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PRAMS: Perinatal Redesign for Accessing Mental Health Support.

NIHR Three Schools Mental Health Programme


Introduction

In today's seminar we will…

1. Provide an overview the PRAMS Project
2. Share early findings from work packages 1 and 2
3. Consider learning points, next steps and reflection points

Themes raised during today's session may be triggering in terms of your own experiences.

Remember to take care of yourself.

Feel free to step away if needed.

Project Overview

AIMS, OBJECTIVES, AND METHODS

What is Perinatal Mental Health?

Peri = around. Natal = relating to birth - the field of mental health concerned with the time around birth.

From the planning of a pregnancy until……..

This is a time with specific, unique features to it in terms of mental health. Pregnancy, birth and transition to parenthood bring with them different risks that need different care.

The perinatal period can be very vulnerable and therefore birthing people may be more susceptible to trauma especially relational trauma

Window of opportunity for intervention.

Impacts are wide ranging and multifaceted.

Barriers in the road

MBRRACE-UK
Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK

- The **MBRACCE report** shows that there are certain groups that are not being represented in services at all due to **systemic injustice** and **lack of access to services**
  - Black women are **4x more likely** and Asian women are **2x more likely** to die then white women (MBRACCE report) – language barriers, stigma, cultural barriers
  - the LD and neurodivergent community report feeling as though they cannot have a baby because of their diagnosis let alone access spaces designed for neurotypical people
- Our experiences of **care-giving systems** have been shown to impact how we **engage** with services later in life (Kezelman & Stravopoulos, 2012)
- During pregnancy and the postnatal there is the **pressure of the expectation** that they should be enjoying pregnancy or being a mother.
- A **fear of having their baby taken away** is a common reason why some women do not disclose any difficulties.
- Known gaps between primary and secondary mental health services

Overview

We're a partnership of 6 organisations

PPI Panel and PSC Group

Funded by the NIHR Three Schools

18 months (Oct 2024 – March 2026)

Our aim: To deliver an experience-based co-design intervention for underserved women with unmet perinatal mental health needs.

LIGHT pre & post natal support

City of Doncaster Council

Proud to care in Sheffield

NHS Sheffield Health and Social Care NHS Foundation Trust

Sheffield City Council

University of Sheffield

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Keele University

Methods – the ‘how’

1

A national online staff survey and semi-structured interviews

2

Focus groups and 1:1 interviews with women from underserved community groups, recruitment via Community Research Link Workers.

3

Co-design workshops with professionals and underserved women with lived experience to develop a bespoke, ‘middle-level’ trauma-informed intervention for PMH care.

Work Package 1: professionals

Online survey opened for 3 months Feb-April 2025 targeting professionals working with perinatal women and birthing people

Submitted an Amendment and reopened for a further month July-August 2025

Recruitment strategy:

- Targeted recruitment at research sites: SCH, SHSC, STH and RDASH
- Professional networks within the project management group and known forums, e.g. NHS Futures

Survey included screening questions (role, organisation, underserved groups) and the Pragmatic Context Assessment Tool (PCAT) to assess barriers and facilitators to change in different clinical contexts

Survey respondents were approached to take part in a follow-up interview based on role, organisation, and who they engage with

Work Package 2 – lived experience

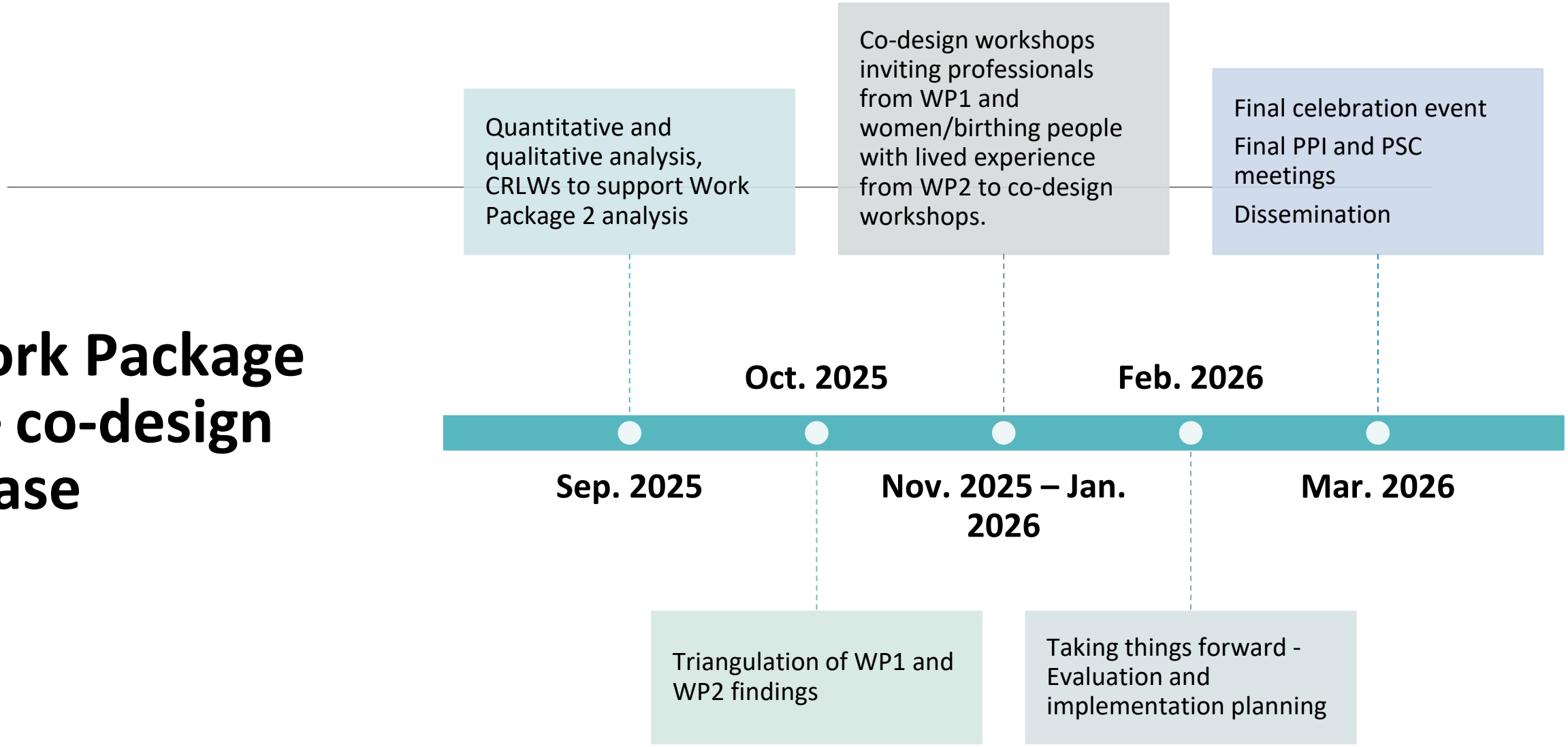
Four Community Research Link Workers recruited and trained

Recruitment from Emotional Wellbeing Clinics in family hubs (Start for Life programme); local Family Hubs and LIGHT peer support groups in Sheffield and Doncaster, personal community networks

From May to August 2025, we have delivered 8 focus groups and three 1:1 interviews held in local community venues including mosques, family hubs, home visits and online.

Final recruitment figure for Work Package 2 is n=50.

Work Package 3 – co-design phase



Findings

WORK PACKAGES 1 AND 2

WP1 - Survey Findings

Final recruitment figures: 130 consented; 113 full responses for analysis

79 (78.2%) were working in Yorkshire, 6 (5.9%) in the Northwest of England, 5 (5.0%) in the East of England, 4 (4.0%) in London, 4 (4.0%) in the Southwest of England, and 2 (2.0%) in the West Midlands.

There were 76 (75.2%)participants who responded that their service has made special arrangements to improve access for underserved patients

Table 1 Participant job titles

Job Title	Frequency
Health Visitor	17 (16.8%)
Midwife	14 (13.9%)
General Practitioner	12 (11.9%)
Family Intervention Worker	10 (9.9%)
Clinical Psychologist	7 (6.9%)
Mental Health Nurse	5 (5.0%)
Cognitive Behavioural Therapist	4 (4.0%)
Parenting Practitioner / Parenting Leads	4 (4.0%)
Perinatal Practitioner	4 (4.0%)
Obstetrician	3 (3.0%)
Occupational Therapist	3 (3.0%)
Peer Support Worker	3 (3.0%)
Psychiatrist	3 (3.0%)
Service / Operational Manager	3 (3.0%)
Family Hubs Practitioner	1 (1.0%)
Support Worker	1 (1.0%)
Support, Time and Recovery Worker	1 (1.0%)
Other	6 (5.9%)
Missing	28

PCAT = Pragmatic Context Assessment Tool (https://cfirguide.org/)

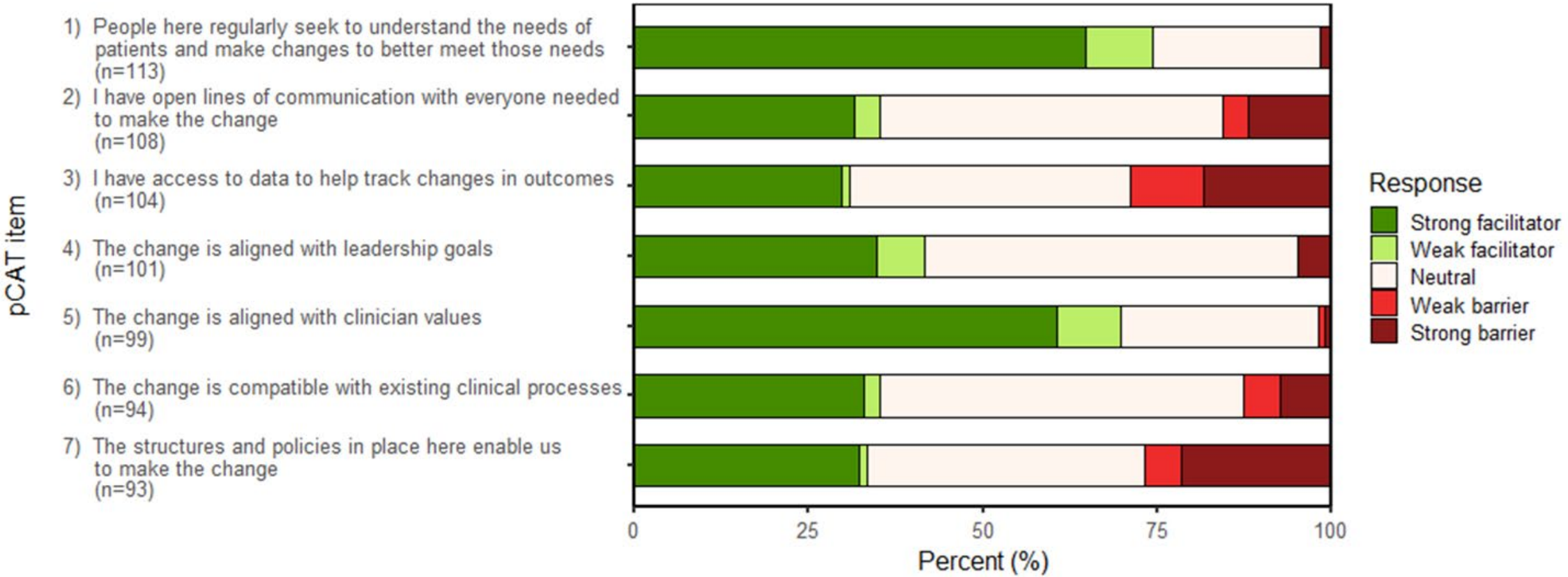


Figure 1. PCAT Items 1-7

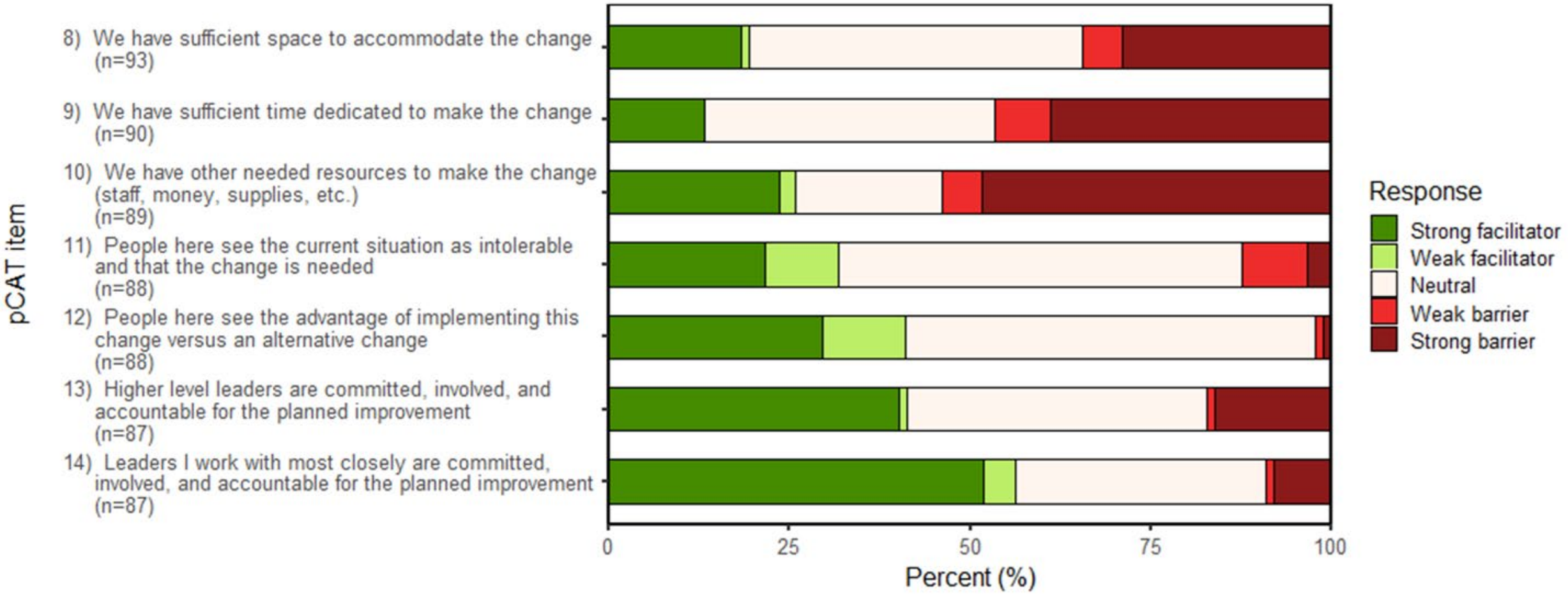


Figure 2 PCAT Items 8-14

Work Package 1 – Interviews with professionals

- 19 professional interviews completed.

- Roles included: Clinical psychologists, specialist perinatal, cognitive behavioral therapists, peer support workers, obstetrician, GPs, neonatal nurse, psychiatrist, health visitors, midwife, service delivery manager.

"You think about developing your cultural awareness or developing something…that feels like quite hard to know how to do that to people in a way that they can use or benefit from."

"The training, being available and planned, and being supported *is a huge, hugely important*."

"If they've had bad experience of services in past, they're worried about you're gonna take the baby away, or then they're gonna be less inclined to trust you and open up about what's going on."

"Hard to keep up isn't it, with everything that we need to do *just for the basic job*. So sometimes, having to go above and beyond and do lots of *extra things which are required* can be quite time-consuming."

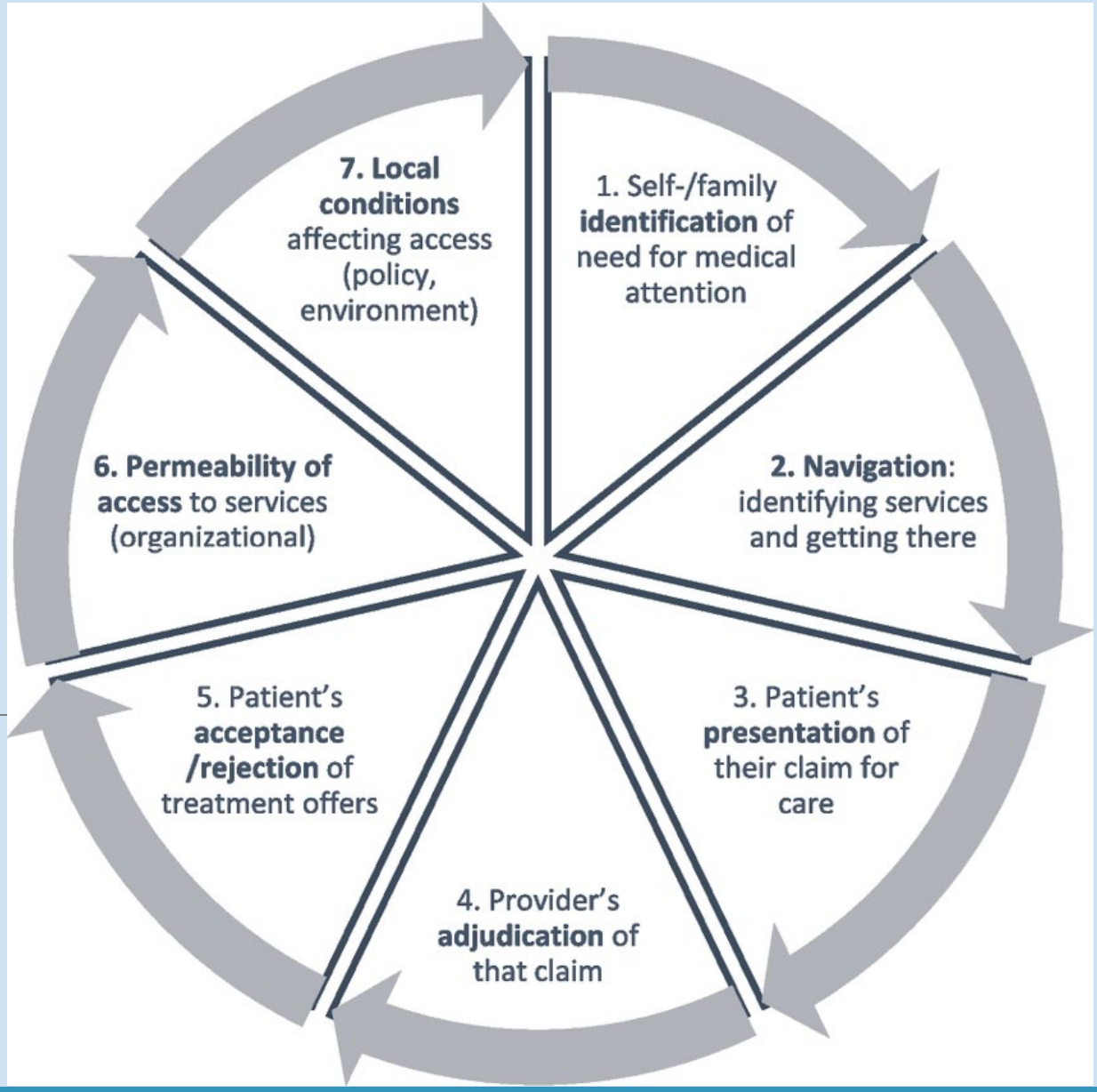
Work Package 2 – who have we spoken to?

We also spoke with 50 women across a range of communities / underserved groups with lived experience of mental health difficulties during their pregnancy and up to 2 years post-birth.

- Ethnic minority backgrounds (South Asian, Arab, Somalian), religious minorities
- Non-English speakers or with limited English proficiency (using Urdu and Somalian interpreters); Limited literacy skills
- Living in alternative residential circumstances (refugee/asylum seeker accommodation), areas of deprivation and across Yorkshire (Doncaster)
- Young mums (<25 years old) and single mums
- Physical health comorbidities (fibromyalgia, IBD, gestational diabetes, thyroid problems) and hearing disability
- Neurodivergent mums (ADHD, Autism) and with children who are neurodivergent and with SEN needs
- Carers
- Lived experience of PNMH across the perinatal journey including pregnancy, birth and postpartum
- A range of mental health presentations including perinatal anxiety, birth trauma, pregnancy loss, preterm births and bereavement, pre- and postnatal depression, loneliness and isolation, complex trauma and interpersonal difficulties

Candidacy framework (Dixon-Woods et al.) introduction

1. **Identification of candidacy**
2. **Navigation of services**
3. **Permeability of services**
4. **Appearance at services**
5. **Adjudication by healthcare professionals**
6. **Offers of, resistance to services**
7. **Operating conditions and local production of candidacy**



Identification - *How people identify themselves as suitable/eligible for services*

- **When are individuals needing support identified:** Late presentation due to cultural help-seeking patterns.

- Those with moderate to severe needs are more likely to be picked up by professionals during routine appointments and referred for specialist support, whereas those with milder concerns are more dependent on self-referal processes.

- **Groups identified by professionals as having unmet needs:** people going through care system, complex trauma histories, cultures where families want to take charge and manage it, asian / african backgrounds (stigma), young mums, migrant groups (non-english speakers).

Navigation - *How people find their way to appropriate services*

- **Referral systems:** Limited in who gets referred to them. Self-referral unlikely in some groups (outreach work important). Reliant on women raising concerns or staff noticing issues. Dependent on appointment attendance to be picked up. Health visitor reported better experience picking up women who may need support as they see most people and can build trust with them.

- **Outreach in community:** More success in getting women to access their service after community outreach work. Raising awareness.

Permeability of services - *How easy it is to get through to services*

- **Setting has an impact:** don't want to be seen attending a 'mental health' service (community locations are better). Emergency department off-putting (noise, wait times).

- **Barriers to access:** Cost to travel, language, distrust, feeling overwhelmed in perinatal period, separation from partner, fear of judgement (young mums) and cultural stigma, fear of baby being taken away. Appointment scheduling creating anxiety and burden.

- **Facilitators to access:** Flexible delivery methods (text, home visits, group sessions, phone calls), multiple therapy options (classes, counselling, CBT). Allocated worker (consistency, building trust).

Asserting Candidacy - *How people present themselves and their needs to services*

- **Assessment of needs:** Standard assessments may be a barrier, trying to fit people to what they can offer. Those who don't fit within the parameters of the assessment tool will need confidence to convey their issues - language, trust and confidence barriers.

- **Not meeting criteria:** Considered, sensitive response to referrals which come through which don't meet their service criteria.

- **Professional validation:** Need for professional validation that feelings are legitimate. Professional advocacy needed against family dismissal of concerns as "just being moody/hormonal"

Professional adjudication - *How healthcare professionals assess and respond to presentations*

- **Staff training gap (cultural competency and community knowledge):** Need for enhanced cultural competency and community-specific knowledge (feeling unprepared). Not aware of all the different support available within community to signpost to. Mandatory equality training every year is not useful in practice.

- **Staff training gap (conversations about mental health):** Need for non-mental health professionals (e.g. midwives) to have training and support to have conversations about mental health, e.g. how to ask about it and respond, relevant skills for managing concerns and distress. And knowledge on how presentation of struggle may differ.

- **Complex trauma histories:** Services limited in addressing those with complex trauma histories - don't have the resource - e.g. doesn't fit within a twelve session model. *"People who have complex trauma histories, I think there's a sense that services go, that's not us and everybody takes a stand back you know".*

Offers and resistance - *What is offered and how people respond*

- **Resistance to medication:** in favor of psychological approaches ("wanted to fight it", "do you not think I'm curable without tablets?")

- **Flexible offers:** emotional wellbeing and mental health support to mums, dads and family members. Group, peer support, one to one via text, call, email or in person. EMDR, CBT, DBT. Practical support (housing, benefits). Community nursery nurse - advice, observations. Parent, baby groups.

- **Factors preventing continued engagement:** demand of engaging with a service with a new baby. Language barriers (not benefitting), cost to travel, fear of baby being taken away, lack of understanding or feeling listened to. Resistance to intensive scheduling (anxiety over weekly hour commitments).

- **Inclusion of partners:** acceptance of support that includes partners and addresses family dynamics.

Operating conditions - *The broader context affecting how candidacy is constructed*

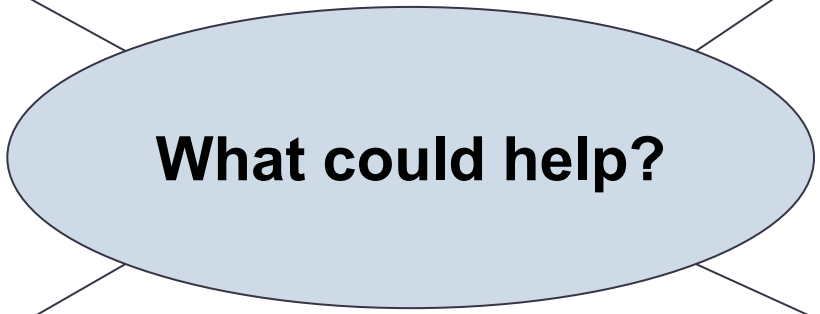
- **Family dynamics:** Strategies to improve care delivery - involving people in the woman's own network. Extended family involvement creating stress while simultaneously preventing help-seeking due to shame. Isolation despite being "surrounded by people" highlighting inadequacy of cultural support structures.

- **Community leaders:** involvement of community leaders is key in implementing a new service for these underserved groups.

Potential ways to address barriers…

Earlier intervention:
(Feeling supported and prepared for pregnancy, birth and after. Access to support throughout whole journey)

Community based support
(peer support workers, outreach work, using family hubs)



More flexible approaches
(continuity of care, flexibility in timing and format, trust building via conversations rather than forms, involving family/partners)

Better staff training
(cultural awareness, sensitive discussions, staff support for difficult situations)

Reflection

KEY LEARNINGS AND NEXT STEPS

Aims of work package 3 (co-design phase)

What are we trying to achieve? What might the finish line look like?

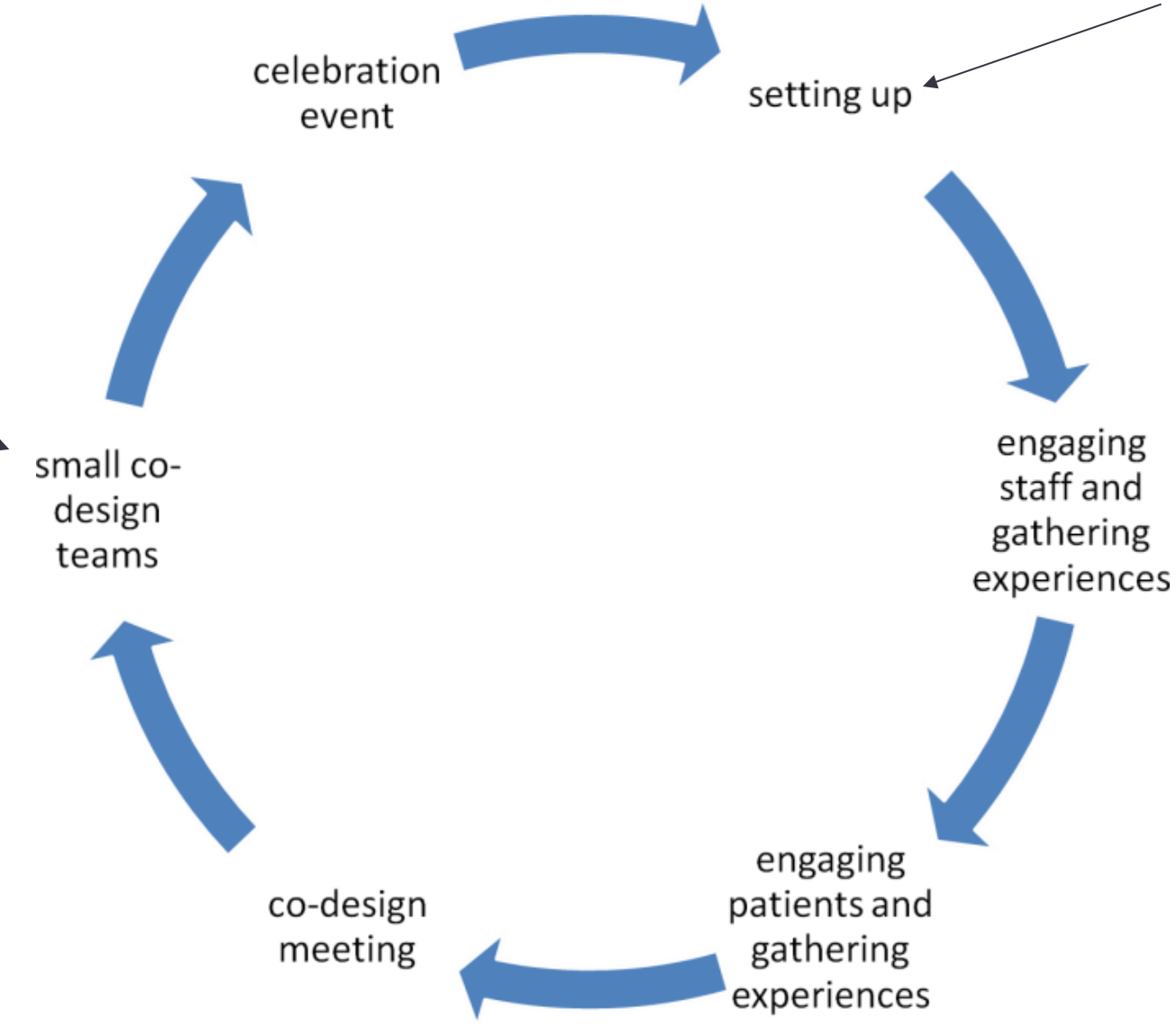
- Aim: Bring together key stakeholders from work packages 1 and 2 (professionals and lived experience)

- Co-design our intervention: An evidence-informed framework for those wishing to address health inequalities in maternity and perinatal mental health care systems across South Yorkshire through service development.

Next steps for work package 3

We started here

We are now here



What has worked well?

- Teamwork in our PMG
- Novel and innovative approach to recruiting underserved women
- Surpassing our recruitment targets, speaking to a wide range of underserved groups with lived experiences across the perinatal journey
- Co-design weaved throughout
- Consultation with our PPI and PSC steering groups who have shaped the project

Reflections from our community research link workers…

Thank you for listening ☺

Follow our progress: https://www.prams-study.co.uk/

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