Stillbirth Foundation Australia

PERINATAL SOCIETY of Australia & New Zealand
PSANZ

SANDA
Stillbirth And Neonatal Death Alliance
a sub committee of PSANZ

Stillbirth
CENTRE OF RESEARCH EXCELLENCE

NATIONAL STILLBIRTH RESEARCH PRIORITIES

REPORT

2023

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EXECUTIVE SUMMARY

Stillbirth is a public health issue that has far-reaching impacts on families and their communities. Every day in Australia, six babies are born still; a statistic that has remained unchanged for decades. 15% of all stillbirths remain ‘unexplained’ and with limited understanding of placental dysfunction, which often leads to unexpected stillbirth, further research into causal pathways is vital to reduce stillbirth rates. With greater understanding, research can be translated into clinical practice to improve maternity care and newborn outcomes. For those who experience the tragedy of stillbirth, research is required to ensure best practice care is provided. The National Stillbirth Action and Implementation Plan (NSAIP) sets out to reduce preventable stillbirth rates by 20% or more in Australia by the year 2025 and to ensure respectful and supportive bereavement care is available when stillbirth occurs. To achieve this vision and continued improvement beyond 2025, a collaborative priority-driven program of research is needed. To this end, the NSAIP aimed to ‘establish agreed national priorities for stillbirth research for the next five years’ as a short-term priority, building on the work of the NHMRC Centre of Research Excellence in Stillbirth (Stillbirth CRE) and the Perinatal Society of Australia and New Zealand (PSANZ).

The purpose of this exercise was therefore to undertake wide consultation across Australia to establish research priorities for stillbirth. Determining research priorities helps to reduce research wastage by enabling a cohesive and agenda-driven research program that is relevant to those most affected. These research priorities have been identified as the most pressing areas to be addressed. This was the first step towards the short-term goal of 'improved coordination and awareness of stillbirth research’ set out in the NSAIP Monitoring and Evaluation Framework. Effective partnerships are critical to this aim.

This national stillbirth research priority setting (RPS) was led by the Stillbirth CRE, in partnership with PSANZ and Stillbirth Foundation Australia. The RPS process was guided by a steering committee, appropriate advisory groups and skilled facilitators to ensure that it was a robust approach. Over 150 research priorities were proposed by over 200 participants across the nation. This included representation from bereaved family members, maternity consumers and members of community-based support organisations, healthcare professionals, researchers in the field and policy makers. Their breadth of experiences and knowledge informed the resultant priorities.

CONSULTATION REFINEMENT PRIORITISATION

2020 2023

200+ Participants | 152 Questions | 6 Priority Areas

An iterative approach of consultation, refinement and prioritisation was taken between 2020 and 2023. There were multiple methods of consultation including multiple key stakeholder forums, an online survey and targeted workshops with bereaved parents, Aboriginal and Torres Strait Islander community workers and bicultural workers from migrant and refugee communities. Six overarching priority areas were determined with specific research questions sitting beneath each.

The national stillbirth research priority areas are:

A Determine the causes of, and pathways that lead to stillbirth

B Identify and implement strategies to prevent stillbirth

C Build the capacity of health services and systems

D Understand and improve care for families after perinatal loss

E Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families

F Ensure culturally safe and responsive care for migrant and refugee communities

These priorities are intended to be addressed by anyone generating or translating stillbirth research in Australia. Critical to these efforts is strong collaboration, including all stakeholders and strengthening the engagement of bereaved families. This will provide the greatest potential to build on existing research and translate findings into policy and practice. Values of collaboration, co-production, equity and diversity will ensure that these priorities have the greatest impact possible on the future of stillbirth research, which results in improved care and outcomes for families in Australia. We have identified key requirements to ensure that these priorities can be adequately addressed. Sufficient resourcing via a range of approaches and funding mechanisms is key to the successful execution of these research priorities.

The key recommendations resulting from this RPS are:

Allocate funding to these research priority areas in stillbirth

Support a stillbirth research registry to enhance research capacity building and effectiveness, and reduce research wastage

Engage and involve bereaved families and pregnant patients in all research activities to ensure research is meaningful and relevant

Strengthen collaborations between community-based and research organisations to enhance engagement of priority populations

Evaluate the impact of these research priorities over the next five years

ACKNOWLEDGEMENTS

We acknowledge the Traditional Owners of this land and their ongoing custodianship. We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country. We acknowledge the diversity across Aboriginal and Torres Strait Islander cultures, language and practices and that it is vital that all health care services respectfully manage protocol and provide a culturally positive health care experience for Aboriginal and Torres Strait Islander people when going through Sorry Business.

We acknowledge all the parents and family members affected by pregnancy and infant loss. While this project and subsequent report focuses on stillbirth research priorities, we highlight that the work we do in this area will contribute to all pregnancy and infant loss research. We acknowledge the parents who have lost a baby at any gestation, including early pregnancy loss (miscarriage), termination of pregnancy for medical reasons and newborn death; and thank them for contributing their views to this project.

By sharing their experiences of immeasurable loss, their babies have contributed to the future of prioritising stillbirth research and working towards a shared vision to ensure all babies in Australia come home in their parents' arms.

We also thank Kit and Blake Norrish for donating their time to thoughtfully design this report in honour of their son, Arlo.

RESEARCH PRIORITY SETTING TEAM

This Research Priority Setting (RPS) would not have been possible without the individuals and partnering organisations across Australia who participated in the consultations and prioritisation process. Thank you for lending your voices. Thank you to those who disseminated the information to help us reach this community. We would like to thank the members of the RPS Steering Committee, Parent Advisory Group and our facilitators, for guiding this process with exemplary leadership and dedication.

Project Team

Kirstin Tindal, Fran Boyle, Christine Andrews, Chrissie Astell, Dominah Devadas, Vicki Flenady

Steering Committee

Adrienne Gordon, Ashleigh Rousseaux, Belinda Jennings, Billie Bradford, Caroline Homer, Carrington Shepherd, Christine Andrews, David Ellwood, Deanna Stuart-Butler, Fran Boyle, Jonathan Morris, Kirstin Tindal, Miranda Davies-Tuck, Philippa Middleton, Robin Cronin, Sailesh Kumar, Sean Seeho, Siobhan Loughnan, Sue Walker, Vicki Clifton, Vicki Flenady

Parent Advisory Group

In 2022, we formed a parent advisory group to inform the RPS process and ensure that parent voices were central to all aspects of the project. The group comprises researchers in varying disciplines from across Australia who are the parents of babies born still.

Danielle Pollock, Brad Farrant, Kirstin Tindal, Fatima El-Assaad, Ashleigh Rousseaux, Aditi Lohan

Facilitators

Thank you to the facilitators who guided this process. Their broad expertise and experience across setting research priorities has been incredibly valuable in facilitating considerate and comprehensive discussions with all stakeholders.

Jane Yelland, Deanna Stuart-Butler, Sarah McIntrye, Bec Jenkinson

FOREWORD

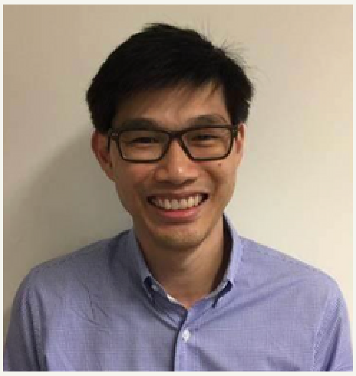
Stillbirth CRE Co-Director, *Vicki Flenady*

Every 16 seconds around the world, a baby is stillborn, and a family is forever changed due to this enormous loss. Stillbirth has been a hidden and poorly understood tragedy for too long, leaving many parents to grieve in unbearable isolation surrounded by stigma. Better understanding of stillbirth, through research and parent voices, has led to the change we are now beginning to see in Australia and around the world to reduce stillbirth rates and the burden of this loss through better bereavement care. But more needs to be done, with six stillbirths in Australia and another two babies who die in the neonatal period every day. Aboriginal and Torres Strait Islander, as well as migrant and refugee families, very young women and those living in rural and remote regions also experience a much higher burden. Focusing our collective efforts to address priority areas of research, from discovery science to unfold new techniques and interventions, through to implementation research to reduce the gap between what is known and what is integrated into everyday care to address stillbirth is everyone’s business. In this exercise, we have brought together the Australian community to set priorities. It is now our responsibility to work together to address each and every one to reduce the number of families who experience this devastating loss. I want to thank all the parents who generously participated in this work and acknowledge the legacy of their precious babies.

Project lead, *Kirstin Tindal*

It has been such a privilege to be a part of this process and witness the important and heartbreaking conversations that took place about stillbirth. These are the things that our community has said they want researched and answered as a matter of top priority. It’s important to highlight that all pregnancy and infant loss has profound impacts on the entire family, the workplace, the healthcare system and the economy. This research must be addressed to meet the needs of this community and equip healthcare workers and services with the training and resources required to improve newborn outcomes and provide best possible care to families. This research priority setting was a huge team effort and a prime example of working collaboratively to make change. These priorities have been determined in honour of all the babies gone too soon and whose little lives will contribute to this national stillbirth research agenda.

FOREWORD



Stillbirth Foundation Australia Chair, *Sean Seeho*

Stillbirth Foundation Australia wholly endorses the 2023 National Stillbirth Research Priorities Report. The publication of the national priorities for stillbirth research for the next five years is a key step in reducing stillbirth and improving the care of every person impacted by stillbirth in Australia. It is specially pleasing that the priority research areas include research questions that address particular knowledge gaps for Aboriginal and Torres Islander women and families, and those from migrant and refugee backgrounds. That bereaved parents were central to the development of these national research priorities has ensured that they are relevant and meaningful to those most affected by this tragedy. Stillbirth Foundation Australia extends its immense gratitude to the bereaved families who shared their stories and provided a powerful voice to this important work. This publication provides sage guidance for researchers to focus their efforts on areas where the evidence gap is most needed. Stillbirth Foundation Australia is confident that significant discoveries will be made in the years ahead, and it is fully committed to partnering with researchers and families in this quest.

PSANZ President, *Miranda Davies-Tuck*

The Perinatal Society of Australia and New Zealand is proud to partner in this important work with the Stillbirth CRE and Stillbirth Foundation Australia. This work brings together researchers, clinicians, and families to identify the future priorities in stillbirth research. Sadly, stillbirth disproportionately impacts Aboriginal and Torres Strait Islander as well as migrant and refugee families. This process therefore prioritised the development of culturally safe care to both reduce stillbirth rates and improve care after loss. We hope this will address the disparities in outcomes experienced and will be best placed to provide culturally appropriate bereavement care to support families who do experience this devasting outcome.

GLOSSARY

Terminology

Women and gender-diverse people

Where appropriate, we use the term ‘women and gender-diverse people’ in acknowledgement and respect that not all pregnant people identify as women. We acknowledge that the experience of stillbirth affects everybody differently and have used the term ‘women and gender-diverse people’ specifically when the research question relates to antenatal care and the pregnant mother.

Bereaved parents

We use the term bereaved parents or families wherever possible to include the experience of the non-birthing partner and acknowledge that stillbirth can also have far-reaching impacts on the entire family and community.

Perinatal loss

Please also note, that we often use the term ‘perinatal loss’, which in Australia, encompasses stillbirth (the death of a baby after 20 weeks’ gestation or weighing greater than 400g, including termination of pregnancy) and neonatal death (the death of a baby in the first 28 days of life).

Acronyms

ACRA
Aboriginal Communities and Families Research Alliance
AMIC
Aboriginal and Maternal Infant Care
CASaND
Care After Stillbirth and Neonatal Death
CRE
Centre for Research Excellence
DoHAC
(The Commonwealth) Department of Health and Aged Care
IAG
Indigenous Advisory Group
FGR
Fetal Growth Restriction
MCWH
Multicultural Centre for Women’s Health
NHMRC
National Health and Medical Research Council
NSAIP
National Stillbirth Action and Implementation Plan
PSANZ
Perinatal Society of Australia and New Zealand
RPS
Research Priority Setting

PURPOSE OF THIS REPORT

This report has been prepared for the Department of Health and Aged Care (DoHAC) in line with the reporting requirements of the National Stillbirth Action and Implementation Plan (NSAIP)[1]. This project contributes towards Action area 13 of the NSAIP with the goal of ‘establish(ing) agreed national priorities for stillbirth research for the next five years, building on the work of the Perinatal Society of Australia and New Zealand (PSANZ) and the NHMRC Centre of Research Excellence in Stillbirth (Stillbirth CRE)’. This was a short-term implementation task of the NSAIP with a targeted completion date of 2023, which has now been achieved. This report summarises the RPS process, outcomes and recommendations following the identification of national stillbirth research priorities.

INTRODUCTION

Within Australia, six babies are born still and another two die in the neonatal period (within 28 days of birth) every day; a statistic that has remained unchanged for decades, making stillbirth the most common form of infant death in Australia[2,3]. Further research is required to meaningfully reduce these rates and to ensure best practice care following a stillbirth. The NSAIP[1] recognises stillbirth as a public health issue and was developed in response to a recommendation of the Senate Select Committee on Stillbirth Research and Education Report[3]. This report identified the need to establish a set of national stillbirth research priorities for the next five years. This recommendation to identify national research priorities will contribute to the NSAIP, which aims to reduce preventable stillbirth rates by 20% or more by the year 2025 in Australia[1].

RPS exercises for stillbirth in Australia have been undertaken previously, drawing on the work of the Lancet Series addressing stillbirth[4,5] which helped to inform the research program of the Stillbirth CRE. The 2015 RPS involved two multi-stakeholder prioritisation exercises including a survey of Australian parents and healthcare professionals and a consultation with policy makers and researchers[6]. The 2015 list of research priorities is presented as Appendix A.

This coordinated research agenda formed the foundations of a bid for funding from the NHMRC to establish the Stillbirth CRE, which has addressed these priorities since its establishment in early 2017. The Stillbirth CRE has now reevaluated these research priorities in partnership with Stillbirth Foundation Australia and PSANZ. The expected outcomes of this renewed research priority setting are 'improved coordination and awareness of stillbirth research’ (short-term) and ‘increased research capability into stillbirth prevention and care’ (long-term)[7].

These key indicators in the NSAIP monitoring and evaluation framework will be measured by an ‘increase in the number of research projects in, and amount of funding granted to, the stillbirth priority research areas’[7]. The set of stillbirth research priorities proposed in this report will enable ‘a cohesive national approach to research into prevention of stillbirth and improvement of bereavement care [and] is crucial to inform the evidence base in relation to stillbirth and ensure the best possible outcomes for families’[7].

THE RESEARCH PRIORITY SETTING PROCESS

This RPS initiative was accomplished via three phases: consultation, refinement and prioritisation. Consultation began in 2020 and involved an initial online workshop with key stakeholders, followed by an online survey. Aboriginal and Torres Strait Islander and Migrant and Refugee forums were held independently to consult the appropriate stakeholders throughout 2020.

Following COVID-19 disruptions and reflection by RPS project team members on the project activities completed so far, further engagement with bereaved parents was considered essential to inform the final list of priorities. The next steps of the project were developed in response to this recommendation. Comprehensive consultation with bereaved parents was essential to ensuring that the research priorities that were determined were relevant and meaningful to those most affected by stillbirth.

Other key stakeholders including researchers, healthcare professionals, policy makers and members of community-based parent support organisations were invited to revise the proposed research priorities in 2023, given that priorities may have changed since 2020. The research questions identified during these extensive consultations were then collated and refined into a preliminary set of research priorities.

This preliminary list was disseminated in a prioritisation survey via previously engaged organisations and networks and was shared on social media by community-based support organisations with large followings of bereaved parents (e.g. Stillbirth Foundation Australia, Bears of Hope). The findings of this survey informed a shortlisted set of priority questions. The shortlist was presented at a final forum, where a multidisciplinary group of representatives reviewed the questions and voted to determine the final list of stillbirth research priorities by consensus.

THE PRIORITY SETTING PROCESS

200+
Participants

152
Questions

6
Priority areas

CONSULTATION

JUL 2020
Initial workshop
46 participants **18** questions

JUN-JUL 2020
Migrant and Refugee forums
15 participants **10** questions

SEP-OCT 2020
Online survey
64 participants **14** questions

SEP 2020 + FEB 2021
Aboriginal and
Torres Strait Islander forums
33 participants **6** questions

AUG 2023
Bereaved parent workshops
29 participants **71** questions

SEP 2023
Key stakeholder workshop
44 participants **20** questions

OCT 2023
Online consultation form
15 participants **27** questions

REFINEMENT

REMOVE ANSWERED
-3 questions

MERGE/REMOVE DUPLICATES
-23 questions

PRIORITISATION

OCT-NOV 2023
Prioritisation survey
219 participants **110** questions

SHORTLIST
26 questions

DEC 2023
Final forum
26 participants **12** questions

CONSULTATION

INITIAL WORKSHOP

An online workshop was held on the 31st of July, 2020 including clinicians, parents, researchers, and other various stakeholders. The purpose of the workshop was to revise the priorities that emerged from the 2015 priority setting exercise and propose new priorities. There were 46 attendees at the 5.5-hour workshop. Program leads presented the Stillbirth CRE's current research programs and cross-cutting themes of public awareness, economics, global perspectives and priority populations. Small breakout groups were then facilitated by each program lead, in which participants reviewed and identified future research questions before whole group discussion which identified 18 potential research priorities.

ONLINE SURVEY

Research questions identified at the initial workshop were then sent out to the wider Australian stillbirth community for feedback in an online survey. A literature review of stillbirth related papers in Australia in the last five years was performed to identify key researchers in the field. The survey was disseminated in September 2020 to 191 stakeholders including those identified in the literature review, previously engaged stakeholders who attended the online workshop and bereaved parents contacted via Stillbirth Foundation Australia's networks.

35
RESEARCH QUESTIONS
WERE PROPOSED
BY KEY STAKEHOLDERS
IN 2020

Respondents were asked to rate the 18 research questions on a scale of 1-9 (1 – Least Important, 9 – Most important) and given free-text opportunities to provide feedback and propose any important questions that they thought were missing from the list. The survey received 67 responses. The average score of each research question was determined and assessed by ranking per group i.e. bereaved parents, clinicians and researchers. This analysis revealed that there were disparities regarding the priorities between bereaved parents and professionals in the field and scores were weighted per group to ensure that the priorities moving forward would be representative of all views.

Free-text responses were then analysed to consider rewording of questions and suggested missing questions. Newly suggested research questions identified many cross-cutting themes including risk factors, education, barriers, equity and diversity and healthcare system issues. 17 new questions were identified.

BEREAVED PARENT WORKSHOPS

In August, 2023, we conducted six, two-hour online workshops to consult bereaved parents about their experiences and what research they believe should be prioritised. Participants were recruited through social media callouts and known networks, via the Stillbirth CRE's parent registry and Stillbirth Foundation Australia's community.

The workshops were attended by 29 participants, who had experienced a stillbirth anywhere within 8 weeks to 23 years prior. There was a wide range of diversity across jurisdictions, with rural and remote settings also represented. One of the workshops was attended exclusively by 5 bereaved fathers, who discussed their perspectives.

Each workshop was co-facilitated by an experienced facilitator and a member of the parent advisory group and took a focused but conversational approach. Before the workshops, parents received an information sheet and video to clarify the purpose of the RPS exercise and a hard copy of 'Getting Involved in Stillbirth Research; A guide for bereaved parents' to support their participation. An e-whiteboard was used to brainstorm mind maps of themes and ideas throughout. These ideas were then formulated into questions that would help form the basis of researchable questions.

Following each workshop, the list of questions was recirculated to parents to review and provide reflections on the wording and interpretation of the questions. This feedback was integrated, with 71 new questions being proposed.

> ***"It was incredibly heart breaking hearing the stories of loss, but such a fulfilling and rewarding time knowing we are trying to help change the future so families in the future either ultimately don't experience loss, or at a minimum have an overall improved experience due to knowledge we have provided to make things better. Thank you for the experience, opportunity and process of this research group.***
>
> ***The women involved were absolutely incredible for sharing their stories. I felt honoured to be part of something that I was able to hear them speak, create space for vulnerability, to be protected and supported in something that no parent should be part of. In something when you can feel so alone in your grief, seeing other people also going through this life adjustment and knowing we are collectively trying to make things better - it was very uplifting."***
>
> *- Bereaved parent who attended a workshop*

KEY STAKEHOLDER FORUM

We invited relevant professional organisations, colleges and societies involved in maternity and bereavement care to nominate a representative to attend a final online forum in September 2023. Organisations were contacted via their most senior gatekeeper (e.g., CEO) with details of the forum and were asked to nominate an appropriate representative if they were not able to attend themselves. A list of the organisations that were consulted is provided as Appendix B. We performed another literature search to identify researchers who had published work regarding perinatal loss in the last five years and invited them to participate in the consultation.

Research questions identified in the initial 2020 workshop and the bereaved parent workshops were collated. The purpose of this online forum was to review the existing list and propose any vital missing research questions. The forum was attended by 44 representatives including researchers, clinicians and policy makers. Those who could not attend and the membership of PSANZ were sent an online consultation form to be able to review the questions and provide additional feedback. In total, 49 new questions were proposed.

Figure 1 *Some of the attendees of the key stakeholder forum*

ABORIGINAL AND TORRES STRAIT ISLANDER FORUMS

Targeted consultation was undertaken to explore the research priorities of Aboriginal and Torres Strait Islander communities. Consultation involved a 1.5-hour online forum in September 2020 and another 1.5-hour face-to-face workshop held in Adelaide in February 2021. The online forum involved nine Aboriginal and Maternal Infant Care (AMIC) workers, midwives, and program managers of Aboriginal and Torres Strait Islander health services. The second face-to-face forum included 24 Aboriginal Communities and Families Research Alliance (ACRA) members.

During the forums, participants were asked prompting questions around prevention, investigation and care after stillbirth specific to Aboriginal and Torres Strait Islander families. Some major themes identified were education, communication, navigating the health care system, barriers to access and family dynamics. These themes were then collated and reviewed by the facilitator to develop a list of priority research questions.

These priorities were revised and endorsed by the Stillbirth CRE Indigenous Advisory Group (IAG) at a virtual meeting held on 18th of December 2023. The IAG includes Aboriginal and Torres Strait Islander representatives from each state and territory and membership consists of health professionals and researchers that have worked in this space for several years as well as lived experiences.

The IAG discussed preferred terminology and questions were reworded accordingly. One question regarding co-design of resources was removed as this was considered partly answered and not a top priority. Although the priority questions were not ranked in a specific order, questions that involved aspects of care after loss and access to services to support women and families through their loss and in subsequent pregnancies were regarded as the highest priority.

6 RESEARCH QUESTIONS **WERE DEVELOPED**
AFTER CONSULTING AMIC WORKERS
AND ACRA MEMBERS

MIGRANT AND REFUGEE FORUMS

Consultation with migrant and refugee groups involved two 1.5-hour online forums, held in June and July 2020. The first forum included eight bi-cultural workers (Research project officers and educators) based in Victoria, who spoke Punjabi, Hindi, Marathi, Arabic, Syrian, Assyrian Chaldean, Dari, Farsi, Karen, Burmese and Vietnamese.

The key themes discussed at this forum were introduced and built upon at the second forum with seven members of the Stillbirth CRE Migrant and Refugee Advisory Group to determine these priorities. Key themes that emerged during the forums included education, language and cultural barriers, risk factors, relationships with healthcare professionals and the healthcare system, family dynamics, co-designing research and community engagement. These themes were compiled by the facilitators of the consultations, who then developed ten research questions based on these themes.

These priorities were reviewed and further refined in 2023 by the Steering Committee. One question regarding uptake and barriers of stillbirth prevention messaging was merged into a question about perceptions of prevention strategies. Another question regarding co-designing stillbirth messaging was considered answered, given recent work by the Stillbirth CRE in co-designing Growing a Healthy Baby[43], in partnership with the Multicultural Centre for Women's Health (MCWH) and Stronger Futures CRE.

10

RESEARCH QUESTIONS
WERE DEVELOPED
AFTER CONSULTING
BICULTURAL WORKERS

REFINEMENT

Following consultation, all research questions were collated. The research questions identified during the Aboriginal and Torres Strait Islander, and Migrant and Refugee forums remained separate for consideration by the appropriate advisory groups as highlighted above. The RPS project team consolidated or removed 23 duplicate questions and reworded questions where the intent was unclear or was not considered a research question. A literature review was conducted by the project lead to identify definitively answered research questions and three questions were removed. The refined list was checked by the relevant advisory groups before moving to the final phase.

PRIORITISATION

PRIORITISATION SURVEY

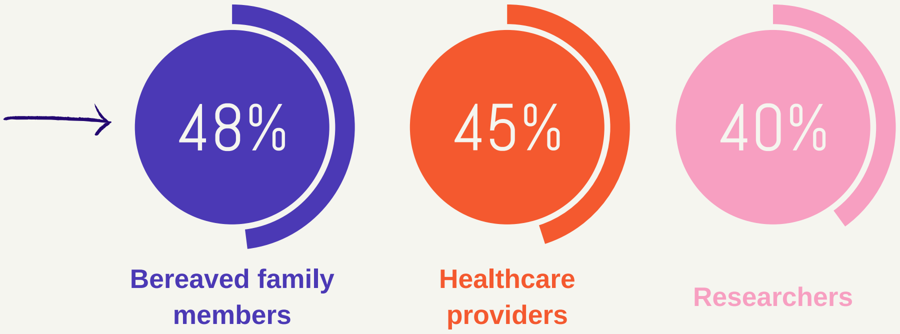
A prioritisation survey with 110 research questions (Appendix C) was circulated between the 24th of October and the 15th of November 2023 to all previously engaged stakeholders and known networks. The survey was also advertised via social media and in partner organisation e-newsletters. Participants were asked to choose their top 10 research questions and rank them from 1-10, with 1 being most important.

219 people completed the survey from various backgrounds and respondents often represented multiple groups.

The survey data were analysed by the project team and members of the steering committee to determine which questions received the greatest overall scores, as well as the average ranking between stakeholder groups. This sub-group analysis was performed to ensure that the questions moving forward to prioritisation were representative of all groups. A shortlist of 26 questions was produced to be reviewed by a multidisciplinary group at the final prioritisation forum.

219

PEOPLE COMPLETED THE SURVEY



FINAL PRIORITISATION FORUM

On Monday, 4th of December 2023, 26 representatives convened in person in Brisbane to review and refine the shortlist of priority questions to determine the final priority list of research questions. Forum participants were identified through the existing collaborative networks of the research team and steering committee including previously engaged people from the consultation phase. Members of the parent advisory group and representatives from relevant community organisations were invited.

The day involved small breakout groups in the morning and afternoon where participants were asked to rank the entire shortlist from A-Z (26 questions, as indicated by * in Appendix C).

Each question was assigned a letter and printed onto A4 cards, with supporting information provided on the back including where the question had originated from (i.e. bereaved parents, clinicians or researchers) and the proportion of each that voted for the question in their top 10 from the survey.

Following each breakout session, each groups' results were collated to provide a median ranking for each question. In the final session, we presented the top 13 ranked questions for group discussion. Two questions were merged into one and a list of 12 research questions were agreed upon. The final order of the rankings was not changed at this final stage, although the wording of some questions was refined. The original wording of the questions is presented in Appendix C.

Figure 2 *Some of the attendees of the final prioritisation forum with the final priorities*

THE SELECTED PRIORITIES

After reviewing the top research priority questions, including the top 12 determined at the prioritisation forum and those identified as part of priority consultations with Aboriginal and Torres Strait Islander, and migrant and refugee communities, we have identified six overarching priority areas. Underpinning these priorities are the values to undertake co-designed approaches with a focus on conducting research that addresses disparities and is translatable and implementable. The priority research questions within each of these priority areas are presented in detail in the sections below. The five research questions that ranked as the highest priority are indicated by an asterisk*.

A **Determine the causes of, and pathways that lead to stillbirth**

B **Identify and implement strategies to prevent stillbirth**

C **Build the capacity of health services and systems to safely reduce stillbirth rates and improve care after perinatal loss**

D **Understand and improve care for families after perinatal loss**

E **Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families to safely reduce stillbirth rates and improve care after perinatal loss**

F **Ensure culturally safe and responsive care for migrant and refugee communities to safely reduce stillbirth rates and improve care after perinatal loss**

A DETERMINE THE CAUSES OF, AND PATHWAYS THAT LEAD TO STILLBIRTH

Priority Area

*How can we better understand and prevent unexplained stillbirth?

In Australia, 15% of all stillbirths remain 'unexplained' and are the second most common classification of stillbirth, following congenital anomalies[2]. Even following thorough investigations, many families never receive an explanation for the cause of death and often anxiously navigate subsequent pregnancies without any answers. To be able to provide answers to families and prevent potential stillbirths, we need better understanding of these unexplained stillbirths.

*What are the shared pathways leading to preterm birth and stillbirth?

83% of all stillbirths occur prior to 36 weeks' gestation (i.e. preterm)[2]. 1 in every 12 babies in Australia are born preterm and more than 15% of these result in a perinatal death[2]. Whilst most of these babies are born preterm due to spontaneous preterm labour[8], others are due to pregnancy complications that require medical intervention or pregnancy complications that result in an antepartum death. For those babies that do survive, there are significant health conditions associated with being born preterm.

What are the impacts of social determinants of health on the prevalence of stillbirth and neonatal death and how do we address them?

Social determinants of health are 'the non-medical factors that influence health outcomes'[9] and include factors such as income, education, occupation, family dynamics, structural conflict, access to services and the environment. Perinatal death disproportionately affects families living in the most disadvantaged areas of Australia, mothers aged under 20 or born overseas and Aboriginal and Torres Strait Islander families[2]. These impacts must be addressed and there are potentially other unrealised social determinants that have a profound impact on the prevalence of perinatal death.

B IDENTIFY AND IMPLEMENT STRATEGIES TO PREVENT STILLBIRTH

Priority Area

*How do we improve monitoring of fetal growth and wellbeing to reduce stillbirth without causing unnecessary interventions or undue harm?

Fetal growth restriction (FGR) is a major contributor to the burden of stillbirth[10]. When detected and appropriately managed, the growth-restricted fetus is, on average, delivered 10 days earlier than the undetected fetus[11] and has up to 20-fold lower risk of stillbirth[12]. However, knowledge gaps regarding the optimal obstetric management of FGR remain[13]. Detection and early planned birth for women whose pregnancy is affected by FGR are important for reducing stillbirth, but earlier birth is also associated with short and longer-term morbidity. Since half of the babies suspected of FGR are normally grown, the desire to prevent stillbirth should be balanced against the risks of prematurity[14]. Current screening and diagnostic approaches perform poorly because they simultaneously have low detection rates (ranging from 15% to 63%) and low positive predictive values (ranging from 5% to 27%) for FGR-associated morbidity[15-17].

What is the utility of screening, including the role of biomarkers, to predict and diagnose adverse pregnancy outcomes, including stillbirth?

Early detection of women with a higher risk pregnancy is critical to inform best care and shared decision-making. There are demonstrated associations between various circulating maternal biomarkers and adverse pregnancy and perinatal outcomes, however their clinical utility has yet to be proven. Circulating biomarkers such as Pregnancy-associated plasma protein-A (PAPP-A), placental growth factor (PlGF) and soluble fms-like tyrosine kinase 1 (sFLt-1) have been associated with placental dysfunction and fetal growth restriction[18], which increase the risk of stillbirth. Other screening techniques to estimate placental volume (EPV)[19] have been proposed to have clinical significance, however, its predictive value is yet to be validated and requires further investigation. Combined screening tests including such biomarkers with maternal characteristics, fetal biometry and ultrasound present a huge opportunity for identifying pregnancies at risk.

B IDENTIFY AND IMPLEMENT STRATEGIES TO PREVENT STILLBIRTH

Priority Area

What approaches to fetal movement assessment will improve the detection and care of women and gender-diverse people at increased risk of stillbirth?

Decreased fetal movements are strongly associated with stillbirth and other adverse perinatal outcomes[20]. Fetal movement assessment is used as an indicator for fetal wellbeing and is currently based on maternal perception. There are no validated clinical tools to assess fetal movement and antenatal education is key to detection of a fetus at risk. Unfortunately, there are still barriers to addressing decreased fetal movements including health-seeking behaviours[21], inconsistency of information and variations in clinical management[22]. Clinical guidelines[23] and the ‘Movements matter’ element of the Safer Baby Bundle aim to address this, however, it is a priority to investigate what other approaches can be taken to improve monitoring and detection.

C

Priority Area

BUILD THE CAPACITY OF HEALTH SERVICES AND SYSTEMS TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

How can we best implement a national standardised perinatal mortality audit program that informs policy and practice improvement to reduce perinatal loss?

Understanding the causes of and factors contributing to stillbirths and neonatal deaths is essential to prevent these deaths from occurring in the future, and to help parents understand why their baby died and plan future pregnancies. Contributory factors relating to care (substandard care factors), which significantly contributed to the death have been identified in 30% of perinatal deaths in Australia[24].

The World Health Organisation's 'Making every baby count: audit and review of stillbirths and neonatal deaths guideline'[25] sets out a standard for audit 'to document the medical causes of each death and contributing systemic failures in order to identify solutions and take action'[25], which has been adapted for Australia[26] and recently updated as part of the Care After Stillbirth and Neonatal Death (CASaND) Clinical Practice Guideline 2024 edition.

Implementation of these national guidelines on perinatal mortality audit for Australia is urgently needed to ensure high quality information is available to drive critical practice change to reduce the tragedy of perinatal death.

This includes offering the option to parents to be engaged by providing their own summary of events and being provided the findings of the audit. Uptake of high-quality perinatal mortality audits remains poor and there is a lag of approximately two years in the reporting of national perinatal mortality data[2]. A national standardised audit program would aid in the timely reporting of data and increasing accountability.

Suboptimal implementation of the guidelines represents a serious missed opportunity in national efforts to reduce stillbirth and neonatal deaths for future families.

C
Priority Area

BUILD THE CAPACITY OF HEALTH SERVICES AND SYSTEMS TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

Which elements of a continuity of pregnancy care model reduce the risk of stillbirth and other related adverse pregnancy outcomes?

Continuity of care and carer is recognised as an important strategy to help reduce stillbirth in Australia[27]. Models of maternity care that allow for greater continuity, and therefore reduce the risk of fragmentation, should be provided and, as far as possible, women and gender-diverse people should see the same maternity care provider throughout pregnancy.

There are a range of models of care which optimise continuity including caseload midwifery or midwifery group practice, private and public obstetrician care and GP obstetric shared care, especially in rural areas. There is high quality evidence that demonstrates reductions in perinatal loss when women receive continuity of care from a known midwife during pregnancy[28].

Midwifery continuity of carer is known to be of additional benefit for women and gender-diverse people at higher risk of stillbirth, such as young mothers[29], Aboriginal women[30], and those from disadvantaged groups[31]. Further research is needed regarding which elements of continuity of pregnancy care reduce the risk of stillbirth and other related adverse pregnancy outcomes and how best to implement these as part of standard care.

D

UNDERSTAND AND IMPROVE CARE FOR FAMILIES AFTER PERINATAL LOSS

Priority Area

*How do we embed processes, training, resources and healthcare capacity to ensure that optimal bereavement care is available to families when a baby dies and in subsequent pregnancies?

The care received by parents and families following perinatal loss is vitally important for their immediate and ongoing wellbeing[32]. The CASaND Clinical Practice Guideline 2024 edition, developed by the Stillbirth CRE and PSANZ provides the latest evidence-based recommendations for perinatal loss care from diagnosis through to subsequent pregnancies. Ensuring health care professionals and the maternal and newborn care services in which they work are equipped and supported to implement these recommendations is critical to ensuring families receive optimal care.

*What are the long-term and inter-generational impacts of stillbirth?

While much is now known about the experiences of parents and families in the early months and years following stillbirth, far less is known about the long-term experience. The potential for detrimental impacts on health and psychosocial wellbeing in the longer-term has been raised in several studies, but more focused and rigorous research is needed to assess these impacts. Understanding different bereavement trajectories and outcomes is important to guide care and support practices that reduce adverse outcomes and promote resilience. This applies to the impacts on the entire families’ health including parents, siblings and grandparents.

D

UNDERSTAND AND IMPROVE CARE FOR FAMILIES AFTER PERINATAL LOSS

Priority Area

What approaches to stillbirth investigation are most valuable and how is this information best communicated to families?

Assuring parents that every effort will be made to find the reasons for their baby’s death is an integral part of perinatal loss care. Decisions about investigations are difficult for grieving parents and discussions to support decision-making are often challenging for healthcare professionals[33]. Various investigations are available and their utility for different clinical scenarios needs to be understood. This requires a multifaceted approach that considers parent perspectives and outcomes, economic costs, and rates of diagnosis of the causes of stillbirth. Ongoing development and evaluation of tailored strategies, including educational programs for healthcare professionals and parent-centred resources are essential to improving this challenging aspect of perinatal loss care.

How do we address the psychosocial and mental health impacts of perinatal loss on all subsequent pregnancies?

Parents who have experienced perinatal loss often have unique medical, social, and emotional needs in subsequent pregnancies[34]. Anxiety, guilt, and conflicting emotions are common as parents navigate the anticipation of a new baby in the context of fear of further loss. Stress may also exert adverse physical impacts on the pregnancy. Approaches to subsequent pregnancy care that responds to the needs of bereaved parents require development and evaluation to optimise the health and wellbeing of mothers, babies, and families during pregnancy and beyond.

E

ENSURE CULTURALLY SAFE AND RESPONSIVE CARE FOR ABORIGINAL AND TORRES STRAIT ISLANDER FAMILIES TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

Priority Area

Stillbirth disproportionately affects Aboriginal and Torres Strait Islander populations in Australia. The stillbirth rate in these populations remains approximately double the non-Indigenous rate[2]. Providing culturally safe and responsive care to Aboriginal and Torres Strait Islander mothers and families during pregnancy and after perinatal loss is vital to improve overall outcomes. Priority research questions to contribute to this goal are below.

Which elements of models of care (or models of care themselves) improve access to antenatal care and referral pathways to services and support after loss for Aboriginal and Torres Strait Islander mothers and families?

Continuity of care is considered a key strategy to improving access to antenatal care for Aboriginal and Torres Strait Islander mothers. Pathways and services to support are often aimed at the mother, however, this care should take a family-centered approach and extend to other family members including the father as well. Care after stillbirth is when families are mostly subjected to trauma and often not offered pathways for support, leaving mothers feeling isolated to deal with their grief. It is essential to understand which elements of continuity of care can reduce this isolation and best support families during pregnancy and after loss.

How can birthing on Country and other culturally appropriate models of care, including care after loss, be scaled-up to support Aboriginal and Torres Strait Islander mothers and families?

‘Birthing on Country is a continuation of thousands of years of knowledge and practice, which provides holistic maternal, child and family health care that embeds cultural integrity and safety during pregnancy, labour, birth and postnatal care’[35]. There is a lack of support for birthing on country and traditional practices in the current healthcare system which inhibits engagement with care[36]. Implementing culturally appropriate models of care and flexibility in care arrangements increases access to care[37] and is more cost-effective compared to standard care[38].

E

Priority Area

ENSURE CULTURALLY SAFE AND RESPONSIVE CARE FOR ABORIGINAL AND TORRES STRAIT ISLANDER FAMILIES TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

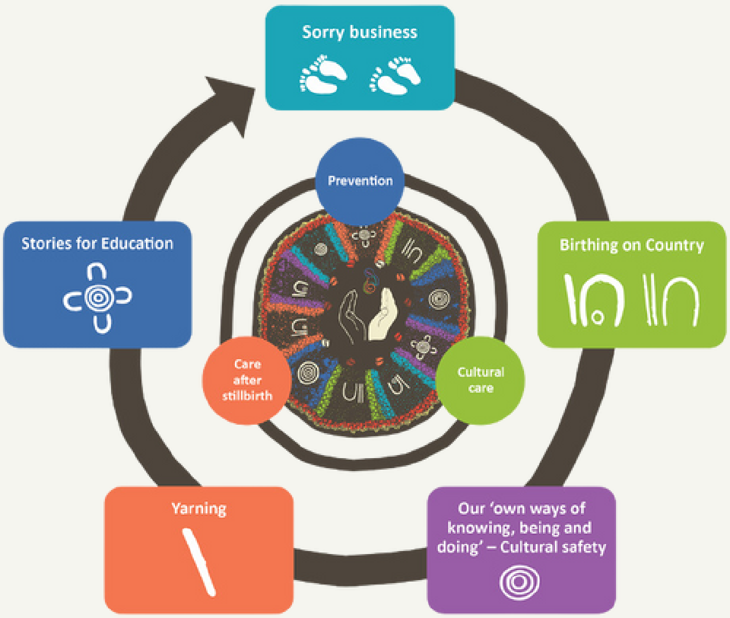
What are the optimal approaches to reviewing stillbirths that reflect the diversity of Aboriginal and Torres Strait Islander cultures?

Mothers are often blamed within their community after a stillbirth or neonatal death. Education for mothers and families around the causes of stillbirth, and the fact that they can often remain unexplained, is key to preventing shame and guilt. This includes supporting shared decision-making and having respectful and culturally sensitive conversations around reviewing stillbirth cases with the family. Key reasons identified for declining an autopsy include[39]:

- not being asked in a culturally sensitive manner
- not having enough time to decide
- distress over the procedure.

More work is required to determine the optimal approach during this sensitive time. Language is also an important consideration, and it has been identified that 'investigations' are not a preferred term amongst communities and that the word 'review' should be used instead so as not to infer blame.

The thematic diagram below was submitted as part of the 'Report summarizing outcomes of the focus testing of stillbirth prevention messages for Aboriginal and Torres Strait Islander communities' in 2022. Through use of the "Protection" artwork commissioned for this work, this figure depicts the overarching Aboriginal and Torres Strait Isander priority areas of stillbirth research around prevention, cultural care and care after stillbirth. This framework was developed during a face-to-face meeting of the Stillbirth CRE Indigenous research team in 2022 to identify common themes across the different consulted communities and priority focus areas identified during those consultations. The diagram represents the vision that culturally safe care and responsive during pregnancy and after stillbirth will encompass acknowledgement of Sorry Business Babies.



E

ENSURE CULTURALLY SAFE AND RESPONSIVE CARE FOR ABORIGINAL AND TORRES STRAIT ISLANDER FAMILIES TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

Priority Area

What are the educational or professional development needs of maternity healthcare providers to support conversations about stillbirth prevention with Aboriginal and Torres Strait Islander mothers and families?

There is often a lack of trust or confidence to engage with healthcare providers and systems. Targeted education and professional development should be implemented to support maternity healthcare providers having culturally appropriate and sensitive conversations with Aboriginal and Torres Strait Islander mothers about stillbirth prevention. Recent consultations for the co-design of prevention resources has revealed some of the barriers experienced by maternity healthcare providers including a lack of access to consistent messaging, particularly around decreased fetal movements and high staff turnover resulting in lack of knowledge transfer. The recent cultural adaptation of the Safer Baby Bundle, *Stronger Bubba Born*, aims to address the issue of consistent messaging, however, further research should be conducted to understand the needs of the healthcare providers having these conversations. This evidence should be gathered to provide additional training and implement appropriate systems and processes into clinical care to support the communication of stillbirth prevention.

What are the educational or professional development needs of maternity healthcare providers to support respectful conversations about autopsy with Aboriginal and Torres Strait Islander mothers and families?

As highlighted above, there are many barriers to autopsy consent amongst Aboriginal and Torres Strait Islander families. Additional research is required to understand the educational and professional development needs of maternity healthcare providers to begin respectful dialogue regarding autopsy and when the appropriate time to have these conversations is. Often, families are in Sorry Business which may mean that they need more time to talk about next steps and autopsy. Emphasis should be placed on supporting shared decision making and two-way learning during this time.

F

ENSURE CULTURALLY SAFE AND RESPONSIVE CARE FOR MIGRANT AND REFUGEE COMMUNITIES TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

Priority Area

Women from migrant and refugee communities in Australia have poorer pregnancy outcomes and are likely to be more dissatisfied with the pregnancy care they receive, compared with women from the general population[40-42]. Women from some migrant and refugee communities in Australia, particularly those born in Melanesia and various African regions have much higher rates of stillbirth compared to the overall Australian population.[2] There are persistent inequities for women and families who experience stillbirth in Australia[4] and action is required to ensure that migrant and refugee women have access to culturally safe and linguistically appropriate maternity care[42].

How can we improve access to information to ensure women from migrant and refugee backgrounds and their babies remain healthy during pregnancy?

Access to information is restricted by a range of factors, including but not limited to, language barriers (speaking and reading), difficulty understanding appointment booking process, lack of or limited transport, insufficient access to interpreter services and ineffective collaboration between care providers that make navigating the healthcare system complex. As a result, the capacity to absorb and act on information may be significantly impacted and it is critical to ensure that health messaging directed to these communities is culturally accessible. Work has been undertaken over recent years to co-design high quality, culturally safe information for women and families of migrant and refugee backgrounds.

The *Growing a Healthy Baby*[43] resources have been adapted for Arabic, Dari, Dinka and Karen speaking families with a specific focus on easy-to-read language and using metaphors to communicate complex ideas. These resources will improve access to culturally safe information and trauma informed care. However, further research is needed to continue development, ensure implementation and critically evaluate the effectiveness on reducing the stillbirth rate in these communities. Further work is required to address the other barriers to accessing information mentioned above.

F

ENSURE CULTURALLY SAFE AND RESPONSIVE CARE FOR MIGRANT AND REFUGEE COMMUNITIES TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

Priority Area

Are we providing understandable information about risk factors for migrant and refugee background women?

Known risk factors of adverse pregnancy outcomes, including stillbirth, can be modified if women are able to access culturally safe, engaging and high-quality care during pregnancy [44]. Management of risk factors requires improved access to culturally appropriate information about risk factors that is easy to understand. The recent cultural adaptation of stillbirth information for migrant and refugee women, *Growing a Healthy Baby*, includes information on addressing risk factors such as smoking cessation, sleeping on the side and being aware of fetal movements. Further work is required to ensure understandable information about risk factors for stillbirth is being communicated to all migrant and refugee women.

What are migrant and refugee background women's perceptions of stillbirth prevention strategies and what are the barriers to uptake of prevention messaging?

Many different communities do not have a word for 'stillbirth' in their language or culturally do not speak about stillbirth. Further research into the experiences and understanding of migrant and refugee women from various backgrounds, living in Australia, is required to inform future co-designed research into the communication of stillbirth prevention strategies. Recent consultation for the *Growing a Healthy Baby* resources has shed light on the barriers to accessing information (as highlighted above). Barriers to the uptake of this information when it is accessible, though, are not well understood.

F

ENSURE CULTURALLY SAFE AND RESPONSIVE CARE FOR MIGRANT AND REFUGEE COMMUNITIES TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

Priority Area

What systems changes are needed to enable health professionals to have effective conversations about stillbirth and stillbirth prevention with migrant and refugee women?

In conjunction with developing the *Growing a Healthy Baby* resources, work has been undertaken to co-design professional development resources for healthcare providers to have effective conversations about stillbirth prevention with migrant and refugee women. There are, however, systemic barriers that impact healthcare professionals' ability to deliver these messages. Research is required into what system changes can be implemented to enable these conversations, for instance ensuring longer appointment times for migrant and refugee women or improving access to interpreters. Visa status is also a key limiter to access, given some women may not be eligible for Medicare. Implementation of these system changes is essential for building rapport and establishing trust between women and their healthcare providers.

What models of care reduce the risk of stillbirth in migrant and refugee communities?

As presented in the above priorities, there are a range of models of maternity care available in Australia. Continuity of care is considered the gold standard, but it is unknown which models (i.e. Group pregnancy care, caseload midwifery, GP shared care) and what elements of these models are most acceptable amongst migrant and refugee communities and if these models reduce the risk of stillbirth specifically in these populations. For example, it was noted during consultations that women arriving from countries where GP/primary care does not gatekeep referral pathways are used to seeing specialists at regular appointments. Women not born in Australia may not understand that midwives in Australia are highly skilled and may view care by a midwife, rather than an obstetrician, as a less skilled professional and therefore discriminatory.

F

ENSURE CULTURALLY SAFE AND RESPONSIVE CARE FOR MIGRANT AND REFUGEE COMMUNITIES TO SAFELY REDUCE STILLBIRTH RATES AND IMPROVE CARE AFTER PERINATAL LOSS

Priority Area

What models of care improve engagement with antenatal care among migrant and refugee women at higher risk of stillbirth due to psychosocial risk factors?

Psychosocial risk factors contribute to the risk of stillbirth by reducing engagement with appropriate antenatal care. Social isolation, economic disadvantage and complex trauma, exacerbated by limited English proficiency all contribute to this increased risk amongst migrant and refugee women[45-47]. There may be certain models of care, or elements of these models that can address inherent barriers and improve engagement with antenatal care. Engagement could be measured by the timing of first visit during pregnancy and the ongoing attendance to antenatal appointments.

How can health professionals build greater understanding of cultural differences in grief response after stillbirth into approaches to the care of migrant and refugee families?

Understanding of the cultural differences in grief response is a significant research gap, given each individual and community grieves in different ways. Research is required to understand the optimal approach for trauma-informed and culturally safe care for migrant and refugee families following a stillbirth. These approaches should be thoroughly explored so that appropriate education and training for healthcare professionals can be developed and implemented into standard practice.

What is culturally safe best practice for bereavement care for migrant and refugee families, including extended family members and considering cultural practices regarding grief and loss?

Many cultures experience grief and loss differently. There are varying cultural beliefs and necessary practices amongst different cultural groups when a baby dies. These can have a profound impact on individual and family experiences of grief. The support needs of varying communities differ during times of loss and further work is required to understand what culturally safe best practice entails to enable immediate and ongoing bereavement care for families of stillborn babies that is adapted to their cultural beliefs.

CONCLUSION AND RECOMMENDATIONS

This RPS exercise identified **six key priority areas** that resonated strongly across comprehensive consultations. These priorities have been robustly developed and are supported by all key stakeholders, including bereaved parents, researchers, healthcare professionals and policy makers engaged throughout this process. There was a high level of agreement amongst the representatives that addressing these research priorities will make a substantial difference to the future of families in Australia. During consultations and the final prioritisation forum, the research that has been conducted to date was discussed at length. Many aspects of the priority research questions are now at the stage where they require implementation into clinical practice. To achieve substantive improvements in national maternity care standards, it is essential to execute targeted evidence-based implementation strategies and embed best practice recommendations into care. Importantly, identifying the most effective processes for implementing and sustaining practice change using implementation science remains a priority.

When comparing this list of research priorities to 2015 (Appendix A), there is apparent overlap. For instance, a high quality and nationally standardised perinatal mortality audit program has still been identified as an unanswered priority that is essential to inform policy and practice in a timely manner. Causal pathways for unexplained stillbirths are yet to be discovered and the appropriate monitoring and management of fetal movements and growth remain top priorities. There are also apparent similarities between research priorities determined in the UK, including questions around fetal growth and movement, the utility of screening and biomarkers, determining causes of stillbirth, support in subsequent pregnancies and ensuring optimal bereavement care[48], indicating ample opportunity for international collaboration. To ensure stillbirth research is most effective across Australia and internationally, the Stillbirth CRE will promote the use of the recently developed core outcome sets to all researchers wishing to address these priorities[49-50] and support parent engagement through the recently established research involvement registry for bereaved parents. Adequate resourcing, however, is required to achieve a priority-driven research program that addresses the tragedy of stillbirth.

A recent publication revealed that globally, stillbirth research receives only 1.5% of all funds awarded to newborn health research[51]. This area of research is critically underfunded and investment in this area is crucial to reduce perinatal mortality rates and provide best care to families during pregnancy. A cohesive, national approach to stillbirth research will have far-reaching impacts to improve pregnancy outcomes overall. **As such, we provide the following recommendations in the table below.**

Recommendation	Expected outcomes
Dedicated funding sources should be identified and allocated to these priorities	Targeted funding to these priority areas will ensure that the research questions that are most important to the community are being swiftly answered.
Support a stillbirth research registry to connect multidisciplinary teams across the nation.	Some of these research priorities remain quite broad and will require a series of projects or approaches to address them appropriately. To reduce research wastage, a publicly accessible and regularly updated stillbirth research registry should be created. Such a registry would facilitate national collaboration between scientists, healthcare professionals, parents and policy makers.
Engage and involve consumers in all research activities	We strongly support that all funded projects should be co-designed with bereaved parents and patients, to ensure that their voices remain central to all research that is conducted. The Stillbirth CRE has initiated a research involvement registry that requires scaling up and could potentially be integrated with the recommended registry above.
Strengthen collaborations between community groups and research organisations to enhance engagement of priority populations	Further iterative consultation, review and refinement of research priorities is an ongoing process and should be undertaken immediately with priority groups including families living in the most disadvantaged areas of Australia, mothers aged under 20 or born overseas and Aboriginal and Torres Strait Islander families that are disproportionately affected by stillbirth. This will ensure that research priorities are continuing to best meet the needs of these populations.
Evaluate the impact of these research priorities over the next five years	These recommendations will aid implementation of research priorities, that should continue to be evaluated against the NSAIP evaluation indicator to ‘increase in the number of research projects in and amount of funding granted to, the stillbirth priority research areas’.

REFERENCES

1.Australian Government Department of Health. National Stillbirth Action and Implementation Plan, 2020.

2.Australian Institute of Health and Welfare. Australia's mothers and babies. Canberra: AIHW, 2023.

3.Australia Co. Select Committee on Stillbirth Research and Education Report. Senate Printing Unit, Parliament House, Canberra, 2018.

4.Flenady V, Wojcieszek AM, Middleton P, et al. Stillbirths: recall to action in high-income countries. Lancet 2016; 387(10019): 691-702.

5.Flenady V, Middleton P, Smith GC, et al. Stillbirths: the way forward in high-income countries. Lancet 2011; 377(9778): 1703-17.

6.Flenady V, Boyle F, Schirmann, A, et al. on behalf of the priority setting working group. NHMRC Centre of Research Excellence in Stillbirth Report on the 2015 Stillbirth CRE Priority Setting Exercise. Brisbane, 2019.

7.Australian Government Department of Health. National Stillbirth Action and Implementation Plan: Monitoring and Evaluation Framework 2022-2030, 2022.

8.Tindal K, Bimal G, Flenady V, et al. Causes of perinatal deaths in Australia: Slow progress in the preterm period. Aust N Z J Obstet Gynaecol 2022; 62(4): 511-7.

9.World Health Organisation. Social determinants of health. https://www.who.int/health-topics/social-determinants-of-health (accessed 8 December 2023).

10. Flenady V, Koopmans L, Middleton P, et al. Major risk factors for stillbirth in high-income countries: a systematic review and meta-analysis. Lancet 2011; 377(9774): 1331-40.

11. Gardosi J, Madurasinghe V, Williams M, Malik A, Francis A. Maternal and fetal risk factors for stillbirth: population based study. Bmj 2013; 346: f108.

12.Selvaratnam RJ, Davey MA, Anil S, McDonald SJ, Farrell T, Wallace EM. Does public reporting of the detection of fetal growth restriction improve clinical outcomes: a retrospective cohort study. Bjog 2020; 127(5): 581-9.

13. Silver RM, Blue NR. Delivery Before 39 Weeks' Gestation for Suspected Fetal Growth Restriction: More Harm Than Good? Jama 2021; 326(2): 135-6.

14. Selvaratnam RJ, Wallace EM, Treleaven S, Hooper SB, Davis PG, Davey MA. Does detection of fetal growth restriction improve neonatal outcomes? J Paediatr Child Health 2021; 57(5): 677-83.

15. Sovio U, White IR, Dacey A, Pasupathy D, Smith GCS. Screening for fetal growth restriction with universal third trimester ultrasonography in nulliparous women in the Pregnancy Outcome Prediction (POP) study: a prospective cohort study. Lancet 2015; 386(10008): 2089-97.

16. Unterscheider J, Daly S, Geary MP, et al. Optimizing the definition of intrauterine growth restriction: the multicenter prospective PORTO Study. Am J Obstet Gynecol 2013; 208(4): 290.e1-6.

17. Kabiri D, Romero R, Gudicha DW, et al. Prediction of adverse perinatal outcome by fetal biometry: comparison of customized and population-based standards. Ultrasound Obstet Gynecol 2020; 55(2): 177-88.

18. Hong J, Kumar S. Circulating biomarkers associated with placental dysfunction and their utility for predicting fetal growth restriction. Clin Sci (Lond) 2023; 137(8): 579-95.

19. Isakov KMM, Emerson JW, Campbell KH, et al. Estimated Placental Volume and Gestational Age. Am J Perinatol 2018; 35(8): 748-57.

20. Bradford BF, Cronin RS, McCowan LME, McKinlay CJD, Mitchell EA, Thompson JMD. Association between maternally perceived quality and pattern of fetal movements and late stillbirth. Sci Rep 2019; 9(1): 9815.

21. Smyth RM, Taylor W, Heazell AE, Furber C, Whitworth M, Lavender T. Women's and clinicians perspectives of presentation with reduced fetal movements: a qualitative study. BMC Pregnancy Childbirth 2016; 16(1): 280.

22. Flenady V, MacPhail J, Gardener G, et al. Detection and management of decreased fetal movements in Australia and New Zealand: a survey of obstetric practice. Aust N Z J Obstet Gynaecol 2009; 49(4): 358-63.

23. Gardener G DL, Bowring V, Burton G, et al. Clinical practice guideline for the care of women with decreased fetal movements. Centre of Research Excellence in Stillbirth.

24. Flenady V, Kettle I, Laporte J, et al. Making every birth count: Outcomes of a perinatal mortality audit program. Australian and New Zealand Journal of Obstetrics and Gynaecology 2021; 61(4): 540-7.

25. World Health Organisation. Making every baby count: audit and review of stillbirths and neonatal deaths. 2016.

26. Flenady V OJ, Gardener G, Masson Vicki, et al. for the PSANZ Care around the time of stillbirth and neonatal death guidelines group. Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death. NHMRC Centre of Research Excellence in Stillbirth. 2020.

27. Centre of Research Excellence in Stillbirth. Statement from the Stillbirth Centre of Research Excellence: The advantages of continuity of carer. 2020.

28. Sandall J, Soltani H, Gates S, Shennan A, Devane D. Midwife-led continuity models versus other models of care for childbearing women. Cochrane Database Syst Rev 2016; 4(4): Cd004667.

29. Allen J, Gibbons K, Beckmann M, Tracy M, Stapleton H, Kildea S. Does model of maternity care make a difference to birth outcomes for young women? A retrospective cohort study. Int J Nurs Stud 2015; 52(8): 1332-42.

30. Kildea S, Gao Y, Hickey S, et al. Reducing preterm birth amongst Aboriginal and Torres Strait Islander babies: A prospective cohort study, Brisbane, Australia. EClinicalMedicine 2019; 12: 43-51.

31. Homer CS, Leap N, Edwards N, Sandall J. Midwifery continuity of carer in an area of high socio-economic disadvantage in London: A retrospective analysis of Albany Midwifery Practice outcomes using routine data (1997-2009). Midwifery 2017; 48: 1-10.

32. Ellis A, Chebsey C, Storey C, et al. Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. BMC Pregnancy Childbirth 2016; 16: 16.

33. Schirmann A, Boyle FM, Horey D, et al. Understanding mothers' decision-making needs for autopsy consent after stillbirth: Framework analysis of a large survey. Birth 2018; 45(3): 255-62.

34. Wojcieszek AM, Boyle FM, Belizán JM, et al. Care in subsequent pregnancies following stillbirth: an international survey of parents. Bjog 2018; 125(2): 193-201.

35. Birthing on Country. https://waminda.org.au/maternity/birthing-on-country/ (accessed 8 December 2023).

36. Roe Y, Allen J, Haora P, et al. Enabling the context for Aboriginal and Torres Strait Islander Community Controlled Birthing on Country services: Participatory action research. Women Birth 2023.

37. Kildea S, Gao Y, Hickey S, et al. Effect of a Birthing on Country service redesign on maternal and neonatal health outcomes for First Nations Australians: a prospective, non-randomised, interventional trial. Lancet Glob Health 2021; 9(5): e651-e9.

38. Gao Y, Roe Y, Hickey S, et al. Birthing on country service compared to standard care for First Nations Australians: a cost-effectiveness analysis from a health system perspective. Lancet Reg Health West Pac 2023; 34: 100722.

39. Kilcullen M, Kandasamy Y, Watson D, Cadet-James Y. Decisions to consent for autopsy after stillbirth: Aboriginal and Torres Strait Islander women's experiences. ANZJOG 2020; 60(3): 350-4.

40. Gibson-Helm M, Teede H, Block A, et al. Maternal health and pregnancy outcomes among women of refugee background from African countries: a retrospective, observational study in Australia. BMC Pregnancy Childbirth 2014; 14: 392.

41. Yelland J, Riggs E, Small R, Brown S. Maternity services are not meeting the needs of immigrant women of non-English speaking background: Results of two consecutive Australian population based studies. Midwifery 2015; 31(7): 664-70.

42. Olcoń K, Rambaldini-Gooding D, Degeling C. Implementation gaps in culturally responsive care for refugee and migrant maternal health in New South Wales, Australia. BMC Health Services Research 2023; 23(1): 42.

43. Growing a Healthy Baby. 2023. https://growingahealthybaby.org.au. (accessed 8 December 2023).

44. Rumbold AR, Yelland J, Stuart-Butler D, et al. Stillbirth in Australia 3: Addressing stillbirth inequities in Australia: Steps towards a better future. Women and Birth 2020; 33(6): 520-5.

45. Ager A, Strang A. Understanding Integration: A Conceptual Framework. Journal of Refugee Studies 2008; 21(2): 166-91.

46. Yelland J, Riggs E, Wahidi S, et al. How do Australian maternity and early childhood health services identify and respond to the settlement experience and social context of refugee background families? BMC Pregnancy Childbirth 2014; 14: 348.

47. Bryant RA, Edwards B, Creamer M, et al. The effect of post-traumatic stress disorder on refugees' parenting and their children's mental health: a cohort study. Lancet Public Health 2018; 3(5): e249-e58.

48. Heazell AEP, Whitworth MK, Whitcombe J, et al. Research priorities for stillbirth: process overview and results from UK Stillbirth Priority Setting Partnership. Ultrasound in Obstetrics & Gynecology 2015; 46(6): 641-7.

49. Kim BV, Aromataris EC, Middleton P, et al. Development of a core outcome set for interventions to prevent stillbirth. ANZJOG 2021; 61(5): 658-66.

50. Bakhbakhi D, Siassakos D, Davies A, et al. Interventions, outcomes and outcome measurement instruments in stillbirth care research: A systematic review to inform the development of a core outcome set. BJOG 2023; 130(6): 560-76.

51. Agravat P, Loucaides EM, Kumar MB, et al. Research funding for newborn health and stillbirths, 2011-20: a systematic analysis of levels and trends. The Lancet Global Health 2023; 11(11): e1794-e804.

APPENDICES

APPENDIX A – 2015 stillbirth research priorities

Care after Stillbirth

- What are the elements of optimal care for parents and families following a stillbirth?
- What education/training is needed for clinicians – what are the gaps?
- What are the psychosocial effects of stillbirth on parents and families?
- How can we optimise parental and baby outcomes in subsequent pregnancies following stillbirth?

Investigation

- What are the elements and approaches of a high-quality national perinatal mortality audit program?
- What is the optimal, cost-effective investigation protocol for investigating the causes of stillbirth?

Prevention

- How can we ensure high-quality, accessible, appropriate maternity care for all women to prevent stillbirth?
- How can we engage with pregnant women, care providers, and the public to identify and address information needs?
- What are the possible causal pathways for unexplained and late pregnancy stillbirth?
- What are the underlying root causes of stillbirth that have known direct causes e.g. placental abruption, pre-eclampsia?
- Does increasing awareness and encouraging maternal reporting of decreased fetal movements (DFM) reduce stillbirth?
- What are the effective strategies to improve detection and management of fetal growth restriction (FGR) and can these reduce stillbirth?
- What are the placental and cord pathologies that cause or contribute to stillbirth?
- Can screening in early pregnancy accurately quantify and reduce the risk of stillbirth?
- What are the modifiable risk factors for stillbirth?
- How can the risk of stillbirth for obese women be reduced?
- For which women, and when, does early planned birth to prevent stillbirth versus expectant management have more benefit than harm?

APPENDIX B – Colleges and organisations consulted for stillbirth research priorities

- Aboriginal Communities and Families Research Alliance (ACRA)
- Australasian Society for Ultrasound in Medicine (ASUM)
- Australasian Sonographers Association (ASA)
- Australian Birth Trauma Association (ABTA)
- Australian College of Midwives (ACM)
- Australian College of Neonatal Nurses (ACNN)
- Australian College of Rural and Remote Medicine (ACRRM)
- Australian Funeral Directors Association (AFDA)
- Australian Institute of Health and Welfare (AIHW)
- Australian Preterm Birth Prevention Alliance (APBPA)
- Centre of Perinatal Excellence (COPE)
- Centre of Research Excellence in Medicines Intelligence (MI-CRE)
- Early Pregnancy Loss Coalition (EPLC)
- Foundation House
- Human Genetics Society of Australasia (HGSA)
- Living Evidence for Australian Pregnancy and Postnatal Care (LEAPP)
- National Association of Specialist Obstetricians and Gynaecologists (NASOG)
- National Rural Health Alliance (NRHA)
- NSAIP Stillbirth Action and Implementation Plan Oversight Committee
- Perinatal Society of Australia and New Zealand (PSANZ)
- Queensland Health
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
- Red Nose Australia
- Still Aware
- Stillbirth Foundation Australia
- The Perinatal Loss Centre
- The Pink Elephants Support Network
- The Royal Australian and New Zealand College of Radiologists (RANZCR)
- The Royal Australian College of General Practitioners (RACGP)
- The Royal College of Pathologists of Australia (RCPA)
- Women’s and Children’s Health Network (WCHN)

APPENDIX C - Preliminary list of 110 stillbirth research questions

denotes the 26 questions that were shortlisted for prioritisation and **questions in bold are the final priorities*

1. How can we improve the transition from hospital to community-based care and parents' ongoing support needs?
2. What is the evidence base around services to be able to develop known pathways of care (after leaving hospital)?
3. What long-term professional services and community support can be implemented in standard practice and offered to bereaved parents following a stillbirth?
4. How can we improve access to thorough physical (including postnatal checkups and lactation consultation) and emotional postnatal care for bereaved parents?
5. **What processes, training, resources and healthcare capacity are needed to ensure the best possible bereavement care is available to all parents when a baby dies? ***
6. What should be the mandatory check-in points from health care professionals or social workers after a loss? (i.e. pre/post 6-week check-in) *
7. How do we best address the support needs of bereaved partners and other family members including siblings and grandparents after stillbirth?
8. How can we improve sensitive communication and compassionate care after a stillbirth? *
9. What are the best approaches to ensure that all health care professionals and services are equipped to provide best practice perinatal bereavement care?
10. How can we best implement memory making opportunities for parents prior to/following a stillbirth and avoid creating harmful or negative memories wherever possible? *
11. Does different pregnancy loss terminology stigmatise or minimise the parent's experience?
12. How do we address and assess the effectiveness of approaches to supporting bereaved parents after perinatal loss?
13. What are the optimal interventions and clinical pathways that shared antenatal care general practitioners (GPs) should offer bereaved parents following a stillbirth?
14. What is the most useful core outcome set for bereavement care after stillbirth or neonatal death in the Australian setting?
15. What types of audit and feedback improve patient experience and outcomes?
16. What are effective ways to facilitate parent engagement and decision-making in investigation and review following a baby’s death?
17. How can we improve the experience of autopsy consent for parents and health professionals?
18. **What is the long-term and inter-generational impact of stillbirth? ***
19. How do bereaved parents experience resiliency and survivorship?

20. How can we best deliver postnatal information to parents following a perinatal loss and what is the optimal timing and desired formats or modes to this information?
21. How can we provide better access to and engagement with perinatal hospice or palliative care?
22. How can we better support bereaved parents living in rural and remote Australia? *
23. What are the specific care requirements for women and gender-diverse people having a medical termination of pregnancy following a prenatal diagnosis (including access to genetic counselling)?
24. How do we best support families that have a loss during a multiple pregnancy but remain pregnant with a surviving baby?
25. What are optimal implementation strategies (including professional training) to address and update evidence-practice gaps in stillbirth prevention?
26. How can we standardise and lift the standard of antenatal care to reduce stillbirth? *
27. What are the optimal approaches (including decision aids) to improve shared decision making and understanding in antenatal care (including early prediction and timing of birth) around risk and outcomes?
28. How do we manage "low risk" pregnancies proactively to prevent stillbirth? *
29. How does continuity of pregnancy care reduce the risk of stillbirth and which models of continuity of care reduce this risk? *
30. What are the benefits of community led design in stillbirth prevention programs and research?
31. How can we reduce the risk of stillbirth in women and gender-diverse people with obesity?
32. How can we reduce the risk of stillbirth in women and gender-diverse people with diabetes in pregnancy?
33. How can we reduce the risk of stillbirth in women and gender-diverse people with advanced maternal age?
34. Can smoking cessation support messaging reduce stillbirth?
35. What are the optimal approaches to informing parents and changing behaviour to reduce their risk of stillbirth during pregnancy?
36. How is the messaging of risk being communicated to pregnant women and gender-diverse people?
37. What are the barriers and enablers of help-seeking behaviour amongst parents when concerned during pregnancy?
38. How can pregnant women and gender-diverse people be informed and empowered about the risks of stillbirth more forthrightly without creating anxiety?
39. Why are the unfavourable outcomes of pregnancy (i.e. stillbirth) not communicated preconception or antenatally?
40. How can we deliver consistent information about fetal movement and when to contact the healthcare team? *
41. What are couple's awareness levels around stillbirth risk and what education should be provided for transparency to parents?
42. What are the optimal approaches to increase awareness of and co-design stillbirth prevention messaging to reach all populations regardless of background and location?

43. What are the experiences for pregnant women and gender-diverse people with an increased risk of stillbirth and increased surveillance in the third trimester?
44. How can we provide trauma-informed care training to all health care professionals treating pregnant women and gender-diverse people?
45. What gaps exist in the service provision of basic antenatal care across different settings? e.g. rural/remote, states/territories, public/private hospital
46. Why do remote areas experience more stillbirths and how do we reduce these?
47. What are pregnant women and gender-diverse people's perceptions and feelings towards increased monitoring and currently non-routine tests being included in standard antenatal care?
48. What specific guidance is required to support the safe use of at home fetal heart monitors?
49. How can we better shape antenatal care to include the partner?
50. What are the causes of unexplained stillbirth and neonatal death in Australia? *
51. Will studying the placental pathology of near-miss stillbirths help to ascertain the placental factors contributing to stillbirth? *
52. What is the aetiology of early gestational stillbirth?
53. What are the common pathways leading to early preterm birth and preterm stillbirth? *
54. Do the causes of stillbirth vary by region, rurality/remoteness and country of birth?
55. What trends can be found from antenatal records and tissue samples of stillborn children to improve our understanding of perinatal loss?
56. How can existing data systems and infrastructure be used to provide timely evidence for monitoring and evaluation of stillbirth and neonatal mortality rates?
57. How can we create data uniformity across all jurisdictions in Australia to be able to access timely and comprehensive statistics for each type of pregnancy loss? *
58. How can we ensure appropriate differentiation in perinatal loss data between terminations of pregnancy (for both medical and non-medical reasons) and spontaneous stillbirth?
59. How can we create and mandate effective data systems to capture and share all perinatal loss data (>20 weeks' gestation) in a timely manner across Australia to inform policy? *
60. Can new approaches for using large population datasets help us to understand the causes and risk factors for stillbirth and adverse neonatal outcomes?
61. What are the digital solutions to improving timely access to perinatal mortality data?
62. What are the gaps in the current landscape of perinatal monitoring and surveillance in Australia?
63. What critical data should be collected in the preconception period that can help reduce perinatal loss and adverse pregnancy outcomes?
64. What samples should be routinely consented and collected for biobanking following a stillbirth?
65. What is the incremental value of investigations following a stillbirth and how can we evaluate this to aid parent decision making? e.g. how much clarity does each investigation add following placental examinations and blood tests? *

66. How can we implement a national standardised perinatal mortality audit program that informs policy and practice improvement to reduce perinatal loss? *
67. What is the acceptability and role of coronial investigation in stillbirth?
68. How can we reduce the interval between stillbirth and receiving investigation results?
69. How do we enforce and evaluate implementation of developed stillbirth guidelines and translate these into standard practice (policy change)?
70. What are the effective approaches to benchmarking to improve practice and reduce perinatal loss?
71. What can we learn from other countries/sectors and what are they doing differently to have more successful live birth rates?
72. How can we improve collaboration and data-sharing between hospitals to ensure best practice and consistent care across Australia?
73. How can we improve transparency and access to information to the public by making reporting of birth outcomes mandatory amongst hospitals and maternity services? e.g. the way IVF clinics report their birth rates
74. Are there biomarkers that identify risk of stillbirth and other adverse outcomes across the birthweight continuum?
75. What is the diagnostic accuracy of placental biomarkers that can be tested in blood that indicate an adverse pregnancy outcome? *
76. What impact do determinants of health have on the prevalence of stillbirth and neonatal death? *
77. How do we measure the impact of social and economic environments towards stillbirth?
78. How do we measure the impact of the physical environment towards stillbirth?
79. Does stillbirth and neonatal death disproportionately impact LGBTQIA+ groups?
80. What are the genetic factors that impact risk of stillbirth or neonatal death?
81. What are the evidence-practice gaps in stillbirth prevention? *
82. What approaches to fetal movement assessment will improve the detection of women at increased risk of stillbirth? *
83. What are the indicated assessments that should be performed and new/emerging technologies that can assess fetal wellbeing and risk?
84. Does increased monitoring in third trimester to assess fetal growth and wellbeing lead to reductions in stillbirth in low-risk populations without causing other unnecessary interventions? *
85. What is the role of first trimester scans to assess fetal growth and wellbeing in preventing late gestation stillbirth and adverse neonatal outcomes?
86. How can we implement a standardised protocol of assessment when women and gender-diverse people present for changes in fetal movement to improve pregnancy outcomes?
87. What is the efficacy of estimated placental volume (EPV) measurements during pregnancy to reduce stillbirth? Should and how can it be routinely implemented?
88. How can we reduce the number of ‘unexplained’ stillbirths? *
89. How can blood clotting and other disorders known to increase the risk of stillbirth be identified better during pregnancy?

90. Can the Safer Baby Bundle be adapted to local needs to reduce stillbirth in low-middle income countries neighbouring Australia?
91. What models and elements of care in subsequent pregnancies after stillbirth lead to the best outcomes for women and gender-diverse people, babies, and their families? *
92. What differences exist in the treatment of pregnancy after loss between public and private settings and how do we align the support that is offered?
93. How do experiences of care in subsequent pregnancies differ between specific pregnancy loss clinics versus standard care or other continuity models?
94. What resources should be provided to support parents who are pregnant after loss throughout their journey?
95. What evidence-based support and advice can we provide to parents around subsequent pregnancies?
96. Are pregnancy outcomes improved when there is continuity of care in a subsequent pregnancy? *
97. How do we ensure that recommendations for future pregnancy are delivered back to the patient and appropriate care providers to mitigate the risk of another loss?
98. What are the barriers and facilitators for health care providers to provide trauma informed care during pregnancy after loss?
99. What are the optimal investigations to offer parents for a subsequent pregnancy after loss?
100. What are the mental health impacts of perinatal loss on all subsequent pregnancies? *
101. What are the impacts of increased fetal surveillance on the mental health of parents in subsequent pregnancies?
102. How do cultural or individual differences and beliefs influence decision-making around investigations and communication following a stillbirth?
103. What is the impact of the cultural conversations and religious messaging around pregnancy risk and grief on how we deliver stillbirth messaging and awareness in Australia?
104. How do religions approach stillbirth and support bereaved parents and the community through stillbirth? What learnings can we take from these?
105. How can we improve access to services and support for people from diverse backgrounds?
106. How do we co-design new interventions and strategies for stillbirth reduction to ensure optimal accessibility and culturally appropriate information is delivered to priority populations?
107. How do we continue to monitor disparities robustly and efficiently in stillbirth rates and risks for priority populations?
108. How can we better provide culturally safe bereavement areas in hospitals and acute settings?
109. What are the barriers and facilitators to implementing and embedding quality improvement and collaboration in culturally co-designed stillbirth research?
110. How can we promote cultural competence for all healthcare providers to ensure that individuals feel culturally safe?