Diversity, ethnicity and voice: enabling women to speak up about safety concerns in pregnancy and the postnatal period

Research background

While for the most part, pregnancy and birth are a normal physiological process, emergencies can develop rapidly and unexpectedly with the potential for serious outcomes for mother and/or baby. Delayed diagnosis and treatment of complications such as pre-eclampsia and altered foetal movements offer opportunities for the reduction of avoidable harm.[1] Women's knowledge of changes in their bodies during the perinatal period is an important resource to help early detection and diagnosis of complications, but women can struggle at times to know when to seek help, and what to say to staff, to get their concerns taken seriously.[2,3]

The Re-Assure project

The Re-Assure project was an arts-science collaboration funded by the Cultural Institute at King's College London.[4] Thirty four women were recruited via Facebook and social media to help a team of social scientists, clinicians and artists create a 5 minute animation to aid help seeking. The film has been widely shared and is being introduced to some hospital waiting areas. A shortened social media version was developed for Tommy's "Always Ask" campaign which was endorsed by the Royal Colleges (RCM, RCOG) and NHS England.
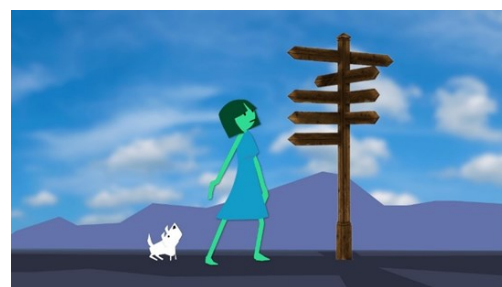
The Diversity, ethnicity and voice project

The women who helped develop the Re-Assure film represented a particular demographic (high levels of education, mostly of white British origin). This follow-on project aimed to explore whether the images and words used in the film were considered meaningful for women and families from South Asian communities, and the role of social and digital networks in communicating health messages. We recruited pregnant women (n= 21) from Indian, Bangladeshi or Pakistani communities via community and faith based networks, and community leads / members (n=11 including 3 pregnant women). We carried out focus groups and individual interviews to explore participants' views of the film. An artist worked with us to produce visual minutes during the focus groups and develop artwork from the narratives.

Participant characteristics: The participants included primips (5) and multips (18). Some of the women were in paid employment but the majority were homemakers. The majority of participants were from Quantile 1 and 2 (highest in terms of social deprivation). A number of women had limited understanding of written English and had difficulties speaking English.

[1] Flenady V, Wojcieszek AM, Middleton P, et al. Stillbirths: recall to action in high-income countries. Lancet. 2016;387:691-702

[2] Rance S, McCourt C, Rayment J. et al. Women's safety alerts in maternity care: is speaking up enough? BMJ Qual Saf. 2013;22:348-355

[3] Mackintosh, N., Rance, S., Carter, W., & Sandall, J. Working for patient safety: a qualitative study of women's help-seeking during acute perinatal events. BMC pregnancy and childbirth. 2017;17(1):232

[4] Mackintosh N, Sandall J, Collison C, Carter W, Harris J. Employing the arts for knowledge production and translation: Visualizing new possibilities for women speaking up about safety concerns in maternity. Health Expectations. 2018 Jan 17.

FINDINGS

Film relevance and content: the central messages 'trust your instinct' and 'knowing *your* normal' resonated with all our participants. They perceived the film to be novel and useful as it enabled reflection about social and cultural norms and 'appropriate' ways to behave in pregnancy. The women highlighted the relational and moral dimensions of help seeking (similar to our original participants), sharing their worries about being a 'timewaster' in an NHS that was increasingly resource constrained.

The imagery: Gen, the central protagonist, was perceived by the majority of participants to represent other women i.e. 'not us' on account of her clothing, her companion (the dog), and her behaviour. While a few participants found the 'top tips to get you heard' useful and enabling, a number reported feeling uncomfortable about the prospect of having to ask for a second opinion given that they relied on and trusted medical expertise.
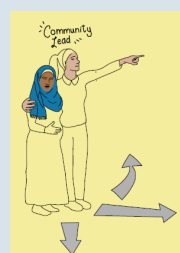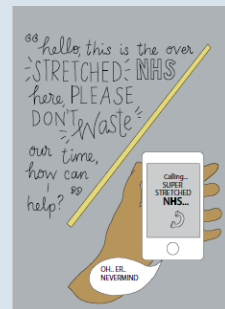
Digital networks: digital literacy was variable. A number of women were dependant on their family members to access and translate online resources for them. Community groups used group chats and forums which provided supportive social spaces for women with concerns (e.g. providing reassurance, peer support, signposting to professional services).

Structural constraints: a number of the women had experienced additional constraints during their pregnancies which limited their ability to act in terms of help seeking. These included social isolation, poor access to interpreting services, poor digital literacy and access to online health resources and material constraints (e.g. childcare responsibilities, reliance on others for transport). A few noted cultural norms in pregnancy which limited their social contact ('when we are pregnant we hide [indoors] and keep it discreet'). The majority of women reported that they felt *processed through* maternity services and appointments were time pressured, which limited the opportunities available for them to discuss concerns.
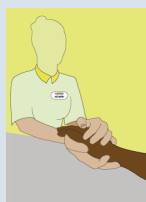
Enabling factors: community networks facilitated help seeking through mechanisms such as advocacy, education (digital skills) and social support. Continuity of midwifery care also enabled women to build trust and relationships.
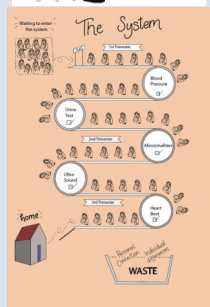
Conclusions and implications for practice:

1. We need to look beyond language and translation to visual messaging and identities incorporated within health information in order to maximise inclusivity

2. The Re-assure film highlights relational elements of help seeking and offers opportunity to enable family, community and professional involvement in this social practice

3. Strategies for enabling responsiveness of maternity services to women's diverse and complex social needs are also required alongside resources such as the Re-Assure film