

IMPROVING THE CAPACITY OF RESEARCHERS AND BEREAVED PARENTS TO CO-DESIGN AND TRANSLATE STILLBIRTH RESEARCH TOGETHER

About the project:

This study was co-designed with bereaved parents and focuses on the specific challenges faced by bereaved parents in getting involved in stillbirth research. It notes common beliefs about the emotional difficulty for parents in participating and addresses concerns raised by ethics committees and maternity care providers. An online survey was co-designed to consult bereaved parents, aiming to understand their experiences, attitudes, and needs regarding involvement in stillbirth research.

[YOU CAN READ THE FULL STUDY HERE](#)

Findings:

The findings indicate a strong desire among bereaved parents to be involved in stillbirth research, with interest in a potential guide to support their engagement. Most participants found the proposed guide valuable and highlighted topics of importance to be included in the guide. The study also provides insights into the preferred design aspects of the guide, emphasising the need for sensitivity and inclusivity.



90 Bereaved parents completed a survey



80% agreed that bereaved parent involvement in research is important

The most common motivation for wanting to be involved was:

'to leave a legacy for my baby'

Barriers included:

- Not being asked/unsure of how to participate
- Lack of training
- Understanding jargon



Significance:

This study explores consumer involvement in health and medical research, emphasising that consumers, including bereaved parents, can contribute to all stages of research, enhancing its relevance and impact. This research emphasises the importance of involving bereaved parents in stillbirth research and highlights the need to address barriers to participation and provide appropriate support to enable their active participation. The voices of bereaved parents are vital to shaping stillbirth research and improving future outcomes for families.

The findings from this survey helped to inform the co-design of:



[TO FIND OUT MORE ABOUT GETTING INVOLVED IN STILLBIRTH RESEARCH, JOIN OUR RESEARCH INVOLVEMENT REGISTRY HERE](#)



Stillbirth Foundation Australia

Stillbirth CENTRE OF RESEARCH EXCELLENCE