Centre of Research Excellence in Stillbirth

2016 – 2021

Final Report

Funded by the National Health and Medical Research Council

mater research

The University Of Queensland
AUSTRALIA

CREATE CHANGE

Centre of Research Excellence in Stillbirth

Final Report

Acknowledgements

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Stillbirth
CENTRE OF RESEARCH EXCELLENCE

Why we do what we do...

Amelia

Sophie

Max

Zara

'Sophie's Story'

by Heidi and Ned Mules

Heidi and Ned Mules with baby daughter Sophie (2011)

We met in Brisbane in 2006 and soon followed a dream to move to London where, after a few years of work and travel, we eventually had our first child Amelie in 2010. In 2011, Heidi fell pregnant again and we decided to move home to have our second baby in Brisbane and set ourselves up to raise our family here in Australia.

Heidi had regular visits to our obstetrician and was considered a low-risk pregnancy. Our baby hadn't arrived by the due date of the 1st of December. We decided not to force the matter so we waited another week to allow baby to arrive naturally, after which time we would induce the birth if needed.

Our baby Sophie was born on the 7th of December 2011. She never opened her eyes and she didn't make a sound. Sophie was stillborn.

Sophie was perfectly healthy as far as we know, but she died due to an abruption of the placenta, which cut off her life support system while she was in the womb. Everything seemed to be normal when Heidi went into labour but we only found out when we were at the hospital that Sophie had died earlier in the day.

No words can describe the feeling of dread and shock that come with being told your baby does not have a heartbeat. The next thing that comes is disbelief that this is even possible. How could our baby, who we had seen healthy and normal on the ultrasound the day before, suddenly pass away? We knew that it was possible for a baby to be stillborn, but of course we didn't think it could happen to us because we didn't personally know anyone who had lost a baby, it was never mentioned as a possibility by our doctors and there is generally very little public awareness of stillbirth. In hindsight, you might think that would mean that we were incredibly unlucky to have lost our baby to a very rare event, but it turns out that stillbirth is very common in Australia and its rate of incidence has hardly decreased in the last 30 years.

In the aftermath of Sophie's death we were very lucky to have the support of our family and friends. They were all as shocked as we were to learn how common stillbirth is in Australia and how little is known about its causes and indicators. So, to give our friends and family a way to show their support and make a difference, we decided to raise some money for research by doing a 10km run as part of the Gold Coast Marathon.

Our friends, family and some generous strangers donated over $7000 in total, which we decided to pass on to ANZSA (The Australian and New Zealand Stillbirth Alliance of the Perinatal Society of Australia and New Zealand, which was the forerunner to the Stillbirth CRE). This money was used to help pay for a priority setting workshop, where social workers, clinicians and researchers gathered to decide the most important areas to focus on to reduce the frequency of stillbirth and its impact on the community. We were invited to attend and add our perspective as parents who have lost a child.

On the back of this set of priorities, Vicki, Fran, and their hard-working teams eventually won a grant to establish the CRE.

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Introduction

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) was established in 2016 based on a strong collaborative group developed over 20 years as part of the Perinatal Society of Australia and New Zealand (PSANZ). A close partnership between these groups continues.

Stillbirth has long been a neglected public health problem; this was brought to light on the global public health stage through the 2011 and 2016 Lancet series. These landmark series showed that 7000 women have a stillbirth every day. Most critically, the data also showed that contrary to common beliefs, most stillbirths globally are preventable by improving care including strategies to improve the health of women before pregnancy, known effective care during pregnancy and childbirth. The Lancet's 2016 series showed Australia's stillbirth rate after 28 weeks was 2.7 per 1000 births, ranking us 15th across all high-income countries (HICs) and almost double that of the best performing country. If we were to reduce the stillbirth rate to that of the country with the lowest rate, over 200 stillbirths could be avoided in Australia each year. Our annual rate reduction of 1.4 was also subpar relative to that of many other HICs. Urgent action was needed.

Advocacy and research groups, such as the Australia and New Zealand Stillbirth Alliance, the Stillbirth Foundation Australia and Red Nose had been working hard to bring attention to the hidden tragedy of stillbirth in Australia, particularly with a message for action to address static stillbirth rates over the previous two decades.

The Stillbirth CRE was established in 2017 by the National Health and Medical Research Council (NHMRC) in response to the call to action presented in the Lancet series and specific priorities we developed for Australia. Ten Chief and ten Associate Investigators from twelve institutions along with their partners aspired to address the tragedy of stillbirth in Australia through this priority driven program.

The vision of the Stillbirth CRE was to reduce the devastating impact of stillbirth for women, families, and the wider community through undertaking high-quality research that translates into improved maternity care to reduce the number of stillborn babies and to reduce the impact of this loss.

The program had five pillars of action: Implementing prevention strategies; Developing new approaches for stillbirth prevention; Implementing best practice in care after stillbirth; Implementing high quality national perinatal mortality audit. A major theme which ran across all programs was that of Equity and Diversity. Across these five areas, we have brought together parents, parent advocates, researchers, healthcare professionals, professional colleges, and policy makers to collectively address the vision of the Stillbirth CRE.

Over the five years, the Stillbirth CRE strengthened international collaborations through the International Stillbirth Alliance [ISA], with Professor Flenady as past Chair and current Board member. The Stillbirth CRE became the Western Pacific regional office of the ISA, promoting and facilitating partnerships to ensure our work in Australia contributed to the global call to action for stillbirths and newborn health.

To support our vision, the team sourced an additional $24.5 million in funding from organisations including the NHRMC, Departments of Health and other agencies.

Developing future leaders in stillbirth research was a major goal for the CRE. The CRE recruited four postdoctoral researchers, supported 33 Higher Degree Research students, and funded 14 PhD students with top-up scholarships.

The Stillbirth CRE is proud to have contributed to the 2020 National Stillbirth Action and Implementation Plan for Australia and internationally to the UN Inter-Agency Group for Child Mortality Estimation: Ending preventable stillbirths report, and to have delivered authoritative programs across the country such as the Safer Baby Bundle to improve antenatal care to reduce stillbirth and Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) to support the care of women and families who have suffered a stillbirth or neonatal death.

In addition to journal publications, the Stillbirth CRE disseminated knowledge about its work through its website, social media, public forums, and scientific meetings.

This report offers a snapshot of activities conducted within each of the CRE's priority areas including key outputs generated during the five years of funding (2016 – 2021). Through continued collaboration and an additional five years of NHMRC funding (2022 – 2026), the Stillbirth CRE will build on its achievements to address major actions within the Australian Federal Government's National Stillbirth Action and Implementation Plan.

Professors Vicki Flenady and David Ellwood, Co-Directors

NHMRC Centre of Research Excellence in Stillbirth

The Team - Chief Investigators

Professor Vicki Flenady

Professor Flenady is the lead investigator and Director of the CRE, and Co-lead for Care After Stillbirth, Risk Factors, and Implementation. She has a clinical background in midwifery and neonatal nursing and a masters and PhD in perinatal epidemiology in stillbirth prevention. Vicki was the lead author on The Lancet's stillbirth series in 2011 and 2016. Her current research focuses on stillbirth prevention through better understanding of causal pathways and risk factors.

Professor Philippa Middleton

Associate Professor Middleton is CRE Co-lead for Implementation and Risk Factors and is a Principal Research Fellow in the Health Mothers, Babies and Children theme of the South Australian Health and Medical Research Institute. She is an Affiliate Associate Professor, School of Medicine, University of Adelaide. Philippa is a perinatal epidemiologist and implementation scientist with expertise in preterm birth and stillbirth and a special interest in indigenous health.

Professor Sailesh Kumar

Professor Kumar is a Maternal and Fetal Medicine sub-specialist at the Mater Mothers' Hospital in Brisbane and Health of the Academic Discipline of Obstetrics & Gynaecology at the University of Queensland. Sailesh is the Stillbirth CRE's Co-lead for Prediction and Placenta.

Professor Euan Wallace

Professor Wallace is the Stillbirth CRE Co-lead for Research Career Development and Prediction and Placenta. He is the current CEO of Safer Care Victoria and Carl Wood Professor, Obstetrics & Gynaecology at Monash Health, previously Director of Obstetric Services at Monash Health. Euan is Secretary of the Victorian Department of Health.

Professor Adrienne Gordon

Professor Gordon is a specialist Neonatologist in the RPA centre for newborn care and is a Clinical Professor in the Discipline of Obstetrics, Gynaecology and Neonatology at the University of Sydney. Adrienne currently leads the CRE's Public Awareness work and is a key member of the Safer Baby Bundle initiative. Adrienne is the Stillbirth CRE's Co-lead for Risk Factors.

Professor David Ellwood

Professor Ellwood is Co-Director of the Stillbirth CRE and Co-lead for Care After Stillbirth and is Director of Maternal-Fetal Medicine at Gold Coast Health. He was previously Deputy Dean at the Australian National University Medical School. David is currently Dean of Medicine and Head of the Griffith University School of Medicine and Dentistry, a past-Chair of the Queensland Maternal & Perinatal Quality Council and is the immediate past-President of the Australian Medical Council.

Professor Chris East

Professor East is a nurse and midwife, Professor of Nursing and Midwifery at La Trobe University/Mercy Health and previously Professor of Midwifery at Monash University and Monash Health. Her research focuses on areas around stillbirth prevention including fetal movements during pregnancy, induction of labour and fetal monitoring during. Chris is CRE Co-lead for Clinical Education and Research Career Development.

Associate Professor Fran Boyle

Associate Professor Boyle Co-leads the Stillbirth CRE's Care After Stillbirth - Bereavement research program. Fran is a health services researcher at the University of Queensland's Institute for Social Science Research. She has a background in psychology and public health and with her own lived experience focused her research on ensuring best possible care following stillbirth and neonatal death.

Professor Jonathan Morris

Professor Morris is the CRE's Co-lead for Clinician Education and Research Career Development. He is Professor of Obstetrics and Gynaecology and a Maternal Fetal Medicine Specialist. He is currently Director of the Kolling Institute based at Royal North Shore Hospital where he also leads the Perinatal Research Division.

Dr Dell Horey

Dr Horey is an Associate Professor in Epidemiology with La Trobe University. Her areas of expertise are in stillbirth, health decision support, cultural competence education. She is CRE Co-lead for Care After Stillbirth – Decision Support

Associate Investigators

Dr Glenn Gardener	Mater Mothers' Hospital / University of Queensland
Professor Vicki Clifton	The Mater Research Institute
Dr Emily Callander	Monash University
Professor Susan McDonald	La Trobe University / Mercy Health
Dr Aleena Wojcieszek	The University of Queensland / Mater Research Institute
Ms Trish Wilson	Mater Mothers' Hospital
Dr Susan Vlack	The University of Queensland
Professor Alison Kent	Centenary Hospital for Women
Professor Jeremy Oats	University of Melbourne
Professor Yee Khong	University of Adelaide

Post-doctoral Researchers

The CRE funded postdoctoral positions that were occupied during the duration of the CRE by the following researchers:

Dr Hanna Reinebrant [Investigating Causes of Stillbirth]

Dr Hanna Reinebrant obtained her PhD from the University of Queensland in 2013 and went on to become the first post-doctoral researcher with the Stillbirth CRE, undertaking work on improving classification of causes of stillbirth and risk factors of stillbirth from 2016-2017. Hanna worked extensively to map classification systems and causes of stillbirth globally.

Dr Miranda Davies-Tuck [team lead – Research Capacity Building and researchers in epidemiology of stillbirth]

Dr Miranda Davies-Tuck obtained her PhD from the School of Public Health and Preventive Medicine, Monash University in 2010 where she worked on a number of large prospective cohort studies developing epidemiological and bio-statistical expertise. She was awarded a Centre for Research Excellence in Stillbirth postdoctoral fellowship in 2019 to roll-out, evaluate and expand guidelines the provide clinicians with new parameters for fetal surveillance in late pregnancy. The project aims to reduce the disproportionately high rate of stillbirth encountered by South Asian mothers due to biological placental differences. This work resulted in changes to clinical care that have lowered the rates of stillbirth in women of South Asian background at Monash Health.

Dr Christine Andrews [team lead – Implementing Prevention Strategies]

Having completed her PhD through the University of Queensland with the Centre for Children's Burns and Trauma Research, Christine joined the Stillbirth CRE as a senior research assistant in 2018. Christine now works as a postdoctoral researcher leading the Safer Baby Bundle projects with a specific interest in the translation and implementation of quality research into evidence-based best clinical practice. Christine currently leads the CRE's Implementing Prevention Strategies stream.

Dr Siobhan Loughnan [team lead – Implementing Best Practice Care After Stillbirth]

Siobhan has a PhD through UNSW Clinical Research Unit for Anxiety and Depression (CRUfAD) and a background in eMental Health, perinatal psychology and cancer care. She joined the CRE in 2019 as a postdoctoral researcher to pursue her interest in development of tailored online psychosocial programs for parents experiencing perinatal loss, working across projects to help optimise and implement best practice bereavement care around the time of stillbirth and neonatal death, and in subsequent pregnancies. Siobhan currently leads the CRE's Implementing Best Practice Care After Stillbirth stream.

Dr Harriet Lawford [team lead – Equity and Diversity]

Since graduating from a Master's degree in Control of Infectious Diseases from The London School of Health and Tropical Medicine, Harriet has lived across Africa and South-East Asia working on projects related to the epidemiology and control of malaria. Her PhD was completed with Mater Research Institute during which time Harriet developed a keen interest in maternal and fetal global health and joined the CRE in February 2021 as a postdoctoral researcher. She has worked on analysis of the My Baby's Movements Multi Centre Clinical Trial and currently leads the CRE's Equity and Diversity stream.

Working with Parents and Families

The CRE has committed to ensuring that the voices of parents who have experienced the tragedy of stillbirth are heard. Our parent-support partners have been instrumental in not only publicising the work of the CRE but also opportunities for parents to actively participate in the research we do.

The Stillbirth Foundation Australia was established in 2005 to raise funds to reduce the incidence and impact of stillbirth through research, education and advocacy and is an integral partner of the Stillbirth CRE. Our organisations recognised the mutual benefit and increased impact to achieving aligned goals, and in 2018 the Foundation and the CRE formalised our strong partnership, confirming our shared aim to reduce stillbirths by 20%. Since that time, we have worked together to promote and jointly support organisations and institutions undertaking research into the cause, prevention, and management of stillbirth and neonatal death, awarding $783,450 in grants over the 5 years of CRE funding. We continue to work together towards these common aims and have built a fruitful and lasting partnership that supports our engagement with parents and families of stillborn babies.

The Stillbirth CRE engages with parents and families through our advocacy and support partners:

Stillbirth Foundation Australia · red nose · sands miscarriage, stillbirth & newborn death support · raisingchildren.net.au · Remembering Riley · bears of hope Pregnancy & Infant Loss Support · The Perinatal Loss Centre

Project Engage – C Andrews, Stillbirth CRE

This project was developed by Dr Andrews to specifically look at ways at improving the communication between bereaved parents and researchers partnering together in stillbirth research. Effective communication and engagement results in high quality research that is more relevant and informed by the lived experience of perinatal loss.

Engaging bereaved parents in stillbirth research in a meaningful way is essential to drive improvements in care and outcomes. Bereaved parents offer unique and valuable insights as research is prioritised, conducted, and translated, helping to ensure research quality and relevance. To engage more effectively with bereaved parents in stillbirth research activities, providing appropriate support to enable their contribution is critically important. Many bereaved parents would like to engage in research but experience barriers to their involvement including a lack of shared understanding of how to best go about this by both parents and researchers. The aim of this project is to build research understanding and capacity of bereaved parents by producing a practical 'guide' to support their involvement across a broad range of research activities. The expected outcome of this project is to narrow the gap between researchers/clinicians and bereaved parents in relation to co-design of research and research translation.

Engaging Government

The Stillbirth CRE has been fortunate to have the strong advocacy of Senator Kristina Keneally who, with lived experience of a stillbirth, used her 2018 maiden speech to Parliament to highlight the urgent need to improve stillbirth rates in Australia. In the same year the Senate established the Senate Select Committee on Stillbirth Research and Education, whose report later informed the National Stillbirth Action and Implementation Plan.

Senator Keneally continues to support the parents and families of stillborn babies and in 2021 introduced the Fair Work Amendment Bill – Improving Paid Parental Leave for Parents of Stillborn Babies. We are delighted to have Senator Keneally's continuing support of the Stillbirth CRE and the vital research we do.

The Stillbirth CRE is grateful for the commitment of the Hon Greg Hunt MP as Minister for Health in accepting the recommendations of the National Stillbirth Action and Implementation Plan that has contributed to the awareness of stillbirth and facilitated our continued research.

We also acknowledge the continued support of jurisdictional health departments in the implementation of the Safer Baby Bundle and their continued engagement with the CRE to support the delivery of clinical education around stillbirth and neonatal death, autopsy and investigations.

Building Collaborations

As part of the CRE's commitment to reducing stillbirths and improving outcomes for families, we have strived to expand partnerships to effectively achieve shared goals.

The CRE developed *Shared Understanding for Collaboration* guidelines that commit us and our partners to values of;

- Woman and family centred; the health and wellbeing of families is kept at the centre of all we do through listening to and engaging with parents from the beginning of all projects within the CRE program
- Sharing and learning; recognising the role of innovation and learning from experience, we believe sharing of information and understanding should be automatic.
- Fairness and equality; everyone has something to give and should be given a fair chance to reach their potential. The most excluded should be supported to contribute in a meaningful way.
- Building trust; people succeed where they work together for a common good. Trusting one another to act with integrity and commitment demands compassion, honesty, transparency and respect.

The CRE proudly partners with:

Stillbirth CRE Advisory Groups

Indigenous Advisory Group

The Stillbirth CRE Indigenous Advisory Group emerged from the Aboriginal and Torres Strait Islander Reference Group that was established in 2014. With the forming of the Stillbirth CRE, this group became the Indigenous Advisory Group, chaired by Arabana woman and Stillbirth CRE Indigenous Research Officer, Deanna Stuart-Butler.
The IAG supports and guides the Stillbirth CRE's program of work to ensure the voice of Indigenous Australians informs all aspects of the Stillbirth CRE's program of work and development of culturally safe resources.

Stillbirth Centre of Research Excellence
Indigenous Advisory Group

The Stillbirth CRE Indigenous Advisory Group has 26 members from across Australia:

Deanna Stuart-Butler	Arabana woman
Cassandra Nest	Ngunnawal woman
Melanie Briggs	Gumbangirr & Dharawal woman
Valerie Ah Chee	Bindajareb woman
Cherisse Buzzacott	Arrernte woman
Cath Chamberlain	Palawa woman
Marni Tuala	Bundjalung woman
Skye Stewart	Wergaia & Wemba Wemba woman
Lauren Sculthorpe	Palawa woman
Yvette Roe	Njikena Jawuru woman
Leona McGrath	Woopaburra & KuKu Yalanji woman
Sue-Anne Hunter	Wurundjeri & Ngurai illum wurrung woman
Joyce Graham	Kamilaroi woman
Lorian Hayes	Bidjara woman
Brad Farrant	Sue Vlack
Anneka Bowman	Karin Birkner
Vicki Flenady	Fran Boyle
Philippa Middleton	Harriet Lawford
Kym Rae	Rupesh Gautam
Carrington Shepherd	Tamara Jones

Assoc. Prof. Kym Rae
co-lead Stillbirth CRE Indigenous research program

Deanna Stuart-Butler
IAG Chair & co-lead Stillbirth CRE Indigenous research program

Skye Stewart
Stillbirth CRE Indigenous midwife researcher - VIC

Carolyn Lewis
Curtin University Indigenous researcher - WA

Rural and Remote Advisory Group

The CRE's Rural and Remote Advisory Group was founded in 2017 to support the Stillbirth CRE in reducing stillbirth rates in rural and remote populations. The R&R AG provides guides the Stillbirth CRE to ensure the needs of clinicians and families in rural and remote Australia are considered in all aspects of the CRE's program of work, and that the needs of rural and remote women and health practitioners are considered and met when developing our resources. The group has developed educational webinars for rural and remote clinicians to support the uptake of the Safer Baby Bundle initiative.

Leonie McLaughlin (co-Chair)	Jenny Bell (co-Chair)	Matilda Wilson	Julie Wright
Vicki Flenady	Amanda Wee	Katherine Michell	Fiona Ballinger
Philippa Middleton	Jared Watts	Sean Seeho	Megan Weller

Migrant and Refugee Advisory Group

The Migrant and Refugee Advisory Group was formed to provide strategic guidance and advice to the Stillbirth CRE on issues facing migrant and refugee women and their families in relation to ending preventable stillbirth and providing better bereavement care. The M&R AG guides the CRE in the development of culturally sensitive and safe approaches to the design, implementation and evaluation of CRE supported interventions and supports the CRE in community engagement and co-design initiatives.

The Stillbirth CRE Migrant and Refugee Advisory Group has 14 members:

Stephanie Brown	Murdoch Children's Research Institute	Danielle Muscat	University of Sydney
Clemmie Due	University of Adelaide	Vicki Flenady	Stillbirth CRE
Jaya Dantas	Curtin University	Alley Wakefield	Mater Refugee Health Network
Maryam Mozooni	University of Western Australia	Sediqa Karimi	Mater Refugee Health Network
Sue Willey	Monash University	Karin Birkner	University of Sydney
Joyce Jiang	Multicultural Centre for Women's Health	Miranda Davies-Tuck	Richie Centre
Ignacio Correa-Velez	Queensland University of Technology		

Stillbirth Foundation Australia, Stillbirth CRE grants

The Stillbirth CRE and Stillbirth Foundation Australia have jointly awarded research grants over the five year period of CRE funding. In all, 15 research projects were funded through these grant rounds with awarded grants totaling $783,450.

2016 The economic impacts of stillbirth in Australia $52,500
Bowring V, Morris J, Russell-Gilford S

2017 Is placental ageing the key to predicting and preventing stillbirth? $50,000
Smith R, Morris J, Aitken R.

Maternal ethnicity and disparities in stillbirth in Victoria $31,516
Davies-Tuck M, Wallace E.

2018 Core Outcomes in Stillbirth (COSTIL) project $50,000
Kim BV, Aromataris EC, Middleton P, Townsend R,Thangaratinam S, Duffy JMN, de Lint W, Coat S, Flenady V, Khalil A, Mol BW

My Baby's movements $33,658
Flenady V, Gardener G, Coory M, Warrilow K, Weller M.

2019 Developing a parent version of a guideline for respectful and supportive perinatal bereavement care. $40,000
Boyle FM, Horey D, Middleton PF, Dillon P, Flenady V.

Maternal region of birth and stillbirth in Victoria, Australia 2000-2011: A retrospective cohort study of Victorian perinatal data $120,000
Davies-Tuck M, Horey D, Wallace E.

Tertiary education Regarding Stillbirth 4 Student Midwives (TEARS 4 SMs) $10,566
Warland J, Glover P.

2020 Developing an implementation-ready parent version of a guideline for respectful and supportive perinatal bereavement care. $40,210
Boyle FM, Dean J, Horey D, Flenady V, Middleton P, Dillon P, Norman B, Forbes M

FetalKicks $50,000
Wallace E, Smith V.

Birthing in grief $48,500
Warland J.

2021 The Endometrial Origins of Stillbirth – Participants Needed $84,000
Davies-Tuck M.

The Causes, Risk Factors and Subsequent Pregnancy Outcomes of Early Stillbirth in NSW $105,000
Ibiebele I, Nippita T, Morris J, Torvaldsen S

Project Engage $19,700
Andrews C.

Caring for parents in a subsequent pregnancy after stillbirth: Availability of services across Australia and a social return on investment analysis $47,800
Loughnan S, Ellwood D, Flenady V, Boyle F, Heazell A, Gordon A, Postle V, Sneddon A, Andrews C, Ludski K.

The CRE in action

Outputs were collected for five years, between October 2016 and October 2021. Together over the life of the CRE, the team produced…

237 Publications

$24,478,680 of research income 2016 - 2021

$24,132,331 as chief investigators
$346,349 as collaborative investigators

33 Students (Higher Degree Research)

Oct 2016-Oct 2021

21 enrolled
10 PhDs completed
2 Masters completed

179 presentations

93 International
86 State & National

59 conferences

16 International
43 State & National

The National Stillbirth Action and Implementation Plan

On 10 December 2020, the Australian Federal Government officially launched the National Stillbirth Action and Implementation Plan (the Plan), the first national plan to strategically address the issue of stillbirth in Australia.

The goal of the Plan is to support a reduction in Australia's stillbirth rate by 20% or more over five years, and ensure that, when stillbirth occurs, parents and families receive respectful and supportive bereavement care. The five key priority areas of the Plan, with recommended actions for the short, medium, and long-term include:

- Ensuring high-quality stillbirth prevention and care
- Raising awareness and strengthening education
- Improving holistic bereavement care and community support following stillbirth
- Improving stillbirth reporting and data collection
- Prioritising stillbirth research

The Stillbirth CRE was pivotal in the development of the Plan from 2015 onward, with co-directors, investigators and collaborators heavily involved in the consultation phase.

In early 2018, the Australian Senate put together a committee to inquire and report on the future of stillbirth research and education in Australia. The Stillbirth CRE submitted jointly with PSANZ, WHA, Australian College of Midwives (ACM), SANDS, Still Aware, and the International Stillbirth Alliance .

In February 2019, the Minister for Health, Greg Hunt, led a roundtable of stakeholders to assist the Government to develop the Plan. In the lead up to this meeting, the Stillbirth CRE, in partnership with Stillbirth Foundation Australia, facilitated a collaborative response to inform the development of the Plan.

The Safer Baby Bundle

The Safer Baby Bundle for Australian maternity healthcare professionals is a collection of change ideas or interventions for Australian maternity healthcare professionals designed to reduce late pregnancy stillbirth. The interventions are based on evidence summaries developed in partnership with the Perinatal Society of Australia and New Zealand (PSANZ), the professional colleges of the Australian College of Midwives (ACM), Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), Royal Australian College of General Practitioners (RACGP) and parents. Development of the SBB has drawn from the expertise and experience of international advisors from the UK Saving Babies Lives Bundle of care that saw a 20% reduction in stillbirth rates in the UK.

Addressing key areas where improved practice can reduce the number of stillborn babies, the Australian SBB contains five evidence-based elements of care that, when packaged together, should result in better outcomes than if implemented individually (Figure 1.).

Collaborative approach to SBB roll out
Establishing key partnerships and employing a collaborative approach to the development of the SBB from the outset has been crucial to ensuring high visibility, acceptability, and feasibility of rolling out the initiative nationally.

In January 2019, the Stillbirth CRE, in partnership with the Stillbirth Foundation Australia, Still Aware and Departments of Health across Queensland (QLD), Victoria (VIC) and New South Wales (NSW), received funding to implement and evaluate the SBB across these three states. First to launch SBB implementation in June 2019 was VIC, who have since shown a 27% decrease in late gestation stillbirth across participating sites. Both NSW and QLD commenced their implementation in 2020 and continue to host state and regional forums to bring together clinicians to support a cohesive approach.

Thanks to successful funding from the Medical Research Future Fund, the Stillbirth CRE has started to partner with health departments of all remaining jurisdictions to commence implementation of the SBB over 2020 to 2022. Both Western Australian (WA) and the Australian Capital Territory (ACT) launched the SBB in late 2020. Tasmania (TAS) has recently established a working group to oversee and coordinate implementation of the SBB and are aiming for a formal launch in late 2021. The Northern Territory (NT) and South Australia (SA) are currently in the preliminary planning stages, with implementation anticipated for early 2022.

In June 2021, the Stillbirth CRE hosted the first National Safer Baby Bundle Virtual Forum, bringing together health professionals, parents, researchers, policy makers, and advocates for stillbirth prevention to highlight latest best practice recommendations and common implementation challenges across the country. With over 300 attendees on day 1 and over 250 attendees on day 2, the event was well attended by representatives from all states and territories.

Whilst all states and territories have made strong strides, COVID-19 has presented real challenges for everyone involved in delivering best-practice maternity care in 2020 and 2021. During this time, the Stillbirth CRE have been working hard with our partnering organisations to help ensure that women and clinicians continue to receive important, timely and relevant updates about maternity care and stillbirth prevention.

Creating resources and education programs
Implementation of the SBB has been supported by a comprehensive package of evidence-based and collaboratively developed resources for clinicians. Some of these resources include evidence summaries, clinical practice guidelines, management algorithms and education programs including the SBB eLearning.

These resources were made publicly available in October 2019 following a formal launch in Federal Parliament. More than 11,000 healthcare professionals have now registered to complete the SBB eLearning module. This is a great result, especially among midwives who comprise 79 per cent of all completions to date. We encourage all healthcare professionals working in maternity care to complete this education program which can be accessed by the following link: https://learn.stillbirthcre.org.au/

Resources around stillbirth prevention and the SBB elements for women and their families have also been co-designed by the Stillbirth CRE and translated into a total of 23 languages. Partnerships with parent-based advocacy groups were critical to ensuring the voices of parents were heard during the development and rollout of these resources.

Upscale and adaptations- taking the next steps
The Stillbirth CRE is currently consulting with communities across Australia to adapt the SBB resources to meet the needs of Aboriginal and Torres Strait Islander, rural and remote and migrant and refugee communities.

C Andrews, D Ellwood, A Gordon, P Middleton, C Homer, E Wallace, M Nicholl, C Marr, K Sketcher-Baker, M Weller, S Seeho, C Flenady. Stillbirth in Australia 2: Working together to reduce stillbirth in Australia: The Safer Baby Bundle initiative, *Women and Birth* 2020. Volume 33, Issue 6, 514-519

C Andrews, D Ellwood, P Middleton et al. Implementation and evaluation of a quality improvement initiative to reduce late gestation stillbirths in Australia: Safer Baby Bundle study protocol. *BMC Pregnancy Childbirth* 2020. 20, 694

My Baby's Movements

The My Baby's Movements (MBM) trial was a multifaceted awareness package for both women and clinicians aimed at reducing stillbirth rates through increased awareness and management of women with decreased fetal movements (DFM).

The MBM intervention included a mobile phone app, which provided women with information about their baby's movements and a feature that allowed women to track both the frequency and strength of fetal movements. The app also provided daily reminders from 27 weeks' gestation to monitor and 'get to know' their baby's pattern of movement. The MBM app was developed through a grant from the Stillbirth Foundation Australia. The clinician intervention included education by the MBM team, updated clinical guidelines and an eLearning module on best care for women with DFM.

The MBM trial was undertaken across 27 maternity care centres in Australia and New Zealand between August 2016-May 2019. The trial was a huge collaborative with a team including doctors, midwives, and data managers across the 27 sites, as well as a team of researchers at the coordinating centre at Mater Research in Brisbane. The MBM results have been presented at numerous conferences nationally and internationally including Scotland, New Zealand and Spain and was featured in Dr. Lisa Daly's PhD thesis. MBM generated significant media attention, being featured in multiple news articles and segments on Channel 7 News.

The trial ended on the 13th of May 2019 with follow-up data finalized in late December 2019. The results were similar to the UK AFFIRM cluster trial of a similar intervention, showing a small reduction in stillbirth rates during the intervention period. However, this reduction was not significant. Encouragingly a significant downward trend in stillbirths was found over the three-year duration of the trial indicating better attention to stillbirth prevention through care of women with DFM or other interventions. A small increase was shown in obstetric intervention. However, no increase was show in adverse neonatal outcomes. Women who used the MBM app found it enjoyable and helpful.

Further research is planned, including an economic analysis and an Individual Participant Data metanalysis in collaboration with the AFFIRM trial investigators.

MBM Collaborating sites:

QLD:
Gold Coast University Hospital
Logan Hospital
Ipswich Hospital
Mater Mothers Private Hospital
Royal Brisbane and Women's Hospital
The Townsville Hospital
Sunshine Coast University Hospital
Cairns Base Hospital
ACT:
Canberra Hospital
VIC:
Monash Medical Centre
Dandenong Hospital
Casey Hospital
Sunshine Hospital
Royal Women's Hospital Melbourne
Mercy Hospital for Women
NSW:
Nepean Hospital
Liverpool Hospital
Royal Prince Alfred Hospital
Royal Hospital for Women
Royal North Shore Hospital
NT:
Royal Darwin Hospital
SA:
Women's and Children's Hospital
NZ:
Auckland Hospital
Christchurch Hospital
Middlemore Hospital

Flenady, V, Gardener, G, Ellwood, D, Coory, M, Weller, M, Warrilow, KA, Middleton, PF, Wojcieszek, AM, Groom, KM, Boyle, FM, East, C, Lawford, HLS, Callander, E, Said, JM, Walker, SP, Mahomed, K, Andrews, C, Gordon, A, Norman, JE, Crowther, C. My Baby's Movements: a stepped-wedge cluster-randomised controlled trial of a fetal movement awareness intervention to reduce stillbirths. BJOG 2021; 129: 29-41

IMPROVE: Improving Perinatal Mortality Review and Outcomes Via Education

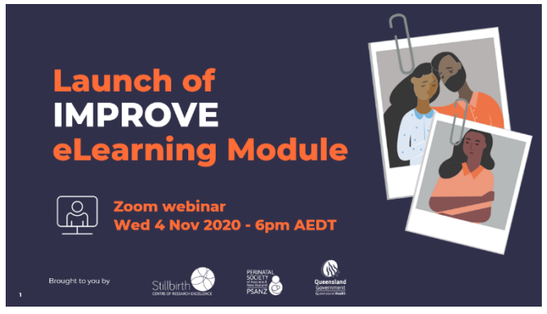
Every day, six babies are stillborn and two die in the first month after birth. Ensuring that healthcare workers are equipped with the training for when this occurs is essential to ensuring parents are supported, and that the reasons for these deaths are understood and can inform our prevention practices.

Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) is a national education program that addresses the educational training needs of health professionals involved in care around the time a baby dies.

IMPROVE is based on the Perinatal Society of Australia and New Zealand's (PSANZ)/Stillbirth CRE Clinical Practice Guidelines for Care After Stillbirth and Neonatal Death. The program covers appropriate practices around principles of bereavement care, communicating with parents about autopsy, clinical examination, placental and post-mortem examination, investigation, classification, and audit of stillbirth.

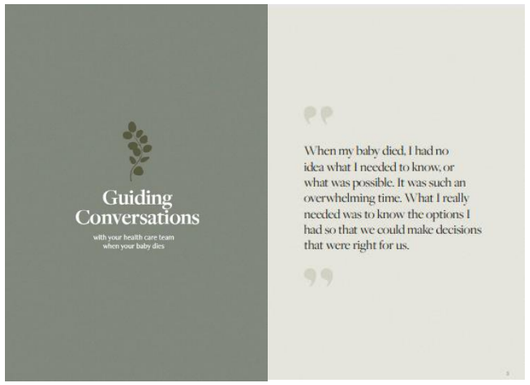
Since 2010, the face-to-face IMPROVE workshops have educated over 1300 clinicians in Australia, improving their knowledge and confidence in caring for families following a stillbirth or neonatal death.

In November 2020, the Stillbirth CRE and PSANZ officially launched the IMPROVE eLearning module, providing this education program in an online package. The six chapters in the IMPROVE eLearning module take approximately 15-20 minutes per chapter to complete and provide this essential training in a more accessible format to obstetricians, midwives, nurses, general practitioners, and antenatal staff.



74% of surveyed participants of this online eLearning have expressed a preference to continue providing a face-to-face option as it provides an "opportunity to ask questions and learn from other people's experiences", however many also noted that the online training is a convenient and appropriate option, particularly for rural and remote services who rarely experience a stillbirth or neonatal death in their setting. Importantly over 1,900 clinicians (1.5 times the number who have attended in person) have registered for the IMPROVE eLearning program since its inception, and whilst it may not be able to provide the full interactive component offered by a face-to-face program, this does provide us with an opportunity to reach a more extensive national audience.
The IMPROVE face to face and eLearning program is a collaboration between PSANZ and Stillbirth CRE and funded across Queensland through the CRE Co-ordinating Centre for 5 years.

Guiding Conversations



Parents need timely, sensitive, and evidence-based information when a baby dies. All too often parents say that they only became aware of options, or consequences of decisions, when it was too late. Guiding conversations with your health care team when your baby dies aims to help parents to explore options, to think about what is most important to them, and to support decisions that are best for them and for their baby.

The Stillbirth CRE partnered with Stillbirth Foundation Australia to develop this parent version of the PSANZ/Stillbirth CRE Clinical Practice Guideline for Respectful and Supportive Perinatal Bereavement Care. The aim was to make available to parents, in an appropriate format, the same information that is available to clinicians to support best practice bereavement care. Based on consultation with parents, clinicians, parent support groups and others who share our vision of best care following the death of a baby, topics include preparing for your baby's birth, honouring your baby, understanding why your baby died, and leaving hospital.

The project was funded by Stillbirth Foundation Australia with design and distribution funded by Sydney2CAMberra.

Since becoming available in February 2022, the guide has been distributed to more than 50 maternity hospitals and organisations across Australia and has been warmly received by maternity care professionals and parents.

Living with Loss

The provision of respectful and supportive perinatal bereavement care to parents and families around stillbirth and neonatal death is a major contributor to their immediate and long-term wellbeing. Our research has demonstrated the vital role of primary care settings in providing ongoing support to parents, yet services are limited.

Living with Loss (LWL) is a new online perinatal bereavement program that aims to support parents' emotional wellbeing following the death of a baby. LWL was co-developed by a team of parents, clinicians, researchers, healthcare professionals, and parent support and advocacy organisations. LWL draws on a range of cognitive and behavioural approaches to bereavement including strategies from mindfulness and compassion-focused therapies. LWL is delivered via a custom-built online learning system.

LWL consists of six modules covering a broad range of topics that bereaved parents and healthcare professionals have highlighted as important. Each module includes a short series of illustrated parent stories and information on key topics, in addition to activities such as meditation.

Module 1: Understanding Grief

Module 2: Managing Intense Feelings

Module 3: Balancing Thoughts

Module 4: Facing Hard Situations and Conversations

Module 5: Strengthening Relationships and Communication

Module 6: The Future

We are currently conducting a gold-standard randomized controlled trial to evaluate the efficacy, acceptability, and cost-effectiveness of the LWL program compared to usual care. Feedback on LWL and each module so far has been positive. Following evaluation, the LWL program will be rolled out nationally for all parents in Australia and will include education and training for healthcare professionals and clear referral pathways.

"I found reading the character's thoughts and feelings helpful as they were often similar to my own"

"This was relatively quick and provided helpful suggestions to put into practice."

LWL will provide an evidence-based, accessible, and flexible support option to help improve psychosocial outcomes for parents and build primary care capacity to deliver respectful and supportive bereavement care to parents. This project is led by Stillbirth CRE postdoctoral researcher, Dr Siobhan Loughnan, with Prof Vicki Flenady, A/Prof Fran Boyle, Prof David Ellwood, A/Prof Dell Horey, A/Prof Emily Callander, Prof Claire Jackson, Sara Crocker, Ann Lancaster, Dr Chrissie Astell, Dr Julie Dean, Dr Antonia Shand and key partners: Mater Mothers' Hospital, Stillbirth Foundation Australia, Red Nose, Bears of Hope, and Brisbane South Primary Health Network. This project is funded by Health Translation Queensland (formerly Brisbane Diamantina Health Partners).

Living with Loss

COCOON Global Research

The COVID-19 pandemic has impacted the lives of millions of pregnant and postpartum women and their families and led to global disruptions to healthcare systems. Evidence suggests that maternal and perinatal outcomes have worsened during the pandemic including an increase in maternal deaths, stillbirth, ruptured ectopic pregnancies, maternal stress, and maternal depression. Decreased access to normal social support systems due to travel restrictions within and between countries have led to increased isolation and loneliness, with several studies highlighting the increased rates of anxiety, and clinically relevant maternal depression.

The pandemic-related disruptions to maternal, newborn and child health care are known to have worsened the standard of care in many instances, leading potentially to an increase in many preventable losses of lives. It is important to understand parent experiences of care during the COVID-19 pandemic, particularly parents who have experienced stillbirth or newborn death and the extent to which recommended perinatal bereavement care practices – which are known to vary widely between countries even in non-pandemic times – are being implemented.

COCOON is a global initiative by the Stillbirth CRE to explore the psychosocial impact of COVID-19 and the experiences of parents who have accessed maternity care services during this time, including those who have experienced a stillbirth or neonatal death, to provide a comprehensive global picture of maternity care during the COVID-19 pandemic.

The COCOON study is an international cross-sectional online survey being conducted in 10 languages across 12 countries through COCOON coordinating centres in Australia, Brazil, Canada, Germany, India, Ireland, Italy, Netherlands, New Zealand, Spain, United Kingdom, and the United States of America with plans to launch in Latin America, Laos, and Pakistan in the near future. So far, more than 16,000 pregnant and postpartum mothers and fathers have completed the COCOON surveys.

Seven COCOON countries are also participating in a nested qualitative study titled 'The experiences of Parents who sUffer pregnancy loss and whose babies die During the pandemic: A qualitative study of late-term miscarriage, Stillbirth and neonatal death (PUDDLES), led by investigators at King's College London UK. This nested study aims to further explore the experiences of bereaved parents during the COVID-19 pandemic. This study is being led by investigators at King's College London, UK, and includes Australia, Brazil, Canada (Francophone), Italy, India, and New Zealand.

Pandemic preparedness and the development of evidence-based maternity care guidelines and practices is imperative. Findings from the COCOON study will inform strategies to improve care for women and their families, provide examples of best practice (both during peak times of outbreaks and during off-peak times) and baseline data for ongoing monitoring and evaluation in high-income, and middle-income countries during this pandemic, and possible future pandemic(s).

This is particularly important for the delivery of appropriate and respectful bereavement care to parents following stillbirth or neonatal death. This project is led by Stillbirth CRE postdoctoral researcher, Dr Siobhan Loughnan and is funded by Professor Vicki Flenady through NHMRC Fellowship and Investigator Grants.

Placental Consortium

This is a national consortium of placental biologists and clinicians led by Professor Vicki Clifton. The Consortium work on placental mechanisms and circulating biomarkers that may be early indicators of pregnancies at risk of a stillbirth.

Professor Vicki Clifton

Part of this work involves developing a national database of placental samples to promote and facilitate collaborative placental research, as well as standardized processes for the collection and analysis of placental samples. Collection protocols are designed as a basic minimal guide to placental tissue collection for biobank storage that meets the agreed standards of the Stillbirth Centre for Research Excellence.

The Placental Consortium was established in 2017 as the Placental Biomarker Group, evolving over the following years as a collaboration of 72 clinicians and researchers working in the field. The Consortium holds a series of seminars to enhance collaboration.

INTERNATIONAL STILLBIRTH ALLIANCE

international stillbirth alliance

The Stillbirth CRE is the Western Pacific Regional Office of the International Stillbirth Alliance. The ISA is a membership organization uniting bereaved parents and other family members, health professionals and researchers to drive global change for the prevention of stillbirth and neonatal death and bereavement support for all those affected.

The Stillbirth CRE and the ISA are united in our goal to help reduce the unacceptably high loss of lives from stillbirth and newborn death and lessen the devastating impact these losses have on families and communities.

The ISA connects families, researchers and clinicians through global conferences, working groups, workshops, shared stories, and more.

The Stillbirth CRE and ISA collaborate on a number of projects:

Prevention Working Group

The ISA'S Prevention Working Group (PreWG) is co-chaired by Vicki Flenady (Stillbirth CRE, Mater Research Institute – University of Queensland, Australia) and Fleurisca Korteweg (Martini Hospital, Groningen, Netherlands) and includes representation from bereaved parents, researchers and clinicians from low-, middle- and high-income countries around the world.

Members of the ISA PreWG are currently working on several key projects to support ISA's mission of prevention of stillbirths and newborn deaths.

Importantly, the Classification System study evaluates a new system for identifying relevant conditions leading to perinatal deaths in well-resourced settings with appropriate access to pathology services. This system (ISA classification system) has been based on the best features of top performing international classification systems and has involved extensive international collaboration. This system aims to not only address current deficiencies in systems used in well-resourced regions of the world but will serve as a benchmark for under-resourced countries as they work towards more effective approaches to collection of data on relevant conditions leading to perinatal deaths.

Bereavement Working Group

The ISA Bereavement Working Group (BeWG) was re-established in 2020, co-chaired by Fran Boyle (University of Queensland, Australia) and Dimitrios Siassakos (University College London, United Kingdom). The group is formed of bereaved parents and those working with them, providing care or doing research. Among current members are bereaved mothers and fathers, midwives, researchers, anthropologists, epidemiologists, obstetricians, neonatal doctors, psychologists, social workers and nurses. Members come from all but one continent and meet bi-monthly to share presentations on key areas of interest.

The BeWG RESPECT project: With widespread recognition of the need for quality bereavement care after stillbirth to reduce stigma and preventable harm to parents, their families, and their communities, this project aimed to develop evidence-based principles for bereavement care. The project team undertook a global survey across 26 countries involving 236 participants – a wide range of experts and healthcare workers actively involved in front-line care - that led to the development of eight core principles for bereavement care after stillbirth.

Shakespeare C, Merriel A, Bakhbakhi D, Blencowe H, Boyle FM, Flenady V, Gold K, Horey D, Lynch M, Mills TA, Murphy MM, Storey C, Toolan M, Siassakos D. The RESPECT Study for consensus on global bereavement care after stillbirth. *Int J Gynecol Obstet* 2020, 149: 137-147.

Stillbirth Advocacy Working Group

The ISA Stillbirth Advocacy Working Group (SAWG) is a group of parents, clinicians, researchers, policymakers, students, and others who are interested in using advocacy as a tool to help end preventable stillbirths and support families and caregivers following the loss of a baby. The SAWG is co-chaired by Susannah Hopkins Leisher (International Stillbirth Alliance and Columbia University, United States) and Hannah Blencowe (London School of Hygiene and Tropical Medicine, United Kingdom)

Global Scorecard

The 'Ending Preventable Stillbirths Global Scorecard' tracks progress against the Lancet's 2016 Ending Preventable Stillbirths Series Call-to-Action in WHO/UNICEF's Every Newborn Action Plan (ENAP) target countries across the 5 areas of the Call-to-Action:

- INTENTIONAL LEADERSHIP
- INCREASED VOICE
- IMPLEMENTATION
- INDICATORS TO MEASURE IMPACT
- INVESTIGATION

In 2018 the SAWG, led by Susannah Leisher and Hannah Blencowe, developed this scorecard and in 2020 the Scorecard reported data for the 93 ENAP target countries within seven regions, including comparisons with data from 2018 and 2019.

Following on from this work, in partnership with the Stillbirth CRE, ISA developed an adaptation of the Scorecard for use in high-income countries and settings, in particular highlighting areas where insufficient progress is being made and where further investments and actions are needed. A draft version of the HIC Scorecard has been trialled in the US, UK and Australia.

iCHOOSE – Development of a core outcome set for stillbirth care research

This study addresses the paucity of evidence needed to inform design and evaluate interventions for care after stillbirth and in subsequent pregnancies. In collaboration with ISA and the Stillbirth CRE, an international team led by Danya Bakhbakhi and Christie Burden (UK) is developing a core outcome set for stillbirth care research, through an international consensus process with key stakeholders including parents, healthcare professionals and researchers – once this core outcome set has been developed, the Stillbirth CRE will evaluate in the Australian context.

“Experts say simple steps have helped Victoria’s stillbirth rate fall for the first time in 20 years

Victorian maternity services that introduced the Safer Baby Bundle between 2019 and 2021 have seen a 21 per cent decline in stillbirths — the first real change to the state’s stillbirth rate in almost two decades.

According to Safer Care Victoria, 20 stillbirths were prevented over an 18-month period after the initiative was introduced to 15 maternity services across the state.

“This is a remarkable achievement and a life-changing outcome for 20 Victorian families,” a summary of the program said.

Experts believe the dramatic drop in deaths was driven by:

- A 200 per cent increase in the number of women who quit smoking during pregnancy
- Improved screening for poorly growing babies
- More expectant mothers being informed about changed baby movements
- Better education around the importance of side-sleeping for women in their third trimester
- And shared decision-making with women around the timing of birth

In December 2020, the Commonwealth government introduced Australia’s first National Stillbirth Action and Implementation Plan, which aims to reduce the number of stillbirths after 28 weeks by 20 per cent by 2025.

The plan found sub-standard care was contributing to up to half of all stillbirths, with 20 to 30 per cent of deaths considered to be preventable with optimal care.

Once the Safer Baby Bundle is operating in all states and territories from early next year, the Stillbirth Centre for Research Excellence (Stillbirth CRE) hopes it will give all mothers access to the best possible care and save hundreds of babies’ lives.

“The data from Victoria … is amazing,” Stillbirth CRE director Vicki Flenady said.

“If we can meet these targets set out in the national plan … 200 or more late gestation stillbirths will be saved, and their families spared that tragedy”

Action at last, but more work needed

Every year more than 2,000 Australian babies are stillborn — that is almost double the national road toll.

After decades of seeing little to no improvement in stillbirth prevention and support, Professor Flenady says there has been “incredible change” over the past five years.

The federal government says it has invested more than $21 million to reduce stillbirths and support families since 2018.

The Safer Baby Bundle is just one example of dozens of initiatives being implemented.

“As a community across Australia, we have made huge inroads into bringing stillbirth out of the shadows to reduce the impact of this tragedy on families and communities and beyond, but there’s more to be done,” Professor Flenady said.

“We’re only just scratching the surface now — we need to keep working together and we will reach our target of reducing stillbirth by 20 per cent by 2025.”

Five lifesaving factors identified

The Safer Baby Bundle highlights five key areas that can help reduce stillbirth rates after 28 weeks’ gestation: quitting smoking, improved screening for fetal growth restriction, better management of decreased fetal movements, encouraging side-sleeping in the later stages of pregnancy, and enhanced decision-making about the timing of birth.

The program was first trialed in Victoria, and by next year should be available across the country.

NSW senator Kristina Keneally, who helped lead the 2018 senate inquiry into stillbirths, says it is heartening to see the rates of stillbirth starting to fall.

“I think it’s amazing that something as straightforward and uncomplicated as the Safer Baby Bundle is so rapidly showing results,” she said.

“Lots of babies are being saved.

“I also think it’s an utter tragedy, that for the past two decades we have failed as a country to do these very basic things.”

Senator Keneally, who lost her daughter Caroline to stillbirth in 1999, said that for decades stillbirth had been treated as a “private tragedy” rather than a “public health crisis”.

But now that this attitude was changing in Australia, many parents could be saved from “heartbreak”.

“What we know from jurisdictions overseas like the Netherlands and Scotland, is that when you make a determination that you’re going to reduce the rate of stillbirth, it is actually something that you can achieve,” she said.

“My only regret for Australia is that the country didn’t take these decisions sooner.”

Lack of data ‘incredibly frustrating’

The Safer Baby Bundle is just one part of Australia’s national plan to reduce the rate of stillbirth.

Experts and policy makers say improved reporting and data collection is key to further lowering the stillbirth rate.

At present, Australia does not have a national databank on stillbirths, partly because each state and territory report on the deaths in slightly different ways.

Even finding an accurate number of how many stillbirths occur each year can be challenging.

“If you look at the Australian Bureau of Statistics and then you look at the Australian Institute of Health and Welfare, you’ll get two vastly different numbers, because of how those two agencies collect their information,” Senator Keneally said.

She says the lack of accessible data is “incredibly frustrating”.

“In Victoria, there’s a great example of why this matters.” She said.

“Victoria started to notice that women of South-East Asian background were having higher rates of stillbirth in the last two weeks of pregnancy than the broader population.”

Subsequently clinicians started noting a mother’s ethnic background when considering risk factors for stillbirths.

“As a result, they intervened earlier in pregnancies, and they ended up saving many babies’ lives,” she said.

“They went from having higher rates, to having no stillbirths in the last two weeks of pregnancy amongst women of South-East Asian background.”

ABC Radio Melbourne / By Matilda Marozzi
Posted Wed 10 Nov 2021 at 6:07am

Highlights from the research programs

The CRE's research was conducted around key programs:

Implementing prevention strategies

Developing new approaches for stillbirth prevention

Implementing best practice care after stillbirth

Improving stillbirth data to drive change

Cross-cutting themes: Equity & diversity

102 projects across the 5 Stillbirth CRE programs have been completed or are still in progress. The following pages showcase highlights of the work conducted under these programs.

Implementing prevention strategies

Program Leads: Professor Vicki Flenady, Professor David Ellwood and Professor Adrienne Gordon

This program area focuses on research to enable informed decision-making in the care of women during pregnancy to avoid stillbirth and other adverse newborn outcomes. It includes expansion of the Safer Baby Bundle to include new research, wide-scale implementation across maternity services, and monitoring of unintended consequences. The current lack of an individualised evidence-based approach to a woman's risk status has resulted in concerning increases in early term and late preterm birth. Indigenous and other disadvantaged groups often have constellations of risk factors (e.g. obesity, smoking, substance use, inadequate nutrition) and poor antenatal care attendance. The Stillbirth CRE is working to adapt the Safer Baby Bundle to meet the needs of Aboriginal and Torres Strait Islander communities, as well as migrant and refugee women and those living in regional and remote settings.

PhD Project: Smoking cessation uptake and referral for pregnant women – Cheryl Bailey, University of Queensland

Many women continue to smoke in pregnancy, despite the health risk to themselves and their unborn baby. In 2019, in Australia, around 9% of pregnant women reported smoking while pregnant. They are 47% more likely to have a stillbirth when compared with women who do not smoke. Six babies are stillborn each day in Australia, with little change in the last two decades. Stillbirth and adverse perinatal outcomes impact the health service and the mental health of parents and families, who often need support for years after the event. To reduce the risk of stillbirth and other adverse perinatal outcomes, women should stop smoking early in pregnancy, as stopping up to the start of the second trimester could reduce their risk of stillbirth to that of a non-smoker.

This project aims to review and generate evidence to inform practice that will lead to more pregnant women who smoke accessing smoking cessation services.

Screening of 1573 studies has been completed with a systematic review of included studies currently underway, and requests to Queensland, New South Wales, Victoria and South Australian data custodians for deidentified Quitline data have progressed to assess effectiveness of health professional referrals and uptake of Quitline.

Final objectives of the project – interviews of pregnant women smokers, co-designing and evaluating a smoking cessation resource, and piloting the resource in maternity care settings will continue throughout 2022.

Improving decision-making around timing of birth – D Ellwood, Griffith University. T Newth, Mater Research Institute. V Flenady, Mater Research Institute/University of Queensland

This study draws on the estimated stillbirth risk by week of gestation as derived from the national data. See – Epidemiology of Stillbirth in Australia. The principles of Experience Based Co-Design (EBCD) methodology will be used to develop The Safer Baby Bundle resources. A major area of focus is resources for the SBB timing of birth element (SBB Element 5) which is anticipated to include a stillbirth risk assessment guide, materials to support women's informed decision-making and a clinician education program. Guided by the Australian evidence-based co-design Toolkit and building on consultation that has already occurred, the key steps in this process will be as follows:

1. Recruitment of a group of clinicians (midwives and doctors) and parents (approximately 15- 20 in each group);
2. A pilot study involving one-to-one interviews and focus groups to gather information about their experiences relevant to resources development.
3. Sharing of the information gathered in a facilitated combined meeting to agree on key aspects of care with a focus on the SBB timing of birth element;
4. Co-design meetings to develop and refine resources;
5. Engagement with Indigenous and CALD women and their care providers will be overseen by the Stillbirth CREs Indigenous and CALD Advisory Groups.

Together we can stop stillbirth: education program

This project includes development and evaluation of a public awareness campaign across Australia. Our approach aimed to improve health outcomes through making the evidenced-based resources of the Safer Baby Bundle, widely accessible to all women with a focus on higher risk and under-served populations. The education campaign provided accurate advice about prevention, through co-designed initiatives, using interactive technology and innovative service delivery models.

Evaluation of the education campaign through surveys of the general community and pregnant women before and after showed a generally increased awareness among women of the stillbirth prevention behaviours of sleeping on your side, quitting smoking, and being aware of baby's movements. Topline metrics from the Still Six Lives campaign are impressive, with 11.7 million impressions from on-line advertising, over 450 news articles with PR coverage and a social media reach of 3.4 million. There was evidence of an increased proportion of people who recalled seeing or hearing messages about stillbirth after the campaign, however the evaluation highlighted the need for sustain and repeated messages to build momentum and facilitate awareness of stillbirth prevention among the community.

This project formed part of the overarching Stillbirth Education and Awareness Grant Opportunity (GO2536) with the Public Awareness campaign component led by Red Nose in partnership with Stillbirth CRE, Stillbirth Foundation Australia and the Stillbirth and Neonatal Death Society (SANDS).

Preventing term stillbirth in South Asian born mothers – M Davies-Tuck, Monash University

Despite decreases in the rates of both neonatal death and SIDS, the rate of stillbirth has remained largely unchanged in Australia for well over a decade. One group of women who have a much higher rate of stillbirth than other women giving birth in Australia are south Asian born women. Previous work from our investigators have shown that not only is the rate of stillbirth at the end of pregnancy significantly higher in South Asian women (i.e. India, Pakistan, Sri Lanka, Afghanistan and Bangladesh) than Australian-born women, the rate also increases earlier in pregnancy and more rapidly. This difference appears to be due to "accelerated placental ageing" in south Asian born women such that South Asian born women have shorter pregnancies and are more likely to have signs of fetal compromise at the end of pregnancy. Most maternity hospitals offer induction of labour or fetal surveillance for women whose pregnancy extends beyond 41 weeks. This is to reduce the risk of stillbirth. However, this may be too late for South Asian women.

This project aims to assess the impact of a new clinical guideline of surveillance or induction of labour for South Asian women at 39 weeks.

Developing new approaches for stillbirth prevention

Program Leads: Professor Sailesh Kumar, Professor Euan Wallace and Professor Vicki Clifton

Novel tests to improve antenatal detection of women at increased risk of stillbirth are needed. Many of the unexplained stillbirths that occur in high-income countries may be due to problems with how the placenta develops and functions. Such problems may contribute to stillbirth, even in babies who appear to be growing well during pregnancy. By assessing the function of the placenta, it may be possible to predict which babies have a greater chance of stillbirth. We may then be able to intervene before stillbirth occurs.

As well as identifying babies who might be at-risk of stillbirth, assessing the function of the placenta and looking at placental biomarkers may help to detect babies who have an increased chance of experiencing distress during labour. Babies who experience distress during labour are at-risk of developing brain injury and resulting disability, such as cerebral palsy. Therefore, detecting babies who have an increased chance of experiencing distress during labour may help to reduce both stillbirth and childhood disability.

A national collaboration has been established to identify novel placental biomarkers for pre-clinical testing. An initial one-day workshop held in Brisbane in July 2017 confirmed support for this national project and ongoing workshops throughout the life of the CRE continue to progress this work and foster new collaborations.

Establishment of a biobank register for stillbirth prevention – V Clifton, University of Queensland/Mater Research Institute

A national consortium of placental biologists and clinicians across five leading academic centres is working collaboratively to better understand placental mechanisms of stillbirth and circulating biomarkers that may be early indicators of pregnancies at risk of stillbirth.

The Stillbirth CRE Placental consortium, in partnership with AZPRA, have set up a national database of placental samples to facilitate collaborative placental research and standardise processes for the collection and analysis of placental samples

So far samples have been collected from 5 collaborating sites around Australia for a project examining gene expression in placentae of small for gestational age (SGA) babies – The Ritchie Centre, Monash Medical Centre, Melbourne; Mercy Health, The University of Melbourne; Kolling Institute, University of Sydney; Griffiths University; Basil Hetzel Institute for Medical Research.

Sildenafil trial – S Kumar, University of Queensland/Mater Research Institute

This four-year multicentre, randomised, double blind, placebo-controlled trial commenced in 2021 and will include 16 Australian hospitals and 3,200 women. The trial will test whether intrapartum Sildenafil can safely avert the risks of contraction-induced hypoxia in labour, preventing fetal distress and improving the short and longer-term health outcomes of both baby and mother.

Fetal kicks – V Smith, Monash University

This study aims to continuously monitor fetal wellbeing in women who present with DFM using a wearable abdominal monitor in a home setting.

Currently, there is no objective way to assess and measure fetal movements and maternity health professionals rely wholly on the mother's own perceptions to evaluate movement. What is needed is a simple, continuous, and objective measure of fetal movements.

By combining obstetric and bioengineering expertise, researchers have invented a novel wearable patch the size of a band-aid, called FetalKicks, to continuously monitor fetal movements. Two studies have already shown that this patch works, detecting fetal movements better than the mother's feelings of movements. The next phase of development of FetalKicks will allow researchers to develop the ability to monitor fetal movements 24/7, automatically detect fetal movements through artificial intelligence and alert the mother when her baby's movements are not normal.

When complete, FetalKicks will give clinicians the ability to track fetal movements continuously, giving vital real-time information to both mothers and the clinicians who care for them.

SliPP: A Multi-centre randomised trial assessing time spent in supine position during sleep in the third trimester of pregnancy with or without a position aid – S Kumar, University of Queensland/Mater Research Institute

This trial will test whether advice alone compared to advice and a pillow device best supports non-supine sleep using the Night Shift device as an objective measure of both sleep duration and position. This design could also be employed in the future for a roll out of sleep position interventions, but crucially the optimum intervention would need to be properly validated, which is what this trial aims to do.

PhD Project: FEMOM – Vinayak Smith, Monash University

Fetal heart rate monitoring (FHR) using cardiotocography (CTG) remains the most commonly used test in pregnancy in ensuring fetal well-being. However, it has several limitations such as being poor at detecting fetal compromise, being an inpatient test and requiring clinician oversight.

To improve these, FEMOM, a wearable ambulatory device, has been invented to enable prescribed woman-centric clinical grade FHR monitoring from home. This uses a state-of-the-art monitoring technology called the non-invasive fetal electrocardiogram (NIFECG) which provides more clarity on how the fetus heart is functioning in contrast to routine CTG.

Initially trialed in hospital environments, this work aims to investigate how intensive monitoring of high-risk pregnancies, particularly those with fetal growth restriction, can aid in avoiding the devastating outcome of stillbirth. Also, it aims to redefine how pregnancy monitoring is carried out as a whole so it can be more lifestyle friendly to the 20th century woman and place more control into their hands.

This early trial of FEMOM will move to a first-in-world pilot of this novel approach to fetal heart rate monitoring and will explore the potential of intensive fetal surveillance in babies with fetal growth restriction.

Implementing best practice in care after stillbirth

Program Leads: Associate Professor Fran Boyle, Associate Professor Dell Horey, Professor Jonathan Morris, and Professor David Ellwood. ECR Siobhan Loughnan

This program area focuses on improving care around the time of stillbirth, and in subsequent pregnancies. The psychosocial impact on mothers and families and society is substantial, yet the care received by parents in Australia is highly variable.

Our studies show parents' needs are frequently unmet. Parents face many critical decisions following stillbirth and more support and guidance is needed, particularly around autopsy consent. For those embarking on subsequent pregnancies, there is up to a five-fold increased risk of stillbirth. Increased anxiety and fear in subsequent pregnancies is common, yet there is little guidance for clinicians on the optimal clinical care for these women and their families.

Every baby counts – V Flenady, Mater Research Institute/University of Queensland

Poor quality data on causes of stillbirth is a significant barrier to future prevention efforts. The proportion of unexplained stillbirth may be overestimated by 50% as a result of inadequate investigation, audit and classification. Our survey for The Lancet Ending Preventable Stillbirths Series indicates 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. Substandard care contributing to stillbirth is evident across Australia. High quality audit can reduce stillbirth but only if linked to practice improvement initiatives.

We have now updated the PSANZ Guideline on *Care Around Stillbirth and Neonatal Death* to include the best available evidence for determining the causes of stillbirth and neonatal deaths through an evidence-based stillbirth investigation protocol, enhancements to the classification of causes and substandard care. Our aim is to implement and evaluate a package to promote best practice in stillbirth investigation. An on-line audit database developed as part of the Investigating the causes of stillbirth; a prospective cohort study examining use and effectiveness of a comprehensive investigation protocol will be refined to measure performance of the implementation strategies.

Expected outcomes: Acceptability and feasibility of the recommended audit process and improvement in quality of care, including stillbirth investigations, classification and audit and addressing substandard care factors; a reduction in unexplained stillbirth.

Care after stillbirth and neonatal death: a survey of Australian maternity Services – V Flenady, Mater Research Institute/University of Queensland. F Boyle, UQ Institute of Social Science. D Horey, La Trobe University.

This study aimed to identify current practices, strengths, and gaps in the provision of best practice perinatal bereavement care in Australian maternity hospitals. An online survey included questions around bereavement care practices and investigation and audit processes – which are the two key components of best practice care around stillbirth and neonatal death.

Over a 12 month period, 108 services across Australia completed this survey representing approximately 36% of all Australian maternity services. Most respondents were working in maternity services in major cities or inner regional areas, and 20% from rural areas. Overall, there appears to be variation in bereavement care practices across services and this may reflect suboptimal care for some parents and families. Stronger organisational capacity and commitment to education and training is needed to ensure best practice bereavement care is available to parents regardless of where their baby is born, and it is important that parents' feedback is incorporated. Parents have many difficult decisions to face when their baby dies. Training and support of staff is critical for the delivery of best practice bereavement care that meets the physical and psychosocial needs of parents and families that empowers them to make decisions around investigations and autopsy that are meaningful and right for them.

The care that parents receive around the time their baby dies has long-lasting impacts on parents' wellbeing. All care must acknowledge the importance of each baby's life and the impact the death of a baby has on parents, families and communities. All maternity services need to establish and foster a strong commitment to delivering best practice perinatal bereavement care with evidence-based policy and guidelines available and used by all relevant staff.

PhD Project: Investigations for stillbirth in Australia – T Marsden, Mater Research Institute

A systematic review revealed that autopsy can provide information on the cause of death in 60% - 84% of cases, changing patient management in up to 26% of women who have a stillbirth, placental pathology provided the cause of death in 61.1 - 65.2% of cases, and genetic analysis was valuable in identifying cause of death in 11.9% to 29 % of stillbirths. Based on these results a pilot study was completed in 2021 on the validation of a tool for determining the clinical utility of stillbirth investigations. The new Stillbirth Investigation Utility Tool showed very good agreement in assigning the cause of death using PSANZ Perinatal Death Classification. Minor refinements will be made based on feedback to enhance usability for wider implementation in research studies to assess the yield of investigations in stillbirths. This project is due to end in 2022.

PhD project- Improving care in a subsequent pregnancy – A Wojcieszek, Mater Research Institute

Dr Aleena Wojcieszek

Most parents conceive again after having a stillborn baby. Expectant mothers who have a history of stillbirth, and their families, comprise a high-risk group that may benefit from specialised medical care and/or psychosocial support. This suite of studies evaluated current international clinical practice in pregnancies after stillbirth. It highlighted gaps in evidence and care and outlined some of the potential solutions to progress this important research agenda, forming vital preliminary work towards the development of high-quality clinical practice guidelines and decision-support resources for care in pregnancies after stillbirth.

Dr Wojcieszek received nine honours and awards during her PhD candidature, including $11,300 in travel funding. For her thesis, Dr Wojcieszek received a 2019 Dean's Award for Excellent Higher Degree Research Thesis from The University of Queensland Graduate School, an award received by fewer than 10% of PhD and MPhil graduates each year.

https://www.evidentlycochrane.net/pregnancy-after-stillbirth/
https://www.evidentlycochrane.net/preventing-stillbirth-the-latest-evidence/

Is care of stillborn babies and their parents respectful? Results from an international online survey – B Atkins

This project aimed to quantify parents' experiences of respectful care around stillbirth globally.

Methods: Parents' perspectives of 7 aspects of care quality, factors associated with respectful care, and 7 bereavement care practices were compared across geographical regions using descriptive statistics. Respectful care was compared between country income groups using multivariable logistic regression with the main outcomes measure self-reported experience of care around the time of stillbirth.

Results: A quarter (25.4%) of 3769 respondents reported disrespectful care after stillbirth and 23.5% reported disrespectful care of their baby. Gestation <30 weeks, and primiparity were associated with disrespect. Reported respectful care was lower in middle-income countries (MICs) than in high-income countries (HICs). In many countries, aspects of care quality need improvement, such as ensuring families have enough time with providers. Participating respondents from Latin America and Southern Europe reported lower satisfaction across all aspects of care quality compared to Northern Europe. Unmet need for memory-making activities in MICs is high.

Conclusions: Many parents experience disrespectful care around stillbirth. Provider training, and system-level support to address practical barriers are urgently needed. However, some practices (which are important to parents) can be readily implemented such as memory-making activities and referring to the baby by name

Atkins, B, Blencowe, H, Boyle, FM, Sacks, E, Horey, D, Flenady, V. Is care of stillborn babies and their parents respectful? Results from an international online survey. BJOG: Int J Obstet Gy. 2022; 00: 1– 9.

PhD Project: Dads Grieve Too – Kate Obst, University of Adelaide

Men's experiences of grief after stillbirth remain under-explored compared to women's. Our research has found that grieving dads often feel under-recognised and struggle to access support, given societal pressure to "be the rock" and care their partner and family. One father shared with us:

"It is all about supporting your wife [but]… [Dads] need support too… Losing my children has changed me in profound ways… There will always be two holes in me, and I often wonder how different it would have been if I had more support at the time and over the years since."

Collating the experiences of Aussie dads, we have developed a comprehensive model of grief to inform support.

Improving stillbirth data to drive change

Program Leads: Professor Vicki Flenady, Professor David Ellwood and Professor Adrienne Gordon

This program area draws on existing and novel systems to gain comprehensive, timely data to improve knowledge of the causes of stillbirth and contributing factors in stillbirth. Knowledge of the causes and contributing factors in stillbirth is crucially important for parents to understand why their baby died and is also the cornerstone of future prevention of stillbirths. Currently, data quality to understand the important contributors for stillbirth is often suboptimal due to under-investigation, inadequate classification and clinical audit of the circumstances surrounding the death.

This research focuses on using data to develop an evidence-based stillbirth investigation protocol and enhance the existing Perinatal Society of Australia and New Zealand stillbirth and neonatal deaths classification system and audit mechanisms.

Epidemiology of stillbirth in Australia: An analysis of national data – H Lawford (post doc), Mater Research Institute

Epidemiological analyses to understand patterns of stillbirth for women birthing in Australia will help inform prevention strategies and monitor the effects of interventions to reduce stillbirth rates. Perinatal data from the national perinatal data collection AIHW of births across Australia 1997-2020, on of the largest datasets to understand stillbirth and will enable a better understanding of how contributors to stillbirth vary across different population groups.

PhD Project: Stillbirth risk prediction – J Sexton, Mater Research Institute

A robust method to predict a pregnant woman's individualized risk of late-pregnancy stillbirth is needed to enable timely, appropriate care to reduce the risk of stillbirth at term. Stillbirth in late pregnancy is more likely to occur unexpectedly in normally developed babies whose mothers have had pregnancies uncomplicated by major pre-existing or arising conditions, thus offering real potential for prevention. This is a retrospective cohort study of all at- or near-term births across Australia (1997-2015) including 7,200 stillbirths among 4.9 million births at an estimated rate of 1.47 stillbirths per 1000 live births. The aim of this study is to develop a risk prediction model for late-gestation stillbirth by week of gestation for an Australian population.

Economic costs of stillbirth – E Callander, Monash University

Relatively little is known about the costs of stillbirth. In comparison a great deal is known about common chronic diseases and their costs to society – the value of health resources used, and the costs to individuals in terms of out-of-pocket fees. Not knowing these costs for families who experience stillbirth makes it difficult to demonstrate the efficiency of stillbirth prevention activities – the real savings that can be made by preventing stillbirth. For this project we have initially quantified the costs of stillbirth between 2012 and 2015; next we will be assessing how these costs have changed over time.

Methods: Mothers and costs were identified by linking a state-based registry of all births between 2012 and 2015 to other administrative data sets. Costs from time of birth to 2 years post-birth were included. Propensity score matching was used to account for differences between women who had a stillbirth and those that did not. Macroeconomic costs were estimated using value of lost output analysis and value of lost welfare analysis.

Results: Cost to government was on average $3774 more per mother who had a stillbirth compared with mothers who had a live birth. After accounting for gestation at birth, the cost of a stillbirth was 42% more than a live birth ($P < .001$). Costs for inpatient services, emergency department services, services covered under Medicare (such as primary and specialist care, diagnostic tests and imaging), and prescription pharmaceuticals were all significantly higher for mothers who had a stillbirth. Mothers who had a stillbirth paid on average $1479 out of pocket, which was 52% more than mothers who had a live birth after accounting for gestation at birth ($P < .001$). The value of lost output was estimated to be $73.8 million (95% CI: 44.0 million-103.9 million). The estimated value of lost social welfare was estimated to be $18 billion.

Discussion: Stillbirth has a sustained economic impact on society and families, which demonstrates the potential resource savings that could be generated from stillbirth prevention.

Callander, EJ, Thomas, J, Fox, H, Ellwood, D, Flenady, V. What are the costs of stillbirth? Capturing the direct health care and macroeconomic costs in Australia. Birth. 2020, 47. 183-190

Improving knowledge of causes & contributors to stillbirth in Papua New Guinea – C Homer, Burnett Institute

It is known that 98 percent of stillbirths occur in low- and middle-income countries (LMIC). Australia's nearest neighbour, PNG and our other close Pacific Island nations (Solomon Islands and Vanuatu) bear the burden of high stillbirth rates. Unfortunately, due to poor data collection processes the full impact of stillbirth in these nations is not realised. In LMICs, stillbirths are largely attributable to preventable or treatable conditions that occur either in conjunction with, or as a result of pregnancy, including malaria, syphilis, anaemia, diabetes, hypertension, pre-eclampsia, and post-term pregnancy. Other risk factors for stillbirth, such as young maternal age, short inter-pregnancy interval, indoor air pollution and interpersonal violence against women during pregnancy also play a role.

Many of these risk factors could be addressed through universal access to good-quality antenatal and intrapartum care. Modelling has suggested that up to 45 percent of all stillbirths could be prevented if a package of 10 proven antenatal and intrapartum interventions (including basic and emergency obstetric care) was made widely available. However, it is unknown whether these interventions would address the key issues in a country like PNG or whether they would even be feasible.

Methods: We used data from an ongoing cluster-randomized crossover trial in 10 sites among 4600 women in Papua New Guinea (from 2017 to date). The overarching aim is to improve birth outcomes. All stillbirths from July 2017 to January 2020 were identified. The Perinatal Problem Identification Program was used to analyze each stillbirth and review associated avoidable factors.

Results: There were 59 stillbirths among 2558 births (23 per 1000 births); 68% (40/59) were classified "fresh" and 32% as "macerated". Perinatal cause of death was identified for 63% (37/59): 30% (11/37) were due to intrapartum asphyxia and traumatic breech birth and 19% (7/37) were the result of pre-eclampsia. At least one avoidable factor was identified for 95% (56/59) of stillbirths. Patient-associated factors included lack of response to reduced fetal movements and delay in seeking care during labor. Health personnel-associated factors included poor intrapartum care, late diagnosis of breech presentation, and prolonged second stage with no intervention.

Conclusion: Factors associated with stillbirths in this setting could be avoided through a package of interventions at both the community and health-facility levels.

Vallely, L.M., Smith, R., Bolnga, J.W., Babona, D., Riddell, M.A., Mengi, A., Au, L., Polomon, C., Vogel, J.P., Pomat, W.S., Vallely, A.J. and Homer, C.S. (2021), Perinatal death audit and classification of stillbirths in two provinces in Papua New Guinea: A retrospective analysis. Int J Gynecol Obstet, 153: 160-168.

Core Outcomes in Stillbirth (COSTIL) – B Mol, Monash University

The COSTIL (Core Outcomes in Stillbirth) project team is based at the University of Adelaide aiming to develop a standardized common outcome set that can be implemented across all clinical research in the field of stillbirth prevention so that every study conducted can be easily compared and combined for better effective use.

Aims: To develop a core outcome set for trials investigating interventions to prevent stillbirth.

Materials & Methods: Outcomes identified from a systematic literature review and semi-structured interviews with parents in Australia and the UK were entered into a two-round online Delphi survey and focus group/consensus meetings.

Results: A core outcome set containing 11 outcomes in two categories. Five outcomes were related to the mother; fetal loss, onset of and mode of delivery, maternal mortality or near miss, psychological and social impact on the women, women's knowledge. Six outcomes were related to the baby; timing of stillbirth, neonatal mortality, gestational age at delivery, birthweight, congenital anomaly, NICU/SCBU or other higher-level neonatal care length of stay.

Conclusions: Implementation and dissemination of this core outcome set in future trials will contribute towards coordinated outcome reporting and advancing usefulness of research to guide clinical practice.

Kim, B.V., Aromataris, E.C., Middleton, P., Townsend, R., Thangaratinam, S., Duffy, J.M.N., de Lint, W., Coat, S., Flenady, V., Khalil, A. and Mol, B.W. (2021), Development of a core outcome set for interventions to prevent stillbirth. Aust N Z J Obstet Gynaecol, 61: 658-666.

This project was funded with a Stillbirth Foundation Australia / Stillbirth CRE grant.

PhD Project: The contribution of asthma to stillbirth and adverse pregnancy outcomes in an Australian population – A Bowman, University of Adelaide

This study focusses on the impact of maternal asthma during pregnancy on fetal and neonatal outcomes with a primary focus on stillbirth. In addition to a systematic review, routinely collected perinatal data from the Mater Mothers Hospital and Queensland Health Perinatal Data Collection (QPDC) is utilised to address the aims and objectives of the project. These data sources provide an opportunity to better scrutinize and understand the impact of maternal asthma during pregnancy on the fetus and neonate.

Cross-cutting themes, equity & diversity

Program Leadership: Philippa Middleton, Vicki Flenady, Deanna Stuart-Butler, Kym Rae

The Stillbirth CRE is committed to reducing inequality in prevention and care after stillbirth in Australia and the wider Western Pacific region. A focus on reducing inequity is an urgent priority identified by the Stillbirth CRE and cuts across all of our research program areas, with a number of projects focused on improving outcomes for Aboriginal and Torres Strait Islander, migrant and refugee, and rural and remote women and communities.

Adaptation and implementation of the Safer Baby Bundle for Indigenous women – Deanna Stuart-Butler, Mater Research Institute

More Aboriginal and Torres Strait Islander women want to participate in models of care that provide culturally safe services e.g. Birthing on Country. The Stillbirth CRE acknowledges and supports these models as a way to improve health outcomes for Aboriginal and Torres Strait Islander women and their babies by providing a comprehensive and culturally safe service during the antenatal period.

This has led to the Stillbirth CRE to continue co-design with communities focusing on key messages to prevent stillbirth and sharing how health services and systems can improve care for women at high risk of stillbirth.

Our consultations continue in SA (Adelaide, Port Augusta, Ceduna and surrounding communities), NT (Darwin, Alice Springs, Gove, Tennant Creek), NSW (Tamworth) and Far North QLD (Cairns, Mossmon, Mapoon, Napranum, Hope Vale) and WA.

The Stillbirth CRE has co-produced and piloted culturally relevant resources for each of the five Safer Baby Bundle elements, a SBB Masterclass for Aboriginal Health Workers for services to implement, videos of introduction to the subject of Stillbirth within Aboriginal and Torres Strait Islander maternity services and the adaptation of the Baby Buddy phone app.

Lived experience of Cape York Aboriginal & Torres Strait Islander women (Parent Stories) – S Vlack, University of Queensland

Stillbirth happens more often among Aboriginal and Torres Strait Islander women compared with non-Indigenous women in Australia.

Much of the research contributing to understanding of social and emotional needs after stillbirth reflects the views of mainstream communities and is missing the voices of Aboriginal and Torres Strait Islander women. A greater understanding of Aboriginal and Torres Strait Islander women's experiences of stillbirth is necessary to guide measures for culturally appropriate after-care.

We aim to document the stories of Aboriginal and Torres Strait Islander women and families affected by stillbirth in Cape York and Cairns.

Living literacy – D Muscat, University of Sydney

The Living Literacy program will be adapted for a culturally and linguistically diverse (CALD) antenatal setting, with a specific focus on improving primigravid women's health literacy skills (i.e., skills to access, understand, appraise and use health information) to support stillbirth risk reduction focusing on the Safer Baby Bundle elements of care. This study will adapt an existing group-based health literacy program for CALD pregnant women in NSW. Co-designed with lived-experience consumers, surveys, intervention materials and videos are being developed to support training of program facilitators.

The ECLIPSE study – L Biggs, S Brown, Murdoch Children's Research Institute

The ECLIPSE study aimed to understand how information about stillbirth prevention is shared with women of refugee and migrant background during pregnancy in Victoria. The study used a qualitative exploratory design to provide a rapid pulse-check of the pregnancy care experiences in migrant and refugee communities.
Four key findings were identified:

- Information and resources from the Safer Baby Bundle are being shared
- There is a strong desire to have conversations about stillbirth prevention during pregnancy
- Adapting the way information is shared provides an important opportunity to improve stillbirth prevention efforts with women and families of refugee and migrant background
- Accessibility and acceptability of psychosocial support is crucial in order to women to feel safe in care

The study showed that there is a clear preference for information to be shared verbally rather than in written format and that audio/visual resources are seen as a good way to support conversations and share information.

Findings from this project will inform a second phase study that will co-design culturally safe resources and approaches to stillbirth prevention for communities of refugee background.

Investigating Aboriginal community knowledge and awareness of stillbirth risks – C Shepherd, Curtin University

This project represents the first step in developing a foundational understanding of the knowledge, perceptions, and beliefs about stillbirth risks among Aboriginal parents, families, and communities in south-west Western Australia. It is generally agreed that there remains a critical need to demystify stillbirth and educate parents and the general public about stillbirth risks. Few studies have sought to understand community experiences, knowledge, and perceptions of stillbirth, and none in an Aboriginal context. The project responds to the calls from an existing network of Elders, community, and other stakeholders to use co-design processes that incorporate a holistic Aboriginal worldview to guide preventative population health strategies that benefit Aboriginal populations in Western Australia.

The specific objectives of the project are to:

- Establish community support for Aboriginal-led research on stillbirth among Aboriginal peoples and communities.
- Undertake a participatory process with communities in order to investigate: (1) knowledge, perceptions, and beliefs about stillbirth risks, and (2) community priorities for stillbirth research.
- Establish a robust Aboriginal governance process for future research on Aboriginal stillbirth, potentially including investigating Aboriginal-specific, culturally appropriate intervention strategies to support stillbirth education and awareness and stillbirth prevention.

MHED - Maternal Health Education for Migrant and Refugee Women Multicultural Centre for Women's Health

As part of the Department of Health Education and Awareness grant, Multicultural Centre for Women's Health (MCWH) sought to increase awareness among migrant and refugee background women with a higher risk of stillbirth about the benefits of preventative health, early intervention, antenatal care, and build capacity among women to access antenatal care in the first trimester.

For this project, MCWH developed a stillbirth prevention educational module, and mobilised sixteen trained bilingual health educators to deliver the sessions. SBB in-language resources and videos were used in these sessions alongside videos developed by Monash Health (in Dari) and used information available on www.betterhealth.vic.gov.au for pregnancy and birth services.

A total of 42 sessions were delivered to 14 women's groups (in Punjabi, Hindi, Arabic, Vietnamese, Dari, Karen, and English for mixed group) covering preconception, antenatal care, and postpartum care. The project reached 300 women through Zoom education sessions and around 3,300 women living in metro and regional Victoria through a Facebook Livestream for Vietnamese women.

The evaluation comparing pre-and post-session results showed that the information shared in the sessions increased the women's knowledge and their readiness to change their behaviour and practice towards preconception care, antenatal care, and ways to reduce the risk of stillbirth.

Baby Buddy app – A Gordon, University of Sydney

The Baby Buddy app is an Australian adaptation of the Best Beginnings UK app of the same name, developed in collaboration with parents and healthcare professional to guide parents through their pregnancy from conception to six months of age.

The Australian Baby Buddy app is contextualised to suit an Australian audience including Aboriginal and Torres Strait Islander women and women located in rural and remote communities and will align with Australian pregnancy guidelines. A key purpose of the Baby Buddy app Australia is to highlight the Safer Baby Bundle messages for women to promote stillbirth prevention measures. Beta testing of the Australian Baby Buddy app commenced in early 2022 with locally-developed content aligned with stillbirth prevention and will occur in three key settings; a large tertiary hospital, a rural base hospital, and a remote setting within NSW.

The project is anticipated to end in December 2022.

Knowledge Translation and Education

Education Committee

The Stillbirth CRE Education Committee develops and promotes resources for healthcare professionals, women and their families to reduce the number of stillborn babies and lessen the impact of stillbirth.

The Committee's primary responsibilities are to;

- Oversee the development of new resources and refinement of existing educational programs for healthcare professionals, and women and their families, as part of the Safer Baby Bundle (SBB) and other Stillbirth CRE initiatives as required
- Oversee the approval of educational resources developed by other Stillbirth CRE working groups and committees prior to their promotion and implementation
- Promote resources, educational programs and the work of the Stillbirth CRE to consumers, healthcare professionals, professional and parent organisations, stillbirth advocacy organisations, and other important stakeholders
- Work collaboratively in the undertaking of the above with the Steering and Operational Committees of the Stillbirth CRE and SBB and with consumers and other key stakeholder organisations, including but not limited to: the PSANZ Consumer Advisory Panel; the Stillbirth CRE Indigenous Advisory Group; the Stillbirth CRE Rural and Remote Advisory Group; the Stillbirth CRE Migrant and Refugee Advisory Group; the PSANZ Equity Committee; Australian College of Midwives; Royal Australian & New Zealand College of Obstetrics & Gynaecology; Australian College of Neonatal Nurses; Royal Australian College of General Practitioners; Australian College of Rural & Remote Medicine; and the National Pregnancy Guidelines Group

Committee Members

Tionie Newth (Co-Chair), Sean Seeho (Co-Chair), Adrienne Gordon, Amanda Poprzeczny, Ana Navidad, Annelise Kirkham, Belinda Jennings, Bonnie Wootton, Caroline Homer, Cheryl Bailey, Chris Lehner, Christine Andrews, David Ellwood, Farah Sethna, Fran Boyle, Glenn Gardener, Jackie Mead, Jane Warland, Jenny Bell, Jo Davis, Joyce Jiang, Kellie Wilton, Kristy Maggs, Leigh Brezler, Natasha Donnolley, Natasha Meredith, Philippa Middleton, Teresa Walsh, Tracy Martin, Vicki Flenady, Wendy Cutchie, Derek McCormack, Nicole Hall, Deanna Stuart-Butler, Megan Weller, Leonie McLaughlin, Jonathan Morris

Resources

Masterclass

The Safer Baby Bundle Masterclass is an interactive presentation that has been developed for maternity health professionals as an overview of what to expect in the Safer Baby Bundle eLearning. This 60-minute Masterclass summarises the five bundle elements, highlights key evidence and clinical recommendations related to the Safer Baby Bundle, and discusses basic principles for implementation.

IMPROVE Train-the-Trainer

In response to the challenges of COVID and delivering face to face training. The IMPROVE Train-the Trainer has been developed into an interactive web-based training program. This training has been designed to train more educators at one time to increase the numbers of educators nationally to deliver more IMPROVE face to face programs.

eLearning

Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) is a free eLearning course for healthcare professionals based on the latest Clinical Guideline for Care Around Stillbirth and Neonatal Death, released in partnership with the Perinatal Society of Australia and New Zealand (PSANZ) and the Stillbirth CRE.

The Safer Baby Bundle evidence-based eLearning module provides a suite of educational resources based on the latest clinical best practice in stillbirth prevention. Maternity care providers will gain access to key clinical recommendations through these eLearning modules. The Safer Baby Bundle eLearning modules are free to access and provide access to include downloadable resources to share with patients. Clinicians who successfully complete the Safer Baby Bundle eLearning modules can be recognised for their training with accredited CPD points.

From 2016 to 2021, the Stillbirth CRE in partnership with PSANZ developed a number of clinical resources including:

4 Position Statements on elements of the Safer Baby Bundle

1 NHMRC Clinical Guideline on decreased fetal movements

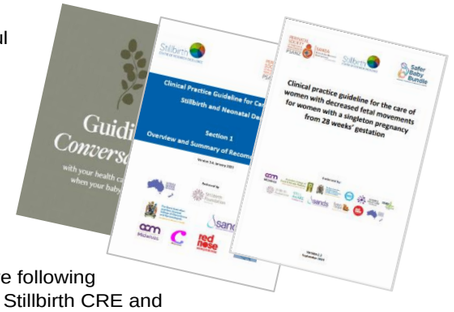
3 Clinical Care Pathways on decreased fetal movements, fetal growth restriction and smoking cessation

2 Fact Sheets for both women and clinicians on the Safer Baby Bundle and COVID-19

5 Information Flyers for women on decreased fetal movements, fetal growth restriction and smoking cessation and

5 corresponding Information Posters for clinical waiting rooms

Clinical Practice Guidelines



The PSANZ/Stillbirth CRE Clinical Practice Guideline section on Respectful and Supportive Perinatal Bereavement Care provides guidance for best practice bereavement care in the form of 49 evidence-based recommendations.

The Parent Guideline project " Guiding Conversations" responds to growing recognition of the importance of translating clinical practice guidelines into appropriate formats to make the same information to those receiving care.

The Parent Guideline has been developed in consultation with parents, clinicians, parent support groups and others who share a vision of best care following the death of a baby. The Parent Guideline was a partnership between the Stillbirth CRE and Stillbirth Foundation Australia and launched in late September 2021.

Stillbirth National Forum

Each year the National Stillbirth Forum seeks to address the issue of stillbirth in Australia.

In August 2019, The Stillbirth CRE held its first Annual National Stillbirth Forum. The forum was extremely well attended and a full and comprehensive program ensured the 296 attendees remained engaged over the 2 day event, which was opened by the Member for Bowman, Andrew Laming on behalf of the Hon. Greg Hunt MP. Labor Senator, Kristina Keneally joined The Hon. Chris Bowen MP in speaking about the importance of developing a Stillbirth National Action Plan as a recommendation of the Select Committee into Stillbirth Research and Education established by Senator Keneally.

Following the forum, attendees were emailed a short 2 minute online survey to provide their feedback on the event that included a mix of multi select, single select questions, rating scales and open ended questions. 69% of attendees went on to rate the event at five stars confirming the Forum a success.

Throughout July and August 2020, the Stillbirth CRE delivered a unique national four-part webinar series to replace the planned in-person National Forum, which was cancelled due to the COVID-19 pandemic. The Hon Greg Hunt MP opened the series, and over 1000 attendees joined virtually to engage with the latest research on key topics and participate in discussion around stillbirth prevention and care, as well as the impact of COVID-19 in practice. Attendance also included guests from UK, USA, Italy, Indonesia, India, Switzerland, and Turkey.

With COVID-19 continuing to disrupt the world in 2021, the Stillbirth CRE's National Stillbirth Forum partnered with the International Stillbirth Alliance and the International Society for the Study and Prevention of Perinatal and Infant Death to deliver a three day virtual event packed with national and international speakers. The National Stillbirth Forum was again opened by the Hon Greg Hunt MP and CRE friend and supporter, Labor Senator Kristina Keneally. 330 attendees, including bereaved parents, participated in the event from USA, Italy, Israel, Georgia, NZ, UK, Germany, Canada, Hong Kong, Netherlands and Australia

A snapshot of pivotal publications

WOMBI Series

In 2020, the Stillbirth CRE published a six-part series in Women and Birth: Journal of the Australian College of Midwives. The series, titled ‘Stillbirth in Australia’, presents an overview of the Stillbirth CRE and highlights key activities that led to the development of the National Stillbirth Action and Implementation Plan. The series also highlights the Safer Baby Bundle (SBB), public awareness, respectful and parent-centred care, inequities for families from Aboriginal and Torres Strait Islander and migrant and refugee backgrounds, and the future of stillbirth research and education.

Lancet Series

The Lancet series on Ending Preventable Stillbirths was published in January 2016 and aims to maintain momentum and build on strategies to prevent stillbirths and provide better care to women and families following stillbirth. Many future Stillbirth CRE investigators and collaborators played a major role in developing and disseminating the series, including Stillbirth CRE Director, Vicki Flenady, who led the fourth paper in the series, titled ‘Stillbirths: Recall to action in high-income countries.’ Overall, the series reports on the state of stillbirths, highlights missed opportunities, and identifies actions for accelerated progress to end preventable stillbirths and reach 2030 maternal, neonatal, and child survival targets.

Cochrane Review: Interventions for investigating and identifying the causes of stillbirth

Published in April 2018, this Cochrane Review publication systematically assessed which approaches are most helpful in finding the causes of stillbirth, how cost-effective different approaches might be, the emotional and social effects of parents, whether the investigations impact future pregnancies, and the end result of future pregnancies.

Cochrane Review: Care prior to and during subsequent pregnancies following stillbirth for improving outcomes

Parents entering a pregnancy after stillbirth face an increased risk of stillbirth, along with many other adverse outcomes. These parents often experience intense anxiety during subsequent pregnancies, which may also contribute to poor outcomes. Expectant parents who have previously had a stillborn baby are likely to benefit from extra medical care and emotional support, but there is currently little evidence to help clinicians provide the best care to these parents. In this study, we assessed the effects of different interventions or models of care prior to and during subsequent pregnancies following stillbirth on maternal, fetal, neonatal and family health outcomes, and health service utilisation. This study has been published in the Cochrane Database of Systematic Reviews

Cochrane Library Special Collection: Stillbirth prevention and respectful bereavement care

This Special Collection has been created to highlight evidence-based interventions to reduce stillbirth and improve care for families after stillbirth and in a subsequent pregnancy, identify women at increased risk of stillbirth, and improve knowledge of causes of and contributors to stillbirth.

AIHW Report: Stillbirths and neonatal deaths in Australia

In 2019 the Australian Institute of Health and Welfare (AIHW) released its first report on stillbirths and neonatal deaths in Australia from 2015 and 2016 referencing the Stillbirth CREs updated Clinical Practice Guidelines for Care Around Stillbirth and Neonatal Death V3 and the PSANZ Perinatal Mortality Group Clinical Practice Guideline for Perinatal Mortality V2.2. The Report was released again in 2021 reflecting stillbirth and neonatal deaths from 2017 – 2018.

UN Inter-Agency Group for Child Mortality Estimation: Ending preventable stillbirths – A renewed call for collective action

In October 2020, the Stillbirth CRE, as the Western Pacific Regional Office of the ISA, partnered with over 20 international organisations, including the United Nations Children’s Fund (UNICEF) and the World Health Organization (WHO) for the launch of the first ever report on global stillbirth trends released by the UN Inter-Agency Group for Child Mortality Estimation. The report featured parent and caregiver voices and experiences from around the world, which were compiled by the Stillbirth CRE on behalf of the ISA. The overall objective of the report was to raise awareness and shed light on the overlooked issue of stillbirth, highlighting that many deaths could be prevented with universal access to quality care before and during birth.

Building a Research Workforce

The Stillbirth CRE provides a number of educational and research opportunities for care providers, researchers, and students.

The aim of the Stillbirth CRE Research Capacity Development program is to provide opportunities to advance the training of new researchers (research only, clinicians, midwives etc), to ensure the Stillbirth CRE legacy carries on beyond the duration of the funded program.

The Workforce agenda is driven by a committee of CRE investigators and early career researchers (ECRs) and supports a number of awards and scholarships for both PhD students and post-doctorate researchers.

Dr Miranda Davies-Tuck

Committee Members

Miranda Davies-Tuck (Chair), Adrienne Gordon, Caroline Homer, Leigh Brezler, Christine Andrews and Siobhan Loughnan

Stillbirth CRE PhD Top-up Scholarships

Through a competitive process, the Stillbirth CRE offers top-up scholarships to eligible PhD students receiving external competitive PhD scholarships (e.g. Australian Postgraduate Award).

These top up scholarships are designed to support exceptional PhD candidates whose projects align with the CRE's priority areas and make a meaningful contribution to the CRE's program of work

- Anneka Bowman (2018)
- Jessica Sexton (2019)
- Loretta Musgrave (2019)
- Roshan Selvaratnam (2019)
- Tabassum Rahman (2019)
- Alyce Wilson (2020)
- Anneka Bowman (2020)
- Jessica Sexton (2020)
- Roshan Selvaratnam (2020)
- Alyce Wilson (2021)
- Esti de Graaff (2021)
- Jessica O'Callaghan (2021)
- Natasha Pritchard (2021)
- Poliana Medeiros (2021)

Stillbirth CRE and ACM Research Fellowship

An opportunity for a Research Fellowship to undertake a research project related to the goals and priority areas of the Stillbirth CRE. One fellowship will be awarded up to the value of $AU 20,500.

- Erin Tulley (2021)

Stillbirth CRE and ACM Travel Fellowship

The purpose of the fellowship is to provide a rural or remotely based midwife the opportunity to attend a Stillbirth CRE annual meeting and update and network with colleagues and leaders from around the country.

- Peta Zupp (2021)

Stillbirth CRE Indigenous Healthcare Worker Scholarship

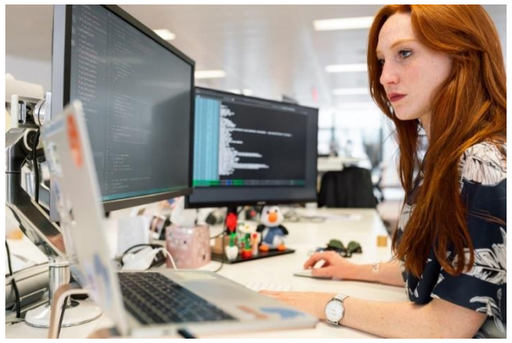
The purpose of the Indigenous Healthcare Worker scholarship is to encourage and support First Nations people to pursue a career in research.

- Skye Stewart (2021)

Stillbirth CRE ECR Grants

CRE ECR grants provide small project grants to enable early career researchers to undertake discreet projects that align with the CRE's priority areas whilst supporting their particular area of interest.

- Christine Andrews (2021)
- Roshan Selvaratnam (2021)



Research Priority Setting

The priority setting process

Establishment of the research and action priorities underpinning the Stillbirth CRE was achieved via two major consultation activities. First, data from large-scale surveys of parents and care providers, initiated as part of the 2016 Lancet series on Ending Preventable Stillbirths, were analysed to extract preliminary research questions. These research questions were then refined with the assistance of invited stakeholders through a one-day priority setting symposium.

The Lancet Ending Preventable Stillbirths Series surveys.
Multi-language web-based surveys of parents, care providers, and general community members were administered as part of the 2016 Lancet series on Ending Preventable. The surveys were broad in content, measuring knowledge of stillbirth risk factors and prevention strategies, experiences of antepartum and bereavement care, processes for the investigation of stillbirth, stillbirth auditing procedures, among other constructs.

The surveys concluded with two open-ended questions addressing Research Priorities (e.g. "What do you think we still need to know more about to help prevent stillbirth, and/or to help parents who have a stillborn baby?") and Action
Priorities (e.g. "What about the knowledge we already have? What do you think should happen now with what we already know to prevent stillbirth, improve management and improve bereavement and postnatal care?").

Priority setting #1.

The first priority setting symposium was held in April 2015 in Brisbane,
as a satellite meeting prior to the Royal College of Obstetricians & Gynaecologists World Congress. This one-day symposium, titled 'Reducing stillbirth and its aftermath in Australia and New Zealand; what needs to happen now?' brought together a multidisciplinary group of individuals with an interest in stillbirth, including prevention, bereavement care, data quality improvement, raising public awareness, and more. This exercise culminated in the report 'Stillbirth CRE Priority Setting Exercise'

https://stillbirthcre.org.au/wp-content/uploads/2021/03/Stillbirth-CRE-2015-Priority-Setting-Exercise-Final-1.pdf

Priority setting #2.

In mid-2020 the CRE commenced a second round of research priority setting in response to action areas of the National Stillbirth Action and Implementation Plan, reviewing the research priorities identified during the 2015 RPS exercise and identify new priorities for stillbirth that are equity-driven and align with the latest research and the needs of women and families in Australia. Consultations in the form of online workshops and survey were conducted in 2020 with parent advocates, researchers, policy makers and healthcare professionals, with specific work on migrant and refugee groups. In 2021 a face-to-face forum with Aboriginal Communities and Families Research Alliance resulted in a handover of work with Indigenous healthcare workers and communities to the Stillbirth CRE Indigenous Advisory Group to develop culturally sensitive research questions to meet the needs of these communities.

The development of research priority questions will continue with further consultations before analysis. A final Research Priority Setting workshop will occur in the first half of 2022.

Higher Degree Research students

10 students have completed their PhDs during the life of the CRE:

1. Dr Billie Bradford: Decreased fetal movements [PhD Thesis]. University of Auckland. Principal Supervisor – L McGowan.
2. Dr Robin Cronin: Modifiable risk factors for late stillbirth [PhD Thesis]. University of Auckland. Principal Supervisor – L McGowan.
3. Dr Jessica Sexton: Epidemiology and prediction of stillbirth risk in Australia [PhD Thesis]. University of Queensland. Principal Supervisor – V Flenady.
4. Dr Aleena Wojcieszek: Care in pregnancies after stillbirth: generating evidence to inform clinical practice [PhD Thesis]. University of Queensland. Principal Supervisor – V Flenady.
5. Dr Vinayak Smith: Investigating the use of a novel fetal movement monitor – FEMOM [PhD Thesis]. Monash University. Principal Supervisor – E Wallace
6. Dr Kate Obst: The psychological impact of pregnancy loss for under-researched populations in Australia [PhD Thesis]. University of Adelaide. Principal Supervisor – P Middleton
7. Dr Alyce Wilson: Quality pregnancy, childbirth, and newborn health services in Papua New Guinea [PhD Thesis]. University of Melbourne. Principal Supervisor – C Homer.
8. Dr Harriet Lawford: Impact of malaria in pregnancy on infant neurodevelopment with a cohort of mothers and infants in Ghana, West Africa [PhD Thesis]. Mater Research Institute/UQ. Principal Supervisor – Samudragupta Bora
9. Dr Chris Flately: The relationship between maternal and obstetric variables and adverse perinatal outcomes in Australia [PhD Thesis]. Mater Research Institute/UQ. Principal Supervisor – S Kumar.
10. Dr Lisa Daly: Decreased fetal movements and mobile phone application interventions during pregnancy [PhD Thesis]. Mater Research Institute/UQ. Principal Supervisor – V Flenady.

2 students have completed a Masters during the life of the CRE:

1. Sediqa Karimi: Global perspectives on care after stillbirth [Master Thesis]. University of Queensland.
2. Aleksandra Olekalns: Developing a parent version of a guideline for respectful and supportive perinatal bereavement care [Master Thesis]. UQ Institute for Social Science Research.

A number of candidates are currently progressing towards completion in 2022

PhD Student	Institution	Research project
Cheryl Bailey PS – V Flenady	UQ Medicine	For women that smoke in pregnancy does carbon monoxide (CO) screening compared to self-disclosure Increase the smoking cessation rate?
Jui Das PS – V Flenady	UQ Medicine	The contribution of asthma to stillbirth and adverse pregnancy outcomes in an Australian population
Tania Marsden PS – V Flenady	UQ Medicine	Quality of autopsy in Australia
Poliana de Barros Medeiros PS – V Flenady	UQ Medicine	Perinatal mortality audit and classification to drive practice change in perinatal death and “near-miss”
Anneka Bowman PS – P Middleton	University of Adelaide	Investigation of social determinants, lifestyle and environmental factors associated with stillbirth.
Shalini Ponnampalam PS – E Wallace	Monash University	An investigation into placental biomarkers of maturation and ageing in South Asian Women
Roshan Selvaratnam PS – M Davies-Tuck	Monash University	Project 1 – Evaluating the impact of statewide FGR workshops (VIC) Project 2 – Maximising the benefit and minimising the harm of driving improved detection of fetal growth restriction to reduce stillbirth
Tabassum Rahman PS – G Gould	University of Newcastle	Investigating cessation of smoking during pregnancy in Indigenous Australian women, drivers of relapse and access to services that might help continue cessation
Benjamin Nowotny PS – E Wallace	Monash University	Using obstetric complaints and litigation as a quality improvement tool
Christopher Beeves PS – E Wallace	Monash University	Improving perinatal outcomes through workforce education
Esti de Graaff PS – N Anderson	University of Auckland	Identification of risk factors and causal pathways associated with adverse perinatal outcome
Natasha Pritchard PS – A Lindquist	University of Melbourne	Identifying which fetal growth charts and birthweight centiles are best able to identify babies and mothers at risk of adverse obstetric and perinatal outcomes
Jessica O’Callaghan PS – E Pelzer	Queensland University of Technology	Investigating placental genes in small for gestational age infants
Haylee Fox PS – E Callander	James Cook University	Medicalised childbirth: Variation in care and drivers of maternal health service provision in Queensland, Australia
Sophia Young PS – K Moritz	University of Queensland	Identifying placental dysfunction caused by prenatal alcohol exposure
Nykola Kent PS – V Clifton	University of Queensland	The impact of hypothyroidism during pregnancy on maternal and fetal outcomes and programmed offspring disease
Loretta Musgrave PS – A Gordon	University of Sydney	Generation of evidence to inform future development and utilisation of preconception and pregnancy specific applications for smartphones
Lucy McCudden PS – A Gordon	University of Sydney	Decreased fetal movements and/or sleep position
Annie Cox PS – E Wallace	Monash	Sulforaphane as a novel therapy for preeclampsia
Ashley Meakin PS – V Clifton	University of Queensland	Understanding the role of androgens and placental AR variants
Elias Roro PS – V Flenady	University of Queensland	Evaluation of Maternal and Perinatal Death Surveillance and Response in Ethiopia: opportunities and challenges of MPDSR implementation progress 2018.

Concluding remarks

The last five years has seen extraordinary activity in relation to our research studies in stillbirth, public awareness and parent advocacy. Despite the difficulties of the last two years, and the impact of the COVID-19 pandemic on the rollout of the Stillbirth National Action & Implementation Plan, the Stillbirth CRE is ideally positioned to push ahead and make a real difference to women, their families and especially their babies. The incredible network of collaborations that have built up over this period is enduring, effective and capable of completing a wide range of projects designed to make a real difference. Working together, the public health tragedy of stillbirth can and will be reduced to the point where we have ended almost all preventable stillbirths and we can truly say that women who suffer this tragedy have been cared for according to best practice guidelines.

Research publications

Between October 2016 and December 2021, the team of CRE investigators and post-doctoral researchers wrote 237 journal articles

Journal articles

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2. Warrilow KA, Gordon A, Andrews CJ, et al. Australian women's perceptions and practice of sleep position in late pregnancy: An online survey. *Women Birth* 2021.
3. Turner J, Flenady V, Ellwood D, Coory M, & Kumar S. Evaluation of Pregnancy Outcomes among Women with Decreased Fetal Movements. *JAMA Network Open* 2021; 4(4), e215071–e215071.
4. Chan L, Gordon A, Warrilow K, Wojcieszek A, Firth T, Loxton F, Bauman A, & Flenady V. Evaluation of Movements Matter: A social media and hospital-based campaign aimed at raising awareness of decreased fetal movements. *Australian & New Zealand Journal of Obstetrics & Gynaecology* 2021; 61(6), 846–854.
5. Turner J, Kumar S. Neurodevelopmental outcomes in infants following intrapartum maternal oral sildenafil citrate treatment. *Am J Obstet Gynecol* 2021; 224(3): 316-7.
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Book chapters

1. Li MSK, Gordon A, Brand-Miller J. The effects of nutrition and micronutrients on reproductive success. How to Improve Preconception Health to Maximize IVF Success: *Cambridge University Press*; 2018: 3-17.
2. Heazell, Alexander and Flenady. Interventions in pregnancy to reduce risk of stillbirth. Fetal Therapy: Scientific Basis and Critical Appraisal of Clinical Benefits. (60)pp. 48-60) edited by Mark D. Kilby, Anthony Johnson and Dick Oepkes. Cambridge, United Kingdom: *Cambridge University Press* 2018
3. Arulkumaran S, Ledger W, Denny L, Doumouchtsis S, Ellwood, D, Flenady V. Stillbirth. In Oxford Textbook of Obstetrics and Gynaecology. Oxford, UK: *Oxford University Press* 2016.
4. The Global library of Women's Medicine. The Continuous Textbook of Women's Medicine. Volume: 3 – Elements of professional care and support before, during and after pregnancy. Editor Professor Vicki Flenady

Research income

The CRE investigators secured additional research income to advance the CRE's aim of accelerating the research agenda in Stillbirth: $24,132,331 million as chief (primary) investigators and $346,349 as collaborative investigators on grants administered by UQ or other institutions.

2016 – Research income secured by CRE researchers

Project Title	Granting Scheme	Amount	Investigators
Investigating the scale of economic impact associated with stillbirth in Australia	Stillbirth Foundation Australia	$52,500	Bowring, V; Morris, J; Russell-Gilford, S
Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE)	Queensland Health: Patient Safety and Quality Improvement Service	$54,545	Flenady, V

2017 – Research income secured by CRE researchers

Project Title	Granting Scheme	Amount	Investigators
Implementing strategies to address stillbirth in Australia: A bundle of care for maternity hospitals	MRI-UQ Clinical Research Seeding Grant	$8,833	Reinebrant, H; Flenady V; Gardener, G; Hickson, L.; Nissen, P
Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE)	Queensland Health: Patient Safety and Quality Improvement Service	$59,000	Flenady, V; Ellwood, D
Maternal ethnicity and disparities in stillbirth in Victoria	Stillbirth Foundation Australia	$31,516	Davies-Tuck, M; Wallace, E
Improving outcomes in pregnancies complicated by asthma: understanding mechanisms and defining interventions	NHMRC Fellowship	$707,370	Clifton, V
Are we there yet? Optimising timing of planned birth to improve newborn outcomes and reduce health service costs	MRFF RART Grant	$100,000	Morris, J; Nicholl, M; McGee, T; Alahakoon, T; Nippita, T; Ford, J
A National Program to address stillbirth	NHMRC CDF 2	$470,144	Flenady, V
Is placental ageing the key to predicting and preventing stillbirth?	Stillbirth Foundation Australia	$50,000	Smith R., Morris J., Aitken R.

2018 – Research income secured by CRE researchers

Project Title	Granting Scheme	Amount	Investigators
Developing a parent version of a guideline for respectful and supportive perinatal bereavement care	Stillbirth Foundation Australia	$40,000	Boyle, F; Horey, D; Middleton, P; Dillon, P, Flenady, V
Fetal Growth Restriction Education Program	Safer Care Victoria	$99,500	Flenady, V; Weller, M; Gardener, G
Public Awareness Campaign – Fetal Movements	Safer Care Victoria	$165,000	Flenady, V; Gordon, A
Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE)	Queensland Health: Patient Safety and Quality Improvement Service	$54,545	Flenady, V
My Baby's Movements	Stillbirth Foundation Australia	$33,658	Flenady, V; Gardener, G; Coory, M; Warrilow, K; Weller, M
Core Outcomes in Stillbirth (COSTIL) Project	Stillbirth Foundation Australia	$50,000	Mol, B; Kim, B; Aromataris, E; Middleton, P; Coat, S

2019 – Research income secured by CRE researchers

Project Title	Granting Scheme	Amount	Investigators
Improving the mental wellbeing of parents after perinatal loss: Development and implementation of a parent-centred online intervention	BDHP MRFF RART	$767,158	Flenady, V; Loughnan, S; Boyle,F; Norman, B; Millard, M; Newby, J; Haskelberg, H; Horey, D; Monk, C; Shear, K; Callander, E
to enhance primary care sector capacity			
Assessing the impact of a stillbirth prevention bundle of care for improving best practice care for women during pregnancy in Australia	NHMRC Partnership Grant	$3,169,927	Flenady, V; Ellwood, D; Middleton, P; Gordon, A; Morris, J; Boyle, F; Coory, M; Stuart-Butler, D; Callander, E; Andrews, C; Wallace, E; Lynch, K; Gardener, G; Davies-Tuck, M; Homer, C
Preventing stillbirth, the Australian Safer Baby Bundle	MRFF Accelerated Research Grant	$3,000,000	Flenady, V; Ellwood, D; Middleton, P; Gordon, A; Nicholl, M; Homer, C; Morris, J; Gardener, G; Coory, M; Davies-Tuck, M
Together we can stop stillbirth: An education campaign	Primary Health Care Development Program: Stillbirth Education and Awareness	$1,500,000	Flenady, V; Middleton, P; Gordon, A; Ellwood, D; Seeho, S; Bauman, A; Murdolo, A; Andrews, C
Developing a parent version of a guideline for respectful and supporting perinatal bereavement care	Stillbirth Foundation Australia	$40,000	Boyle, F; Horey, D; Middleton, P; Dillon, P; Flenady, V
Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE)	Queensland Health: Patient Safety and Quality Improvement Service	$54,545	Flenady, V

2020 – Research income secured by CRE researchers

Project Title	Granting Scheme	Amount	Investigators
Can intrapartum SildEnafil safely Avert the Risks of Contraction-induced Hypoxia in labour? iSEARCH – a pragmatic Phase 3 Randomised Controlled Trial	NHMRC, MRFF RCRDUN	$3,418,152	Kumar, S; Mol, B; Tarnow-Mordi, W; Flenady, V; Liley, H; Badawi, N; Walker, S; Hyett, J; Askie, L; Callander, E
Having a small placenta is a risk for stillbirth	Stillbirth Foundation Australia	$30,000	Khong, Y; Flenady, V
Developing an implementation-ready parent version of a guideline for respectful and supportive perinatal bereavement care	Stillbirth Foundation Australia	$40,210	Boyle, F; Dean, J; Horey, D; Flenady, V; Middleton, P; Dillon, P; Norman, B; Forbes, M
Birthing in grief	Stillbirth Foundation Australia	$48,500	Warland, J; Boyle, F; Horey, D

2021 – Research income secured by CRE researchers

Project Title	Granting Scheme	Amount	Investigators
Cultural Adaptation of the Safer Baby Bundle	Department of Health	$2,131,493	Flenady, V; Shepherd, C; Jiang, J; Brown, S
Preventing stillbirths and improving care after loss	NHMRC Investigator Grant	$3,372,570	Flenady, V
Novel approaches to preventing perinatal death and disability from birth asphyxia	NHMRC Investigator Grant	$2,174,514	Kumar, S
The Causes, Risk Factors and Subsequent Pregnancy Outcomes of Early Stillbirth in New South Wales	Stillbirth Foundation Australia	$105,000	Ibiebele, I; Nippita, T; Morris, J; Torvaldsen, S
Centre of Research Excellence in Stillbirth	NHMRC	$2,500,000	V Flenady, D Ellwood, P Middleton, A Gordon, C Homer, J Morris, S Kumar, S Walker, F Boyle, M Davies-Tuck
Reducing emergency caesarean birth for fetal distress in women with small or poorly grown infants using Sildenafil Citrate – The RidStress 2 RCT	RBWH Foundation	$150,000	Kumar, S

Notes

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