



Australian Government
Department of Health

National Stillbirth Action and Implementation Plan

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Acknowledgement

We would like to acknowledge the families who have experienced stillbirth and their loved ones. Stillbirth is one of the most devastating and profound events that any parent is likely to experience. A culture of silence around stillbirth may mean that bereaved parents and families are left to deal with difficult personal, social and financial consequences with little or no support.

This Plan outlines actions towards reducing the rate of stillbirth and ensuring that, when stillbirth does occur, respectful and supportive bereavement care is available.

Please be aware that information in this document may trigger emotional responses among families who have experienced stillbirth.

Introduction

Stillbirth* has a profound and long-lasting effect on parents and families and often on their care providers. Globally, stillbirth continues to be a hidden tragedy surrounded by stigma and taboo. Although Australia is one of the safest places in the world to give birth, six babies are stillborn here every day, making it the most common form of infant death in Australia¹. In 2016, Australia's late gestation (28 weeks or more) stillbirth rate was estimated to be 35% higher than countries with the lowest rates². While the Australian stillbirth rate has decreased consistently - following a peak of 7.8 per 1,000 births in 2009 to 7.0 per 1,000 births in 2018 - the reduction is small, particularly when compared to that in neonatal deaths³.

While any pregnancy can result in stillbirth, there are significant equity gaps in stillbirth rates in Australia. Rates of stillbirth remain higher among Aboriginal and Torres Strait Islander women (see Action area 2), women from some migrant and refugee groups (see Action area 3), women living in rural and remote Australia or in the most socially disadvantaged areas of Australia, and women younger than 20 years (see Action area 4)⁴. Specific individualised strategies are required to reduce stillbirth rates among these groups.

Stillbirths are most frequently related to congenital anomaly and various maternal conditions⁴. However, for many a cause is never found. In 2015-16, almost 20% of all stillbirths and 45% of term stillbirths were classified as unexplained¹.

The Lancet stillbirth series in 2011⁵ and 2016² brought attention to the need to reduce stillbirth rates and to improve care for families who experience this tragedy. While not every stillbirth is preventable, countries including the United Kingdom, Northern Ireland and New Zealand have had success in reducing stillbirth rates. Their efforts can inform strategies to reduce stillbirth in Australia. It is anticipated that the development and implementation of this Plan - along with a range of activities already being undertaken by both government and non-government organisations (NGOs) - can contribute to significant reductions in stillbirth rates in Australia and improve bereavement care for families who have a stillborn baby.

Development of the Plan

In recent years, there has been considerable advocacy work undertaken by bereaved parents, advocacy groups, researchers, health professionals and NGOs to raise the profile of stillbirth. In 2017, a Centre of Research Excellence in Stillbirth (Stillbirth CRE) was funded by the National Health and Medical Research Council (NHMRC) to undertake a priority-driven research program working with key organisations representing the stillbirth community in Australia. This has occurred among growing recognition of the need for a strategic approach to reducing stillbirths in Australia and ensuring high quality care is provided to families who experience stillbirth.

In March 2018, the Senate established the Select Committee on Stillbirth Research and Education to inquire into the future of stillbirth research and education in Australia. The committee received 269 submissions and took evidence over six days of public hearings. The committee tabled its [report](#) in December 2018. As an initial response to the Senate Committee's recommendations, the Australian Government announced a National Stillbirth Action and Implementation Plan would be developed. This is the first national plan to strategically address the issue of stillbirth in Australia.

A draft Plan was developed based on the Senate Select Committee Report, the outcomes of a Stillbirth Roundtable held with key stakeholders in February 2019 and a document prepared by the Stillbirth CRE and Stillbirth Foundation Australia. In December 2019, a second Roundtable was held to enable key stakeholders to consider the draft Plan and have input into its content prior to broader consultation. Stakeholders involved in the process are listed in Appendix A.

* Stillbirth in Australia is defined as the birth of a baby without signs of life after 20 or more completed weeks of gestation or after attaining a weight of 400 g or more.

Between March and July 2020, a public consultation process was undertaken to seek feedback on the draft Plan. We are grateful to the individuals and organisations who took part in this process and further informed the development of the Plan.

This Plan has emerged from the efforts of bereaved parents, advocacy groups, health professionals and researchers to have stillbirth recognised as a public health issue. Strong political interest and bipartisan support have also helped raise the profile of stillbirth and pave the way for this Plan.

About this Plan

Vision

The vision for the National Stillbirth Action and Implementation Plan is to:

- reduce the number of stillbirths in Australia
- reduce disparities in stillbirth rates between population groups
- raise community awareness and understanding of stillbirth
- ensure high quality bereavement care and support is available to families who experience stillbirth.

Overarching goal

The Plan supports a sustainable reduction in rates of preventable stillbirth after 28 weeks, with a primary goal of 20% or more reduction over five years. It also aims to ensure that, when stillbirth occurs, families receive respectful and supportive bereavement care.

The focus of the Plan is on stillbirth after 28 weeks, as most preventive interventions are specific to the third trimester. We acknowledge the tragedy of stillbirth at any gestation however, and anticipate that the number of earlier stillbirths may also be reduced as a result of the actions outlined in the Plan.

Priority areas

This Plan includes five priority areas:

- ensuring high quality stillbirth prevention and care
- raising awareness and strengthening education
- improving holistic bereavement care and community support following stillbirth
- improving stillbirth reporting and data collection
- prioritising stillbirth research.

Each priority area includes high-level action areas, goals and implementation tasks. For each implementation task, indicative timeframes are included. Short-term tasks are to be completed in 2020-2023, medium-term tasks in 2024-2027 and long-term tasks in 2027-2030. Lead agencies are identified.

Scope

This Plan aims to inform the development and implementation of interventions and programs that raise stillbirth awareness and support a reduction in the rate of stillbirth in Australia. Specific aspects of antenatal care are beyond the scope of the Plan and are covered in the national *Clinical practice guidelines: Pregnancy care*. Likewise, the specifics of bereavement care are covered in the *Clinical practice guideline for care around stillbirth and neonatal death*.

Audience and context

This Plan is intended to be used across governments, policy makers, stakeholder organisations, health professionals, researchers and academics, families and communities to support efforts to reduce stillbirth and provide high quality care for bereaved families.

To be effective, efforts to reduce stillbirth rates in Australia will require a collaborative approach between pregnant women and their families, governments at all levels and NGOs. In Australia, the Commonwealth provides national direction and supports efforts to improve pregnancy and birth outcomes. Maternity services are delivered through a mix of public and private service providers, with planning and delivery predominantly undertaken by state and territory governments through publicly funded programs. The Commonwealth subsidises access to private maternity services through the Medicare Benefits Schedule (MBS). The development and implementation of effective strategies to reduce stillbirths and ensure high quality bereavement care requires co-design with bereaved parents and the active engagement of a range of maternity health professionals. NGOs also play a key role and perform many functions including advocacy, research, bereavement care and providing advice to governments.

Monitoring and reporting

Annual progress reports will be provided to Commonwealth, state and territory Health Ministers and made publicly available. The Plan is intended for review in 2025 and again in 2030. A monitoring and evaluation framework will be developed in consultation with key stakeholders. This will incorporate measures to assess progress against reducing inequities among groups who are at increased risk of stillbirth.

Linkages

The Plan is aligned with *Woman-centred care: strategic directions for Australian maternity services* (August 2019)⁶, which has been endorsed by all Australian Governments. *Woman-centred care: strategic directions for Australian maternity services* is structured around four values - safety, respect, choice and access. These values ensure that Australian maternity services are equitable, safe, woman-centred, informed and evidence-based. The document includes a number of principles based on current evidence and feedback provided by women and health professionals, outlined in Figure 1. This Plan is underpinned by these principles and is intended to support implementation of Strategic Direction 2: *Service providers implement measures to reduce the rates of stillbirth and maternal and neonatal morbidity and mortality in partnership with women*. Additional principles of relevance to this Plan are listening to the voices of bereaved parents and reducing disparities in outcomes.

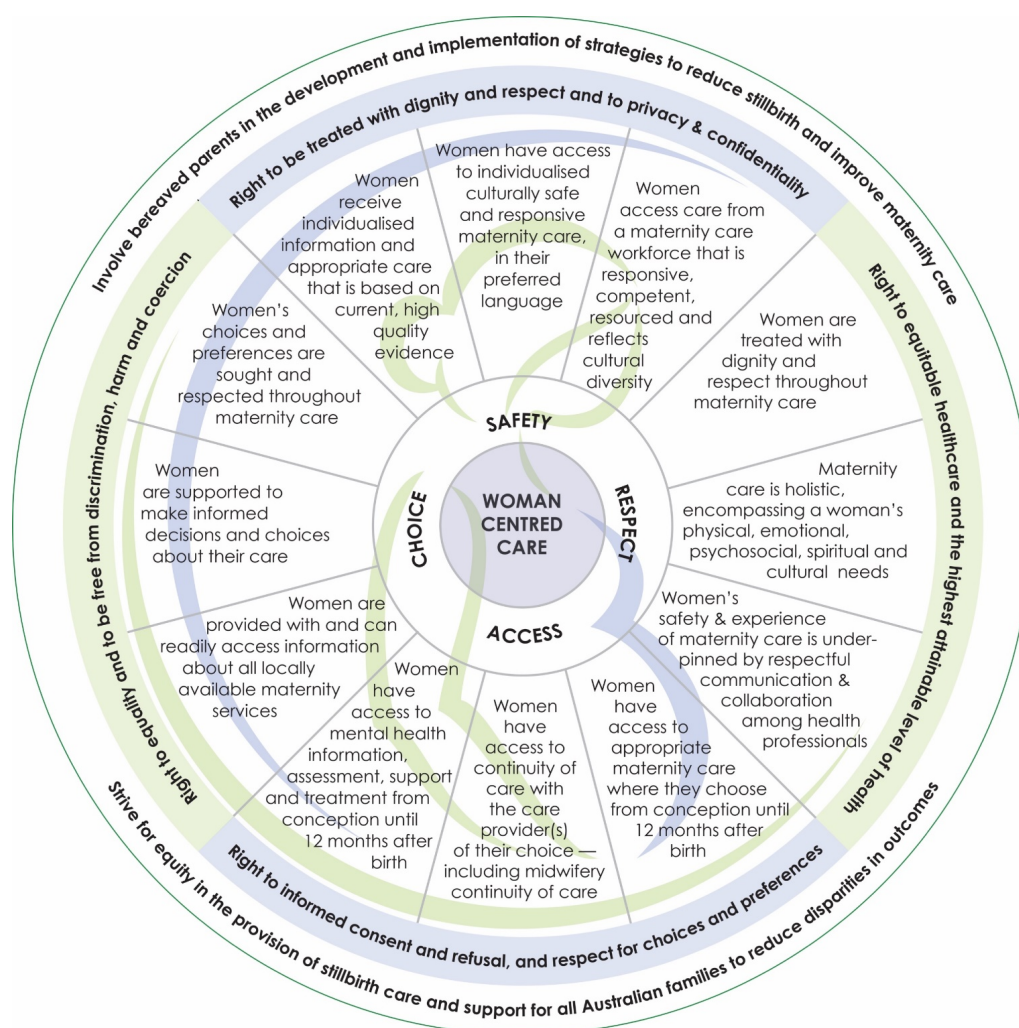


Figure 1 Woman-centred care

The diagram above gives a visual representation of the purpose, values and principles outlined in *Woman-centred care: strategic directions for Australian maternity services*, with an additional outermost ring that includes additional principles of relevance to this Plan. The inner ring represents the purpose of the document and is surrounded by the values. The rays present the principles and the third ring represents the *Respectful maternity charter: the universal rights of childbearing women*⁷.

In addition, the Plan will link to and intersect with a range of other national and state and territory strategies and programs. These include the national *Clinical practice guidelines: Pregnancy care*, the

Australian Preterm Birth Prevention Alliance, the Safer Baby Bundle and national and state and territory strategies that cover Aboriginal and Torres Strait Islander health, women's health, perinatal mental health, preventive health and substance use. The Plan will also complement the work of other agencies such as the Australian Bureau of Statistics (ABS), the Australian Institute of Health and Welfare (AIHW), the Australian Commission for Safety and Quality in Health Care, the Medical Research Future Fund and the NHMRC.

Priorities and action areas

1 Ensuring high quality stillbirth prevention and care

Action area 1 Implementing best practice in stillbirth prevention

Rationale

In recent years, there has been increasing evidence that many stillbirths can be prevented. Sub-standard care has been identified as contributing to up to 50% of stillbirths, with 20-30% of stillbirths considered to be preventable if optimal care had been provided⁵. Ensuring pregnant women are provided with high quality, evidence-based care during pregnancy and labour is therefore vital to reducing stillbirths.

Quality improvement through a bundle of care

The Safer Baby Bundle (the Bundle), developed by the Stillbirth CRE through extensive stakeholder consultation, aims to reduce the rate of stillbirth after 28 weeks' gestation by focusing on improving the care of pregnant women who may be at increased risk of stillbirth. A primary aim of the Bundle is to encourage health professionals to have conversations with women about their personalised risk profile in relation to stillbirth, and how antenatal care will be individualised according to those risks.

Implementation of the Bundle commenced in Victoria in 2019, in New South Wales in early 2020, Queensland in October 2020 and other states and territories later in 2020. The evidence-based components of the Bundle are as follows[†]:

- *Supporting women to stop smoking in pregnancy* – smoking in pregnancy is associated with many adverse outcomes including miscarriage, preterm birth and stillbirth⁴. Initiatives under the Bundle and the National Preterm Birth Prevention Alliance complement other tobacco control initiatives at Commonwealth and state and territory levels.
- *Improving detection and management of impaired fetal growth* – fetal growth restriction due to placental insufficiency is a major risk factor for stillbirth. Babies who are small for gestational age (a proxy for fetal growth restriction) have a three- to four-fold increased risk of stillbirth at all gestational ages, and this risk rises as term approaches. Improved detection and management of fetal growth restriction, particularly in late pregnancy, has been shown to reduce the rate of stillbirth by 3.3 per 1,000 small-for-gestational age babies⁸. However, the study also noted an increase in intervention (induction, caesarean section) among babies with normal growth⁸.
- *Increasing awareness about fetal movements among women and improving care of women with changes in fetal movements in late pregnancy* – studies have reported associations between changes in fetal movements and risk of adverse outcomes, including an increased likelihood that the pregnancy will end in induction of labour, emergency caesarean section, stillbirth or neonatal death⁹. This element emphasises the importance of women getting to know their own baby's movements and contacting their health professional, without delay, if concerned. The results of the large-scale awareness trial across Australia and New Zealand (My Baby's Movements) are awaited and, combined with the recent results of the Awareness of Fetal Movements and Care Package to Reduce Fetal Mortality (AFFIRM) trial, may provide further guidance to ensure optimal outcomes for women reporting concerns about fetal movements. This includes consequences associated with unnecessary intervention.
- *Providing advice for women on maternal sleep position* – going to sleep safely on her side in lieu of the supine position (lying flat on the back) from 28 weeks of pregnancy is an identified and modifiable risk factor for stillbirth¹⁰.

[†] The evidence around some of the elements of the Safer Baby Bundle is inconclusive and, for fetal movement awareness in particular, there is evidence that this intervention is potentially harmful. Individual jurisdictions may choose to seek advice about the applicability of Bundle elements or the Bundle as a whole to their local circumstances before deciding on whether or not to implement these at their local level.

- *Supporting shared decision-making around timing of birth for women with risk factors for stillbirth* – while the adverse outcomes of preterm birth are well understood, it is apparent that early term birth (37-38 weeks' gestation) is also associated with increased mortality and short and long-term morbidity, including impaired cognitive development¹¹. In the absence of clear, evidence-based guidelines, a trend has emerged towards increased late preterm inductions of labour to reduce the risk of stillbirth among women with risk factors. The premise of this element of the Bundle is that screening all women for risk factors and providing appropriate care will reduce unnecessary intervention as well as stillbirth rates.

A similar bundle of care in the United Kingdom (the Saving Babies' Lives care bundle)¹² and quality improvement initiatives by the Scottish Maternity and Children Quality Improvement Collaborative¹³ have reduced stillbirth rates by up to 20%.

Continuity of care

Continuity of care with a health professional of the woman's choice, including midwifery continuity of care, is a core principle in *Woman-centred care: strategic directions for Australian maternity services*⁶. The Senate Select Committee on Stillbirth Research and Education report¹ recommended the development of a national continuity of care model aimed at reducing the rate of stillbirths in Australia, particularly among groups identified as having a higher risk of stillbirth.

The Safer Baby Bundle notes that reducing fragmentation of care is particularly important for women at increased risk of stillbirth⁹.

Effective models of maternity care have a focus on the individual woman's needs and preferences, collaboration and continuity of care⁶. Continuity of maternity care may be provided by midwives, general practitioners, general practitioner obstetricians, obstetricians, the Aboriginal and Torres Strait Islander health workforce and/or bilingual or bicultural health workers. Studies have shown that women provided with continuity of midwifery care have a reduced risk of stillbirth before 24 weeks¹⁴.

The successful initiatives in the United Kingdom were carried out in the context of increased availability of midwifery continuity of care¹⁵. In Australia, access to such midwifery continuity of care and carer models is variable. Women may be unable to access this type of care due to workforce organisation, geography, risk factors or, in the case of private midwifery care, for financial reasons.

Perinatal mortality audit

Another fundamental requirement for implementing the Safer Baby Bundle is to conduct high-quality perinatal mortality audit (see Action area 11) to identify areas for practice improvement and reduce future risk.

All maternity services are strongly encouraged to undertake high quality perinatal mortality audit according to relevant jurisdictional processes and the *Clinical practice guideline for care around stillbirth and neonatal death*¹⁶ from the Perinatal Society of Australia and New Zealand (PSANZ) and Stillbirth CRE⁹. A systematic national approach to enable timely perinatal mortality audit and reporting is urgently needed.

Goals

- All pregnant women are provided with high quality, evidence-based information and care that reduces the risk of stillbirth.
- All women have access to continuity of care and/or carer with the health professional(s) of their choice, including midwifery continuity of care.

Implementation

Task	Lead agency	Timeframe
Implement and evaluate the Safer Baby Bundle across Australia	Stillbirth CRE	Ongoing
Develop and implement smoking cessation in pregnancy resources and measures tailored to different groups and individuals	Governments in partnership with NGOs	Ongoing
Increase access to continuity of care models for all women, including midwifery continuity of care and/or carer	State and territory governments	Medium term
Develop and implement approaches to enable parent-centred care and informed decision-making for women based on the presence of risk factors for stillbirth	State and territory governments	Medium term

Action area 2 Ensuring culturally safe stillbirth prevention and care for Aboriginal and Torres Strait Islander women†

Rationale

While there has been some progress in reducing the disparity in stillbirth for Aboriginal and Torres Strait Islander women, this varies across jurisdictions. In Queensland¹⁷ and New South Wales,¹⁸ for example, rates of stillbirth are reducing, in Western Australia there has been no change¹⁹ and in Victoria the stillbirth rate among Aboriginal and Torres Strait Islander women has fallen to that of non-Indigenous women²⁰.

In Australia in 2015-16, the rate of stillbirth among babies born to Aboriginal and Torres Strait Islander women was higher than that among babies born to non-Indigenous women (9.4 per 1,000 births compared to 6.6 per 1,000 births)⁴.

There have been improvements in perinatal outcomes for Aboriginal and Torres Strait Islander mothers and babies in recent years. The proportion of Aboriginal and Torres Strait Islander mothers who attend antenatal care in the first trimester has increased from 51% in 2012 to 63% in 2017³. Antenatal care is associated with positive outcomes for both mothers and babies. It provides an opportunity for health professionals to provide advice that is tailored to the woman's needs and increases the likelihood risk factors for stillbirth, such as fetal growth restriction, are detected. Accessing six or more antenatal visits during pregnancy has been associated with a lower stillbirth rate than that among women who accessed fewer antenatal visits or who had not accessed antenatal care at all²¹.

There have also been improvements in the rate of Aboriginal and Torres Strait Islander mothers who smoke during pregnancy, which decreased from 51% in 2009 to 44% in 2017³. It is likely that further improvements can be achieved through culturally safe, evidence-based models of care that provide holistic, individualised care and support.

A range of initiatives implemented at state and territory level have found improved outcomes associated with models of maternity care that are culturally safe and responsive, provide continuity of care and incorporate partnerships with Aboriginal and Torres Strait Islander health staff and services²². Access to care using *The 'Birthing on Country' service model and evaluation framework*²³ has been proposed as an enabler to improved care for Aboriginal and Torres Strait Islander women in *Woman-centred care: strategic directions for Australian maternity services*⁶. 'Birthing on Country' is described as 'a metaphor for the best start in life for Aboriginal and Torres Strait Islander babies and their families because it provides an integrated, holistic and culturally appropriate model of care'²³.

† While it is important that each action in this plan encompasses the diversity of culture and language among women having babies in Australia, Action areas 2 and 3 are specific to reducing the high rates of stillbirth among Aboriginal and Torres Strait Islander women and among some groups of migrant and refugee women.

Note, *Woman-centred care: Strategic directions for Australian maternity services*⁶ includes the development and implementation of culturally safe, evidence-based models of maternity care in partnership with Aboriginal and Torres Strait Islander people and communities and with migrant and refugee women and their communities.

Aboriginal and Torres Strait Islander cultures take a holistic view of wellbeing and have many strengths that provide a positive influence on wellbeing and resilience for Aboriginal and Torres Strait Islander women and their families²⁴. These include a supportive extended family network and kinship, connection to country, and active cultural practices in language, art and music²⁴.

These factors all need to be considered and incorporated into strategies that aim to improve maternal and infant health outcomes and prevent stillbirth. Aboriginal people around Australia are from diverse nations and co-design of services with local communities is important to ensure that their unique needs are reflected in local maternity service design and delivery.

The *National Aboriginal and Torres Strait Islander health workforce strategic framework 2016-2023*²⁵ recognises the importance of having Aboriginal and Torres Strait Islander health professionals in clinical and non-clinical roles, and includes strategies to build a skilled workforce that provides culturally safe and responsive care. It complements the *Cultural respect framework for Aboriginal and Torres Strait Islander health 2016-2026*²⁶. This document sets a 10-year framework that commits the Commonwealth Government and all states and territories to embedding cultural respect principles into their health system, to ensure that the health system is accessible, respectful, and safe for Aboriginal and Torres Strait Islander people.

Cultural safety and respect training programs for health professionals, and other staff working in both clinical and non-clinical roles in the health sector, can make an important contribution to ensuring health services are culturally safe. Some jurisdictions, like NSW, deliver mandatory cultural respect training.

Supporting retention of the Aboriginal and Torres Strait Islander health workforce and health professional training require careful consideration when developing and implementing strategies to reduce stillbirth among Aboriginal and Torres Strait Islander women (see Action area 7).

Goals

- All Aboriginal and Torres Strait Islander women have access to culturally safe maternity services, including access to Birthing on Country models of care, advice on stillbirth prevention and care following stillbirth.
- Rates of stillbirth among Aboriginal and Torres Strait Islander Australians are no greater than those among non-Indigenous Australians.

Implementation

Task	Lead agency	Timeframe
Co-design stillbirth prevention messages and implementation strategies for community settings in partnership with Aboriginal Community Controlled Health Organisations	Governments in partnership with NGOs	Medium term
Increase access to and engagement of professional interpreters in maternity services providing care to Aboriginal and Torres Strait Islander women	State and territory governments	Medium term
Support implementation of the strategies in the <i>National Aboriginal and Torres Strait Islander health workforce strategic framework 2016-2023</i>	Governments in partnership with CATSINaM and other NGOs	Ongoing
Support the implementation of cultural safety in the <i>Cultural respect framework for Aboriginal and Torres Strait Islander health 2016-2026</i> and <i>Health Practitioner Regulation Law Act 2009</i>	Commonwealth and state and territory governments	Short term
Implement consistent cultural respect and safety training for undergraduates and health professionals involved in maternity	Commonwealth government	Ongoing

Task	Lead agency	Timeframe
care, with particular reference to stillbirth prevention and bereavement care		

Action area 3 Ensuring culturally and linguistically appropriate models for stillbirth prevention and care for migrant and refugee women⁵

Rationale

At a national level, there was little overall difference in rates of stillbirth between women born overseas and those born in Australia in 2015-16⁴. However, women born in Melanesia, Polynesia, north, central and west Africa and central Asia had considerably higher rates of stillbirth (≥ 10 per 1,000 births)⁴. A Western Australian study found that women who migrated from India or Africa were more likely to experience stillbirth²⁷ in the first two years after migration²⁸. A Victorian study found an increased risk of stillbirth among women born in South Asia²⁹.

Pregnant women who were born in non-English speaking countries are less likely to attend antenatal care in the first trimester than pregnant women born in Australia and other main English-speaking countries³. It appears that risk of stillbirth is not increased among migrant women who attend antenatal care before 14 weeks²⁸.

Barriers to accessing antenatal care for migrant and refugee women may include language, culture, fear, confusion and distrust or misunderstanding of the health system. Strategies that consider and aim to overcome these barriers are likely to improve outcomes for migrant and refugee women and reduce stillbirth rates.

Health professional education, including information on culturally safe models of care, also needs to be incorporated into strategies to reduce stillbirth among migrant and refugee women (see Action area 7).

Goals

- All migrant and refugee women have access to culturally safe models of care for stillbirth prevention and care.
- Rates of stillbirth among migrant and refugee groups are no greater than those among the general population.

Implementation

Task	Lead agency	Timeframe
Co-design stillbirth prevention messages and implementation strategies for community settings with migrant and refugee communities	Governments in partnership with NGOs	Medium term
Develop and implement culturally safe approaches to the provision of maternity care in partnership with migrant and refugee women and service stakeholders	State and territory governments	Medium term
Increase access to and engagement of professional interpreters in maternity services providing care to migrant and refugee women	State and territory governments	Medium term

⁵ While it is important that each action in this plan encompasses the diversity of culture and language among women having babies in Australia, Action areas 2 and 3 are specific to reducing the high rates of stillbirth among Aboriginal and Torres Strait Islander women and among some groups of migrant and refugee women.

Note, *Woman-centred care: Strategic directions for Australian maternity services*⁶ includes the development and implementation of culturally safe, evidence-based models of maternity care in partnership with Aboriginal and Torres Strait Islander people and communities and with migrant and refugee women and their communities.

Action area 4 Ensuring equity in stillbirth prevention among other high-risk groups

Rationale

In Australia in 2015-16, the national stillbirth rate was 6.8 per 1,000 births³. Higher rates of stillbirth were experienced among women living in very remote areas (13.6 per 1,000 births), remote areas (7.5 per 1,000 births), outer regional areas (7.5 per 1,000 births) and the most socially disadvantaged areas (7.6 per 1,000 births) and among women aged under 20 (13.6 per 1,000 births)³. Rates of attendance of antenatal care are lower and rates of smoking during pregnancy are higher among these groups³.

Goal

- Rates of stillbirth among women who live in rural and remote or socially disadvantaged areas or are younger than 20 years are no greater than those among the general population.

Implementation

Task	Lead agency	Timeframe
Co-design and implement strategies and tools to reduce stillbirth with target communities	Governments in partnership with NGOs	Medium term

Action area 5 Providing national guidelines on stillbirth prevention

Rationale

The national *Clinical practice guidelines: Pregnancy care*³⁰ include information on some aspects of stillbirth prevention, including smoking cessation, assessing fetal growth, discussing fetal movements and discussing options in prolonged pregnancy, but not sleep position in late pregnancy.

The PSANZ and the Stillbirth CRE *Position statement: Mothers going-to-sleep position in late pregnancy* provides guidance on this aspect of prevention³¹.

The national *Clinical practice guidelines: Pregnancy care* will need to be reviewed and updated to ensure that the evidence-based messages contained in the Safer Baby Bundle are incorporated.

Goal

- All health professionals and pregnant women and their families have access to consistent evidence-based, culturally safe guidance on stillbirth prevention.

Implementation

Task	Lead agency	Timeframe
Include information on discussing risk factors for stillbirth with women in the national <i>Clinical practice guidelines: Pregnancy care</i> and ensure consistency between the Guidelines and the Safer Baby Bundle	Commonwealth Government	Medium term

2 Raising awareness and strengthening education

Action area 6 Promoting community awareness and understanding of stillbirth

Rationale

The Senate Select Committee Report on Stillbirth Research and Education¹ identified the need to increase public awareness of stillbirth, with a view to ensuring consistent messages to improve understanding of stillbirth, educating parents and the general public about the risks of stillbirth, and encouraging conversations about stillbirth.

Community awareness programs in Australia in other related areas have been successful. For example, the Red Nose community awareness campaign led to an 80% reduction in preventable sudden unexpected deaths in infants between 1989 and 2017³².

A national stillbirth awareness campaign in Australia would provide a consistent and collaborative approach to promoting public awareness of stillbirth and its risk factors, and minimise duplication across jurisdictions.

The 2016 Lancet Ending Preventable Stillbirth series highlighted differences in the rates of late gestation stillbirth (≥ 28 weeks) between high-income countries, ranging from 1.7 per 1,000 births to 8.8 per 1,000 births, with New Zealand and Australia at 2.3 and 2.7 per 1,000 births respectively². These variations suggest it is possible to further reduce late-gestation stillbirth and achieve the recommended goal of < 2 late stillbirths per 1,000 births by 2030. These reductions are based on communication of relative risk and risk factors (e.g. smoking, sleep position and changes in fetal movements). Incorporating these messages into community awareness messages has the potential to contribute to reductions in stillbirth, while also promoting awareness and understanding of stillbirth across the Australian community. Messages for specific audiences, including Aboriginal and Torres Strait Islander and migrant and refugee communities, will require specialised input from organisations with relevant expertise.

The community awareness initiative also needs to align with the messages of the Safer Baby Bundle and other campaigns - for example Every Week Counts, which promotes the benefits for babies who are born closer to their due date at 40 weeks as long as the pregnancy is healthy and progressing without any complications. It needs to encourage conversations about stillbirth as a public health issue and incorporate information about modifiable risk factors for stillbirth, such as smoking and alcohol consumption. It is critical that the community awareness package is developed in consultation with bereaved parents, communities and peak bodies. Strategies to evaluate community awareness programs and initiatives also need to be considered and incorporated.

Alcohol as a risk factor for stillbirth

In 2011 a systematic review of high-quality studies identified a paucity of data on the association between alcohol intake during pregnancy and stillbirth³³. The authors concluded that, based on the available evidence, high alcohol intake (usually described as ≥ 5 drinks/week) may be associated with up to a doubling of the risk of stillbirth, but an association with lower levels of intake could not be confidently excluded. Binge drinking may also be associated with an increased risk of stillbirth.

An update of the systematic review is currently underway. Nine additional studies have been identified. Based on a preliminary assessment of these data, the conclusions on the 2011 review appear to be upheld. Data from a study undertaken in Western Australia³⁴ indicated that heavy alcohol intake might contribute to 0.8% of stillbirths in non-Aboriginal women and 7.9% of stillbirths in Aboriginal women.

Goal

- The broader Australian community is aware of the rates of stillbirth and has an understanding of stillbirth risk minimisation strategies.

Implementation

Task	Lead agency	Timeframe
Develop, deliver and evaluate a community awareness package that provides consistent and considered messaging about stillbirth and informs expecting parents and the general public about the chances of stillbirth and factors that affect risk	Commonwealth Government in partnership with NGOs	Short term

Action area 7 Developing and implementing a national evidence-based, culturally safe stillbirth education program for health professionals

Rationale

Education for health professionals in the prevention and clinical care of stillbirth has the potential to improve outcomes for women and families, as recognised in the Senate Select Committee Report on Stillbirth Research and Education¹. This could potentially be incorporated into undergraduate education, clinical placement training and/or professional development for a range of health professions. This includes, but is not limited to, obstetricians, midwives, nurses, general practitioners, the Aboriginal and Torres Strait Islander health workforce, bilingual/bicultural health workers, allied health workers and sonographers.

Health professional education needs to include information on culturally safe care (see Action area 2 and Action area 3) and be consistent with national guidelines (see Action area 5 and Action area 10) and the community education program (see Action area 6).

A stillbirth education program for health professionals is a critical component of the implementation plan for the Safer Baby Bundle (see Action area 1). The *Safer Baby Bundle handbook and resource guide*⁹ has been developed to support implementation of the Safer Baby Bundle and provides a useful, evidence-based guide for health professionals and managers of maternity services. In addition, Improving Perinatal Mortality Review and Outcome Via Education (IMPROVE) workshops have been developed, based on the *Clinical practice guideline for care around stillbirth and neonatal death*, to address the educational needs of health professionals involved in caring for families following stillbirth³⁵. These educational resources should support the changes in practice required for the success of the Safer Baby Bundle⁹.

In addition, stillbirth has an impact on health professionals involved in a woman's care and may contribute to loss of skilled staff³⁶. Education for health professionals and support (for example, debriefing after a stillbirth) may help them to manage the emotional stress they face when dealing with stillbirth, as well as provide high quality stillbirth prevention and bereavement care to parents and families³⁶. The *Clinical practice guideline for care around stillbirth and neonatal death* outlines organisational responses to support health professionals and prevent burnout among those working in highly emotionally demanding roles, including those who deal regularly with perinatal loss¹⁶.

The development of a national Clinical Care Standard for stillbirth prevention and clinical and bereavement care would also support health professionals to provide optimal, evidence-based care. Clinical Care Standards are developed by the Australian Commission on Safety and Quality in Health Care. They can play an important role in ensuring appropriate care and reducing unwarranted variation. They identify and define the care people should expect to be offered or receive, regardless of where in Australia care is provided³⁷. The Clinical Care Standard for stillbirth prevention and clinical and bereavement will be based on current evidence, including the *Clinical practice guideline for care around stillbirth and neonatal death*.

Goals

- Health professionals involved in maternity care receive consistent education that reflects best practice in stillbirth prevention and care (including respectful and supportive discussion of risk and poor prognosis or outcomes).
- The maternity care workforce has the capacity and capability to provide culturally safe and linguistically appropriate stillbirth prevention and care.
- Health services ensure that support is available for health professionals involved in the care of parents who experience stillbirth.

Implementation

Task	Lead agency	Timeframe
To complement implementation of the Safer Baby Bundle, deliver and evaluate a national health professional education program to improve consistency in stillbirth prevention and care	Stillbirth CRE	Ongoing
Include education about stillbirth - including how to have potentially difficult and balanced conversations - in all training and orientation related to maternity care, including for midwives, nurses, obstetricians, general practitioners, the Aboriginal and Torres Strait Islander workforce, rural generalists, bilingual/bicultural health workers, sonographers and allied health professionals	Commonwealth and state and territory governments	Long term
Develop a national clinical care standard for stillbirth prevention and clinical and bereavement care in maternity services	Commonwealth Government	Short term

3 Improving holistic bereavement care and community support following stillbirth

Action area 8 Implementing best practice care for parents and families who experience stillbirth

Rationale

Stillbirth is a highly distressing and potentially traumatic event which has significant personal, social and financial consequences for families and frequently involves feelings of shock, disbelief, confusion, sadness, anger, anxiety and guilt. Up to 70% of women will experience clinically significant grief-related depressive symptoms in the year after stillbirth³⁸. The care provided to parents during and after stillbirth influences how they cope³⁸. Bereavement care needs to be holistic and individualised and encompass clinical, community and cultural aspects.

Bereavement care for parents who experience stillbirth

Improving bereavement care following stillbirth is a global priority identified in The Lancet Ending Preventable Stillbirths Series³⁹. The *Clinical practice guideline for care around stillbirth and neonatal death*¹⁶ provides recommendations designed to contribute to respectful and supportive perinatal bereavement care, including emotional and psychological, practical and physical support. These are based on current available evidence, women's experiences and maternity care providers' insights. They will require updates as new evidence is reviewed and distribution to health professionals using an appropriate digital platform. The Guidelines complement the Sands *Australian principles of bereavement care*⁴⁰, which outline key actions and behaviours to ensure that parents receive high-quality care following the death of a baby, including practices that support shared decision-making, recognition of parenthood and memory making.

The Senate Select Committee on Stillbirth Research and Education report¹ noted that guidelines for bereavement care (see Action area 10) need to continue to reflect the current evidence and be adapted to outline care for women and the specific needs of:¹

- bereaved fathers, siblings, grandparents and other family members
- families from rural and remote communities and socially disadvantaged areas
- Aboriginal and Torres Strait Islander families
- families from migrant and refugee communities.

Guidelines need to acknowledge cultural norms around death and bereavement.

Support during and after stillbirth investigations

Stillbirth investigations can be of value to parents as they can help to determine the cause of death or contributing factors. This information can help parents to understand the reasons for the death and may also help to prevent recurrence in subsequent pregnancies. Making decisions about the investigation process can be stressful and traumatic for parents. Discussion of the value and results of stillbirth investigations requires timely and sensitive communication to help parents make informed decisions and to avoid added distress, including later regret. (See also Action area 11).

The *Clinical practice guideline for care around stillbirth and neonatal death*¹⁶ assists health professionals in the investigation and audit of perinatal deaths, and includes information on communicating with parents in relation to stillbirth investigations. Recommendations in relation to communicating with parents in a culturally safe manner are also provided.

Continuity of information sharing for parents experiencing stillbirth

Information sharing between health professionals involved in a woman's care (for example ensuring that a woman's general practitioner and other community health professionals involved in her care are informed that stillbirth has occurred) is critical in supporting bereaved parents. Electronic health records and streamlined processes for accessing community support and government agencies (for example, Centrelink, Births, Deaths and Marriages) also have the potential to improve the care provided to bereaved parents.

Physical environments for care of bereaved families

The *Clinical practice guideline for care around stillbirth and neonatal death*¹⁶ notes that private and quiet spaces need to be available for conducting difficult conversations and for the birth to take place, but with access to staff for necessary physical and emotional care.

Parental leave

A key issue related to employment raised in submissions to the Senate Select Committee on Stillbirth Research and Education concerned leave entitlements for parents who experienced a stillbirth¹. The Senate report identified some ambiguity in the current legislative entitlements for employees who have experienced stillbirth, and some inconsistency in leave provisions.

Goal

- Families who experience stillbirth receive personalised, respectful, supportive and holistic clinical and community care.

Implementation

Task	Lead agency	Timeframe
Update the information on bereavement care in the <i>Clinical practice guideline for care around stillbirth and neonatal death</i> (see also Action area 10)	PSANZ/Stillbirth CRE	Short term
Develop and implement protocols for information sharing between health professionals involved in the care of bereaved parents and incorporate into the <i>Clinical practice guideline for care around stillbirth and neonatal death</i>	PSANZ/Stillbirth CRE	Short term
Increase access to continuity of care and/or carer models, including pathways to community care following bereavement, and ensure that community supports are culturally sensitive and inclusive of all types of parenting	State and territory governments	Medium term
Support maternity facilities (current and planned) to provide quiet, private, appropriate spaces where bereaved parents can receive physical and emotional care	State and territory governments	Ongoing
Review and amend the National Employment Standards of the <i>Fair Work Act 2009</i> (Cth) to improve leave entitlements for parents who experience stillbirth	Commonwealth Government	Short term
Include information in the community awareness package (see Action area 6) to assist families, workplaces and the broader community to support bereaved families	Commonwealth Government in partnership with NGOs	Short term

Action area 9 Improving care in subsequent pregnancies for women who have experienced stillbirth

Rationale

Women who have had a previous stillborn baby have a five-fold increased chance of having a stillborn baby in their next pregnancy⁴¹. They also have an increased risk of preterm birth, low birthweight, placental abruption, pre-eclampsia, gestational diabetes and other adverse pregnancy outcomes⁴²⁻⁴⁴. In addition, many women experience high levels of anxiety in subsequent pregnancies⁴⁵⁻⁴⁷.

It is critical that these women are identified and provided with individualised multidisciplinary care that considers and addresses the risk of having a subsequent stillbirth, and includes psychosocial support and mental health care where required. An initiative in the United Kingdom found that providing a specialist pregnancy care service for women with previous experience of stillbirth, which combined regular appointments, therapies for specific indications, continuity of carer and identification of case notes, improved outcomes in subsequent pregnancies⁴⁸.

Standardised clinical practice guidance would inform care within specialised services and outline care pathways where such services are not available (for example, via telehealth). Currently, there are no Australian national clinical practice guidelines on subsequent maternity care for women who have experienced stillbirth, across the continuum of interpregnancy care. However, this topic could be incorporated into the *Clinical practice guideline for care around stillbirth and neonatal death*.

Goal

- Women who have experienced stillbirth in a previous pregnancy are offered collaborative care to reduce the risk of recurring stillbirth and other adverse pregnancy outcomes and to support the social and emotional wellbeing of parents.
- All women who have experienced stillbirth have access to continuity of care models in subsequent pregnancies.

Implementation

Task	Lead agency	Timeframe
Include information on care in subsequent pregnancies in the <i>Clinical practice guideline for care around stillbirth and neonatal death</i> (see also Action area 10)	PSANZ/Stillbirth CRE	Short term
Improve access to specialised pregnancy care services for women who have previously experienced stillbirth, including in rural and remote areas	State and territory governments	Medium term

Action area 10 Providing national guidelines on bereavement care following stillbirth

Rationale

The PSANZ, the Stillbirth CRE and the Stillbirth and Neonatal Death Alliance (SANDA) have developed the *Clinical practice guideline for care around stillbirth and neonatal death*¹⁶. These guidelines aim to reduce the risk of perinatal death through better understanding of causes and contributing factors, and to support appropriate bereavement care for parents. They are intended to assist health professionals in the investigation (including autopsy) and audit of perinatal deaths, including communication with parents, to enable a systematic approach to perinatal mortality audit in Australia and New Zealand.

The Senate Select Committee on Stillbirth Research and Education report¹ specifically identified provision of bereavement care as an area requiring ongoing professional development, mentoring and supervision to provide quality evidence-based bereavement care (see Action area 8). Other topics identified through the Senate inquiry that could be incorporated include managing autopsies and other investigations into stillbirths, counselling for autopsy and other medical investigations, care of stillborn babies (including those held in morgues), information sharing between health professionals involved in the care of bereaved parents, and care in subsequent pregnancies. Some of these matters are already covered in the *Clinical practice guideline for care around stillbirth and neonatal death*, but there is a need to review and update the guideline to identify other areas that should be incorporated.

To meet NHMRC standards, guideline development needs to involve consumer representatives, including representatives of Aboriginal and Torres Strait Islander peoples and migrant and refugee communities⁴⁹. Bereaved parents, consumers and organisations representing the interests of groups at increased risk of stillbirth are key groups who should be involved in the development, review and updating of any guidelines relating to stillbirth.

Goal

- All health professionals and pregnant women and their families have access to consistent evidence-based, culturally safe guidance on bereavement care.

Implementation

Task	Lead agency	Timeframe
Review and update the <i>Clinical practice guideline for care around stillbirth and neonatal death</i> to incorporate other topics identified as relevant and seek NHMRC approval of the recommendations (see also Action area 8 and Action area 9 for areas for inclusion in the guidelines)	PSANZ/Stillbirth CRE	Short term

4 Improving stillbirth reporting and data collection

Action area 11 Improving investigation and reporting of stillbirth

Rationale

The Senate Select Committee on Stillbirth Research and Education report¹ identified the need for the development of a comprehensive, standardised, national perinatal mortality data collection.

Perinatal mortality audit

High quality perinatal mortality audit linked to practice improvement initiatives can reduce stillbirths and neonatal deaths². The World Health Organization's *Making every baby count: audit and review of stillbirths and neonatal deaths*⁵⁰ sets out a step-by-step process for review of all perinatal deaths. Implementation of national perinatal mortality review programs using rapid reporting systems is increasing internationally (for example, in New Zealand, England, Ireland and Scotland).

While no such system currently exists in Australia, an online system based on the New Zealand model⁵¹ has been piloted - the Australian Perinatal Mortality Audit Tool (APMAT). The primary purpose of APMAT is to support high quality investigation, audit and classification of all perinatal deaths in a timely way to enable local, jurisdictional and national reporting. Secondary aims include supporting clinician education and informing future research.

Autopsy and other investigations

The Senate Select Committee on Stillbirth Research and Education report¹ recommended the Australian government seek advice from the Medical Services Advisory Committee (MSAC) on the economic costs and benefits of adding stillbirth autopsies as a new item in the MBS. Advice has been sought and MSAC has advised that the MBS is not a suitable mechanism for funding autopsy services. Alternative strategies to increase stillbirth investigations therefore need to be explored.

The value of perinatal autopsy has been demonstrated in several studies where the information obtained changed diagnoses or provided important additional findings¹⁶. While autopsies may be declined by parents for a variety of reasons (for example, not wanting the baby to be harmed, delays in funeral arrangements and long waiting times for results), other stillbirth investigations are available that are minimally or non-invasive (for example, external examination of the baby, placental and umbilical cord examinations and medical imaging)¹⁶.

Rates of autopsy following stillbirth are currently lower than recommended¹⁶. Provision of education for health professionals about the value of stillbirth investigations and how to discuss the available options and their benefits sensitively and respectfully with bereaved parents is crucial to increase the rates of perinatal autopsy¹⁶. The *Clinical practice guideline for care around stillbirth and neonatal death* and the *Sands Australian principles of bereavement care* (see Action area 8) provide guidance for health professionals on stillbirth investigations, including good communication and shared decision-making. These complement other education and training measures, such as the IMPROVE workshops (see Action area 7).

Accuracy of stillbirth data

Poor-quality data for stillbirths is a major problem across high-income countries². Access to high quality investigation into the causes of stillbirth, including autopsy and placental histopathology by a skilled perinatal pathologist, should be available to all parents who experience stillbirth². The need for strategies to increase the number of perinatal pathologists available to undertake stillbirth investigations in Australia was highlighted in the Senate Select Committee on Stillbirth Research and Education report¹.

A challenge in many high-income countries in determining an accurate burden of stillbirth by cause is that fetal death records may be initially marked as "unknown" (which may include non-apparent infection) and not routinely updated when the cause of death is determined.

The ABS receives data from health services shortly after a death has occurred and frequently before investigations have been completed and causation determined. While timely, ABS stillbirth data reflect only registered stillbirths and there is no national system to follow up unregistered stillbirths. As a result, ABS stillbirth counts are understated, which has resulted in significant discrepancies between AIHW, ABS and jurisdictional data.

Learning from bereaved parents

Respectful and supportive bereavement care needs to be informed by the voices of parents who have experienced stillbirth in the Australian health system. Information from parents about their experience of stillbirth care (for example patient-reported outcome measures [PROMs] and patient-reported experience measures [PREMs]) is critical to informing future care provision. Parental engagement in the perinatal review process following stillbirth or neonatal death is now strongly advocated by bereaved parents, their support organisations and many health professionals^{52,53}. In the UK, findings of the PARENTS1 study⁵² suggest that many parents would welcome the opportunity to be offered the option to engage in the perinatal mortality review process. Ideally, this would occur with a system in place that could provide them with feedback, outcomes and lessons learned from the review. Parents are commonly unaware that a review of their baby's death took place. Moreover, not being involved or kept informed can be an added source of distress⁵².

Goals

- Australia has a nationally consistent, high-quality perinatal mortality audit program, including high quality investigation, audit and classification, and timely reporting on causes and contributing factors to inform and monitor prevention strategies.
- Autopsy and other investigations are undertaken following stillbirth across all cultural and religious groups as appropriate to the circumstances.
- Services have processes for involving bereaved parents in the development of bereavement care.

Implementation

Tasks	Lead agency	Timeframe
Develop and implement a standardised approach to data collection on causes and contributing factors for perinatal deaths, across maternity services linked to perinatal mortality review committees to ensure timely review and reporting of stillbirth deaths	Commonwealth Government	Medium term
Review and update the <i>Clinical practice guideline for care around stillbirth and neonatal death</i> and relevant training to ensure it supports standardised clinical pathways for appropriate investigations following stillbirth	PSANZ/Stillbirth CRE	Short term
Expand training that supports the uptake of the <i>Clinical practice guideline for care around stillbirth and neonatal death</i>	PSANZ/Stillbirth CRE	Medium term
Identify strategies to increase the number of perinatal pathologists and radiologists available to undertake stillbirth investigations in Australia, in particular in areas of need (for example, in rural areas)	Commonwealth Government	Medium term
In partnership with bereaved parents, clinicians and policy makers, identify strategies to increase uptake of stillbirth investigations	Commonwealth Government	Medium term

Tasks	Lead agency	Timeframe
Partner with bereaved parents to develop resources for parents and families to support decision-making about stillbirth investigations	Commonwealth Government in partnership with NGOs	Medium term

Action area 12 Tracking progress to reduce inequity

Rationale

The 2016 Lancet Ending Preventable Stillbirths series³⁹ sought to highlight missed opportunities and identify actions for accelerated progress to end preventable stillbirths. The series concluded with a Call to Action, which covered: 2030 mortality targets; universal health care coverage targets; and global and national milestones to improve the care and outcomes for all mothers and their babies (Every Newborn Action Plan), specifically for women and families affected by stillbirth.

A Global Scorecard has been produced by the International Stillbirth Alliance through its Stillbirth Advocacy Working Group to track progress against the Call to Action. In high income countries, the focus will be to use the Global Scorecard to identify disparities. In Australia, recognised disparities for Aboriginal and Torres Strait Islander women, migrant and refugee women and women living in regional and remote areas will be measured.

Goal

- Measures are in place to compare Australia's performance in stillbirth prevention with other high-income countries, including a stillbirth rate equity target.
- Data quality on country of birth and Aboriginal and Torres Strait Islander status is sufficient to inform reporting on equity.

Implementation

Task	Lead agency	Timeframe
Implement annual reporting against the global score card	Stillbirth CRE	Short term

5 Prioritising stillbirth research

Action area 13 Prioritising research into stillbirth prevention

Rationale

A cohesive national approach to research into prevention of stillbirth and improvement of bereavement care is crucial to inform the evidence base in relation to stillbirth and ensure the best possible outcomes for families. Translation of evidence into clinical practice and implementation of effective interventions in a timely manner also need to be prioritised. It is also vital that women and their families, including those from Aboriginal and Torres Strait Islander peoples, migrant and refugee peoples and other groups at higher risk of stillbirth, are involved in establishing priorities for research and identify interventions that meet their needs.

Funding of research

The Senate Select Committee on Stillbirth Research and Education report¹ recommended that the Australian government review current research funding arrangements administered by the NHMRC to examine options for longer-term funding cycles for targeted, large-scale, collaborative research partnerships, potentially through the Medical Research Future Fund.

Following a review of its grant program, NHMRC implemented a revised grants program in 2018-19. Early stage outcomes from the inaugural 2019 funding round indicate that the new grant program has been effective in awarding long-term and large-scale collaborative grants. Most NHMRC competitive grant funding is now allocated to long-term grants (five years in duration) and average grant funding was \$1.2 million, an approximate 50% increase over previous years.

Evaluation of research priorities

The Senate Select Committee on Stillbirth Research and Education report¹ identified the need to establish a set of national stillbirth research funding priorities for the next 10 years, drawing on those developed by PSANZ and the Stillbirth CRE.

The PSANZ has undertaken stillbirth research priority setting for Australia to inform the research program of the NHMRC Centre of Research Excellence for Stillbirth, drawing on the work of the Lancet series of 2011⁵ and 2016³⁹. Four major themes emerged through synthesis of surveys of Australian parents and health professionals, and consultation with policy makers and researchers:

- improving care and outcomes for women with risk factors for stillbirth (see Action area 1)
- developing new approaches for identifying women at increased risk of stillbirth (for example, using biomarkers)
- implementing best practice in care after stillbirth and in subsequent pregnancies (see Action area 8 and Action area 9)
- improving knowledge of causes and contributors to stillbirth.

The Stillbirth CRE has addressed these priorities since its establishment in early 2017 and proposes to re-evaluate research priorities in 2020.

Developing relevant research priorities

Involving groups at increased risk of stillbirth, for example, Aboriginal and Torres Strait Islander peoples, migrant and refugee peoples, people living in rural and remote regions and parents who have experienced stillbirth, in setting priorities would enable identification of research of value to these groups.

Establishing a national biobank

Stillbirth is frequently the result of pathological processes involving the placenta. It is feasible to examine maternal blood samples to identify and measure markers of placental function, which offer the opportunity to identify women at risk of stillbirth.

The Senate Select Committee on Stillbirth Research and Education report¹ recommended that the Australian government give 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.

The development of a national birth cohort registry and biobank would provide researchers with access to samples from a number of birth cohorts. Supporting new research approaches, such as use of biomarkers, to identify women at increased risk of stillbirth may inform strategies to prevent stillbirth in the future.

A tool to identify women at high risk of stillbirth

Stillbirth represents the apex of a large group of at-risk fetuses often sharing similar pathophysiological pathways³⁹. In Australia, hypoxic peripartum death is the third leading cause of mortality in term infants. Most of these events occur despite a lack of obvious risk factors. Stratification of women at apparently low risk is complicated by the heterogeneity of known risk factors and the lack of knowledge about the interaction between them. Understanding the contribution of various maternal and ultrasound variables to overall risk is one option being modelled to determine the probability of an adverse event occurring. Development of risk prediction models requires large datasets and statistical analysis to determine factors that enhance the accuracy of any predictive model. When accurate and reliable risk factors for serious adverse neonatal outcomes are known, it may be possible to develop a risk stratification model, for example, a tool to assist in identifying women at high risk of stillbirth.

Goals

- Australia has a cohesive, funded, priority-driven research program related to stillbirth prevention and care.
- Stillbirth research is prioritised and co-designed with practising maternity clinicians, women and their families, including those from Aboriginal and Torres Strait Islander peoples, migrant and refugee peoples and other groups at higher risk of stillbirth.

Implementation

Task	Lead agency	Timeframe
Establish agreed national priorities for stillbirth research for the next five years, building on the work of PSANZ and the Stillbirth CRE	Stillbirth CRE and PSANZ	Short term
Establish a national placenta biobank as an enabler for research into stillbirth	Commonwealth Government	Long term
Develop and implement a risk stratification tool to inform clinical care for women with risk factors for stillbirth	Commonwealth Government	Long term

Action area 14 Providing broader access to stillbirth research

Rationale

The availability of high-quality evidence is critical to inform healthcare decision-making, and reduce fragmentation and duplication.

The Senate Select Committee on Stillbirth Research and Education report¹ recommends the Australian government creates and maintains an online register of current international and Australian research and clinical guidelines relating to stillbirth, accessible to all interested stakeholders including the public.

The lack of a central repository of past, current and planned stillbirth research is an impediment to the collaboration required to ensure effective conduct of high quality research. Key to quality research into stillbirth is the need to engage parents and the community as partners.

The Stillbirth CRE is collaborating with 12 academic organisations nationally and internationally and maintains up-to-date records of all research undertaken as part of these collaborations. Currently 80 studies are included in the Stillbirth CRE research register. However, further work is required to make this register comprehensive and accessible to the general community.

Goal

- Members of the public, researchers and others have access to a repository of Australian and international medical and social stillbirth research, including recent publications and guidelines.

Implementation

Task	Lead agency	Timeframe
Develop a comprehensive, publicly accessible register of current research and guidelines relating to stillbirth	Commonwealth Government in partnership with NGOs	Short term

Appendix A: Stakeholders involved in the development of the Plan

Participants in the 12 February 2019 Roundtable discussion

Organisation	Representative
Australian College of Midwives	Associate Professor Jane Warland
Australian Institute of Health and Welfare	Dr Fadwa Al Yaman
Department of Health - Australian Medical Research Advisory Board	Dr David Abbott
Congress of Aboriginal and Torres Strait Islander Nurses and Midwives	Ms Marni Tuala
Department of Health	Adjunct Professor Debra Thoms
Department of Health	Professor Brendan Murphy
Griffith University, School of Medicine	Professor David Ellwood
Mater Research - Centre of Research Excellence in Stillbirth	Professor Vicki Flenady
Monash University / Monash Health	Professor Euan Wallace
Multicultural Centre for Women's Health	Dr Adele Murdolo
National Perinatal Epidemiology and Statistics Unit, University of New South Wales	Assoc Professor Georgina Chambers
National Rural Health Alliance	Dr Joanne Walker
Perinatal Society Australia and New Zealand	Professor Jonathan Morris
Red Nose	Ms Keren Ludski
Royal Australian and New Zealand College of Obstetricians and Gynaecologists	Professor Michael Permezel
Royal Australian College of General Practitioners	Dr Nicole Hall
Royal Prince Alfred Hospital	Dr Adrienne Gordon
SANDS	Ms Jackie Mead
Still Aware	Ms Claire Foord
Stillbirth Foundation of Australia	Ms Kate Lynch
The Royal College of Pathologists of Australasia	Dr Diane Payton
Perinatal Institute, Birmingham UK	Professor Jason Gardosi (via teleconference - Panel 1 only)

Participants in the 2 December 2019 Roundtable discussion

Organisation	Representative
Ampersand Health Science Writing (Technical Writer)	Ms Jenny Ramson
Attorney-General's Department	Ms Lace Wang
Attorney-General's Department	Ms Virginia Jay
Australian College of Midwives	Dr Megan Cooper
Australian Commission on Safety and Quality in Health Care	Ms Gillian Giles
Australian Institute of Health and Welfare	Ms Bernice Cropper
Australian Medical Research Advisory Board	Dr David Abbott
Bereaved Parent Representative	Mr Andrew McBride
Bereaved Parent Representative	Ms Samantha Isfahani
Burnet Institute	Professor Caroline Homer
Congress of Aboriginal and Torres Strait Islander Nurses and Midwives	Ms Marni Tuala
Griffith University, School of Medicine	Professor David Ellwood
Mater Research - Centre of Research Excellence in Stillbirth	Professor Vicki Flenady
Mater Research - Centre of Research Excellence in Stillbirth	Ms Deanna Stuart-Butler
Multicultural Centre for Women's Health	Dr Adele Murdolo
Murdoch University	Ms Valerie Ah Chee
National Perinatal Epidemiology and Statistics Unit, University of New South Wales	Assoc Professor Georgina Chambers
National Rural Health Alliance	Dr Gabrielle O'Kane
Pillars of Strength	Ms Julia Bowen
Red Nose	Ms Keren Ludski
Royal Australian and New Zealand College of Obstetricians and Gynaecologists	Dr Sean Seeho
Royal Australian and New Zealand College of Radiologists	Ms Melissa Doyle
Royal Prince Alfred Hospital	Dr Adrienne Gordon
SANDS	Ms Jackie Mead
SIDS SA	Ms Helen Shaw
South Australian Health and Medical Research Centre	Assoc Professor Philippa Middleton

Organisation	Representative
Still Aware	Assoc Prof Jane Warland
Stillbirth Foundation of Australia	Ms Leigh Brezler
Telethon Kids Institute	Prof Carrington Shepherd
The Royal College of Pathologists of Australasia	Dr Diane Payton
University of Melbourne	Professor Jeremy Oats
States and Territories	
Queensland	Mr Michael Rice
New South Wales	Professor Mike Nicholl
Northern Territory	Ms Belinda Jennings
South Australia	Ms Helen Thomas
Tasmania	Assoc Professor Francine Douce
Australian Capital Territory	Ms Sarah Stewart
Politicians (attended part day)	
Liberal Party of Australia	Hon Greg Hunt MP
Liberal Party of Australia	Ms Nicolle Flint MP
Australian Labor Party	Hon Chris Bowen MP
Australian Labor Party	Senator Malarndirri McCarthy
Australian Labor Party	Senator Kristina Keneally
Department of Health staff	
Department of Health	Dr Andrew Singer
Department of Health	Ms Alison McMillan
Department of Health	Ms Chloe Stoddart
Department of Health	Ms Bridget Carrick
Department of Health	Ms Samantha Diplock
Department of Health	Ms Miika Coppard
Department of Health	Ms Anita Soar

Acronyms and abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
APMAT	Australian Perinatal Mortality Audit Tool
GP	general practitioner
IMPROVE	Improving Perinatal Mortality Review and Outcome Via Education
MBS	Medicare Benefits Schedule
MSAC	Medical Services Advisory Committee
NHMRC	National Health and Medical Research Council
PREM	patient-reported experience measure
PROM	patient-reported outcomes measure
PSANZ	Perinatal Society of Australia and New Zealand
SANDA	Stillbirth and Neonatal Death Alliance
Stillbirth CRE	Centre of Research Excellence in Stillbirth

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