returning to work following a stillbirth;
- increasing awareness of stillbirth amongst the broader Australian community; and
- providing flow-on effects for stillbirth research and education in the form of increased funding and opportunities to establish public-private partnerships.

23 Mrs Donnolley, *Committee Hansard*, 8 August 2018, p. 3.

24 Red Nose, *Submission 63*, p. 11.

Strategy 4: Models of care

8.35 The committee heard ample evidence about the merits of a continuity of maternity care model that can be adopted by hospitals, clinicians and other health professionals.

8.36 Professor Caroline Homer, Distinguished Professor of Midwifery, University of Technology Sydney, considered that the National Maternity Services Plan 2011 had understated the importance of continuity of care, and argued that a new national strategy was required to ensure consistency and continuity in maternity services for all Australian women.

> Maternity services in hospitals are generally not on the top list of things to worry about, and so the impetus for change is not really there. Hospitals funded by the state governments are generally worried about their emergency room and their waiting lists. With maternity services, generally everything goes well and nicely and it just doesn't get political push and it doesn't get hospital mandate—'Actually it's terrible that 300 of our 6,000 women get what we consider evidence based practice but the rest just get ordinary care.' It sort of gets put on the side.[25]

Committee view

8.37 There has never been a national target or federal government commitment to reducing the rate of stillbirth in Australia. However, the evidence suggests that, in countries like Scotland where such a commitment has been made, policies and practices have been changed and stillbirth rates have declined significantly as a result.

8.38 The committee acknowledges that the AHMAC is currently consulting stakeholders on the development of a National Strategic Approach to Maternity Services (NSAMS), with the aim of guiding national maternity services policy, aligning delivery of services with available evidence, and monitoring performance and outcomes so that progress can be measured and improvements identified.[26]

8.39 The committee notes that submissions in the first consultation phase closed on 18 June 2018, and that a second round of face-to-face consultations is underway in October−November 2018 with the NSAMS due to be completed by July 2019.

8.40 Recognising that the outcomes of the NSAMS development process will not be available within the timeframe for this inquiry, the committee urges the Australian government to consider the information and recommendations arising from this inquiry when considering how stillbirth research and education will be addressed in the NSAMS.

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25 Professor Caroline Homer, Distinguished Professor of Midwifery, University of Technology Sydney, *Committee Hansard*, 8 August 2018, p. 34.

26 The Hon. Greg Hunt, MP, Minister for Health, *Media release*, 2 March 2018, http://www.health.gov.au/internet/ministers/publishing.nsf/Content/8FCA64944BFBB90CCA258243007CF802/$File/GH022.pdf (accessed 3 October 2018).

8.41 In addition, whilst acknowledging the current process to develop a national strategic approach for Australian maternity services, the committee strongly recommends that a National Stillbirth Action Plan should also be developed for specific consideration and endorsement by the AHMAC.

8.42 The committee recognises that a National Stillbirth Action Plan requires partnerships between governments, philanthropic organisations, academic institutions and health services, and that such partnerships should inform the development of the National Stillbirth Action Plan.

8.43 The committee considers that the Action Plan should form part of the NSAMS, and include the following elements:

- a national target of 20 per cent reduction in the rate of stillbirth in Australia over the next three years;
- guidelines for establishing nationally-coordinated and consistent stillbirth reporting standards and dataset;
- an online register of current research and data relating to stillbirth designed for researchers and health professionals and available to the general public;
- a set of national research priorities focused on reducing stillbirth, especially in relation to unexplained stillbirth; and
- an public education campaign drawing on successful public health campaigns such as SIDS and Quit Smoking.

Recommendation 15

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

- **a nationally-coordinated and consistent framework for stillbirth reporting and data collection;**
- **an online register of stillbirth research and data;**
- **national research priorities; and**
- **a public education campaign.**

8.45 In addition, the committee considers that the Australian government should develop continuity of maternity care guidelines that encourage hospitals, clinicians and other health professionals to provide consistency and continuity in maternity services for all Australian women.

8.46 Details of each of these elements are discussed in previous chapters, but the committee considers that they represent the key strategic areas to be addressed in the National Stillbirth Action Plan.

8.47 The committee considers that annual progress reports on the development and implementation of the National Stillbirth Action Plan to reduce the rate of stillbirth in Australia should be provided to COAG's Health Council and made publicly available.

Recommendation 16

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

Senator Malarndirri McCarthy
Chair