Stillbirth
CENTRE OF RESEARCH EXCELLENCE

PROJECT
Engage
ANNUAL REPORT

2024

Parents & Researchers
walking side by side

Acknowledgements

We acknowledge all of the babies gone too soon who continue to inspire us in research and healthcare. We thank bereaved families for their continued dedication to drive improvements in outcomes for future families and honour the everlasting legacy of all of our babies.

We thank everyone involved in this work and mentioned in this report contributing to the pursuit of enhancing partnerships between bereaved parents (and those impacted by baby loss), researchers, and healthcare professionals in research.

Thank you to Mater Research, the coordinating centre of this work, and the Stillbirth Centre of Research Excellence (CRE) and Stillbirth Foundation Australia for funding this partnership and continuing initiatives to support *Project Engage*.

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.

Protection artwork by Leona Macgrath

Our Vision

Create equitable opportunities for bereaved parents (and those impacted by baby loss) to partner with the research community to ensure meaningful research

Our Mission

1. Identify the challenges, solutions and opportunities for bereaved parent involvement in research

2. Co-design a sustainable framework to support partnerships between bereaved parents and researchers

3. Demonstrate the impact of Project Engage on the involvement of bereaved parents in research

Introduction

The lived experience of bereaved parents and families who have suffered baby loss is integral to informing best practice for pregnancy and postnatal care. Bereaved parent involvement in research undoubtedly improves outcomes for future families.

The Stillbirth CRE is committed to strengthening research partnerships with bereaved parents. In 2021, in partnership with Stillbirth Foundation Australia, we began *Project Engage* to explore and enhance the experiences of bereaved parents involved in stillbirth research. Since then, we have co-produced a large program of work together with bereaved parents to embed lived experience voices at every step of research.

We have encountered unique challenges and accomplished many achievements in sustaining meaningful research partnerships.

We are proud to detail this journey to date in this report and thank those involved and those who continue to support us.

Working together to create "an environment in which everyone feels safe so that research opportunities can be fostered, explored and partnerships can be encouraged and formed."

-Bereaved Parent

Bereaved Parent Advocacy Committee

In April 2024, the Stillbirth CRE Bereaved Parent Advocacy Committee was established. After several years of *ad hoc* bereaved parent involvement, this is a momentous achievement.

The term ‘advocacy’ rather than ‘advisory’ was determined purposefully by the group to reflect its inherent goal to advocate for research partnerships, rather than act passively as an advisory group. It indicates our commitment to continue to advocate for bereaved families and translate research findings back to the community.

The committee is the governing body developing a framework to enhance and sustain meaningful research partnerships amongst bereaved families, researchers, and healthcare providers.

The committee comprises of 16 bereaved parents (recruited via the stillbirth research involvement registry), including representatives from Red Nose, Still Aware and Bears of Hope, stillbirth researchers, and collaborators with experience and interest in consumer engagement.

Vision

Creating equitable opportunities for bereaved parents and those impacted by baby loss to partner with the research community to ensure meaningful/impactful research.

“Parents and researchers walking side by side”

Bereaved Parent Advocacy Committee

Christine Andrews,
Stillbirth CRE, Co-lead

Kirstin Tindal,
Co-lead, Aurora's mum

Danielle Pollock,
Still Aware, Sofia's mum

Bec Leonard,
Bears of Hope

Kelly Merchant,
Bears of Hope

Till Heike,
Red Nose, Claudia's mum

Brad Farrant,
Kaya's dad

Sarah McIntyre,
Cerebral Palsy Alliance

Jules Mallia,
Willow's mum

Emily Judd,
Jack's mum

Kylie Stewart,
Alexander's mum

Bereaved Parent Advocacy Committee

Steph Chaumont,
Ivy’s mum

Rachel Hill,
Tommy’s mum

Sarah Matheson,
Aksel’s mum

Sarah Lawrence,
Harry’s mum

Edith Drajkopyl,
DJ’s mum

Kiralee Innes,
James’ mum

Sophie Hickingbotham,
Reggie’s mum

Ashely Pade,
Stillbirth CRE

Emma Porter,
Stillbirth CRE

Siobhan Loughnan,
Stillbirth CRE

Valerie Ah Chee,
Stillbirth CRE

Vicki Flenady,
Stillbirth CRE

Not pictured: Hannah Fitzpatrick (*Olive’s mum)*, Sarah Fogarty, Megan Warren, Monique Lumley, (*Abbey’s mum)*, Bruce McMillan

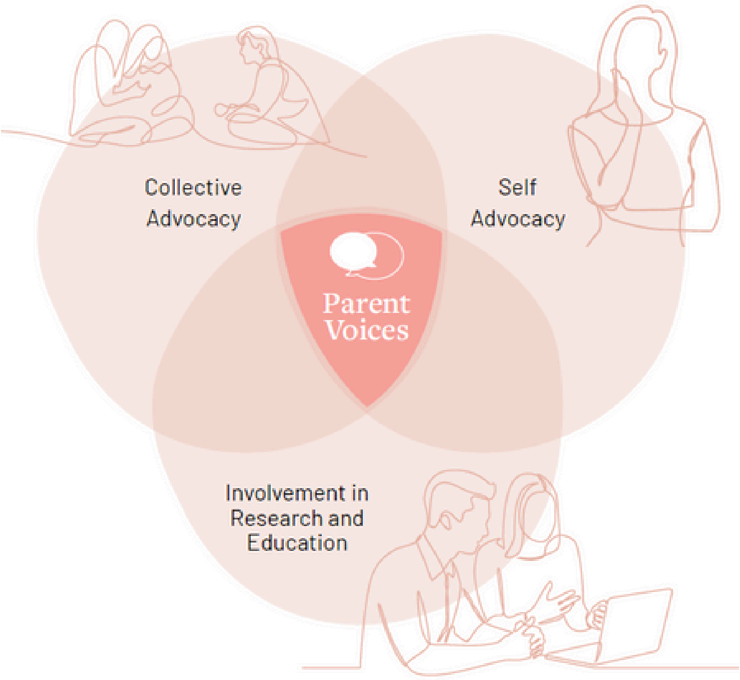
Stillbirth Research Involvement Registry

The Stillbirth Research Involvement Registry was established in May 2023. Since then, **over 200** bereaved parents and family members have joined the registry.

The Registry is a way for people to indicate their interest to be involved in stillbirth research and is open to anyone in Australia who identifies as a bereaved parent or family member or has been impacted by baby loss. This includes grandparents, siblings and those who have also experienced early pregnancy loss, termination of pregnancy or infant loss.

Registry members are offered an optional welcome chat to tell more of their story and indicate their main research interests.

Engaging in research is a form of advocacy

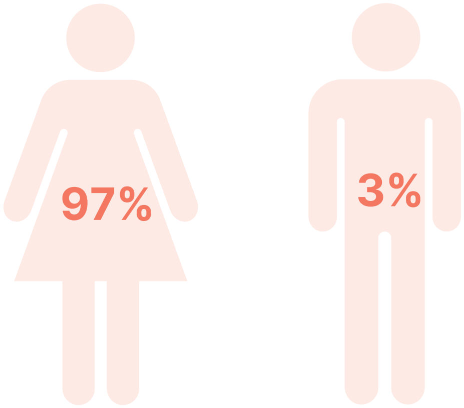


Members are also sent a quarterly newsletter detailing all current research opportunities or contacted directly if there are specific criteria for the opportunity.

Access to promote research opportunities to the registry is open to all Stillbirth CRE researchers and collaborators nationwide. To promote, researchers must demonstrate ethical approval for the research and funding to support bereaved parent involvement. This open policy of collaboration has made the Stillbirth CRE aware of further research in this area that we were previously unaware of and opened the door for future collaborations.

Where our registry members come from

"Behind every statistic is a story"

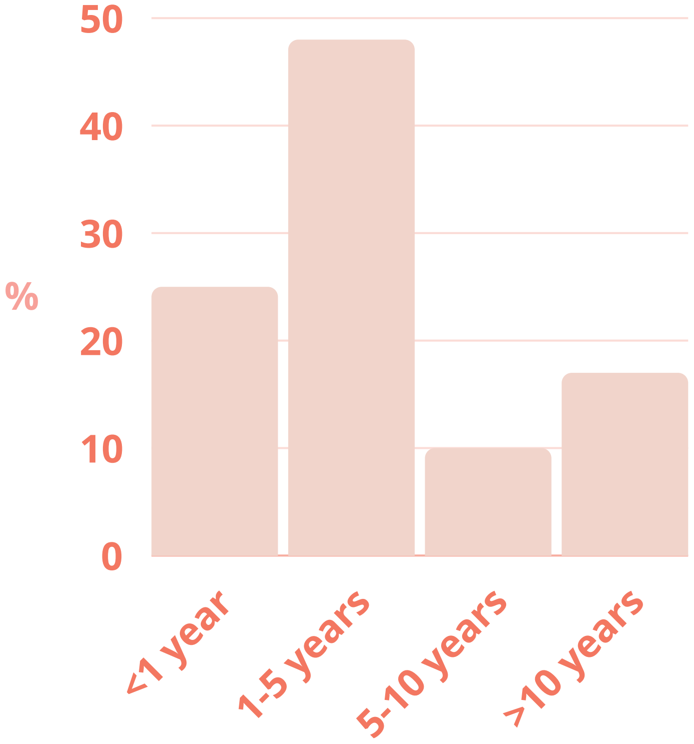


There are disparities across those who sign up for the registry.

Majority identify as female, are highly educated, of Caucasian background and live on the East coast of Australia.

Where our registry members come from

Many newly bereaved parents are also joining the registry just weeks or months post-loss. We encourage members to access the necessary support services and emphasise that getting involved in research is not in itself bereavement support, whilst acknowledging that research involvement can be a cathartic outlet for grief for many parents.



Time post baby loss when joining the registry

Strategies and sensitivity are required to increase the diversity of voices involved in stillbirth research and to ensure the emotional, psychological and cultural safety of all involved.

Honouring our babies' legacies

Quotes from bereaved parents on why they joined the stillbirth research involvement registry

“I want to help spread awareness and help other parents going through stillbirth”

“Finding purpose in pain”

“Making sure other families who experience a perinatal loss can access support”

“Brings me some personal meaning”

“Interested in being part of a community to give back to research”

“Want to contribute in a practical way”

“I wanna help other women...
and honour her memory”

“I wish I knew what I know now”

“Passionate about sharing the outcomes of research”

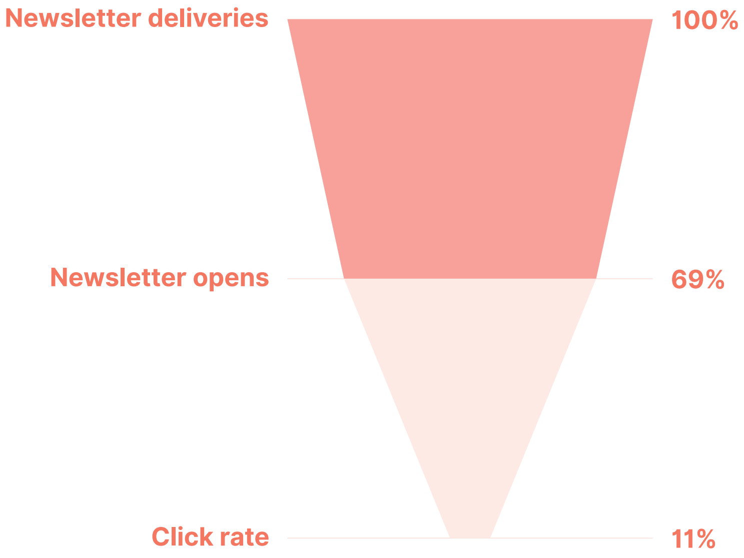
“Connection with others”

“Being around other bereaved mothers is proof that the grief won't kill me, even though I wanted it to”

Research Involvement Registry Newsletter

This year, three newsletters have been distributed to the research involvement registry. Each newsletter includes a bereaved parent spotlight, updates on Stillbirth CRE activities and research opportunities (example below). Over two-thirds of the registry membership consistently read the newsletters and around 10% click on the appropriate links to indicate interest in opportunities or read more. Nearly all who click through are placed with a research opportunity or participate in a project.

Members of the Research Involvement Registry have been involved in research in several formats. These include sitting on committees and advisory groups, co-designing research projects, being co-investigators (CIs) and associate investigators (AIs) on funding applications, raising awareness and helping translate research through media opportunities and presenting at conferences; not to mention the countless research participants who have contributed to several surveys, interviews and workshops.



The membership now far outweighs the number of available research opportunities and **further efforts should be made to explore how bereaved parents can be involved more so that registry members do not feel undervalued.**

Read past Newsletters here

Newsletter Example 08/24

Bereaved Parent Spotlight

"You learn that grief is love with nowhere to go. So you seek out opportunities to extend that love towards making the experience of other families, that little bit less lonely."

Jules is a member of the Bereaved Parent Advocacy Committee who recently co-facilitated a session at the Waves of Change Conference. Read more about Jules' journey here.

`Photo: @kayleighmcglynn Heartfelt`

In the news

Thank you to the parents on this registry who have used their voices to bring attention to stillbirth. By sharing our stories, we hope to create change for families of the future.

- Vicki Flenady emphasises that we need a nationally concerted effort to reduce stillbirth, and Kirstin adds a parent lens in turning tragedy into purpose: Plan to reduce stillbirths at risk of falling short, research centre says - ABC News
- Stillbirth CRE Indigenous researchers Deanna Stuart-Butler and Valerie Ah Chee launch the Healthy Yarning Guide to address racial disparities in stillbirth rates: First Nations women are at greater risk of stillbirth. Here's why – and what we can do about it(theconversation.com)
- Lilly shares a little piece of Vincent from the lens of a mother and midwife alongside Stillbirth CRE researchers Fran Boyle and Emma Porter: How should parents be supported after stillbirth? - ABC listen

Further updates

Bereaved parent involvement in research workshop

Waves of Change Conference 2024: Improving perinatal care

Research Involvement

The table below demonstrates how members of the research involvement registry have been involved in research activities and advocacy in 2024 with the Stillbirth CRE and collaborators (not including involvement as research participants in research studies).

Type	Description	Members involved
Committee position	Bereaved Parent Advocacy Committee	16
Committee position	National Stillbirth Evidence and Implementation Committees (NSEIC)	4
Committee position	IMPROVE 2.0 Steering Committee	5
Project CIs	Cochrane review - Perinatal care after loss	1
Project CIs	Survey of researchers and healthcare professionals - Project Engage	5
Funding application	NHMRC Partnership Project Grant - Workshop attendance	3
Funding application	MRFF Infertility, Pregnancy Loss and Menopause Grant - CIs & AIs: Streams 2,3 & 5	5
Social campaign	Perinatal mental health week - Lived experience stories	2
Media launch	Living with loss - Newspaper and radio interview	1
Education event	Shared antenatal care education event - Parent perspective	1
Conference	Waves of Change - Co-facilitation & parent perspectives	8

Researcher Reflections

"I personally think engagement with parents is going really well… Parents want to help, be involved and make a difference, and understanding this has really helped with my confidence and nerves when doing interviews. I was worried about how upset they might get during an interview, but it's inevitable and totally normal that they're going to feel emotional when talking about their babies and experience. Now it's just become a normal part of the discussion for them to shed a tear here and there, and I don't feel as worried or nervous about it anymore. We just take the time needed to chat through what they're willing to share."

-Researcher

"I think their (bereaved parents) participation is so valuable — it helps keep the conversation about pregnancy loss grounded in both humanity and compassionate language."

-Researcher

What's Next?

For the next steps of *Project Engage*, we recently surveyed researchers and healthcare professionals to understand their perspectives and experiences of partnering with bereaved parents in research. We received **45** complete responses. Survey analysis will be undertaken with the co-design team in early 2025. We are also following two case studies of research partnerships with bereaved parents.

Stillbirth Foundation Australia

Stillbirth Centre of Research Excellence

ARE YOU A RESEARCHER OR HEALTHCARE PROFESSIONAL?

We are exploring perspectives and experiences of how you involve the community in **perinatal loss research** via an online survey

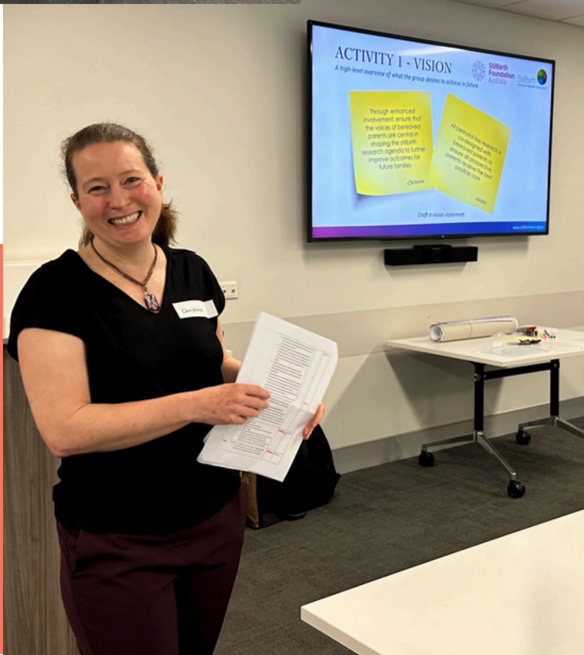
Complete the survey now

This study has been approved by Mater Misericordiae Ltd Human Research Ethics Committee: HREC/MML/88291.

Program Logic Workshop

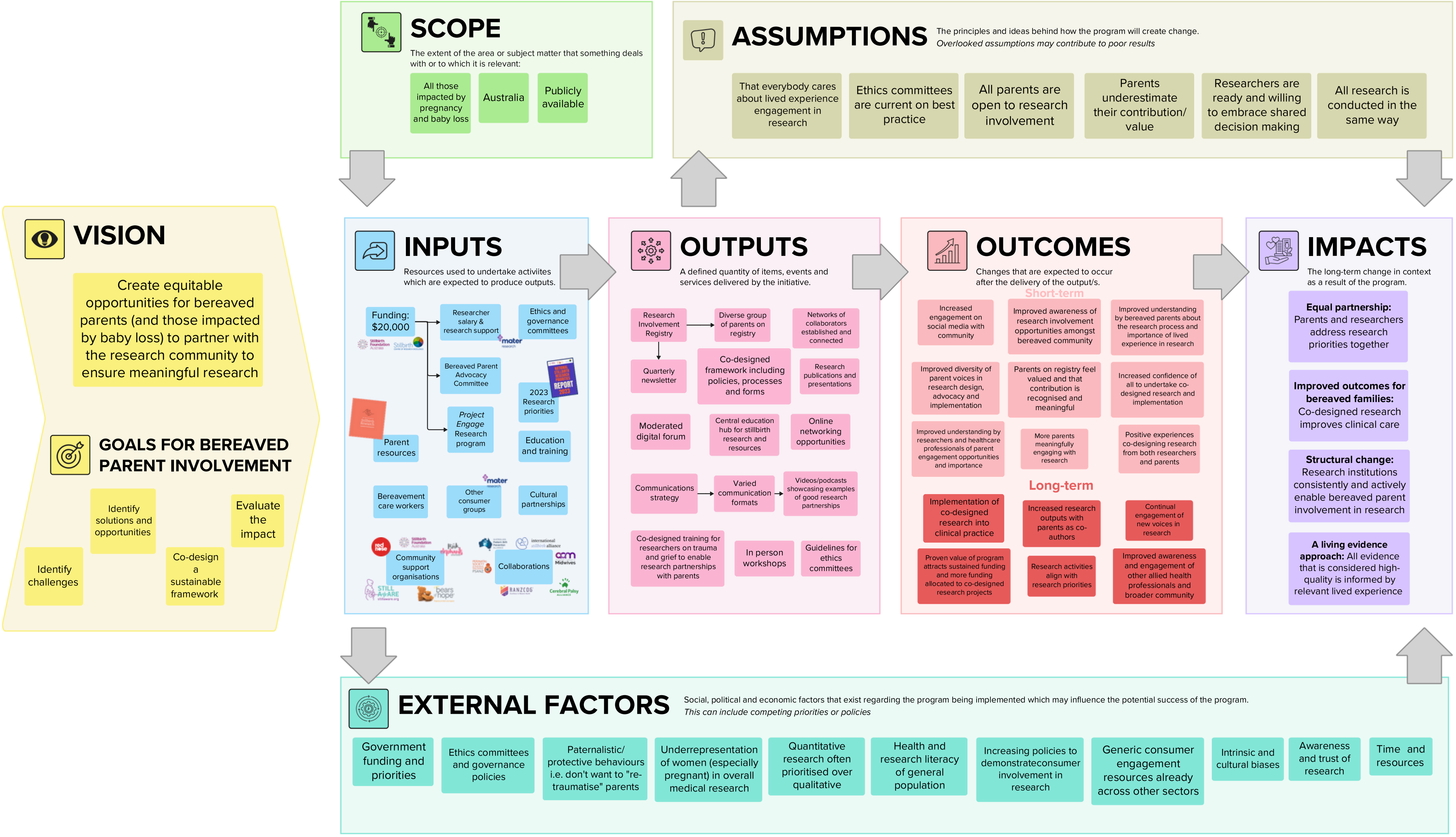
On August 8th, we held a workshop with the Bereaved Parent Advocacy Committee and invited researchers and healthcare professionals specialising in stillbirth. We worked through a program logic to determine the future vision and outcomes of effective bereaved parent involvement in research.

In small groups, the attendees discussed the current inputs, opportunities and challenges, required outputs, desired outcomes, and impact of enhancing research partnerships with bereaved parents. The Committee further refined the logic model to guide the co-design and evaluation of a sustainable framework for bereaved parent involvement in research.



See the Program Logic Model developed at this workshop on the next page

Program Logic Model



VISION

Create equitable opportunities for bereaved parents (and those impacted by baby loss) to partner with the research community to ensure meaningful research

GOALS FOR BEREAVED PARENT INVOLVEMENT

- Identify challenges
- Identify solutions and opportunities
- Co-design a sustainable framework
- Evaluate the impact

SCOPE

The extent of the area or subject matter that something deals with or to which it is relevant:

- All those impacted by pregnancy and baby loss
- Australia
- Publicly available

ASSUMPTIONS

The principles and ideas behind how the program will create change.

Overlooked assumptions may contribute to poor results

- That everybody cares about lived experience engagement in research
- Ethics committees are current on best practice
- All parents are open to research involvement
- Parents underestimate their contribution/ value
- Researchers are ready and willing to embrace shared decision making
- All research is conducted in the same way

INPUTS

Resources used to undertake activites which are expected to produce outputs.

- Funding: $20,000
- Researcher salary & research support
- Bereaved Parent Advocacy Committee
- *Project Engage* Research program
- Ethics and governance committees
- 2023 Research priorities
- Education and training
- Parent resources
- Bereavement care workers
- Other consumer groups
- Cultural partnerships
- Community support organisations
- Collaborations

OUTPUTS

A defined quantity of items, events and services delivered by the initiative.

- Research Involvement Registry → Diverse group of parents on registry
- Research Involvement Registry → Quarterly newsletter
- Networks of collaborators established and connected
- Co-designed framework including policies, processes and forms
- Research publications and presentations
- Moderated digital forum
- Central education hub for stillbirth research and resources
- Online networking opportunities
- Communications strategy → Varied communication formats → Videos/podcasts showcasing examples of good research partnerships
- Co-designed training for researchers on trauma and grief to enable research partnerships with parents
- In person workshops
- Guidelines for ethics committees

OUTCOMES

Changes that are expected to occur after the delivery of the output/s.

Short-term

- Increased engagement on social media with community
- Improved awareness of research involvement opportunities amongst bereaved community
- Improved understanding by bereaved parents about the research process and importance of lived experience in research
- Improved diversity of parent voices in research design, advocacy and implementation
- Parents on registry feel valued and that contribution is recognised and meaningful
- Increased confidence of all to undertake co-designed research and implementation
- Improved understanding by researchers and healthcare professionals of parent engagement opportunities and importance
- More parents meaningfully engaging with research
- Positive experiences co-designing research from both researchers and parents

Long-term

- Implementation of co-designed research into clinical practice
- Increased research outputs with parents as co-authors
- Continual engagement of new voices in research
- Proven value of program attracts sustained funding and more funding allocated to co-designed research projects
- Research activities align with research priorities
- Improved awareness and engagement of other allied health professionals and broader community

IMPACTS

The long-term change in context as a result of the program.

- **Equal partnership:** Parents and researchers address research priorities together
- **Improved outcomes for bereaved families:** Co-designed research improves clinical care
- **Structural change:** Research institutions consistently and actively enable bereaved parent involvement in research
- **A living evidence approach:** All evidence that is considered high-quality is informed by relevant lived experience

EXTERNAL FACTORS

Social, political and economic factors that exist regarding the program being implemented which may influence the potential success of the program.

This can include competing priorities or policies

- Government funding and priorities
- Ethics committees and governance policies
- Paternalistic/ protective behaviours i.e. don't want to "re-traumatise" parents
- Underrepresentation of women (especially pregnant) in overall medical research
- Quantitative research often prioritised over qualitative
- Health and research literacy of general population
- Increasing policies to demonstrateconsumer involvement in research
- Generic consumer engagement resources already across other sectors
- Intrinsic and cultural biases
- Awareness and trust of research
- Time and resources

Publications

‘Improving the capacity of researchers and bereaved parents to co-design and translate stillbirth research together’ was published in *Women and Birth* in February and reports the outcomes of a survey which informed the co-design of **Getting Involved in Stillbirth Research; A guide for bereaved parents.**

Contents lists available at ScienceDirect

Women and Birth

journal homepage: www.sciencedirect.com/journal/women-and-birth

ELSEVIER

Improving the capacity of researchers and bereaved parents to co-design and translate stillbirth research together

C. Andrews [a,*], A. Pade [a], V. Flenady [a], J. Moore [a], K. Tindal [a,b], B. Farrant [c], S. Stewart [a], S. Loughnan [a], N. Robinson [d], Y. Oba [a], D. Pollock [e]

[a] *Centre of Research Excellence in Stillbirth, Mater Research, University of Queensland, Brisbane, Australia*
[b] *The Ritchie Centre, Hudson Institute of Medical Research, Melbourne, Australia*
[c] *Telethon Kids Institute, The University of Western Australia, Nedlands, Australia*
[d] *The Phoebe Joan Foundation Australia, Stanthorpe, Australia*
[e] *Health Evidence Synthesis, Recommendations and Impact (HESRI), School of Public Health, Faculty of Health and Medical Science, University of Adelaide, Australia*

Read the article

A second manuscript, **‘Bereaved parent involvement in co-designed stillbirth research: Experiences of Project Engage’** was also accepted by *Women and Birth* in October and evaluates the experience of bereaved parents as co-investigators on Project Engage. We look forward to sharing this with you when it is published.

See the key recommendations resulting from this manuscript on the next page.

KEY RECOMMENDATIONS FOR EFFECTIVE CO-DESIGNED STILLBIRTH RESEARCH WITH BEREAVED PARENTS

with practical examples!

FORM A TEAM

Establish the co-design team early as foundational members to help with initial planning stages. This will benefit both the project and team cohesion.	☐ Consider how many bereaved parents you need to sustain the project (Can it continue if someone drops out? Do you have a diverse team?)
Provide a clear set of expectations (verbally and written) to all parties involved (project team, institution and bereaved parents).	☐ Assess whether an agreement is necessary/appropriate and include details of the role, remuneration and expected commitment.

HAVE A SHARED GOAL

Keep the teams' 'why' front of mind to ensure a project's continued success. Co-designing research is about putting words into action and making the lived-experience perspective central.	☐ Ask your co-investigators to share their 'why' (i.e. their baby's name or story) openly from the outset with the group when discussing project aims.

GENERATE A SUPPORTIVE ENVIRONMENT

Ensure all co-investigators' opinions and contributions are given equal respect and consideration.	☐ Establish group rules/values for working together.
Have accessible support services if a co-investigator is distressed.	☐ Supply a directory of support lines, have a 'buddy' system with a lived-experience researcher or regular check-in sessions with the lead.
Provide bereaved parents with resources about co-designing stillbirth research.	☐ Supply co-investigators with the guide for bereaved parents 'Getting Involved in Stillbirth Research' (16)

COMMUNICATE

Articulate concepts clearly and in lay terms. Do not make assumptions that everyone understands and be specific and descriptive in all communications.	☐ When asking for feedback, specify the type and scope of review required for each task (Do you want comments via email or track changes in a document?)
Avoid research jargon and acronyms wherever possible.	☐ If acronyms are used, provide a summary page of common terms.

CREATE A FRAMEWORK

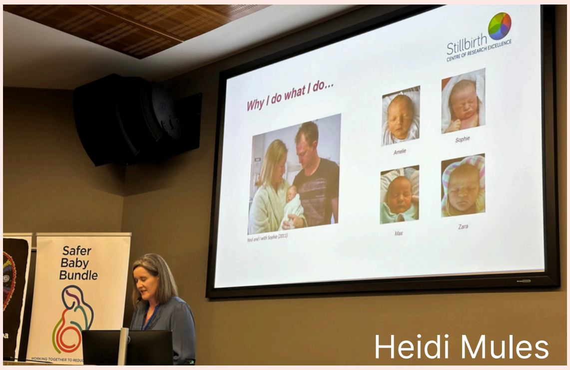
Develop and implement a framework for bereaved parent engagement within your department and organisation.	☐ Embed evaluation of the co-design experience throughout the project to maintain transparency and inform future studies.

Recommendations from 'Bereaved parent involvement in co-designed stillbirth research: Experiences of Project Engage'

Presentations

Waves of Change, *Brisbane, August*

Eight bereaved parents from the research involvement registry co-facilitated sessions or shared their story at the Waves of Change forum. Heidi Mules shared her story of Sophie, 13 years on.



Heidi Mules

Jules Mallia & Glenn Gardener

International Stillbirth Alliance (ISA), *Colombo, November*

Kirstin TIndal

Rob Saunders

Kirstin Tindal presented on behalf of the *Project Engage* team at the ISA conference to share our work to date co-designing research, the parent guide and the registry as well as future directions co-designing a framework and understanding the experiences of bereaved parents and researchers partnering in research together.

Rob Saunders, a registry member also had a fabulous presentation on grief, growth & resilience, in honour of Billie.

In the media

Bereaved Parents from the Research Involvement Registry have graciously leant their voices to various media outlets and shared stories of their experiences and precious babies.

Lilly Castor, from Orange NSW recently completed the Living with Loss program and spoke about support after stillbirth with ABC during the launch.

ABC RN | LIFE MATTERS →

How should parents be supported after stillbirth?

Thu 18 Jul 2024 at 9:06am

Listen to the interview

Brought to you by

ABC Radio National

NATIONAL

'Ever present': help for families after infant loss

By AAP Newswire
Sep 19, 2024

Read the article

Lilly Castor was supported by an online program after her first baby Vincent was stillborn in 2022. -AAP Image

As soon as Lilly Castor found out she was pregnant, she imagined a future filled with family adventures and tales from the school yard.

Thank you to all involved for shedding a light on the fabulous work bereaved parents are doing on a national and international stage to honour our babies and progress baby loss research.

Online Engagement

The Stillbirth CRE website has a dedicated page to Involvement in Research. In 2024, **835** people visited this webpage. Most were redirected from a Google search or social media, with some traffic via Stillbirth Foundation's website.

The 'Getting Involved in Stillbirth Research' guide has been downloaded **107** times.

Centre of Research Excellence in Stillbirth
29 October at 08:00 ·

Meet Sarah Lawrence. Sarah is a member of the Stillbirth CRE's Bereaved Parent Advocacy Committee and she told us about her drive to get involved in research.

"Each year in Australia over 2000 families endure the heartbreak of stillbirth. For many of these devasted families, the cause of their baby's loss remains unknown. These numbers drive my commitment to the Bereaved Parents Advocacy Committee. Research into stillbirth turns statistics into knowledge, and knowledge into meaningful change—helping to prevent other families from experiencing this dark grief and pain." Sarah said.

The Bereaved Parent Advocacy Committee of the Stillbirth CRE was established to create meaningful partnerships between bereaved parents and the research community in honour of all babies gone too soon. October is Pregnancy and Infant Loss Awareness Month, and we want to thank all parents who continue to advocate for the importance of research to ensure less families experience this heartbreak.

Learn more:
https://stillbirthcre.org.au/.../international-pregnancy.../

To get involved, visit our website:
https://stillbirthcre.org.au/parents/get-involved/ See less

This Facebook post drove **167** visits in October & demonstrates the effectiveness of social media driving traffic to our research outputs.

/parents/get-involved/

	Page path and screen class	Views	Active users	Views per active user	Average engagement time per active user	Event count file_download	Key events All events	Total revenue
☑	Total	835 0.61% of total	511 0.95% of total	1.63 Avg -35.76%	25s Avg -48.11%	107 0.03% of total	0.00	$0.00
☑ 1	/parents/get-involved/	835	511	1.63	25s	107	0.00	$0.00

Summary

Project Engage is currently funded until the end of 2025. This report demonstrates the enormous achievements of the project team and the Bereaved Parent Advocacy Committee to date; from securing funding, to research translation.

During our final committee meeting for 2024, we reflected on these achievements and what remains to be done in 2025.

The key objectives determined were:

- Advocate to government to increase awareness of baby loss, funding and research.
- Increase equity and diversity across the Research Involvement Registry and involvement across projects.
- Broaden collaborations with researchers to create and advertise more involvement opportunities.

We remain committed to supporting research partnerships and recognise the value of including bereaved parent voices in everything we do.

Email Address

stillbirthcre@mater.uq.edu.au

Website

www.stillbirthcre.org.au/parents/get-involved

Stillbirth
CENTRE OF RESEARCH EXCELLENCE