

WHEN NO ONE HAS ASKED BEFORE:

ENGAGING YOUNG ADULTS, PARENTS AND CLINICIANS TO SHAPE RESEARCH ON SURVIVORSHIP CARE AFTER FERTILITY TISSUE PRESERVATION

Authors

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01 Background

As childhood cancer survival improves, attention has shifted to the long-term consequences of cancer treatment for health, identity, and life choices, with fertility impairment a significant concern. Fertility tissue preservation (FTP) offers infants and prepubertal children the potential to safeguard future reproductive choices and represents both a biomedical and psychological intervention. To develop patient-centered survivorship care, the impact of FTP must be understood through patients' lived experiences, including perceived autonomy and long-term acceptability.



02 Aims

To engage young people with stored fertility tissue, their parents, and healthcare professionals (HCP) in shaping the design and delivery of research on patient-centered survivorship care following FTP.

03 Methods

An iterative Patient and Public Involvement and Engagement (PPIE) approach was used, with methods designed to address the sensitivity of the topic, isolation, and potential power imbalances through informal one-to-one conversations, flexible online formats, optional small-group discussion, and emotional safeguarding. Reflexive practice was embedded to manage the researcher's role and ethical boundaries.

• Sensitive topic	Informal chats one to one, emotional space, no pressure.
• Isolation	Space to share, opportunity to join larger group if wanted.
• Power imbalance	Equality of voices, transparency, consent.
• Small participant pool	Multiple recruitment routes (charities, clinicians, advocacy groups).
• Selection bias	Consent to use quotations, background context collected.
• Potential for harm	Distress protocol, signposting, limited probing, emotional safety.



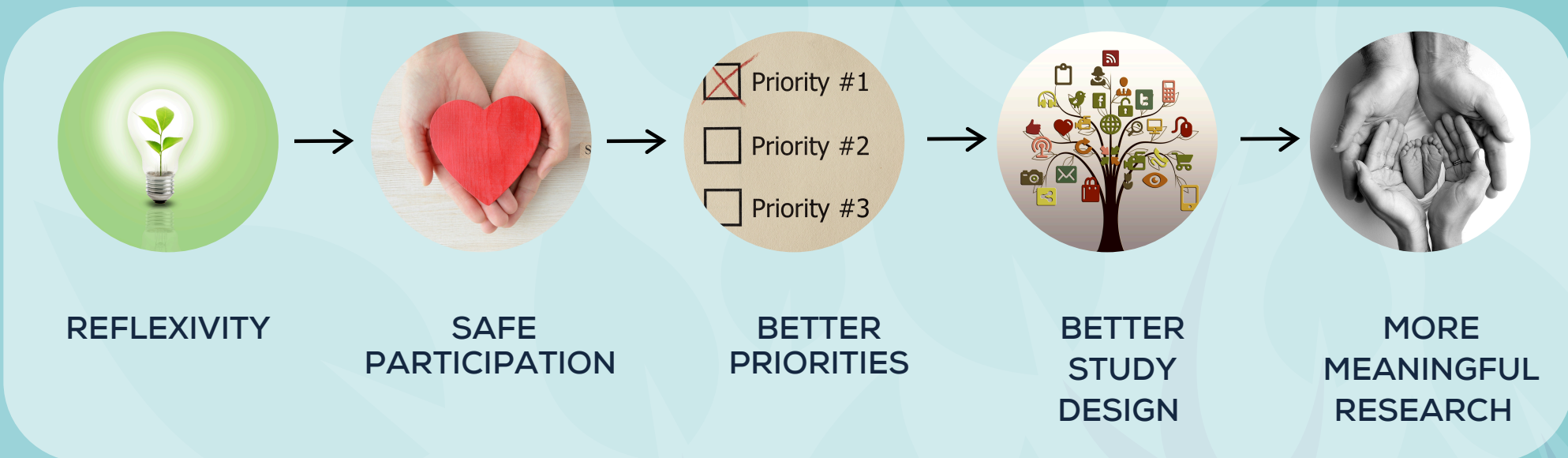
04 Findings

PPIE enabled participation from five young adults aged 16-29 years and six parents who had not previously discussed their experiences of FTP within healthcare or research settings, and supported open discussion of emotionally sensitive concerns. Four HCP took part in individual interviews. We found critical gaps in communication, emotional support, and continuity of follow-up care within existing services, and a need for developmentally appropriate information and opportunities to revisit fertility discussions across adolescence and early adulthood. PPIE partners directly informed the priorities, design and data collection tools for the planned study.



05 Conclusion

PPIE was critical in shaping survivorship-focused FTP research and identifying service priorities in a sensitive and under-researched context, demonstrating the importance of tailored engagement approaches for effective patient involvement.



Further reading

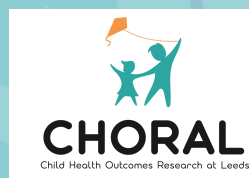
R. Mottram et al., "From Storage to Survivorship: A Scoping Review of Young Adult Cancer Survivors' Experiences and Preferences in Reproductive Survivorship Care after Fertility Tissue Preservation," Journal of Pediatric and Adolescent Gynecology, 2024.

R. Mottram et al., "Understanding the needs and experiences of young cancer patients, caregivers and healthcare professionals in the UK following childhood fertility tissue preservation (FTP): a qualitative study informed by patient and public involvement and engagement," BMJ Open, 2025.



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