

Draft National Stillbirth Action and Implementation Plan

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Acknowledgement

We would like to acknowledge the families and their loved ones who have experienced stillbirth. 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.

Introduction

Stillbirth* has a profound and long-lasting effect on women and families and often on their care providers. Globally, stillbirth has been 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 child death in Australia.² In 2016, Australia's late gestation (28 weeks or more) stillbirth rate was estimated to be 35% higher than countries with the lowest rates.³ While the Australian stillbirth rate has decreased slightly but consistently following a peak of 7.8 per 1,000 births in 2009 to 7.1 per 1,000 births in 2017, the reduction is small particularly when compared to that in neonatal deaths.⁴

Stillbirths are most frequently related to congenital anomaly and various maternal conditions.¹ However, for many a cause is never found. In 2015-16, almost 20% of stillbirths were classified as unexplained, which increased to 45% at term.⁴ There are significant equity gaps in stillbirth rates in Australia. Rates of stillbirth remain higher among Aboriginal and Torres Strait Islander women, women from some migrant and refugee groups, women living in rural and remote Australia or in the most socially disadvantaged areas of Australia and women younger than 20 years.¹ Specific individualised strategies will be required to reduce stillbirth rates among these groups.

The Lancet stillbirth series in 2011⁵ and 2016³ brought attention to the need to reduce stillbirth rates and to improve care for families who suffer 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 and 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, 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 non-government organisations 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, and report on, the future of stillbirth research and education in Australia. The committee received 269 submissions and took evidence over 6 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 that a National Stillbirth Action and Implementation Plan (the 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 discussion was held to enable key stakeholders to consider the draft Plan and have input into its content prior to broader consultation.

This consultation draft of the 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.

* 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.¹

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 aims to support a reduction in rates of stillbirth in Australia of 20% or more over 5 years and ensure that, when stillbirth occurs, families receive respectful and supportive bereavement care.

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, with short-term tasks to be completed in 2020-2023, medium-term tasks in 2024-2027 and long-term tasks in 2027-2030. Lead agencies will be identified and included in the final document based on feedback provided through the consultation process.

Audience and context

This Plan is intended to be used across governments, policy makers, stakeholder organisations, the public and private health sectors, researchers and academics, families, and communities to support efforts to reduce stillbirth and provide high quality care for bereaved families. While the Plan aims to reduce the rates of both early and late stillbirth, available evidence indicates that stillbirths occurring after 28 weeks are most likely to be preventable.

To be effective, efforts to reduce stillbirth rates in Australia will require a collaborative approach between governments at all levels, non-government organisations and pregnant women and their families. Pregnancy care and birthing services in Australia are provided through a mix of public and private services with planning and delivery predominantly undertaken by the states and territories through publicly funded programs, with the Commonwealth providing national direction and supporting efforts to improve care and outcomes. The development and implementation of effective strategies to reduce stillbirths and ensure high quality bereavement care requires active engagement of the range of health professionals involved in providing pregnancy care and birthing services through various models of care, and need to be actively involved in developing and implementing strategies to reduce stillbirth and provide high quality bereavement care. Non-government organisations also play a key role and perform many functions including advocacy, research, bereavement care and providing advice to governments.

Monitoring and reporting

Progress reports on implementation of the Plan will be provided to the Australian Health Ministers' Advisory Council and the Council of Australian Governments Health Council annually. 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 once the Plan is finalised. 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, and aims to ensure that Australian maternity services are equitable, safe, woman-centred, informed and evidence-based. It includes a number of principles based on current evidence and feedback provided by women and health professionals, which are 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 woman*. Additional principles of relevance to this Plan are listening to the voices of bereaved parents and reducing disparities in outcomes.

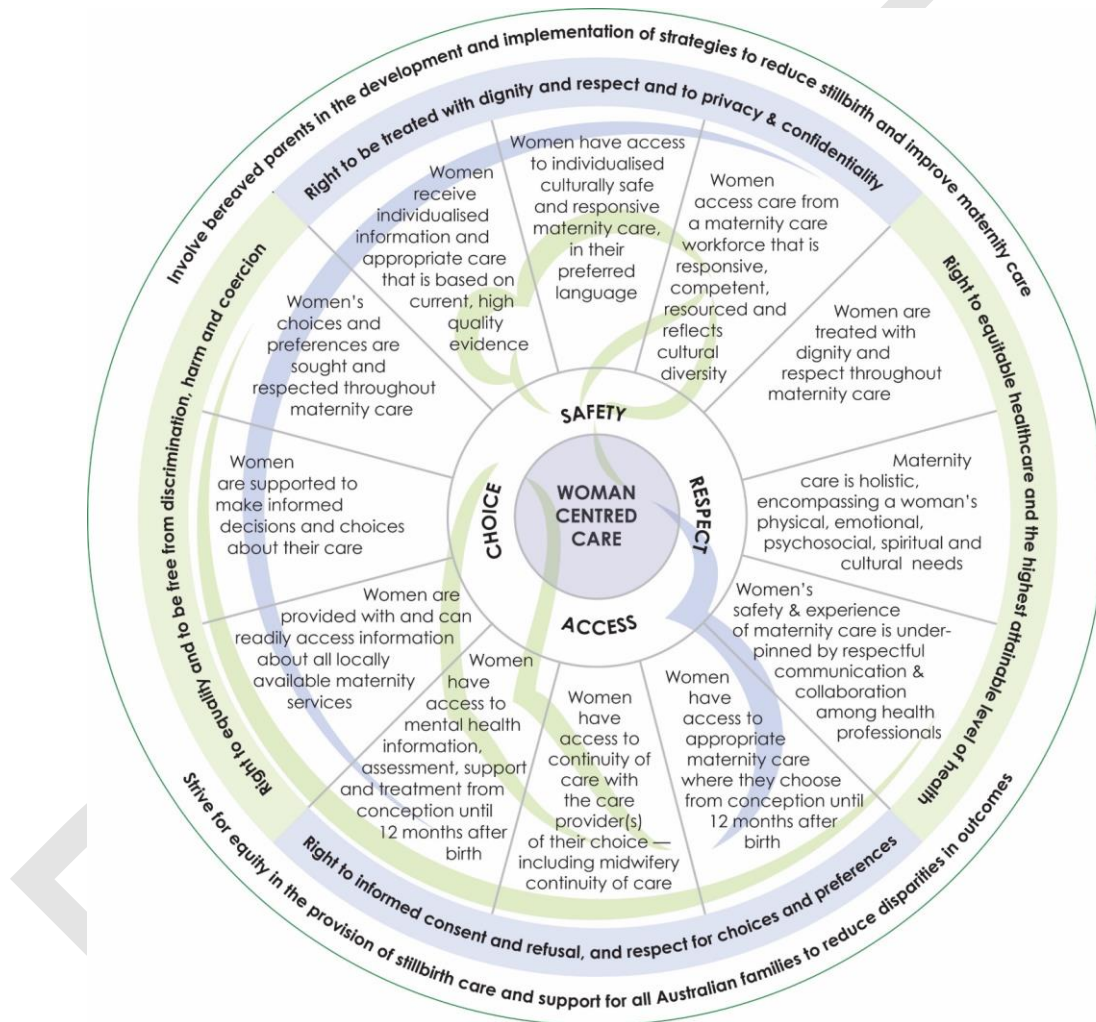


Figure 1 Woman-centred care

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 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 *Clinical practice guidelines: Pregnancy care*, the National Preterm Birth Prevention Alliance 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 provided.⁵ 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 focussing on improving the care of pregnant women who may be at increased risk of stillbirth. Implementation of the Bundle commenced in Victoria in 2019, in New South Wales and Queensland in early 2020, and is expected to be rolled out across 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 stillbirth.¹ 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 babies.⁸
- *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 death.⁹ This element emphasises the importance of women getting to know their own baby's movements and contacting their health provider, 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 AFFIRM trial may provide further guidance to ensure optimal outcomes for women reporting concerns about fetal movements including consequences associated with unnecessary intervention.
- *Providing advice for women on maternal sleep position* – going to sleep in the supine position (lying flat on the back) from 28 weeks of pregnancy is an identified and modifiable risk factor for stillbirth.¹⁰
- *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 development.¹¹ 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 stillbirth rates and unnecessary intervention.

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

In addition to the five elements outlined above, the Safer Baby Bundle emphasises the need for maternity services to address other important aspects of best practice care to reduce stillbirth rates. This includes reducing the risk of fragmentation of care through maternity services increasing the availability of midwifery continuity of care models to all women and, in particular, for women at increased risk of stillbirth.⁹

Effective models of maternity care have a focus on the individual woman's needs and preferences, collaboration and continuity of care.⁶ 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 midwifery continuity of care have a reduced risk of stillbirth before 24 weeks.¹⁴ In Australia, access to such midwifery models of care is variable. Women may be unable to access this type of care due to 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 the conduct of high-quality perinatal mortality audit (see Action area 11) to identify areas for practice improvement and reduce future risk.

All maternity services implementing the Safer Baby Bundle 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*¹⁵ from the Perinatal Society of Australia and New Zealand (PSANZ) and Stillbirth CRE.⁹ 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 care that reduces the risk of stillbirth
- All women have access to continuity of care with the care provider(s) of their choice, including midwifery continuity of care

Implementation

Task	Lead agency	Timeframe
Implement and evaluate the Safer Baby Bundle across Australia		Short, medium & long term
Develop and implement smoking cessation in pregnancy resources and measures tailored to different groups and individuals		Short term
Increase access to continuity of care models, including midwifery continuity of care, with particular attention to women at increased risk of stillbirth		Medium term
Develop and implement a risk stratification tool to inform care for women with risk factors for stillbirth		Medium term

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

Rationale

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).¹

While there has been some progress in reducing the disparity for Aboriginal and Torres Strait Islander women, this varies across jurisdictions. In Queensland, for example, rates are reducing,¹⁶ in Western Australia there has been no improvement¹⁷ and in Victoria the stillbirth rate among Aboriginal and Torres Strait Islander women has fallen to that of non-Indigenous women.¹⁸

There have been some improvements in outcomes for Aboriginal and Torres Strait Islander mothers and babies in recent years. The proportion of Aboriginal and Torres Strait Islander mothers who attended antenatal care in the first trimester has increased from 51% in 2012 to 63% in 2017.⁴ 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 of risk factors for stillbirth, such as fetal growth restriction, being 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 all.¹⁹

The rate of Aboriginal and Torres Strait Islander mothers who smoke during pregnancy has decreased from 51% in 2009 to 44% in 2017.⁴ It is likely that further improvements can be achieved through providing 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 services.²⁰ These factors need to be considered and incorporated into strategies that aim to improve maternal and infant health outcomes and prevent stillbirth. 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 advice on stillbirth prevention and care following stillbirth.
- Rates of stillbirth among Aboriginal and Torres Strait Islander Australians are the same as among the non-Indigenous population.

Implementation

Task	Lead agency	Timeframe
Co-design stillbirth prevention messages and implementation strategies for community settings in partnership with Aboriginal Community Controlled Health Organisations		Medium term
Increase access to continuity models of care for Aboriginal and Torres Strait Islander women		Short term

† 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.

Task	Lead agency	Timeframe
Support the implementation of cultural safety in the <i>Health Practitioner Regulation Law Act 2009</i>		Short term
Implement consistent cultural respect and safety training for undergraduates and health professionals involved in maternity care, with particular reference to stillbirth prevention and bereavement care		Ongoing

Action area 3 Ensuring culturally and linguistically appropriate models for stillbirth prevention and care for migrant and refugee women[‡]

Rationale

While there was little overall difference in rates of stillbirth between women born overseas and those born in Australia, in 2015-16 women born in Melanesia, Polynesia, north, central and west Africa and central Asia had considerably higher rates of stillbirth (≥ 10 per 1,000 births).¹

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 countries.⁴ 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 and linguistically appropriate models of care for stillbirth prevention and care
- Rates of stillbirth among migrant and refugee groups are the same as those for the rest of the population.

Implementation

Task	Lead agency	Timeframe
Co-design stillbirth prevention messages and implementation strategies for community settings in consultation with representatives of migrant and refugee communities	Stillbirth CRE	Medium term
Develop and build on existing culturally and linguistically appropriate models of care in consultation with migrant and refugee women	State and territory Governments	Medium term
Increase access to interpreters in maternity services providing care to migrant and refugee women	State and territory Governments	Medium term

[‡] 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 outcomes among other high-risk groups

Rationale

In Australia in 2015-16, the national stillbirth rate was 6.8 per 1,000 births.⁴ 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).⁴ Rates of attendance of antenatal care are lower and rates of smoking during pregnancy are higher among these groups.⁴

Goal

- Rates of stillbirth among women who live in rural and remote or socially disadvantaged areas or are younger than 20 years are the same as those for the rest of the population.

Implementation

Task	Lead agency	Timeframe
Undertake research to identify specific strategies to reduce stillbirth among groups women who live in rural and remote or socially disadvantaged areas or are younger than 20 years		Medium term

Action area 5 Providing national guidelines on stillbirth prevention

Rationale

The national *Clinical practice guidelines: Pregnancy care*²¹ include information on some aspects of stillbirth prevention, including ceasing smoking, assessing fetal growth, discussing fetal movements and discussing options in prolonged pregnancy.

The PSANZ and the Stillbirth CRE *Position statement: Mothers going-to-sleep position in late pregnancy* provides guidance on this aspect of prevention.²²

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

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 <i>Clinical practice guidelines: Pregnancy care</i> and ensure consistency between the Guidelines and the Safer Baby Bundle		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 Education² 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 2017.²³

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 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 respectively.³ 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 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 different audiences, including Aboriginal and Torres Strait Islander and migrant and refugee communities, will require special consideration and input from organisations with relevant expertise.

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 with the aim of creating consistency in messaging about stillbirth, inform parents and the general public about the chances of stillbirth and factors that affect risk, and encourage public conversations about stillbirth as a public health issue		Short term
Tailor the community awareness package to different communities and contexts in consultation with peak bodies		Short term

Action area 7 Developing and implementing a national best-practice, culturally respectful 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 Education.² This could potentially be incorporated into undergraduate education, clinical placement training and/or professional development for a range of health professionals, including but 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 respectful and safe models of 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 stillbirth.²⁴ These educational resources should support the changes in practice required for the success of the Safer Baby Bundle.⁹

In addition, stillbirth has an impact on health professionals involved in a woman's care and may contribute to loss of skilled staff.²⁵ Training for health professionals and support (e.g. debriefing after a stillbirth) may help them to deal with the emotional stress they face when dealing with stillbirth as well as providing high quality stillbirth prevention and bereavement care to parents and families.²⁵

The development of Clinical Care Standards for stillbirth prevention and clinical and bereavement care would also support health professionals to provide optimal, evidence-based care. Clinical Care Standards can play an important role in ensuring appropriate care and reducing unwarranted variation, as they identify and define the care people should expect to be offered or receive, regardless of where in Australia care is provided.²⁶

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) relevant to their profession
- The maternity care workforce has the capacity and capability to provide culturally 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		Ongoing
Include education about stillbirth – including how to have potentially difficult conversations – in all health professional development programs, including for midwives, nurses, obstetricians, general practitioners, the Aboriginal and Torres Strait Islander workforce, bilingual/bicultural health workers and allied health professionals		
Establish ways of embedding stillbirth education into current training for all relevant health professionals		
Develop clinical care standards for stillbirth prevention and clinical and bereavement care in maternity services		Short term

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3 Improving holistic bereavement care and community support following stillbirth

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

Rationale

Stillbirth is extremely traumatic, which carries significant personal, social and financial consequences for families and frequently involves feelings of shock, disbelief, confusion, anxiety and guilt. The impacts are often long lasting with up to 25% of bereaved parents suffering severe symptoms years after the death of their baby.²⁷ The care provided to parents during and after stillbirth influences how they cope.²⁸ 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 Series.²⁹ The *Clinical practice guideline for care around stillbirth and neonatal death*¹⁵ provides recommendations designed to contribute to respectful and supportive perinatal bereavement care, including supporting family, social and emotional wellbeing. These are based on current available evidence, women's experiences, and maternity care providers' insights. They complement the *Sands Australian principles of bereavement care*,³⁰ which outline key actions and behaviours to ensure that families receive high-quality care following the death of a baby.

Guidelines for bereavement care (see Action area 10) need to continue to reflect the current evidence base and be adapted to outline care for women and the specific needs of:²

- 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.

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 can help parents to understand the reasons for the death and may also help in preventing recurrence in subsequent pregnancies. Making decisions about the investigation process can be extremely stressful and traumatising for parents. Discussion of the value and results of stillbirth investigations requires sensitivity, with every effort made to avoid re-traumatising parents. (See also Action area 11).

The *Clinical practice guideline for care around stillbirth and neonatal death*¹⁵ 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 care

Information sharing between health professionals involved in a woman's care (for example ensuring that a woman's general practitioner (GP) 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 (e.g. 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*¹⁵ 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 Investigation concerned leave entitlements for parents who experienced a stillbirth.² 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 individualised, respectful and holistic clinical and community care

Implementation

Task	Lead agency	Timeframe
Review information on bereavement care in the <i>Clinical practice guideline for care around stillbirth and neonatal death</i> (with particular reference to 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) and update as required to ensure high quality bereavement care is provided following stillbirth (see also Action area 10)		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>		Short term
Increase access to continuity of care models, including pathways to community care following bereavement, and ensure that community supports are culturally sensitive and inclusive of all types of parenting		Medium term
When planning or redeveloping maternity facilities, include appropriate spaces where bereaved parents can receive care		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		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		Short term

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

Women who have had a previous stillborn baby have a five-fold increased chance of having a stillborn baby in their next pregnancy.³¹ They also have an increased risk of preterm birth, low birthweight, placental abruption, pre-eclampsia, gestational diabetes and other adverse pregnancy outcomes.³²⁻³⁴ In addition, many women experience high levels of anxiety in subsequent pregnancies.³⁵⁻³⁷ It is therefore critical that these women are identified and provided with individualised multidisciplinary care that considers and addresses the risk of having a subsequent stillbirth. An initiative in the United Kingdom found that providing a specialist pregnancy care service for women with previous experience of stillbirth improved outcomes in subsequent pregnancies.³⁸

Standardised clinical practice guidance would inform care within specialist clinics and outline alternative care pathways where such specialist services are not available. Currently, there are no Australian national clinical practice guidelines on subsequent maternity care for women who have experienced stillbirth. 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 individualised multidisciplinary pregnancy care to reduce the risk of recurring stillbirth and other adverse pregnancy outcomes and to support the social and emotional wellbeing of parents

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)		Short term
Establish specialist pregnancy care services for women who have previously experienced stillbirth		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*.¹⁵ These guidelines aim to reduce the risk of perinatal death through better understanding of causes and contributing factors and provide 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 report² specifically identified provision of bereavement care as an area requiring clinical guidance (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 held in morgues, information sharing between health professionals involved in the care of bereaved parents, and care in subsequent pregnancies. Some of these issues 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 and representatives of Aboriginal and Torres Strait Islander peoples and migrant and refugee communities.³⁹ Bereaved parents, consumers and organisations representing the interests of groups at increased risk of stillbirth are all 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)		Medium term

4 Improving stillbirth reporting and data collection

Action area 11 Improving investigation and reporting of stillbirth

Rationale

Perinatal mortality audit

High quality perinatal mortality audit linked to practice improvement initiatives can reduce stillbirths and neonatal deaths.³ The World Health Organization's *Making every baby count: audit and review of stillbirths and neonatal deaths*⁴⁰ sets out a step-by-step process for review of all perinatal deaths. Implementation of national perinatal mortality review programs utilising rapid reporting systems is increasing internationally (e.g. in New Zealand, England, Ireland, Scotland).

While no such system currently exists in Australia, an online system based on the New Zealand system⁴¹ 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 value of perinatal autopsy has been demonstrated in several studies where the information obtained changed diagnoses or provided important additional findings.¹⁵ While autopsies may not be acceptable to parents for a variety of reasons (e.g. 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 (e.g. external, placental and umbilical cord examinations and medical imaging).¹⁵

Rates of autopsy following stillbirth are currently lower than recommended.¹⁵ Provision of education for health professionals about the value of stillbirth investigations and how to discuss the available options and their benefits respectfully with bereaved parents is crucial to increasing the rates of perinatal autopsy.¹⁵ 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 countries.³ Access to high quality investigation into the causes of stillbirth, including autopsy and placental histopathology by a skilled perinatal pathologist, should be made available to all parents after stillbirth.³

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

The ABS receives their data shortly after the death has occurred and frequently before investigations have been completed and causation determined. While timely, ABS stillbirth data reflect only registered stillbirths and no national system is in place to follow up on unregistered stillbirths. As a result, ABS stillbirth counts are under-stated, 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 (e.g. 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 newborn death is now strongly advocated by bereaved parents, their support organisations and many health professionals.^{42,43} In the UK, findings of the PARENTS1 study⁴² 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 distress.⁴²

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
- Appropriate autopsies and other investigations are undertaken following stillbirth across all cultural and religious groups

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		Medium term
Partner with parents in developing and implementing optimal ways to engage bereaved parents in perinatal audit following stillbirth		Ongoing
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		Ongoing
Expand training that supports the uptake of the <i>Clinical practice guideline for care around stillbirth and neonatal death</i>		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 (e.g. in rural areas)		1 year
Identify strategies to increase uptake of stillbirth investigations		Medium term
Develop resources for parents and families to support decision-making about stillbirth investigations		Medium term

Action area 12 Tracking progress to reduce inequity

Rationale

The 2016 Lancet Ending Preventable Stillbirths series²⁹ 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 improving 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

Implementation

Task	Lead agency	Timeframe
Implement annual reporting against the global score card		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 communities, migrant and refugee communities and other communities at higher risk of stillbirth, are involved in establishing priorities for research.

Evaluation of research priorities

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 2016.²⁹ Four major themes emerged through synthesis of surveys of Australian parents and health care providers 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 (e.g. 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 (e.g. Aboriginal and Torres Strait Islander communities, migrant and refugee communities and rural and remote communities) and parents who have experienced stillbirth in priority setting 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 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.

Defining maternal and ultrasound predictors for stillbirth in late pregnancy and developing a national biobank for severe neonatal morbidity

Stillbirth represents the apex of a large group of at-risk fetuses often sharing similar pathophysiological pathways.²⁹ 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 is possible to develop a risk stratification model.

Goals

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

Implementation

Task	Lead agency	Timeframe
Establish agreed national priorities for stillbirth research for the next 5 years, building on the work of PSANZ and the Stillbirth CRE		Short term
Establish a national placenta biobank as an enabler for research into stillbirth		Medium term
Develop and implement a risk stratification tool to inform management for women with risk factors for stillbirth		Medium term

Action area 14 Providing broader access to stillbirth research

Rationale

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

The lack of a central repository of past, current and planned stillbirth research studies is an impediment to 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

- Parents and researchers have access to a repository of Australian and international medical and social stillbirth research, including recent publications and guidelines

Implementation

Task	Lead agency	Timeframe
Publish a collection of Cochrane reviews on stillbirth in the Cochrane Library		Short term
Develop a comprehensive, publicly accessible register of current research and guidelines relating to stillbirth		Short term

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
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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