

Capturing Roma Women's Experiences and Perspectives of the Quality and Safety of Maternity Care: Co-Designing an Engagement Strategy



Thérèse McDonnell², Jaspreet Kaur Dullat², Louise Hendrick¹, Léan McMahon³, Gemma Moore¹, Marianna Prontera⁴, Emily Murphy⁴, Carmen Nae⁴, Danut Nae⁴, Eilish McAuliffe²

(1) National Quality and Patient Safety Directorate, Health Service Executive, Dublin, Ireland

(2) UCD IRIS Centre, School of Nursing, Midwifery and Health Systems, University College Dublin, Dublin, Ireland

UCD DUBLIN

(2) UCD IRIS Centre, School of Nursing, Midwifery and Health Systems, University College Dublin, Dublin, Ireland

(3) National Women and Infants Health Programme, Health Service Executive, Dublin, Ireland

(4) Roma Project, Cairde, Dublin, Ireland

In collaboration with the UCD IRIS Centre, the National Quality and Patient Safety Directorate and the National Women and Infants
Health Programme are developing a national suite of measures of the quality and safety of maternity and neonatal services for
inclusion in a national surveillance system (QS Signals)

INTRODUCTION & BACKGROUND

Measuring quality in healthcare can be challenging due to its multifaceted and complex construction [1]. This study is part of a larger proof-of-concept project (QS Signals) that aims to develop and report measures of quality and safety of maternity and neonatal services in Ireland.

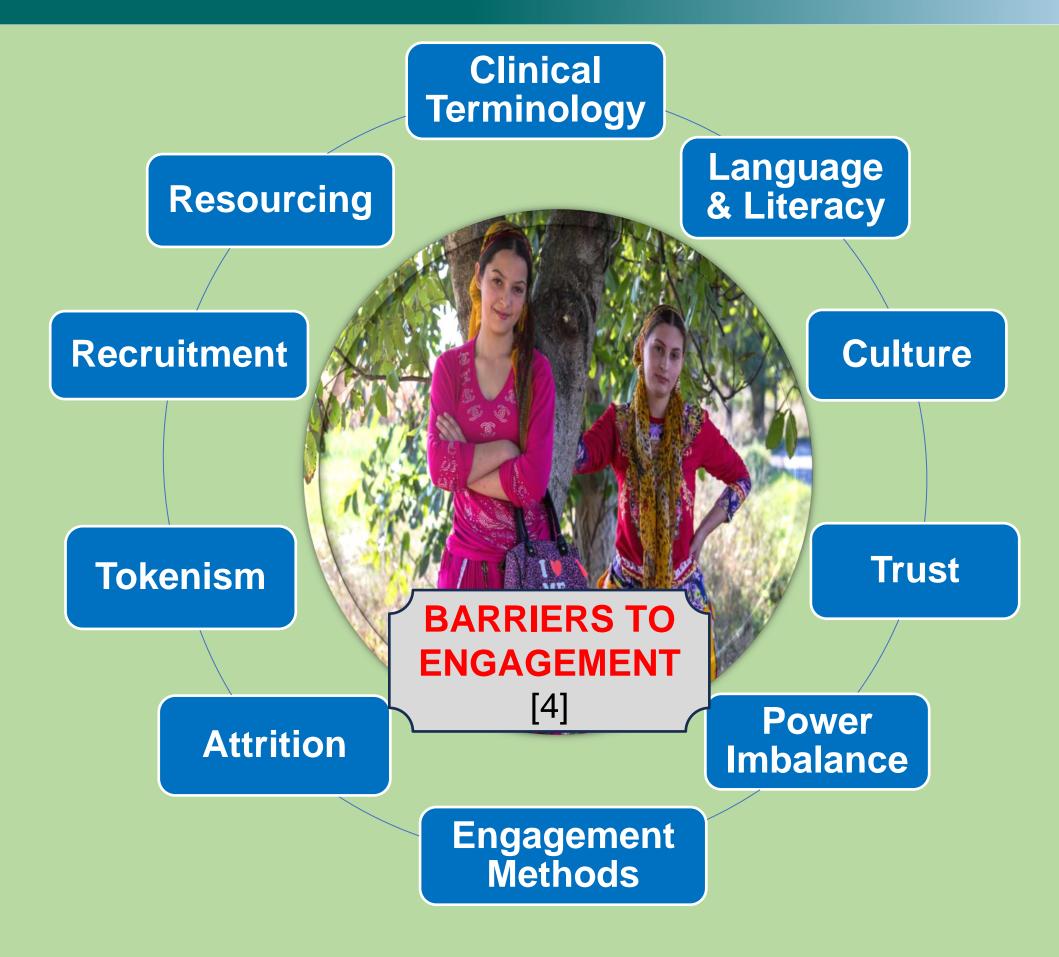
Public and patient involvement (PPI) in the design of a comprehensive set of quality measures results in more meaningful measures that are informed by the experiences of those in receipt of the services. Engagement with communities with poorer health outcomes and for whom there are known inequities in healthcare provision will provide insights on the relevant measures of quality. Factors such as poverty, low levels of education, poor nutrition, and neighbourhood are associated with poor maternal and infant outcomes [2,3].

Recognizing the lack of diversity in traditional co-design processes, this study focused on engaging with women from the Roma community in the Republic of Ireland, a marginalized group at higher risk of obstetric complications.

THE ROMA COMMUNITY

<u>OBJECTIVE:</u> To engage with women from the Roma community living in the Republic of Ireland to assess if a suite of proposed measures of the quality and safety of maternity services captures their experience of maternity and neonatal care in Ireland.

largest and most marginalised ethnic minority group in Europe tend to marry young, high birth rate, high risk of obstetric complications have low utilisation of antenatal services mistrust health services due to discrimination, cost, cultural barriers face difficulty accessing healthcare



METHODOLOGY: OPTIMISING CO-DESIGN WITH ETHNIC MINORITY COMMUNITIES [4]

Ensure "seldom heard" invited

Meet support needs and

allocate resources

Enable diversity of

contributions in co-

design process

AIMS

PRACTICAL TECHNIQUES USED

- Collaborated with Cairde, a Community Health Development Organisation with longstanding connections to Roma communities in Ireland [5]
- Peer-led community engagement to provide a trusted/ safe/ familiar environment
- Four online workshops conducted provision of laptops (Cairde)
- Scheduling, reminders by Cairde
- Educational component delivered by HSE Consultant in Public Health
- Translation and interpretation by Roma Community Representatives- Script provided in advance
- Materials designed for low literacy Slides (pictures only, no words), Use of non-technical language
- Reimbursement (Participants & Organisation)
- Survey completion (Post-workshops) with Cairde staff through 1-to-1 approach
 & translation support
- Co-design engagement strategy developed with Cairde and HSE
- Post workshop reviews were carried out: what worked, and improvements needed
- Co-developed dissemination strategy

OUTCOMES

8 Roma women participants recruited
 Pre-established connections between
 Cairde staff & the Roma women helped
 to promote openness and honesty
 around sensitive areas

Four Workshops

You and your Having your You and your Mental Health,
Pregnancy Baby Baby Data capture

- Language, financial, access, cultural and other support needs met to optimise participation and helped prompt discussion
- Found educational sessions beneficial
 All participants attended all four workshops & completed survey
- Equal power distribution, co-leadership and diverse contributions to the co-design process enabled

OUTCOMES

Accessible and culturally sensitive workshops, leading to meaningful participation.

Each participant had between 2 and 6 children, and their first child was born when they were aged between 15-18 years. All women faced significant challenges due to low levels of education, language barriers and precarious housing.

Most participants stated they had been treated well by healthcare professionals. They also explained some of the reasons their community may be reluctant to engage with services, thus providing a deeper understanding of what, from their perspective, constitutes quality in maternity services.

- > Difficulty communicating with healthcare professionals
- > Low levels of engagement with health/ maternity services during antenatal period
- Lack of an interpreter when needed
- > Hesitancy by some in disclosing their Roma identity
- > Unwillingness to complain
- > Low levels of understanding of available services
- > Hesitancy in discussing mental health which influences both their engagement with maternity services and the capture of information that reflects their experiences.

PLAN FOR SUSTAINABILITY

Insights gained from this study will be incorporated in the design of measures of quality that reflect the experience of marginalized groups. Partnerships with community organizations like Cairde are essential to ensuring the voice of marginalized groups is incorporated into the assessment and improvement of the quality and safety of maternity services.

References

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