

Key Principles for research partnership with bereaved parents

- 1. Respect** – *researchers and parents are valued as partners in practice.*
 - Recognise and honour all perspectives, don't dismiss anyone's experience.
 - Allow time and space to build trust and share perspectives.
 - Uphold ethical integrity and keep conversations confidential.
- 2. Communication** – *communicate sensitively and clearly to meet the needs of parents.*
 - Recognise emotions and body language. Approach discussions with empathy.
 - Use appropriate language and mirror the parent (e.g. use the baby's name).
 - Ask parents about their experience and actively listen so that they feel valued.
 - Share why you're asking a certain question and empower parents to decide if their perspective and experience is relevant at any point in time.
 - Set clear expectations about how research works and how long it takes.
 - Regularly keep in touch, even if the correspondence is 'no updates'.
- 3. Knowledge co-creation** - *recognise lived experience as essential expertise.*
 - Actively involve parents in all research aspects including shaping research questions, project design, data collection, interpretation and outputs.
 - Maintain focus on research that prioritises parent views and benefits families.
 - Highlight the influence parent contribution had on the research insights.
 - Consider if the research findings make sense from the point of view of lived experience and academically. If not, why is there a disparity?
 - Embrace mutual learning which could be key to unlocking crucial insights.
- 4. Safety and support** – *enable growth, stronger partnerships and psychological safety.*
 - Engage in reflective practice to better appreciate individual experiences.
 - Actively address power differentials - uneasiness may come from both sides.
 - Ensure everyone feels safe to provide honest feedback that is valued.
 - Resolve any conflicts promptly, transparently and with mutual respect.
 - Provide access to emotional support or counseling and refer to professional bereavement care services proactively (e.g. RedNose).
- 5. Equity and Diversity** - *be aware of cultural, religious or personal factors.*
 - Adapt approaches responsive to these diverse factors that influence grief.
 - Actively engage diverse perspectives from the outset including different cultures, genders, ages, locations and experiences.