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Practice case study

Challenges and opportunities of sustained public involvement in maternal health research: a practice case study with reflections from researchers and public contributors

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Abstract

It is widely agreed that collaboration with people with lived experience of specific health conditions or health services is both a moral imperative and a utility to improve research quality, validity and impact. However, there is little agreement about *how* to practise public involvement. In this article, we describe the formation and work of the Nottingham Maternity Research Network, an ongoing research reference panel that supports public involvement in maternal health research. Drawing on nine years' experience, researchers and public contributors reflect together on the key issues to consider when co-producing research with maternity service users: first, pragmatic considerations, and second, creating a safe space for drawing on intimate and sometimes traumatic experiences. We argue that a sustained model of public involvement and engagement – that is, a standing group rather than a series of project-based, time-limited opportunities for involvement – brings opportunities to build trust and to develop a community that is supportive and inclusive. However, the sustained model of public involvement also brings practical challenges.

Keywords health research; maternity care; patient and public involvement; equality, diversity and inclusion; co-production; community engagement and involvement; sustainability

Key messages

- Effective collaboration between researchers and maternity service users requires attention to practical issues, such as providing childcare or child-friendly meeting spaces, but also creating a safe space to share experiences that may be traumatic.
- A sustained approach to public involvement in research provides public contributors with a range of topics and roles to choose from, offering flexibility and ongoing interest.
- A sustained approach to public involvement in research may facilitate diversity and inclusion by allowing time to develop confidence and trust between individuals and in the research process.

Background

Patient and public involvement (PPI) in health research

According to the Health Research Authority, 'Public involvement in research means research that is done "with" or "by" the public, not "to", "about" or "for" them. It means that patients or other people with relevant experience contribute to how research is designed, conducted and disseminated' (HRA, n.d.: n.p.). The rationales for patient and public involvement (PPI) can be categorised as substantive or normative (Gradinger et al., 2015; Ives et al., 2013). Where the rationale for involvement is substantive, the focus is on the effectiveness of PPI to improve the quality, relevance and validity of research. This is a rationale commonly employed in health sciences, and it is reflected in the guidance of national funding bodies such as the National Institute for Health Research (NIHR). This rationale is widely accepted within the research community, despite acknowledged deficits in the evidence base for the impact of involvement (Mockford et al., 2012). Normative rationales for involving the public in research focus on the intrinsic value of involvement as a mechanism of transparency and public accountability in what is often publicly funded research, but also as a means to empower patients and the public. There is less agreement on *how* to involve the public in research. Greenhalgh et al. (2019) identify over 60 frameworks, almost all used exclusively by the individuals and groups who devised them. It is a truism that public involvement practitioners are prone to 'reinvent the wheel'; we often work in isolation, with limited learning from similar work. This is partly a reflection of the paucity of detail of PPI that is usually published alongside research results, but it may also be because of the specificities of involvement in different topic areas and with different populations. Accounts of sustained approaches to involvement, which extend over time and specific projects, are sparse, and guidance tends to focus on the level of projects rather than on an organisational level (Jinks et al., 2013).

This article reflects on the collaboration at the core of a standing research reference panel, the Nottingham Maternity Research Network (NMRN). We share learning about a sustained approach to public involvement in research, while paying attention to issues that might be specific to, or more relevant to, the context of maternal health research.

Public involvement in maternal health research

A small number of published articles report on public involvement in maternity research. The majority (10) report on practice in the UK, with contributions also from Sweden, the USA and Uganda. Articles describe involvement in different stages of the research process from priority setting (Cheyne et al., 2013; Ditai et al., 2020; Franck et al., 2020; Ross et al., 2004), designing interventions (Abayomi et al., 2020; Carlsson et al., 2020; Salmon et al., 2021), advising on study design (Goodwin et al., 2021; Levene et al., 2022; Newburn et al., 2020; Rayment et al., 2017) and co-production of research projects (Collins et al., 2020). There is little commentary so far available on what the specific needs of pregnant people and parents of young infants might be. One exception is from the Parenting Science Gang, who describe co-production of research with 'time-poor' parents facilitated via Facebook groups, which reduced the burden on participants, and reduced barriers due to financial status or living in a particular location (Collins et al., 2020). There may also be a need to think of public contributors in maternity research differently from, for example, those with chronic health conditions, as pregnancy and birth are both transient experiences and, for many, life events rather than medical conditions (Moss et al., 2017). Both these factors have the potential to impact the sustained approach to involvement described here.

A note about how this article was written

This article is based on knowledge and reflections shared at a 'world cafe' event in February 2023. A world cafe is a creative method for facilitating collaborative dialogue; it is recommended to engage diverse groups in creating collective knowledge in response to questions that matter (Brown and Isaacs, 2005). It was therefore suitable as an accessible way to bring together members of the NMRN community and generate the content for this article. The world cafe method has a simple design based on seven fundamental principles, including creating a hospitable space, encouraging everyone's contribution, and connecting diverse perspectives (Brown and Isaacs, 2005). People who attended the world cafe worked together to respond to the following groups of questions: (1) What does the NMRN look like? How can we best describe it? Can you draw it?; (2) What is important to ensure that women can get involved in research during pregnancy and alongside parenting? What attracted you to the NMRN? What makes it easier or more difficult for you to take part?; and (3) What are the benefits/challenges of a group that is sustained over time? Twelve people took part in the world cafe. Attendees worked in small groups to write and draw on large sheets of paper in response to the questions. Each group had time to work on each of the questions. Responses were shared with the whole group to prompt further discussion. The lead author grouped the ideas and reflections from this event to produce a first draft of the article, which was collaboratively edited by the co-authors. Co-authors are a subgroup of the world cafe attendees, both researchers and public contributors, who expressed interest and were able to commit time to co-authorship.

Nottingham Maternity Research Network (NMRN)

There is a long tradition of maternity consumer and advocacy groups, in the UK and beyond, which have sought to shape maternity *services* to best meet the needs of women and families (Mander and Murphy-Lawless, 2013). Public involvement in maternity research is distinct from the co-production of services, but it shares an approach that respects, values and seeks to actively incorporate consumer experience.

The NMRN is associated with the Maternal Health and Wellbeing Research Group at the University of Nottingham, UK. Public engagement and involvement has been central to our research practice over time. The idea of the NMRN came from a consideration of other approaches to public involvement in research that tended to focus on individual illnesses or health conditions, and that included those receiving ongoing treatment or services. This approach is often seen for researchers who hold clinical as well as academic responsibilities. Groups may be convened around individual projects, or around more programmatic work. Our research group includes researchers from diverse disciplinary backgrounds, including social sciences, and it required other approaches that would enable researchers to collaborate with individuals with experience of maternity and related services. Additionally, the means to do this beyond a project-by-project basis were required. Other sources of public contribution to research, including maternity, came from national groups working with and on behalf of childbearing women, through the involvement of their staff and members. This support was extremely helpful in linking individual researchers to wider networks, and it often supported horizon-scanning for research teams. However, unavoidably, challenges of capacity could be encountered through this route.

It felt important to develop a different approach which would support researchers' responsiveness to funding calls and emerging priorities, and which would enable a sustained, relational approach to public involvement. We hoped that this could also forge links between the researchers, based in an academic context that may seem remote, with the local community, albeit in a modest way. A newly established team – Helen Spiby, Denis Walsh, Bernie Divall and Julie Roberts – developed a new approach to PPI, with this activity included in the role profile for Divall and Roberts as research fellows. The early stages of developing the group were supported by a number of small grants, some internal to the university (£500 Catalyst Funding as start-up), and others from local funders (£1,500 from East Midlands Academic Health Sciences Network for outreach activity).

The model of public involvement that we employ has evolved in response to national guidance and, most importantly, to feedback from the community of public contributors. This article reflects the current configuration of the NMRN.

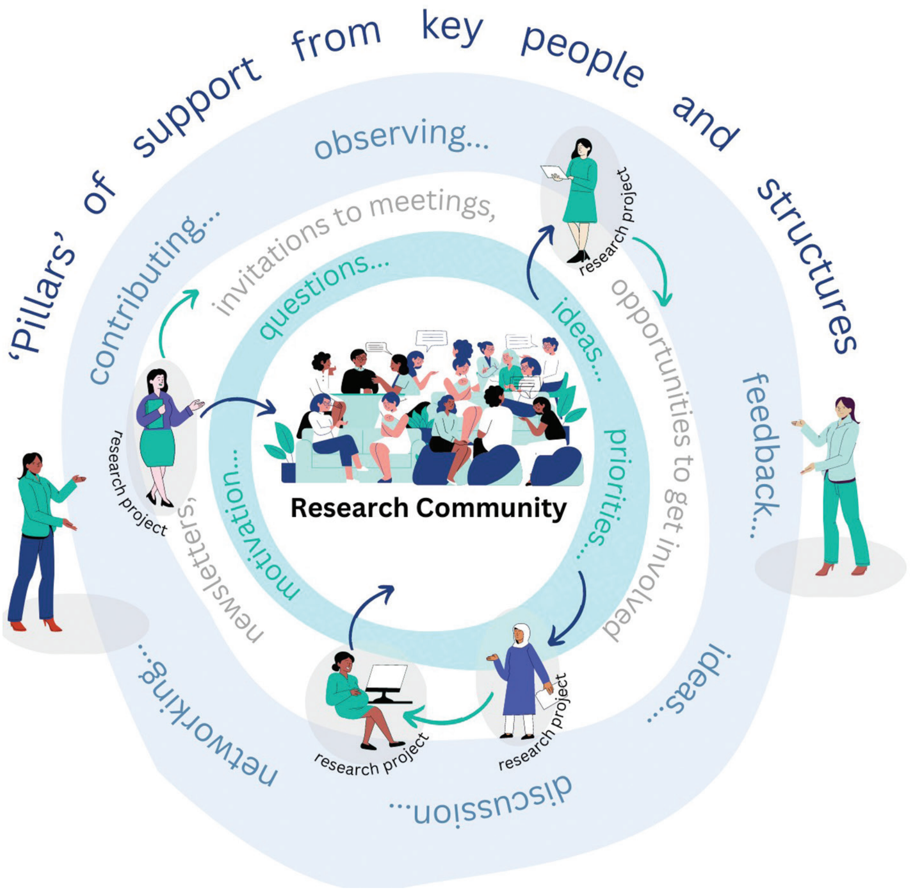
We asked public contributors at the world cafe to describe or draw the network. Participants drew hearts and cups of tea to convey the 'warm, comforting, supportive' environment that they experience. This was 'refreshing', and often in contrast with their expectations of science or academia, and it was important to facilitate their involvement, and to build trust that their diverse and unique voices are valued and important. Together, we drew a model of the NMRN (Figure 1) as a series of 'bubbles', supported by 'pillars' in the form of key staff, who were described as the 'heart of the community'. In this case, the research group lead and researcher who primarily facilitated the NMRN were identified as supportive 'pillars'. The model shows processes, but also the importance of relationships and experiential dimensions that public contributors tell us are important to making the processes work.

The central bubble represents a community of people with experience of using maternity services and an interest in research. We put no time limit on how recent their experience should be, so that women can come to the group when they feel ready to draw on those experiences in the PPI context. The NMRN maintains a mailing list of about a hundred women who receive a newsletter three or four times per year with reports of NMRN activities and ongoing projects, and which usually features a researcher or public contributor who is part of the NMRN. This bubble is flexible, and it has 'free-flowing' information with no fixed expectations for members to necessarily contribute or attend meetings. This is a welcome first step for many women who may 'observe' from here, before deciding whether to get more involved.

At any one time, a core group of approximately 20 public contributors actively attend meetings or participate in research teams. Regular meetings are held every two months, and they are open to anyone on the mailing list. Before 2020, meetings were held in-person, either on the university campus or in community venues, at varied days and times. When Covid-19 pandemic restrictions were introduced, meetings moved online (via Microsoft Teams). At the time of writing, meetings are a mixture of in-person and online. People attend on a voluntary basis, and they are reimbursed for any additional childcare costs incurred, and for travel expenses. Refreshments are provided. Here, we usually discuss two or three projects, at different stages of the research process, including postgraduate student research. For example, a researcher might bring for discussion an initial idea or a difficulty in recruitment, or seek ideas for dissemination. An agenda of topics for discussion is circulated in advance, and people are encouraged to join the discussion.

Around these sustained bubbles are time-limited research projects on specific topics. Women on the mailing list, and those who attend regular meetings, are invited to join these specific projects,

Figure 1. A visual representation of the Nottingham Maternity Research Network



depending on interest and relevant experience. These usually require more time commitment, although, in line with good practice for inclusive PPI, they remain as flexible as the project allows. Public contributors join specific projects, usually during the design stage as co-applicants or advisory board members (depending on funders' rules and requirements). There is an expectation that public contributors receive payments for their time from grant funds and in line with INVOLVE/NIHR guidance. Principal investigators and their teams run their own subgroups with their own schedule of meetings and activities, but with the support of the wider NMRN. Researchers and public contributors involved in individual research projects typically feedback research findings and their experiences of collaboration to the wider NMRN community. This is an important part of sharing with the wider community, revealing how public input has made a difference and building confidence in the PPI process. Public contributors are motivated by wanting to create change, and they value a feeling that they had 'done [their] bit' to achieve this.

Key issues for involving maternity service users in research

Good practice in public involvement requires consideration of pragmatic issues for those you want to involve in the research community. Many issues will be universal. For example, being flexible about the days and times for meetings will allow more people to attend. Hybrid approaches or alternating remote and in-person meetings can also help some people to fit involvement in research into their busy lives, or can make involvement more accessible to people with mobility impairment or who are neurodivergent. Reimbursement of travel costs ensures that opportunities to get involved are not limited by ability to pay. For maternity research, childcare is a vital consideration to ensure that public involvement is inclusive.

NMRN offers reimbursement of additional childcare costs incurred by attending any meetings. We also welcome babies and children to any meeting. Public contributors told us that, when they were new to the group, they needed reassurance that it is *truly* acceptable to bring their children with them. When meeting face to face, we provide a changing mat, toys and books. While these items have a practical use, their visible presence also helps to reinforce the message that babies and children are a very welcome part of our community, and to give mothers a sense of belonging.

Public contributors emphasised the need to create a safe space for people to freely share their knowledge and experience. An inclusive approach to involvement, and a diverse PPI community (in terms of identity and experiences), allow public contributors to feel welcomed and respected. While our aim is not therapeutic, we do seek to enable members to have their voices heard through sharing their personal, sometimes traumatic, maternity experiences. For some, these experiences include issues of race or discrimination, and it is important to be able to share these without fear of being ignored and judged. This contributes to creating confidence, and a space for members to be vulnerable.

Persistent inequalities of experience and outcomes have been identified in maternity care (Knight et al., 2022). It is therefore essential that public involvement is inclusive, to ensure that research does not reinforce or exacerbate existing inequalities. We reflected together on how diversity in the NMRN helps to develop cultural understanding about different racial backgrounds, and our public contributors value the opportunity to culturally represent their communities within this space, although we are cognisant of diversity *within* as well as between communities.

Opportunities and challenges of a sustained approach

A sustained approach means that the infrastructure and processes that support public involvement remain in place and do not need to be created anew for each new research project. The NMRN is a standing resource through which we can explore emerging ideas for research and co-design studies. Public contributors perceived that sustaining the NMRN relies on the strong belief of the academics who facilitate it in the value of public involvement in research, and the experience of public contributors that their input is valued and has impact.

There is turnover of members of the group, both public contributors and researchers. Some people have been part of the group since it was first formed. Inevitably some members leave. They may leave the area, or return to work after maternity leave, or their interest may move on as their children grow. Public contributors find that a mix of long-term members and newer members means that there is a strong feeling of a safe space, while also being open to new ideas. With a sustained approach, public members grow in confidence to speak up in potentially challenging situations and about sensitive topics, because there is a strong feeling that key members of the community protect and support the safe space; they 'have our backs'.

Public contributors value the sustained approach that enables members to see the beginning, middle and end of research projects, and to gain insights into the way research is conducted. This approach builds skills, and also trust, in both individual researchers and in the research process. Our experiences reflect those of Jinks et al. (2013), who suggest that a sustained approach to PPI gives public contributors time to gain confidence and trust. Public contributors can move between roles depending on how much time they have available, and on interest, from joining a group discussion, to sitting on an advisory board for a research project, to being co-investigators. Group members reflected that seeing the research process from new perspectives may allow for relief of distrust in science and the healthcare system, both of which are sometimes negatively perceived, particularly within ethnic minority communities.

Concluding thoughts

Some very practical steps are important to enable women to be involved in research during pregnancy and early parenthood. However, the creation of a safe space is equally important, and it may be especially important for this group, a proportion of whom will have experienced trauma or discrimination during their care. In this context, maintaining a welcoming environment in which individuals' voices are heard is essential.

We reflect that a sustained model of PPI allows time for trust to be established, and that this is vital for hearing diverse perspectives, and for research approaches to be challenged. This mirrors findings by Goodwin et al. (2021), who found that relationships built over time enabled women to share more critical perspectives. It also provides time for researchers and public contributors to build their skills and experience. A sustained model has utility for capacity building, as postgraduate research students can be introduced to PPI in practice, with supervision. However, the sustained model is not necessarily a good fit with the existing systems and processes of PPI, which tend to assume a project-by-project basis for PPI. While our funded research does contribute to the running costs, securing ongoing funding to sustain and grow our research community can be challenging.

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Declarations and conflicts of interest

Research ethics statement

Not applicable to this article.

Consent for publication statement

Not applicable to this article.

Conflicts of interest statement

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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