NIHR | Applied Research Collaboration South London

How do peer researchers make a difference?

Report of a maternity peer-researcher listening event – a Lambeth Parents' Lunch

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With thanks

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Members of the co-production research team took the photographs. Copyright resides with members of the team.

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Contributions
ZB initiated and coordinated the writing up of the event and wrote the first draft of the report. MN provided overall guidance and developed the draft. VM and MN lead on planning the participatory appraisal activities and planning the event. RB, VM and others recruited participants using their networks and contacts. AE, VM, RB and ZV contributed information and comments. VM liaised with service users and collated their feedback. AE provided participant demographics. MN and ZV transcribed notes and collated the workshop data. MN and AE raised the funding. MN, AE, VM, RB, ZB, ZV, KDB, HRJ and ZK contributed to planning, hosting, facilitating and reflecting on the event. JS contributed additional funding from her NIHR Senior Investigator award. All authors contributed to reporting and signed off the report.

The authors are co-production research partners in the ARC South London maternity and perinatal mental health research theme.

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1. Introduction

The maternity and perinatal mental health theme

The ARC South London maternity and perinatal mental health theme's research focuses on addressing the poorer health outcomes for women and babies living in areas of social disadvantage and from minoritised ethnic groups, particularly in southeast London.[1] Researchers aim to inform ways to reduce health inequities and have a positive impact on health and wellbeing of women and families in the local community. Questions being asked include: What are the reasons for poorer health for these groups of families? What models of care can help? And, how can care and outcomes for women with mental illness be improved?

The theme's public involvement questions include how is it best to engage and involve people, women, communities, and relevant organisations? We have created a diverse network of public involvement members through online meetings, a WhatsApp group, regular emails and other social media (e.g. Twitter and Facebook). We aim to motivate continued commitment to working together and a sense of a community of interest. We hold Patient and Public Involvement and Engagement (PPIE) advisory group meetings three times a year. Additionally, we hold a PPIE Strategy Group meeting annually.

We advertised the event described in this report using the term 'parents' as gender-neutral language. A limited number of socio-demographic questions were asked of participants at the start of the event. As all of those attending described their sex as female and their gender identity being the same as their sex at birth, we often refer to 'women', 'mothers' and 'mums' in this report to reflect the characteristics of participants and the language they tended to use. Our objectives refer to 'people who have current or recent experience of using maternity services'. We acknowledge that not all those accessing maternity services will identify as a woman. We continually strive to ensure that our research and public involvement is inclusive and sensitive to the needs of everyone.

Funding for public involvement and participatory research

The co-produced listening event described in this report was funded by ARC South London Involvement Fund 2022-23, which invited themes to submit applications in March 2022 for the purpose of 'involvement activities' as defined by NIHR.

NIHR defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.[2]

[1] Writing about ethnicity. Cabinet Office. https://www.ethnicity-facts-figures.service.gov.uk/style-guide/writing-about-ethnicity

[2] Briefing notes for researchers – Public involvement in NHS, health and social care research. https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#briefing-note-two-what-is-public-involvement-in-research

As part of the ARC South London Involvement Strategy, each of the 11 themes within the ARC were encouraged to use the opportunity to carry out 'participatory research', which the NIHR Glossary defines as: 'a type of research where researchers and people who use services or carers are partners in a research project. The research addresses an issue of importance to service users or carers, who are involved in the design and conduct of the research, and the way the findings are made available. The aim of the research is to improve people's lives. This isn't a research method – it's an approach to research, a philosophy.'

The purpose of the funding call was to 'advance participatory research' and the philosophy which underpins it. This report details the work undertaken with funding from this call, a first step to developing longer-term participatory research based on the needs, experiences and priorities expressed by communities of south London women and mothers. The Lambeth Parents' Lunch was a listening event, laying the foundations for further co-production. 'Participatory research blurs the traditional distinction between "researcher" and "subjects", as all are equally engaged in the pursuit of knowledge for a common purpose. It assumes that the purpose of research is not only to gain knowledge, but also to use that knowledge to produce change that is consistent with the vision of a more equitable society'.[3] Many different traditions and methodologies can fulfil the principles of participatory research.[4] However, there is also a risk that inflated claims can be made about stakeholder involvement.[5] We know from experience as a team how important it is for there to be a real commitment to a critical approach, with active relationship building, addressing power differentials and issues of inequity and diversity and committing the time required to listen and to sustain cycles of communication, mutual reflection and further action.

The opportunity to carry out peer-led research was timely and important for the maternity and perinatal mental health theme. Previous peer-led joint training for researchers and public involvement network members using participatory appraisal methodology, had surfaced challenges in community involvement in research, and participants collaboratively generated potential solutions or ways forward.[6] The proposed ways of working in this project closely followed the co-produced recommendations from our earlier work:

1. Focus on communities – Build trust and create partnerships with diverse communities, involve them and their interests when setting research priorities. Engage with the populations you wish to serve. Provide opportunities for communities to be involved on their terms and develop their own capacity.

2. Prioritise communication – Work on ways and means of communicating more effectively.

[3] United Nations. Participatory Dialogue: Towards a Stable, Safe and Just Society for All. 2007 (p44). https://www.un.org/esa/socdev/publications/prtcptry_dlg%28full_version%29.pdf

[4] Macaulay AC. Participatory research: What is the history? Has the purpose changed? Family Practice, 2017, 34;3, 256–258.

[5] Macaulay, see above.

[6] Ahmed E, Newburn M, Moltedo V, Umutoni K, Agyepong A, Silverio SA, Sandall J and Easter A. Involving diverse communities in maternity and perinatal mental health research – insights and learning from a co-production training event. NIHR Applied Research Collaboration South London, 2021. https://arc-sl.nihr.ac.uk/sites/default/files/uploads/files/Maternity%20and%20perinatal%20mental%20health%20theme%20PA%20report%20october%202021%20FINAL.pdf

3. Ensure diversity in research teams – Address the diversity and representation of relevant communities within your research team.

4. Raise appropriate funding to be able to ensure participants' perspectives and diverse communities can be at the core of the research process and co-produce whenever possible.

5. Address power imbalance – Be aware of power imbalance and address it through structures, training, behaviour, reading and reflection. Recognise and value people's involvement, ask what they want and need.

6. Focus on trust and respect – Build trust by actively demonstrating regard for people and communities, and by committing to fairness and enhancing community wellbeing.

Our co-production training had in turn been shaped and influenced by a blog written by one of the public involvement network members, Agnes Agyepong.[7] We continue to strive for creative ways for minoritised ethnic groups, individuals, network leaders, online groups and community organisations to be involved and participate in research. This can provide positive opportunities for both communities and researchers.

Members of our co-production group are aware that in maternity research and maternity services the phrase 'hard to reach' has often been used when referring to families living in areas of deprivation, and to women from different ethnic and religious groups. In contrast 'not listened to' may be used by those same groups of service users. Patient and public involvement and engagement (PPIE) in research, and participatory research, are intended to promote closer working relationships between researchers and the public, greater understanding of community perspectives, and active participation in research processes.

The Lambeth Parents' Lunch project

In this report, we share our aim and objectives for the Lambeth Parents' Lunch project, the values that underpin our work, and how we planned the event. We describe the different activities organised, who came along and how we managed the day. We report on the key themes and issues that emerged and the aspects of the event that we feel contributed to its success. We also discuss learning points and next steps.

Aim

To find ways to understand how the maternity journey is experienced by a diverse group of south London women to inform research, through co-production and principles of participatory research.

Objectives

1. To build on our established values and previous co-production training, to involve diverse communities in research.[8]

[7] Agyepong A. Service user involvement in maternity and perinatal mental health research. Applied Research Collaboration South London, 29 September 2020. https://arc-sl.nihr.ac.uk/news-insights/blog-and-commentary/service-user-involvement-maternity-and-perinatal-mental-health

[8] Ahmed E, Newburn M, Moltedo V et al (see above, p5).

Peer researchers (left to right) Vita Moltedo, Zenab Barry and Rachael Buabeng.

2. To hold a peer-led listening event in a community venue for up to 12 people who have current or recent experience of using maternity &/or perinatal mental health services, in a suitable community space regularly used by local families.

3. To enable the women participating to explore and express their experiences and views, and ask them what changes might be positive, and what might reduce barriers to health and wellbeing.

4. To involve three members of the ARC South London's maternity and perinatal mental health theme's PPIE Network as peer researchers to collaborate in planning the event and facilitating interactive activities using participatory appraisal methods.

5. To reflect on how research involvement relationships and opportunities can contribute to building social capital.[9]

Definitions

Co-production – involves 'sharing power and responsibility from the start to the end of the project, including the generation of knowledge'.[10]

Maternity journey – the transformative process of pregnancy, birth and becoming a mother, or extending the size of a family.[11] This is a dynamic and in some respects unpredictable, mind, body and life-changing phase in the life-course with

[9] Office for National Statistics. Social Capital in the UK: April 2020-March 2021). 24th May 20222. https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/bulletins/socialcapitalintheuk/april2020tomarch2021

[10] NIHR. Guidance on co-producing a research project. NIHR, 2021. https://www.learningforinvolvement.org.uk/wp-content/uploads/2021/04/NIHR-Guidanceon-co-producing-a-research-project-April-2021.pdf

[11] Oakley A. From here to maternity (reissued): Becoming a mother. Bristol University Press, Policy Press. 2018 (pp. 51-75)

significant implications for the health, wellbeing and future life chances of women and their children. Social implications include a change to one's social identity and opportunities, including in the workforce.[12]

Peer researcher – The Institute for Community Studies' 2020 report on peer research defines a peer researcher as generally being 'someone who participates in the research process as a member of a geographical or social community being studied'.[13]

Social capital – a term used to describe the extent and nature of our connections with others and the collective attitudes and behaviours between people that support a well-functioning, close-knit society.[14]

[12] Costa BM, Walker A, Zinkiewicz L, et al. The Maternity Journey in an Organisational Context: A Case Study. Australian and New Zealand journal of organisational psychology, 2012, Vol.5, p.43.

[13] Yang C and Dibb Z. Peer Research in the UK. The Institute for Community Studies. 2020. https://www.youngfoundation.org/wp-content/uploads/2020/10/TheYoungFoundation-PeerResearchInTheUK-final-singles.pdf#:~:text=Peer%20researchers%20%28also%20referred%20to%20as%20'community%20researchers'%29,generate%20information%20about%20their%20peers%20for%20research%20purposes4. Accessed 13.08.2023.

[14] Office for National Statistics (as above).

2. How we planned the event

This was our first community listening workshop in which researchers, peer researchers recruited from our PPIE Network, and the PPIE lead (a service user researcher), worked together to arrange and facilitate the event. Vita Moltedo and Mary Newburn had previously had training and used participatory appraisal methodology. Zenab Barry and Rachael Buabeng are experienced in facilitating maternity and mothers' groups and maternity voices partnership meetings. Among the academic researchers there were four midwife researchers and a social psychologist.

We planned to meet with women in a south London area where there is considerable ethnic diversity and areas of social deprivation to talk to local women about their experiences of being pregnant, giving birth and becoming a mother or adding to their family, and their experiences of using related services. We wanted to hear about their perspectives, their sources of support, their values and observations, their concerns and what made a difference for them, to inform our future research plans.

Maternity and perinatal mental health theme researchers and community members from the theme's PPIE Network were used to meeting together online. Regular online planning meetings were held, generally on the same day and time, to consult, brainstorm, update and move arrangements forward. Roles and responsibilities were fluid to begin with and became clearer over time. Everyone in the group generated ideas about venues that we might use, and each person undertook to speak to one or more relevant contacts, such as community services in south London, maternity voices partnerships close to Lambeth, their social media networks or third sector organisations with whom they had a relationship. Two food banks were also contacted.

The project team (left to right) Abigal Easter, Zahra Khan, Zenab Barry, Rachael Buabeng, Kaat De Baker, Hannah Rayment-Jones, Mary Newburn, Zoe Vowles, Vita Moltedo.

A marketing poster (see Appendix 1) was created with the input of a professional designer, and a cover email drafted explaining why we wanted to bring together a group of parents who had recently accessed maternity care. Our aim was to create an opportunity for them to talk about their experiences and, if necessary, their suggestions for better services and support for new mothers, families of babies and pregnant women. Wherever possible, a phone call was made by a member of the team who had a personal contact, or who could visit in person. We wanted community partners to identify and approach two women or parents who might be interested in attending, or to display the poster.

After open discussions and sharing of ideas, individuals took overall responsibility for the key event management tasks of developing the poster, booking venue, catering, and crèche workers. Vita Moltedo, a peer researcher, took on administering expressions of interest, bookings, information about dietary requirements, allergies, languages spoken and need for translation services, numbers of children attending, where people had heard about the event, and contact details. Vita was a befriender as well as a link person, following up in a friendly and encouraging way.

We agreed early in the process that an experienced community leader/Black peer researcher, Rachael Buabeng, the founder of Mummy's Day Out, would start the workshop with a lively ice breaker activity. The peer researchers all discussed essential ingredients for success, such as informality and structure, possible approaches and how best to use the time. Those with experience of participatory appraisal then planned the activities in detail and briefed colleagues.

Rachael (left) leading the ice breaker activity.

We discussed various possible community and children's centre venues and decided to approach Carla Stanke, Public Health Specialist, Lambeth Early Action Partnership (LEAP), to see if LEAP could offer us a space to host the event. A venue visit was undertaken in order to check the layout of the space and whether it would meet the needs of mothers and young children, conducting small-group work, and providing lunch. It was agreed that we would use Myatts Field North Centre. The café was a lovely light area with good proportions (not cavernous,

but with space to move around). The tables and chairs were ideal for small group work, and the café counter was helpful for serving food and drinks. A temporary crèche could be set up in a large, light hall.

LEAP arranged for us to have use of the community centre café and hall free of charge, and toys for the temporary crèche. They recommended a provider of crèche workers and a social enterprise providing catering services. Healthy Living Platform employs local food ambassadors to cook nutritious food which reflects the cultural diversity of the local communities. Vegan food was selected to ensure dietary needs and inclusivity were respected, and care taken to record any allergies of those attending. A crèche was made available for the duration of the event, and two experienced childcare workers were booked.

The Healthy Living Platform food ambassadors who cooked and served the lunch.

Recruitment of participants was managed carefully. The aim was to recruit the right number of mainly Lambeth-based parents, while avoiding too many coming forward and being disappointed if they had to be turned away. Altogether, we contacted 10 south London organisations and asked them to invite individuals to take part in the event, or to signpost their service users to the event by sharing fliers or putting up a poster. Initially, take-up was slow. We were aware that everyone was busy managing their own priorities and had little or no additional time to publicise our event. Personal relationships were important in generating

interest. The poster offered mothers and other parents a chance to talk in a small, friendly group, a welcoming space to bring their babies and a crèche, a hot lunch and a shopping voucher. A week before the event, as there were still places available, we advertised the event on social media and shared the link with key contacts and organisations in south London.

The budget for running the project was small (£2,200), even after receiving a second allocation of funding, so we were particularly grateful to be given free use of a venue by LEAP, and that other budgets covered researchers' time and some PPIE lead costs. In applying for the funding, Abigail Easter and Mary Newburn were committed to making public voice payments to all participants, paying for peer researchers' time, and providing a hot, healthy lunch and a crèche, values supported fully by the wider group. The community parents were in a kind of hybrid role, for they were participants in this event, but also had a public involvement role, implicitly advising researchers through their stories and discussion about potential future research questions. We calculated that we had sufficient funding to offer 'public voice' payments to mothers for one hour only. So, we designed, three sessions of around 20 minutes each, after an informal ice-breaker session, followed by the final voting on priorities for change, immediately before or over lunch.

Participatory appraisal methods

In preparation, peer researchers discussed various ways that we could facilitate friendly, informal conversations that would nevertheless ask attendees some probing questions, so that we could gather data to inform future research by members of the team. We decided to draw on participatory appraisal methods and tools to guide planning of activities, and to help us make good use of the available time.

Participatory appraisal methods are usually highly visual, structured, easy to explain and fun to take part in. They often include kinesthetic activities such as drawing, sorting, voting, moving around, and so on. Data are recorded during the activity, so there is a clear record of what has been raised or discussed, sometimes with an indication of how many people feel that way. Several of the team had had experience of using participatory appraisal methods before, including during co-produced online training that had produced important outputs.[15, 16] We planned to ask for consent to take photographs for use in publications and to share learning. The consent form emphasised that agreeing to photographs being used was completely optional. We understood that using photographs is a great way to communicate the atmosphere, activities, and diversity of those attending an event.

Participatory appraisal upholds democratic principles of everyone being able to express what matters to them, and it values people as experts in their own lives. It offers a dynamic and active way of discussing topics. Participants should feel able to represent themselves, and that they have a clear voice, yet not feel in any way exposed or exploited.

[15] Ahmed E, Newburn M, Moltedo V et al (see above, p5).

[16] Easter A, Agyepong A, Newburn M. Involving diverse communities in research - insights and learning from a co-production training event. Presentation at Inside Research Seminar, ARC South London. 3 November 2021. https://arc-sl.nihr.ac.uk/sites/default/files/uploads/files/Involving%20diverse%20communities%20in%20research%20-%20insights%20and%20learning%20from%20a%20co-production%20training%20event.pdf

We planned activities so that the participants would first begin to focus on different time points in the maternity journey and, progressively, explore themes in greater detail, while maintaining a friendly informal atmosphere. We included a session on looking at possible solutions to problems, which would have the potential to be tested in practice, and in future research studies.

We planned to use post-it notes, asking women to jot down their thoughts and have researchers and peer researchers also note what the women were saying. We would draw on flipchart paper, and have observers (the academic researchers) taking notes. The planning was done over four months, including a Christmas break.

Why work with peer researchers?

There are many reasons put forward for working with peer researchers such as enabling greater involvement and participation in research of important social groups, particularly marginalised communities. Peer researchers are generally closer to community members and know people who experience challenges with accessing public services, or who have negative experiences or poorer health than other groups. 'Peer researchers may bring a level of empathy, sensitivity and understanding to the work that those without lived experience may lack.' [17]

Rachael, peer researcher, emphasised that 'engaging the community via people they trust encourages them to be more willing to share. Knowing a person or feeling a person is like them, and knowing that they are involved in the work is reassuring. No one wants to feel they are simply being used.'

Zenab, peer researcher, said: 'It is human nature to be more relaxed and at ease when talking to someone we can relate to, at a familiar, local place or social setting, and in a relaxed environment. ... Having understood this from our personal experiences and previous involvement in research, we decided to ensure that the listening event was planned and conducted in a way that would be conducive to natural expressions of feelings — within a warm, caring and relatable environment. We felt that that approach would enable participants to freely share their opinions and personal experiences.'[18]

Further, acknowledging some of the known barriers to people in the community engaging with researchers,[19] we explored ways to reduce distrust and make people feel welcome, relaxed and in a place that felt familiar.

[17] Yang and Dibb (see above, p 8).

[18] Barry Z. Doing research within the community: an enriching listening event in Lambeth. Blog and commentary. ARC South London. 3 Apr 2023. https://arc-sl.nihr.ac.uk/news-insights/blog-and-commentary/doing-research-within-community-enriching-listening-event-lambeth

[19] Ahmed E, Newburn M, Moltedo V et al (see above, p5).

3. What did we do on the day?

On the day, the organising group assembled, many having taken their own children to school first, and had a final briefing on the planned activities and each person's role (see Appendix 2). We set up the crèche, the activity areas, a small informal registration desk, and laid out tea, coffee and healthy snacks.

We put up a 'washing line' (string and pegs) ready for coloured-paper 'washing' post-it notes. Two sets of pre-prepared pictures and words were scattered on two tables at opposite ends of the room. And flipchart paper and pens were made ready. Everyone was asked to write their first name on a sticky name badge.

We introduced ourselves to the crèche workers, and to each of the mothers as they arrived. Vita, who had been the link person, knew each person a little already. A hot drink was provided one-to-one as each participant sat down to fill in a consent form and provide their socio-demographic details. We needed plenty of space for buggies, some with sleeping babies inside them, and accessible toilets and baby changing facilities. The community centre was well equipped.

Rachael (left) with people filling out forms and chatting one-to-one.

It was a wet day, and it took about forty-five minutes from the advertised start time for all the mums, babies and buggies to arrive. Some children were settled in the crèche, but many wanted to stay with their mother.

Who came to the Lambeth Parents' Lunch?

In all, 13 pregnant women and mothers of babies and toddlers attended the Lambeth Parents' Lunch. They had heard about the event or been referred from several sources (numbers in brackets), including a community-led social support project, Parents and Communities Together (PACT) (4), Mummy's Day Out (3), Lambeth Early Action Partnership (LEAP) (1), an Indonesian mothers' group (1), referral by 'friends', potentially via one of the Maternity Voices Partnerships (MVPs) or social media (4). A local playground play leader also attended, making 14 in total. One mother from Happy Baby Community had booked but did not

A mother and baby being greeted. Everyone wore a label showing their first name.

attend. Of these 13 women, six identified as Christian, five as Muslim, one as non-religious, and one did not respond. They were of diverse ethnicity and heritage including, African (5), Caribbean origin (1) and Black unspecified (1), mixed African and Asian heritage (1), White English, Welsh, Scottish, Northern Irish or British (1), White any other (3) including one Albanian, and one Latin American. Fifteen children attended, five toddlers and ten babies under the age of 12 months. Most women spoke English as their first or a subsequent language. One woman felt more comfortable communicating in her mother tongue. Zenab was able to speak with her in Pular (also known as Fulani or Fulah), ...and translate more complex or subtle things she wanted to express

The mothers were offered the opportunity to book places for their children, in the pop-up crèche, to enable them to participate fully in the activities and discussion. Care was taken to ensure that legal requirements were met of a minimum of two crèche workers in the room with an appropriate ratio of workers to children based on their ages. Mothers also had the option of bringing their children into the workshop room as often as needed. Younger babies and those being breastfed tended to be with their mothers throughout the session.

Ice breaker

After informal chatting while we waited for most of those expected to arrive, Rachael facilitated a lively and light-hearted icebreaker designed to get everyone moving around and laughing together. Everyone joined in as equals. Researchers and peer researchers were not identified specifically. The activity showed that people who are similar in some respects hold different views and preferences; that all perspectives are valid, and priorities vary. It demonstrated some of the beliefs and experiences that researchers and community mothers share, such as how we like to dress our children, and attitudes about the importance of our mobile phones! Also, we can be different, yet similar. Then the data gathering part of the event began with the washing line activity.

Participatory appraisal activities

Four participatory appraisal activities were used during the event to facilitate conversations about women's maternity journeys and quantify perceived priorities: the 'washing line', 'people and places', a spider diagram and voting with beany counters. The objectives and process for each of these is described below.

Washing line

The main aim of this activity was to gain a general understanding of the women's experiences during different stages of the maternal journey (early pregnancy, labour and birth, postnatal and infant feeding), with four broadly sequential time-points, or key phases, selected in advance. We wanted everyone to have a chance to contribute and be supported and heard, while we were unable to spend time listening to detailed stories. One peer researcher, Vita, facilitated this activity. And, using the line hung across the room, we all filled in shaped pieces of paper and post-its and pegged them along it. One end was marked with a happy face and the other a sad face. The middle represented 'just OK' or mixed experiences. Women spoke with researchers and hung messages along the line, at places to represent their experiences. See Appendix 3.

A mother pegging a post-it note with her experiences on the 'washing line'.

People and places

Next, the women were divided into two groups. Each group of women and researchers sat around a table where different word and picture cards were spread out. The women were invited to pick up a picture or a word to represent a person or place that had been positive for them during pregnancy, birth or afterwards. They were asked: 'Where did you get – or are you getting – support, help or care when pregnant or adjusting to being a new mum'. (Guidance included the use of inclusive language according to the make-up of the group.) After everyone had had an opportunity to contribute two or three positive sources of care or support, the focus was switched to areas where the women felt care or support had been lacking or disappointing. The aim was to get a holistic sense of

the women's lived experience during their maternity journey and how the social, community and clinical parts of their informal networks and NHS services came together, interconnected, created tensions or left gaps. We encouraged them to communicate to us how the specific words or pictures that they picked related to their experiences.

Vita (centre) facilitates 'people and places' discussion while mothers and researchers look after the babies.

Spider diagram
Next, there was an opportunity to explore possible solutions to difficulties raised earlier. For this activity, three new groups were formed to enable a different set of interactions. With a peer researcher or the PPIE lead facilitating, each group responded to one of the following questions:

- What would improve your experience during pregnancy, birth and afterwards?
- How could your culture or traditions be better understood?
- What kinds of community support and ongoing professional care do parents need?

Beany counter
The last activity, the beany counter, was undertaken just as lunch was being served. The women voted, each using a same-number strip of sticky dots (seven in practice), according to what topics on all three spider diagrams they felt were most important.

Lunch

Freshly-cooked, hot, vegan food was brought into the centre and served to the mums and older children by the Healthy Living Platform food ambassadors, themselves Muslim women from an ethnic minority background. Everyone appreciated the generous portions of a savoury course (vegetable chickpea curry with rice and salad) and a low-sugar pudding (fruit crumble and custard).

Over lunch, women and their children continued talking in animated and informal small groups as if they were known friends. Researchers and peer researchers participated with mothers, ensuring that everybody had food, sitting informally to eat and chat, holding babies, and participating in conversations that were rich and personal. Few women seemed in a hurry to leave, and several were still chatting

and enjoying themselves an hour later. At a time of the cost of living crisis, to serve a hot, healthy meal seemed to be particularly appreciated, and some women responded to the offer of an extra portion of of food to take home afterwards, ensuring nothing was wasted.

Small groups of mothers and researchers chat during lunch. Zoe holds a baby so a mother can eat.

4. Themes and issues emerging

After the event, all the post-its and hand-written notes were transcribed. The data collected during each activity are summarised here.

Washing line activity

Positive and negative experiences at key points in the maternity journey

This was an 'easy entry' activity. Not demanding too much thought to get people used to sharing information. The washing line was colourful and felt to be fun. There were several mentions in feedback afterwards.

There were around five minutes (only) for each of the four questions, so not everyone contributed each time, but by the end, most people had put up at least one shape or post-it, either working alone or with a researcher-scribe if they needed encouragement or had their hands full with a baby.

There were more negative comments than positive ones, indicating that women found their experiences of using maternity services and contacts with health professionals were often difficult for them. The need for further information or guidance in early pregnancy came up. In relation to labour and birth, the participants emphasised that services were busy and overstretched, resulting in them being given less personalised (and possibly less safe) care than they needed. Words like 'distressing', 'traumatising', 'scary' and 'horrible' were used as well as 'kept me informed' and 'happy with care'. For women who had previously experienced baby-loss, such as a miscarriage, pregnancy was a worrying time when they needed good support, clear information about their current pregnancy and an opportunity to discuss their concerns. The tables below shows how the data were written up.

A mother pegs an image of a pregnant woman with her experience on the 'washing line'.

Table 1: Women's experiences of their maternity journey at key stages

Question	Responses:		
	Positive	Mixed/middling	Negative
How did you feel when you first saw a GP or midwife early **in your pregnancy?**	■ Kept me well informed and answered all my questions.	■ Was given information on a website neither/ positive or negative felt like a non-event.	■ Felt nervous. ■ Didn't get much guidance from GP. ■ GP didn't give much info. ■ Had previous stillbirths, miscarriages and received no support (even though following miscarriage, I was monitored throughout my last pregnancy until birth).
Was your **birth** how you were hoping?	■ Very good, they were able to read my notes and address me correctly in the hospital.	■ Felt worried and had health concerns for the baby. (Things are) much better now and (I/she) managed stress thanks to peer support groups.	■ Had an emergency CS and the midwives were too busy. ■ Long and distressing, received no information. ■ I was not informed properly of the different scenarios and was not aware of the different methods it entails. *(NB: it doesn't say but this possibly relates to induction of labour?)* ■ Traumatising. ■ No beds available either time, staff lovely but overstretched.

Question	Responses:		
	Positive	Mixed/middling	Negative
How did you feel in the **first month after your baby was born?**	■ Felt happy to have baby, was happy with care in the hospital. ■ Had an extra day in the hospital and had breastfeeding support from a research midwife that helped to establish feeding.	■ This was a challenging and scary time as the baby had sepsis but hospital care and community nurse care was good.	■ Horrible, worst experience ever, I wouldn't wish it on my worst enemy.
What was your experience of **feeding your baby?**	■ Had a great experience, because of (my) mum.	■ Survived mastitis and tongue tie which has scary, had lots of support from Lambeth breastfeeding support.	■ Would have liked more support from GP and other healthcare workers. ■ Frustrating ■ Found it very difficult. ■ Painful, frustrating, alone. ■ Stayed in for feeding support but this was very minimal. Very sore nipples when at home and eventually hired a private lactation consultant. Confidence was knocked. Only got information on breastfeeding support 3 weeks after birth from the HV (health visitor).

People and Places

Key sources of care, information and support

This activity brought to the surface where and from whom women felt they received most noteworthy support, help, information or care when pregnant or adjusting to being a new mum. It also highlighted negative experiences. In tables 2 and 3 below, the ordering is broadly consistent with the order in which members of each group mentioned particular people or places, with some adjustment so that the same people or places raised in both groups are presented on the same row. There was considerable consistency.

A lot of the participants relied on family members, mainly female, (mother, sister, 'aunties') and friends for support and information about the process they were going through, and for practical support. The informational and emotional support of family, friends, and places of worship for those with religious belief, was valued because its cultural relevance gave it important meaning for them. This was sometimes in sharp contrast with interactions with healthcare professionals, which were often perceived as blind to people's personal circumstances or culture of heritage.

Some women felt that they were not listened to by their midwives or GPs, others said the care received during their maternity journey was satisfactory, or at times exceeded their expectations.

Relational care, with continuity from a midwife, health visitor and/or GP was highly valued. Community support in the form of mother and baby groups, breastfeeding support, and parenting and mental health support were wanted. Religious community support and their faith were highly important to some women. It was important for community services to be provided, and for families to be signposted to them. Getting to know people as individuals seemed to be important: recognising their values, being willing to learn about and acknowledge their personal circumstances, cultural background and spiritual beliefs.

Women feared being judged, and possible repercussions, and so were sometimes reluctant to seek help for mental health issues, especially if they did not have a trusting relationship with a health professional. Having opportunities to talk about concerns and anxiety, to be really listened to, and to have access to practical help, for example, with accommodation, baby bank items, breastfeeding and mental health were noted.

Being asked questions, including neutral, open questions, by a healthcare professional about their mental health and sleep were experienced as challenging by some. Some women sensed that the questions were loaded, that there was always an agenda. If they already felt anxious or had no prior experience from which to make sense of current feelings, they felt additional pressure, and fear. The early postnatal period with a first baby was highlighted as an especially vulnerable time, particularly if they had had no opportunity to establish a trusting relationship with a healthcare professional. One of the key themes that emerged was that well-established trusting relationships and empathy are fundamental to positive experiences and coping with big life transitions.

Table 2: People and places providing notable care, support or information

Group facilitated by Vita and Rachel	Group facilitated by Mary and Zenab
My family / my partner – 'Support from my family and from my partner, but not enough'.	**Family** – Having mealtimes with family as I didn't want to cook. Mum, husband, dad and family cooking and around to help. Mum was really supportive.
Church (religious group) – I had a lot of support from my Church family (none from my actual family).	**Church (religious group)** – Church family supportive in person and virtually.
Friends – Had a lot of support from them; offered me accommodation; told me to speak to the midwife. Helped with breastfeeding.	**Friends** – A friend's sister did my cooking for over a year.
Health visitor – helped with high BP. 'I preferred the HV to MW (unclear word). She helped me a lot.'	**Health visitor** – Met my HV a week before having the baby and have been seeing her regularly. Had continuity with the HV and this was really helpful. HV was really homely, supportive 'like an auntie'. HV acknowledged my partner. My HV went off sick but the team was still really supportive.
Peer support, specifically Mindful Mums peer support – I had bad anxiety. I went for more than 3 weeks. It was so helpful.' And Mum and Baby groups – the support you get is outstanding. 'It's a big effort to leave the house, but it's worth it'. '(I went) from the baby being 10 days old.' 'Amazing mum and baby group'.	**Peer support, specifically other pregnant people/new mums** – Peanut, online forum, very important for one; it led to a supportive face-to-face friendship. Met new friends through a baby group and looked forward to going to this.
Midwife – MW helped me with accommodation and put me in touch with 'Baby Bank' (e.g. https://www.goodto.com/family/where-to-find-your-local-baby-bank-458436).	**Midwife** – I was discharged by midwives but my baby wasn't feeding. I contacted [trust] and another midwife came and gave lots of support including a breast pump and a referral to the tongue tie service. Another had continuity antenatally and then had known midwives during birth, so had midwives she had got to know, and this felt positive. Also saw them postnatally and had their mobile numbers. Another said: The midwife that cared for me during labour came to see me in ITU which felt good.

Table 2: continued

Breastfeeding drop-in – 'really helped me'. 'No one worried because the baby was fine, but only the drop-in listened to me'. La Leche League – helped so much.	**GP** – gave a thorough 8-week check and was known to the woman.
Hospital – 'Amazing, super-busy but (they) were really thoughtful and helpful.' 'Despite having sepsis, hospital was great.'	

Table 3: Gaps in care support and information

Group facilitated by Vita and Rachel	Group facilitated by Mary and Zenab
Breastfeeding support – In hospital there was no help with breastfeeding. Care at **private tongue-tie service** was 'done badly'.	**Breastfeeding support** – lack of breastfeeding support in the hospital.
Services for mothers – The Mum and Baby group, 'It didn't work for me, or my baby. Who's it for, baby's benefit or mum's benefit?'	**Services for mothers** – Mother's need access to postnatal therapy which feels safe, away from maternity services.
Healthcare professionals in positions of authority – Mum didn't like to be asked global open-questions about mental health such as 'How's your mental health?' I felt overwhelmed with the question. I didn't appreciate what 'normal' was. I didn't feel like myself but felt perhaps that was down to having a baby. "How is your sleep?" I felt this was a silly question connected to mental health'.	**Healthcare professionals (HCPs) in positions of authority** –There is stigma and concern around children being removed and women can feel a need to put on a facade that they are strong and coping even if feeling lonely and isolated. Talking to HCPs didn't feel safe (even when known), family felt safer. Mother worried about the reaction of professionals if she asked for help. There needs to be trust and transparency in the information recorded about people.
Family (neutral impact) – 'I didn't want my worries and anxiety to impact my family. It was a terrible time even though not my first pregnancy'.	**GP** – Didn't feel supported in pregnancy or postnatally by the GP and then had phone calls out of the blue about immunisations. I had to call GP to see if 8 week check was due/needed. GPs change and 'we don't have a family doctor anymore, no one that knows us'.

Midwife – I didn't get an opportunity to build a relationship with a midwife. I didn't get to see the midwife again following the birth. Midwives asking 'how are you doing?' It isn't helpful as you can just say 'fine'.

Spider diagrams

Discussion on how could we make things better

Sitting at three tables, each considering a different aspect of services, the final organised group activity encouraged the groups to identify solutions to problems. Later, just before and over lunch, all participants were invited to cast their beany counter votes across any of the proposed 'solutions' on the three spider diagrams.

What would improve your experience during pregnancy, birth and afterwards?

Regarding improving experiences during pregnancy, birth and afterwards, as the table below shows, 'more resources' was proposed, and then voted for more than any other option. It should be noted that several of the participants had been pregnant during the Covid pandemic (March 2020 to the start of 2022) and their comments may relate in part to the particular challenges during that period, including social isolating, virtual care, stretched healthcare staffing, and temporary closure of usual community face-to-face services. This may explain in part the emphasis on negative experiences and feelings.

Other priorities highlighted were more frequent health assessments (check-ups); more community-based parent support services, including non-stigmatising talking therapies, breastfeeding support, and peer support, antenatal preparation and what to expect in the postnatal period; continuity of carer; more personalised care – including more responsive support after recurrent miscarriage; clear signposting to services that are free of charge and to information on grants and benefits; plus greater access to language support and translation services.

In terms of overarching messages, being listened to came up many times. As did knowing where to access particular kinds of informational, clinical/practical and emotional support, and being able to get an appointment and be provided with personalised care without a long wait.

Table 4: What would improve your experience during pregnancy, birth and afterwards?

Possible solutions proposed	Beany votes
1. **Not having just online services** – participant highlighted not wanting to be expected to do everything online by GPs.	4
2. **Knowing where to go and who to speak to about concerns.**	1
3. **Seeing the same person (continuity of carer).**	4
4. **Personalised care (links with 3).**	1

5. **More resources** – participants discussed lack of staff and beds, queuing for labour ward, with two women describing waiting to be induced until the staffing level was considered safe, and the length of waiting lists. For example participants felt that the drop-in physio service at their hospital was not working well due to insufficient staff. Another participant didn't get support for a prolapse antenatally (this was also mentioned in another leg of the spider that more postnatal physio/pelvic floor care was needed).	8
6. **Support from GPs** – one participant said when the GP was supportive she got the help and referral she needed. Other participants said that they were told by GPs 'there is nothing we can do for you' or didn't get the help they felt they needed after several miscarriages.	4
7. **Support groups with other women** – it was suggested that events such as this listening event would have been helpful.	2
8. **Asking for help** – a participant felt that their problems weren't always considered relevant, and another participant described the challenge of a language barrier and finding it hard to explain in English.	4
Other general points **More scans** – no further information on this point.	4
Regular check-ups – participants described feeling scared due to issues such as miscarriages, diabetes, high blood pressure but felt the hospital was supportive.	6

Women discuss how their culture or traditions could be better understood during the spider diagram activity.

How could your culture or traditions be better understood?

It was anticipated that this topic would be important, particularly for some of the Black women and those not born in the UK, and it provided a rich seam of ideas.

Popular suggestions for better understanding of culture and traditions were:

- encourage conversations about different cultural traditions and approaches;
- employ diverse staff in the maternity services;
- encourage a culture of willingness to learn from each other with openness and without judgement;
- include local people in cultural competency training and communications;
- provide continuity of carer with understanding and respect for the woman and her partner/family;
- and ensure that education and policies on pain management and support during labour are culturally informed.

Table 5: How could your culture and traditions be better understood?

Possible solutions proposed	Beany votes
1. **Encourage conversations about different cultural traditions and approaches** so that British/English healthcare workers have a better understanding of diverse beliefs and practices around childbirth/ feeding/baby-care/postnatal period, and therefore greater cultural competency. Encourage HCPs to ask questions about any usual family ways or cultural practices in an open and respectful way. Explain why the English/UK health services approach may be different. Explore meanings, reasons for, pros and cons of different approaches, etc. Include examples, local stories and local people, in cultural competency training.	5
2. **Having diverse staff in the maternity services was considered important, and a willingness to learn from each other.** (see 1 above)	3
3. **Potential research topic: How traditions, heritage, and cultural practices affect women and families and their interactions with UK healthcare staff. How women and partners feel about, and navigate, different expectations, advice and cultural traditions from family or heritage and NHS health services.** For example, one Black participant said that it was helpful to have a Black HV from her country of heritage. **These staff could be asked to share their knowledge with other staff.** Another Black participant said that she would have preferred 'a White healthcare worker'. Some wanted their individual needs and personal preferences supported first and foremost, others wanted more support for understanding of their cultural heritage.	3
4. **Pain management during labour** – see 3 above. Several participants felt that assumptions were made about Black women having a higher pain threshold than White women. It wasn't always White HCPs who made assumptions about what women needed/didn't need. The crucial thing was being listened to and believed.	1

5. **Continuity of care –** considered important. Participant referred to not having to repeat yourself all the time. 'Continuing conversations' was an important theme. Also, building up relationships with and understanding the **woman's partner** (and their role in the family, their feelings). Important not to make assumptions about the kind of person/role taken by the partner. If this is combined with racial stereotypes, especially unhelpful.	5
General point – Participant(s) wanted healthcare workers that they could relate to – this might be their culture or heritage, or (geographical or class) background, or being a mother themselves.	4

A potential research topic emerged: how traditions, heritage, and cultural practices affect women and families and their interactions with UK healthcare staff. This might question how women and partners feel about and navigate different expectations, advice and cultural traditions from their family or heritage and from NHS health services.

What kinds of community support and ongoing professional care do parents need?

Provision of free community services and clear signposting to them was considered of vital importance. Support for breastfeeding was seen as a gap, and women wanted access to quality antenatal preparation for what to expect after the birth, as well as for labour and birth itself. Participants wanted a range of specialist services (e.g. talking therapies, mental health support and breastfeeding support) and peer support. Cultural relevance was considered important; women wanted to feel that the service was welcoming for people like them. Services beyond healthcare were wanted, such as information on grants and benefits.

Women discuss changes to services and support that would improve their experiences.

Table 6: What kinds of community support and professional care do parents need?

Possible solutions proposed	Beany votes
1. **Breastfeeding/feeding –** communicating where support is and a need for both general and urgent/specific support.	5
2. **Antenatal preparation** – including expectations of early postnatal period.	3
3. **Peer support from other mums/parents** (this links to point 7 in Table 4 above 'what would improve your experience during pregnancy, birth and afterwards').	2
4. **Information on grants and benefits**.	2
5. **Clear signposting** – Knowing where to go for support (this links to point 1 on feeding and point 8 on Table 4 on what would improve your experience during pregnancy, birth and afterwards,' and also to point 4 above).	2
6. **Free, or affordable, support for all** – this is linked to point 1 above and is linked to point 7 on Table 4.	4
7. **Access to (ethnically) diverse support groups** – so that everyone feels a sense of belonging and comfortable to participate. This is linked to point 6 above.	4
8. **Access to postnatal (talking) therapy** – including general mental health/wellbeing support and support which is non-stigmatising and is separate from the hospital.	6

5. What did we learn?

We learned a lot from the Lambeth Parents' Lunch project. The event and its organisation were complex and there were overlapping areas of learning about running a welcoming, culturally competent, participatory, community-based listening event, working as a team made up of peer researchers, a service user researcher PPIE lead and academic researchers, and gathering information from mothers in South London about their maternity experiences and sources of information, support and care.

A welcoming, culturally competent, participatory, community-based listening event

An important way to judge the success of the event, in terms of whether it was welcoming, culturally competent for a mixed group of south London women, and participatory in ways that people found enjoyable, is to ask those who participated.

After the event, Vita, the peer researcher who had managed bookings administration and supported each person individually before the event, wrote to participants who had attended, fellow peer researchers, and an ARC South London maternity and perinatal mental health PPIE Network colleague, who had helped to publicise the event, and asked them for their feedback. We wanted to know how they felt about the event, what they had found positive and anything that could have been done differently to improve their experience. We didn't ask specifically about people's practical or cultural needs. Most of the feedback about the event was very positive, and there were also learning points to consider. The words of all those who responded are included, as a matter of principle to ensure that all voices are heard. For some of these women, being asked for their opinion and seeing it published, alongside their name, may be a first.

> The activities that were done made me think... It was good learning from others and sharing... So it was a really good event. So well done everyone!
> **Abigail Baidoo**

> What a great session!
> **Trudy Mensah-Bonsu**

> A fabulous event. It was so nice to meet other mums, get to share our experiences and to see that we are not alone. It was nice to feel that our ideas and suggestion were listened to and hopefully it will help the system and process to improve for mums in the future.
> **Megan**

> During one of the activities I took a step back to take a few photos of the event. As I stood still and focused, what I saw was a group of women working together for a common cause. At that moment it was impossible to distinguish between researchers and participants. Despite the joyful noisiness, there was a trusting and calm atmosphere where everyone was completely at ease. We had succeeded in creating a safe space where people were able to talk about their experiences in an authentic and sincere way, empowered by the knowledge they were truly part of the process.
> **Vita**

> Thank you for organizing this fantastic event. It was a pleasure to meet everyone and be able to share experiences.
> **Renata Chajerova**

I had a great day, the activities were engaging and reflecting. I liked the fact that we were able to talk about our experiences right from the beginning of pregnancy till that very moment, both the good and bad and also show appreciation...
Mutiat Hamed

The event was beneficial, but most importantly enjoyable.

When an event is organised well, you can see the fruitfulness of the outcome. Great games were used, especially the washing line.

I truly enjoyed being in the atmosphere of women who were able to feel comfortable to talk about their faith, culture and their differences. Having food at an event, proper food helps a lot, as we know food brings people together. I would definitely love to see this event quarterly or at least twice a year, as this type of event brings diverse communities together.
Abigail Mensah

It was a great opportunity for me to share this event to the local mums in my area (SE16 and beyond). I believe all stories and information that's shared between mums are so lovely and crucial.
Tania Sutedja

The event was really good. It really did feel like you were being listened to. It was nice the mums and researchers all joined together as equals. I wish it was something that all new parents got a chance to do. It was only afterwards that I realised I had never spoken to anyone about some of these questions e.g. the first GP appointment after finding out you're pregnant. It was so nice to hear from another mum who felt exactly like me. The activities like the washing line made it fun and having lunch at the end was so lovely. Not everyone felt the same e.g. the debate over too many scans for some and not enough for others made me think how personal this experience is. Lack of resources and continuity was something that came out again and again which sadly with the funding and staffing crisis isn't going to change anytime soon. The event was great and the researchers friendly and welcoming.
Kim

It was great to meet other mothers and chat through our pregnancy and labour experiences. I really hope our suggestions help improve services for others in the future.
Roberta Johnson

Mothers chatting at a café table while they ate a hot meal together.

Although no one had expressed the need for a translator, a positive effect of peer researcher involvement and diversity in the team was the opportunity for responsiveness and flexibility in relation to cultural and language support. The make-up of the small groups was adjusted to enable the participant who speaks Pular to join the group that Zenab was co-facilitating. Having language support so she could express what she wanted to convey was appreciated by this mother who obviously felt welcomed and a real connection.

Zenab cradles one of the sleeping babies allowing a mother to take a break.

One mother said that she would have been able to relax more if there had been a safety gate or other barrier between the café area where the workshop took place and the kitchen. This was useful learning for us. In future, we might use a space large enough for the crèche workers to manage a play area in the workshop room, and we would make sure that the kitchen area was closed off. The reasons for having the crèche in a separate space was to reduce the overall noise level to enable participants to hear each other clearly during activities, and to have sufficient space. Some of the 2-3 year-olds really enjoyed running around in the large separate hall, used for the crèche.

Working as a team of peer researchers, PPIE lead and academic researchers

A lot of work went into the planning, organising and marketing of the event which was novel in terms of a group of peer researchers and academic researchers collaborating to co-produce a project and, holding a participative listening event in a community centre. Two of us, Mary and Hannah Rayment-Jones, had had experience of running involvement events for the theme in 2017 and 2019.[20,21] Since then, we have consolidated our learning, approach and working practices. Several of the team have had training and used participatory appraisal approaches,[22] and we have worked consistently on building and maintaining links with community leaders, online networks and community organisations. As we had not worked together as a nine-person mixed team of researchers and peer researchers before, we did a lot of learning through practice. Previous shared training, and establishment of trust and mutual respect over 2-3 years working collaboratively as part of ARC South London, had created cultural capital within the team. Although the process of planning and preparation was almost all carried out online, and without a worked-up blueprint for roles and ways of working, we found a way to share and delegate responsibilities.

We had a planned debrief immediately after the event to reflect together as a team and each note our thoughts and observations. Everyone felt that the event had been hugely successful in terms of achieving what had been aimed for, the running of a well-attended, respectful, welcoming and fun Parents' Lunch as an inclusive, participatory, listening event. One person questioned whether there had been enough opportunity for individuals who had had difficult experiences to talk one-to-one and be signposted to relevant services. On balance, we felt that all the women had enjoyed the group activities and taking any individual aside, might have detracted from their experience. Also, the high ratio of organising team members to mothers (approximately 1:1.5), had ensured that there were many small-group opportunities for empathetic listening, and the mothers actively made friends and supported each other.

Creating harmony between ensuring the event provided a relaxing, inviting and a safe space for members of the community to share their experiences, and making sure that the listening event met the more structured aims and ambitions of the project was a delicate balance at times. But one we hope we achieved. One peer researcher reflected: 'There is no need to overcomplicate things or impose … rigid protocols. Flexibility is important and, oftentimes, we just need to go with the flow. … This event has taught us that underrepresented groups are not hard to reach. Rather, they actually want to be involved in research and share their perspectives. However, for that to happen, the approach needs to be right for them and relevant to them.' [23]

[20] Report of a maternity and women's health research workshop ORTUS Learning and Events Centre, Denmark Hill, 29 November 2017. NIHR CLAHRC 2017.

[21] Ahmed E. Patient and Public Involvement in Maternity Research Workshop report. NHS North East London Commissioning Support Unit. March 2019.

[22] Ahmed E, Newburn M, Moltedo V et al (see above, p5).

[23] Barry Z. Doing research within the community: an enriching listening event in Lambeth. Applied Research Collaboration South London. April 2023. https://arc-sl.nihr.ac.uk/news-insights/blog-and-commentary/doing-research-within-community-enriching-listening-event-lambeth

How we capture these values and atmosphere when developing a future participatory research project with the necessary research ethics approvals, protocols, information sheets etc, which can impose more formality, remains an important question. These kinds of considerations need to be worked through when there are broad collaborations, and there are questions, too, about how much theoretical and empirical research literature to draw upon and include.

The funding available was less than was needed to write up the event as well as to plan and facilitate it. Several individuals put in additional unpaid hours, and additional funding from the ARC South London Maternity and Perinatal Mental Health Theme was used to part fund some of the activities. An upside was that we knew we would be able to set up and run a similar event in future, in less time by drawing on what we had learned. There have been some tensions along the way, but the whole team has worked on resolving them, by focusing on the bigger picture, finding ways to share our feelings in respectful ways, and by looking at things from different people's perspectives. Several small groups met to hear about different perspectives and to discuss learning. Everyone in the team has endorsed this report and agreed to work together on another, similar, project.

South London mothers' experiences of their maternity journey

The event was successful in gathering an overview of the most pressing issues of concern for a diverse group of south London mothers, and thus helping to inform and shape future research proposals. We learned that women felt maternity services were under-resourced, with midwifery staffing pressures causing interruptions and longer waiting times. It was unclear how much the women's experiences were exacerbated by the Covid pandemic or its direct aftermath, as we did not specifically focus on this question. Discussions highlighted that much of the information, support and care that women feel they need came from their family, friends and other non-healthcare sources when they had these kinds of resources available to them. For women with limited or no support network, particularly those who needed an interpreter to communicate with English speakers, pregnancy and new motherhood could be a lonely time. Most of the women who came to the event were able to express themselves in English. Zenab facilitated greater involvement for one mother as she could speak with her in Pular, and translate particular words and phrases.

For NHS maternity services to deliver more integrated, culturally sensitive, maternity care in which women feel safe and do not have to continuously repeat themselves, continuity models of care are needed. Women wanted access to free specialist care, such as obstetric physiotherapy, and community services including peer support, breastfeeding support and postnatal wellbeing groups. Cultural competency was needed, and services that actively consider how to achieve equity, diversity and inclusion. This included the importance of sharing different cultural norms and practices and finding ways that different cultural knowledge can be exchanged, e.g. through midwifery education, local learning, peer support, and matching of a family with a health professional or peer, according to their preferences. Adequate pain management, being listened to, and involving partners positively in information provision and support, were also key issues that the women considered important.

It was pointed out that there is not much understanding and encouragement expressed towards new fathers when services are stretched, and (an unintended) consequence of routine domestic abuse screening and lack of a whole-person focus, can mean that partners may seem to be talked about with

women predominantly in negative terms. Overall, the event highlighted the importance of finding ways to integrate clinical maternity care with women's and families' practical, cultural, social and emotional needs during this enormous, all-encompassing, transition in their lives. Women needed to be listened to empathetically, so that they could process all the changes they were experiencing.

6 Conclusion and recommendations

The project has enabled us to work in ways that we aspire to, focusing on communities, building trust and creating partnerships with diverse communities. We were able to engage with the populations we want to work with and for, and feel that an opportunity was provided for communities to be involved on their own terms. Although just one event, the work is a foundation for further collaborative work with the potential for individual development and strengthening of community connections and confidence.

Clear enabling communication has been prioritised throughout, in the planning and marketing, and in the collaborative and inclusive writing up. Visual images have been used to good effect to demonstrate our values and ways of working. Diversity in the research team has been central, and recruitment of women by peer researchers from diverse backgrounds and communities, was fundamental to the range of people who attended and the atmosphere on the day.

Addressing power imbalance is complex and an ongoing challenge. It intersects with available resources of time and funding, with opportunities for training and planning together, conscious and unconscious beliefs and expectations, and different strengths. It is a work in progress in which we aim to value people's involvement, ask what they want and need, and focus actively on building trust and respect at all levels. Values of regard for people and communities, fairness and working to promote community wellbeing, unite us, and help us to work through differences.

The Lambeth Parents' Lunch, conducted with peer researchers in a community setting and using participatory research methods, enabled us to be trusted with women's personal stories about their pregnancy and becoming a mother. They discussed how they fared while using maternity and community health services, including their anxieties, uncertainties, sources of support and good care. They also shared their frustrations and disappointments and some unsafe care. Importantly, the event was viewed positively by the women who attended.

The women valued making local connections with other mothers and continued their conversations outside after leaving the venue.

We have called for more opportunities for community-based involvement and peer research.[24] Co-production and events of this kind can provide a real insight into the lived experiences and perspectives of women from diverse backgrounds, who are often not heard. By enabling the involvement of seldom heard groups in maternity and perinatal mental health research, we aim to make future research more relevant and ultimately, improve women's and babies' health and experiences. We believe that these kinds of community activities also mobilise greater community connectivity and resourcefulness, contributing to social capital.

As a team, we agreed to build on this project by undertaking further community-based participatory listening and research. The maternity and perinatal mental theme has been awarded KERN stage I funding to expand on this work using Photovoice and/or Maternal Journalling as participatory research methods, after training together as a team.[25] We hope to be awarded stage II funding after having held a further community involvement listening event with the same group of Lambeth mothers to find out what they feel about working together using one of these approaches. By peer researchers and researchers undertaking Photovoice training together at the beginning of the new project, we hope to build an integrated sense of preferred ways of working. We have also discussed developing a research charter, to bring us together and renew our expectations and values, explicitly.

A risk of both small budgets and time-poverty, a feature of the lives of researchers working on multiple projects and community leaders with young children, is that essential work on roles, expectations and ways of working together may not be explored collaboratively at key time points in a project. A challenge in many, if not all, projects is to find sufficient time for team building, shared training and work on agreeing values, while also being pragmatic and grasping positive opportunities when conditions are less than ideal.

We support the development of resources, training and proposed networking opportunities for peer researchers;[26] and sharing of public involvement in research guidance and good practice for the public[27] and for academic researchers, including ways of building capacity in public involvement leadership.[28]

Having clear values and opportunities for training and team building are building blocks for this kind of work. In addition, our recommendations for others

[24] Barry Z, Buabeng R, Moltedo V and Newburn M. 'How was it for you? Community involvement in ARC South London's maternity research: some unexpected benefits of Covid-19 ways of working', Applied Research Collaboration South London, 15 December 2021.

[25] MORE – Tackling inequalities in maternity care https://arc-sl.nihr.ac.uk/news-insights/latest-news/more-tacking-inequalities-maternity-care

[26] Yang and Dibb (See above, p8).

[27] An interactive course for new and experienced patient/public reviewers of health and social care research. NIHR. https://www.learningforinvolvement.org.uk/an-interactive-course-for-new-and-experienced-patient-public-reviewers-of-health-and-social-care-research/

[28] Building capacity in public involvement leadership. 13 September 2023. ARC South West peninsular/ARC South London. https://www.eventbrite.co.uk/e/building-capacity-in-patient-and-public-involvement-ppi-leadership-tickets-677263141287

organising similar participative community involvement research events would include the need to be clear about multiple objectives and the ways they overlap and interact. Teams need to attend to the practical details of how to host a welcoming, accessible, culturally sensitive event; to work on how to achieve a well-integrated team of peer and academic researchers with a clear, shared brief; and also, set research objectives and develop suitable participatory methods and activities. It is no small undertaking.

Women's and children's lives

Many stories of isolation, anxiety, pregnancy loss, babies with health concerns and lack of support were shared. Some women had been traumatised or suffered other mental health conditions. This raises the question of whether there will be long-term consequences of the Covid pandemic and for this post-Covid cohort of new mothers. Will they be able shake off the impact of additional negative experiences and bad feelings, or will they carry them forward?

The women very much wanted opportunities to come together with peers in empathetic, facilitated spaces. They make a powerful case for more free-at-point-of-entry community services with clear signposting. Research is needed that looks into women's maternity journeys prospectively and what their health and social trajectories are in relation to models of care, and the extent and kinds of community services provided. Women can provide support for each other and are hugely resourceful. We hope to continue working creatively over several months with the group we brought together. This might realise more substantial shared social capital and social change, the ultimate aim of participatory research.

Contributors

Zenab Barry is a political scientist and an international development specialist. She is a director at the National Maternity Voices, a visiting research fellow at the Faculty of Life Sciences and Medicine at King's College London, a PPIE member at the NIHR's HSDR Bevan Funding Committee, an NHS peer leader, a PPI contributor at THIS Institute (University of Cambridge), a strategic adviser for NIHR ARC South London's maternity and perinatal mental health research theme, King's College London and a coach, mentor and consultant at Zenab Barry Consulting.

Rachael Buabeng, Multi-award-winning founder of Mummy's Day Out, author, maternal health and hyperemisis gravidarum' advocate (severe vomiting in pregnancy), and Co-chair of Homerton Black and Black-mixed heritage Maternity Voices Partnership.

Kaat De Backer is a Perinatal Mental Health Specialist Midwife and midwife researcher Kaat holds an NIHR Doctoral Research Fellowship at the Department of Women & Children's Health at King's College London. Her PhD research focuses on maternity experiences and outcomes of women with social care involvement.

Abigail Easter, Reader in Perinatal Mental Health in the Department for Women and Children's Health, King's College London. Deputy theme lead for the maternity and perinatal mental health theme of the ARC South London.

Zahra Khan, Midwifery lecturer at King's College London, is undertaking a PhD in the Department of Women and Children's Health, School of Life Course & Population Sciences. Her project aims to apply an intersectional approach to tackling health inequalities while exploring community-based models of midwifery care in areas of high ethnic diversity and social deprivation.

Vita Moltedo, Participatory appraisal-trained peer researcher, mother, speaker of English as a second language, founder of Maternity Voices Matter network, member of the NIHR ARC South London Public Research Panel. Vita was trained in PA approaches, as part of the co-produced 2018 North Central London (NCL) Better Births maternity transformation patient and public involvement strategy, by Emily Ahmed, Participatory Appraisal Trainer and Facilitator, whose specialises in ensuring diversity in engagement.

Mary Newburn is a freelance public involvement consultant with a background in maternity evidence, public health and health services research. She has learned about PA approaches working alongside Emily Ahmed to plan and run a community event, and co-producing a PA-based training event. She is patient and public involvement and engagement lead for the maternity and perinatal mental health research theme at NIHR ARC South London.

Hannah Rayment-Jones is a midwife and NIHR Advanced Research Fellow in the Department of Women and Children's Health at King's College London. Her research focuses on maternal and newborn health inequalities and she is committed to ensuring the patient voice is heard to improve research and the development of safe, equitable service.

Jane Sandall is a Professor of Social Science and Women's Health at King's College London, and Leads the Maternity and Perinatal Mental Health Theme of the ARC South London. She is an NIHR Senior Investigator Emerita.

Zoe Vowles, is research midwife and pre-doctoral clinical academic fellow at Guy's and St Thomas' NHS Foundation Trust/King's College London and a researcher in the ARC South London's maternity and perinatal mental health theme.

Appendix 1 – Marketing poster

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Lambeth Parents' Lunch

Tell us about your community and having a baby

Are you a pregnant woman/parent who lives in Lambeth, or close by?

Date: Thursday 9 March, 10.30am to 12.30pm

Location: Myatts Field North Centre, 24 Crawshay Road, London, SW9 6FZ

We want to hear about what helped you have a positive experience when you were having a baby (family and friends, community services and support, maternity professionals and services), what was not OK, and what changes you would like to see.

- Join a small, informal group of pregnant women/people/mothers/parents.
- Children are welcome. There will be space to play by parents and a creche will be available.
- We are offering each woman/family a £25 shopping voucher as a thank you.
- There will be a hot lunch at 12pm.

Please note: We are aware that some of the conversations may trigger memories. Tell us if there is any way we can help to make this session feel safer for you.

To book a place: text Vita Moltedo 07779 087310
email vita.moltedo@kcl.ac.uk
with the following information:

- Name
- Mobile number
- London borough where you live in
- Number of children attending
- Age of children attending
- Number of creche places needed
- Dietary requirements
- Any allergies
- Languages spoken
- Is translation needed?
- Where did you hear of the Lambeth Parents' Lunch?

Appendix 2 – Event timetable and activities

Team	**Peer researchers: Rachael, Vita, Zenab, Mary** **Researchers: Kaat, Zoe, Zahra, Hannah, Abby**	**Who**
9.30	**Arrive/open up/set up** – tables, washing line, register travel expenses, socio-demographic forms, consent forms, creche, posters up outside/in street, liaise with Herbie, help with mats/toys, buy & put out snacks/milk/ tea/coffee	All
10.00	**Creche** – staff: Zainab Adam Abdi and Imane Meftah	Mary
10.30	**Registration** – Participants arrive (Register; email addresses. Forms: consents; socio-demographic; expenses. "Vouchers organised through Amazon, you will be notified by email") Check creche registrations/numbers	Vita and Zenab Hannah and Abby assisting
10.30	**Meet and welcome, offer snack and hot drink, introduce to creche**	Rachael, Zahra, Kaat
10.45	**Ice breakers and intro to the session**	Rachael Anti-sab: Hannah (throughout)
11.00	**Washing line activity** – for all	Vita to lead with Abby, Zenab, Zoe assisting
11.15	**People and places activity** – 2 tables / cards	T1 Mary & Zenab with Zoe notetaker/observer T2 Vita & Rachael with Zahra notetaker/ observer
11.35	**Spider diagram activity** – 3 tables / flipchart sheets	T1 Mary & Zenab with Zoe notetaker/observer T2 Vita & Hannah with Zahra notetaker/ observer T3 Rachael & Abby with Kaat notetaker/ observer
11.55	**Beany counter** on Spider diagrams, 6 stickers each	Zenab with Rachael, Vita, Zahra assisting
12.00	**Lunch**	All
12.30	**Participants leave / Team debrief**	All
1.00	Team: clear/tidy hall, wipe down all equipment. Liaise w Herbie/return equipment to Liz Atkinson. Leave.	All

Appendix 3 – Example of an activity briefing

Washing Line Activity

Required

1. String

2. Pegs

3. Post-its of 4 different shapes and colours (1 different shape – or colour - for each question)

4. Smiley face / sad face /neutral face – possibly laminated (Vita)

The activity

Questions about chronology of experiences from early pregnancy to motherhood:

1. How did you feel when you first saw a GP or midwife early in your pregnancy?

2. Was your birth how you were hoping?

3. What was your experience of feeding your baby?

4. How did you feel in the first month after your baby was born?

The facilitator and assistants' roles

● Facilitator will take each question in turn and ask participants to peg a piece of shaped paper on the washing line in a place to represent their experience. 1 different shape – or colour – for each question

● There is no limit to the number of items people can add, but everyone needs to have a turn.

● Facilitator/assistants, encourage people to explain their experiences/views. Ask them to write – or an assistant to write clear, key phrases – on the coloured paper and peg onto the line.

● Observer/notetaker – make a note of any conversations, any observations you make.

● Photograph the washing line.

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