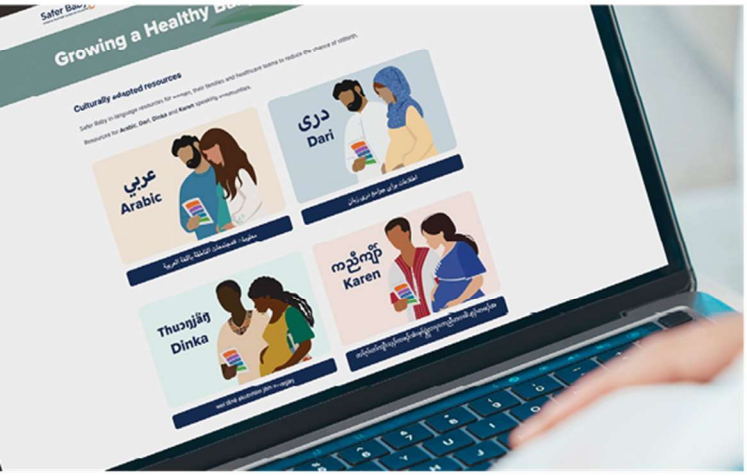
Pre-Budget Submission



Stillbirth
CENTRE OF RESEARCH EXCELLENCE

“

The National Stillbirth Action and Implementation Plan was released three years ago and was a tremendous contribution to this issue and a great credit to the Stillbirth Centre for Research Excellence, which was so central in its development. Now it’s up to all of us to accelerate action, and implement this national roadmap on stillbirth and pregnancy loss.

December 2025 isn’t far away. That’s the target date for reducing stillbirth rates in Australia by 20 per cent or more. And our government remains absolutely committed to that goal...

Ged Kearney
Assistant Minister for Health and Aged Care
Opening Remarks at the Annual National Stillbirth Forum, 24 October 2023

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Stillbirth CENTRE OF RESEARCH EXCELLENCE

EXECUTIVE SUMMARY

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) is leading the development and application of national research, resources and evidence-based advice to prevent stillbirth and improve health and social outcomes for women.

Every day in Australia, around six babies are lost to stillbirth. This is a higher rate than in other top performing countries. Stillbirth is a personal tragedy for the families involved and a serious public health problem with far reaching social, emotional and financial impacts.

In 2020, the Australian Government launched the *National Stillbirth Action and Implementation Plan* (the NSAIP) with the goal of reducing stillbirth in Australia by 20 per cent for women from 28 weeks' gestation and beyond, by December 2025. The Stillbirth CRE played a critical role in the development of the NSAIP, and continues to play a vital role in its implementation.

Under the NSAIP, the Stillbirth CRE has led the implementation of the Safer Baby Bundle, which has successfully decreased the gap between what is *known* and what is *done* in maternity care to prevent stillbirth. While data demonstrating a national reduction in the late gestation birth rate are not yet available, we have seen exceptional outcomes in Victoria where the SBB was able to safely reduce the number of Victorian women experiencing late gestation stillbirth by 21 per cent.[1] Victoria was the only jurisdiction to commence implementation before COVID disruptions, further jurisdictional data will be available at the end of 2024.

The Stillbirth CRE's remit extends well beyond research into innovation, impact and effectiveness. We recognise that our key role is to translate and apply research findings through a range of practical, accessible and actionable programs and resources that are user-centred, culturally relevant and targeted to priority populations. After two years of consultations and co-design, we launched new co-designed resources in October 2023 to specifically address the disproportionately high rates of stillbirth among First Nations communities, as well as some migrant and refugee communities. This is vital work to address systematic healthcare barriers, and drive down stillbirth rates for all communities.

Our remit is focused on stillbirth, but recognises that there are obvious opportunities to expand across the maternity care continuum. As our work progresses and matures, there is increasing scope to carry over lessons and materials from stillbirth to support women experiencing early pregnancy loss and women in their subsequent pregnancies. This extension of our work is already evident in the $980,000 the Australian Government provided Stillbirth CRE to

[1] Safer Care Victoria, Safer Care Collaborative - Summary, 17 February 2021

expand the *Improving Perinatal Mortality Review and Outcomes via Education* (IMPROVE) program for healthcare professionals who are working with mothers and families experiencing stillbirth *and* miscarriage[2].

It is impossible to consider women's health, women's mental health and women's economic equality without properly examining maternal health, maternal equity and the specific needs of women who have experienced the loss of stillbirth. A key part of our approach is to acknowledge, listen and learn from the parents of stillborn babies. Too often, these voices are absent and bereaved mothers go unheard. This lowers their quality of care, diminishes their capacity to recover and limits the learnings needed to improve policy responses for others.

The Stillbirth CRE has established a wide range of partnerships with parent-based advocacy and support organisations, including Stillbirth Foundation Australia and Red Nose. This has been critical to ensuring the voices of parents are heard throughout the development of resources.

Every stillbirth is a tragedy and every stillbirth prevented matters. The Stillbirth CRE's work, in close collaboration with a wide range of partners, is important to women and families and needs to continue, at scale. This work cannot stand still. As we have demonstrated through the culturally sensitive adaptations of the Safer Baby Bundle, it needs to constantly evolve, mature and benefit from new research, best practice and lived experience.

Since 2016, the Federal Government has counted on the Stillbirth CRE to support women across the maternity care continuum. As this submission outlines, our work has advanced well, but the job is not yet done. This pre-Budget submission offers the government a range of sensible policy options that reinforce the work undertaken so far. These options include:

- Ongoing implementation support to ensure the established Safer Baby Bundle can be more broadly implemented, disseminated and embedded;
- A National Safer Baby Bundle Roadshow to reach into priority populations;
- The Baby Buddy App for Mums - "Safer Baby Bundle resources in the palm of your hands";
- Tommy's Clinical Decision Tool for Health Care Professionals - as an additional, integrated strategy to reduce stillbirth rates by improving pregnancy risk assessment; and
- A comprehensive National Perinatal Loss Care Pathway that is supported by user-centred resources for parents and care providers.

[2] The Hon Ged Kearney MP, "Support for high-risk communities for stillbirth and miscarriage bereavement care," *Media Release*, 14 April 2023

These policy options are designed to further progress the National Stillbirth Action and Implementation Plan, which supports Australia's progress against the National Women's Health Strategy 2020-2030. The five-year funding timelines of these proposed initiatives are attached and align with the completion of the NSAIP and the ongoing progress of the National Women's Health Strategy through to 2030.

INTRODUCTION

It is impossible to consider women's health, women's mental health and women's economic equality without properly examining maternal health, maternal equity and the specific needs of women who have experienced the loss of a stillbirth.

Since 2016, the Federal Government has counted on the Stillbirth CRE to support women across the maternity care continuum.

In the first part of this submission, we outline our record of achievement by focusing on two key areas of delivery by the Stillbirth CRE - the Safer Baby Bundle and Bereavement Care.

The second part of this submission outlines the ways that the Australian Government can continue to be a world leader in stillbirth prevention and care by proposing a series of policy options for consideration in Federal Budget 2024-25. These policy options include:

- Ongoing implementation support to ensure that the established Safer Baby Bundle can be more broadly implemented, disseminated and embedded;
- A National Safer Baby Bundle Roadshow to reach into priority populations;
- The Baby Buddy App for Mums - "Safer Baby Bundle resources in the palm of your hands";
- Tommy's Clinical Decision Tool for Health Care Professionals - as an additional, integrated strategy to reduce stillbirth rates by improving pregnancy risk assessment; and
- A comprehensive National Perinatal Loss Care Pathway that is supported by user-centred resources for parents and care providers.

Each of the above policy options have been carefully crafted to leverage and expand the work completed so far.

As this submission shows, our work has advanced well, but the job is not yet done. It is vital that the Stillbirth CRE and its partners can continue to update, develop and disseminate their established work more broadly, and most particularly amongst priority communities.

1. THE ROLE AND REMIT OF THE STILLBIRTH CRE

In 2017, the National Health and Medical Research Council (NHMRC) established the Stillbirth CRE in response to a global call to action developed by *The Lancet* series, "Ending Preventable Stillbirths".

The Lancet series recognised the "heavy burden" of psychosocial and economic costs of stillbirth - affecting women, families, caregivers, communities and society more broadly. It recognised that there is a "stigma and taboo" around this devastating issue that exacerbates the trauma for families and impedes further prevention work.[3]

The Stillbirth CRE's establishment marked a turning point for maternal health policy by helping build public awareness around an issue that is too often dealt with silently, and by informing new practices and programs that are designed to prevent stillbirths and provide responsive care where stillbirth occurs.

The vision of the Stillbirth CRE is to reduce the devastating impact of stillbirth through high-quality research that prevents stillbirth where possible, while also improving bereavement care for mothers and families where stillbirth could not be prevented.

We do this by:

1. Developing new approaches for stillbirth prevention;
2. Implementing prevention strategies;
3. Implementing best practice in care after stillbirth and subsequent pregnancies; and
4. Improving stillbirth data to drive change (including high quality perinatal mortality audit to improve care)

The principles of equity and diversity underpin all that we do. We also advocate for continuity of care for women by a known healthcare provider. Continuity of care is a core principle of woman-centred care, with studies finding that this continuity can reduce the risk of stillbirth before 24 weeks.[4]

[3] An Executive Summary of *The Lancet*'s Series, Ending preventable stillbirths, January 2016, p2

[4] Sandall J, Soltani H, Gates S et al. Midwife-led continuity models versus other models of care for childbearing women. Cochrane Database Syst Rev. 2016; 4: CD004667 *as cited in* Australian Government Department of Health, *National Stillbirth Action and Implementation Plan*, 2020, p9

The Stillbirth CRE brings together parents, parent advocates, researchers, healthcare professionals, professional colleges, and policy makers to collectively address the vision of the Stillbirth CRE through collaborative partnerships.

1.1 Practical, accessible and actionable research outcomes

Since 2016, the Australian Government (including the NHMRC, MRFF and Department of Health and Aged Care) has provided $20.05 million in funding to support the foundational work of the Stillbirth CRE. Appendix two provides an overview of annual Commonwealth Funding (including NHMRC and MRFF funding provisions) leading up to 2026. This demonstrates a reduced level of support from the Federal Government over coming years, which would seriously undermine the progress that has been made so far. A reduction in funding would also jeopardise the established team at the Stillbirth CRE, and their collective experience which has been built up over many years.

The Stillbirth CRE is committed to ensuring its vital research findings are translated into practical, accessible, and actionable resources that reduce the risk of stillbirth and support families who are grieving a baby's death. Strong evidence shows there is a natural pathway to support the 80 per cent of parents who are pregnant again within 12 months of a pregnancy loss. These parents are navigating the increased anxiety and risk of a subsequent pregnancy, while still grieving.

The Stillbirth CRE is systematically working to raise the profile and awareness of this important issue and its significant societal ramifications. **We are driven by the need to achieve a level of continuity that eliminates the current "lottery of care" which results in a woman receiving very different levels of maternal support based on the practice of her clinicians, or her geographical location.** The Community Affairs Senate References Committee recently identified a "postcode lottery" in its inquiry into the barriers to achieving priorities of the National Women's Health Strategy.

The Committee highlighted "service gaps in rural and remote regions and First Nations communities" where "women without access to adequate local birthing services must relocate and give birth away from home"[5]. Recommendation 12 of the report calls on governments to ensure that maternity care services in non-metropolitan public hospitals are "available and accessible for all pregnant women at the time they require them"[6]. The Safer Baby Bundle and *Clinical practice guideline for care around stillbirth and neonatal deaths* are practical resources that can help ensure a consistent level of maternal care across postcodes and directly support the ambitions of the National Women's Health Strategy.

We are also actively monitoring the work of the NSW Parliament's Select Committee Inquiry into Birth Trauma and commend them for properly examining this important issue.

A recent Nous review into the NSAIP found that there are "promising indicators of progress on stillbirth outcomes, which can be attributed (in part) to the Action Plan."[7] The Nous report particularly highlights improvements in the "provision of quality prevention and care"[8] and in culturally safe maternity care for First Nations women. The report highlights a need to focus on the priority populations, including some migrant groups who face disproportionately higher stillbirth rates (compared with both the general population and the general migrant population). The Stillbirth CRE's culturally adapted resources were released at the Stillbirth CRE National Forum during October 2023 (after the Nous evaluation report was completed in May 2023). This included "Stronger Bubba Born" tailored to First Nations communities and "Growing a Healthy Baby", tailored to Migrant and Refugee communities.

The Stillbirth CRE continues to develop and expand its work with priority communities disproportionately affected by stillbirth. In addition to our ongoing focus on First Nations, migrant, refugee, rural and remote communities, we are pleased to have recently secured a working partnership with the Brave Foundation to amplify our efforts with mothers under the age of 20 years. Brave is an Australian not-for-profit that equips expecting and parenting young people with resources, referral and education opportunities to facilitate happy, healthy and skilled families over time.

The Stillbirth CRE's new working relationship with Brave will allow us to get the Safer Baby Bundle materials and messages to this very difficult-to-reach cohort.

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[5] Community Affairs References Committee, "Ending the postcode lottery: Addressing barriers to sexual, maternity and reproductive healthcare in Australia," May 2023 https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ReproductiveHealthcare/Report, p53

[6] Ibid, p74

[7] Nous, First Evaluation Report - National Stillbirth Action and Implementation Plan, Commissioned by the Australian Government Department of Health and Aged Care, May 2023, p8

[8] Ibid.

Partnerships such as this are vital because they allow us to disseminate best practice throughout the range of priority populations where we can have the most significant impact. We are excited to work with Brave and look forward to exploring the ways we can adapt our materials for this cohort of young mothers. This is an important step forward in our work to address the rates of stillbirths in this age cohort. In each case, the number of deaths per thousand births is higher for women under 20, than in any other age bracket, including those over 40.[9]

While the Stillbirth CRE continues to focus on priority populations, we do not accept or agree with the Nous finding that greater awareness of stillbirth has led to increased anxiety and disproportionate interventions on the timing of birth. As detailed on page 16, recent evaluations of the SBB have not identified a negative change in trends observed for planned births before 39 weeks.

As we demonstrate in this submission, greater awareness of the risk of stillbirth can lead to important conversations between a mother and her GP that can ensure preventative steps are taken. Data from QLD and NSW shows that implementation of the SBB resulted in:

- more women recalling conversations with their clinician about stillbirth and risk reduction (increasing from 25.9% to 46.5%);
- more clinicians reporting that they include these conversations as routine care (up from 35.1% to 83% after SBB); and
- clinicians discussing with all women, regardless of their risk status (up from 57.3% to 87.5%).

This education is vital amongst priority communities. In some cases, on the advice of their GP, decisions on timing of birth can save lives and spare parents the trauma of stillbirth.

Stillbirth is an issue that spans women's health, women's mental health and women's economic equality, making it imperative that where we cannot prevent it, we must improve the support around women and families grieving a pregnancy loss, at all its different stages. The following provides more detail on our work in the prevention and bereavement space.

[9] Australian Institute of Health and Welfare, *National Perinatal Data Collection Annual Update 2021 - data tables*, Table 4.3

1.2 Established best practice - prevention through the Safer Baby Bundle

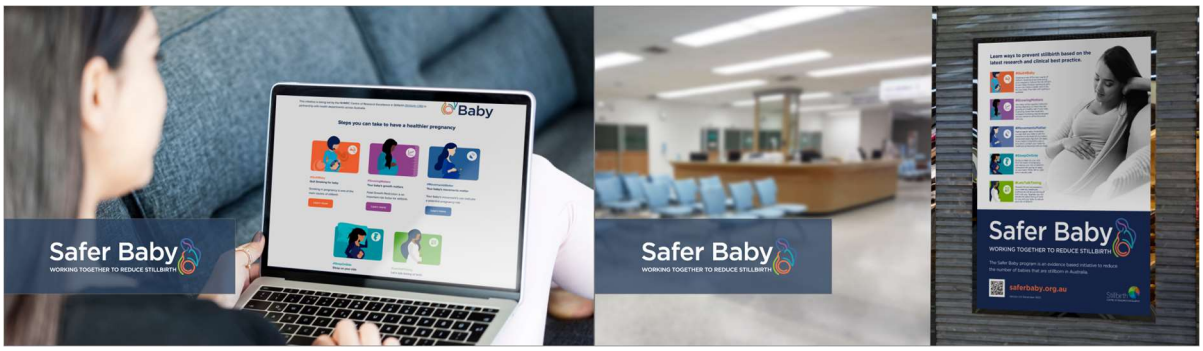
Safer Baby Bundle
WORKING TOGETHER TO REDUCE STILLBIRTH

The Safer Baby Bundle (SBB) for Australian maternity healthcare professionals is a collection of evidence-based steps and interventions that are designed to reduce late pregnancy stillbirth. The SBB encourages health professionals to have conversations with women about their personalised risk profile, and how antenatal care can be individualised in line with those risks.

A range of woman-facing resources have also been developed under the SBB program, including flyers translated into 25 different languages and digital resources (such as animated waiting room videos). The resources are easily accessible through the SBB woman-facing website (Safer Baby Website) and have been tailored for First Nations (Stronger Bubba Born), Migrant and Refugee communities (as Growing a Healthy Baby).

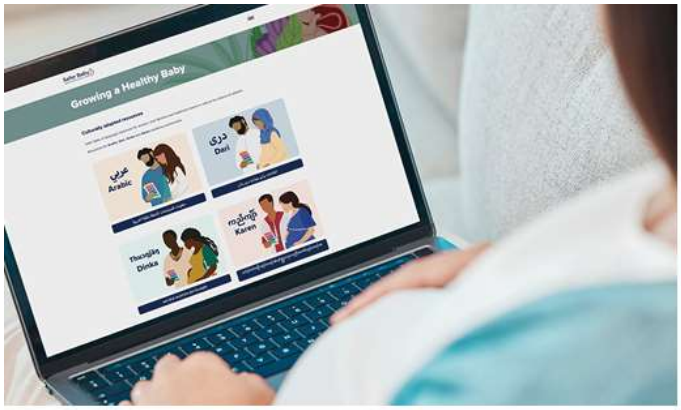
The SBB has successfully decreased the gap between what is *known* and what is *done* in maternity care to prevent stillbirth and allow women to have safer pregnancies. The SBB is designed to improve the care women and their families receive by targeting **five areas** where research shows lives can be saved. These are:

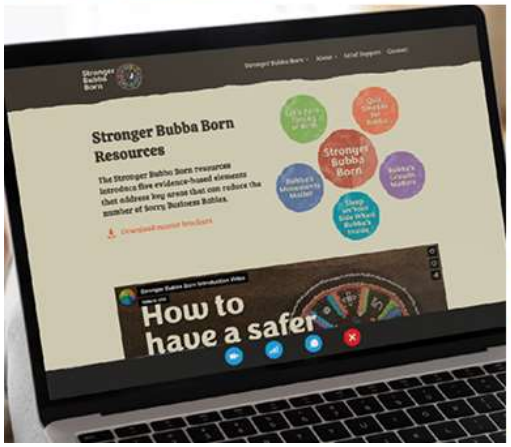
1. **Supporting women to stop smoking in pregnancy;**
2. **Improving detection and management of fetal growth restriction;**
3. **Raising awareness and improving care for women with decreased fetal movements;**
4. **Improving awareness of sleeping on either side after 28 weeks; and**
5. **Improving shared decision-making about the timing of birth for women with risk factors for stillbirth.**



Formal partnerships and collaboration with expert organisations and jurisdictional health departments have been established, including across all Australian states and territories with each represented on the National SBB Operational and Steering Committees. This sets the foundation for strong and ongoing national collaboration, which has already been crucial to ensuring the high visibility, acceptability and feasibility of a national rollout.

Broad consultations through the co-design process were crucial to achieving improvements in antenatal care at scale and have laid important foundations for scalable work. At various points, the culturally adapted resources were reviewed by the Stillbirth CRE Indigenous Advisory Group and the Migrant and Refugee Advisory Group. This resulted in tailored and culturally sensitive in-language resources (website, videos, booklets and digital audio booklets for Arabic, Dari, Dinka and Karen speaking communities. The First Nations resources (website, flyers and videos) reflect the language, illustrations and formats needed for these women, their communities and healthcare teams.





A key focus of the SBB is optimising care for all women by improving access to high-quality and culturally safe maternal healthcare. Despite substantial disruptions posed by the COVID pandemic, our evaluation shows that maternity healthcare professionals all over Australia have engaged well with the SBB initiatives and have improved their practices for monitoring and detecting if a baby is not growing well enough - a vital strategy to prevent stillbirth.

CASE STUDY 1 - Townsville Hospital

When you walk into Townsville Hospital you will quickly notice a strong adoption of the Safer Baby Bundle resources. Townsville Hospital was the site for the QLD launch back in early 2021. More than two years later, local midwives and mums have come to rely on the resources. Preliminary data has shown that these vital conversations with pregnant women about how to reduce stillbirths are now part of standard practice. These discussions cover education on maternal smoking, detection and management of fetal growth restrictions, maternal sleep positions, timing of birth and improved detection of impaired fetal growth.

Townsville University Hospital Midwife Teena Nuss said,

> ***"Not all stillbirths are preventable, but some are...If educating the women throughout their pregnancy on prevention measures saves just one baby from being born not breathing, then the launch of SBB has been successful."***

First time mum Sophie Kippin said the materials had been of immense help, and emphasised the importance of the care continuity - from her very first appointment and throughout her pregnancy - the midwife

> ***"kept coming back to it, which was really good because sometimes you forget among all the information you try to take in."***

The SBB E-learning program for health care professionals (HCP) was launched in October 2019. Since then, 18,325 clinicians have completed the program. The SBB eLearning program has successfully increased their reported knowledge and confidence to provide care to women on strategies designed to reduce stillbirth. After completing the program, most participants (more than 96%) reported having a sound level of knowledge and confidence to discuss each element of the SBB with women including the chance of stillbirth.

Participants also rated the eLearning module very highly in terms of suitability and acceptability, with almost all (98.3%) agreeing that it was helpful and relevant to their learning needs. The SBB eLearning has been made part of mandatory yearly education in many services.

Launched in February 2021, the **SBB Masterclass** is widely available to health care professionals and maternity services across the country. The SBB Masterclasses have been designed as a complement to the SBB e-Learning program and to be easily accessed by rural and remote health care professionals. The Stillbirth CRE Rural and Remote Advisory Group undertook pilot testing of the SBB Masterclass with clinicians from the Torres and Cape Hospital and Health service. To ensure the program was culturally appropriate, further consultation was undertaken with the Sillbirth CRE Indigenous Advisory Group and the Migrant and Refugee Advisory Group. The health care professional content has also been developed to ensure culturally appropriate care for First Nations, along with migrant and refugee communities as part of the Safer Baby Bundle. This content is currently in the process of receiving wider buy-in and endorsements from professional colleges.

The national roll out of the SBB has driven policy and practice change across all jurisdictions.

We have seen exceptional outcomes in Victoria, which was the first jurisdiction to implement the program. SBB was able to safely reduce the number of women experiencing late gestation stillbirth by 21 per cent[10]. As the first to roll out the SBB, Victoria's implementation began before COVID disrupted its roll out in other states and territories.

Data from NSW and QLD[11] has shown improvements in the frequency of performing best practice recommendations as a result of the SBB. Highlights include:

- Increased provision of advice on the benefits of quitting smoking to pregnant women (from 54.5% to 74.5%);

[10] Safer Care Victoria

[11] Internal evaluation data

- Assessing risk factors for growth restriction in early pregnancy (from 59.2% to 84.1%);
- Increased provision of information about maternal safe sleeping position (from 20.4% to 79.4%).

This is all complemented by an increased confidence amongst clinicians - noting that their level of knowledge and comfort discussing all five elements increased but most especially improved for timing of birth discussions. 85% agreed that the SBB recommendations had become part of their routine practice, had been well implemented at their service (75%) and improved the quality of antenatal care they and their service provides (70%). Reassuringly, no negative change in trends are observed for planned births before 39 weeks. Rates for late pre-term or early term births and rates for nursery admissions after 36 completed gestation weeks remains stable.

Nationally the rates for smoking cessation shows an encouraging trend toward improvement. In NSW, the smoking cessation rate went from 16% to 27% and, most recently, 29%. In Victoria, smoking cessation increased from 11% to 33% during the Safer Baby Collaborative time period.

Interviews with women have also shown that they view the SBB resources positively and agreed that these should be provided as part of 'routine care'. Women felt this information was important and that communication was enhanced by the consistency of messaging. Women agreed that raising these topics early and repeatedly throughout pregnancy was desirable and that they felt reassured and empowered when having conversations about stillbirth prevention and risk with their health care provider.

This brief summary of SBB only scratches the surface of its achievement - and its potential. For example, SBB is also enabling better reporting. While there is no nationally structured system or process to make timely and contemporary perinatal data available, some of that data is now available by virtue of the SBB evaluation and monitoring. SBB's scope reaches beyond interacting with the healthcare profession and parents to play a unique role in building timely access to data through its evaluation and monitoring. The lack of data remains a basic, yet significant, barrier to achieving and sustaining change.

The Stillbirth CRE is also working in partnership with **Women's Healthcare Australasia (WHA) to develop a Safer Baby Bundle clinical dashboard**, with the aim of sharing SBB performance indicator data with public maternity service leaders and clinicians by June 2024. The Stillbirth CRE will participate in a key stakeholder meeting being hosted by WHA in 2024 to explore how clinical data is being collected and shared to inform ongoing efforts to prevent stillbirth and preterm birth.

1.3 Established best practice - bereavement care and support

Stillbirth and neonatal death are devastating pregnancy outcomes with long-lasting psychosocial consequences for parents and families, and wide-ranging economic impacts on health systems and society. Up to 70 per cent of women will experience clinically significant grief-related depressive symptoms in the year after stillbirth. The care families receive around the time of loss is strongly linked to their recovery. The National Women's Health Strategy rightly calls out the need to provide mental health support for "women who experience miscarriage or stillbirth,"[12] along with an emphasis on prevention and early intervention.[13]

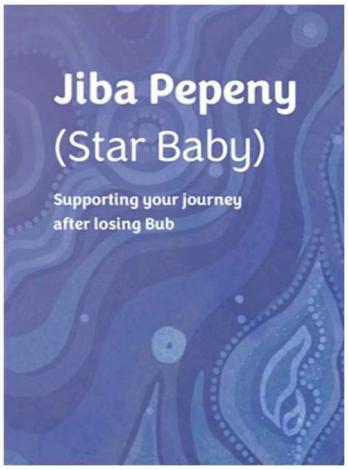
Through its work on bereavement care, the Stillbirth CRE has established a wide range of partnerships with parent-based advocacy and support organisations, including Stillbirth Foundation Australia and Red Nose. This has been critical to ensuring the voices of parents are heard throughout the development of resources. Crucial partnership and endorsement from professional organisations such as the Perinatal Society of Australia and New Zealand (PSANZ), the Royal Australian and New Zealand College of Obstetrics and Gynaecology (RANZCOG), the Australian College of Midwives (ACM), Women's Healthcare Australia (WHA), CRANAplus and Royal Australian College of General Practitioners (RACGP) helped establish high visibility, acceptability and feasibility of the Stillbirth CRE's national program of work on bereavement care.

Improving perinatal bereavement care is a global priority. The Stillbirth CRE's *Clinical practice guideline for care around stillbirth and neonatal deaths* provide recommendations designed to contribute to respectful and supportive perinatal bereavement care, including emotional, psychological, practical and physical support.

[12] National Women's Health Strategy 2020-2030, p26

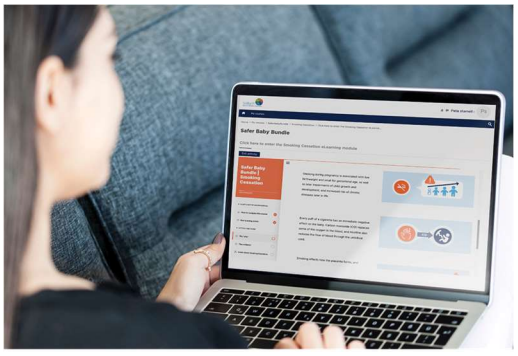
[13] Ibid, p37

Guidelines such as these are living documents that must be regularly updated and refined based on latest evidence. Parent-facing resources for general populations (Guiding Conversations) and for First Nations women and families (Jiba Pepeny), make this same information available to parents. As with the SBB work, these Guidelines and related documents also need to be adapted to the specific needs of those in rural, regionally remote and socially economically disadvantaged areas, Aboriginal and Torres Strait Islander families and families from migrant and refugee communities, as well as parents aged under 20 years.



Bereavement care needs to be holistic, individual and encompass clinical, community and cultural considerations. Best practice care at the time of perinatal loss is vital, but cannot end there. It needs to support the mother and family as they leave the hospital and return home without their baby. There is also a need for proactive approaches to ensure parents have access to the support they need during subsequent pregnancies. Given that subsequent pregnancy care primarily relies on GPs and frontline maternity care providers, we must ensure they are equipped for this challenging role.

Improving Perinatal Mortality Review and Outcomes Via Education **(IMPROVE)** is a national education program that addresses the training needs of health professionals involved in care around the time a baby dies. 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 five years. The IMPROVE eLearning module was officially launched on 4 November 2020 and updated in 2023. The online training supports healthcare professionals to provide best practice care for women and families who have experienced a stillbirth, including investigations and audits to determine causes and contributing factors relating to care. Perinatal mortality audits are fundamental to identifying substandard care factors in stillbirth.



Since the training became available in December 2019, nearly 3,000 (2,895) healthcare professionals have registered for the program and more than 2,000 have completed it.

CASE STUDY 2 - The perspective of bereaved parents - Heidi and Ned Mules share their story about baby Sophie

HEIDI - *"I have no recollection of anyone ever discussing stillbirth as a risk. With my limited knowledge, it's something that very rarely happened and it is not something to worry about.*

It doesn't need to be the biggest thing that is spoken about but it needs to be addressed because it is a risk."

NED - *"That conversation has to happen, we really should have been told."*

HEIDI - ***"I feel that the launch of the Safer Baby Bundle is well and truly overdue. The resources to clinicians are essential in what could have prevented our story from happening.*** *Awareness and education is so important, so I think it is fabulous that it is actually happening.*

If it wasn't a taboo word, if it is a phrase that is in the community, that the community is generally aware of, then the conversation that the clinician needs to have with a family is so much easier to initiate. It's important. Everybody needs to have that conversation".

2. THE POTENTIAL FOR STILLBIRTH CRE'S WORK OVER THE NEXT FIVE YEARS

Now that the foundational work on the Safer Baby Bundle and the *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (CASaND)* is complete, this pre-budget submission seeks to **bolster the dissemination of this best practice through approaches and resources that are tailored to priority communities.**

The Stillbirth CRE's collective work to date demonstrates significant, measurable progress but also allows wider reach by applying these materials more broadly and consistently across practice, with a special focus on priority populations.

This significant work needs to be treated as a living document that can be updated and adapted to different communities over time. For example, our proposal for funding to ramp up implementation and dissemination of the Safer Baby Bundle would help ensure we continue to build on this important work and expand its reach. Similarly, the CASaND guidelines exist and are proven - but the consistent application and take up needs to be the focus of a comprehensive implementation strategy to reduce the "lottery of care" referred to earlier.

Stillbirth CRE is uniquely positioned to significantly scale up integration, implementation and dissemination of these best practice models, with a focus on addressing disparity. The following policy items are fully costed by the Stillbirth CRE and would help accelerate progress against the NSAIP, while also supporting key aims of the National Women's Health Strategy 2020-2030.

2.1 Building on the success of Safer Baby Bundle

2.1.1 Ongoing implementation support

The extensive suite of materials and resources encapsulated in the SBB program have now been culturally adapted for First Nations, migrant and refugee communities, as well as translated in 25 different languages for targeted use in migrant and refugee communities. SBB presents great potential for an ongoing impact and provides an extensive platform of evidence based resources that can be practically applied. Yet this work cannot stand still. It is vital that the Stillbirth CRE and its partners can continue to update, develop and disseminate the SBB more broadly, and most particularly amongst priority communities.

Having now established a range of Indigenous, migrant and refugee cultural

adaptations of the SBB, an additional budget would allow us to ensure the materials reach and are effectively integrated and embedded within the communities who need them, as well as expand resources for the benefit of other priority groups.

CONTINUED FUNDING FOR VITAL PREGNANCY SUPPORT THROUGH THE SAFER BABY BUNDLE (over 5 years)	
Dedicated staff Including clinical leads, midwives, implementation coordinator, research assistants and project officers	$2,420,957
Resources for clinicians (through education programs), parents and evaluation Including further cultural adaptation, translations and timing of birth resources	$400,000
Running costs Data support through WHA, IT and miscellaneous administration costs	$335,000
Communications and promotion Stakeholder communications, targeted social campaigns, website enhancements, digital content creation and printed resources	$400,000
TOTAL	**$3,555,957**

The above provide only initial options, noting that there are also opportunities to develop new modules as new evidence emerges, covering topics such as diabetes, obesity and late gestation monitoring for South Asian women (MRFF trial submission awaiting outcome) and optimal approaches to shared decision making about timing of birth to reduce stillbirth (Evaluation of a Decision Aid is underway and will be reported in 2024).

2.1.2 SBB Roadshow Clinics - Taking Safer Baby Bundle resources to priority populations in hard to reach communities

Under this proposal, Stillbirth CRE would plan, coordinate and deliver a National Roadshow to engage and equip priority populations. The Stillbirth CRE and its partners would stage a wide series of tailored workshops to build awareness

amongst clinicians and parents. This work would enable face-to-face delivery of key education modules, providing opportunities to connect with people in their communities.

This face-to-face delivery would provide an important opportunity to train and educate within priority populations, including in regional and remote communities. Recognising the range of needs across different priority populations, the Roadshows would adapt to the community they are visiting. For example, a Roadshow visit to Western Sydney would leverage the migrant and refugee resources, while a Roadshow visit to Ceduna would leverage the First Nations resources. The Roadshows would also provide a valuable opportunity for Indigenous healthcare professionals to build cultural knowledge and understanding amongst non-Indigenous healthcare professionals. Cultural safety is not just a checklist or a manual - it is about establishing a level of trust between healthcare providers and Indigenous families. A culturally unsafe environment can deter Indigenous people from seeking care in their subsequent pregnancies.

Enabling culturally safe care is a massive step forward in reducing the healthcare disparities that Indigenous communities face - this is an essential component of care. Indigenous communities have specific social, emotional and health needs that are deeply rooted in their culture and history. The Roadshow will enable better connections and insights into Aboriginal and Torres Strait Islander communities, and more interaction between Indigenous and non-Indigenous healthcare professionals.

The Roadshow clinics would raise awareness, as well as link the community up with SBB resources and other tools to stay in contact with Stillbirth CRE. This engagement would include the basics for healthcare professionals - such as a binder of SBB printed resources for easy reference in maternity wards and posters for clinics, along with woman-facing materials that can be downloaded on mobile phones and referred to later, even when out of network range.

Having just launched a range of new, culturally adapted materials, Stillbirth CRE stands ready to operationalise a Roadshow as soon as possible. The Roadshows provide an opportunity to disseminate Stronger Bubba Born and the translated migrant resources in key, targeted communities of priority populations and rural and regional areas that might not have previously experienced the benefits of the Safer Baby Bundle materials.

We also see a really important opportunity to incorporate a range of community stakeholders, such as cultural and religious leaders. Stillbirth CRE would also alert Local MPs and Federal Ministers when the Roadshow visits their local community. MPs and Ministers play an integral role in connecting different parts of the community and we want them to play a big role in disseminating the SBB

materials to those who can best utilise the information. Their understanding and awareness of the maternity care continuum, and the importance of the SBB resources in their communities, will play a highly constructive role in embedding best practice locally.

The Stillbirth CRE team would also seek to build ongoing relationships with the healthcare professionals, mothers and families who attend the Roadshow clinics. This would ensure that the Stillbirth CRE and its local partners can continue to leverage the initial face-to-face contact by continuing to update and upskill these priority communities, from a distance and over the long term.

ROADSHOWS TO PRIORITY POPULATIONS	
Clinical lead and midwifery consultant	$2,810,598
Jurisdictional support	$400,000
Educators and their travel (including additional modules for Aboriginal and Torres Strait Islander communities, as well as Migrant and Refugee communities)	$329,600
Community event logistics and materials	$260,000
Communications and engagement with the priority populations, stakeholder communications, content creation for local media, printed resources and targeted social media	$350,000
TOTAL	**$4,150,198**

Embedded in this program of work is funding to support the inclusion of Stronger Bubba Born resources in the Certificate 4 in Aboriginal Torres Strait Islander Health Practitioner.

Additional funding to further expand migrant language groups, support a national clinician education approach and establish a new National Multicultural SBB Network would complement the work of the Roadshow and could be carried out for a further $1.92 million over five years.

2.1.3 Baby Buddy – For mums

Baby Buddy is an evidence based mobile phone App that has been developed in the United Kingdom through a partnership between health professionals and consumers.

With support from the Department of Health, the Stillbirth CRE has already adapted the Baby Buddy app to the Australian context so that it aligns with current Pregnancy Care Guidelines and links to Australian health resources from early pregnancy, through to the first four weeks post-natal.

Enhancing its functionality and providing universal access to Baby Buddy would improve the capacity of families to make informed decisions about their health and care options, as well as provide tailored information from their local maternity services. An expanded Baby Buddy would leverage existing resources and increase access to antenatal education - which would relieve pressure on already overburdened GPs and maternity services. This could be further achieved by extending the App through the first year of life.

In line with the Stillbirth CRE's previously funded work on Baby Buddy, we would continue to work closely with our colleagues in the UK to further develop and adapt the Australian version.

In time, the Baby Buddy App would act as a perfect complement to the Roadshows. Where the Roadshows would provide the face to face introduction to this sensitive topic, the App would offer a parent-facing point of contact for follow up and education. The App is ideal for difficult to reach populations, where they can download the information and then access it when needed (whether or not they have internet coverage).

UNIVERSAL ACCESS TO BABY BUDDY - OVERLAID WITH PRIORITY POPULATION TARGETING	
Dedicated digital and content team Full time staff members, including a Head of Digital, Head of Content, Digital Lead Content Write and support staff	$716,800
Project Management, coordination and strategic support Including scoping for appropriate program modeling, admin and legal support	$640,632
App development, hosting and maintenance **Communications, Design and Branding** To help profile availability of the app, and ensure consistency	$216, 510

Communications, design and branding	$38,720
TOTAL	**$1,612,662**

Working in tandem, the Roadshows and the Baby Buddy App would provide a good demonstration of proportionate universalism in health policy. While universally accessible, the App's profile and scale would be targeted at priority populations, proportionate to the level of disadvantage. The Roadshows would be targeted at providing communities with low or no literacy materials in a form they can understand and apply, through pictures and animations.

2.1.4 Tommy's Clinical Decision Tool - for healthcare professionals

Each year in Australia more than 9,000 pregnancies are impacted by pre-eclampsia (PE), 27,000 babies are born preterm and 2,200 babies are stillborn. Many of these are preventable.

Despite strong evidence for risk prediction models and effective interventions, rates vary significantly between hospitals. There are limitations within current pregnancy risk assessment - and progress is impeded by the lack of translational tools.

An effective clinical decision support tool will help ensure every Australian woman receives the right care, at the right time to improve maternal and perinatal outcomes. In the United Kingdom, the Tommy's Clinical Decision Tool (Tommy's Tool) is shared between healthcare professionals and pregnant women to facilitate the delivery of the highest possible standard of care.

The tool integrates three clinically effective prediction models to enable personalised risk-based management of women at increased risk of PE, pre-term birth and stillbirth; one for placental disorders (PE, stillbirth) and two for preterm birth (one at the beginning of pregnancy and another during pregnancy if women present with symptoms indicating preterm labour). These algorithms have already been externally validated and comply with current national and international guidelines.

The following outlines the various costs associated with building the tool here in Australia. These costs are largely staff costs, but will also involve key IT support, particularly when the program is scaled across six different hospitals. Key here will be ensuring seamless integration into the healthcare infrastructure. The funding will cover cloud data hosting, secure and accessible storage of patient information and ongoing IT support to maintain the tool's efficiency.

CLINICAL IMPLEMENTATION OF "TOMMY'S TOOL" IN 6 AUSTRALIAN HOSPITALS OVER THREE YEARS	
Key staff, including: Project and Education Manager; Data and Quality Control Manager; Site midwifery coordinators; Biostatistician; and Health Economist.	 $612,554 $597,447 $1,00,000 $41,013 $28,553
Consumer representatives remuneration	$20,000
Training related costs	$172,550
IT implementation, data hosting and maintenance	$476,000
TOTAL	**$2,948,117**

In time, the Stillbirth CRE and its partners envisage that the Baby Buddy App and the Tommy's Clinical Tool will work seamlessly together on one, comprehensive, maternal digital portal. The portal will be aligned with the digital pregnancy records and will enable further research and insights that can help prevent perinatal loss. These two proposals are key to building the infrastructure needed to help inform and understand the maternity care continuum.

2.2 Expanding the perinatal loss care pathway to all those who need it

The care provided to parents during and after stillbirth influences how they cope and recover. While best practice national guidelines and standards of recommended care have been established, their widespread and consistent application is vital to ensure that parents are receiving the best possible care - regardless of where or when perinatal loss occurs.

The bereavement care trajectory begins in maternity settings but extends well beyond and includes subsequent pregnancies. Unfortunately, the gap in care between hospital and community has been recognised for some time, with many parents feeling abandoned and unsure of how and where to locate support.

CASE STUDY 3 - Remote communities and the journey home

Parents in remote communities experience this on a whole other level. Many of these women need to travel to capital cities to receive appropriate maternal support and care. In the event of a stillbirth, bereavement care needs to incorporate their journey back to their community, without their baby. In the case of one Aboriginal woman we worked with, the journey home included a 12 hour bus trip from Adelaide to a remote area. Her local GP needed to support her adjustment home from hospital - recognising that women grieving their loss are also experiencing the physical outcomes of having just given birth, including bleeding and lactating.

Bereavement care offerings also need to be mindful of the fact that 80 per cent of women who have experienced a stillbirth become pregnant again within 12 months. Women who have had a previous stillborn baby have a five-fold increased chance of having a stillborn baby in their next pregnancy. They also have an increased risk of pre-term birth, low birthweight, placental abruption, pre-eclampsia, gestational diabetes and other adverse pregnancy outcomes. In addition, many women experience high levels of anxiety in subsequent pregnancies.

There is a priority need to build on the CASaND Guidelines by ensuring care follows parents from the maternity setting to their home and community. Now that these Guidelines are established and proven, there is also a need to ensure that more women can benefit from them. We believe these guidelines should be instigated for women who present to hospital after a miscarriage; and that elements of this support needs to carry through to subsequent pregnancies.

Red Nose estimates that there are 110,000 miscarriages a year but, because there is no formal mechanism by which a parent can report or register a miscarriage, we have no accurate figure on how many women and families endure a miscarriage. The number of women who present to hospital for miscarriage management is also unknown, but clearly warrants much further investigation.

And while there is a standard six week post-partum check up, there is nothing readily available for parents who experience a miscarriage.

By applying the CASaND Guidelines to this broader audience, we can tap into a previously unknown and unsupported population of women, while also gathering much-needed data on miscarriages. This can only be achieved by broadening the dissemination of the Guidelines beyond maternity wards, to include GPs and emergency nursing staff.

An expanded remit for the Stillbirth CRE's existing work can quickly help resolve these key challenges, and better support women and families who experience perinatal loss each year. This could include: the currently unknown number of women who present to hospital for miscarriage management; the more than 2,200[14] who experience stillbirth a year; the more than 700 who experience neonatal deaths each year[15]; and the more than 1,800 women who become pregnant again within 12 months of experiencing stillbirth. As we have seen with the SBB program, this level of support can also help us build an informative data source around the maternal experiences of women and families, which helps us support them and others better.

2.2.1 National Perinatal Loss Care Pathway

A centralised one-stop portal for healthcare professionals, services and bereaved parents and families would make meaningful gains in the way Australian practitioners facilitate the consistent application of best practice bereavement care.

A National Perinatal Loss Care Pathway would cover the period from pregnancy, to one year after birth, and then support parents with subsequent pregnancies and extend the reach of Stillbirth CRE best practice to more than 100,000 families.

The centralised portal would ensure all services, healthcare professionals and families have access to evidence-based guidance and resources for care. The National Perinatal Loss Pathway would include:

- Guideline and care pathways, including expansion to cover early pregnancy loss and a focus on priority populations (in line with IMPROVE);
- Standardised evidence-based resources accessible to all parents and clinicians (via the toolkit, digital and printed copies, along with cultural adaptation of key resources);

[14] Australian Institute of Health and Welfare, Table 4.1

[15] Ibid

- Clear referral pathways to bridge the gap between maternity and community-based services by raising healthcare professional and parent awareness of the value of community services and options available, including building capacity in primary care settings through development of HealthPathways for care around perinatal loss;
- Minimum training and education standards for all services "centres of excellence" via the IMPROVE training; and
- Education and support for service quality improvement through perinatal mortality audit, including improvement in national reporting requirements.

Taking a proportionate universalism approach and utilising a co-design process, our focus is on all parents affected by perinatal loss (including in a subsequent pregnancy) with additional and targeted attention to those with the highest need (including Aboriginal and/or Torres Strait Islander parents and families, South Asian and African-born families, and families from rural and remote communities).

Stillbirth CRE would deploy its strong record in co-design to ensure the portal is fit for purpose and provides targeted information and attention to those with the highest needs.

NATIONAL PERINATAL LOSS CARE AND PATHWAY TOOLKIT (over 5 years)	
National hub This new custom-built portal will provide user-friendly access to the Guidelines, national care pathway and evidence based resources (compatible with smart phones for parents seeking support referrals) including an online educational program on conducting high quality perinatal audit and a service to respond to specific queries on the process of audit and classification. Funding includes IT and build costs.	$639,650
Co-design and develop a customisable national care pathway The pathway will build on, and align with, the IMPROVE program update and Guideline implementation and include an implementation toolkit.	$2,309,391
Expansion of CASaND guideline to include early pregnancy loss To include a parent-facing version of the guidelines for early pregnancy loss and align with IMPROVE program update and incorporate into the national care pathway.	$650,232

Evidence-based resources in digital and printed formats Printed copies of *Guiding Conversations* and *Joba Pepeny: Star Baby* to be provided to all Australian maternity facilities (3,500 copies per year, plus distribution costs = $25,000 per year by two resources = $50,000)	$520,000
Expansion of the Living with Loss online bereavement program This will include a greater focus on early pregnancy loss and miscarriage, a new focus on parents in pregnancy after loss and its evaluation as a self-guided and guided support program within a stepped-care model by parent organisations. This will help reduce long waiting lists, and extend reach into rural areas where services are limited.	$2,079,427
Lived experiences national Consumer Engagement Group This builds on the work of the Stillbirth Research Involvement Registry and includes funding for the relevant coordinator roles.	$436,862
Clinician research placement Bereavement midwife clinicians rotating through every six to twelve months in capacity and backfill capacities.	$440,316
Communications and promotion Stakeholder communications, targeted social campaigns, website enhancements.	$150,000
TOTAL	**$7,225,878**

The proposals above would build on the Stillbirth CRE's existing programs and serve to bring together the communities that support women and families through perinatal loss - covering early pregnancy, miscarriage and stillbirth as well as preparing for, and navigating, subsequent pregnancies.

These policy adjustments would take us a long way toward ensuring women, families and babies are supported across the maternity care continuum, with continuity and consistency. It would also serve to build our knowledge and understanding of this life-stage so that we can better support healthcare professionals, women and families during this time.

CONCLUSION

The Stillbirth CRE was established to help address the "heavy burden" of stillbirth with the aim of identifying and disseminating best practice, raising public awareness, and informing stronger responses to stillbirth. This includes respectful and supportive care for women and families when stillbirth occurs.

With so much important foundational work achieved in its first phase, the Stillbirth CRE and its many partners are well-placed to now ramp up implementation and dissemination.

The policy options provided in this pre-budget submission outline the various ways that we can address the "enduring challenges" posed in the recent Nous evaluation of the NSAIP, while ensuring we continue to support the progress of the National Women's Health Strategy over the next five years.

This submission has outlined the ways that the Australian Government can continue to be a world leader in stillbirth prevention and care by ensuring the compelling work completed so far is more broadly implemented and adopted, particularly amongst priority populations.

We know that stillbirth and other adverse pregnancy outcomes disproportionately affect Aboriginal and/or Torres Strait Islander women, women living in remote settings, and women of migrant and refugee background, particularly those from countries in South Asia and Africa and young women.

We also know that the care provided to parents during and after stillbirth influences their long term social and emotional recovery. Many parents will become pregnant again within a year of the death of their baby and these subsequent pregnancies present an increased risk of a range of obstetric complications and adverse pregnancy outcomes. Understandably, high levels of anxiety, depression, and fear are common during subsequent pregnancies.

The Stillbirth CRE has demonstrated its strength in co-design and collaboration. We have translated excellent research into practical, accessible and actionable resources for women and healthcare professionals. In doing so, we are bridging the gap between what is *known* and what is *done*; we are bridging the gap between the knowledge of healthcare professionals and the understanding of women and families; and we are raising the previously silent voices of bereaved parents to ensure we support them better, and learn from their experiences for the benefit of others.

There is so much needed to strengthen maternal health equity and ensure continuity across the maternity care continuum. Where we cannot prevent stillbirth, we can do better to provide the support needed for women and families

to recover.

We call on the Australian Government to continue its investment in the wellbeing of women and families through the range of policy options presented and costed in this submission.

APPENDIX 1 -

POLICY OPTIONS SUMMARY TABLE

Policy recommendation	$ Costing (over five years*)
Continued funding for vital pregnancy support through the Safer Baby Bundle	3,555,957
Safer Baby Bundle Roadshows to priority populations	4,150,198
Universal access to Baby Buddy - overlaid with priority population targeting	1,612,662
Clinical implementation of "Tommy's Tool" in 6 Australian hospitals over three years	2,948,117
National Perinatal Loss Care and Pathway Toolkit	7,225,878
TOTAL	19,492,812

*unless specified otherwise in the recommendation column

APPENDIX 2 -

ANNUAL COMMONWEALTH FUNDING BETWEEN 2016 AND 2026