Submission to Inform the Stillbirth National Action Plan

KEY PRIORITY AREAS AND RECOMMENDATIONS

2019

AUSTRALIA | #ENDSTILLBIRTHS #RESPECTSTILLBIRTHFAMILIES

VERSION 4

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. The Senate Select Committee went to extraordinary lengths to ensure that each public hearing included testimony from those who knew the impact best – bereaved families. It is critical that the voice of bereaved parents be integrated in to every aspect of the national action plan. Bereaved parents seek the opportunity to influence all approaches to reducing the rates of stillbirth. They believe that this is how Australia can honour their babies and acknowledge that our efforts to date have not been acceptable in reducing the rates of stillbirth.

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 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, Greg 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, the Shadow Minister for Health, Catherine King, announced funding commitment to stillbirth.

Together with our partners and many others, the Stillbirth CRE and Stillbirth Foundation Australia have facilitated a call for consultation to develop a collaborative response to inform the development of a Stillbirth National Action. Key stakeholders within the Australian stillbirth community, including research organisations, health departments, parents and parent advocacy groups, have responded to this call. This document is a reflection of this collaborative response and outlines a series of solution based actions to address the recommendations put forward in the Senate Report.

An underlying principle of the action plan is that outcomes must address equity for high risk and priority groups, including Aboriginal & Torres Strait Islander women and women living in rural and remote Australia. It is acknowledged that the action items outlined in this document may not be directly transferrable to the rural and remote setting. Service models and care pathways must be tailored to meet not simply the constraints, but also the opportunities afforded by these unique contexts and cultures.

Summary of priority areas and recommendations

Government responsibility

Chapter 3: Quantifying impact of stillbirth

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 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 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 a national stillbirth public awareness campaign

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

Recommendation 14: Public education kits that assists family and broader community to support bereaved parent

Priority 5

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

Recommendation 1: Parental leave

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

Contents

Priority 1: Stillbirth reporting and data collection

Action 1.1: Making every baby count in Australia; Implementing a national program for in-depth clinical audit of stillbirths and neonatal deaths to inform and drive the rates of stillbirth in Australia

Action 1.2: Australian Bureau of Statistics; Improving accuracy of stillbirth data

Action 1.3: Tracking progress in reducing inequity; A global scorecard across high income countries

Action 1.4: Improving data quality and collection in Australia

Action 1.5: Updating fetal death records with final diagnosis

Action 1.1: Making every baby count in Australia; Implementing a national program for in-depth clinical audit of stillbirths and neonatal deaths to inform and drive the rates of stillbirth in Australia

1.1 Recommendation

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

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Jeremy Oats (Australian Institute of Health and Welfare)
- Tanya Farrell (Consultative Council on Obstetric and Paediatric Mortality and Morbidity – CCOPMM, Victoria)
- Vicki Flenady (Queensland Maternal Perinatal Quality Council - QMPQC)
- David Ellwood (Queensland Maternal Perinatal Quality Council)
- Yee Khong (Royal College of Pathologists Australia)
- Adrienne Gordon (University of Sydney)
- Natasha Donnolley (University of New South Wales)
- Belinda Jennings (Northern Territory Government, Department of Health)
- Sony Criddle (King Edward Memorial Hospital, Western Australia)
- Aaron David (Stillbirth Foundation Australia and Bereaved Parent)
- Diane Payton (Royal College of Pathologists Australasia)
- New Zealand Perinatal Mortality and Morbidity Review Committee (PMMRC)
- Partnership with RANZCOG, ACM, and RACGP is proposed
- Consultation to include: Stillbirth CRE Indigenous Advisory Group and other orgs representing disadvantaged groups; PSANZ Guidelines Chapter authors, parent advocacy and support organisations and the AIHW perinatal mortality advisory group (consultation with AIHW is underway – Prof Michael Humphrey and Al-Yaman Fadwa)

1.3 Overview

Stillbirth is too common – 6 Australian babies are stillborn each day. Stillbirth is a serious public health problem with far reaching psychosocial and financial burden for families. There has been little improvement in rates for over two decades, and in Australia it is 35% higher than top performing countries globally. For Aboriginal and Torres Strait Islander, South Asian women and disadvantaged women, stillbirth rates are doubled (Davies-Tuck, Davey, & Wallace, 2017; Ibiebele et al., 2015).

Accurate causes and contributing factors for perinatal deaths (i.e. stillbirth and neonatal death, and timely and consistent reporting) is critical to inform effective prevention strategies.

In Australia, up to 50% of stillbirths at term are classified as unexplained (Measey et al., 2007).The lack of a cause is distressing for parents as they struggle to understand "what went wrong" and whether this will happen in future pregnancies. However, the proportion of unexplained stillbirth may be overestimated by 50% as a result of inadequate investigation, clinical audit and classification (Flenady et al., 2011). Our survey for The Lancet Ending Preventable Stillbirths Series (Flenady et al., 2016) indicates there is room for improvement in stillbirth investigation with 50% of parents feeling that not everything possible had been done to find out why their baby died. The PARENT study (Downe, Schmidt, Kingdon, & Heazell, 2013) in the UK has highlighted the importance of engaging parent in the review process.

Audit is defined as an investigation into whether an activity meets explicit standards defined in an auditing document. In audits of stillbirths and neonatal deaths, in Australia (Queensland Maternal and Perinatal Quality Council, Feb 2018; The Consultative Council on Obstetric and Paediatric Mortality and Morbidity, Jun 2017) and internationally (MBRRACE-UK, 2013; Richardus, Graafmans, Verloove-Vanhorick, & Mackenbach, 2003) 50% have substandard care factors identified and in around one-third the death is deemed potentially avoidable due to these factors. Recent events and reports have highlighted the need for timely audit of all perinatal deaths to identify and address these factors. For example, an independent investigation in the case of ten perinatal deaths at Bacchus Marsh and Melton Regional Hospital in Victoria in 2013-4 found that seven of these deaths may have been avoidable. In Victoria in 2016, comprehensive reviews of all the 839 perinatal deaths, contributing factors were identified in 123 of the 501 stillbirths (24.6%) and 43 of the neonatal deaths (20.2%) (Consultative Council on Obstetric and Paediatric Mortality and Morbidity, 2016). An audit of 60 term/near term perinatal deaths in Queensland, identified substandard care factors in 60%, with one third classified as potentially avoidable (the vast majority were stillbirths) (Queensland Maternal and Perinatal Quality Council, Feb 2018). Commonly reported substandard care factors include missed cases of fetal growth restriction, inadequate management of women reporting decreased fetal movements, maternal smoking often linked with inadequate smoking cessation support, poor antenatal care attendance often linked with cultural and social circumstances.

High quality perinatal mortality audit linked to practice improvement initiatives can reduce stillbirths and neonatal deaths (Flenady et al., 2016). The WHO's Making every baby count: audit and review of stillbirths and neonatal deaths (World Health Organisation, 2016a)sets out a step by step process for review of all perinatal deaths which is being implemented globally with a focus on training in low and middle-income countries.

Implementation of national perinatal mortality review programs utilizing rapid reporting systems is increasingly used internationally (New Zealand, England, Ireland, Scotland). In the UK MMBRACE has implemented a national program using an on-line tool for all perinatal deaths with a focus on accuracy in causes of death. Ireland has implemented a similar program which has been very successfully. The RCOG in the UK has developed a successful perinatal audit program to identify areas for practice improvement in a subset of potentially avoidable perinatal deaths and adverse neonatal events. The highly successfully national perinatal mortality (and morbidity) audit system in New Zealand (Perinatal and Maternal Mortality Review Committee, 2017) provides an excellent model to draw upon for Australia.

In Australia, the lack of such a system is a major impediment to effectively reducing the rates of stillbirths and neonatal deaths. Data collection and reporting in Australia is suboptimal with laborious and disparate processes resulting in lengthy delays and limited data across jurisdictions and nationally. To mount effective strategies for maternity services to reduce the gap between "what is known and what is done" in every day clinical practice, a rapid response system is needed.

The Perinatal Society of Australia and New Zealand (PSANZ)/Stillbirth CRE Clinical Practice Guideline for maternity services on care around stillbirth and neonatal death (V Flenady et al., 2018) outlines a comprehensive approach to investigating and classifying the clinical cause as well as contributing factors for perinatal deaths based on the WHO guidelines (World Health Organisation, 2016b). The guideline also includes communication and support for families. While uptake into practice appears to be improving(V. Flenady et al., 2018) there is substantial room for improvement. The IMPROVE workshop, is an educational program for maternity health care professionals to assist health care providers in implementing the guidelines has been extremely well-received (Gardiner et al., 2016), however lack of funding has limited is uptake.

AIHW has established a national advisory group on perinatal deaths, a minimum data collection and is now producing bi-annual reports (Australian Institute of Health and Welfare, 2018) although this activity is limited due to inadequate resourcing and data availability including the collection and reporting of contributing factors.

Through funding provided by NHMRC, an online system for Australia has been piloted which is heavily based on the NZ system based; Australian Perinatal Mortality Audit Tool (APMAT). The primary purpose of APMAT is to support high quality investigation, audit and classification all perinatal deaths in a timely way for the purpose of local, jurisdictional and national reporting to health departments for the purposes of practice improvement. Secondary purposes include supporting clinician education in care after perinatal death including recommended PSANZ perinatal deaths investigation protocols and to inform future research. The systems captures details clinical information to understand the events surrounding the death and investigations undertaken to determine the causes and contributing factors. However, significant duplication of data entry with that of the perinatal data collections across Australia has stalled implementation.

Key to undertaking high quality audit into stillbirths, is access to high quality guidelines. In partnership with NHMRC, professional colleges, parents, the Indigenous Advisory Group and others the Stillbirth CRE aims to compile a readily accessible repository of best practice guidelines in stillbirth prevention (See action 3.6 of Document Informing a National Action Plan for Stillbirths).

1.4 Target/Goal

To implement a nationally consistent and timely clinical audit program for stillbirths and neonatal deaths in Australia by 2020.

1.5 Policy response

AHMAC is requested to enable the following:

- Funding to support the program at the jurisdictional level;
- Mandatory reporting of an agreed MDS for perinatal deaths as part of this program to AIHW (National Health Care Agreement);

Specific objectives of the national program:

- In partnership with parent based organisations to develop a process for engaging parents in the audit program including capturing a detailed parent summary of events as part of the investigation and to seek parents' feedback on the process;
- Expand the national minimum data set (MDS) for all perinatal deaths including: whether the death was as a result of a termination pf pregnancy, timing of stillbirth (antepartum or intrapartum), investigations undertaken, substandard care factors;
- Australian Institute of Health and Welfare to expand data collection for perinatal deaths and develop a more comprehensive data set on all births in Australia;
- National agreement on the cases for in depth review for substandard care e.g. 34 weeks' gestation or more without major congenital abnormalities and also major neonatal morbidity;
- Develop effective data collection systems for the audit program including woman's summary of the events surround the death and care received during pregnancy and postpartum;
- Agreement on a single definition of stillbirth and neonatal death and statistical methods to ensures valid peer benchmarking nationally and internationally across Australia;
- Develop equity targets for stillbirth and neonatal death rates reduction with annual benchmarking across jurisdictions;
- Annual forums to share quality improvement experiences from the audit program across jurisdictions to assists in escalating improvements;
- Provide recurring funding for the IMPROVE educational program (face to face and eLearning).

1.6 Cultural diversity and Indigenous health

The collection of data on indigenous status, country of birth, primary language spoken by the mother will assist the assessment of the contribution of ethnicity to perinatal outcomes and to the development of culturally appropriate implementation strategies. Ensure appropriate engagement with relevant stakeholders to determine data collection and reporting mechanisms.

1.7 Timeframe

Year 1: Establishment phase. This will be undertaken as a partnership between the CCOPMM and the QMPQC with AIHW.

Years 2-3: Implementation across Australia.

1.8 Resources

Based on the New Zealand model around $2 million is required for establishment and management over the initial 3 years as follows:

- Re-development of APMAT to reduce duplication of data entry. year 1 = $300,000;
- Full time national coordinator: Years 1 -3 = $350,000;
- Annual running costs Years 2 and 3: $900,000 ($450,00 annually);
- Clinician education using the existing IMPROVE program and additional face-to-face education site meetings and national forums;
- Data management, cleaning and analysis; reporting years 2 and 3;
- Technical database support.

Action 1.2: Australian Bureau of Statistics; Improving accuracy of still birth data

The Australian Bureau of Statistics receives their data shortly after the death has occurred and frequently before investigations have been completed and causation determined. While timely, ABS stillbirth counts reflect only registered stillbirths, and no active system is in place to follow up on unregistered stillbirths. As a result, ABS stillbirth counts are under-stated in line with levels of under-registration. This has resulted in there being significant discrepancies between AIWH data and ABS data. This can confuse data users and call into question the meaningfulness of the ABS collection as it is currently reported.

Proposed work from the ABS

The ABS receives information on registered stillbirths from the eight jurisdictional Registries of Births, Deaths and Marriages (RBDMs) on a monthly basis. Registries (in the main) also provide copies of Medical Certificates of Causes of Perinatal Death associated with stillbirths which are received from hospitals. These records are generally not matched by the RBDMs but are instead matched by the ABS during the compilation of data.

The lack of connectivity in this system for delivering data to the ABS can result in several outcomes:

- Registrations can be received and matched with a corresponding MCCPD (occurs in the majority of cases);
- Registrations can be received with no corresponding MCCPD (common in some jurisdictions but being addressed);
- An MCCPD can be received that has (currently) has no registration.

Work could be undertaken to address the following:

1. Work with the RBDMs to enhance the completeness of capture of MCCPDs relating to stillbirths from the hospitals, through the RBDMs and on to the ABS.
2. Implementation of a more systematic way of reconciling registrations with MCCPDs, focussing on registration lag times, points at which registrations are unlikely to occur and the residual numbers of MCCPDs that cannot be matched with registrations.
3. Look at causes derived from MCCPDs to provide further information to data users on conditions that are captured well through registration based data and those that are not. Of particular interest would be those causes associated with unregistered stillbirths.
4. Develop ways of enhancing ABS outputs on stillbirths to provide additional information to users on the magnitude of under-registration, the areas of higher vs lower quality by cause and perhaps supplementary information on un-registered stillbirths.
5. Investigate how differences in data affect key perinatal statistical outputs.

It is estimated that this body of work would cost in the region of $80,000. (Approximately 0.2 APS4, 0.1 APS5, 0.1 APS6 and 0.05 EL1).

Action 1.3: Tracking progress to reduce inequity; A global scorecard across high income countries

Developing a global scorecard that focuses on inequity in high-income countries transcends Priority 1 and includes elements from all priority areas.

1.1 Recommendations

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

Recommendation 4: Increase number of perinatal pathologists.

Recommendation 5: Set a national stillbirth research funding priority 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 Medical Research Future Fund.

Recommendation 7: Development of National biobank for stillbirth placenta research.

Recommendation 8: Continuity of care and care-provider models, particularly for high risk groups.

Recommendation 9: National best practice guidelines.

Recommendation 10: Develop and implement a national stillbirth public awareness campaign.

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 stillbirth babies in morgues, communicating with bereaved parents.

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

Recommendation 14: Public education kits that assist families and broader communities to support bereaved parents.

1.9 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Hannah Blencowe (London School of Hygiene and Tropical Medicine, UK)
- Susannah Leisher (International Stillbirth Alliance)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)

- David Ellwood (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Griffith University)
- Fran Boyle (Centre of Research Excellence in Stillbirth, PSANZ SANDA, The University of Queensland)
- Caroline Homer (Centre of Research Excellence in Stillbirth, Burnet Institute)

Collaborators to be confirmed:

- Danielle Pollock (Parent Representative)
- Keelin O'Donoghue, (University College of Cork, Ireland)
- Robert Silver (University of Utah, USA)
- Dimitrios Siassakos (University of Bristol, UK)
- Alex Heazell (Manchester University NHS Foundation Trust, University of Manchester, UK)
- Jan Jaap Erwich (University of Groningen, Netherlands)
- Margaret Murphy (University College of Cork, Ireland)
- Katy Gold (University of Michigan, USA)
- Claire Storey (International Stillbirth Alliance)
- Mechthild Gross (Hannover Medical School, Germany)

Consultation to include: Indigenous and other orgs representing disadvantaged groups, parent advocacy and support organizations, professional colleges, researchers and policy makers.

1.10 Overview

Each year an estimated 2.6 million babies are stillborn. Progress to reduce this large burden has been slow. The 2016 Lancet Ending Preventable Stillbirths series (de Bernis et al., 2016) sought to highlight missed opportunities and identify actions for accelerated progress to end preventable stillbirths. The series concluded with a Call to Action.

The call to action covers three distinct areas – 2030 mortality targets, Universal health care coverage targets and milestones to improving the care and outcomes for all mothers and their babies (Every Newborn Action Plan global and national milestones (REF)) and specifically for women and families affected by stillbirth.

This Global Scorecard has been produced by the Stillbirth Advocacy Working Group (SAWG) to track progress at a global level towards this Call to Action. The SAWG is a group of academics, researchers, parents and advocates (International Stillbirth Alliance, 2019).

Two and a half years since this call was made, how much progress is being made at a global level towards these targets and milestones? We hope that this global scorecard will be a useful resource to the global community, including UN bodies, bilateral organisations, donors and NGOs to highlight areas where insufficient progress is being made and where further investments and actions are needed.

In high income countries the focus will be to use the Global Scorecard to identify disparities in measures for Aboriginal women and women living in disadvantaged circumstances.

2016 Lancet Ending Preventable Stillbirth Series Call to Action

THE LANCET

Ending preventable stillbirths

An Executive Summary for *The Lancet's* Series

Mortality targets by 2030 (included in Every Newborn Action Plan)

- 12 stillbirths or fewer per 1000 total births in every country;
- All countries set and meet targets to close equity gaps and use data to track and prevent stillbirths.

Universal health care coverage targets

- Family planning: by 2020, 120 million more women and girls with access to contraceptives; by 2030, universal access to sexual and reproductive health-care services and integration of reproductive health into national strategies and programmes;
- Antenatal care: by 2030, universal quality of care and comprehensive antenatal care for all women, and;
- Care during labor and birth: by 2030, effective and respectful intrapartum care to all women in all countries.

Milestones

- Respectful care, including bereavement support after a death: by 2020, global consensus on a package of care after a death in pregnancy or childbirth for the affected family, community, and caregivers in all settings;
- Reduce stigma: by 2020, all countries to identify mechanisms to reduce stigma associated with stillbirth among all stakeholders, particularly health workers and communities;
- Every Newborn global and national milestones met by 2020, including the Measurement Improvement Roadmap (tracked separately by UNICEF/ WHO) Every Newborn Progress Report 2018 (see: https://www.healthynewbornnetwork.org/hnn-content/uploads/Final-Country-Progress-Report-v9-low-res.pdf).

Selection of indicators to track Call to Action

Indicators were chosen by a subgroup of the SAWG to reflect the three areas of the Call to Action. Where possible, indicators already collated by UN and other organisations were used. In particular, the annual tracking tool undertaken by UNICEF and WHO to monitor progress towards Every Newborn Action Plan (ENAP) provides many indicators to track progress for maternal and newborn health, including stillbirths. Chosen indicators sought to capture both the ultimate outcomes and processes and policies that are required to achieve these.

The draft list of proposed indicators and draft scorecard was circulated in several rounds to the wider SAWG, and targeted organisations including UNICEF, WHO, and White Ribbon Alliance for comments and further suggestions, prior to finalizing.

Indicators were scored according to benchmarks – from red (below expectation), through to purple (fully achieved). Black indicates that no information is currently available. A full description of the indicators is given in Appendix 1. Overall global results are shown where available. In addition, results are shown for 74 high burden countries participating in the ENAP tracking tool (Appendix 1) The simplified scorecard is shown below in Figure 1.

Main Findings of pilot in 74 high burden countries participating in ENAP tracking tool:

The scorecard shows that whilst some progress is being made towards the targets and milestones from the Ending Preventable Stillbirths Call to Action, that further efforts are needed. Information is currently lacking to track equity and quality of care indicators, although work is currently underway by WHO and UNICEF to close this information gap. No data are currently available to track country's progress towards taking steps to reduce stigma, and more work is needed in this area.

1.11 Target/Goal

- To implement bi-annual reporting of Australia's performance to the Lancet's call to action to address stillbirth using the Global Stillbirth Scorecard specifically focusing on disadvantaged women;
- In partnership with International Stillbirth Alliance and The London School of Hygiene and Tropical Medicinal to compare Australia's performance with other high-income countries;
- To convene international and national forums to review the findings of the above and identify areas where action is required.

1.12 Policy response

Under development.

1.13 Cultural diversity and Indigenous health

We will work with relevant agencies across high income countries to ensure relevance of the scorecard to specific communities

1.14 Timeframe

Pilot in 2019.

1.15 Resources

Under development.

Action 1.4: Improving data quality and collection in Australia

1.1 Recommendations

Under development.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Australian Institute of Health and Welfare

1.3 Overview

Under development.

1.4 Target/Goal

Under development.

1.5 Policy response

Under development.

1.6 Cultural diversity and Indigenous health

Under development.

1.7 Timeframe

Under development.

1.8 Resources

Under development.

Action 1.5: Updating fetal death records with final diagnosis

1.1 Recommendations

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

1.2 Collaborators

- Marti Perhach (Group B Strep International)
- James McGregor (Group B Strep International)

1.3 Overview

A challenge in even many developed countries in determining an accurate burden of stillbirth by cause is that fetal death records initially marked as "unknown" (which might include non-visually apparent infection) are often not routinely updated with the final diagnosis.

1.4 Target/Goal

- 100% of fetal death records are updated if a final diagnosis is available;
- All updates are reflected accurately in surveillance data.

1.5 Policy response

- Confirm if procedures are currently in place for the routine updating of fetal death records nationwide;
- If necessary, implement steps to facilitate the updating of fetal death records nationwide to accurately inform surveillance data.

1.6 Cultural diversity and Indigenous health

Any challenges to be determined.

1.7 Timeframe

Suggest confirming if any gaps in routine updating by mid-2019.

Suggest implementing procedures if needed to routinely update all fetal death records by early 2020.

1.8 Resources

Priority 2: Stillbirth Research

Action 2.1: Prioritising high value research to effectively prevent stillbirth and improve care for families who have a stillborn child

Action 2.2: Establish an Australian stillbirth research registry

Action 2.3: Identification of placental biomarkers that determine risk of stillbirth

Action 2.4: Define maternal and ultrasound predictors for adverse perinatal outcomes in late pregnancy (>28w) and development of a national biobank for severe neonatal morbidity ("stillbirth near misses")

Action 2.5: Improved detection of fetal growth restriction

Action 2.6: Reducing smoking rates in pregnancy

Action 2.7: Harmonisation of state-based health data collections for pooled analyses – a big step towards the development of a comprehensive standardised national stillbirth data collection

Action 2.8: Generating up-to-date data on resource use and costs associated with stillbirth to enable rapid evaluation of stillbirth prevention and care improvement initiatives

Action 2.9: Research towards prenatal-onset Group B Strep disease (POGBSD) prevention and in preparation for a potential GBS vaccine

Action 2.10: Novel interventions to reduce the risk of stillbirth

Action 2.1: Prioritising high value research to effectively prevent stillbirth and improve care for families who have a stillborn child

1.1 Recommendations

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

Recommendation 6: Prioritising high value research to effectively prevent stillbirth and improve care for families who have a stillborn child.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)
- Philippa Middleton (Centre of Research Excellence in Stillbirth, PSANZ SANDA, South Australian Health and Medical Research Institute)
- David Ellwood (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Griffith University)
- Jonathan Morris (Centre of Research Excellence in Stillbirth, PSANZ SANDA, University of Sydney)
- Fran Boyle (Centre of Research Excellence in Stillbirth, PSANZ SANDA, The University of Queensland)
- Adrienne Gordon (Centre of Research Excellence in Stillbirth, PSANZ SANDA, University of Sydney)
- Euan Wallace (Centre of Research Excellence in Stillbirth, Monash University)
- Georgina Chambers (National Perinatal Epidemiology and Statistics Unit, USNW Sydney)
- Kate Lynch, Stillbirth Foundation Australia
- Partnerships TBC: RANZCOG, ACM, RACGP, RCPA, Sands, Red Nose, Still Aware, Bears of Hope

1.3 Overview

With an international team, the Stillbirth CRE/ Perinatal Society of Australia and New Zealand SANDA members have undertaken a large body of work on stillbirth globally published in two series in The Lancet in 2011(Flenady et al., 2011) and 2016 (de Bernis et al., 2016). The 2016 series focused on quantifying the response to the call to action of the previous Lancet stillbirth series of 2011. A number of priority areas for practice and research were identified in 2011 and refined in 2016 series for high income country settings drawing on research priority setting initiatives in the

UK (Heazell et al., 2016) and findings of an international survey we conducted of parents and health care providers.

Drawing on this work, stillbirth research priority setting for Australia was undertaken in 2015 by the Perinatal Society of Australia and New Zealand to inform the research program of the NHMRC Centre of Research Excellence for stillbirth.

Please refer to the summary report of the 2015 prioritisation exercise here: https://www.stillbirthcre.org.au/assets/Uploads/Stillbirth-CRE-2015-Priority-Setting-Exercise-Final.pdf

Through synthesis of the Australia data from the above mentioned international surveys of parents and health care providers and subsequent consultation with parents, clinicians, policy makers and researchers four major themes and three cross cutting themes as follows:

1. Improving care and outcomes for women with risk factors for stillbirth.
2. Developing new approaches for identifying women at increased risk of stillbirth (e.g. using biomarkers).
3. Implementing best practice in care after stillbirth and in subsequent pregnancies.
4. Improving knowledge of causes and contributors to stillbirth
5. Crosscutting themes
    a. Indigenous Health
    b. Public Awareness
    c. Health Economics

The Stillbirth CRE has systematically addressed these priorities since it's establishment in early 2017 and had proposed to re-evaluate research priorities in 2019/2020. Therefore, it is timely that this process now informs the proposed 10-year research priority plan for Australia as part of the National Action Plan. We aim to draw upon the findings of the 2015 report and submissions to the national action plan with this document to undertake this work.

1.4 Target/Goal

- To identify and make publically available research priorities in research into stillbirth for the next 10 years building on the work of PSANZ and the Stillbirth CRE;
- Identify priority areas both in the short, medium and longer-term (up to 10 years);
- Establish source and funding mechanism for future targeted rounds addressing revised priorities by 2020.

1.5 Policy response

To be considered further.

1.6 Cultural diversity and Indigenous health

Please refer to the Action on culturally and linguistically appropriate care (Action 3.3).

1.7 Timeframe

Research priority redevelopment - by Jan 2020 if funds are made available by May 2019.

Allocation of MRFF research funds for priority areas in the short, medium and longer term.

Establish source and mechanism for funding future priorities.

1.8 Resources

Development of research priorities for next 10 years $300,000

Project office 1 FTE 12 months.

Indigenous researcher 0.6 FTE 6 months.

CALD researcher 0.6 FTE 6 months.

Parent sitting fees.

Focus groups.

Workshops.

Action 2.2: Establish an Australian stillbirth research registry

1.9 Recommendations

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

1.10 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Philippa Middleton (Centre of Research Excellence in Stillbirth, PSANZ SANDA, South Australian Health and Medical Research Institute)
- Lisa Askie (NHMRC Clinical Trials Centre)
- Adrienne Gordon (Centre of Research Excellence in Stillbirth, PSANZ SANDA, University of Sydney)
- Jane Warland (Centre of Research Excellence in Stillbirth)
- Caroline Homer (Centre of Research Excellence in Stillbirth, Burnet Institute)
- Jonathan Morris (Centre of Research Excellence in Stillbirth, PSANZ SANDA, University of Sydney)
- David Ellwood (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Griffith University)
- Fran Boyle (Centre of Research Excellence in Stillbirth, PSANZ SANDA, The University of Queensland)
- Euan Wallace (Centre of Research Excellence in Stillbirth, Monash University)
- Kate Lynch (Stillbirth Foundation Australia)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)
- Brad Farrant (Telethon Kids)
- Helen Bailey (Telethon Kids)
- Partnerships TBC: Carrington Shepherd, RANZCOG, ACM, RACGP, RCPA, Sands, Red Nose, Still Aware, Bears of Hope.
- In partnership with the International Stillbirth Alliance – Katy Gold, ISA chair

1.11 Overview

The lack of an easily accessible central repository of planned and ongoing stillbirth research studies is an impediment to collaboration to ensure effective conduct of high quality research to address stillbirth. Key to quality research into stillbirth is the need to engage parents and the community as partners. Easy access to current research is key to this endeavour.

The NHMRC Centre of Research Excellence in Stillbirth (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 the Stillbirth CRE research register. However, this register is not comprehensive of all relevant research and limited information is available to the general community. The Stillbirth CRE as a regional office of the International Stillbirth Alliance (ISA) will work closely with ISA to identify all relevant international studies.

The NHMRC ANZCTR is a register of clinical trials and also captures studies using other research designs. We propose to adapt the ANZCTR to meet the needs of a register of planned and ongoing stillbirth research including an interface to the Stillbirth CRE website to publically display details of this research for the community.

1.12 Target/Goal

To establish a comprehensive publically accessible online register of stillbirth research by mid-2020.

1.13 Policy response

To be considered further.

1.14 Cultural diversity and Indigenous health

please refer to the Action on culturally and linguistically appropriate care.

1.15 Timeframe

Fully operational register of stillbirth research by 2020.

1.16 Resources

Online register of stillbirth research for 5 years–$ 460,000.

$160,000 technical and administrative set-up.

$60,000 annual maintenance for 5 years.

Action 2.3: Identification of placental biomarkers that determine risk of stillbirth

1.1 Recommendations

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.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Stillbirth CRE National Placental Working Group partnered with Australian and New Zealand Placental Research Association (ANZPRA) and Fetal-Neonatal Physiological Society (FNPS)
- Vicki Clifton (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland)
- Sailesh Kumar (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland)
- Roger Smith (University of Newcastle)
- Vicki Flenady, (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland)

1.3 Overview

Stillbirth is frequently the result of pathological processes involving the placenta. Markers of placental function and health can often be identified and measured in the maternal circulation and this offers a great opportunity to identify women at risk of stillbirth using biomarkers reflecting defective placentation and function. Early identification of at risk pregnancies can then allow clinicians to either increase fetal monitoring or plan an early birth to protect the fetus from death.

One major issue in the discovery of placental biomarkers for stillbirth is that most stillbirth placentae are often not viable for use in research studies. The placenta and baby are not always delivered at the time of death but some days after death resulting in tissue degradation before collection. Furthermore, stillbirth placentae that are archived in Pathology Services are not always accessible for research due to legislative restrictions. However, it is feasible to examine prospectively collected blood samples from mothers who have consented to be involved in birth cohort studies and who subsequently experience a stillbirth. These samples could be used for the validation of data generated on placental biomarkers. Researchers need to have access to samples from multiple birth cohorts across Australia to obtain enough numbers of stillbirth samples for valid conclusions. The best approach to address this issue is a National birth cohort registry and biobank.

The main approach for the discovery of biomarkers of placental compromise will be from placentae of pregnancies that may be a near miss for a stillbirth or associated with a serious complication. These complicated pregnancies can include but are not limited to fetal growth restriction, severe pre-eclampsia, severe chronic maternal disease, placental abruption, preterm labour, fetuses associated with hypoxic events at birth, stillbirths and neonatal deaths. To collect these placentae at one site would take many years to accrue sufficient numbers to make valid conclusions and would limit the capacity to rapidly translate findings into practice. However, a national approach with many research teams and sites involved in the project would increase the capacity for effective outcomes in this area. The establishment of a national biobank of samples and data is therefore essential to progress research to reduce the numbers of stillbirths in Australia.

As part of the Stillbirth CRE, Prof Vicki Clifton has lead the establishment of a consortium of placental researchers from around Australia and partnered with ANZPRA and FNPS to promote the initiative. Members of the consortium are committed to contributing to the joint initiative for the identification of placental biomarkers that determine risk of stillbirth. By sharing data and samples from both complicated and uncomplicated pregnancy cohort studies, it is possible to rapidly generate placental data for the identification of biomarkers. The consortium consists of teams from Brisbane, Gold Coast, Townsville, Melbourne, Sydney, Newcastle, Adelaide and Perth who each have a variety of technological skills and samples that could be used for generating new knowledge about stillbirth as well as animal models for testing causality from the observations made in human samples.

This consortium has had a number of meetings to discuss approaches to address the major issue of identifying pregnancies at risk of stillbirth throughout 2018. To date we have established collaborations between teams to investigate specific research questions, examined ethics and governance issues related to the sharing of samples, and developed a RedCap database for researchers to share de-identified meta-data about the biological samples from their cohorts. However, to continue and expand the consortium's stillbirth research on-going support and funding are required for the development and maintenance of a national birth cohort registry and virtual biobank to enable sharing of samples and data from complicated and near miss pregnancies and stillbirths across laboratories for identification of placental biomarkers. Funding support specifically targeted to placental research in stillbirth will be essential for the success of this initiative.

1.4 Target/Goal

- To establish a National Birth Cohort Registry that includes Indigenous and culturally diverse cohorts;
- To develop a virtual biobank of de-identified data and samples from complicated, near miss pregnancies and stillbirths;
- To allocate NHMRC/MRFF funding to placental research in both humans and animal models.

1.5 Policy response

The Commonwealth would establish and maintain the registry and virtual biobank providing the appropriate legislation for its maintenance, access and usage.

The purposes of the registry relate to:

- supporting research programs focussed on pregnancy and pregnancy complications including stillbirth; and
- providing access to data and biological samples from birth cohorts assuming ethics approval is obtained; and
- pregnancy research questions more broadly.

The establishment of placental research as a priority research area for NHMRC and a special call for funds for placental projects focussed on stillbirth to include researchers across Australia (and New Zealand).

1.6 Cultural diversity and Indigenous health

Where possible data and samples derived from different ethnicities and Indigenous groups will be examined. There are several teams involved in the national consortium that work with these specific groups.

1.7 Timeframe

Registry and virtual biobank 2019-2021.

Allocation of funding for 2020 NHMRC round and special call in 2019.

1.8 Resources

Total estimated cost

Research Assistant (1.0 FTE) to manage receipt and storage of biological samples and track sample usage.

Database/Registry Manager (1.0 FTE) to manage RedCap database of pregnancy and birth cohorts, manage requests for samples and data, and write reports.

Aliquotting (Research Assistant time and consumables) and shipping of samples on dry ice $100,000 in first year then $50,000 per year afterwards.

-80C freezers (72cu.ft., 3 in year 1 and additional as required in subsequent years at $20,000 each).

Fund annual workshops of placenta/pregnancy researchers and other Stillbirth stakeholder groups, including consumers, in the consortium including airfares and one night's accommodation for each attendee plus meeting costs ($50,000 per year).

Consumer focus group meetings to hear the woman’s voice, co-design research, provide information about the cohorts involved $20,000 per year.

Action 2.4: Define maternal and ultrasound predictors for adverse perinatal outcomes in late pregnancy (>28w) and development of a national biobank for severe neonatal morbidity (“stillbirth near misses”)

1.1 Recommendations

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

Recommendation 7: Development of National biobank for stillbirth placenta research.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Sailesh Kumar (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)
- Vicki Clifton (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland)
- David Ellwood (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Griffith University)
- Roger Smith (University of Newcastle)
- Consumer consultation through the PSANZ Consumer Advisory Panel, Stillbirth CRE Indigenous Advisory Group

1.3 Overview

Stillbirth is a tragedy and a neglected public health issue in Australia. Further, as recognised by The Lancet series (de Bernis et al., 2016), stillbirth represents the apex of a large group of at-risk fetuses often sharing similar pathophysiological pathways. Some of these babies suffer considerable morbidity that impacts both their short and longer-term outcomes. In Australia hypoxic peripartum death is third leading cause of mortality in term infants. Globally, late pregnancy hypoxic complications are major contributors to stillbirth, hypoxic ischemic encephalopathy (HIE) and cerebral palsy. For parents and families, the psychological and financial ($1.5 billion in Australia) impacts are profound and long-lasting. A 2017 UK report (‘Each Baby Counts’) of stillbirths, neonatal deaths and perinatal brain injury has set an ambitious 50% reduction target by 2020. The majority of these catastrophic events occur despite a lack of obvious risk factors.

Stratification of women at apparently low risk for complications is suboptimal because of the heterogeneity of known risk factors and the paucity of knowledge regarding the interaction between these variables. Difficulties in incorporating risk factors into an overall risk assessment for clinicians often means women are simplistically assigned to either “high” or “low” risk categories. This approach is inherently inaccurate and misleading for clinicians and women. Understanding the contribution of various maternal and ultrasound variables to overall risk is therefore essential to determine the probability of an adverse event occurring.

Central to the concept of defining risk is accurate determination of prognostic variables and the interaction between them. Development of risk prediction models therefore require large datasets and complex statistical analysis to tease out valid contributory factors that enhance the accuracy of any predictive model. Once accurate and reliable risk factors for serious adverse neonatal outcomes (severe acidosis at birth, hypoxic ischemic encephalopathy, very low Apgar score at birth, prolonged neonatal intensive care unit stay, perinatal death) are known, development of a risk prediction model or risk assessment tool becomes possible.

We have recently developed a predictive model for adverse neonatal outcomes using a large perinatal dataset (>180,000 women) at the Mater Medical Research Institute which is promising for its predictive utility for this outcome.

Using the same large dataset, we have shown that some ultrasound features are predictive that some normally grown fetuses have evidence of cerebral redistribution characterised by a low cerebroplacental ratio (CPR) (ratio of the Middle Cerebral Artery Doppler Pulsatility Index to the Umbilical Artery Doppler Pulsatility Index). The CPR is predictive for stillbirth and serious hypoxia related morbidity. In two of the largest prospective studies to date, we have shown that term fetuses with a low CPR (<10th centile) have significantly higher risk of developing pathological fetal heart rate patterns in labour. In one of the largest studies of low risk women we showed that low birth weight is independently correlated with poor obstetric and perinatal outcomes and that this risk is greatest in infants with birth weight <5th centile. We have published also CPR centiles relevant to this application and have recently developed a model to predict adverse neonatal outcomes as well as for fetal distress in labour. We also have pilot data showing that in some women with apparently normally grown term significantly elevated levels of Carbonic Anhydrase IX (CAIX) and Ubiquitin C-terminal hydrolase 1 are present. CAIX is postulated to be a biomarker of placental hypoxia and is elevated in conditions where placental dysfunction is present, including pre-eclampsia and fetal growth restriction. UCHL1 is a protein that is normally heavily and specifically concentrated in neuronal tissue and has been detected in high levels in neonates with hypoxic-ischemic encephalopathy. Although we do not have any evidence that the elevated levels of UCHL1 protein detected in our assay was fetal in origin, this finding is particularly intriguing as a low CPR is indicative of cerebral redistribution secondary to placental dysfunction. If the elevated UCHL1 levels are indeed fetal in origin, it raises the possibility of prenatal identification of such at-risk fetuses.

We now have a biobank of maternal plasma and serum samples and cord blood samples from almost 1500 term pregnancies some of which have experienced adverse perinatal outcomes. These samples are backed by detailed, prospectively collected maternal, intrapartum and ultrasound variables

The primary aims of this proposal is thus to extend our current risk factor analysis using a national dataset to refine our risk prediction models and to use this to guide maternal and neonatal samples for the development of a maternal and fetal biobank to enable stillbirth and stillbirth "near miss" research. Statistical analysis and development of the prediction model will be performed in collaboration with a senior bio-statistician and epidemiologist (A/Prof Cameron Hurst) at the Queensland Institute of Medical Research.

This proposal also aligns with other key work on improving decision-making around timing of birth for women with risk factors at term.

1.4 Target/Goal

- Development of risk prediction models for late gestation stillbirth, intrapartum fetal compromise and composite adverse neonatal outcome. These models will allow women to be accurately risk assigned using objective and validated variables and thus managed appropriately throughout pregnancy;
- Development of a biobank of maternal and neonatal samples for hypoxia related severe neonatal outcomes from 5 tertiary centres as an initial pilot endeavour to understand barriers to feasibility (this will feed into Action plan 2.3).

1.5 Policy response

To be developed further

1.6 Cultural diversity and Indigenous health

Stillbirth and severe adverse neonatal outcomes are disproportionately higher in women of indigenous background, refugee and lower socio-economic status and non-English speaking background. The work proposed in this proposal will specifically investigate the contribution of variables from these communities into the risk prediction models.

1.7 Timeframe

2 years.

1.8 Resources

Total estimated cost: $624,400

Annual costs: $312,200.

1 FTE Research Officer (Lead): $71,700.

0.5 FTE Biostatistician: $68,200.

5 0.5FTE Research Midwives: $40,300.

Development of biobank and storage of samples: $120,000.

IT Support/Site management: $12,000.

Action 2.5: Improved detection of fetal growth restriction

1.1 Recommendations

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.

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

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Sue Walker (University of Melbourne)

1.3 Overview

FGR due to placental insufficiency is the single biggest risk factor for stillbirth. Babies that are small for gestational age (birthweight <10th centile) have a three- to four-fold increased risk of stillbirth at all gestational ages, and this risk rises steeply as term approaches. Improved detection of FGR - particularly in late pregnancy- is acknowledged internationally as a leading priority to reduce stillbirth risk, since fetuses found to be small can be offered closer monitoring and timely delivery. This approach has been shown to halve the risk of stillbirth.

Surprisingly, the detection of FGR with current antenatal care remains poor. Standard care involves measuring the pregnant abdomen in the clinic, which identifies only 20% of fetuses destined to be born small (<10th centile). While it might be expected that universal measurement of the baby with ultrasound would substantially improve this detection rate, this approach still detects- at best- just over half of small babies. There is an urgent clinical need for a more sophisticated approach to detect FGR and reduce stillbirth risk.

Discovery projects (recommendation 5) should involve discovery, validation and translation of

- Biomarkers of placental dysfunction that can significantly improve detection of small babies;
- Standardised fetal growth assessment so that clinicians have the tools to correctly diagnose FGR during pregnancy;
- New ultrasound parameters to identify babies at risk.

1.4 Target/Goal

- To substantially improve detection of FGR from that of current clinical care (20%) in pregnancy;
- To reduce the incidence of post term (measure of undetected) FGR;
- To reduce the incidence of FGR stillbirth.

1.5 Policy response

TBC

1.6 Cultural diversity and Indigenous health

The collection of data on indigenous status, country of birth, primary language spoken by the mother will assist the assessment of the contribution of ethnicity to perinatal outcomes and to the development of culturally appropriate implementation strategies. Ensure appropriate engagement with relevant stakeholders to determine data collection and reporting mechanisms.

1.7 Timeframe

Pilot the system in 2019/2020 with roll out in 2021.

1.8 Resources

Total estimated cost

Costing under development.

Action 2.6: Reducing smoking rates in pregnancy

1.1 Recommendations

To be confirmed.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Philippa Middleton (Centre of Research Excellence in Stillbirth, PSANZ SANDA, South Australian Health and Medical Research Institute)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)
- Cheryl Bailey (Gold Coast Health)
- Paula Medway (Australian College of Midwives)

1.3 Overview

Smoking in pregnancy is associated with many adverse outcomes including preterm birth and stillbirth. For example, in South Australia in 2016, nearly 1 in 10 pregnant women (9.4%) were smoking at the first antenatal visit. In 2016 rates of smoking in pregnancy for Indigenous women were 44% and 8.1% for non-Indigenous women. Two national initiatives aim to address smoking in pregnancy (National Preterm Birth Prevention Alliance and the Stillbirth CRE). Smoking in pregnancy is one of the five elements of care to be implemented. These elements of care are cohesive sets of evidence-based practices that, when performed collectively and reliably, improve health outcomes.

The smoking cessation element will comprise usual care supplemented with opt-out referral to QuitLine (motivational interviewing), smokealyzer (carbon monoxide) testing, online augmented reality resources, for example demonstrating the visual effect of smoking on the unborn baby; and nicotine replacement therapy if required. This provides an excellent opportunity to embed a co-design project between pregnant women and health professionals to improve and tailor smoking cessation resources for different levels of health literacy, using the Health Literacy Universal Precautions Toolkit.

Objectives: To use co-design methods to refine and tailor health literacy tools for different groups of women smoking in pregnancy.

Research Plan: Develop and refine smoking cessation in pregnancy resources, through quality improvement co-design workshops in urban, regional and remote settings. The Health Literacy Universal Precautions Toolkit will be used to design and test different versions to address needs of different groups of pregnant women, and to optimise shared decision-making.

Expected outcomes: A suite of smoking cessation in pregnancy resources which are tailored to different groups and individuals, including level of health literacy; and feedback from women about the suitability and usefulness of the resources.

1.4 Target/Goal

30% increase in smoking cessation rates during pregnancy for Indigenous and women from culturally and linguistically diverse backgrounds (using national key performance indicator).

1.5 Policy response

Under development.

1.6 Cultural diversity and Indigenous health

Under development.

1.7 Timeframe

3 years.

1.8 Resources

FTE Research Officer (Lead) - $71,700.

FTE Research Officer (Lead) - $71,700.

PTE Administrative Assistant – $26,010.

Workshops - $14,010.

Materials - $5,000.

Publication fees - $6,000.

IT Support/Site management - $12,000.

Annual: $180,400.

Total: $541,200.

Action 2.7: Harmonisation of state-based health data collections for pooled analyses – a big step towards the development of a comprehensive standardised national stillbirth data collection

1.1 Recommendations

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.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Carrington Shepherd (Telethon Kids Institute, Western Australia)
- Brad Farrant (Telethon Kids Institute, Western Australia)
- Helen Bailey (Telethon Kids Institute, Western Australia)
- Emily Callander (Griffith University, Centre of Research Excellence in Stillbirth)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)
- TBC: perinatal research teams in each state/territory who have current ethical approval and access to state/territory linked data collections
- TBC: representatives of State Health departments data linkage branches (e.g. Qhealth) and data custodians (Health Department clinical coding consultants, perinatal collection etc.)
- TBC: PSANZ representatives; obstetrics, midwifery (potential to expand to neonatology as well)
- TBC: AIHW, Population Health Research Network (PHRN)
- TBC: Ngangk Yira Research Centre for Aboriginal Health and Social Equity (WA), Kulunga Aboriginal Research Development Unit (WA)
- TBC: Bereaved parents and support organisations (for input into the development of new variables for the new comprehensive standardised national data collection)
- TBC other groups/individuals identified as stakeholder during initial consultations

1.3 Overview

Population-based research into stillbirth depends on high quality data about all births in order to identify differences in pregnancies that result in stillbirths to those which result in livebirth, and also follow-up health service use data to identify differences in patterns of follow-up care. Two of the major factors that hamper current national epidemiological stillbirth research are the lack of detailed data available in Perinatal National Minimum Dataset and the lengthy delays in obtaining access to these data.

The Perinatal National Minimum Dataset is drawn from much richer perinatal datasets held by each State and Territory health authorities, who can also link these datasets to other health related data collections such as hospital admissions, congenital anomalies, birth and death registries. There are currently research teams using these linked data from most jurisdictions to research poor perinatal outcomes including stillbirth, neonatal and maternal morbidity (e.g. NSW- Menzies Centre for Health Policy, Sydney School of Public Health and Kolling Institute, University of Sydney; NT- Mothers and Babies Research Center, Hunter Medical Research Institute; QLD- Mater Research Institute, University of Queensland; SA - Robinson Research Institute, University of Adelaide; VIC- The Ritchie Centre, Hudson Institute of Medical Research, Monash University; WA- Telethon Kids Institute, School of Public Health, Curtin University). The linkage of perinatal dataset to other datasets allows for more in-depth research.

However, often individual state/territory based research cannot investigate rare factors or high risk subpopulations because of small numbers. The proposed comprehensive standardised national data collection will take time to develop so we propose a short-term solution to combine the currently available resources of existing perinatal epidemiological research teams into a national consortium to undertake parallel analyses which can be combined. This will also be a big step towards the development of a comprehensive standardised national data collection.

This action will utilise and share the existing knowledge about linked data and complex analyses that has developed across Australia in recent decades. As well as stillbirth, this consortium will also have the potential to investigate other adverse maternal, perinatal and early life outcomes.

1.4 Target/Goal

Develop a consortium of stillbirth/perinatal research teams in each state/territory who have current ethical approval and access to state/territory linked data collections.

Specifically:

- Establish a coordinating centre;
- Develop ideas for parallel research;
- Create a national data dictionary of available variables by research groups in each jurisdiction;
- Harmonise variables to similar format and categories;
- Develop ideas for creation of new variables (e.g., extraction of diagnoses/procedures from hospital admissions, identification of risk factors in previous pregnancies);
- Undertake parallel analyses using harmonised datasets;
- Combine findings of individual jurisdictions into national (pooled) estimates using meta-analytical methods;
- Provide input to facilitate the development of a comprehensive standardised national data collection.

1.5 Policy response

The Federal Government (possibly via AHMAC) is requested to do the following:

- Enable funding for establishment of coordinating centre;
- Provide funding for each of the consortium members to facilitate data harmonisation and analyses.

1.6 Cultural diversity and Indigenous health

By pooling findings, we will have considerably greater power to examine inequalities within and between Indigenous and ethnic minority groups and other populations. This includes examinations of the factors and risk profiles associated with stillbirth in Indigenous communities across Australia (e.g. remote communities in different jurisdictions). The proposed coordinating centre will be based at Telethon Kid's Institute which has a well-established record in undertaking research in collaboration with Indigenous communities and other partners. We will also be able to explore other at-risk groups such as mothers born outside Australia by region of birth.

1.7 Timeframe

Commence as soon as possible in 2019 and continue until timely access to a comprehensive standardised national data collection has been established.

1.8 Resources

Total estimated cost

Resources will be required for:

- Consultation with existing research teams and other relevant stakeholders including bereaved parents and support organisations;
- The initial set up of the Consortium;
- Establishment of the proposed coordinating centre;
- Data preparation and analysis by each state/territory-based team;
- Regular consortium meetings.

Action 2.8: Generating up-to-date data on resource use and costs associated with stillbirth to enable rapid evaluation of stillbirth prevention and care improvement initiatives

1.1 Recommendations

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

1.2 Collaborators

- Emily Callander (Griffith University, Centre of Research Excellence in Stillbirth)

1.3 Overview

Current evidence is sparse on the health services that are consumed as a part of a stillbirth event. Evidence is only emerging about the additional costs associated with this health service use, and the follow-on impacts that a stillbirth event may have on parental labour force participation and the wider influence this has on the macroeconomy through reduced aggregate output and investment. Initial estimates, place the additional health service use at a value of $2.2 million annually and the value of lost output at $74 million, based on 2015-16 data. However, with perinatal care rapidly changing, these estimates will need to be updated over time in order to accurately capture the costs of stillbirth.

The accurate quantification of the costs associated with stillbirth is essential to facilitate the economic evaluation of interventions to reduce stillbirth, and to improve bereavement care. Insufficient cost data is an impediment to cost effectiveness analysis and makes it difficult to identify health expenditure and other costs that could be avoided through a reduction in stillbirth rates or better bereavement care. Health departments internationally are seeking to incorporate Health Technology Assessment, including economic evaluation, into formal decision-making processes to ensure the efficacy, effectiveness and efficiency of new intervention(Kanavos, Nicod, Van Den Aardweg, & Pomedli, 2010) (Intergrowth21.tghn.org, 2018). Thus, all interventions to reduce stillbirth, and to improve bereavement care are likely to require economic evaluation to demonstrate cost-effectiveness to government funders. Robust and up-to-date data on resource use and costs associated with stillbirth will thus unable rapid evaluation and roll-out of stillbirth prevention and bereavement care improvement initiatives.

1.4 Target/Goal

- Quantify the incremental costs associated with stillbirths relative to livebirths, disaggregated into different payers' perspectives, updated biennially;
- Quantify these costs by different population groups.

1.5 Policy response

Roll-out and routine implementation of initiatives demonstrated to be clinically effective and cost-effective to target populations.

1.6 Cultural diversity and Indigenous health

This priority will specifically identify costs associated with babies born still to Indigenous mothers, thus allowing accurate identification of the cost-effectiveness on any initiatives seeking to reduce stillbirths to Indigenous parents.

1.7 Timeframe

Ongoing.

2019 – publication in peer-reviewed literature of cost estimates for 2015-16 financial year.

Late-2019/early2020 – update of results for 2017-18 financial year.

1.8 Resources

$25,000 purchase of updated MBS/PBS data – triennially.

$5,000 secure access to administrative data – annually.

$19,000 Research Officer for data analysis – biennially.

TOTAL: $22,833 annually.

Action 2.9: Research towards prenatal-onset Group B Strep disease (POGBSD) prevention and in preparation for a potential GBS vaccine

1.1 Recommendations

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

1.2 Collaborators

- Marti Perhach (Group B Strep International)
- James McGregor (Group B Strep International)

1.3 Overview

Research regarding the extent to which group B strep (GBS) contributes to stillbirth in Australia could be very informative not only towards preventing GBS-caused fetal harm, but also when later conducting cost-benefit analyses for any potential GBS vaccine (several of which are in clinical trials).

Research topics to consider:

- the different genetic types/strain types of GBS that cause stillbirth;
- the presence of any host (maternal) factors that increase the likelihood that a GBS-colonized mother will suffer from GBS-related stillbirth;
- the mechanisms of stillbirth driven by GBS;
- determining to what extent is inflammation contributing versus infection of the fetus per se.

1.4 Target/Goal

- Understand how to prevent POGBSD to help guide prevention protocols;
- Prepare for implementation of a potential GBS vaccine which could offer increasing measures of protection for unborn babies between 28 weeks gestation and term.

1.5 Policy response

- Determine what research is currently being done nationally/internationally regarding POGBSD;
- Allocate funding as deemed appropriate to close the gaps in knowledge.

1.6 Cultural diversity and Indigenous health

Include focused research in the indigenous and other minority populations.

1.7 Timeframe

2019 - Suggest determining current research being done.

Late 2019 – Suggest determining what gaps need to be filled.

Early 2020 – Request research proposals.

1.8 Resources

To be determined.

Action 2.10: Novel interventions to reduce the risk of stillbirth

List recommendations.

1.1 Recommendations

To be confirmed.

1.2 Collaborators

Under development.

1.3 Overview

Under development.

1.4 Target/Goal

Under development.

1.5 Policy response

Under development.

1.6 Cultural diversity and Indigenous health

Under development.

1.7 Timeframe

Under development.

1.8 Resources

Under development.

Priority 3: Improving quality of care

Action 3.1: Implementation of best practice in stillbirth prevention across maternity care services in Australia through a bundle of care; The Australian Safe Baby Bundle

Action 3.2: Improving decision-making around timing of birth for women with risk factors at term

Action 3.3: Ensuring culturally and linguistically appropriate models of pregnancy care and bereavement care

Action 3.4: Implementation of best practice in stillbirth prevention across maternity care services in Australia; the implementation of midwifery continuity of carer for all women.

Action 3.5: Optimising care and outcomes for mothers and families in subsequent pregnancies following a stillbirth

Action 3.6: Establishing a national register of best practice guidelines on stillbirth to improve care across maternity services

Action 3.7: Informed consent prior to membrane stripping

Action 3.8: Minimally invasive tissue sampling (MITS) as an autopsy alternative

Action 3.1: Implementation of best practice in stillbirth prevention across maternity care services and the community in Australia through a bundle of care; The Australian Safe Baby Bundle

1.1 Recommendations

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

Recommendation 10: Develop and implement national stillbirth public awareness campaign.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)
- David Ellwood (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Griffith University)
- Jonathan Morris (Centre of Research Excellence in Stillbirth, PSANZ SANDA, University of Sydney)
- Philippa Middleton (Centre of Research Excellence in Stillbirth, PSANZ SANDA, South Australian Health and Medical Research Institute)
- Adrienne Gordon (Centre of Research Excellence in Stillbirth, PSANZ SANDA, University of Sydney)
- Euan Wallace (Centre of Research Excellence in Stillbirth, Monash University)
- Emily Callander, (Centre of Research Excellence in Stillbirth, Griffith University)
- Fran Boyle (Centre of Research Excellence in Stillbirth, PSANZ SANDA, The University of Queensland)
- Kirstine Sketcher-Baker (Clinical Excellence Division, Queensland Health)
- Glenn Gardener (Centre of Research Excellence in Stillbirth, Mater Health Services)
- Deanna Stuart Butler (Indigenous Advisory Group - Centre of Research Excellence in Stillbirth, Women's and Children's Health Network, South Australia)
- Michael Nicholl (Royal North Shore Hospital)
- Caroline Homer (Burnett Institute, Centre of Research Excellence in Stillbirth)
- Michael Coory (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland)
- Miranda Davies-Tuck (Centre of Research Excellence in Stillbirth, Hudson Institute of Medical Research)
- Kate Lynch (Stillbirth Foundation Australia, Centre of Research Excellence in Stillbirth,)

- Sarah Goss (Stillbirth Foundation Australia and Bereaved Parent)
- Claire Ford (Still Aware)
- Sue Vlack (Centre of Research Excellence in Stillbirth, PSANZ SANDA, The University of Queensland)
- Christine Andrews (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland)
- Megan Weller (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland,)
- Glenn Gardener (Centre of Research Excellence in Stillbirth, Mater Health Services)
- Lynn Sinclair (PSANZ)
- Gillian Gould (University of Newcastle, Hunter Medical Research Institute)
- Sally Green (Monash University)
- Tanya Farrell (Safer Care Victoria)
- Keren Ludski (Red Nose)
- Nicole Hall (RACGP).
- Jane Warland (Australian College of Midwives)
- Sean Seeho, Teresa Macdonald, Alexis Shub, Antonia Shand, Elizabeth McCarthy, Scott White, Amy Keir (RANZCOG)
- Belinda Jennings (Northern Territory Government, Department of Health)
- Sony Criddle (King Edward Memorial Hospital, Western Australia)
- Alex Heazell and Kate Widdows (International advisers: University of Manchester, UK. Saving Baby's Lives Bundle)
- Consultation: Sands, Bears of Hope, and others

1.3 Overview

Stillbirth is too common – 6 Australian babies are stillborn each day. Stillbirth is a serious public health problem with far reaching psychosocial and financial burden for families. There has been little improvement in rates for over two decades(Flenady et al., 2016), and in Australia it is 35% higher than top performing countries globally(Flenady et al., 2016). For Aboriginal and Torres Strait Islander and disadvantaged women, stillbirth rates are doubled.

Priorities for prevention are clear. In up to 50% of stillbirths, substandard care factors are identified and in 20-30% death is avoidable had these been addressed(Flenady et al., 2011).

We urgently need to decrease the gap between what is known and what is done in maternity care in Australia to reduce stillbirth rates. A widespread introduction of a 'bundle of care' is an effective, efficient and evidence-based approach to decrease this gap. Bundles of care combining recommendations for maternity care improvement in the UK, through the Saving Baby's Lives care bundle (SBLCB)(Widdows, Reid, Roberts, Camacho, & Heazell, 2018) and the Scottish Maternity and Children Quality Improvement Collaborative (MCQIC)(Healthcare Improvement Scotland, 2016), have reduced stillbirth rates by 20%.

We propose a similar process in Australia. The priority areas included in this proposed 'Safe Baby Bundle' (SBB) are:

1) improved detection and management of impaired fetal growth;
2) increasing awareness and management of women with decreased fetal movements;
3) smoking cessation support;
4) provision of maternal safe sleeping advice; and
5) improved decision-making around timing of birth for women with risk factors.

If effective and scaled-up across Australia, over 200 lives each year could be saved. Other important outcomes include a reduction in other adverse neonatal outcomes and improvement in women's experience of care.

1.4 Target/Goal

20% reduction in stillbirths after 28 weeks' gestation within 3 years

Other measures include:

Pregnancy outcomes*:* Overall stillbirth rates (20 weeks' or more gestation and neonatal death rate, term stillbirth rate, neonatal hypoxic ischaemic encephalopathy (HIE) requiring therapeutic hypothermia, preterm birth, early term birth (37-38 weeks), labour induction, caesarean section, mode of birth, maternal admission to intensive care, post-partum infection requiring antibiotics, unplanned returned to theatre.

Health service utilisation: antenatal ultrasound scans, maternal and neonatal length of stay.

Woman's experience of care and psychosocial outcomes.

To reach the target the following steps are required:

1. Develop and embed an educational program for health care providers on stillbirth prevention across all maternity services in Australia. This will include an interaction online program to ensure access across the country (See action under Recommendation 11).
2. Develop, test and implement an iterative quality improvement cycle with benchmarking across jurisdictions to enhance uptake of the bundle recommendations.
3. Develop and implement a system for collection of patient reported outcomes and experiences of maternity care focussing on elements of the Safe Baby Bundle for all women (consider linking with the bereavement action plan to incorporate experience of care following stillbirth - Actions 5.1 and 5.3).
4. Develop culturally and linguistically appropriate resources including decision-support tools for women and families for use during pregnancy such as decision support for timing of birth for women with risk factors (addressed in Action plan 3.3).
5. Promote the implementation of a national process for high quality perinatal mortality audit as a key mechanism for ongoing practice improvement in stillbirth prevention (addressed in Action plan 1.1).
6. Develop a risk prediction tool to inform a shared decision-making around timing of birth for women with risk factors (addressed in Action plan 3.2).

7. Development of NHMRC endorsed clinical practice guidelines on interventions to prevent stillbirth (addressed in Action plan 3.6).
8. Undertake a public education program aligned with SBB elements (addressed in Action plan 4.1).

1.5 Policy response

AHMAC to enable implementation including annual national benchmarking of the KPI's for Safe Baby Bundle recommendations across maternity services in Australia.

1.6 Cultural diversity and Indigenous health

Culturally and linguistically appropriate resources for women will be developed through a consultation process (please refer to the Action on culturally and linguistically appropriate care)

1.7 Timeframe

Roll out mid-2019, stage 1 evaluation 2020 then annually for 3 years.

1.8 Resource

Resources are required to upscale SBB across Australia through an on-line and face to face educational program for HCP (including bereavement care) $1,000,000 over 3 years.

Culturally and linguistically appropriate resources. $1,000,000 over 3 years

Action 3.2: Improving decision-making around timing of birth for women with risk factors at term

1.1 Recommendations

Recommendation 9: National best practice guidelines.

Recommendation 11: Develop and implement a national best-practice kit for healthcare professionals.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- David Ellwood, Adrienne Gordon, Euan Wallace, Vicki Flenady, Miranda Davies-Tuck Emily Callander, Philippa Middleton, Jonathan Morris, Helen Cooke, Christine Andrews, Sailesh Kumar, Michael Beckmann, Caroline Homer, Fran Boyle, Jess Sexton (PhD candidate) (Centre of Research Excellence in Stillbirth)
- Georgina Chambers (University of New South Wales)
- Sue Walker (University of Melbourne)
- Kate Lynch (Stillbirth Foundation Australia)
- Natasha Donnelley (PSANZ Consumer Advisory Panel)
- Deanna Stuart Butler (Indigenous Advisory Group - Centre of Research Excellence in Stillbirth)

1.3 Overview

Current resources for risk assessment and management of risk factors during late pregnancy are insufficient. While the adverse outcomes of preterm birth are well understood, it is becoming increasingly apparent that early term birth (37-38 weeks' gestation) is also associated with increased short- and long-term mortality and morbidity, such as admission of the baby to the NICU, neurodevelopmental delay in childhood, poor breastfeeding outcomes. In the absence of clear, evidence-based guidelines, a concerning trend of increased late pre-term interventions to reduce the chance stillbirth has emerged.

Decision making around timing of birth is often a preference-sensitive decision, further complicated by the presence of risk factors associated with stillbirth. The 2011 Stillbirth Lancet series identified a number of risk factors associated with stillbirth. Key risk factors associated with stillbirth include maternal education level, ethnic background (Indigenous status, Asian, Indian, or African ethnicity), small for gestational age (SGA), maternal overweight and obesity, smoking, maternal age (> 35 years), alcohol consumption, illicit drug use, previous stillbirth or previous pre-term growth-restricted baby, diabetes, antepartum haemorrhage, and hypertension. Pregnant women and clinicians need better information around risk factors and timing of birth to make informed decisions on birth management in a way that is culturally sensitive, individualized, and medically appropriate.

Central to the development of improved guidance on risk management is the concept of woman-centred care and shared decision-making – both of which are key components of high-quality maternity care. Shared decision-making is "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences." To address issues associated with decisional conflict, limited information, and inadequate patient-carer engagement, we propose to leverage existing information on risk factor management and develop a care guideline to improve decision-making around timing of birth.

We aim to:

- Develop and testing the robustness of a clinical risk algorithm/tool for stillbirth using risk estimates from an analysis of the national perinatal data collection AIHW and additional datasets;
- Develop a NHMRC endorsed management guideline to promote individualized care for women presenting with risk factors at booking and subsequently at each antenatal visit. The guideline will use evidence-based information to guide monitoring and evaluation of decision-making around timing of birth based on the risk prediction tool (Please refer to Action 3.2);
- Implement and evaluate the risk tool and guideline through:
    - an educational program for midwives and doctors as a face to face and e-learning module as part of the Safe Baby Bundle of care (please refer to Action 3.1).
    - an information package/materials for women to support shared-decision making through focus groups of women and care providers.

1.4 Target/Goal

Goal: To reduce stillbirth and unnecessary intervention and associated consequences through improved identification of women at risk.

Three key performance indicators/targets will be assessed as part of the Safe Baby Bundle of care implementation plan.

Key performance indicators:

- Total inductions stratified by indication for induction, pregnancy outcome, and weeks' gestation;
- Total stillbirths, livebirths, and neonate intensive care admissions, neonatal HIE and death;
- Risk tool performance (predictive accuracy).

1.5 Policy response

Under development.

1.6 Cultural diversity and Indigenous health

- Women with diverse cultural and linguistic backgrounds often experience health inequity in obstetric care. The development of a standard guideline with a special focus on risk factors and individualized care is expected to improve the care continuum for women who would benefit from a more sensitive and tailored approach to timing of birth and management of risk (refer to Action 3.3).

1.7 Timeframe

3 years; risk tool and guideline developed in 2019. Implementation and evaluation 2020-2021.

1.8 Resources

Total estimated cost:~ $2 million over 3 years

Project Coordinator 1 FTE Research Officer (Lead): $110,000 annually = $330,000.

Clinician consultation/focus groups including transcriptions and analyses: $65,000.

IT webpage development, resources: $150,000.

Evaluation: on-line tool including feedback from women and clinicians $300,000.

Research midwives across sites: $990,000. (30 sites 0.15 FTE for 2 years).

Action 3.3: Ensuring culturally and linguistically appropriate models of pregnancy care and bereavement care

1.1 Recommendations

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 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 a national stillbirth public awareness campaign

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

Recommendation 14: Public education kits that assists family and broader community to support bereaved parent

Priority 5

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

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Sue Vlack (Centre of Research Excellence in Stillbirth, The University of Queensland)
- Philippa Middleton (Centre of Research Excellence in Stillbirth, PSANZ SANDA, South Australian Health and Medical Research Institute)
- Deanna Stuart-Butler (Indigenous Research Officer, Stillbirth CRE and Women's and Children's Health Network, South Australia)
- Jane Yelland (Murdoch Children's Research Institute)
- Sue Kildea (Mater Research Institute-The University of Queensland)
- Kate Lynch (Stillbirth Foundation Australia)
- Yvette Roe (Mater Research Institute-The University of Queensland)

- Adele Murdolo (Multicultural Centre for Women's Health)
- Louella Villadiego-Logge (Multicultural Centre for Women's Health)
- Fran Boyle (Centre of Research Excellence in Stillbirth, PSANZ SANDA, The University of Queensland)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)

1.3 Overview

Indigenous women and other women from CALD communities have an increased rate of stillbirth, largely as the result of less access to care, and substandard, insensitive or untailored care. While it is important that each strategy in the action plan considers how to encompass the diversity of culture and language, management of a planned response led by Indigenous advocates in the clinical area may assist in improving care.

1.4 Target/Goal

Narrow the gap in care outcomes for Aboriginal and Torres Strait Islander and for other culturally and linguistically diverse women and their families.

1.5 Policy response

Require mandatory inclusion of Indigenous status and of ethnicity in pregnancy – related clinical data collection.

Conduct a national review of implementation barriers to best practice stillbirth prevention and care for families resident in remote and very remote areas, as the basis of a support plan.

Establish a quality review process for cultural safety of pregnancy care at organisational level including, for example:

- Presence of Reconciliation Action Plan;
- Proportion of Indigenous clinical staff and CALD background clinical staff;
- Proportion of clinical and administrative staff that have undertaken cultural safety training;
- Client satisfaction surveys that oversample Indigenous and CALD families;
- Proportion of Indigenous and CALD women offered continuity of pregnancy care;
- Proportion of Indigenous and CALD women/ families receiving autopsy results and accepting bereavement counselling.

Contract Indigenous and CALD health organisations to develop national best practice clinician education modules pertaining to their communities, to complement stillbirth prevention, care and autopsy management education (recommendation 11 and 12).

1.6 Cultural diversity and Indigenous health

Under development.

1.7 Timeframe

Under development.

1.8 Resources

Under development.

Action 3.4: Implementation of best practice in stillbirth prevention across maternity care services in Australia; the implementation of midwifery continuity of carer for all women.

1.1 Recommendations

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

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- The development of national policy, healthcare agreements and jurisdictional resourcing is a collaboration through AHMAC
- Australian College of Midwives
- Miranda Davies-Tuck (Centre of Research Excellence in Stillbirth, Hudson Institute)
- Emily Callander (Centre of Research Excellence in Stillbirth, Griffith University)

1.3 Overview

Numerous studies have shown that women being provided continuity of midwifery care have a reduction in the rate of stillbirths and a reduction in all fetal or neonatal loss (Sandall, Soltani, Gates, Shennan, & Devane, 2016)

Women cared for by a known midwife or a small group of midwives attend more antenatal visits, are more likely to disclose risk factors, and experience greater satisfaction compared to standard models of maternity care (Sandall et al., 2016).

The benefits of this continuous relationship are extended into the postnatal period, when women and families are especially in need of individualised and continuity of care which has been shown to be an essential component of women's care following stillbirth.

Midwifery continuity of care models are not available to all women in Australia, and currently only 8% of women access care through this model. Women may be unable to access this type of care due to geography, risk factors or financial reasons. Many models of care only cater for low risk healthy women – more efforts need to go into ensuring women with risk factors, especially for stillbirth, have midwifery continuity of care in collaboration with members of the multidisciplinary health team.

1.4 Target/Goal

Expand and increase midwifery continuity of care models, where women see a small number of midwives throughout their maternity care journey with consultation, referral and collaboration with medical and other specialists as needed, as an intervention to reduce stillbirth rates especially in groups at higher risk and support bereaved parents.

Increase accessibility of midwifery continuity of care models to all Australian women (especially women at-risk) as a measure to reduce stillbirth, as well as to provide support to women and families who do experience stillbirth. Create targets using policy similar to the UK Better Births Policy.

- 90% of women accessing the public health system have access to a known midwife by 2025;
- 100% of women accessing the public health system have access to a known midwife by 2030.

Research targets

- How can midwifery continuity of care be best implemented for the most disadvantaged and vulnerable women (see the POPPIE study in the UK -https://www.medscinet.net/POPPIE/) Is this trial repeatable in Australia? How? Where? Why/Why not?;
- How can innovations in maternity services be made so that all public women get access to midwifery continuity?;
- Does antenatal midwifery continuity of care (no more than 3 midwives) affect stillbirth rates (this needs to be a trial of AN COC). While this is not ideal it might be easier to do and is very targeted at stillbirth.

New midwives are supported post-graduation through pathways which allow them to provide midwifery continuity of care in all risk models.

Funding is allocated at state and territory levels to enable health services to provide all-risk midwifery continuity of care to all women.

Enable equal access to all Medicare items for all women to promote midwifery continuity of carer (including homebirth).

Jurisdictions implement Determination in full – providing access to continuity of carer through private models.

Australian Health Service Safety and Quality Accreditation Scheme includes targets for midwifery continuity of carer.

1.5 Policy response.

AHMAC develops policies which foster midwifery continuity of carer for all women including funding models and incentives.

Creation of policy similar to the NHS Better Births Policy 2016 (https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf).

- Every woman should have a midwife, who is part of a small team of 4 to 6 midwives, based in the community who knows the women and family, and can provide continuity throughout the pregnancy, birth and postnatally;
- Each team of midwives should have an identified obstetrician who can get to know and understand their service and can advise on issues as appropriate;
- The woman's midwife should liaise closely with obstetric, neonatal and other services ensuring that she gets the care she needs and that it is joined up with the care she is receiving in the community (Better Births UK, p. 9).

4.15. Therefore, the NHS should offer greater continuity of the healthcare professional supporting the woman, her baby and the family. It should involve:

- a midwife who will normally provide continuity throughout a woman's journey, if that is what she and her partner want;
- the midwife will usually work in and be supported by a small team of four to six midwives, one of whom could be a buddy and take responsibility for the woman's care if her midwife is not available;
- each team of midwives should have an identified obstetrician who can get to know and understand their service and can advise on issues as appropriate;
- having a midwife the woman knows at the birth. Ideally this will be her own midwife, but if that is not possible, a midwife from the same team of four to six; and
- where a woman needs on-going obstetric support, this should be from a single obstetric team and the care should be fully integrated across the midwifery and obstetric services. (Better Births UK, Page 45);
- Localities have been asked to produce "Sustainability and Transformation Plans" over the first half of 2016 to show how local services should transform and ensure they are sustainable over the next five years. As part of this, local health economies have been asked to plan how they will transform their maternity services in line with the vision outlined within this report. The following box highlights key elements of this vision which commissioners will particularly wish to consider as they develop these plans. (Better Births UK, p. 87).

1.6 Cultural diversity and Indigenous health

Midwifery continuity of care models provide individualised, woman-centred care. Programs such as Birthing on Country and Midwifery Group Practice which are for specific at-risk groups provide culturally safe, woman-centred care and promotes increased antenatal attendance and decreased perinatal morbidity and mortality.

1.7 Timeframe

- Develop a national policy for the implementation of midwifery continuity of carer by 2020.

- Implement the above policy such that 15% of women access midwifery continuity of carer by 2025 etc.

1.8 Resources

The Commonwealth requires targets for midwifery continuity of carer for all women through Australian Healthcare Agreements.

Jurisdictions reconfigure health funding to support and encourage midwifery continuity of care for all women.

Action 3.5: Optimising care and outcomes for mothers and families in subsequent pregnancies following a stillbirth

1.1 Recommendations

Please note this particular area of need was not explicitly addressed within the Senate report recommendations, but many are in agreement that it is critical to address this important area.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- David Ellwood (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Griffith University)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)
- Aleena Wojcieszek (Centre of Research Excellence in Stillbirth, Mater Research Institute-The University of Queensland)
- Adrienne Gordon (Centre of Research Excellence in Stillbirth, PSANZ SANDA, University of Sydney, iSAIL Clinic at Royal Prince Alfred Hospital)
- Vanessa Postle (iSAIL Clinic, Royal Prince Alfred Hospital)
- Elizabeth McCarthy: MFM specialist, STAR clinic at Mercy Hospital for Women; University of Melbourne
- Sue Heath (Rainbow Baby Program, Westmead Hospital Sydney)
- Yee Khong (Royal College of Pathologists Australia, SA Pathology, Women's and Children's Hospital Centre of Research Excellence in Stillbirth)
- Belinda Norman (Mater Mothers' Hospital - Bereavement Service
- Jacqueline Binks (Pregnancy After Loss Clinic - Mater Mothers' Hospital)
- Emily Callander (Centre of Research Excellence in Stillbirth, Griffith University)
- Others TBA including psychiatrics/psychologists, clinical geneticists, additional pathologists and midwives, and other relevant professions

1.3 Overview

Most parents who have a stillborn baby will conceive again. Women who have had a previous stillborn baby have a five-fold increased chance of having a stillborn baby in their next pregnancy. They also have an increased risk of preterm birth, low birthweight, placental abruption, pre-eclampsia, gestational diabetes and other adverse pregnancy outcomes. In addition to the medical risks, many parents experience high levels anxiety and fear in their subsequent pregnancies, which can only intensify as the pregnancy progresses, and at specific pregnancy milestones. The lead up to antenatal care visits and scans can also be incredibly stressful and anxiety-provoking. This anxiety and stress may only further increase risk, as stress during pregnancy has also been associated with adverse pregnancy outcomes, such as preterm birth and low birthweight. Some parents may even avoid attaching to their baby during pregnancy, which may increase these infants' risk of psychological and behavioural problems in childhood.

Given these increased medical and psychosocial risks, standard antenatal care is unsuitable for many parents in a pregnancy subsequent to stillbirth. The parents may benefit greatly from specialist obstetric care alongside emotional support in the form of dedicated services for pregnancy after loss. Existing models include the Pregnancy after loss clinic ('PALC') in Brisbane and the 'STAR' clinic in Melbourne (https://mercyperinatal.com/clinic/rainbow-clinic). Similar clinics also operate overseas in Manchester (the 'Rainbow clinics'; https://mft.nhs.uk/saint-marys/services/maternity-services-obstetrics/antenatal-care/rainbow-clinic/) and Toronto (https://sunnybrook.ca/content/?page=wb-subsequent-pregnancy) and early evaluations have shown these services hold great promise in improving parents' experiences, well-being, and outcomes.

In addition to specialist services, standardised clinical practice guidance is an essential component of providing care that meets the unique needs of parents in pregnancies subsequent to stillbirth. Such clinical practice guidelines are needed both to inform care within specialist clinics and to outline alternative care pathways where such specialist services are not available. Currently, no such clinical practice guidelines exist in Australia.

1.4 Target/Goal

The goal is to provide individualised multidisciplinary care for parents in a pregnancy subsequent to stillbirth to reduce the risk of recurrent stillbirth and other adverse pregnancy outcomes and support the mental health and wellbeing of families. Through the Stillbirth CRE and Perinatal Society of Australia and New Zealand (PSANZ), we aim to develop clinical practice guidelines outlining best practice care for pregnancies subsequent to stillbirth and implement these guidelines through an educational program for health care professionals (through the IMPROVE program). In addition, we propose to establish a network of services across Australia to provide specialist care to these families, spanning pre-conception through to birth (and early postpartum care where possible). The multidisciplinary staff will provide obstetric care and psychological and social support. Importantly, these clinics can also provide a platform for ongoing clinical and basic science research to study placental health and disease. Placental pathology is a known cause of stillbirth in up to 60% of cases and such pathology may recur in subsequent pregnancies, making placental monitoring a critical component of subsequent pregnancy care in many cases.

Specific targets include:

- 80% of tertiary centres with an established pregnancy-after loss service by 2021;
- All existing specialist pregnancy-after-loss services in compliance with PSANZ guidelines and agreed standards by 2022;
- 80% of existing specialist pregnancy-after-loss services participating in collection of placental samples by 2022.

1.5 Policy response

- Funding for development and ongoing updating of PSANZ guidelines.
- Formalisation of an accreditation process for maternity hospitals based on the PSANZ guidelines and its standards for evidence-based care in pregnancies subsequent to stillbirth;
- Funding to ensure accessibility for all maternity services to the IMPROVE program
- Funding to establish the network of specialist pregnancy-after-loss services to ensure standardisation care and compliance.
- Funding for midwifery training specific to the pregnancy-after-loss context

1.6 Cultural diversity and Indigenous health

The services recommend are not specific to any particular ethnicities or cultural groups. As for the existing services listed, we envisage that services would be attached to or within broader hospital campuses. Depending on the particular setting, culturally specific care would therefore be accessible where required and would align with the proposed multidisciplinary nature of subsequent pregnancy care.

1.7 Timeframe

2020: Initial network establishment across existing services in Australia + others providing care or who are interested in establishing services as a starting point.

2020-2021: Development of consensus on a set of principles and elements of care based on existing research and guidelines (also constituting a newly established component of the PSANZ guidelines on 'Care Around Stillbirth or Neonatal Death').

2021-2022: Development of an evaluation framework including core outcomes and processes for data collection; full establishment of services and ongoing research and evaluation, including cost-benefit analyses.

1.8 Resources

Total estimated cost = $720,000

Staffing: $680,000

1 1.0 FTE Postdoctoral Research Officer (3 years)

1 0.8 FTE Project Coordinator (3 years)

5 0.1 FTE Research Midwives (2 years)

Research costs $25,000

Parent consultation, focus groups

Materials

Publication fees

Biobank for storage of samples (linking with other national action plans)

Action 3.6: Establishing a national register of best practice guidelines on stillbirth to improve care across maternity services

1.1 Recommendations

Recommendation 13 b): Create an online register of current international and Australian stillbirth guidelines.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

Philippa Middleton, Caroline Homer, Jonathan Morris, David Ellwood, Fran Boyle, Adrienne Gordon, Euan Wallace, Vicki Flenady, Jane Warland, Deanna Stuart Butler (Centre of Research Excellence in Stillbirth)

Partnerships TBC: RANZCOG, ACM, RACGP, RCPA, Stillbirth Foundation Australia, PSANZ, Sands, Red Nose, Still Aware, Bears of Hope

1.3 Overview

A plethora of disparate and often poor-quality guidelines and protocols currently exist across Australia in stillbirth prevention and bereavement care. The Perinatal Society of Australia and New Zealand, The Stillbirth CRE and SANDS have developed guidelines/standards for care in this area however acknowledge that revision is required to ensure these meet NHMRC standards.

The National Pregnancy Guidelines Group has been highly successful in developing high quality guidelines for pregnancy care including areas of importance to stillbirth.

We propose that the National Pregnancy Guidelines Group expand its activity to include stillbirth prevention and bereavement care guidelines in partnership with the Stillbirth CRE and other key stakeholders' organisations.

1.4 Target/Goal

To establish a suite of NHMRC endorsed guidelines for stillbirth prevention and bereavement care with 5 completed in the first 12 months.

1.5 Policy response

To be considered further

1.6 Cultural diversity and Indigenous health

Please refer to the Action on culturally and linguistically appropriate care Timeframe

1.7 Timeline

Over the next 12 months we will update 4 existing guidelines and one new guideline as follows:

Existing PSANZ/Stillbirth CRE guidelines/position statements

1. Detection and management of women with decreased fetal movements
2. Detection and management of women with fetal growth restriction
3. Guidelines for care after stillbirth or neonatal death
4. Smoking cessation support for pregnant women

New guidelines

5. Informed decision-making around timing of birth for women with risk factors at or near term

1.8 Resources

Guidelines $300,000

1.0 FTE Project Officer for 2 years

Consultation with Indigenous and CALD women and communities

Action 3.7: Informed consent prior to membrane stripping

Recommendation 9: National best practice guidelines

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

1.1 Collaborators

- Marti Perhach (Group B Strep International)
- James McGregor (Group B Strep International)

1.2 Overview

Fetal membrane stripping or sweeping (FMS) is a "traditional" obstetrical procedure intended to induce labor, shorten gestation, or, more recently, reduce the occurrence of prolonged gestation (> 42 weeks). Among pregnancy providers, FMS is considered a long accepted procedure which 1) does not require procedural explanation or patient consent prior to performance and 2) does not have any known billing code or electronic medical record (EMR) category. This procedure has not been evaluated with rigorous scientific methods to demonstrate effectiveness and determine risk (including patient discomfort and potentially inoculating the lower uterine segment with microorganisms known to cross intact membranes causing fetal injury and death) vs. benefit ratios.

gbs-intl.org/uploads/9/9/9/4/99946050/gbsi-information-statement-on-fms-with-red-circle__1__rev_012618.pdf

1.3 Target/Goal

Adopt written informed consent procedures for membrane stripping.

1.4 Policy response

- Determine if written informed consent is obtained in any health care settings in Australia and interview providers in any such settings for guidance with universal implementation
- Formulate a written consent form that may be adapted by various health care settings
- Formulate guidelines for implementing the consent form
- Formulate a health care professional education kit explaining how to convey the risks vs. benefits of membrane stripping to patients
- Promote guidelines

1.5 Cultural diversity and Indigenous health

Translation of informed consent forms needed.

1.6 Timeframe

Suggest determination and formulation begins in 2019 and implementation of guidelines by mid-2020

1.7 Resources

To be determined.

Action 3.8: Minimally invasive tissue sampling (MITS) as an autopsy alternative

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

1.1 Collaborators

- Marti Perhach (Group B Strep International)
- James McGregor (Group B Strep International)

1.2 Overview

Parents are often hesitant to authorize an autopsy due to the invasiveness of the procedure. Offering previously examined alternatives such as MITS[1] may alleviate some anxiety in parents to help them decide to pursue finding the cause of death, which if found, can provide closure, help prepare for strategies in future pregnancies and inform research.

Byass P (2016) Minimally Invasive Autopsy: A New Paradigm for Understanding Global Health? PLoS Med 13(11): e1002173.

1.3 Target/Goal

Include minimally invasive tissue sampling as an option for parents to consider.

1.4 Policy response

- Do background research to evaluate the initiation and performance of MITS to ensure that there are affordable and reproducible benefits.
- If benefits are acceptable, update hospital protocols to include offering MITS as an alternative to autopsy as well as initiate appropriate training for pathology staffs and counsellors.

1.5 Cultural diversity and Indigenous health

To be determined

1.6 Timeframe

Suggest background research be completed by end of 2019 and, if benefits are acceptable, incorporate into hospital protocols during 2020.

1.7 Resources

To be determined.

Priority 4: Public education

Action 4.1: National public awareness campaign on stillbirth prevention

Action 4.2: Educational program for health care professionals to reduce stillbirth rates and improve care after stillbirth in Australia

Action 4.3: Stillbirth education

Action 4.4: Development and implementation of a national best-practice, culturally appropriate education kit

Action 4.5: Prenatal infection prevention messaging

Action 4.1: National public awareness campaign on stillbirth prevention

1.1 Recommendations

Recommendation 10: Develop and implement national stillbirth public awareness campaign.

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

Investigators and partners on the NHMRC Centre of Research Excellence Safe Baby Bundle project (see Action 3.1). Stillbirth CRE Public Awareness Committee in partnership with the Charles Perkins Centre, University of Sydney,

Suggested coordinating team:

- Adrienne Gordon (Centre of Research Excellence in Stillbirth, PSANZ SANDA, University of Sydney)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute-The University of Queensland)
- Adrian Bauman (Prevention Research Collaboration, The University of Sydney)
- Lilian Chan (Prevention Research Collaboration, The University of Sydney)
- Melody Ding (Prevention Research Collaboration, The University of Sydney)
- Kate Lynch (Stillbirth Foundation Australia),
- Claire Ford (Still Aware)
- Jackie Mead (Sands Australia)
- Keren Ludski (Red Nose)
- Amanda Bowles (Bears of Hope)
- Sue Walker (University of Melbourne)
- Camille Raynes-Greenow (University of Sydney)
- Philippa Middleton (Centre of Research Excellence in Stillbirth, PSANZ SANDA, South Australian Health and Medical Research Institute)
- Jane Warland (Australian College of Midwives)
- Lesley McCowan (Centre of Research Excellence in Stillbirth, University of Auckland)
- Robin Cronin (Centre of Research Excellence in Stillbirth, University of Auckland)
- Alex Heazell (International advisers: University of Manchester, UK. Saving Baby's Lives Bundle)
- Deirdre Barra and Kate Davies (Tommy' UK)
- Gavin Youngman (Stillbirth Foundation Australia and Bereaved Parent)
- Consultation: Sands, Red Nose, Still Aware, Bears of Hope, RANZCOG,

1.3 Overview

National Public Awareness Campaign on Stillbirth Prevention

To deliver rolling prevention messages across Australia including:

1) Awareness and management of reduced Fetal Movements
2) Awareness of maternal safe sleeping position
3) Reducing smoking in pregnancy
4) Timing of birth for women with risk factors

Prevention of stillbirth remains one of the greatest challenges in modern obstetric practice. Despite great advances in the care of women and their babies in the past century an estimated 2.64 million babies die before birth globally each year. The burden of stillbirth has far reaching psychosocial impacts on women, families, caregivers and communities, and wide-ranging economic impact on health systems and society. Stillbirth in late pregnancy (>28 weeks) is more likely to occur unexpectedly in normally developed babies whose mothers have often had uncomplicated pregnancies, thus offering real potential for prevention. There is now a Global and National health focus on prevention of stillbirth. The 2016 Lancet Ending Preventable Stillbirth series highlighted differences in rates of late stillbirth (≥28 weeks') between high-income countries ranging from 1.7/1000 to 8.8/1000 births, with New Zealand and Australia at 2.3 and 2.7/1000 births respectively. These between country variations suggest it is possible to further reduce late-gestation stillbirth and achieve the recommended goal of <2 late stillbirths/1000 births by 2030. Such reductions can only be achieved by identifying modifiable risk factors.

Awareness and timely evaluation of women reporting decreased fetal movements (DFM) is one such modifiable risk factor and a stillbirth research priority identified in both 2011 and 2016 Lancet Stillbirth Series. Delayed reporting by pregnant women and variable clinical management on presentation to hospital are key issues. Campaigns to increase public awareness and to standardise clinical management have been part of bundles of care that have led to reduced stillbirth rates > 28 weeks in Norway, the UK and Scotland.

Other modifiable risks included in these bundles of care are strategies for surveillance for fetal growth restriction. The Stillbirth CRE completed a survey in 2018 which gaps in care for elements of a similar care bundle with around one-third reporting that the recommended practices for each element were performed either “never”, “not much of the time”, or only “half of the time”. Smoking cessation support, risk assessment for FGR and providing advice on sleep position were least likely to be performed “all the time”. Reassuringly, 70% of respondents indicated their willingness to participate in implementing a bundle of care. Around 1 in 5 hospitals did not have guidelines in place for smoking cessation, detection and management of women with FGR and DFM. The stillbirth CRE have recently been successful with an NHMRC partnership grant to implement such a stillbirth prevention bundle in Australia and a public awareness campaign is an essential aspect of this implementation.

We already have expertise in a state-wide public awareness campaign around one bundle aspect – decreased fetal movements. Despite an Australian National Clinical Practice Guideline there remains a need for improvement in awareness and appropriate management of decreased fetal movements for pregnant women and clinicians. Recent Australian data shows that 50-60% of women wait 24 hours or more to report DFM and 60% say it is normal for movements to decrease towards term. Of concern, 70% indicate awareness of FM would NOT help identify a baby at risk. Lower socio-economic status is associated with less understanding of DFM and reporting of information received

The Stillbirth CRE were commissioned by Safer Care Victoria in 2018 to develop, disseminate and evaluate a campaign targeting both pregnant women and clinicians in Victoria. Campaign aims were:

- To educate both clinicians and pregnant women about the importance of fetal movements;
- To provide a clear course of action in the case of decreased fetal movements;
- To empower pregnant women by offering a non-judgmental, evidence-based, solution focused approach;
- To support nationally consistent messaging and clinical practice regarding awareness and management of decreased fetal movements.

A public awareness campaign targeting pregnant women and clinicians in Victoria was launched in October 2018. Pre-campaign surveys were collected from 3 metropolitan and 2 regional hospitals in Victoria over a 2 week period from 14th to 28th August. Pregnant women were eligible if at or beyond 28 weeks gestation and receiving care in one of the 5 sites and were invited to complete the survey using an iPad in the antenatal clinic. Clinicians at each site were invited to complete an online survey by the relevant clinical director. Post campaign surveys were collected from the same sites over 2 weeks from November 19th – Dec 3rd to assess impact of the campaign and interpreted with digital analysis of campaign reach and dose-exposure.

Pre- Campaign data from 1142 pregnant women and 372 clinicians. Revealed that a large proportion of women (40%) stated that a baby moves less at the end of pregnancy and only 35% would contact their care provider immediately if concerned about movements. Although clinician knowledge was high with 98% regarding this as routine care, only 1 in 5 discuss the link of DFM with stillbirth.

The paid social media campaign engaged with 85% of the target population reaching 620,536 of the 730,000 target. Over 2.4 million ad impressions were served, achieving a frequency of 3.94 per woman. Combined organic and paid social media reached 540,163 people in October, and 653,262 in November.

Post-Campaign data from 443 women shows modest increases in knowledge regarding movements as pregnancy progresses with 31% pre-campaign and 46% post campaign stating that movements should remain the same. However similar numbers of women around 1 in 2 both pre and post campaign state that concern about being a nuisance or wasting the Dr or Midwives time would prevent them from calling. There was a 20% increase in women reporting that they had received both verbal and written information regarding fetal movements from 28 to 48%. When questioned on both unprompted and prompted recall of the MovementsMatter campaign there was 32% unprompted but on 38% when prompted. The vast majority of the 171 who recognised the campaign has seen or heard of it at the hospital or antenatal clinic (143/171 – 84%) with only 51/171 (30%) having seen it on Facebook or 12/171(7%) on Instagram despite it being a digital campaign targeting social media.

Evaluation of a state wide public awareness campaign has demonstrated modest increases in knowledge especially regarding the fact that movements should not slow down in later pregnancy. There however remains a need for clearer messages to reinforce that presentation to hospital is not "wasting clinical time". There is also evidence that a National Campaign should go beyond social media and use a multilayered approach to improve its reach.

A National Campaign with rolling stillbirth prevention messages is essential and complementary to the implementation of stillbirth prevention bundles in clinical practice.

1.4 Target/Goal

To design and deliver a National Stillbirth Prevention Campaign

- Step wise structure to develop and document processes in the campaign such as the Flowproof Model
- Message development for National Campaign by communications agency
- Further testing of additional media modalities using effects from the pilot Victorian Campaign to define the areas that require more focus or alternative media/dissemination routes.
- Further stakeholder analysis of all collaborating agencies/ advocacy groups
- National dissemination plan to include scale up of any existing campaign elements, development of new messaging to support the St. and additional communications components beyond social media alone

1.5 Policy response

All Maternity Services to have access to or local adaption of the existing National Clinical Practice Guidelines relevant to stillbirth prevention

Addition of these Clinical Practice Guidelines to existing Pregnancy Care Guidelines

Enhancement of existing e-learning programs e.g. decreased fetal movements and stillbirth risk factor as to allow ease of access on mobile devices in Maternity Care Settings

1.6 Cultural diversity and Indigenous health

Further work required to assess suitability of existing resources e.g. in MovementsMatter and development of culturally appropriate new resources to assess what changes if any would be required in both design, messages and dissemination routes for CALD and indigenous women

1.7 Timeframe

3 months for scale up of existing Movements Matter campaign for National Application.

3 months to design series of simple rolling prevention messages

3 months to consider development of resources for culturally and linguistically diverse groups,

3 months National Campaign,

6 months evaluation

1.8 Resources

Research Staff:

Project officer 0.6 FTE 18 months – Development based with CRE team

Project officer 0.4 FTE 18 months – Evaluation based with PRC team at University of Sydney

Indigenous researcher 0.2 FTE 12 months

CALD researcher 0.2 FTE 12 months

Communications Agency:

Workshop with Stakeholders: Refine Key Messages in communication with Stillbirth CRE and campaign partners.

Develop a full range of campaign communications materials

Development of a detailed media engagement plan

- Develop and deliver a range of briefing materials for stakeholders and spokespeople.
- Developing a section on the CRE website to host campaign information and materials and working to further develop digital media platforms
- Delivery of the campaign
- Reporting and Debrief in collaboration with Stillbirth CRE evaluation

Action 4.2: Educational programs for health care professionals to reduce stillbirth rates and improve care after stillbirth in Australia

1.1 Recommendations

Recommendation 11: Develop and implement a national best-practice education kit for current and future health care professionals – prevention and care after stillbirth (culturally and linguistically appropriate)

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- David Ellwood, Glenn Gardener, Vicki Flenady, Adrienne Gordon, Philippa Middleton, Euan Wallace, Jonathan Morris, Megan Weller, Fran Boyle, Dell Horey, Christine Andrews, (Centre of Research Excellence in Stillbirth and Perinatal Society of Australia and New Zealand)
- Sue Vlack, Deanna Stuart-Butler (Stillbirth CRE Indigenous Advisory Group)
- Jane Warland, Caroline Homer, Hiliary Rorison (Australian College of Midwives)
- Yee Khong (Royal College of Pathologists Australasia, Centre of Research Excellence in Stillbirth)
- Sean Seeho (Royal Australian and New Zealand College of Obstetricians and Gynaecologists)
- Nicole Hall, RACGP
- Jacki Mead (Sands Australia)
- Kate Lynch (Stillbirth Foundation Australia)
- Keren Ludski and Jane Wiggall (Red Nose)
- Amanda Bowles (Bears of Hope)
- Sonya Criddle (King Edward Memorial Hospital, Western Australia)
- Belinda Jennings (Northern Territory Health Department)

A clinician stillbirth prevention education kit is a critical component of the implementation plan for Safe Baby Bundle (see Action Item 3.1). The educational program will be aligned with the Public education program (see Action Item 4.1).

1.3 Overview

We propose an educational program in a modular form using both face-to-face and online formats for maternity service covering:

a) Prevention. Addressing each of the elements of the 'Safe Baby Bundle' (SBB) are:

- improved detection and management of impaired fetal growth;
- increasing awareness and management of women with decreased fetal movements;
- smoking cessation support;

- provision of maternal safe sleeping advice; and
- improved decision-making around timing of birth for women with risk factors.

b) Care after stillbirth and neonatal death.

- **Provision of the IMPROVE program**

  The workshops are designed for health care professionals including obstetricians, midwives, neonatal nurses, neonatologists, pathologists, bereavement specialists, social workers, or those interested from a policy or public health perspective. IMPROVE workshops provide an opportunity for participants to understand the PSANZ/Stillbirth CRE Guidelines in care after stillbirth or neonatal death.

- **A training and support program for HCP and parents on respectful supportive care for families after stillbirth.**
  The workshop and accompanying on-line program will build on the IMPROVE workshop to equip all HCP to provide care according to the national guidelines and provide support to families who have a stillborn baby. The program will include organisational responses required including provision of support for HCP.

1.4 Target/Goal

- 80% of staff across maternity services with more than 100 births per year have completed the educational programs (a and b)
- A hub and spoke approach to outreach support by tertiary services implemented by 2022 to enable optimal care for all stillbirths and neonatal death in Australia
- Improvement in parent's experience with care and decision-making after stillbirth
- Unexplained stillbirth reduced by 10% nationally
- 20% reduction in stillbirths after 28 weeks' gestation within 3 years

1.5 Policy response

AHMAC to enable uptake of the educational programs across jurisdictions.

1.6 Cultural diversity and Indigenous health

Culturally and linguistically appropriate resources for women will be developed through a consultation process (please refer to the Action Plan culturally and linguistically appropriate care)

1.7 Timeframe

Development and piloting 2019 and roll out nationally over 2020/21

1.8 Resources

$500,000 2019-2021

Project officer educational expertise 1 FTE for 6 months = $50,000

Clinician advisor 1 FTE for 6 months = $50,000

Consultation to ensure cultural appropriateness = $300,000

Technical support (Hosting on-line) annual fees for 3 years = 6,000.

Content update first 3 years 0.1 FTE = $50,000

Action 4.3: Stillbirth education

1.1 Recommendations

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

That the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) contributes to the development of the education kit and in embedding the education kit into the Registrars' training program. RANZCOG also promotes the education kit to current Fellows of the College and assists in the education of Fellows through the College journal (ANZJOG) and by other means (such as education seminars and College meetings).

Please refer to Action Plan 4.2 for supplementary information.

1.2 Collaborators

- Sean Seeho (Fellow and nominated representative - Royal Australian and New Zealand College of Obstetricians and Gynaecologists)

1.3 Overview

Obstetricians care for pregnant women, and women and families following a stillbirth. It is imperative that current and future RANZCOG Fellows' clinical practice reflects best practice with regard to discussing the risks of and strategies to prevent stillbirth, and the care of women and families of all backgrounds following a stillbirth.

1.4 Target/Goal

That all future and current RANZCOG Fellows' clinical practice reflects best practice with regard to discussing the risks of and strategies to prevent stillbirth, and in caring for women and their families of all backgrounds following a stillbirth.

1.5 Policy response

ANZCOG can assist in the program's implementation through its Registrar trainee program and through its contact with Fellows/Members of the College.

1.6 Cultural diversity and Indigenous health

This action will ensure that all obstetricians are able to care for women of all backgrounds using culturally and linguistically appropriate information.

1.7 Timeframe

12 months, but ongoing as there are new obstetric trainees each year

1.8 Resources

Fellows of RANZCOG who champion the program (volunteers with a strong interest in stillbirth and its prevention): I expect that Fellows will volunteer their time and thus there will not be any monetary cost.

Action 4.4: Development and implementation of a national best-practice, culturally appropriate education kit

1.1 Recommendations

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

1.2 Collaborators

- Leanne Boase (Australian College of Nurse Practitioners)

1.3 Overview

There is some acknowledgement of the impact on health care professionals throughout the report, however there is minimal consideration of the strategies that could be implemented to retain experienced staff who may otherwise be lost due to emotional and professional stress following stillbirth. The retention issue is also mentioned, however not addressed. Retaining experienced staff, including those who have cared for families experiencing stillbirth would ensure these families receive the best support and education.

The Australian College of Nurse Practitioners appreciates the opportunity to contribute to the Select Committee on Stillbirth Research and Education report - Stillbirth National Action Plan.

It was a very thorough review overall, all aspects of stillbirth were well reviewed, including research, the effect on grieving parents, the health care system to support the families and improvements possible, bench marked against other countries' responses to the silent tragedy of still birth.

The health services available to provide improved services to improve outcomes for families touched by stillbirth (pg. 7) would be strengthened by inclusion of Nurse Practitioners who as autonomous health practitioners, are positioned well to improve timely cost-effective interventions. Interventions such as lifestyle risk factor minimisation, individualised person and family centred follow up care and referral to relevant health services, especially in remote and rural areas of Australia.

Impact on health care professionals was discussed in relation to economic impacts, and the loss of healthcare workers from the industry as a result of witnessing stillbirth was only briefly mentioned.

1.4 Target/Goal

To incorporate support mechanisms for health care professionals into the recommendations, with the aim of managing the impact on them, and retaining them within their specialty area.

1.5 Policy response

It was a very thorough review overall, all aspects of stillbirth were well reviewed, including research, the effect on grieving parents, the health care system to support the families and improvements possible, bench marked against other countries' responses to the silent tragedy of still birth.

The health services available to provide improved services to improve outcomes for families touched by stillbirth (pg. 7) would be strengthened by inclusion of Nurse Practitioners who as autonomous health practitioners, are positioned well to improve timely cost-effective interventions. Interventions such as lifestyle risk factor minimisation, individualised person and family centred follow up care and referral to relevant health services, especially in remote and rural areas of Australia.

Impact on health care professionals was discussed in relation to economic impacts, and the loss of healthcare workers from the industry as a result of witnessing stillbirth was only briefly mentioned.

1.6 Cultural diversity and Indigenous health

1.7 Timeframe

Action 4.5: Prenatal infection prevention messaging

1.1 Collaborators

- Marti Perhach (Group B Strep International)
- James McGregor (Group B Strep International)

1.2 Overview

Infection does not always figure prominently in stillbirth prevention messaging although, according to one study1, up to 24% of stillbirths in developed countries have been attributable to infection.1

Infectious causes of stillbirth: a clinical perspective. EM McClure et al. Clin Obstet Gynecol. 2010;53(3):635-45.

1.3 Target/Goal

Include messaging focused on preventing prenatal infection such as the following:

1) Pregnant women should see their healthcare providers promptly for diagnosis and appropriate treatment if they experience any vaginitis symptoms.

2) To help reduce the risk of cytomegalovirus (CMV) infection, pregnant women should be advised to avoid the saliva of young children when kissing them and to not share food, utensils or cups with a child. Pregnant women should also be advised to wash their hands after changing diapers as CMV can also be passed through urine.

3)Appropriate cautions to pregnant childcare providers and elementary school teachers regarding CMV and fifth disease

4) Many microorganisms that can harm unborn babies are not considered to be sexually transmitted infections, but are still sexually transmissible. Safe sex precautions may still be warranted.

5) If a blood transfusion is needed, pregnant women should inform their healthcare providers if they are pregnant to ensure that the blood has tested negative for CMV.

6) Awareness that some microorganisms can cross intact membranes and that cervical exams and membrane stripping can transport microorganisms closer to the baby, empowering the pregnant woman to make informed decisions regarding her health care

7) Inform all pregnant women to have their urine cultured for bacteria early in pregnancy, understand the difference between urine culturing and the routine "dipstick" check, and to follow-up for urine culture results and any recommended treatment.

8) Promote healthy pregnancy behaviors to help prevent the wide variety of prenatal infections. Example infograph

1.4 Policy response

Ensure that healthcare providers and staff are knowledgeable and adequately trained regarding prenatal infection and also promote infection prevention messaging and prevention practices in their healthcare settings.

1.5 Cultural diversity and Indigenous health

Translations needed to reach the non-English speaking population and be considerate of any cultural differences.

1.6 Timeframe

Suggest preparing awareness campaign in 2019; launch in 2020.

1.7 Resources

To be determined

Priority 5: Support bereaved parents

Action 5.1 Implement best practice in care after stillbirth in maternity hospitals and transition to the community

Action 5.2: Expand support in the community for bereaved parents

Action 5.1: Implement best practice in care after stillbirth in maternity hospitals and transition to the community

1.1 Recommendations

Recommendation 9: Develop national best practice guidelines for hospitals and health centres

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 stillbirth babies in morgues, communicating with bereaved parents

Recommendation 14: Public education kits that assist families and broader communities to support bereaved parents

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Fran Boyle (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Institute for Social Science Research - The University of Queensland)
- Dell Horey (Centre of Research Excellence in Stillbirth, PSANZ SANDA, La Trobe University)
- Vicki Flenady (Centre of Research Excellence in Stillbirth, PSANZ SANDA, Mater Research Institute - The University of Queensland)
- Philippa Middleton (Centre of Research Excellence in Stillbirth, PSANZ SANDA, SAHMRI)
- Jackie Mead (Sands Australia)
- Amanda Bowles (Bears of Hope)
- Kate Lynch (Stillbirth Foundation Australia)
- Keren Ludski, Jane Wiggall (Red Nose)
- Barb Vernon, Women's Healthcare Australasia
- Australian College of Midwives
- Amelia Druhan (Council of Remote Area Nurses of Australia)
- Jo Walker (National Rural Health Alliance)
- Jane Yelland (Murdoch Children's Institute)
- Members of the Indigenous Advisory Group: Deanna Stuart Butler, Sue Vlack,
- Members of the National Perinatal Bereavement Care Group

1.3 Overview

Stillbirth places an enormous psychological and social toll on mothers, fathers, families and society (Heazell et al., 2016). It is estimated that 60-70% of affected women will experience grief-related depressive symptoms at clinically significant levels in the year following their baby's death. Intense distress will endure for at least four years after the loss in about half of those women. Similar data are not available for other family members, but it is likely that partners, siblings and grandparents are also profoundly affected.

The care available to parents around the time of stillbirth and beyond strongly influences their immediate and future wellbeing but the quality of that care varies widely and is often poor. Health care professionals report feeling they lack the specific skills and expertise required, and often carry their own personal and professional burden after stillbirth (Shorey, Andre, & Lopez, 2017).

Good bereavement support includes access to relevant and accurate information, particularly as so many difficult decisions need to be made in circumstances where time pressures exist. Some decisions, such as those surrounding autopsy may directly impact on the quality of data and information for research purposes.

Improving bereavement care following stillbirth is a global priority identified in The Lancet Ending Preventable Stillbirths Series 2016. In Australia, the imperative is to ensure that all parents and families receive the best possible care regardless of where stillbirth occurs.

This requires a coordinated multisectoral effort that encompasses high quality research; parents' lived experiences, including those of parents from marginalised groups; the insights of health care professionals; and policy direction and frameworks. Australia is a world leader in perinatal bereavement care but more can be done to ensure that all parents and families receive the best possible care following stillbirth. Our approach to realizing this vision is founded on **partnerships between researchers, health care professionals, parents and communities** to ensure **best possible evidence-based care is embedded in all settings** and is subject to **ongoing rigorous evaluation**.

Bereavement support organisations, including Sands Australia, Bears of Hope, and Red Nose, play a vital role in supporting parents and families and in advocating for health and other service improvements that address the needs of families. Professional organisations such as Women's Healthcare Australasia have a key role in disseminating and implementing best practice guidelines.

The Perinatal Society of Australia and New Zealand (PSANZ)/Stillbirth Centre of Research (Stillbirth CRE) *Clinical Practice Guideline for Respectful and Supportive Perinatal Bereavement Car*e provides a set of recommendations that are designed to contribute to this goal. Sands Australia and Women's Healthcare Australasia are key partners and the Guideline aligns closely with the *Principles of Bereavement Care* developed by Sands Australia.

The *Clinical Practice Guideline for Respectful and Supportive Perinatal Bereavement Care* provides a clear roadmap for advancing the development, implementation and evaluation of effective parent-centered perinatal bereavement care. The Guideline points to areas of action that range from **hospital-based care and practices**, to **organisational responses**, the **interface between hospital and community** and a range of **longer-term support options** for families. A National Perinatal Bereavement Care Working Group, including many members of the original Guideline Update Group, has been established to ensure stakeholder-driven implementation.

Developing a comprehensive approach to perinatal bereavement care requires targeted action in five overarching areas (that often overlap):

1. Supporting and empowering parents: Information and decision support for parents
2. Developing a skilled workforce: Education and support for staff
3. Organisational response
4. Support in the community
5. Avenues for parents to participate in health services improvement and research

The Guideline captures the best and most current research evidence, parents' lived experiences, and maternity care providers' insights and contains a set of 49 implementable recommendations that address the needs of bereaved parents. Sands Australia and Women's Healthcare Australasia are key partners in the development and implementation of the Guideline, which was overseen by a Guideline Update Group of 50 parents, clinicians, researchers and policy makers. A newly established National Perinatal Bereavement Care Working Group will continue to inform stakeholder-driven implementation.

The following Targets and Goals include research and implementation activities that leverage off existing and proposed work built on partnership and collaboration.

1.4 Target/Goal

Supporting and empowering parents

Parents have ready access to nationally consistent information and resources, including:

- Parent version of perinatal bereavement care guideline designed to support and inform parents about their care options including birthing, stillbirth investigation and the perinatal mortality review process.
- Decision support resource to assist parents in deciding about autopsy for their baby
- Access to online resources to provide information and support mental wellbeing

Culturally safe care is provided, based on understanding of experiences of pregnancy loss and views of best practice care gained through consultation with Aboriginal and Torres Strait Islander women and migrant and refugee women in Australia

Developing a skilled workforce

Healthcare professionals are equipped and supported to deliver best-practice perinatal bereavement care

A coordinated evidence-based multidisciplinary training strategy that appropriately targets different segments of the maternity care workforce and that can be adapted to local contexts. This strategy is based on sound pedagogical principles and draws together the best features of existing training initiatives (including the IMPROVE program, an online module of bereavement care for midwives developed by Sands Australia, and other current training and educational initiatives)

Short and engaging case based videos are available for use in a range of training and educational settings

Health care professional education that begins pre-graduation through inclusion of bereavement support in health care curricula, including for medical, nursing and midwifery, paramedic students

Organizational response

- Assessment of current activity and development of capacity for the provision of best possible perinatal bereavement care in Australian maternity services
- Implement monitoring and evaluating for maternity settings
- Implement a support service for staff

Support in the community

- The interface between hospital and community is an important priority to ensure support is provided across the continuum, from pre-admission through hospital to home, including for families who live in rural and remote areas. Evidence shows that a **flexible menu of support options** that are culturally and linguistically appropriate is needed to meet the varied needs of women and families in the immediate and longer-term.
- A low-cost accessible online program that improves the mental wellbeing of parents after perinatal loss: Program development, evaluation, and translation to clinical practice (including alternative delivery mode for women who have internet connectivity limitations).

Avenues for parents to participate in health services improvement and research

- Guidance to ethics committees about the involvement of bereaved parents in research and development of module to form part of the existing NHMRC consumer engagement in research guideline

To measure change, we need:

- Nationally consistent methods for monitoring parent reported outcomes and parent experience based on a core outcome set relevant to the Australian context
- Information about the capacity of maternity care settings and the barriers and enablers, including the ability of their staff, to implement best practice care recommendations

1.5 Policy response

We call upon Government to support maternity hospitals to:

- Implement and monitor the impact of best practice bereavement care guidelines
- Establish a hospital network alliance so that all settings (including those where stillbirth may be a rare event) are connected to and have ready access to experience and expertise in perinatal bereavement care

1.6 Cultural diversity and Indigenous health

Addressing the needs of women and families from Indigenous and other culturally diverse backgrounds is essential, particularly given the higher stillbirth rates among some groups.

Indigenous health is a cross-cutting issue for all Stillbirth CRE activities and an Indigenous Advisory Group provides guidance, input and advice. A Culturally Appropriate Information Working Group has been established. The advice and guidance of these groups will help to optimize the reach and appropriateness of the activities outlined above.

1.7 Timeframe

Development and pilot testing over 18 months followed by full rollout over 4 years.

1.8 Resources

Development of a bundle of care for maternity services

Components of the bundle will include:

1. Resources for women and families including:
    - Parent version of the clinical practice guidelines
    - Tools to help with decision-making including autopsy consent
    - On-line support program

2. Educational program for health care professional – face to face and on-line
    - Key performance indicators
    - Define women's reported outcomes and experiences relating to bereavement care and develop on-line reporting system

Implement and evaluate the bundle of care across 20 maternity care settings

References

Heazell AE, Siassakos D, Blencowe H, et al. Stillbirths: economic and psychosocial consequences. *Lancet* 2016; **387**.

Shorey S, André B, Lopez V. The experiences and needs of healthcare professionals facing perinatal death: A scoping review. *International Journal of Nursing Studies* 2017; **68**: 25-39.

Action 5.2: Expand support in the community for bereaved parents

1.1 Recommendations

Recommendation 1: Best Practice Parental leave provisions

Recommendation 9: National best practice guidelines on providing support and information for bereaved families.

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

Recommendation 14: Public education kits that assist families and broader communities to **support bereaved parents**

1.2 Collaborators

Please note that these names are indicative and in no way final. Please add your name/organization if you would like to be included in this working group.

- Jackie Mead (Sands Australia)
- Keren Ludski (Red Nose)
- Amanda Bowles (Bears of Hope)
- Kate Lynch (Stillbirth Foundation Australia (Kate Lynch)
- NHMRC Stillbirth Centre of Research Excellence (Fran Boyle, Dell Horey, Vicki Flenady and others) with key partners to be confirmed
- Members of the National Perinatal Bereavement Care Group

1.3 Overview

Bereavement support is critical to reducing the risks of grief associated depressive disorders and to addressing anxiety during subsequent pregnancies.

Good bereavement support includes raising awareness in the community, particularly among organisations that interact with bereaved parents. Workplaces are an important part of the lives of many bereaved parents and it is critically important that workplaces offer appropriate support. At present there is great variation in the leave entitlements being offered to bereaved parents

Current federally-funded support services for bereaved parents includes a national phone line, which like a lot of bereavement support in Australia relies on volunteering–with one parent helping another through the most difficult of times. Raising awareness of the prevalence and impact of stillbirth, and other perinatal grief, is likely to increase demand for all support services, including those that are volunteer-based, and for parents with delayed grief response needs. It is important to acknowledge the variety of models of bereavement support that can be offered as choice for the grieving family member is likely to be critical to good outcomes, but more evidence is needed about the effectiveness of different support models.

1.4 Target/Goal

Information and decision support for parents

- Fact sheets / checklists to support parents with the decisions and administration associated with the death of a baby.
- Development of a mobile telephone app that provides relevant information and advice for bereaved parents
- Online support options.

Education and support for related service providers and the community

- Bereavement Awareness training provided for frontline staff at Centrelink and other service hubs
- Development of best practice support resource for bereaved parents returning to work, including support and education for work colleagues and management staff on how to best care for a bereaved staff member
- Resources to support and enable community service providers who are likely to interact with bereaved parents, including GPs, pharmacists, child care workers, teachers and others

Expanded service offerings

- All bereaved families to be given access to the information and support needed in the community in which they live
- Establishment of bereavement hubs in key locations around Australia.

Workplace entitlements

- The Fair Work Act (2009) and the National Employment Standards should enshrine a right to paid parental leave for bereaved parents that is equal to those of all other parents.
- These same instruments should also enshrine the right to request flexible return to work arrangements that mirror all other parents.

To measure change, we need:

- Nationally consistent data that monitors outcomes related to parent experience and that are based on a core outcome set relevant to the Australian context
- Nationally consistent data collection by bereavement services

1.5 Policy response

Budget for additional and expanded bereavement services particularly focused on:

- Transitioning families from hospital to home
- Establishing bereavement hubs in cities across Australia. This will allow volunteers services to expand and collaborate as well as providing "safe spaces" for families as the move through the grieving process.
- Expanding the terms under which grief counselling can be accessed and expanding options for counselling
- Funding the development and evaluation of online support and a telephone app that addresses the immediate needs of bereaved families.
- Engagement with Primary Health Networks to develop and improve access to appropriate services

1.6 Timeframe

3 years.

1.7 Resources

Pilot program transitioning parent's - hospital to home pilot $800,000

On line app $30,000 - $50,000

Recommendation Letter: Maternity Consumer Network

We have focused on the two priority areas that we feel we can provide the most insight into, whilst attempting to bring forward the voice of consumers.

Priority 3

For Recommendation 9-12 and 16, the effective implementation and uptake of training and action plan will depend on Recommendation 8. Having continuity of carer is essential, but there also needs to be specific mention of continuity of midwifery carer. Not only were women less likely to lose their baby overall when cared for in a midwifery-led continuity of care model, but a known midwife spends many hours with the woman through pregnancy and is there for the whole (or majority of) birth. Women have consistently preference this model of care throughout the many state and federal reviews.

Using loose definitions such as "continuity of care" simply means that women are going to the one place to receive care, which is still going to be highly fragmented and less likely to have the recommendations 9-12 implemented when seeing many different midwives and doctors, often for very brief (15 minute appointments) that rarely cover the Pregnancy Care Guidelines. The fragmentation in care is where we continually hear from consumers that dissemination of important information is lost.

A simple solution the federal government could implement quickly is through Medicare and the private midwifery profession. Currently, they account for only a small percent of maternity care, though this is largely due to "red tape" restrictions rather than lack of interest by midwives wanting to step into private practice. Providing a smooth pathway that is more supportive, rather than restrictive, will see much greater availability and access to continuity of midwifery carer through the private midwifery profession. The current Medicare Review Taskforce has tabled the private midwifery report, which offers many solutions for increasing consumer access to continuity of midwifery carer.

The current National Strategic Approach to Maternity Services also has suggestions for decreasing Stillbirth rates, so it would be good to have cross references between both strategies to ensure these recommendations are more likely to be implemented, particularly if there is accountability or reporting of the recommendations when implemented. This is a Federal document, with Deb Thom's (Chief Nurse/Midwife for the DOH) taking the lead on.

We have a consumer representative involved with both the above-mentioned committees, so are happy to provide insight where we can.

Priority 4

Recommendation 10 needs to also dispel the many myths that are still given out many parents around reduced fetal movement and "count the kicks". Given the handheld records are now electronic and there are fewer pamphlet distributions, social media platforms and short educational clips that can be shown in antenatal clinics would be more effective.

We have had many consumer representatives work on guidelines and various maternity strategies, so are happy to share with our consumer representative network if there is an opportunity to participate in education/public awareness campaign development.

Recommendation Letter: The Royal College of Pathologists

The College supports the findings of the Senate Enquiry and will collaborate with other institutions, health agencies and researchers to enable implementation of the recommendations. The particular responses to pertinent recommendations are listed.

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

The committee recommends that the Australian Health Ministers' Advisory Council agrees to prioritize the development of a comprehensive, standardized, national perinatal mortality data collection.

The College will encourage perinatal pathologists to continue to participate in the development of a national perinatal mortality data collection system, including advising on the feasibility of data fields, field testing of proposed forms and, subsequently supplying data from the performed autopsies. This data collection and classification should be undertaken by a multi-discipline team with the appropriate scope of knowledge to assign appropriate classification to the death.

The College will support this activity by advocating that local health authorities recognize that this is part of the workload of a perinatal pathologist with the implication for increased staff numbers and funding.

Recommendation 3: Obtain medical services advisory committee advice on economic costs of autopsy as new Medicare benefits item

The committee recommends that the Australian government seeks advice from the Medical Services Advisory Committee on the economic costs and benefits of adding stillbirth autopsies as a new item in the Medicare Benefits Schedule.

The College is aware that several attempts have been made at local levels to calculate costs for a perinatal autopsy. However, it is also aware that a review of the costs will need to be harmonized across the different states and territories and be evidenced-based, against established guidelines for investigations in stillbirths and miscarriages.

The development of costing and a funding arrangement will require that the autopsies (which includes fetuses <20 weeks' gestation) performed and all investigations undertaken are to a uniform high standard as recently updated and proposed by PSANZ (Perinatal Society of Australia and New Zealand) and are performed by a perinatal Pathologist or under the supervision of a perinatal pathologist with appropriate training. This requires that the autopsy funding should be linked to appropriate scope of practice which should be linked to training, currency of the Pathologist's perinatal and miscarriage autopsy practice and number performed each year. Guidelines need to be developed by RCPA as to the number of cases required to maintain an appropriate level of skill.

Recommendation 4: Increase number of perinatal pathologists

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

The College supports this recommendation. It would also suggest that a comprehensive properly funded study be performed, in collaboration with various health authorities and data collection centres, to ascertain where and by whom perinatal autopsies are being performed. This should also include data on autopsies of non-registrable births.

The College would also suggest that an in-depth examination of the demographics of current practicing perinatal pathologists, including their intended length of continuing service, be conducted to accurately determine where the current and projected future shortfall of expertise is located.

Appropriate funding (available as required above the usual pathology trainee funding) will be required for specialist training time in perinatal pathology. This could be developed as a Fellowship year potentially funded along the lines of the STP funding for pathology positions in rural laboratories. Other possibilities also need to be explored.

The College has already developed a post-Fellowship Diploma in Pediatric Pathology.

Recommendation 7: Development of National biobank for stillbirth placenta research

The committee recommends that the Australian government considers 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 College supports this recommendation and the Biobank Working Party of the College will be able to provide advice, if sought, regarding various aspects of a tissue repository, including important aspects of quality. The College participates in the NATA-RCPA accreditation process and will endeavour that quality aspects will be practiced.

Recommendation 8: Continuity of care and care-provider models, particularly for high risk groups

This is important in the high-risk group minorities, is the indigenous population who need more support with some groups making inroads in this area but requiring more funding and appropriate cultural care including engaging the elders. Remote areas need consideration from both indigenous as well as the rural population. Other minority groups and refugee groups also require appropriate culturally appropriate engagement.

Transportation of the deceased from regional/remote health services to a location where perinatal autopsy services are provided should be appropriately funded.

Recommendation 9: National best practice guidelines

The guidelines set out by PSANZ which have by default become the guidelines most people follow as the majority of those in this field are involved in PSANZ as it is the only organization that covers all disciplines in this area.

Recommendation 10: Develop and implement a national stillbirth public awareness campaign

The College is happy to participate with appropriate committees to assist in the development of this.

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

IMPROVE covers all aspects of pregnancy loss from the beginning to end. The 6 stations cover the different aspects including bereavement, classification, placenta and autopsy, asking for an autopsy and how to treat the mother initially and tests needing to be done at the time of the stillbirth. Participant knowledge before and after the course is assessed and marked improvement in knowledge is noted by the participants. The way the course is run is also rated highly.

IMPROVE courses are available and should be funded in each state to run regularly so that all medical and ancillary persons involved with perinatal deaths and still births in all areas of the states can be educated.

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

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

- Managing autopsies or other investigations into stillbirths;
- Counselling for autopsy and other medical investigations;
- Care of stillborn babies held in morgues; and
- Communicating with bereaved parents.

The College supports the participation of pathologists in discussions with bereaved parents and families regarding the autopsy process, by participating with the relevant care-giver at the time of seeking consent if requested.

With the current change in emphasis of the medical course in several states many doctors have never seen an autopsy and do not understand the process involved with an autopsy and are subsequently unaware of the benefits of an autopsy. They also find themselves unable to answer the questions asked by parents about an autopsy.

With appropriate staffing the provision of autopsy reports in appropriate lay language may be provided.

The College would support health authorities to factor working time and funding for perinatal pathologists to participate in these clinical services.

Problems have been identified since many pathology departments have decided not to have the mortuary within their departments and not been involved in running them. There have been some serious problems due to absence of appropriate protocols, policies, personnel in charge and knowledge of correct procedures and processes.

Recommendation 14: Public education kits that assist families and broader communities to support bereaved parents

The College is happy to co-operate with medical and community groups to assist as required e.g. in the development of fact sheets

Support for Bereavement counsellors in hospitals and the community to liaise with families and ensure support for the parents should be available.

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

This is not an area in which the college can contribute hugely apart from contributing to the causes of still birth and ensuring high quality autopsies are being performed by people with appropriate training and recent practice within an appropriate setting.

Recommendation 16: Development and implementation of a national stillbirth action plan

This will need to be multidiscipline with PSANZ and CRE very involved in the area and probably benefitting from the support of the college in implementing appropriate guidelines and practices.

References

Australian Institute of Health and Welfare. (2018). *Perinatal deaths in Australia: 2013–2014.Cat. no. PER 94*. Retrieved from Canberra:

Consultative Council on Obstetric and Paediatric Mortality and Morbidity. (2016). *2012 and 2013 Victoria's Mothers and Babies*. Retrieved from Melbourne:

Davies-Tuck, M. L., Davey, M. A., & Wallace, E. M. (2017). Maternal region of birth and stillbirth in Victoria, Australia 2000-2011: A retrospective cohort study of Victorian perinatal data. *PLOS ONE, 12*(6), e0178727. doi:10.1371/journal.pone.0178727

de Bernis, L., Kinney, M. V., Stones, W., ten Hoope-Bender, P., Vivio, D., & Leisher, S. H., for the Lancet Ending Preventable Stillbirths series study group. (2016). Stillbirths: Ending preventable deaths by 2030. *Lancet, 387*(10019), 703-716. doi:10.1016/s0140-6736(15)00954-x

Downe, S., Schmidt, E., Kingdon, C., & Heazell, A. E. P. (2013). Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. *BMJ Open, 3*(2), e002237. doi:10.1136/bmjopen-2012-002237

Flenady, V., Dane, A., Reinebrant, H., Weller, M., Andrews, C. J., Middleton, P., . . . Ellwood, D. (2018). *Development of a bundle of care to reduce stillbirths in Australia; a survey of Australian maternity hospitals.* Paper presented at the International Conference on Stillbirth, SIDS and Baby Survival, Glasgow.

Flenady, V., Middleton, P., Smith, G. C., Duke, W., Erwich, J. J., Khong, T. Y., . . . committee., L. s. S. S. s. (2011). Stillbirths: The way forward in high-income countries. *Lancet, 377*(9778), 1703-1717. doi:10.1016/S0140-6736(11)60064-0

Flenady, V., Oats, J., Gardener, G., Masson, V., L, M., Kent, A., . . . Khong Y for the PSANZ Care around the time of stillbirth and neonatal death guidelines group. (2018). *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*. Retrieved from Brisbane, Australia:

Flenady, V., Wojcieszek, A. M., Middleton, P., Ellwood, D., Erwich, J. J., Coory, M., . . . Group., L. S. I. H.-I. C. I. (2016). Stillbirths: Recall to action in high-income countries. *Lancet, 387*(10019), 691-702. doi:10.1016/s0140-6736(15)01020-x

Gardiner, P. A., Kent, A. L., Rodriguez, V., Wojcieszek, A. M., Ellwood, D., Gordon, A., . . . Flenady, V. (2016). Evaluation of an international educational programme for health care professionals on best practice in the management of a perinatal death: IMproving Perinatal mortality Review and Outcomes Via Education (IMPROVE). *BMC Pregnancy Childbirth, 16*(1), 376.

Healthcare Improvement Scotland. (2016). *Scottish Patient Safety Program Maternity and Children, End of phase report, August 2016*. Retrieved from Scotland: HIS:

Heazell, A. E. P., Siassakos, D., Blencowe, H., Burden, C., Bhutta, Z. A., Cacciatore, J., . . . group., L. E. P. S. i. (2016). Stillbirths: Economic and psychosocial consequences. *Lancet, 387*(10018), 604-616. doi:10.1016/S0140-6736(15)00836-3

Ibiebele, I., Coory, M., Boyle, F. M., Humphrey, M., Vlack, S., & Flenady, V. (2015). Stillbirth rates among Indigenous and non-Indigenous women in Queensland, Australia: Is the gap closing? *BJOG, 122*(11), 1476-1483. doi:10.1111/1471-0528.13047

Intergrowth21.tghn.org. (2018). Symphysis-Fundal Height- INTERGROWTH-21st. . Retrieved from https://intergrowth21.tghn.org/symphsis-fundal-height/#sfh1

International Stillbirth Alliance. (2019). Global scorecard to track progress towards milestones of Lancet Ending Preventable Stillbirth's Call to action. Retrieved from https://stillbirthalliance.org/about-us/isa-working-groups/stillbirth-advocacy-working-group/

Kanavos, P., Nicod, E., Van Den Aardweg, S., & Pomedli, S. (2010). The impact of health technology assessments: an international comparison. *Euro Observer, 12*(4), 1-7.

MBRRACE-UK. (2013). *Mothers and Babies: Reducing Risk through Audits and Confidential Enquires across the UK*. Retrieved from

Measey, M.-A., Charles, A., D'Espaignet, E. T., Harrison, C., DeKlerk, N., & Douglass, C. (2007). Aetiology of stillbirth: unexplored is not unexplained. *Australian and New Zealand Journal of Public Health, 31*(5), 444-449. doi:doi:10.1111/j.1753-6405.2007.00116.x

Perinatal and Maternal Mortality Review Committee. (2017). *Eleventh annual report of the Perinatal and Maternal Mortality Review Committee: Reporting mortality 2015*. Retrieved from Wellington, New Zealand:

Queensland Maternal and Perinatal Quality Council. (Feb 2018). *Queensland Mothers and Babies 2014 and 2015: Report of the Queensland Maternal and Perinatal Quality Council 2017*. Retrieved from

Richardus, J. H., Graafmans, W. C., Verloove-Vanhorick, S. P., & Mackenbach, J. P. (2003). Differences in perinatal mortality and suboptimal care between 10 European regions: results of an international audit. *BJOG, 110*(2), 97-105.

Sandall, J., Soltani, H., Gates, S., Shennan, A., & Devane, D. (2016). Midwife-led continuity models versus other models of care for childbearing women. *Cochrane Database of Systematic Reviews*(4). doi:10.1002/14651858.CD004667.pub5

Shorey, S., Andre, B., & Lopez, V. (2017). The experiences and needs of healthcare professionals facing perinatal death: A scoping review. *Int J Nurs Stud, 68*, 25-39. doi:10.1016/j.ijnurstu.2016.12.007

The Consultative Council on Obstetric and Paediatric Mortality and Morbidity. (Jun 2017). *Victoria's mothers, babies and children 2014 and 2015*. Retrieved from

Widdows, K., Reid, H. E., Roberts, S. A., Camacho, E. M., & Heazell, A. E. P. (2018). Saving babies' lives project impact and results evaluation (SPiRE): a mixed methodology study. *BMC Pregnancy Childbirth, 18*(1), 43. doi:10.1186/s12884-018-1672-x

World Health Organisation. (2016a). *Making every baby count: Audit and review of stillbirths and neonatal deaths*. Retrieved from Geneva, Switzerland:

World Health Organisation. (2016b). *The WHO application of ICD-10 to deaths duirng the perinatal period: ICD-PM*. Retrieved from Geneva, Switzerland:

Appendix: The ending preventable stillbirths scorecard

The Ending Preventable Stillbirths Scorecard:

Global, December 2018

Tracking progress against the Lancet's Ending preventable stillbirths series call to action (2016)

Suzanne Lee/Save the Children/India

Developed by the Stillbirth Advocacy Working Group, co-chaired by the International Stillbirth Alliance and the London School of Hygiene & Tropical Medicine, founded by the Partnership for Maternal, Newborn and Child Health.

For more details and references, please visit: https://bit.ly/2LdGUDH

Introduction to the Ending Preventable Stillbirths Scorecard: Global

Each year an estimated 2.6 million babies are stillborn. Progress to reduce this large burden has been slow. The 2016 Lancet Ending Preventable Stillbirths series sought to highlight missed opportunities and identify actions for accelerated progress to end preventable stillbirths. The series concluded with a Call to Action.

The Call to Action covers three distinct areas – (1) 2030 mortality targets, (2) universal health care coverage targets, and (3) global and national milestones for improving care and outcomes for all mothers and their babies (as specified by the Every Newborn Action Plan, or ENAP) and specifically for women and families affected by stillbirth.

The Global Scorecard has been produced by the Stillbirth Advocacy Working Group (SAWG) to track progress at a global level towards this Call to Action. The SAWG, founded by the Partnership for Maternal, Newborn and Child Health in 2016 and co-chaired by the International Stillbirth Alliance and the London School of Hygiene & Tropical Medicine, is a group of academics, researchers, parents and advocates from diverse organizations including UNICEF, FIGO, ICM, national and global non-governmental organizations, universities, and parent organizations. The SAWG's mission is to use advocacy for stillbirth prevention and post-stillbirth support.

Three years since the Call to Action was launched, how much progress has been made at a global level towards these targets and milestones? We hope that this global scorecard will be a useful resource for the global community, including UN bodies, bilateral organisations, parent organizations, donors and NGOs, in particular for highlighting areas where insufficient progress is being made and where further investments and actions are needed.

The 2016 Lancet Ending Preventable Stillbirth series Call to Action

Mortality targets by 2030 (included in the Every Newborn Action Plan)

- **National level**: 12 stillbirths or fewer per 1000 total births in every country
- **Subnational level**: All countries set and meet targets to close equity gaps and use data to track and prevent stillbirths

Universal health care coverage targets

- **Family planning**: By 2020, 120 million more women and girls with access to contraceptives; by 2030, universal access to sexual and reproductive health-care services and integration of reproductive health into national strategies and programmes
- **Antenatal care**: By 2030, universal quality of care and comprehensive antenatal care for all women
- **Care during labour and birth**: By 2030, effective and respectful intrapartum care to all women in all countries

THE LANCET

Ending preventable stillbirths

An Executive Summary for The Lancet's Series

Stillbirth Advocacy Working Group

Milestones

- **Respectful care**, including bereavement support after a death: By 2020, global consensus on a package of care after a death in pregnancy or childbirth for the affected family, community, and caregivers in all settings
- **Reduce stigma**: By 2020, all countries to identify mechanisms to reduce stigma associated with stillbirth among all stakeholders, particularly health workers and communities
- **Every Newborn global and national milestones** met by 2020, including the Measurement Improvement Roadmap (tracked separately by UNICEF/ WHO) **Every Newborn Progress Report 2018**

Selection of indicators to track the Call to Action

Indicators were chosen by a subgroup of the SAWG to reflect the three areas of the Call to Action. Where possible, indicators already collated by UN and other organisations were used. In particular, the annual tracking tool used by UNICEF and WHO to monitor progress towards the Every Newborn Action Plan (ENAP) provides many indicators to track progress for maternal and newborn health, including stillbirths. Indicators were chosen in order to capture not only the ultimate outcomes of a component of the Call, but also the processes and policies required to achieve them.

The draft list of proposed indicators and draft scorecard were circulated in several rounds to the wider SAWG as well as targeted organisations including UNICEF, WHO, and the White Ribbon Alliance for comments and further suggestions, prior to finalising.

Indicators were scored according to benchmarks – from red (below expectation or no data), through to dark green (fully achieved). A full description of the indicators and scoring criteria is given in Annex 1. Overall global results are shown where available. In addition, results are shown for 74 high burden countries participating in the ENAP tracking tool (see Annex 2 for list). The simplified scorecard is shown below, with the detailed version in Annex 3.

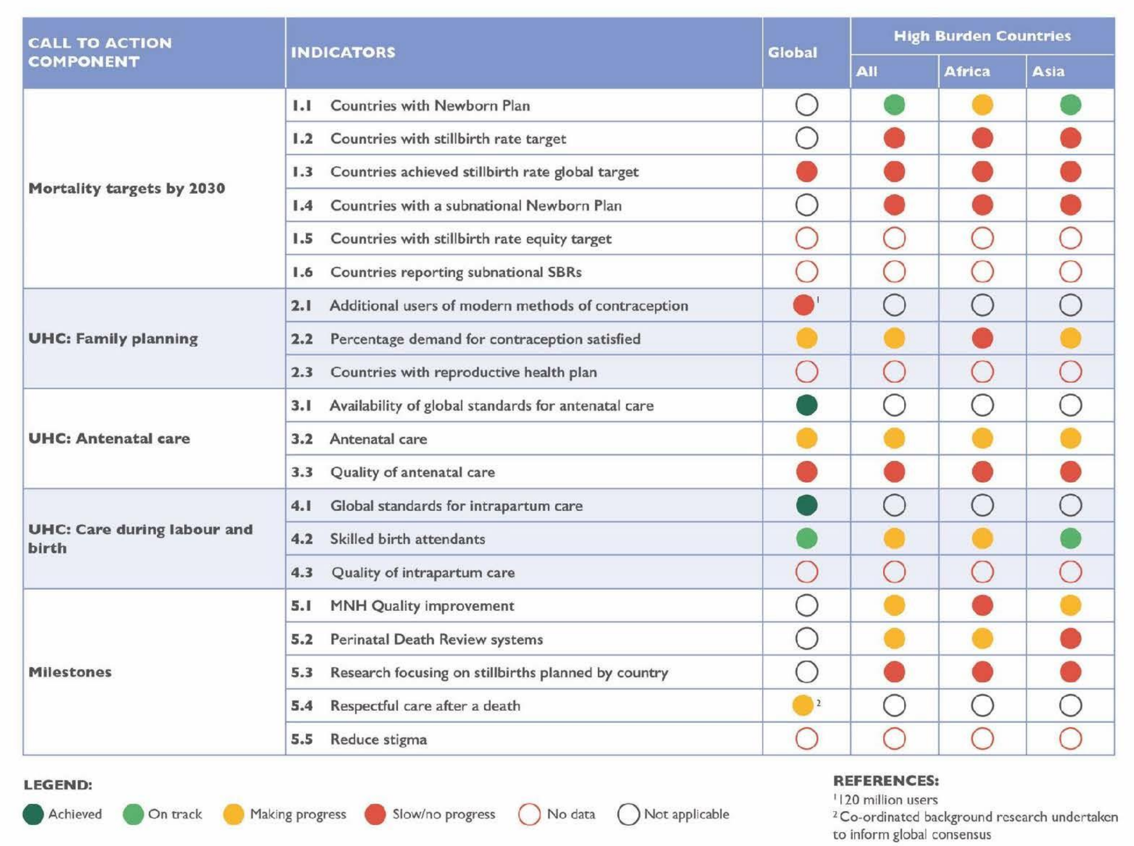
Main Findings

The 2018 scorecard shows that whilst some progress is being made towards the targets and milestones from the Ending Preventable Stillbirths Call to Action, further effort is needed. Information is currently lacking to track equity and quality of care indicators, although work is currently under way by WHO and UNICEF to close this information gap. No data are currently available to track country progress towards taking steps to reduce stigma, and more work is needed in this area.

There is evidence of some progress being made at a policy level towards these targets as well; for example, WHO has recently released recommendations on antenatal care for a positive pregnancy experience and intrapartum care for a positive childbirth experience, and the Every Newborn Action Plan has encouraged the setting of newborn plans at a country level in high burden settings. However, there is still scope to improve attention and action for stillbirths prevention and post-stillbirth care within these initiatives and beyond, especially in the area of respectful supportive care after a death and actions to reduce stigma associated with stillbirth.

Ending Preventable Stillbirths Scorecard: Global. December 2018

Figure: The Ending Preventable Stillbirths Scorecard: Global (Summary Version)



CALL TO ACTION COMPONENT		INDICATORS	Global	High Burden Countries		
				All	Africa	Asia
Mortality targets by 2030	1.1	Countries with Newborn Plan	○	🟢	🟡	🟢
	1.2	Countries with stillbirth rate target	○	🔴	🔴	🔴
	1.3	Countries achieved stillbirth rate global target	🔴	🔴	🔴	🔴
	1.4	Countries with a subnational Newborn Plan	○	🔴	🔴	🔴
	1.5	Countries with stillbirth rate equity target	⭕	⭕	⭕	⭕
	1.6	Countries reporting subnational SBRs	⭕	⭕	⭕	⭕
UHC: Family planning	2.1	Additional users of modern methods of contraception	🔴[1]	○	○	○
	2.2	Percentage demand for contraception satisfied	🟡	🟡	🔴	🟡
	2.3	Countries with reproductive health plan	⭕	⭕	⭕	⭕
UHC: Antenatal care	3.1	Availability of global standards for antenatal care	●	○	○	○
	3.2	Antenatal care	🟡	🟡	🟡	🟡
	3.3	Quality of antenatal care	🔴	🔴	🔴	🔴
UHC: Care during labour and birth	4.1	Global standards for intrapartum care	●	○	○	○
	4.2	Skilled birth attendants	🟢	🟡	🟡	🟢
	4.3	Quality of intrapartum care	⭕	⭕	⭕	⭕
Milestones	5.1	MNH Quality improvement	○	🟡	🔴	🟡
	5.2	Perinatal Death Review systems	○	🟡	🟡	🔴
	5.3	Research focusing on stillbirths planned by country	○	🔴	🔴	🔴
	5.4	Respectful care after a death	🟡[2]	○	○	○
	5.5	Reduce stigma	⭕	⭕	⭕	⭕

LEGEND:

● Achieved 🟢 On track 🟡 Making progress 🔴 Slow/no progress ⭕ No data ○ Not applicable

REFERENCES:

[1] 120 million users

[2] Co-ordinated background research undertaken to inform global consensus

*See Annex 2 for full list of countries

Ending Preventable Stillbirths Scorecard: Global. December 2018

Annex 1: Description of indicator thresholds using colour codes

Indicator	**Indicator Definition**	**Data Source**	🟩	🟩	🟨	🟧
Mortality targets						
1.1 Countries with Newborn Plan	Percentage of high burden countries with ENAP plan or sharpened maternal-newborn component within the RMNCAH plan	ENAP tracking tool undertaken in 74 high burden countries annually by UNICEF	100%	≥75%-<100%	≥50 - <75%	0 - <50% or no data
1.2 Countries with stillbirth rate target	Percentage of high burden countries with target for stillbirth rate within ENAP or RMNCAH plan	ENAP tracking tool undertaken in 74 high burden countries annually by UNICEF	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
1.3 Countries achieved stillbirth rate global target	Percentage of all countries reached SBR target of 12 or fewer per 1000 total births	WHO global health observatory (for year 2015) UNIGME from 2018 onwards (next estimates expected 2020)	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
1.4 Countries with a sub-national Newborn Plan	Percentage of high burden countries with a sub-national ENAP plan or sharpened maternal-newborn component within the RMNCAH plan[1]	ENAP tracking tool undertaken in 74 high burden countries annually by UNICEF	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
1.5 Countries with stillbirth rate equity target	Percentage of all countries with a stillbirth equity target	Equity targets not being routinely tracked. Case studies may be available for high-income countries (eg Australia, possibly Ireland).	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
1.6 Countries reporting subnational SBRs	Percentage of all countries reporting subnational SBRs	UNIGME will commence to collect this data from administrative data sources as part of ongoing stillbirth estimates work. No current plan for modelling subnational stillbirth rates in UNIGME	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
UHC Family planning						
2.1 Additional users of modern methods of contraception	The number of additional women (or their partners) of reproductive age currently using a modern contraceptive method compared to 2012	http://www.track20.org/ Estimated using data from surveys such as the DHS, RHS, MICS, PMA2020 and other nationally representative surveys, service statistics and population data. Updated annually	120 million additional users	≥90 million -<120 million additional users	≥60 million - <90 million additional users	<60 million additional users
2.2 Percentage demand for contraception satisfied	The percentage of women (or their partners) who desire either to have no additional children or to postpone the next child and who are currently using a modern contraceptive method. Women using a traditional method are assumed to have an unmet need for modern contraception.	http://www.track20.org/ Estimated using data from surveys such as the DHS, MICS, PMA2020, RHS and other nationally representative surveys; modelling using surveys and service statistics	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
2.3 Countries with reproductive health plan	Percentage of high burden countries with a reproductive health plan or sharpened reproductive component within the RMNCAH plan?	No data	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
UHC: Antenatal care						

Indicator	**Indicator Definition**	**Data Source**	🟩	🟩	🟨	🟧
3.1 Global standards for antenatal care	Availability of global standards for antenatal care	WHO clinical guidance updated for 'Pregnancy, childbirth, postpartum and newborn care' (2015). 'WHO Antenatal care for a positive pregnancy experience' (2016). 'Managing complications in pregnancy and childbirth' (2017).	Fully Achieved	NA	NA	NA
3.2 Antenatal Care	Percentage of women who receive at least 4 antenatal care visits	Joint tracking by WHO/ UNICEF based on population based national household survey data and routine health systems	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
3.3 Quality of antenatal care	No validated indicator currently available for effective coverage of ANC, but methodological work ongoing at WHO.	TBC	TBC	TBC	TBC	TBC
UHC: Care during labor & birth						
4.1 Global standards for intrapartum care	Availability of global standards for intrapartum care	WHO clinical guidance updated for 'Pregnancy, childbirth, postpartum and newborn care' (2015). 'Managing complications in pregnancy and childbirth' (2017).'Intrapartum care for a positive childbirth experience' (2018)	Fully Achieved	NA	NA	NA
4.2 Skilled birth attendants	Proportion of births attended by skilled health personnel (SDG 3.1.2)	Joint tracking by WHO/ UNICEF based on population based national household survey data and routine health systems	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
4.3 Quality of intrapartum care	No validated indicator currently available for effective coverage of intrapartum care, but methodological work ongoing at WHO.	TBC	TBC	TBC	TBC	TBC
Milestones						
5.1 MNH Quality improvement	Percentage of high burden countries reporting a national Quality Improvement plan with a specific focus on maternal and newborn health	ENAP tracking tool undertaken in 74 high burden countries annually by UNICEF	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
5.2 Perinatal Death Review systems	Percentage of high burden countries reporting a perinatal death review system in place, either stand-alone or as part of maternal death review and response programmes	ENAP tracking tool undertaken in 74 high burden countries annually by UNICEF	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
5.3 National Stillbirth Research	Percentage of high burden countries reporting research focusing on stillbirths underway or planned in their country	ENAP tracking tool undertaken in 74 high burden countries annually by UNICEF	100%	≥75%-<100%	≥50 - <75%	0- <50% or no data
5.4 Respectful care after a death	Global consensus on a package of care after a death in pregnancy or childbirth for the affected family, community, and caregivers in all settings agreed by global stillbirth community including WHO	International Stillbirth Alliance is leading a multi-partner initiative to develop consensus on a global package *to include a wide range of stakeholders from all geographical regions, including parents and front-line health workers	Global consensus reached and included in WHO guidance	Inclusive & transparent process underway *	Co-ordinated background research undertaken to inform global consensus	Limited or no co-ordinated global focused work begun

Ending Preventable Stillbirths Scorecard: Global. December 2018

Indicator	Indicator Definition	Data Source	🟩	🟩	🟨	🟥
5.5 Reduce stigma	Number of countries instituting a process to identify mechanism to reduce stigma associated with stillbirth among all stakeholders, particularly health workers and communities	TBC	TBC	TBC	TBC	TBC

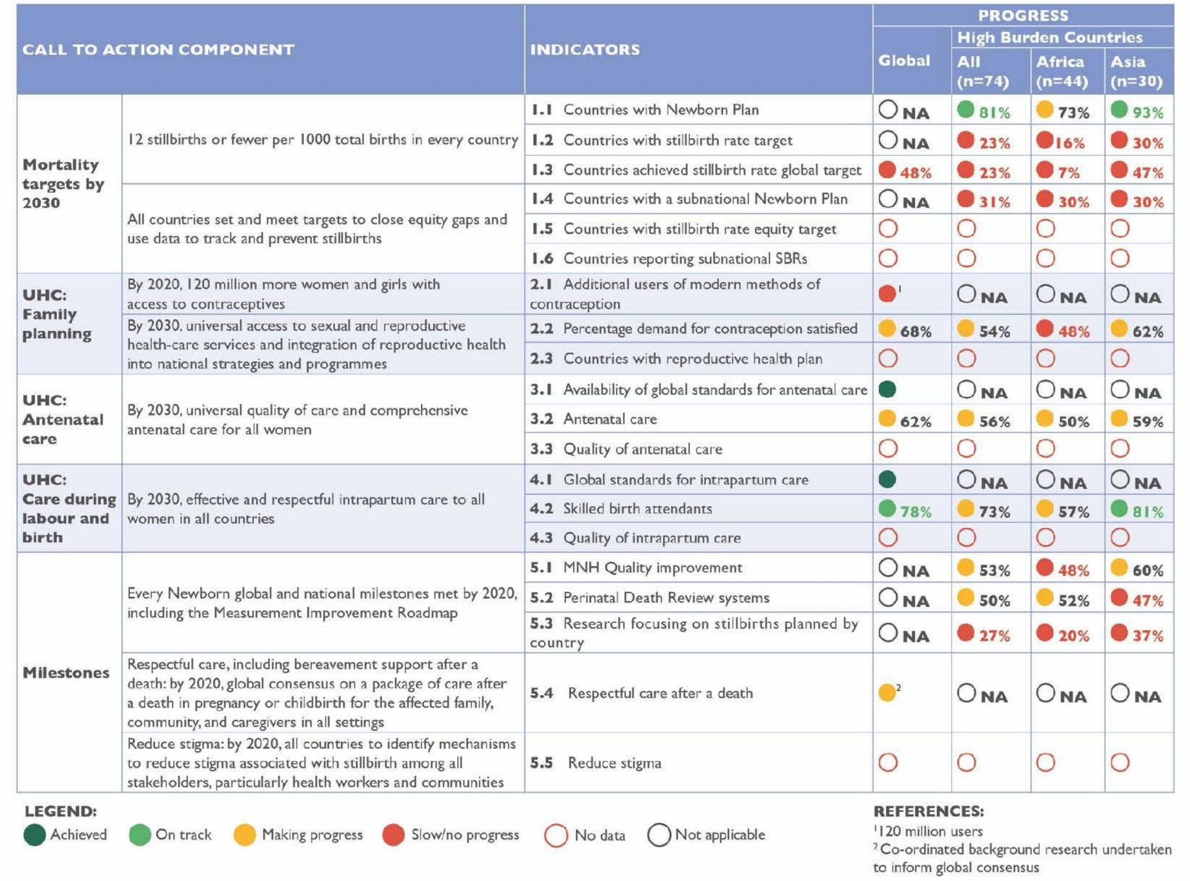
Annex 2: List of 74 high burden countries participating in ENAP tracking tool

Afghanistan	DR Congo	Kazakhstan	Namibia	Swaziland
Angola	Djibouti	Kenya	Nepal	Syrian Arab Republic
Armenia	Egypt	Kyrgyzstan	Niger	Tajikistan
Azerbaijan	Eritrea	Lebanon	Nigeria	Timor-Leste
Bangladesh	Ethiopia	Lesotho	Pakistan	Togo
Benin	Gambia	Liberia	Papua New Guinea	Tunisia
Bhutan	Georgia	Libyan Arab Jamahiriya	Philippines	Turkmenistan
Botswana	Ghana	Madagascar	Rwanda	Uganda
Burkina Faso	Guinea	Malawi	Senegal	Tanzania
Burundi	Guinea-Bissau	Maldives	Sierra Leone	Uzbekistan
Cameroon	India	Mali	Somalia	Viet Nam
Chad	Indonesia	Mauritania	South Sudan	Yemen
China	Iran (Islamic Republic of)	Morocco	Sri Lanka	Zambia
Comoros	Iraq	Mozambique	State of Palestine	Zimbabwe
Côte d'Ivoire	Jordan	Myanmar	Sudan	

Annex 3: Detailed Scorecard Acronyms and definitions

ANC – Antenatal Care
CRVS – Civil Registration and Vital Statistics
DHS – Demographic and Health Surveys
ENAP - Every Newborn Action Plan
MICS – Multiple Indicator Cluster Surveys
MNH - Maternal and Newborn Health
QI - Quality Improvement
RMNCAH – Reproductive Maternal Newborn Child and Adolescent Health
SAWG - Stillbirth Advocacy Working Group
SBR – Stillbirth Rate
UHC – Universal Healthcare
UNICEF – United Nations Children's Fund
UNIGME – United Nations Inter-agency Group for Child Mortality Estimation
WHO – World Health Organization

Annex 4: The Ending Preventable Stillbirths Scorecard: Global (detailed version)



CALL TO ACTION COMPONENT		INDICATORS	PROGRESS			
				High Burden Countries		
			Global	All (n=74)	Africa (n=44)	Asia (n=30)
Mortality targets by 2030	12 stillbirths or fewer per 1000 total births in every country	**1.1** Countries with Newborn Plan	○ NA	🟢 81%	🟡 73%	🟢 93%
		1.2 Countries with stillbirth rate target	○ NA	🔴 23%	🔴 16%	🔴 30%
		1.3 Countries achieved stillbirth rate global target	🔴 48%	🔴 23%	🔴 7%	🔴 47%
	All countries set and meet targets to close equity gaps and use data to track and prevent stillbirths	**1.4** Countries with a subnational Newborn Plan	○ NA	🔴 31%	🔴 30%	🔴 30%
		1.5 Countries with stillbirth rate equity target	⭕	⭕	⭕	⭕
		1.6 Countries reporting subnational SBRs	⭕	⭕	⭕	⭕
UHC: Family planning	By 2020, 120 million more women and girls with access to contraceptives	**2.1** Additional users of modern methods of contraception	🔴[1]	○ NA	○ NA	○ NA
	By 2030, universal access to sexual and reproductive health-care services and integration of reproductive health into national strategies and programmes	**2.2** Percentage demand for contraception satisfied	🟡 68%	🟡 54%	🔴 48%	🟡 62%
		2.3 Countries with reproductive health plan	⭕	⭕	⭕	⭕
UHC: Antenatal care	By 2030, universal quality of care and comprehensive antenatal care for all women	**3.1** Availability of global standards for antenatal care	●	○ NA	○ NA	○ NA
		3.2 Antenatal care	🟡 62%	🟡 56%	🟡 50%	🟡 59%
		3.3 Quality of antenatal care	⭕	⭕	⭕	⭕
UHC: Care during labour and birth	By 2030, effective and respectful intrapartum care to all women in all countries	**4.1** Global standards for intrapartum care	●	○ NA	○ NA	○ NA
		4.2 Skilled birth attendants	🟢 78%	🟡 73%	🟡 57%	🟢 81%
		4.3 Quality of intrapartum care	⭕	⭕	⭕	⭕
Milestones	Every Newborn global and national milestones met by 2020, including the Measurement Improvement Roadmap	**5.1** MNH Quality improvement	○ NA	🟡 53%	🔴 48%	🟡 60%
		5.2 Perinatal Death Review systems	○ NA	🟡 50%	🟡 52%	🔴 47%
		5.3 Research focusing on stillbirths planned by country	○ NA	🔴 27%	🔴 20%	🔴 37%
	Respectful care, including bereavement support after a death: by 2020, global consensus on a package of care after a death in pregnancy or childbirth for the affected family, community, and caregivers in all settings	**5.4** Respectful care after a death	🟡[2]	○ NA	○ NA	○ NA
	Reduce stigma: by 2020, all countries to identify mechanisms to reduce stigma associated with stillbirth among all stakeholders, particularly health workers and communities	**5.5** Reduce stigma	⭕	⭕	⭕	⭕

LEGEND:
● Achieved 🟢 On track 🟡 Making progress 🔴 Slow/no progress ⭕ No data ○ Not applicable

REFERENCES:

[1] 120 million users

[2] Co-ordinated background research undertaken to inform global consensus

Ending Preventable Stillbirths Scorecard: Global. December 2018