

# NHMRC Centre of Research Excellence in Stillbirth Shared Understanding for Collaboration

Version 2.0 November 2020



## Formal Name

"Centre of Research Excellence in Stillbirth"

## Abbreviated name:

"Stillbirth CRE"

Preferred logo:



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#### 1. Introduction

The <u>Centre of Research Excellence in Stillbirth (Stillbirth CRE)</u> is a collaboration of parents, parent advocates, clinicians, researchers, professional colleges, and policy makers across Australia, to generate new knowledge through high quality research that translates into practice change to reduce the rates of stillbirths and to improve care for women and families who experience this loss. improved outcomes. The Stillbirth CRE recognises that stillbirth has enormous economic and psychosocial impacts; that there has been virtually no reduction in rates for over 20 years; that large equity gaps exist; and that families whose child is stillbirth often receive suboptimal care.

The Stillbirth CRE's research program is based on <u>The Lancet 2016 Ending Preventable Stillbirths</u> call to action, and the specific priorities identified for Australia in 2015 and subsequently revised in 2020. In recognition of the links between stillbirth and adverse maternal, neonatal (neonatal death and near-miss) and longer-term child outcomes<sup>1</sup>, the Stillbirth CRE's program addresses stillbirth as part of the continuum of pregnancy and newborn outcomes. Shared pathways leading to stillbirth and other adverse pregnancy outcomes include that of placental insufficiency and preterm birth. Further, we will closely monitor, and guard against, unintended consequences of interventions to reduce stillbirth<sup>2</sup>.

Inclusivity and collaboration are at the heart of the Stillbirth CRE. We aim to engage all who share the CRE vision to create a strong and unified voice for stillbirth action in Australia. We are committed to ensuring that the voices of parents who have experienced the tragedy of stillbirth are heard and that avenues exist for parents to participate in guiding the activities of the CRE through its steering committee and various working groups. Structures for effective and meaningful parent engagement in all aspects of the CRE will be facilitated partnerships with parent support and advocacy organisations including <u>Stillbirth Foundation Australia</u>, <u>Sands</u>, <u>Bears of Hope</u>, <u>Australian College of Midwives (ACM)</u>, <u>Still Aware</u>, <u>Red Nose</u>, <u>Remembering Riley</u>, <u>Raising Children's Network</u>, <u>Multicultural Centre for Women's Health</u> and <u>Women's Healthcare Australasia</u>.

As a regional office of the <u>International Stillbirth Alliance (ISA)</u>, the Stillbirth CRE will promote and facilitate partnerships to enhance the work of the CRE and to ensure our work in Australia contributes to the global call to action for stillbirths and also newborn health as outlined in the <u>Every</u> <u>Newborn Action Plan</u>. Further, the CRE will work towards building a strong health and medical workforce to ensure sustained improvement in care and outcomes for future families. For further information on the Stillbirth CRE people and program of work please refer to our website: <u>www.stillbirthcre.org.au</u>.

The Stillbirth CRE is funded by the National Health and Medical Research Council through the Mater Research Institute-University of Queensland.

## 2. Purpose of this document

A cohesive national collaboration is key to reduce 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:** Data to drive change. This program will draw on existing and novel data systems to gain comprehensive, timely data to drive practice and policy change. The focus on preventing stillbirth after 28 weeks remains a high priority. With over half stillbirths occurring before 28 weeks, this program will undertake research to better understand shared pathways to stillbirth and preterm birth<sup>3</sup>.
- **Priority area 2:** Implementing best practice to reduce stillbirth and adverse neonatal outcomes by reducing key the evidence practice gaps through embedding the Safer baby Bundle as part of routine care across maternity setting, resources for women to support informed decision-making and stronger links with the Australian Preterm Birth Alliance.
- **Priority area 3:** New approaches to prevent stillbirth and adverse neonatal outcomes includes new partnerships to more effectively identify novel solutions through discovery science and carry out large scale trials in the prevention of stillbirth. A major challenge to further reducing adverse pregnancy outcomes is to more clearly identify which babies can safely remain in utero awaiting spontaneous onset of labour and how to facilitate informed decision-making about appropriate timing of birth.
- **Priority area 4:** 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 regional and remote areas.
- **Priority area 5:** Improving care after stillbirth and neonatal death builds on the current program to undertake research and remains a key focus of the CRE's program. This program has been expanded to include immediate care after neonatal death and care in a subsequent pregnancy and has an emphasis on share decision-making<sup>4</sup>.

#### 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 senior researchers and clinicians nationally and internationally while forming new collaborations across a range of government and community organisations.

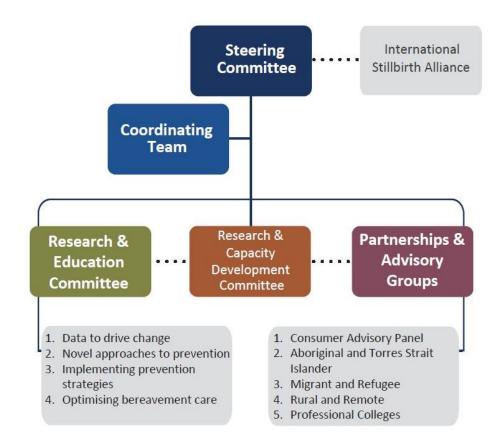
#### Building collaborations:

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 CRE Steering Committee will be made up of the NHMRC investigators to oversee the CRE program (Figure 1.). The Stillbirth CRE Steering Committee will oversee day-to-day function of the CRE. 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 on 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 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
- As a member of a Stillbirth CRE committee, be an active participant
- Abide by relevant Stillbirth CRE policies around authorship, and marketing
- Disclosing of interests 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 is funded through Australian Government



## **Stillbirth CRE Partners**



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

2. Selvaratnam R, Davey MA, Wallace EM. Reducing stillbirth safely in Australia. *The Medical journal of Australia* 2020; **213**(1): 9-.e1.

3. Ellwood DA, Flenady VJ. Stillbirth in Australia 6: The future of stillbirth research and education. *Women and Birth* 2020; **33**(6): 537-9.

4. Boyle FM, Horey D, Dean JH, et al. Stillbirth in Australia 5: Making respectful care after stillbirth a reality: The quest for parent-centred care. *Women and Birth* 2020; **33**(6): 531-6.