

**Towards development and implementation of  
a Stillbirth National Action Plan:  
A preparatory document from key stakeholders across Australia**

**21 December 2018**

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## Timeline for developing preparatory document

<b>Activity</b>	<b>Dates</b>
Consultation opens to stillbirth community to develop proposed actions to inform the Stillbirth National Action Plan	8 <sup>th</sup> January 2019
Deadline to include completed proposed Action Templates for the open forum	1 <sup>st</sup> February, 2019
Collation of feedback and finalisation of preparatory document	4 <sup>th</sup> February – 8 <sup>th</sup> February, 2019
Presentation at the Parliamentary Stillbirth Round Table	12 <sup>th</sup> February, 2019

## Purpose of the document

The recently released Select Senate Committee Inquiry into Stillbirth Research and Education recommended that the Australian government leads a process to develop and implement a Stillbirth National Action Plan to reduce the rate of stillbirth by 20% over the next three years and to improve quality of care in relation to stillbirth.

As part of this process, the Federal Minister for Health has proposed that a roundtable of stakeholders meet in February 2019 to advise on collaborative research partnerships and funding mechanisms.

The purpose of this document is to provide a process to draft a preparatory document to inform the development and implementation of a Stillbirth National Action Plan at the roundtable.

## Collaborators

Please refer to Appendix 1 for further details on the collaborating organisations.

The Centre of Research Excellence in Stillbirth (Stillbirth CRE)

Stillbirth Foundation Australia

Australian College of Midwives (ACM)

Bears of Hope

Red Nose

Sands

Still Aware

Women's Healthcare Australasia

The Royal College of Pathologists of Australasia

## Background

On 4 December 2018, the Select Senate Committee Inquiry into Stillbirth Research and Education tabled its Report (“the Senate Report”) in the Australian Parliament. We acknowledge the outstanding work of Senate Select Committee members, Senator McCarthy, Senator Molan, Senator Gichuhi, Senator Keneally, Senator Rice and Senator Bilyk.

This ground-breaking Senate Report highlights the way for new action and approaches when it comes to stillbirth research and education. The Senate Report gives voice to the parents of stillborn children, to the health and medical professionals, politicians and government employees who wish to work together to reduce the rate of stillbirth and provide best possible support and care for bereaved parents.

We congratulate the Senate Committee for their comprehensive report, which reflects the depth of the tragedy of each stillbirth, and demonstrates clear intent to reduce the number of stillbirths in Australia and to improve care for bereaved parents and families.

We support all the recommendations made by the Senate Committee. The Stillbirth community supports all the recommendations made by the Senate Committee. Some of the recommendations (e.g. parental leave, new Medicare items) are responsibilities of the Government. We note the Committee’s suggestion that the Stillbirth National Action Plan should form part of the National Strategic Approach to Maternity Services and request further discussion about this.

The Federal Liberal and Labor parties have both committed to funding and action to address stillbirth in Australia, the first time that bipartisan action to address this public health crisis has ever been proposed.

Health Minister Hunt announced, on 4 December 2018, an immediate response to the Senate Report to convene a national roundtable to address the rate of stillbirth in Australia, along with an initial commitment of \$7.2 million for medical research and education programs.

On 14 October 2018, Shadow Health Minister King announced an initial \$5 million for health and medical research and education programs. The Australian Labor Party has given a commitment to match and progress any work commenced by the current Federal Government if a Labor Government is elected at the next federal election.

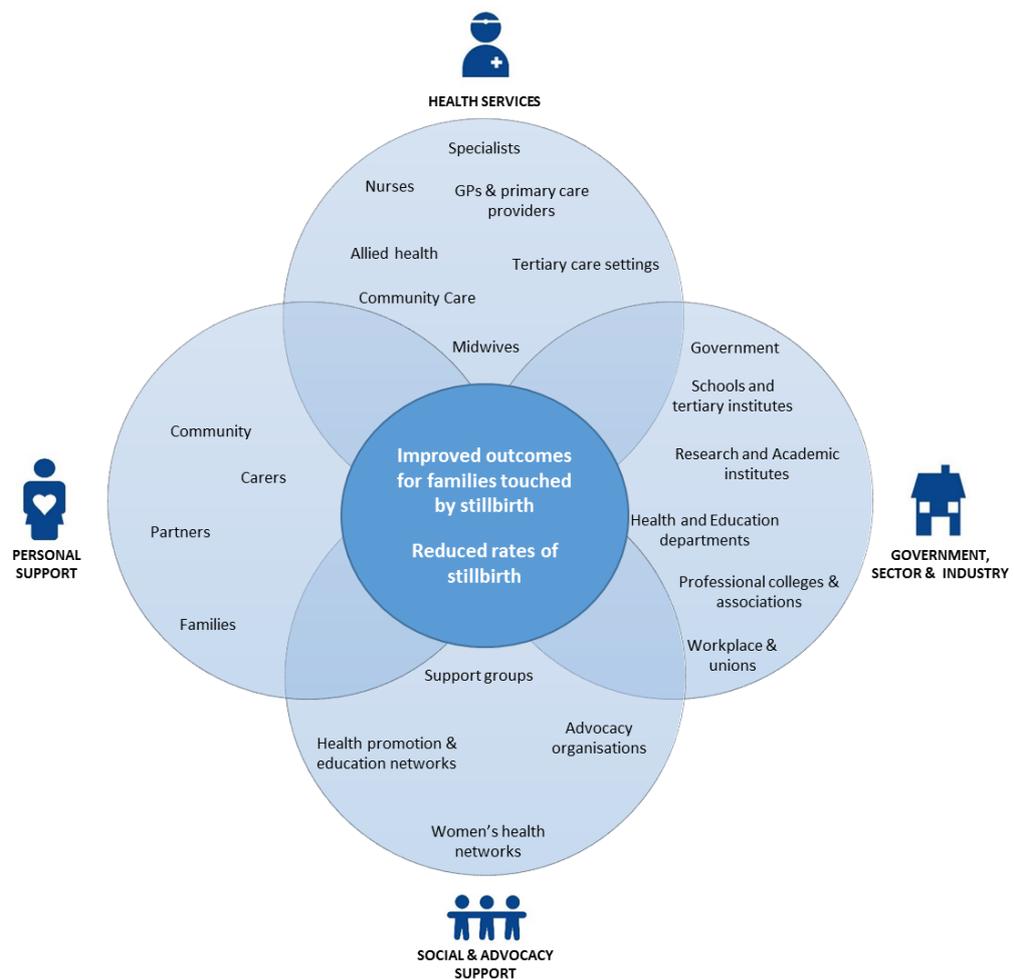
## Enablers

To improve the experiences of and outcomes for families and health care professionals touched by stillbirth and to reduce the rate of stillbirth, collaborative and continued effort is required across multiple domains. Collaboration on the development and implementation of the priorities and actions identified in a Stillbirth National Action Plan has the potential to markedly improve outcomes.

Collaboration must go beyond a simple network to be an inter-professional and consumer engaged collaborative practice. Government both state and federal, parents and families, clinicians and healthcare professionals, researchers, grief counsellors and other support services, organisations and agencies are direct partners. These partners are critical to the provision of responses that maximise the use of resources to drive change, together with advocacy and support improved outcomes.

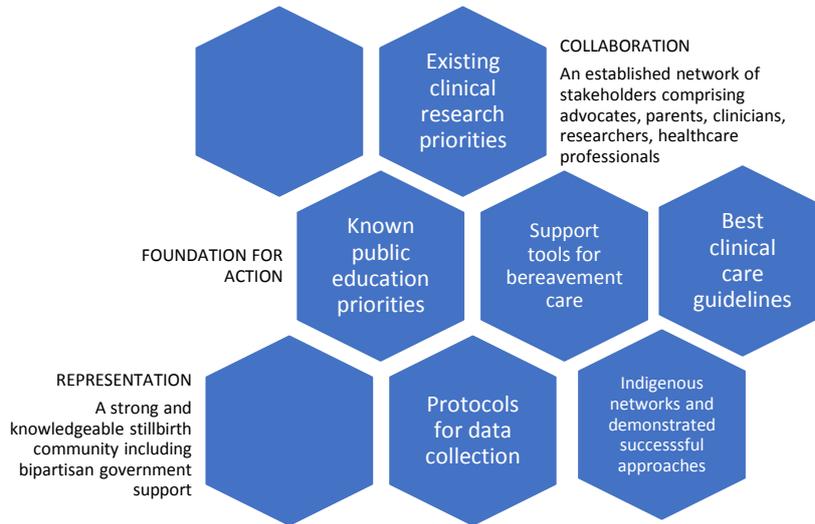
A Stillbirth National Action Plan would provide a roadmap for all partners and enable attention to be better focused on key areas drawing on the strengths of collaborating partners, identifying gaps and ensuring investments are appropriately directed.

Partnership is key to successful implementation and execution



There are many existing strengths to build upon in a Stillbirth National Action Plan. An established network of diverse stakeholders comprising advocates, parents, clinicians, researchers, healthcare professionals has united to form a highly motivated community that is dedicated to transforming the stillbirth research and education landscape.

### Enablers to support action



## Structure of the preparatory document to inform the Stillbirth National Action Plan

We believe that the Senate Select Committee listened and responded most appropriately to submissions and so we believe that the Stillbirth National Action Plan should adopt the priorities as set out in the Senate Report.

Government responsibility

### **Chapter 3: Quantifying impact of stillbirth**

Recommendation 1: Parental leave

Recommendation 3: Obtain Medical Services Advisory Committee advice on economic costs of autopsy as new Medicare Benefits Item

### **Priority 1**

#### **Stillbirth reporting and data collection (chapter 4 of the Senate Report)**

Recommendation 2: Australian Health Ministers' Advisory Council prioritise nationally consistent data collection including cause of death, autopsy, termination of pregnancy, links to National Death Index

Recommendation 4: Increase number of perinatal pathologists

### **Priority 2**

#### **Stillbirth research (chapter 5 of the Senate Report)**

Recommendation 5: Set a national stillbirth research funding priorities drawing on those developed by PSANZ and the Stillbirth CRE

Recommendation 6: Review current research funding administered by National Health and Medical Research Council and also Medical Research Future Fund

Recommendation 7: Development of National biobank for stillbirth placenta research

Recommendation 13: Create an online register of current international and Australian stillbirth research

### **Priority 3**

#### **Improving quality of care (chapter 6 of the Senate Report)**

Recommendation 8: Continuity of care and carer models, particularly for higher risk groups

Recommendation 9: National best practice guidelines

Recommendation 11: Develop and implement a national best-practice education kit for health care professionals

Recommendation 12: Hospital protocols for managing autopsies, counselling for autopsy, care of stillborn babies in morgues, communicating with bereaved parents

### **Priority 4**

#### **Public education (chapter 7 of the Senate Report)**

Recommendation 10: Develop and implement national stillbirth public awareness campaign

Recommendation 14: Public education kits that assist family and broader community to support bereaved parents

### **Priority 5**

#### **Support bereaved parents (chapter 7a of the Senate Report)**

Defines the approach and over-arching metric

#### **Chapter 8: The future of stillbirth research and education in Australia**

Recommendation 15: Reduce rate of stillbirth by 20% over 3 years

Recommendation 16: Development and implementation of a National Stillbirth Action Plan

## Process to draft preparatory document to inform Stillbirth National Action Plan

### Drafting of Actions under Action Plan

We are seeking consultation from organisations who gave testimony at the Select Senate Inquiry into Stillbirth Research and Education to assist with a collaborative response to inform the development and implementation of a Stillbirth National Action Plan at the roundtable.

As a first step in developing the Stillbirth National Action Plan, collaborating individuals or organisations are invited to use the attached template to identify and define required actions.

The template provides for:

- Overview of the issue requiring action
- Target / goal
- Required policy response
- How the action addresses cultural and linguistic differences /Indigenous health
- Implementation / by who
- Timeframe
- Proposed resourcing / costing

The Action Template is available on page 11 to all organisations wishing to put forward an Action.

As actions are developed under the relevant priorities, the preparatory documents of each Action Template can be used to inform the Government's round table in February 2019 to develop the Stillbirth National Action Plan.

### Document consultation process

Specifically, organisations who gave testimony at the Select Senate Inquiry into Stillbirth Research and Education will be made aware of the Action Template and invited to contribute. The Action Template is also being forwarded to other organisation known to have an interest in contributing to this process.

Completed Action Templates can be emailed to [stillbirthcre@mater.uq.edu.au](mailto:stillbirthcre@mater.uq.edu.au) **by 1<sup>st</sup> February, 2019**, and will be made available on the [Stillbirth CRE website](#).

## Template

<b>Relevant Senate Select Committee Priority / Recommendation</b>	
<b>Action Title</b>	Description of action
<b>Responsible working group (Names and contact details)</b>	
<b>Overview of the issue</b>	
<b>Target/goal</b>	
<b>Policy response</b>	
<b>How the action addresses cultural and linguistic differences / indigenous health</b>	
<b>Timeframe</b>	
<b>Proposed resourcing/costing</b>	

## Appendix 1

### Collaborators

#### The Centre of Research Excellence in Stillbirth (Stillbirth CRE)

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) was funded in 2016 by the National Health and Medical Research Council to promote national collaboration to effectively address the neglected tragedy of stillbirth. Stillbirth CRE brings together parents, parent advocates, health care professionals, researchers, professional colleges, and policy makers, to reduce stillbirth rates and improve the quality care for women and families after stillbirth. Through a priority driven program, the Stillbirth CRE aims to address this major public health issue in Australia through a cohesive national program of research and implementation.

The vision of CRE Stillbirth is that stillbirth rates will be reduced to at least equal the best performing country globally and that supportive, respectful care will be provided to all women and families who experience the tragedy of stillbirth, irrespective of where in Australia they live. The mission is to create strong partnerships for high-quality research and increased public awareness around stillbirth and to generate knowledge that translates into better care and outcomes for women and families.

The Stillbirth CRE is built on collaboration and encourages Australian entities pursuing improved health outcomes to address stillbirth in Australia to co-ordinate their efforts for maximum impact. The Stillbirth CRE invites members of the stillbirth community who share their vision and mission to join their collaborative effort.

#### Stillbirth Foundation Australia

The Stillbirth Foundation Australia is the only Australian charity dedicated to stillbirth research, and is 100 percent community funded.

It was launched by Emma McLeod in October 2005 after Olivia, Emma's second child and first daughter, died unexpectedly in utero and was born still on 31 July 2002.

Since 2005, the Stillbirth Foundation has allocated over \$1million to funding the most rigorously designed studies aimed at finding a means of preventing stillbirth and supporting the families of stillborn babies.

Today, The Stillbirth Foundation Australia is recognised nationally as a leading voice on stillbirth and represents the voices of thousands of Australian families who have been touched by stillbirth.

The Stillbirth Foundation Australia's mission is to significantly reduce the incidence of stillbirth through research, education and advocacy, including

- Supporting researchers to generate new knowledge about stillbirth and encouraging the translation of research into practice
- Supporting the community and health professionals to change behaviours that will help to reduce the incidence of stillbirth
- Extending the reach and impact of the Stillbirth Foundation Australia by being a leader and advocate in the field of stillbirth.

## Australian College of Midwives (ACM)

ACM is committed to being the leading organisation shaping Australian maternity care, to ensure the best possible maternity outcomes for all Australian women. It is guided by research evidence that pregnant women and mothers benefit from having access to midwifery care throughout their childbearing experience.

ACM's work is guided by the following:

### ***Ethical practice***

- Applying evidence to everything we do
- Following our code of ethics, conduct, practice and standards

### ***Collaboration***

- Working cooperatively with external groups and respecting their role and interaction
- Listening, hearing, discussing and passing the agreed message on
- Protecting those who are not present and talking to the source

### ***Trusting and respectful relationships***

- Treating each other as we would wish to be treated

### ***Respect diversity***

- Respecting a person's right to have a different opinion

### ***Innovation***

- Be open to new ideas and understand that there is always another way and that anything is possible
- Striving for continuous improvement

In addition, The ACM:

- supports and promotes midwives and the midwifery profession across all areas of practice and regulation.
- represents the midwifery profession at all levels of government and industry by fostering relationships, attending meetings, undertaking presentations and writing submissions.
- sets or influences standards in regards to maternity practice with its guidelines, standards and position statements.
- provides continuing professional development (CPD) opportunities to midwives through educational events, webinars, online courses, workshops, conferences, seminars, focus groups, research opportunities and our printed and electronic communications.
- leads the way in Australia for Midwifery related research publication with the Women and Birth journal, published by Elsevier. ACM also provides updates to current midwifery issues at a local level via its member magazine Australian Midwifery News and our quarterly electronic Branch Matters.
- disseminates a range of CPD opportunities to midwives through its CPD Recognition program, thus enabling midwives to have confidence that the CPD they are accessing is of relevance to their midwifery practice.
- facilitates midwives to network with their peers through events and conferences.

The ACM is committed to working in partnership with the Stillbirth CRE and will utilise all of its communications resources to disseminate information or requests for assistance. The ACM will also participate in areas of work programs or projects through the provision of expert volunteers from amongst our membership.

## Bears of Hope

There are two key elements to the Bears of Hope service, and each are provided nationally:

- Families receive a Bear of Hope donated by another bereaved family. This allows the donating family to give their child's brief life a purpose and lasting legacy, whilst filling the empty areas of another family as they walk out of the hospital without their baby. It reinforces the understanding that they are not alone, and that there is an existing community of support.
- Families also receive extensive information to guide them through their keepsake and memory decisions.

Bears of Hope's Beyond the Bear support provides a credible foundation of psychologist facilitated support groups, private online groups, phone, email, Skype, face-to-face counselling, and annual community events.

Bears of Hope's role as a partner with Stillbirth CRE is to help establish greater guidelines for health professionals to follow when caring for a family experiencing stillbirth, and to use its experience and expertise on behalf of many families when considering what are the important messages that health professionals need. Bears of Hope also act as a voice to facilitate better understanding into the grief associated with baby loss throughout the years and milestones and are passionate about creating greater awareness and compassion through the wider community for these families.

## The Perinatal Society of Australia and New Zealand

The Perinatal Society of Australia and New Zealand is a multidisciplinary society dedicated to improving the health and long term outcomes for mothers and their babies. PSANZ encompasses and strongly encourages research focused on mothers and babies during pregnancy and at birth as well as the health of the newborn as its development continues after birth.

The Society fosters communication and collaboration between all those involved in perinatal research and in the care of the mother and baby during pregnancy, birth and the postnatal period and offers professional, political, administrative and educational advice.

The Perinatal Society of Australia and New Zealand Stillbirth and Neonatal Death Alliance (PSANZ SANDA) played a major role in the development of the Stillbirth CRE. We continue to work together seamlessly to improve outcome for future families.

PSANZ aims to:

- Advance the theory and practice of Perinatology
- Encourage training and research
- Provide expert advice to government and other bodies
- Collaborate with all relevant organisations or professions
- Establish and maintain positive relationships with relevant international bodies

## Red Nose

Red Nose provides world-class research, advocacy and education, and envisions a future where no child dies suddenly and unexpectedly during pregnancy, infancy or in childhood.

Red Nose relies on the generosity of the community through Red Nose Day and other fundraising events, and through partnerships with small businesses and corporations. Red Nose Grief and Loss services and Indigenous programs are partly funded by Commonwealth and State Governments.

## The Royal College of Pathologists of Australasia

The RCPA is the leading organisation representing pathologists in Australasia. Its mission is to train and support pathologists and to improve the use of pathology testing to achieve better healthcare

## Sands

Sands provides support, information and education to bereaved families and healthcare professionals across Australia.

- **Support:** We provide peer to peer services for bereaved parents around the clock through our telephone support line, email, local support groups and online live chat.
- **Information:** We are here to provide vital information to bereaved parents following the death of a baby. This also includes real life stories from other parents and our wider community.
- **Education:** We are here to provide support and training for Healthcare Professionals and Funeral Home Directors to ensure bereaved parents are provided with appropriate care and support.

Sands' mission is to ensure all bereaved parents receive high quality care and support following the death of a baby. Sands will work closely with the Stillbirth CRE and all its partners and collaborators to help deliver on this mission with particular focus on guidelines and training for healthcare professionals. On a broader scale, Sands will also look to deliver on our common purpose – to reduce the rates of stillbirth in Australia

## Still Aware

Still Aware are committed to raising awareness of the very real statistics of stillbirth in Australia working to end preventable stillbirth. Still Aware educate clinicians, mothers and families about stillbirth prevention and promote open communication. We encourage and support dialogue around the realities of loss, in order to break the silence and taboo surrounding stillbirth. Still Aware is invested in sharing stillbirth research and actively lobbies for stillbirth to be listed and remain on the policy agenda at a national level. Still Aware continue to work with key researchers in the field to gather and report data of care provisions already offered internationally, but which are not offered to Australian patients.

Still Aware is the only not-for-profit organization in Australia dedicated to raising awareness of stillbirth. At Still Aware every dollar donated goes directly to funding awareness and education to bring about change.

Still Aware's mission is to:

- Raise awareness of the very real statistics of stillbirth in Australia
- Do good work to end preventable stillbirth
- See a reduction in preventable stillbirth by 20% by 2025
- Empower pregnant families to connect daily with their baby's
- Educate clinicians, mothers and families about stillbirth prevention and promote open communication
- Lift the level of stillbirth understanding to that of SIDS
- Encourage and support dialogue around the realities of loss, in order to break the silence and taboo surrounding stillbirth and combat the greater societal and emotional impact of such tragedy
- Bring about change to the way in which we talk about and acknowledge a baby born still

- Share stillbirth research and actively lobby for stillbirth to be listed and remain on the policy agenda at a national level

#### Women's Healthcare Australasia

Around 100 maternity services participate in WHA, including all of the dedicated Women's Hospital, and a majority of metropolitan and regional services. There is also growing participation from small rural maternity units. Together, WHA members care for more than 60% of public births each year in Australia.

WHA's mission is to support excellence in healthcare for women and newborns. WHA facilitate networking, and sharing of performance data, experiences and innovations among member hospitals, to support their ongoing efforts to improve healthcare for women and their families.

WHA facilitates networking among staff of member hospitals through 12 separate Special Interest Groups, as well as in face-to-face and online forums. These Interest Groups draw people together with a common interest, such as Midwifery Group Practice or Maternal Fetal Medicine, to share common challenges and strategies for overcoming them.

WHA's benchmarking program provides participating hospitals with annual data about both their clinical and business performance in relation to peers of similar size and capability. The clinical data helps hospitals to identify how their labour and birth and early newborn care compares with peers, as well as trends in up to 30 different indicators, such as rates of induction, rates of caesarean section, rates of postpartum haemorrhage and rates of stillbirth.

WHA also advocates on behalf of the maternity services sector to relevant government agencies, ensuring our members' expertise and views are considered in national policy-making arenas.

WHA is proud to be a partner to the Stillbirth. Our members are highly motivated to provide the best possible care to women to minimise the risk of stillbirth, and to respond in the best possible way to support women and their families when it occurs. WHA is committed to working closely with the CRE to facilitate translation of the CRE's research into clinical practice across Australia.