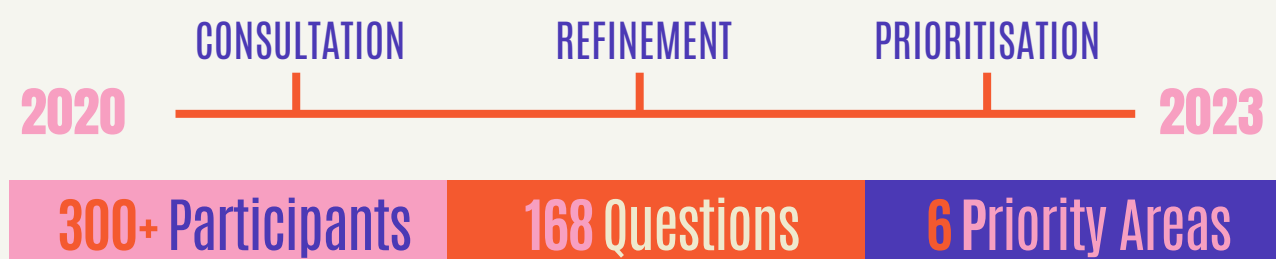


# STILLBIRTH RESEARCH PRIORITIES

**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. 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) aims to reduce preventable stillbirth rates by 20% or more by the year 2025 and ensure respectful and supportive bereavement care is available when stillbirth occurs. To achieve this vision and continued improvement beyond 2025, a collaborative priority-driven research program 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 160 research priorities were proposed by over 300 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.



An iterative approach of consultation, refinement and prioritisation was taken between 2020 and 2023. There were multiple methods of consultation including several 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:*

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|----------|---|----------|--|
| <b>A</b> | Determine the causes of, and pathways that lead to stillbirth                                 | <b>B</b> | Identify and implement strategies to prevent stillbirth                        |
| <b>C</b> | Build the capacity of health services and systems   | <b>D</b> | Understand and improve care for families after perinatal loss                  |
| <b>E</b> | Ensure culturally safe and responsive care for Aboriginal and Torres Strait Islander families | <b>F</b> | 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


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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


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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



# A

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

- How can we better understand and prevent unexplained stillbirth?
- What are the shared pathways leading to preterm birth and stillbirth?
- What are the impacts of social determinants of health on the prevalence of stillbirth and neonatal death and how do we address them?

# B

## Identify and implement strategies to prevent stillbirth

- How do we improve monitoring of fetal growth and wellbeing to reduce stillbirth without causing unnecessary interventions or undue harm?
- What is the utility of screening, including the role of biomarkers, to predict and diagnose adverse pregnancy outcomes, including stillbirth?
- What approaches to fetal movement assessment will improve the detection and care of women and gender-diverse people at increased risk of stillbirth?

# C

## 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 or reduce perinatal loss?
- Which elements of a continuity of pregnancy care model reduce the risk of stillbirth and other related adverse pregnancy outcomes?

# D

## Understand and improve care for families after perinatal loss

- 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?
- How do we address the psychosocial and mental health impacts of perinatal loss on all subsequent pregnancies?
- What approaches to stillbirth investigation are most valuable and how is this information best communicated to families?
- What are the long-term and inter-generational impacts of stillbirth?

## E

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

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

## F

### Ensure culturally safe and responsive care for families of migrant and refugee background

- How can we improve access to information to ensure women from migrant and refugee backgrounds and their babies remain healthy during pregnancy?
- Are we providing understandable information about risk factors for women of migrant and refugee background?
- What are migrant and refugee background women's perceptions of stillbirth prevention strategies and what are the barriers to uptake of prevention messaging?
- What systems changes are needed to enable health professionals to have effective conversations about stillbirth and stillbirth prevention with migrant and refugee background women?
- What models of care reduce the risk of stillbirth in migrant and refugee communities?
- What models of care improve engagement with antenatal care among migrant and refugee women at higher risk of stillbirth due to psychosocial risk factors?
- 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?
- 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?