NIHR | Applied Research Collaboration South London

Maternity and perinatal mental health research

Involving diverse communities in research – learning from a co-production training event

"Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge" (NIHR, April 2021)

October2021

With thanks

Thanks to all those involved in this six-month project, January to July 2021, for the passion, energy and hours they have dedicated. Thanks to our funders, the NIHR for supporting patient and public involvement and engagement (PPIE) in research, and to NIHR ARC South London for its work on PPIE, including the Equity, Diversity and Inclusion Working Group and the communications team for all their support. Special thanks to the communities and service users who have volunteered their time and insights to help inform the work of ARC South London and the wider academic communities with whom we hope to share these insights and recommendations.

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Contributions

The report was written by EA and MN. The whole team planned the training event. EA created the Jamboard. EA, VM and KU created a promotional video. EA, VM, KU and MN facilitated the training and coded and summarised the workshop outputs. AE, AA, EA and JS presented at the training. MN gathered post-event feedback. AE and MN secured the funding. All the authors contributed ideas and approved the final version.

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1. Introduction and aims

In April 2021, the patient and public involvement and engagment (PPIE) group for the maternity and perinatal mental health theme at the NIHR Applied Research Collaboration (ARC) South London co-produced a training event to explore barriers, issues and solutions to community involvement in research. The training used participatory appraisal (PA) methodology and brought together researchers and community members.

The key aim was to explore how researchers can be more effective in involving diverse communities in maternity research. Some of the learning from the event is also relevant to ensuring greater diversity and equity in research participation (ie who is studied and how they are involved), and research engagement activities (ie how we share knowledge and engage with the public about research findings) (NIHR, 2015).

This report includes our values, the methodology used, a description of the training, organisers' reflections, participants' feedback, and key themes and recommendations arising from the event.

The report is aimed at researchers, funding bodies, healthcare practitioners, maternity and perinatal mental health service users, community network leaders, activists, parents and other members of the public. We hope this will facilitate mutual understanding between researchers and communities, contributing to greater involvement and participation in research.

The group that co-produced the training, facilitated by Emily Ahmed, public engagement consultant, included PPIE advisers, PA peer researchers, King's College London (KCL) researchers working in the maternity and perinatal mental health theme, and the PPIE lead. They were:

Agnes Agyepong, recent service user, maternal health advocate, PPIE adviser

Emily Ahmed, recent service user, public engagement consultant, PPIE adviser

Abigail Easter, senior lecturer in maternal and newborn health, deputy maternity and perinatal mental health theme lead at NIHR ARC South London

Vita Moltedo, PA peer researcher, member of Maternity Voices Matter

Mary Newburn, PPIE lead, maternity and perinatal mental health theme, NIHR ARC South London

Sergio A Silverio, research associate in social science of women's health, King's College London

Jane Sandall, professor of social science & women's health, King's College London; maternity and perinatal mental health theme lead at NIHR ARC South London

Katherine Umutoni, PA peer researcher, member of Maternity Voices Matter

Our team for this workshop

Hi I'm Emily Ahmed... recent maternity service user, public engagement specialist... work freelance currently doing some work wit Newham Public Health and Royal College of Midwives.

twitter: @emily_ahmed

I also just started a PhD at Warwick exploring how we can implement co-production in applied health research

Hello! I'm Vita, I am a mother, a service user and I'm passionate about improving healthcare services for all and making PPI a norm.

Always a keen promoter of the Participatory Appraisal research method.

Acti Maternity Voices Matter, the UCL MVP, Patient and Public Involvement adviser to the Maternity and Perinatal Mental Health research theme of ARC & a member of the ARC's Public Research Panel.

Hi! I'm Abby. A lecturer and researcher at King's College London. I co-lead the Maternity and Perinatal Health theme of the ARC south London with Jane Sandall.

Passionate about improving outcomes and experiences for women and new mum women experiencing mental health difficulties, and reducing health inequalities for women and babies.

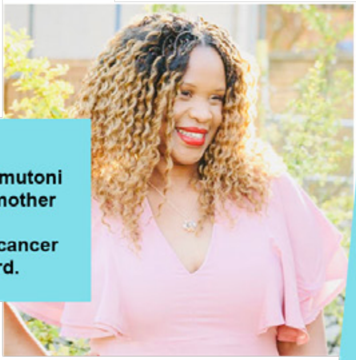
Twitter: @arc_S_Lppi We support patient and public involvement (PPI) in the NIHR Applied Research Collaboration (ARC) South London. Find us https://facebook.com/groups/62958849

Hi, I'm Mary. I lead on PPI&E for the Applied Research Collaboration (ARC) maternity and perinatal mental health theme. Phew, what a mouthful! Research seems to be full of long words and titles.

I'm also now working as a project manager for Best Beginnings charity & Surrey Heartlands ICS (that's NHS+ local authorities).

Hello! I'm Sergio, a researcher at King's College London. I co-ordinate the Maternity & Perinatal Mental Health Theme of the South London ARC with Abby & Jane.

I'm passionate about qualitative methods & women's mental health. I've also just started a PhD in women's experiences of pregnancy loss and perinatal death, here at King's.

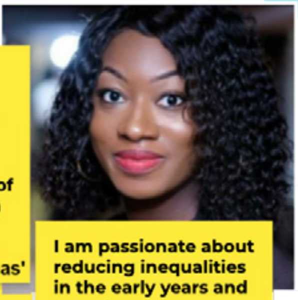


My name is Katherine Umutoni Rwandese mother of three.
I work on a cancer surgical ward.

In the past I have been working as a strengthening communities parenting skills facilitator. I am also apart of the Matenity voice matters research group .

I am an advocate for change for unheard voices in Matenity services and also passionate about improving better care for cancer patients and Matenity services.

My Motto is if you're passionate about what you do, do not be afraid to challenge existing practice if you think it can be improved.



Hi I am Agnes, a mother of 3 and maternal health advocate. I currently work at the national charity Best Beginnings as Head of Engagement and am the Maternity Voice Partnership Co Chair at Guy's and St Thomas'

I am also the founder of the GLOMAMA Awards, a prestigious award which encourages mothers to rediscover their "Glow" after pregnancy.

I am passionate about reducing inequalities in the early years and ensuring that marginalised voices are centred in research done about. My philosophy is "nothing about us, without us".

2. Our values

The maternity and perinatal mental health theme at ARC South London has a patient and public involvement and engagement (PPIE) strategy group. Our goal is a culture of active PPIE in maternity and perinatal mental health research, where research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. We aim to develop strong links and networks with individuals and organisations to ensure that Black, Asian and minority ethnic communities are at the centre of our research in south London, and that those living in poverty, facing disadvantage or with socially complex lives are well represented and supported to be involved in research.

PPIE strategy

The strategy group's purpose, agreed in November 2021, is to:

- Advise on ways of working towards our goal, for example, by co-producing agreed values and good practice for collaborative, partnership working
- Promote diversity and inclusion in research, among researchers, research participants and stakeholder advisers
- Model good practice and share, promote and occasionally provide guidance on PPIE matters, from the design and funding application stages to analysis, writing up and sharing research findings
- Identify suitable training on PPIE and co-production collaborating with ARC South London colleagues, and other ARCs and organisations leading on PPIE, and look for sources of funding for PPIE training.

Diversity and inclusion

We use Health Education England definitions of inclusion and diversity.

"When we talk about 'diversity', we mean making sure that we recognise, respect, value and celebrate the differences that everyone has, as well as leveraging the opportunities that different people bring to the work that we do" (Health Education England: Diversity and Inclusion Our Strategic Framework 2018-2022:8)

"We define 'inclusion' as taking an approach to our work where we consider people, their diversity, their preferences and their abilities. It is about creating a workplace where everyone can be themselves and feel that they can contribute their views, which will be valued" (Health Education England: Diversity and Inclusion Our Strategic Framework 2018-2022:8).

We also follow NIHR guidance on diversity and inclusion, and their 'things to think about'. The following is their list of key points, each with a short example of the ideas they convey.

1. **Check your power** – Researchers and the public have unequal power in a research context. "Try to understand power relationships within your context, your role and how to operate to promote inclusion."
2. **Value the people you work with** – "Recognise and nurture the people who become involved in research."
3. **Use language carefully** – Avoid jargon. Use glossaries. Agree together on use of language.

4. **Consider inclusive locations** – It's possible to meet anywhere. Decide together what feels right.
5. **Listen and seek agreement** – Practice active listening; always give feedback and explanations.
6. **Get from A to B, perhaps via Z** – "Be flexible and allow time to find the route together. Consider structural constraints as well as value the commonalities and differences in your partnership. Be prepared to have some discussions about sensitive subjects."
7. **Collaborate** – "community organisations have a huge amount of knowledge and expertise about public involvement. … eg ethnic minority groups, asylum seekers, etc. Understand and work with organisations to enable communities to lead and own their involvement in research."
8. **Invest in the workforce** – Support people from diverse backgrounds to enter the research and involvement workforce.
9. **Commit to a relationship** – Nurture people who get involved. Acknowledge that PPI/researcher relationships may not always go smoothly but long-term relationships can flourish, and will end.
10. **Evidence, evaluate, share, reflect** – Be curious about the public involvement process: "Capture, evaluate, publish if you can." Theory of change approaches may be useful.
11. **Act small, think big** – "A small social change can make a big difference. Supporting researchers and members of the public to develop confidence, learning and skills is valuable for further change and growth."
12. **Be values-based, socially innovate** – Avoid any kind of 'tick-box' approach. Think about values and outcomes. "Support the ideas of the diverse and the many, not the few."

Health inequities

"Equity is the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically. Health inequities involve more than inequality with respect to health determinants, access to the resources needed to be healthy or health outcomes. They also entail a failure to avoid or overcome inequalities that infringe on fairness."
World Health Organization (underlining added for emphasis)

A recent commentary in the *BMJ* warns that traditional methods of quality improvement "can maintain or worsen health inequities across subpopulations" (Hirschhorn, *et al*, 2022) unless action is taken to address inequities specifically. In the ARC's research and involvement activities, we aim to address these issues of power inequity and disadvantage directly by asking pertinent questions and building relationship with relevant individuals, community networks and organisations.

Confidential enquiries into maternal and perinatal deaths have found consistently that Black and Asian women and others in minority ethnic groups in the UK, and those living in deprived areas are more likely to experience mental illness, to lose their babies, or die during or after their pregnancy (Knight, *et al*, 2019; Draper, *et al*, 2019). The Covid-19 crisis has exacerbated persisting vulnerabilities and the socio-economic and structural disadvantage faced by many communities (Fernandez Turienzo, *et al*, 2021).

It is the priority of the ARC's maternity and perinatal mental health theme to address poorer outcomes for women and babies living in areas of social disadvantage and from Black, Asian and minority ethnic groups in south London (Fernandez Turienzo, *et al*, 2021). ARC researchers are asking:

- What are the reasons for this?
- What models of care can help?
- How can care and outcomes for women with mental illness be improved?

Involvement of women, communities, and relevant organisations in answering these questions is vital. Our researchers want to build relationships and seek advice on community knowledge, personal lived-experiences, attitudes and beliefs from the beginning of research studies. They want advice on how best to engage and involve people. For people suffering inequities to trust researchers, and for community members to be willing to prioritise research involvement or participation, specific values and practices need to be adopted, and listening and learning needs to be active and ongoing. We recognise the need for reciprocity (NIHR, 2015 and 2021) in which both parties are considered, respected, valued and rewarded, in ways that matter and make sense for them.

We consider co-production values and practices as important for researchers and community members to be able to work together on more equal terms. Co-production involves "sharing power and responsibility from the start to the end of the project, including the generation of knowledge" (NIHR, 2021). A range of different methodologies are consistent with co-production. We chose to use participatory appraisal.

Who attended the joint training event?

In keeping with our values and commitment to diversity and inclusion, we recruited from our PPIE network, which includes women from a range of ethnicities. The event was attended by 29 people – 14 community members with experience of using maternity or perinatal mental health services and 15 researchers/policymakers. The community members were Black (9), White European (2), White British (2) and Mixed ethnicity (1). We were not able to identify the ethnicity of the researchers who attended but are working on the most appropriate way to do this, respecting confidentiality and data protection requirements.

3. Methodology

We have followed a process of reflective co-production throughout the planning, delivery and writing up of the training project, and we have used participatory appraisal methods of working.

Participatory appraisal (PA) is a community-based approach to qualitative action research that values people as “experts in the own lives”. It actively engages communities to identify, explore and find solutions to issues that affect them. This peer-led research methodology often uses visual and creative tools such as mapping, timelines and causal impact activities that enable people to overcome barriers to participation, and explore their experiences, feelings and opinions. It has been used extensively in international development, health and education. Robert Chambers, who developed the method through application of his respectful values and empirical testing in rural areas, said:

“The task for outsiders became to hand over the stick, to empower local people, to enhance their confidence, to enable them to define, express and analyse their reality, and not to reflect that of the upper (outsider).”

Participatory methods and values are designed to be inclusive and empowering. They start from the position of needing to address inequities and an imbalance of power. Co-production is possible when researchers and the public work together and share responsibility from start to finish.

In April 2021 the NIHR published new guidance on co-producing a research project, highlighting the key principles as:

“sharing power”, “including all perspectives and skills”, “respecting and valuing the knowledge of those working together on the research”, “reciprocity” and “building and maintaining relationships”.

These are all values that the ARC’s maternity and perinatal mental health PPIE group aspires to, and we have endeavoured to uphold and embody them within this project. It has been an iterative process of learning, reflection and development for all involved.

In response to Covid-19 pandemic, we ran the training session virtually using Zoom and Google Jamboard, over 2.5 hours. The session activities were planned, and facilitated by experienced PA peer researchers Vita Moltedo, Katherine Umutoni and public engagement specialist and PA trainer Emily Ahmed (all of whom had used maternity services) and Mary Newburn (the PPIE lead for the ARC’s maternity and perinatal mental health theme).

4. Nothing about us without us

The service user-led, joint training project came about as the result of a series of prior developments.

The ARC's maternity and perinatal mental health theme has a well-established, pro-active, PPIE culture. We have developed PPIE structures and practices. These include a PPIE strategy group, co-chaired by a service user advocate and a researcher; a 30-strong network of London service users, community activists and charity contacts, and four-monthly meetings of the PPIE Advisory Group, to which members of the network are invited.

We value diversity and inclusivity. Our initial ARC online engagement meetings in June 2020, were attended by seven Black Londoners; the recent advisory group meeting was attended by six Black women and six white service users, including one of white European origin, and 10 researchers.

During the October 2020 meeting, Agnes Agyepong presented on relationships between researchers and policymakers and Black, Asian and minority ethnic (BAME) communities. Emily Ahmed and Vita Moltedo presented on their use of participatory appraisal in engaging diverse communities within health research. Researchers and academic staff discussed the challenges of reaching and building trust with diverse communities, in particular Black families and those living with social complexity or in deprived communities. Service user representatives backed Agnes' call:

"a paradigm shift not only in engagement, but also within the research communities' approach" (Agyepong, 2020).

In response, we agreed to seek funds for a training workshop for service users and researchers to do further learning together, using PA methods, and to write-up the emerging practical learning and recommendations.

A successful application was submitted to the Public Engagement Small Grants Scheme.

The training was grounded in Agnes' blog. At the start of the workshop, she presented on her experiences and reflections on why Black women are not engaging in research and what can be done to change this. For example, she says:

"Social media as a whole can be a great tool for service user engagement IF the engagement is truly authentic and trust is established. And researchers are missing a huge mark if they are not utilising these platforms properly."

5. Training activities and analysis overview

A project team was established made up of a public engagement facilitator, two PA-trained peer researchers, the ARC's maternity and perinatal mental health theme PPIE lead and three researchers. We planned the training and invited ARC South London researchers and members of the PPIE network to enrol. The aim during the training was to facilitate a series of activities to explore perceived challenges and solutions relating to involving diverse communities in maternity and perinatal mental health research. Some definitions were discussed and a list of acronyms created (see appendix 1).

Co-creation: The project team reflected on previous discussions within the PPIE group and used these to decide on our key areas of interest. We co-created the training plan using a Google Jamboard and some PA tools (see appendix 2). We explored areas of interest and formulated key questions. This enabled the whole team to be equally involved in discussing and agreeing how to explore the need for a 'paradigm shift'.

We were keen to explore:

- How researchers work with diverse communities
- How we share power
- How we overcome barriers to PPIE within research systems.

We were aware that our areas of interest were very wide and that we would not be able to interrogate them all within one workshop. We decided to use more open and flexible research questions so that the participants would be able to help shape the direction of focus. The peer-researchers met again to discuss our main research training question. It became: 'What are the main barriers and solutions to engaging with diverse communities within research?' We planned which PA tools to use to facilitate discussion about participants' perceptions, lived experiences and ideas.

Introductory video: All participants were sent a short video that explained the session aims, who would be attending and what to expect from taking part in the session.

Workshop: We decided the most accessible way to run the workshop would be via Zoom. This is a platform the group were familiar with and allowed us to plan the event within Covid-19 restrictions. Within the 2.5 hour workshop we introduced people to the Jamboard (a digital whiteboard) and facilitated an introductory ice-breaker in which people described what was important to them about engaging with diverse communities.

We had three short presentations:

- an introduction to the Applied Research Collaboration (ARC) by Dr Abigail Easter
- an introduction on views from the Black community by Agnes Agyepong
- an introduction to participatory appraisal by Emily Ahmed.

We used a range of PA tools designed to encourage participants to explore and reflect on their experiences of involvement in research. Participants worked in small breakout groups to explore perceived barriers using spider diagrams and fed back key points to the larger group. After a further short talk by Professor Jane Sandall, maternity and perinatal mental health theme lead, they then identified solutions and top tips for implementation using an H-Form (see section 6, below).

Data and analysis: Each breakout room was facilitated by a peer researcher who made written notes on the discussions. Participants shared their thoughts verbally and wrote down key points on digital post-it notes. Each group then summarised their key points and discussions back to the main group (these were recorded and transcribed). The peer research team transcribed the post-it notes into Word and began to pull-out key themes and order proposed solutions. Using a basic process of thematic analysis we reviewed the data, looked for patterns, and generated category codes, which we used to group similar data. The codes were not pre-set; they developed as we worked through the grouping and ordering process. We met to discuss the codes and emerging themes twice, gradually refining them as we applied them to all sections of our data.

Dissemination: We were keen to share our learning in accessible formats that can be used in a practical way by researchers and community members. This project report will be published on ARC South London's website, shared with all involved in the workshop and our wider networks. We have published a blog. We are also hoping to create visual infographics on #diversityinmaternity research top tips; our training/research methodology; and the themes and issues that emerged.

6. A closer look at participatory appraisal tools

When planning the training workshop, the peer researchers decided to use the spider diagram and the H form, two participatory appraisal (PA) tools, to facilitate the participatory activities and discussion, focusing on:

1. What are the main barriers to engaging with diverse communities?

2. What are the potential solutions?

3. How could these be implemented?

The spider diagram

The spider diagram is an effective tool for identifying barriers and potential solutions. The topic discussion 'barriers to engaging with diverse communities' was written in the centre. Participants worked in four small groups, with separate groups for researchers and community members, initially.

We decided to split the groups at the outset so that both groups of participants would feel able to speak as freely as possible. The groups discussed the topic and used yellow post-it notes to write perceived barriers based on their lived experience.

Later, each group swapped their diagram with a different group (researcher-identified barriers going to community members, and community-identified barriers going to researchers). The groups then began to work on exploring possible solutions to the barriers using green post-its.

Spider diagram – an illustration of barriers and potential solutions

The H form

The H form is often used to gather opinions about a topic and suggestions for action. We used it to explore ways of implementing some of the solutions suggested through the previous spider diagram activity.

In the final small-group session of the training event, participants worked in small mixed groups of researchers and community members. Combining the groups at this stage enabled the sharing of ideas and views between perspectives and facilitated joint working. Participants discussed ways of working and wrote ‘do’ and ‘don’t’ tips on post-it notes. Facilitators encouraged discussion on unanswered questions and areas that needed more exploration.

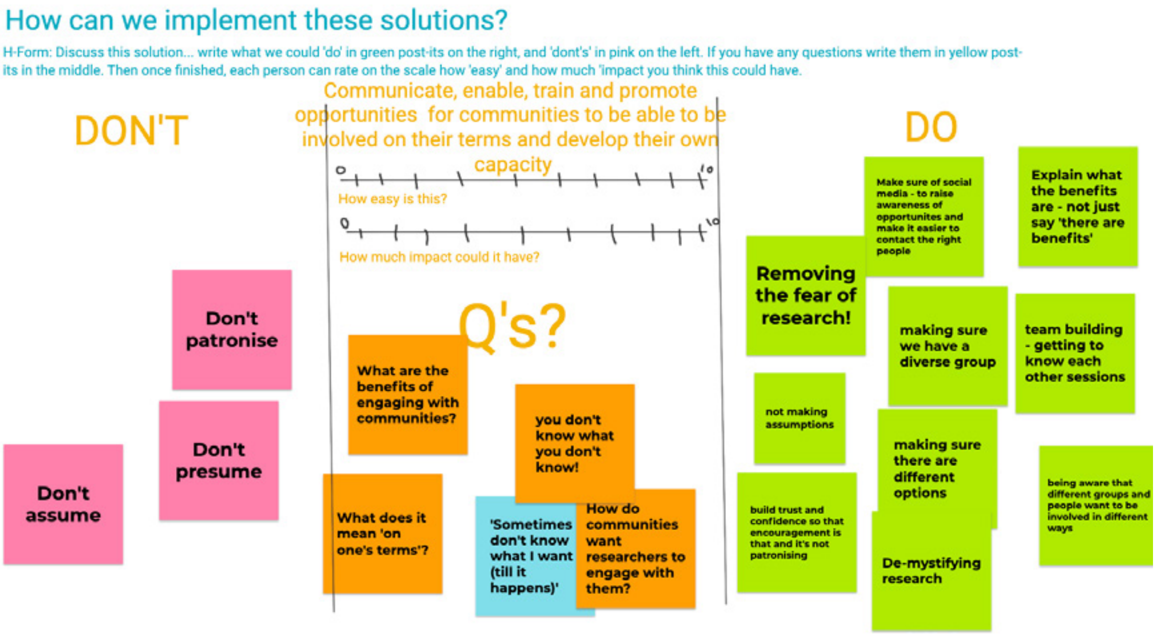
Participant-led and solution focused

The methodology of PA is very much about respect and empowerment. Facilitators use active listening and reflect back on what has been raised with affirmations. Participants are given opportunities to make choices and to work on issues that matter to them. The work is practical and solution-focused, once barriers have been identified.

Participants began to explore solutions on:

- Ensuring participants are at the core of research and co-produce at all levels
- Communicating, enabling, training and promoting opportunities for communities to be involved on their terms and to develop their own capacity
- Increasing social capital and giving more opportunities for people to develop and progress
- Making sure research teams are diverse (academic and community researchers) and developing capability and capacity of professionals
- Planning the right amount of funding for working with community groups and remuneration for those involved.

The H form – an illustration of dos, don’ts and questions



How can we implement these solutions?

H-Form: Discuss this solution... write what we could 'do' in green post-its on the right, and 'dont's' in pink on the left. If you have any questions write them in yellow post-its in the middle. Then once finished, each person can rate on the scale how 'easy' and how much 'impact you think this could have.

7. Emerging themes

The following themes emerged, and the potential solutions worked on by mixed groups of researchers and community members include a range of possible changes from major structural changes to quick-win, immediate, practical actions. Some codes occurred multiple times, such as “respect” or “adequate funding”. Some themes were broad and we have divided, showing sub-themes. We have included illustrative quotes from post-its and discussion. Quotes have also been transcribed from the recording.

1. **Community**
2. **Communication**
3. **Diversity in research teams**
4. **Funding: Structure and capacity, and remuneration and recognition**
5. **Power imbalances**
6. **Trust and respect**

Some of the midwives, researchers, obstetricians, gynaecologists, service users and service managers from across England, who gathered at an ARC event in July 2019 to discuss the implications of our NIHR-funded research for how maternity care is delivered in England.

7.1 Community

> **We need to prioritise research questions which are important to local communities… not just driven by funding bodies. And I guess that means making sure there are conversations, processes, to really understand what communities think are important.** (workshop participant)

Throughout the workshop one of the main messages was the need to put community voices and interests first. We should ensure that service users are involved at the earliest stages of research and have continued involvement all the way through the process (designing and applying for funding, recruitment, analysis, writing up and dissemination). Being seen to value the involvement of communities through actions – putting them at the core of everything we do – demonstrates our respect and commitment. Involvement needs to be at the community members' level of interest and meet their needs.

There was concern that 'top-down' research priorities are not necessarily the same as community priorities. We need to avoid "parachuting in" and "mining information". The group explored whether new evidence-based information, or other products from research, that support health and wellbeing across communities, could be shared in creative ways. This might encourage people to be more willing to take part in research.

Recommended actions:

- **Prioritise the community; ask what is important to relevant groups and individuals.**
- **Budget for a PPIE lead to work with researchers and community members to develop good practice in involvement and support co-design or full co-production.**
- **Think reciprocity. Can you build community research capacities, offer mentoring and support?**
- **Advocate for community-led research projects with training for peer researchers.**

7.2 Communication

> **Technical or formal language being used, which works for ethical approval and might score highly for 'respectful' can seem distant and cold and therefore either nothing to do with me, or positively alienating"** (workshop participant)

It is important that we improve our communication so that it meets the needs and interests of those we are trying to reach. Workshop participants discussed the importance of spending time considering which are the most appropriate places, formats and social media platforms to use in order to connect with the communities we are trying to reach. For example, for recruitment to studies, Instagram is important for younger adults. It is important to explore which digital platforms are popular with the community you are trying to reach, to seek advice and work with community contacts.

Community members shared their experience of being given information sheets, payment and consent forms that were too long, not user-friendly, and that created a barrier to people's involvement.

Consulting relevant community groups and charities about levels of digital access, ways of overcoming barriers is important. These may include budgeting for small but significant financial costs, such as additional data-usage; the need to supply mobile phones, iPads or community access to digital resources; the need for hard-copy documents, interviews and/or community-led word of mouth information. Also consider levels of literacy and language barriers, cultural appropriateness, and the need for written translation, or audio and video-based information - approaches that can be more inclusive for diverse groups of people.

Recommended actions:

- **Support accessibility by ensuring information sheets, and payment and consent forms are short and written in clear language; support digital access.**
- **Push back or advise university ethics committees about community advice on communications**
- **Get advice on which social media platforms to use to connect with the communities we are trying to reach. Instagram is currently widely used by young adults.**

7.3 Diversity in research teams

> **Natasha Smith, Founder of The Women's Health and Wellbeing Initiative ... brought to my attention that a fund to research Covid and BAME communities awarded £0 from a pool of £4.3 million to Black academic leads, despite Black academic leads applying to the fund.**
> (Agnes Agyepong, blog)

Researchers

There were discussions around the problem of research teams lacking diversity, particularly ethnic diversity, and being culturally set apart from the communities they are researching as a result. This can create a sense of 'them' and 'us', which felt wrong to both researchers and community members. Researchers who did not have the same lived experiences or shared identity as the group they were researching, expressed discomfort, even fear of potentially causing offence, and worried about not using the right language when reaching out to communities. There was recognition that this presented challenges for public involvement in research, for research recruitment, and for research participants to feel their lived experience was reflected in research tools or feeling comfortable to express themselves in interviews.

Structural barriers, such as lack of career development opportunities and funding being channelled in traditional rather than innovative ways, were acknowledged. Given the ethnically diverse workforce within the NHS there are clear opportunities for creating fast-track research development opportunities to expand research capacity of people from Black, Asian and other minority ethnic groups and diverse cultural backgrounds.

As well as providing creative, more inclusive opportunities for health professionals and early-career researchers to develop and progress in research, involving more people working explicitly from a service user perspective to carry out peer research or study for a PhD would support principles of inclusion and diversity. Sharing information about existing opportunities as well as extending funding for community-led research and proactively offering academic support would be beneficial. Further engagement is needed, so that the public know more about research and researchers in their local area. Community-based learning, training and co-production research-planning events would all raise awareness of research opportunities, research methodology and ethics, and help to create the conditions for developing mutual regard and trust.

Community involvement

> **There is a problem with just using the same groups over and over again, even if that group is quite diverse, it's still the same voices being heard.... How do you reach and include fresh voices whilst also using the groups and the relationships** (workshop participant)

Where researcher teams already have good connections with community groups and individuals it is important to both sustain and develop those relationships, and to continue extending reach and involving new people. The group discussed the need to "keep things fresh" and not to repeatedly bring in the same people, which often results in the same voices being heard and does not promote diversity.

Recommended actions:

- **Monitor and review the diversity of the research team. Consider how to make the team more inclusive and diverse in terms of protected characteristics, particularly representation of those community groups who are the focus of current research programmes.**

- **Plan and budget for engagement and involvement events, campaigns or recruitment drives. Allow time and flexible ways of involving non-researchers who will have other commitments and priorities.**

- **Plan outreach activities carefully, thinking about appropriate social media and messages, suitable images, warm and engaging language, and teamwork with community ambassadors. Ask: "What's in it for communities?"**

7.4 Funding

> **Money and funding came up... not having the money to do things properly, not having the resources... wanting to do things better, but not being able to do it.** (plenary discussion)

Structure and capacity building

Challenges around funding were discussed throughout the event and in several of the breakout groups. Researchers expressed a concern about not having enough funding or resources to approach PPIE in ways that would enable them to develop positive relationships and involve community members in the design and doing of research. We heard about some excellent examples of building in appropriate after-care for study participants which we felt could be extended to those community members who were advising and working as co-researchers, particularly when the subject is sensitive.

There is a need to ensure that PPIE activities at all levels, in individual studies, within themes, and at institutional level are thought-through, planned in detail and realistically funded. Ensuring that research structures and senior management recognise that PPIE is important and that there are mechanisms for the public, particular communities and service users to be listened to and to be heard, makes a difference. This can help to ensure that training, community involvement, listening events, and implementation of good practice guidance are funded. Budgeting may need to include costs of childcare; personal carers; individual PPIE payments; payments to charities or community groups in an intermediary/ambassador, recruitment, or advisory role; PPIE coordinator costs; translations of materials; and improved communications – including sourcing or commissioning suitable images and active engagement of relevant social media, such as Instagram or Facebook. (Our post-event blog discusses funding.)

Recommended actions:

- **Plan in detail, with a PPIE coordinator as co-applicant and in consultation with relevant charities, community groups and service-user advisers, and apply for appropriate and adequate PPIE funding from the start.**
- **Make explicit all the aspects of work for which funding will be needed and ensure this covers all costs at appropriate rates, using the published guidance and literature on PPIE.**
- **Include budget for team building and 'getting to know each other' sessions, as well as for training in PPIE for researchers and the public.**

Remuneration and recognition

> **I have spoken about my trauma previously in a public domain. I often get asked to be part of research and I challenge them… what's in it for me?… Why are you not saying to me 'When we get the grant, you will be part of the project team'?** (workshop participant)

A central theme within the discussion was around how we 'value' people and their involvement. People spoke of sometimes feeling as if they had been taken for granted and that this contributed to a breakdown in trust.

It was recognised that research funding now often includes some payments for public involvement in design and doing research and/or for research participation in a study. This is essential if we are committed to including diverse groups and breaking down barriers. However, during the workshop we heard that PPIE payments don't always cover all the hours involved in PPIE work, or out-of-pocket expenses, such a travel or childcare, or that people may be asked to cover their expenses and claim later. This can cause embarrassment, isolation, distrust or resentment. Delays in payment of PPIE fees or reimbursement of costs can exacerbate negative feelings. In contrast, involving service users from the outset in planning the PPIE element of the research budget can help researchers understand potential costs, and increase transparency about how funding is spent.

Remuneration and recognition also need to be in place to support both individual community members and groups, social enterprises and charities that are often asked to participate by giving lived-experience advice, sharing their specialist knowledge and assisting communication using their networks.

In addition to monetary payments, we need to ask and listen to what motivates people to participate. We should reflect on and explore what else we can offer. The group gave many examples such as support, training, professional development, access to research papers, and supporting community members to undertake their own research. Involving a range of people and networks in research creates an opportunity for them to 'have a voice'. Being able to influence and participate in creation of knowledge and make new connections or 'communities of interest' is fulfilling and valuable in terms of generating social capital. Research involvement can amplify community voices and support ways for people to progress and develop, so there is potential for genuine reciprocity in the relationship between researchers and the communities with whom they work.

Recommended actions:

- **Keep guidance on PPIE remuneration and expenses up to date and make it easy to claim payments.**
- **Ask what motivates people and explore a range of ways of providing recognition and support.**

7.5 Power imbalances

> **Power imbalances... sometimes we find ourselves in a situation where everybody should be equal but actually there's a power imbalance and certain people feel less important, that their opinions and experiences are less important. That's a big barrier to sharing with trust and sincerity** (workshop participant)

The underpinning principles of co-production and participatory appraisal include finding ways for everyone involved in a process to feel comfortable and relaxed, to have a voice, to be given time to communicate, to be listened to, and acknowledged. Active listening involves making time for everyone to speak one-to-one or in small groups, encouraging speakers with nods and short words that show interest and empathy, and reflecting verbally, using words and phrases to indicate that you have listened and understood. People can practice doing this on non-challenging subjects before moving on to community-researcher relations, health service experiences or research design. The opposite of this is being in a place that feels unfamiliar, uncomfortable or intimidating, feeling there is no time to explore views and feelings or half-worked out thoughts and ideas, and being shut down, ignored or talked over.

It may be helpful for research groups to spend some time thinking about and discussing power imbalances, but it may also be uncomfortable. Differences in status and influence exists among researchers as well as between researchers and the groups they are researching.

Think about how we can share power equitably. Make explicit the needs of different stakeholders within a research process and think about how these can be addressed while applying equity, diversity and inclusion principles. Agree together how people will each contribute, and the limitations. There may need to be compromises, such as agreed time deadlines and how final decisions are taken. Discussing these openly and agreeing these together may be a step forward.

Recommended actions:

- **Think about power imbalance. Who doesn't have power and influence? Explore ways to address power imbalances between organisations, researchers and communities, and within the research team.**
- **Practice active listening.**
- **Think about diversity, inclusion and equity. Consider protected characteristics; how you relate to these groups and involve relevant people?**
- **Be explicit about what the PPIE working arrangements are going to be.**

7.6 Trust and respect

> **We also spoke about trust being very, very important, and providing information and representation at all levels of decision making, as well as adequate funding** (plenary discussion)

Many of the key themes and challenges raised in the workshop impacted on the quality of relationships between researchers and the public. The need to build trust between researchers and communities in a proactive and sustainable way was one of the central themes that ran throughout our conversations. There are many reasons for wariness or lack of trust. Examples included previous negative experiences with organisations or individuals in authority, the history of Black women being treated badly by researchers, particularly in the United States, the legacy of slavery and colonialism and growing activism in response, research fatigue, concerns about being taken for granted, and fear of being observed and judged by the social care system.

Recommended actions:

- **Make a point of being respectful and appreciative.**
- **Work out collaboratively ways of working together with reciprocal benefits.**
- **Build trusting relationships with key influencers within communities and listen to their advice.**
- **Support active development and doing of research by community members.**
- **Ask yourselves are we sharing power? What might we do differently?**

8. Reflections and feedback after the event

Immediately after the participants had left the online training forum, the organisers reflected on the training and shared their views on what had gone well, the extent to which all participants seemed comfortable and engaged and what might be done differently another time. This reflection is part of PA practice. Generally, both researchers and service users felt that the event had worked well. We acknowledged that we had overlooked the need for a hashtag for social media in advance but felt it worked well that the group members created their preferred hashtag for tweeting about the training and its ambition: #diversityinmaternity research.

It was agreed that MN would draft and circulate a feedback form for participants to capture their reflections and feedback. Service users for whom there was not already a diversity monitoring form on record were asked to complete one.

Nine people returned feedback after the event. Of these, six were people who identify as having lived experience relevant to maternity and/or perinatal mental health (PMH) and use of maternity or PMH services, and three were participating primarily as researchers. Two of those involved in representing perspectives of service users or communities had also worked as researchers.

We asked participants 'How useful did you find the Jamboard for exploring barriers and solutions to diversity in maternity research?' providing a scale for responses from very useful to very limited or difficult to use, and providing an 'other' box and inviting an explanation from everyone.

Seven people said they found Jamboard useful or very useful, and two felt it was a bit limited or difficult to use. One researcher commented: "This is my first experience of using the Jamboard and I thought this was a great way to make an online event more interactive. I felt the session to familiarise people to this new tool at the beginning of the training was very valuable."

We asked participants their thoughts and perceptions about what they had felt at the start of the day were the most important issues around ensuring greater diversity and inclusion in research, and then what they felt were the most important issues on this subject after having participated in the training. We invited them to submit up to three issues (see appendix 3). The responses indicate that everyone, bar one participant, felt that the training changed their perceptions.

Participants were asked what they had found most useful about the training session. Responses included: small group working, "Meeting others and listening to their experiences", and mutual understanding that "We recognise the same barriers and constraints". The icebreaker was valued as it "set the scene very well", and the session enabled researchers and service users to have "healthy honest discussions". It was summed up by one of the researchers:

> "It was very useful to hear the perspectives and ideas of all these different people/groups and be able to look at solutions together".

In terms of what should be done differently if we held joint training on for #diversityinmaternity research in future, participants wanted more time for discussion as there was so much more to explore and the need for a more worked up 'manifesto' for change; and more researchers to attend similar training so that the awareness of community perspectives could be extended further. There were a few other ideas. One person said: “As someone who is currently pregnant, I would have appreciated more short breaks.”

Motivation to promote diversity in maternity research

We asked the participants ‘What particularly motivates you to promote good practice in diversity in maternity research?’

The responses from service users were direct, thoughtful and moving:

“The negative experiences I have received during maternity care.”

“(Generating) the knowledge to promote safety.”

“I want systems to change so service users don’t have to. Voices from within the system at all levels need to be heard and representation needs to shift, from the top.”

“Desire for fairness. How we bring children into the world often involves cultural factors; it’s so important to be aware of them.”

“I understand the meaning of active participation in decision-making; and how the outcomes of decisions affect people. That is why I want to ensure that more people, from a range of backgrounds (especially the under-represented groups), take part in maternity research. Developing and promoting good practice in this area is key to achieving this objective.”

“I am a mother. The maternity space directly impacts me. I am also a leader within my community of mums, and this affects them. Finally, the research in maternity will eventually impact the future of my children.”

The researchers said:

“I feel strongly that promoting good practice in diversity in maternity research is important to make sure research is meaningful, that it meets the needs of families and communities, and will lead to improvements in the safety and quality of maternity care.”

“Promoting diversity in research ensures that the outputs are more robust and useful.”

“We need to serve our community from our research and not only focus on what we find interesting (which may not be of interest or issue to our community!)”

9. Summary and conclusion

There is a growing body of evidence on the importance of involving service users and the wider public in the planning and design of research to ensure it is relevant, acceptable and well-tailored to the needs and experiences of service users and the wider public. Community groups, social enterprises, charities and individuals are keen to be involved in research, and to ensure that they and their children benefit in the longer term.

Valuing and strengthening relationships between researchers and patient and public contributors has been identified as important element of successful PPIE in research (Wilson, *et al*, 2015; NIHR 2015 and 2021). We felt there was considerable mutual learning that researchers and PPIE advisers could share if they worked together more closely (Agyepong, 2020).

This training event, co-designed by a group of community members and researchers, with equal numbers of researchers and community members taking part online, fully involving Black women and minority ethnic groups, has worked well. It was facilitated by a public engagement specialist using participatory appraisal methodology and activities, with trained PA peer researchers and the PPIE lead for the theme leading breakout group activities. We would recommend commissioning similar, co-produced, PA training events to others.

Jessica George and her baby Storm, at an ARC involvement and engagement in maternity research event in south London in July 2019. At the event, Jessica spoke about her experience of a new model of maternity care in Lewisham, in which women who are likely to give birth prematurely receive continuity of care from a team of midwives working with a specialist pre-term birth clinic (the POPPIE trial).

Challenges in community involvement and ways forward

The training surfaced challenges in community involvement in research and participants collaboratively generated potential solutions or ways forward.

In summary, these were:

- **Communities – Build trust and create partnerships with diverse communities**, involve them and their interests when setting research priorities. Provide opportunities for communities to be involved on their terms and develop their own capacity. Ensure appropriate diversity and that the relationship between researchers and community members is based on the value of reciprocity.

- **Communicate – Work on ways and means of communicating more effectively** (eg. appropriate language and formats, images, social media, community ambassadors). Seek advice from communities and those with PPIE expertise on how to do this.

- **Diversity in research teams – Address the diversity and representation of relevant communities within your research team**, and engage with the populations you wish to serve.

- **Funding – 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. Include funding for PPIE leadership and capacity building to involve, train and build relationships, as well as appropriate payments for community groups and charities, individual service users working on PPIE members, and research participants, and costs for other benefits.

- **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.

- **Trust and respect – Build trust by actively demonstrating regard for people and communities**, and by committing to fairness and enhancing community wellbeing., and commitment to fairness and wellbeing, is fundamental. Reflect on how research involvement relationships and opportunities can contribute to building social capital. Strive to create growing opportunities for Black, Asian and minority ethnic individuals, network leaders, online groups and community organisations to develop and progress through their involvement and engagement in research.

10. References

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Appendix 1 **Definitions and acronyms**

A list of acronyms and definitions was created as part of developing shared understandings.

Definitions

Community engagement: Where there is a working and learning environment shared by communities and community members with researchers before, during, and after research based on power sharing, maintenance of equity, and flexibility in pursuing goals, methods, and time frames.

Community/peer researchers: Service users or members of the community that have been trained in participatory action research.

Involvement: Where people are actively involved in doing research or designing research projects and they advise research organisations.

Participation: Where people take part in a research study.

Engagement: Where information and knowledge about research is shared with the public.

Inclusion: This is about taking deliberate action to meet the needs of different people and to promote environments where everyone feels respected, valued for who they are and able to achieve their full potential.

Diversity: Means understanding that each individual is unique, respecting and valuing all forms of difference. People vary in all sorts of ways which may not always be obvious or visible. These differences might include race, ethnicity, culture, belief, gender, sexuality, age and social status, ability and use of health and social care services.

Acronyms

ARC – Applied Research Collaboration
EDI – equality, diversity and inclusion
GSTT – Guy's and St Thomas' NHS Foundation Trust
KCH – King's College Hospital NHS Foundation Trust
KCL – King's College London
MPMH – maternal and perinatal mental health
MVP – Maternity Voices Partnership
NHS – National Health Service
NHSE – National Health Service England
NIHR – National Institute for Health Research
O&G – obstetrics and gynaecology
PA – participatory appraisal
PPG – patient participation group
Q&A – question and answer
RCM – Royal College of Midwives
RCOG – Royal College of Obstetricians & Gynaecologists
UCL – University College London
UCLH – University College London Hospital
VCSE – voluntary, community and social enterprise

Appendix 2 **Programme for the training**

ENGAGING WITH DIVERSE COMMUNITIES

ARC MATERNITY & PERINATAL MENTAL HEALTH THEME

PARTICIPATORY APPRAISAL

Date: 19 April 2021

Time: 9.45am-1pm

Location: Zoom Meeting ID: 846 5346 7366
Passcode: EjQ245

Please bring a photo of yourself to upload/share on our Jamboard

Agenda items

9.45am	JAMBOARD PLAY AND LEARN (optional) If you're new to Jamboard, join us to play and learn how to use this interactive tool. We'll be using it throughout the session.
10 am	INTRODUCTIONS, PRESENTATIONS and Q&A Bringing together maternal health researchers, voluntary sector professionals and community members Presentations: Abigail Easter, Agnes Agyepong, Emily Ahmed
11 am	BARRIERS AND SOLUTIONS Using a 'spider diagram activity' we will work in break-out rooms and the main group to explore our perceived barriers and solutions to patient and public involvement and engaging diverse communities in maternal health research
11.35 am	Presentation: Professor Jane Sandall
11.50 am	IMPLEMENTING SOLUTIONS Using an 'H-Form activity' we will work in break-out rooms and the main group to discuss some of the potential solutions, creating tips on how to approach this and exploring questions that arise
12.45 – End	SUMMARY, NEXT STEPS, ACTIONS & THANKS Think about next steps and potential actions.

Watch our YouTube video to find out more about what to expect from this session https://youtu.be/CUbvXs5zMs8

Read Agnes Agyepong's blog https://www.arc-sl.nihr.ac.uk/news-insights/blog-and-commentary/service-user-involvement-maternity-and-perinatal-mental-health

Join our Jamboard to take part in activities during the session (if you're new to Jamboard join the session early at 9.45am to learn how) https://jamboard.google.com/d/1x3-qMt5mRoMv9SmKaTRJ8tIXv-btJnBWMI7SK4rpox8/edit?usp=sharing

Appendix 3 Post-event participant feedback

Feedback responses from nine participants - Perceptions of issues around ensuring greater diversity and inclusion in research

	Before training	After training
P1	Communication	Funding
	Continuity	Barriers of past experiences
	Simpler recruitment process	Power imbalance
P2	Trust	Social capital
	Affective listening	Capacity building
	appropriate communication	Trust
P3	The genuine (not tokenistic) involvement of participants in collaborative research	Appropriately rewarding participants for their participation (eg not just travel expenses)
		Communicating research findings in culturally credible ways (ie not always behind a paywall)
P4	Access in terms of seeing you could join	Access in terms of seeing you could join
	Access in terms of it being convenient and made simple	Access in terms of it being convenient and made simple
	Payment in money, not vouchers	Payment in money, not vouchers
P5	Appropriateness of research for the community we serve	The need to remove the “fear” from research
	Being respectful of cultures which I have limited knowledge of	Need to refresh PPI groups to ensure representability
P6	Accessing communities	Funding panels
	(Creating) authentically safe spaces	Different types of reimbursement for PPI involvement
	Representation within research	Keeping communities at the centre of research throughout the whole process
P7	Ensuring participants are diverse and renumerated	Renumeration and ensuring planning for participation is at the point of applying for research (funding)
		Ensuring that relationships with participants is a two-way stream and participants should know what benefits are available to them engaging in research not just the financial benefit
		The them and us feeling within research should be dispelled and both researchers and participants should feel as a team

P8	Building trust with diverse communities and ensuring they can shape (co-produce) and participate in research	Ensuring appropriate funding/remuneration for community members/groups and service users to ensure people can participate and are appropriately funded for their contribution/time/expertise
	Making sure research meets the needs and priorities of those it will impact	Making sure that people from diverse communities can develop and progress in/through research and that their involvement/contribution is appropriately recognised (such as through becoming peer researchers/authorship etc.)
	Making sure people are appropriately remunerated/recognised for their contribution	Making sure research teams are diverse
P9	Ensuring a wide range of voices are included to make sure important issues aren't overlooked due to the researchers' personal biases	Be aware of research fatigue for people involved in PPIE
		Include and consider aftercare for participants when discussing sensitive topics
		Build trust and respect with participants, and where possible, follow up and engage people with the whole research process, from proposal development to discussion of results and impact