

What outcomes are important to families with a lived experience of stillbirth?

A qualitative study to inform the development of a core outcome set and free online support web-resource on stillbirth

Danya Bakhbakhi, Christy Burden, Anna Davies, Abigail Fraser, Dimitrios Siassakos & Lisa Hinton on behalf of the iCHOOSE Collaborative Group

INTRODUCTION

There is a need for a core outcome set (COS) in stillbirth care research to ensure consistent reporting of outcomes that reflect the needs of bereaved families. A COS is a consensus-derived minimum set of outcomes that should be measured and reported in all clinical trials of a specific disease or trial population.

Current research shows significant variation in outcomes and a lack of patient involvement, limiting the ability to draw meaningful conclusions. Many important outcomes may be overlooked due to a focus on researcher priorities.

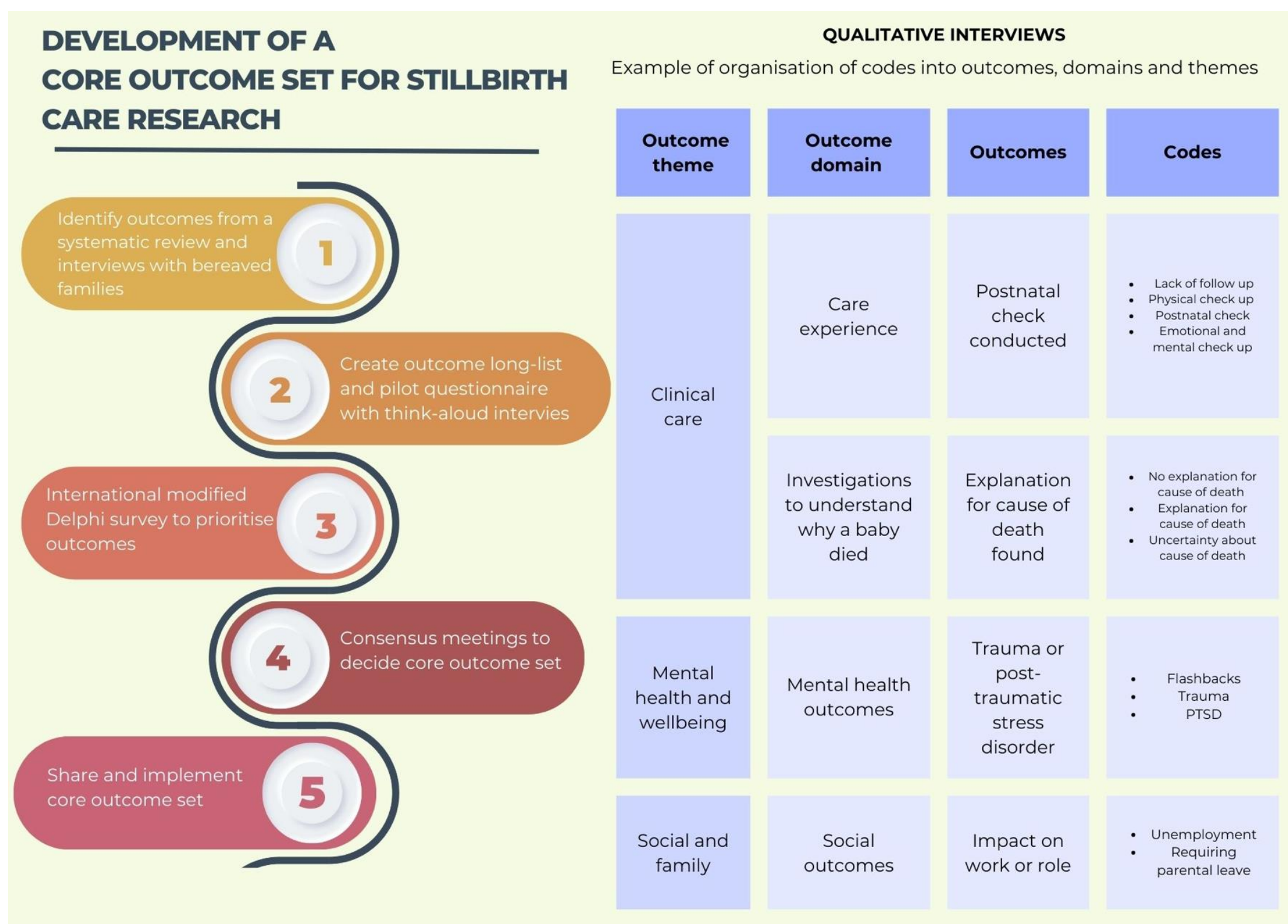
The iCHOOSE Study seeks to develop a COS by incorporating the perspectives of parents, healthcare professionals, researchers, and charities. The aim of this research was to capture the lived experience of stillbirth to identify important outcomes for future studies.

OBJECTIVE

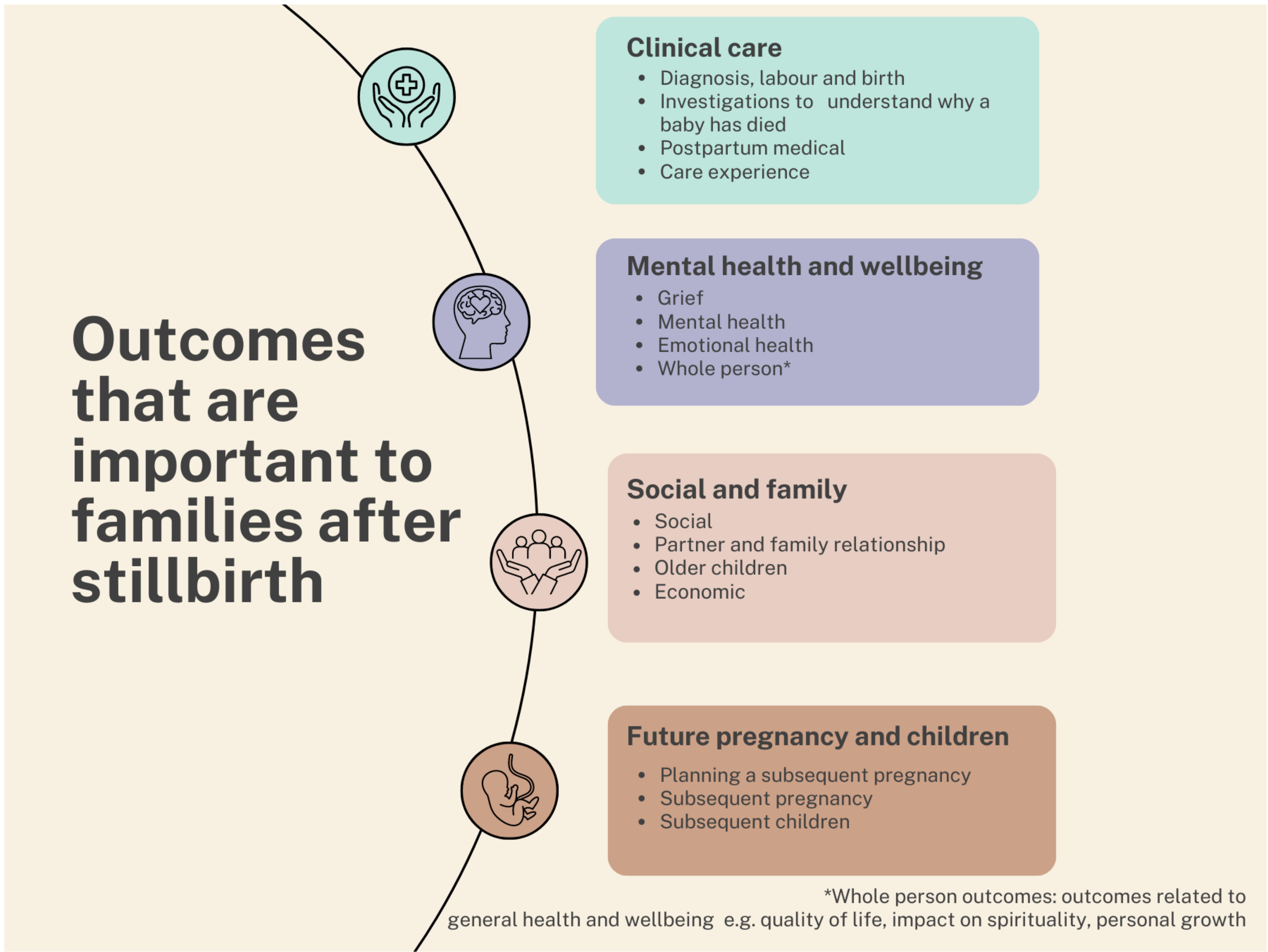
To explore the lived experience of stillbirth and identify outcomes that are important to families for the development of a core outcome set for stillbirth care research. To develop a public-facing resource on parents' experiences of stillbirth, published on the Health Experience Insights website.

METHODS

This was a national interview study in the United Kingdom (UK) with a diverse sample of parents with a personal history of stillbirth. Data collection, coding and analysis were used a modified Grounded Theory approach. Analysis of parents' lived experiences of stillbirth informed outcomes for the purpose of developing a core outcome set.



Interviews were audio- and video-recorded for analysis and the development of a free online support web-resource for the Health Experience Insights website. This website aims to gather narratives from personal interviews to illustrate the broader impact of health conditions, including pregnancy and childbirth, on people's lives. With consent from participants, topic summaries and participant biographies were written with use of media clips for the website.



RESULTS

Forty parents and family members were interviewed. Analysis identified 343 potential care outcomes, 298 (87%) of which have not been previously reported by stillbirth care studies. Outcomes were organised into four major care outcome themes: 1) Clinical 2) Mental health and wellbeing 3) Social and family 4) Future pregnancy and children. Short- and long-term outcomes related to the labour, birth, investigations to understand why a baby had died, stillbirth in a multiple pregnancy, postpartum, psychological and subsequent pregnancy care were reported. Outcomes infrequently measured in previous stillbirth care research yet discussed by most participants were social isolation, impact on occupation and need for mental health support. Parents spoke of the importance of counselling to help them understand their grief, however, the provision of this service was reported to be varied throughout the UK.

Circumstances of stillbirth	
Gestation of stillbirth, median weeks (range)	37 (24-41)
Time of interview since stillbirth, median years (range)	3.5 (1-52)
Stillbirth in a multiple pregnancy, n	3
Parity, n	
Nulliparous	20
Multiparous	7
Ethnicity, n	
White British	31
Minority ethnic group*	9
Subsequent pregnancy after stillbirth, n	22

*Asian Indian, Mixed White Asian or Black Caribbean and White European (other than White British)

Topic summaries (n=15) for the website include narratives on finding out about the stillbirth, giving birth, spending time with the baby, the funeral, coping with grief, subsequent pregnancy care and key messages to parents and healthcare professionals.

CONCLUSION

A comprehensive outcome inventory was constructed, from which the final core outcome set was determined. Future care should be developed and evaluated using outcomes that directly relate to the lived experiences of parents and families exposed to stillbirth. The Health Experience Insights web module on Stillbirth will be available to view on <https://hexi.ox.ac.uk> in the Autumn 2025.

ACKNOWLEDGEMENTS & FUNDING

We thank the parents, families, and professionals who contributed to this study. Funded by the **NIHR Doctoral Fellowship** (DRF-2017-10-130). The views expressed are those of the authors and not necessarily those of the NHS, NIHR, or the Department of Health.