MAKING LOSS VISIBLE

USING DEMOGRAPHIC DATA TO IMPROVE EQUITY IN BEREAVEMENT AND MENTAL HEALTH CARE

HELIX
Healing Experience of Loss & Trauma

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Introduction/Background

What's the issue and why it matters

Parents from the global majority experience higher rates of pregnancy complications, infant loss, and perinatal mental health difficulties, yet are less likely to access support (MBRRACE-UK, 2023).

Black and South Asian women face increased risks due to racism, adverse childhood experiences, and socio-economic disadvantage (Pilav et al., 2022; Redshaw et al., 2019; NHS England, 2021).

These inequities highlight the need for culturally safe, trauma-informed, and inclusive care.

Rationale / Problem Statement

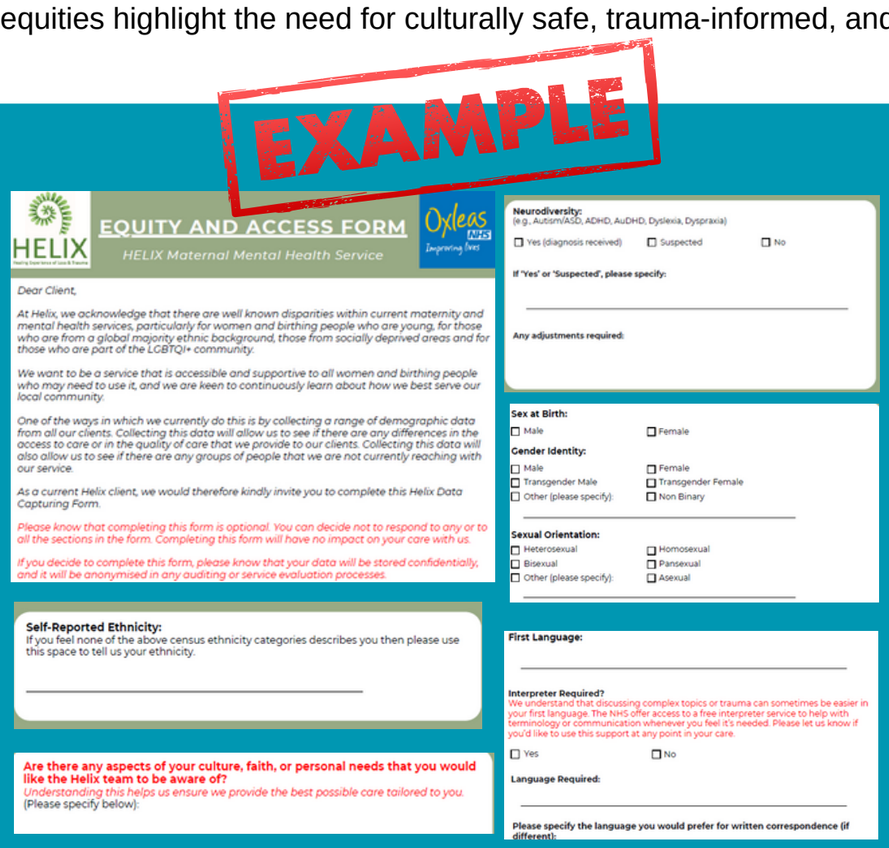
Why demographic data matters

Collecting demographic data helps identify underrepresented groups, uncover systemic racism, and guide culturally safe outreach.

However, asking about ethnicity, gender, or identity during times of grief or distress can feel intrusive.

Using trauma-informed and relational approaches—clear explanations, opt-out options, and empathetic communication—reduces distress and builds trust (Hughes et al., 2019).

Being able to comfortably discuss identity supports culturally safe care and improves engagement.



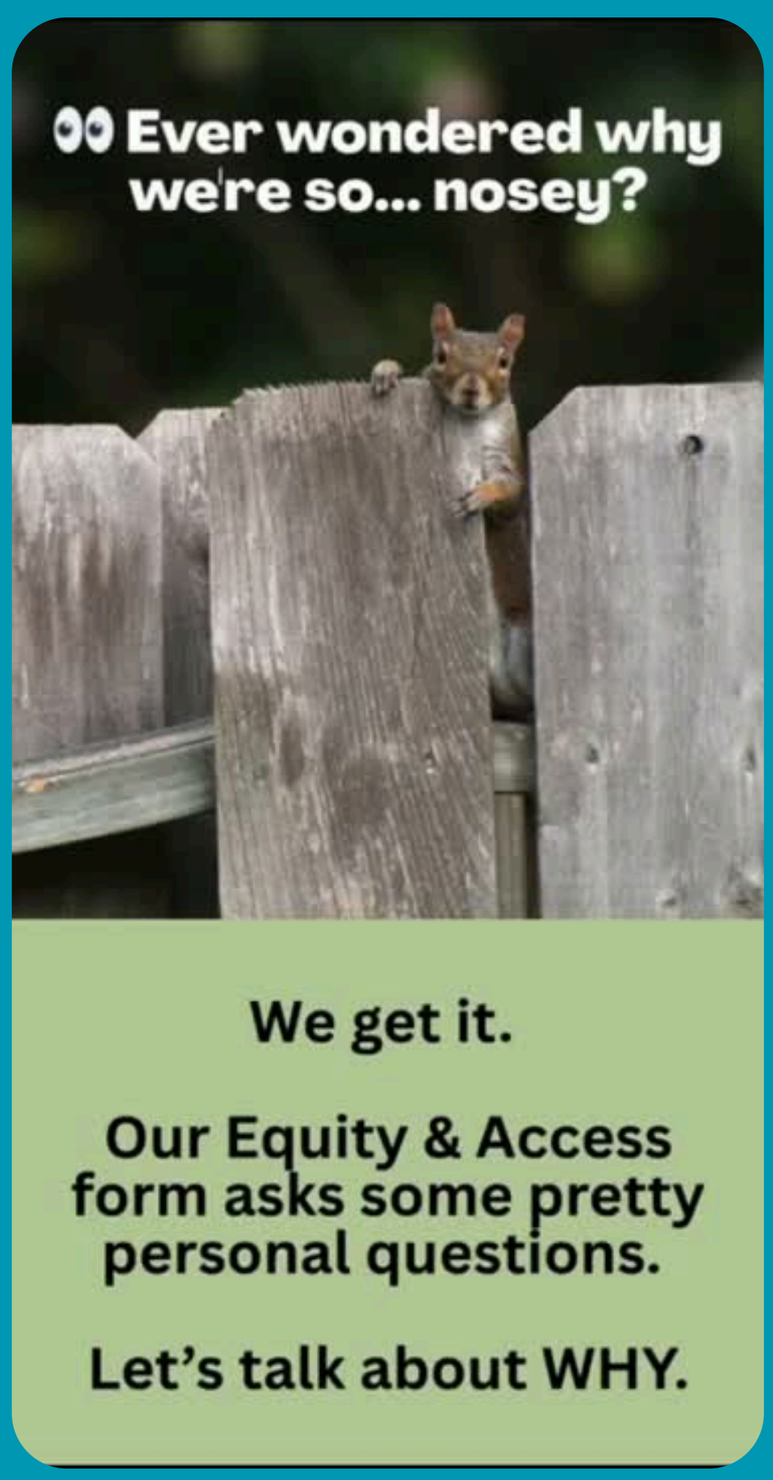
Co-Production and Tool Development

Developing tools with, not for, communities

The Helix demographic tool was co-produced with parents who experienced pregnancy loss, including neurodivergent service users.

The design used plain language, visual cues, and alternative formats to improve accessibility. This included option to complete with interpreter or staff support.

Co-produced video was added, to help normalise sensitive conversations, explain why data is collected, and build trust among underrepresented communities (INVOLVE, 2019; Robert et al., 2020).



Implementation and Practice

How it was put into action

Guided by Cheshire & Merseyside Specialist Perinatal Service recommendations (Wynter et al., 2023).

Staff received training and resources to support sensitive data collection and explain its purpose.

The embedded video was co-produced and shared with those accessing our service prior to assessment and also added to our team Instagram account.

Early Findings / Impact

What's changed so far

Early Helix data showed fewer referrals from LGBTQIA+ parents and Roma/Gypsy Traveller communities.

In response, collaboration with community leaders and charities began to raise awareness, improve communication, and increase access.

These partnerships informed the co-produced video and further tool refinement—closing the gap in engagement and making loss visible for all families.

Conclusion / Key Messages

- Collecting demographic data ethically and collaboratively can transform equity in bereavement and mental health care.
- Co-production and trauma-informed practice are essential for culturally safe, inclusive support.
- When families understand why data is collected, trust and engagement grow —helping make every family's loss visible.

HUGHES, K., BELLIS, M.A., HARDCASTLE, K.A., SETHI, D., BUTCHART, A., MIKTON, C., JONES, L. AND DUNNE, M.P., 2019. THE EFFECT OF MULTIPLE ADVERSE CHILDHOOD EXPERIENCES ON HEALTH: A SYSTEMATIC REVIEW AND META-ANALYSIS. THE LANCET PUBLIC HEALTH, 2(8), PP.E356–E366.
INVOLVE, 2019. CO-PRODUCTION IN ACTION: NUMBER ONE. NATIONAL INSTITUTE FOR HEALTH RESEARCH (NIHR). AVAILABLE AT: HTTPS://WWW.INVO.ORG.UK/
MBRRACE-UK, 2023. SAVING LIVES, IMPROVING MOTHERS' CARE: LESSONS LEARNED TO INFORM MATERNITY CARE FROM THE UK AND IRELAND CONFIDENTIAL ENQUIRIES INTO MATERNAL DEATHS AND MORBIDITY 2019–2021. OXFORD: NATIONAL PERINATAL EPIDEMIOLOGY UNIT, UNIVERSITY OF OXFORD.
NHS ENGLAND, 2021. CORE20PLUS5: AN APPROACH TO REDUCING HEALTH INEQUALITIES. AVAILABLE AT: HTTPS://WWW.ENGLAND.NHS.UK/ABOUT/EQUALITY/EQUALITY-HUB/CORE20PLUS5/
PILAV, S., BEESON, J. AND MCCOURT, C., 2022. UNDERSTANDING ETHNIC INEQUALITIES IN MATERNITY CARE: A QUALITATIVE EVIDENCE SYNTHESIS. BMC PREGNANCY AND CHILDBIRTH, 22(1), P.69.
REDSHAW, M., HENDERSON, J. AND HAMILTON, K., 2019. MOTHERING THROUGH ADVERSITY: BLACK AND MINORITY ETHNIC WOMEN'S EXPERIENCES OF MATERNITY CARE. ETHNICITY & HEALTH, 24(8), PP.897–915.
ROBERT, G., CORNWELL, J., LOCOCK, L., PURUSHOTHAM, A., STURMEY, G. AND GAGER, M., 2020. PATIENTS AND STAFF AS CODESIGNERS OF HEALTHCARE SERVICES. BMJ QUALITY & SAFETY, 24(7), PP.505–512.
WYNTER, K., FISHER, J., ROWE, H., AND THE CHESHIRE & MERSEYSIDE SPECIALIST PERINATAL SERVICE, 2023. GUIDANCE FOR COLLECTING EQUALITY AND DIVERSITY DATA IN PERINATAL SERVICES. CHESHIRE & MERSEYSIDE SPS.