



Australian Government

Australian Government response to:

*The Senate Select Committee on Stillbirth Research
and Education Report*

July 2019

Acknowledgements

The Australian Government thanks the individuals and organisations that have contributed to the inquiry, especially those who have shared their personal stories. The Australian Government acknowledges the many families and loved ones who have lost babies through stillbirth and expresses its sincere condolences to them.

Foreword

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

The Australian Government welcomes the Report and the Committee's recommendations. Stillbirth has a devastating impact on women, their partners, and families. The Australian Government is committed to reducing stillbirth rates, and has a number of initiatives that are intended to prevent stillbirths and support parents and families affected by stillbirth.

In 2016, the National Health and Medical Research Council (NHMRC) awarded a \$2.5 million grant over five years (2016-17 to 2021-22) for stillbirth research, under its Centres of Excellence (CRE) funding scheme. This grant, administered through the University of Queensland, aims to strengthen collaborations locally and internationally, reduce stillbirth and improve care for parents and families following stillbirth.

On 5 December 2018, as an initial response to the Report, the Australian Government announced \$7.2 million in initiatives designed to reduce stillbirths:

- \$3 million for stillbirth education and awareness programs for women and medical practitioners;
- \$1.2 million to the University of Melbourne for research to minimise preventable stillbirth through the use of biomarkers and ultrasound in late pregnancy; and
- \$3 million for stillbirth research through the Medical Research Future Fund.

The Australian Government also announced that it will develop a National Stillbirth Action and Implementation Plan, in collaboration with a range of stakeholders including State and Territory Governments, health professionals, researchers, bereaved parents and non-government organisations.

A Stillbirth Roundtable was held with key stakeholders on 12 February 2019 to further the process of identifying national priorities and discuss strategies to reduce stillbirth.

A major Australian Government funded initiative that is currently under way involves the national rollout of the Safer Baby Bundle. This evidence based package aims to

reduce risk factors for stillbirth and improve management of pregnant women who may be at increased risk of stillbirth. The Safer Baby Bundle is currently being implemented in New South Wales, Queensland and Victoria and will be extended to all states and territories. It is jointly funded through a NHMRC Partnership Project and the Medical Research Future Fund (MRFF).

Supporting bereaved parents is a key component of the Australian Government's approach to stillbirth. At the Stillbirth Roundtable in February 2019, a further \$26 million towards supporting perinatal mental health was announced. This initiative, which was increased to \$43.9 million in the 2019-20 Budget, will include support for families experiencing grief following the death of a child. Organisations will be invited to apply for grants focusing on perinatal mental health support, perinatal loss and bereavement peer support and perinatal mental health promotion and awareness programs. In addition to this, Sands Australia is receiving funding of \$1.3 million to deliver an intensive support service to families affected by stillbirth. This will commence support while bereaved mothers are in hospital and continue that support when the family returns home.

These elements combined represent a \$52.4 million investment.

This document represents the Australian Government's response to the Report recommendations. It has been coordinated and prepared by the Department of Health. The Attorney-General's Department has been consulted in relation to the response to Recommendation 1. Recommendations 2, 5, 8, 15 and 16 reference the the Council of Australian Governments (COAG) Health Council or the Australian Health Ministers Advisory Council (AHMAC).

The Australian Government recognises that many of the issues identified will require a cooperative and collaborative approach between the Australian Government and States and Territories. The Australian Government is committed to developing the National Stillbirth Action and Implementation Plan mentioned above in close consultation with State and Territory governments and in collaboration with other stakeholders and families.

Recommendation 1

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

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

Agreed.

The Australian Government accepts the recommendation and will review the operation of the *Fair Work Act 2009* (Fair Work Act) to ensure all related provisions provide a clear and consistent minimum standard, with improved support for those employees who have experienced stillbirth to recognise the grief and emotional trauma of such circumstances.

The Fair Work Act, including the National Employment Standards, sets out the minimum safety net for all national system employees. Employers and employees can agree to arrangements above any minimum standard specified in the Fair Work Act.

In addition to workplace leave entitlements under the Fair Work Act, parents in stillbirth situations may also receive Parental Leave Pay and Dad and Partner Pay, provided under the *Paid Parental Leave Act 2010* and administered by Centrelink.

Recommendation 2

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

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

Agreed in principle.

The Australian Government recognises that there is a need to improve national perinatal mortality data collections. The Australian Government currently funds the Australian Institute of Health and Welfare (AIHW) to collate and analyse perinatal data at a national level. The Australian Government will discuss this issue with States and Territories through AHMAC and other relevant health and data related government advisory councils and committees and will explore options for improving

perinatal mortality data collections. The AIHW Maternal and Perinatal Health Unit will also be consulted on this issue.

While the Australian Government cannot commit the State and Territories, we will submit the proposal to AHMAC with our support.

Recommendation 3

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

Agreed in principle.

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

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

Autopsies can collect useful information that can identify causes of stillbirth and contributing factors. State and Territory governments fund autopsy services as these are generally delivered in a public hospital setting. Strategies to support bereaved parents to make informed decisions in relation to autopsies and increase the number of autopsies undertaken following stillbirths will also be discussed with States and Territories.

Recommendation 4

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

Agreed in Principle.

The Australian Government delivers up to 7 per cent of non-general practice specialist medical training nationally, with state and territory governments responsible for funding and delivering the majority of specialist training in public hospital settings. In addition, the states and territories are the main employers of specialist trainees and fellows. The Australian Government supports this recommendation in principle and will discuss this issue with States and Territories when developing the National Stillbirth Action and Implementation Plan.

Recommendation 5

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

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

Agreed in Principle.

The Australian Government recognises the importance of building on existing support for stillbirth research in to the research agenda. This will be discussed with States and Territories through AHMAC.

In December 2018, the Australian Government announced an initial commitment of \$7.2 million for stillbirth related medical research and education programs. This includes \$3 million for stillbirth education and awareness programs for women and medical practitioners across Australia.

Recommendation 6

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

Agreed in Principle.

There are initiatives and opportunities available under the Medical Research Future Fund (MRFF) in the 2019-20 Budget. The Australian Government will provide \$3 million to the Stillbirth CRE (University of Queensland) to support stillbirth research under the MRFF. The MRFF is additional and complementary to the NHMRC and is set to enhance the research funding landscape through prioritised research investment. A number of MRFF initiatives are emerging as foundational, multi-year platforms that may benefit and be attractive to stillbirth researchers. Foundational MRFF initiatives focus on fellowships, clinical trials and research

translation. The funding principles that support MRFF principles have a strong emphasis on collaboration, contestability, impact and engagement with end users.

The NHMRC reviewed the structure of its grant program in 2016-17. This involved extensive consultation with external stakeholders, including the public, research sector, government, non-government organisations and international funding agencies. This review led to the development of a revised grant program which the NHMRC began implementing in 2017-18. Funding for the majority of NHMRC's grant opportunities is now for five years duration. The Government will request the NHMRC to conduct a review into the effectiveness of longer term funding cycles.

Recommendation 7

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

Agreed in principle.

Support for the establishment of a national biobank will be considered under infrastructure or data priorities as identified in the MRFF Priorities 2018-2020.

Recommendation 8

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

Agreed in principle.

The Australian Government supports the notion that all health care, including maternity care, should be culturally appropriate. The Australian Government is not directly involved in the planning and delivery of maternity services as it is a state and territory government responsibility. Each state and territory determines the models of maternity care it offers, taking into account the needs of their population. The Australian Government recognises that continuity of care models promote optimal health outcomes for mothers and babies and will write to all State and Territory Ministers seeking their support for action through AHMAC.

Recommendation 9

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

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

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

Agreed in principle.

The Australian Government recognises the need for high quality national guidelines that provide culturally appropriate support and information for bereaved families who have experienced stillbirth. The Australian Government will identify options to progress the development of such guidelines when developing the National Stillbirth Action and Implementation Plan, and will ensure they are evidence based and comply with NHMRC guideline development standards.

The Australian Government agrees that it is important to ensure that all families, including families from culturally and linguistically diverse backgrounds, are provided with culturally appropriate support and information to enable better health outcomes. As an example, funding of \$1,274,000 is being provided to the Multicultural Centre for Women's Health from 2019-20 to 2022-23 to improve the capacity of immigrant and refugee women and their families to make informed choices about family planning and reproductive health by:

- providing nationally-focused health education and information sharing via national media and new technologies;
- building capacity of family planning and reproductive health professionals to work in more culturally appropriate ways; and
- providing up-to-date, evidence based policy advice and information to the Australian Government and other stakeholders.

Recommendation 10

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

Agreed.

The Australian Government agrees that national stillbirth public awareness campaigns can be effective to promote public awareness of stillbirth. As an initial

response to the Senate Committee Report, the Australian Government announced it would provide \$3 million for stillbirth education and awareness programs. A Roundtable was held with key stakeholders on 12 February 2019. Reducing smoking in pregnancy, awareness of fetal movements and side sleeping in pregnancy were identified as important evidence based messages to be included in public awareness campaigns. These messages will be key components of stillbirth education and awareness programs that are being developed.

The education component of the funding will be delivered in conjunction with the Safer Baby Bundle program being delivered by the States and Territories.

Further opportunities will be explored as part of the development of a National Preventative Health Strategy.

Recommendation 11

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

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

Agreed in principle.

The Australian Government recognises the importance of equipping health professionals with up to date, evidence based knowledge in relation to stillbirth. The Australian Government-funded Safer Baby Bundle, now being rolled out nationally, will help ensure that health professionals involved in antenatal care are able to identify risk factors for stillbirth and improve management of pregnant women who may be at increased risk of stillbirth. The Australian Government is also aware that the Stillbirth CRE has been working in partnership with the Australian College of Midwives, Royal Australian College of General Practitioners and Royal Australian and New Zealand College of Obstetricians and Gynaecologists to develop training modules for their respective professions. These two initiatives will help ensure that comprehensive training on stillbirth prevention is available to general practitioners, midwives and obstetricians.

As mentioned in the foreword, the Australian Government is committing a total of \$52.4 million to support parents and families experiencing grief following a stillbirth or the death of a child.

On 5 December 2018, as an initial response to the Report, the Australian Government announced \$7.2 million in initiatives designed to reduce stillbirths:

- \$3 million for stillbirth education and awareness programs for women and medical practitioners;
- \$1.2 million to the University of Melbourne for research to minimise preventable stillbirth through the use of biomarkers and ultrasound in late pregnancy; and
- \$3 million for stillbirth research through the Medical Research Future Fund.

The Australian Government is providing \$43.9 million in the 2019-20 Budget for perinatal mental health, including support for parents and families following the death of a child. Organisations will be invited to apply for grants focusing on perinatal mental health support, perinatal loss and bereavement peer support and perinatal mental health promotion and awareness programs.

In addition, Sands Australia is receiving funding of \$1.3 million from 2019-20 to 2020-21 to deliver an intensive support service to families affected by stillbirth. This program will provide a trained support person to support bereaved parents and families following stillbirth. Support will be tailored to each family and may include assistance with memory making activities, medical appointments, obtaining and understanding autopsy results, administration and paperwork associated with losing a child, and returning to work and school.

Additional strategies for training and educating health professionals and supporting bereaved parents and families will be considered when developing the National Stillbirth Action and Implementation Plan.

Recommendation 12

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

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

Agreed in principle.

States and Territories are the system managers of the public hospital system. Community health services are managed by state and territory governments, with local government playing a role in some instances. It is up to each state and territory to determine the protocols that apply to the hospitals and health facilities that fall under their responsibility. The development of such protocols will be discussed through AHMAC.

As noted above, the Australian Government is providing \$43.9 million in the 2019-20 Budget for perinatal mental health, including support for parents and families following the death of a child. Organisations will be invited to apply for grants focusing on perinatal mental health support, perinatal loss and bereavement peer support and perinatal mental health promotion and awareness programs. In addition

to this, Sands Australia is being funded to deliver an intensive support service to families affected by stillbirth.

The Australian Government will write to all States and Territories through AHMAC encouraging them to adopt the above recommendations.

Recommendation 13

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

Agreed in principle.

With regard to research, Australians currently have access to 82 stillbirth related evidence reviews via the Cochrane Library. The Australian Government will explore the feasibility of a special collection of evidence reviews on stillbirth from the Cochrane Library.

The Australian Government supports the use of the NHMRC clinical practice guideline portal and register (<https://www.clinicalguidelines.gov.au/>) as the primary access portal for evidence based Australian guidelines relating to stillbirth.

The NHMRC advises that an important distinction should be drawn between evidence based clinical guidelines relating to stillbirth which are applicable to Australia and clinical guidelines relating to stillbirth generally. NHMRC has developed national standards for guidelines which should be applied and supported. Promotion of poor quality guidelines and/or guidelines that are not applicable to Australian clinical practice could detract from guidelines that meet the rigorous NHMRC guideline development standards and have a potential adverse impact on clinical practice and health outcomes.

Recommendation 14

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

Agreed in Principle.

The Australian Government recognises the importance of ensuring bereaved parents and their families are supported at work and in the broader community after experiencing a stillbirth. The Australian Government is funding Sands Australia to deliver an intensive support service to families affected by stillbirth. This service will provide support to bereaved parents and families in hospital following stillbirth and include support for transitioning back to work and school environments. The Australian Government will consider additional strategies for supporting bereaved

parents and families in consultation with States and Territories when developing the National Stillbirth Action and Implementation Plan.

Recommendation 15

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.**

Agreed.

On 5 December 2018, the Australian Government announced that it will develop a National Stillbirth Action and Implementation Plan. This will be developed in collaboration with States and Territories through AHMAC. Bereaved parents, health professionals, researchers, advocacy groups, and other key stakeholders will be consulted when developing the National Stillbirth Action and Implementation Plan.

The recommendations contained in the Report will be considered in the development of the National Stillbirth Action and Implementation Plan.

Recommendation 16

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.

Agreed in Principle.

Reporting will be amongst the issues considered in the development of the National Stillbirth Action and Implementation Plan. As the plan will be national, any reporting measures will be developed in consultation with states and territories, and agreed by all jurisdictions through AHMAC.

