

NHMRC Centre of Research Excellence in Stillbirth
Shared Understanding for Collaboration

Version 3.0

2024



Formal Name

"Centre of Research Excellence in Stillbirth"

Abbreviated name:

"Stillbirth CRE"

Preferred logo:



Website:

www.stillbirthcre.org.au

Contact details:

Postal address

Centre of Research Excellence in Stillbirth
Mater Research Institute
Level 3 Aubigny Place
Raymond Terrace
South Brisbane Qld 4101

Phone / email

Stillbirth CRE Coordinating Office

07 3163 2463

stillbirthcre@mater.uq.edu.au



1. Introduction

The [Centre of Research Excellence in Stillbirth \(Stillbirth CRE\)](#) has been established to address the tragedy of stillbirth in Australia through a cohesive national program of research and implementation. The Stillbirth CRE is funded by the [National Health and Medical Research Council](#) and functions as a network made up of individuals and partner organisations sharing a common vision.

Our vision is to reduce the devastating impact of stillbirth for women, families and the wider community through improving care to reduce the number of stillborn babies and to reduce the impact of this loss.

We embrace the core pillars of successful collaboration - equity, transparency, and mutual benefit. We encourage a collaborative approach to research and education to more effectively answer important questions and improve outcomes for women and families. Strong links internationally through the [International Stillbirth Alliance](#) serves to ensure a high-quality program which contributes to reducing the global burden of stillbirths.

The Stillbirth CRE brings together parents, parent advocates, healthcare professionals, researchers, professional colleges and policy makers to reduce stillbirths and improve the quality care for women and families after stillbirth. The Stillbirth CRE program focuses on research that translates into improved maternity care and better health outcomes for women and their babies.

We are an Australia-wide initiative, our host institution being [Mater Research Institute](#), within [The University of Queensland Faculty of Medicine](#). Our chief investigators are associated with The [University of Queensland](#), [Griffith University](#), [South Australian Health and Medical Research Institute](#), [University of Sydney](#), [Burnet Institute](#), [University of Melbourne](#), and [Hudson Institute of Medical Research](#).

2. Purpose of this document

A cohesive national collaboration is key to reducing the burden of stillbirth in Australia. This document details the shared understanding and commitment required from all parties involved in the Stillbirth CRE to ensure success.

3. Vision

The Stillbirth CRE's vision is to reduce the devastating impact of stillbirth for women, families and the wider community through improving care to reduce the number of stillborn babies and to reduce the impact of this loss.

4. Mission

To enable strong partnerships in undertaking high quality research and increased public awareness around stillbirth that translates into better care and outcomes for women and families.

5. Our ethos and values

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

6. Objectives of the Stillbirth CRE

The Stillbirth CRE will systematically address the Lancet 2016 series on Ending Preventable Stillbirths call to action and the specific priorities identified for Australia across the following areas:

Addressing priorities across five major program areas:

- **Priority area 1:** This program area draws on existing and novel systems to gain comprehensive, timely data to improve care to reduce adverse pregnancy outcomes with a focus on perinatal deaths. Knowledge of the causes and contributing factors in stillbirth is crucially important for parents to understand why their baby died and is also the cornerstone of future prevention of stillbirths. Currently, data quality to understand

the important contributors for stillbirth is often suboptimal due to under-investigation, inadequate classification and clinical audit of the circumstances surrounding the death. In partnership with the Perinatal Society of Australia and New Zealand, the Stillbirth CRE undertakes research to enhance protocols for investigations, classification and audit to identify causes and contributing factors to inform prevention strategies. The Stillbirth CRE has linked with the Australian Institute of Health and Welfare (AIHW) through the National Maternal and Perinatal Mortality Advisory Group to optimise future implementation and drive practice and policy change. With international collaborators (through ISA and WHO) it will also inform the development of international solutions. Ongoing monitoring of the impact of the Safer Baby Bundle (SBB) through a clinical dashboard for health care professionals is another key area of the work of this program in partnership with Women's Hospitals Australasia a SBB clinical dashboard.

- **Priority area 2:** Novel tests to improve antenatal detection of women at increased risk of stillbirth are needed. Many of the unexplained stillbirths that occur in high-income countries may be due to problems with how the placenta develops and functions. Such problems may contribute to stillbirth, even in babies who appear to be growing well during pregnancy. By assessing the function of the placenta, it may be possible to predict which babies have a greater chance of stillbirth. We may then be able to intervene before stillbirth occurs. As well as identifying babies who might be at-risk of stillbirth, assessing the function of the placenta and looking at placental biomarkers may help to detect babies who have an increased chance of experiencing distress during labour. Babies who experience distress during labour are at-risk of developing brain injury and resulting disability, such as cerebral palsy. Therefore, detecting babies who have an increased chance of experiencing distress during labour may help to reduce both stillbirth and childhood disability.
- **Priority area 3:** This program area focuses on research to enable informed decision-making in the care of women during pregnancy to avoid stillbirth and other adverse newborn outcomes. It includes implementation and updating of the Safer Baby Bundle to include new research, wide-scale implementation across maternity services, and monitoring of unintended consequences. The current lack of an individualised evidence-based approach to a woman's risk status has resulted in concerning increases in early term and late preterm birth. The Timing of Birth research program aims to improve shared decision making on planned birth to reduce the chance of stillbirth based on the woman's risk factors. The Stillbirth CRE has adapted the Safer Baby Bundle to meet the needs of Aboriginal and Torres Strait Islander communities (see Stronger Bubba Born), as

well as migrant and refugee women (see Growing a Health Baby) and those living in regional and remote settings.

- **Priority area 4:** The Care after stillbirth and neonatal death (CaSaND) program area focuses on improving care around the time of stillbirth, and in subsequent pregnancies. The psychosocial impact on mothers and families and society is substantial, yet the care received by parents in Australia is highly variable. Our studies show parents' needs are frequently unmet. Parents face many critical decisions following stillbirth and more support and guidance is needed, particularly around autopsy consent. For those embarking on subsequent pregnancies, there is up to a five-fold increased risk of stillbirth. Increased anxiety and fear in subsequent pregnancies is common, yet there is little guidance for clinicians on the optimal clinical care for these women and their families. The additional economic costs of stillbirth need to be quantified for efficient health service planning. Based on our strong clinical and research experience in this area including clinical practice recommendations included in our recently updated NHMRC approved guidelines (CaSaND Guideline), we will implement best practice on immediate care after a stillbirth or neonatal death and develop a model of best practice in a subsequent pregnancy.
- **Priority area 5:** Working with diverse communities to address & reduce inequities. Through three advisory groups, the Stillbirth CRE has now established strong partnerships to support communities in action to reduce stillbirth rates and improve bereavement care for Aboriginal and Torres Strait Islander women, migrant and refugee women and women from regional and remote areas.

Raising public awareness:

With our partners, the Stillbirth CRE aims to increase understanding and prevention awareness in the community through development and evaluation of public awareness programs.

Building the health and medical workforce:

Stillbirth CRE pathways provide students and future leaders unique opportunities to interact and work closely with leading senior researchers and clinicians nationally and internationally while forming new collaborations across a range of government and community organisations.

Building collaborations:

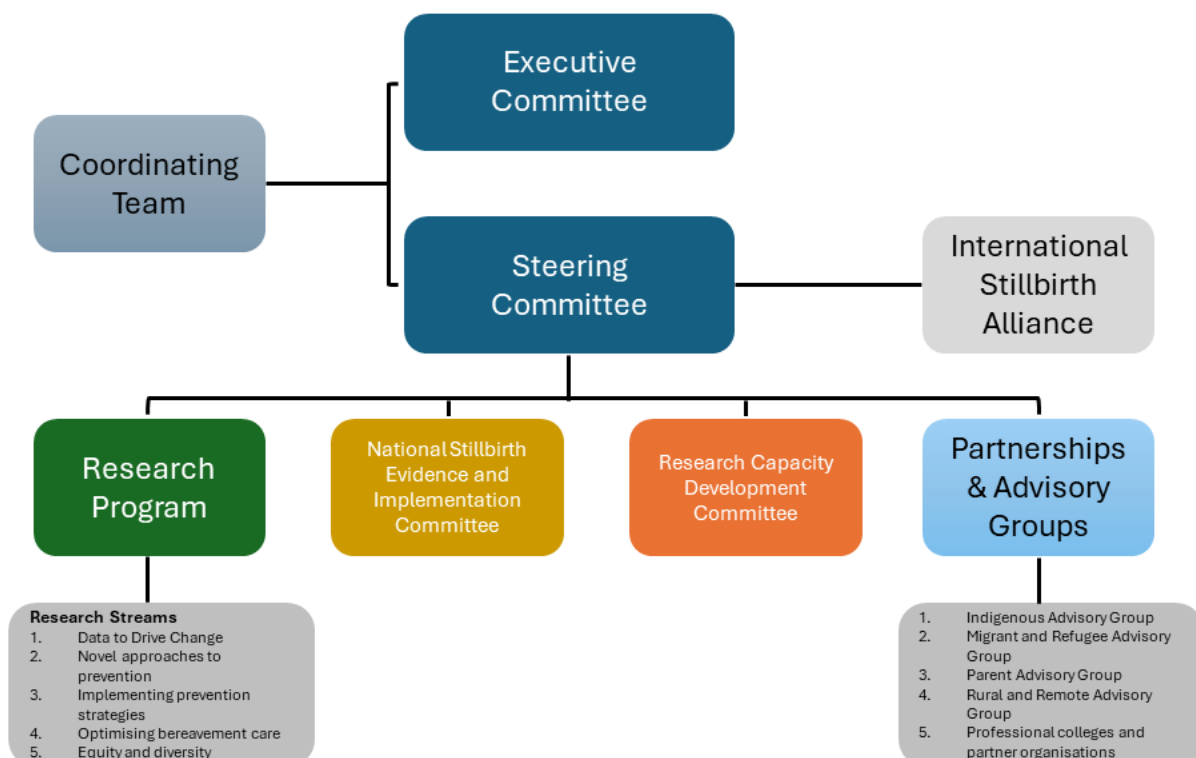
The Stillbirth CRE was established in 2015, through a NHMRC grant to the University of Queensland, and functions as a network made up of individuals and partner organisations sharing a common vision. The Stillbirth CRE has grown from the work of the Perinatal Society of Australia and New Zealand (PSANZ) and the strong partnership between the Stillbirth CRE and PSANZ will ensure optimal outcomes.

We embrace the core pillars of successful collaboration of equity, transparency, and mutual benefit. We encourage a collaborative approach to research and education to more effectively answer important questions and improve outcomes for women and families. Strong links internationally through the International Stillbirth Alliance serves to ensure a high-quality program which contributes to reducing the global burden of stillbirths.

The Stillbirth CRE Structure

The Executive Committee oversees governance of the Stillbirth CRE program. The CRE Steering Committee includes all NHMRC-listed Chief and Associate investigators and is responsible for providing advice to the Executive on all aspects of CRE program (Figure 1), including day-to-day function. Standing subcommittees, working and advisory groups will progress the work of the CRE.

Figure 1: Stillbirth CRE structure



7. What can collaborators and partners expect from the Stillbirth CRE?

A number of opportunities exist for those who join the CRE collaboration either as part of a research team, working group or committee. Any individual or organisation may collaborate with the CRE through participation in one or more subcommittees, working groups or advisory groups. In addition, organisations which make a substantial contribution to address one or more CRE priorities are acknowledged as partner organisations. Partner organisations collaborate with the Stillbirth CRE in specific projects under agreed guiding principles or, where required depending on the project, formal research agreements.

Partners and collaborators are encouraged to support a collaborative approach to research by providing a plain language description of their projects for inclusion on the CRE website, enabling PhD students to engage in activities and grant calls available to Higher Degree Research (HDR) students and avail themselves of other opportunities provided.

The following opportunities are available to all Stillbirth CRE collaborators:

- Opportunity to build or extend inter-institutional collaboration, and collaboration with industry, government agencies, and the general community;
- Access to international and national collaboration and cooperative arrangements, including visits to overseas institutions and international conferences;
- Involvement in strong teams that increase the likelihood of external financial support, such as award of national competitive grants, funding from public/private sectors;
- Contribution to overall impact and contribution to the public good and/or to the stillbirth field of research, by means of publications, developmental input into social, health, and/or economic policy, press coverage or other media, participation in public debate;
- Access to quality education and training through training of Higher Degree Research students, HDR completions, workshops and short courses for academic, clinical, and wider community groups;
- Access to support and education in research (including consumers) through a number of programs such as PhD top-ups and post-doctoral Fellowships;
- Contribution to peer recognition in terms of awards to members, invitations to present keynote addresses at major forums, election to learned societies and academies;
- Involvement in the marketing awareness and promotion of Stillbirth CRE activities among academic, health, government and community sectors, social media and general

media platforms, participation in related forums; and leadership, management and effectiveness of Stillbirth CRE processes.

8. What can the Stillbirth CRE expect from collaborators and partners?

Collaborators and partners are asked to:

- Support the ethos and values of the Stillbirth CRE
- Contribute to development of the Stillbirth CRE priorities
- Be an active participant as a member of a Stillbirth CRE committee or working group
- Register relevant research in the research register
- Be familiar with parent engagement procedures of the Stillbirth CRE
- Abide by relevant Stillbirth CRE policies around authorship, and marketing
- Disclose interests and conflicts when working as part of working groups or committee

9. Communication

The CRE aims to ensure open and effective communication, establishing and maintaining a transparent process and communication pathways, conflict resolution strategies, nurturing a “team-work” mentality. Each party is responsible for notifying the other about any actual or potential conflict of interest, defined as

“Interest means any pecuniary or other interest in relation to the matter being considered and includes shareholders, ownership, employment, being the past or future recipient of benefits in any form from another entity also having an interest in the matter being considered, as well as any known family, social, business, or other relationship, past present or future with owners, principals or agents of such other entity”.

A conflict of interest exists where

- a person's individual interests or responsibilities have the potential to influence the carrying out of his or her role or professional partnership obligations; or
- an organisation's or institution's interests or responsibilities have the potential to influence the carrying out of partnership obligations

All Stillbirth CRE collaborators and partners will negotiate and cooperate with each other in good faith to resolve any disputes or conflicts that arise. If the parties cannot resolve a dispute or conflict of interest between them, then they will endeavour to have the matter mediated or arbitrated on terms mutually acceptable to each other. The CRE Executive will act as the final arbiter for unresolved disputes.

Stillbirth CRE Collaborating Partners



Stillbirth CRE is funded through the University of Queensland

