

Finding islands of good practice: a public involvement travel guide

Report of a public involvement in research webinar mini-series

NIHR Children's Health and Maternity National Priority Programme

Mary Newburn and Naomi Morley



Illustration by [Storyset](#)

With thanks

The authors would like to thank all those who attended the webinars, both the amazing speakers and the wide range of participants. We would like to acknowledge the generous support of our colleagues at the National Institute for Health and Care Research (NIHR) Applied Research Collaboration South West Peninsula (PenARC), the Applied Research Collaboration Yorkshire and Humber (YH), the Applied Research Collaboration North East North Cumbria (NENC), in particular Felicity Shenton, and the Applied Research Collaboration South London (ARC SL), including the communications team members who helped with publicity, recording and publication of the workshop presentations; as well as members of various public involvement networks, such as the NIHR Children's Health and Maternity National Priority Programme (CHM) Public Involvement Community of Practice, and the ARC SL Maternity and Perinatal Mental Health Public Advisory Group who inspired the work, participated and helped to spread the word about the events.

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Watch online The presentations of each webinar can be accessed at [NIHR Children's Health and Maternity National Priority Programme - Public Involvement webinar series.](#)

Foreword

There is much guidance on involvement and engagement of the public in research (PPIE), but less practical information and opportunities to share experiences. This webinar series on Building capacity in Patient and Public Involvement (PPI) leadership, Equity, ethics and budgeting for public involvement in research and Emotional work in public involvement begins to fill this gap by addressing important topics not normally covered.

The maternity and perinatal mental health theme at ARC South London has really benefitted from close collaboration with the third sector organisations in doing the vital public involvement in research work that we have all been developing during the last decade. Our collaboration with charities, and with public involvement consultants who have backgrounds in the third sector, community engagement and peer research have enabled us to introduce many innovations to our public involvement. This webinar series, created in collaboration with PenARC, has enabled many academics and non-academics to share methods, challenges and learning. I endorse the message that more work and investment is needed to ensure we have the infrastructure to support cross-sectoral working in the future and opportunities for on-going capacity building for meaningful public involvement.

These webinars were clearly very popular and this report is packed with resources. I hope they will be followed up in the future.

Jane Sandall, Professor of Social Science and Women's Health, Kings College London; ARC South London Maternity and Perinatal Mental Health research lead

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Summary

In a collaboration arising from networks of the NIHR Applied Research Collaboration (ARC) Children's Health and Maternity National Priority Programme and ARC South London Maternity and Perinatal Mental Health theme, three online webinars were planned as a pilot to address some of the many practical, unanswered questions about ways to do public involvement and identify the support that researchers and public member co-applicants may need to build capacity in public involvement leadership. The webinar series was designed to be collaborative, allowing supportive peer learning and sharing of experiences in a safe space. Its goals were to build connections, explore the needs of those working in public involvement to improve shared learning and access to resources, and consider practical public involvement issues and solutions.

The series was intended for people with an interest in public involvement in research and services: community members and activists, experienced and early-career researchers, public involvement leads, peer researchers, third-sector organisations (e.g., charities, community interest companies) and any others with an interest, including research funders. The speakers would mostly discuss public involvement in maternity and child health research, but not exclusively so.

The webinars

The titles of the three webinars were:

- Building capacity in Patient and Public Involvement (PPI) leadership
- Equity, ethics and budgeting for public involvement in research
- Emotions in public involvement.

The series included doing peer research and furthering expertise by means of a Community of Practice, the role and experiences of public co-applicants, ways to build capacity in public-led PPIE, learning from a co-produced training event to involve diverse communities in research, the interplay between researchers' intentions and the context challenges of health services research, inclusive trauma-informed research with groups whose needs are complex, including youths with care-experience and mothers who have had a baby removed at birth, and the role of emotions in research and public involvement work.

The webinars were participative with breakout discussion groups. Overall, there was a strong sense that ethical, equitable, and well-resourced public involvement is essential, requiring intentionality, and a genuine commitment to valuing public partners' contributions.

Attendance and feedback

Each of the three webinars was attended by around 50-70 people, which included PPIE leads, individual public partners, academics, early career researchers, health professional researchers, speakers and facilitators. Attendees valued the opportunities that the webinars provided. Around two thirds of those who provided feedback expressed interest in joining a new Community of Practice on public involvement in research. Most attendees wanted access to a shared repository for good practice resources, as well as a way to hear about upcoming discussions and webinars related to public involvement in research. Around three quarters wanted access to recommended training and development initiatives, and to receive alerts about new public involvement publications. Over half felt a Community of Practice could usefully offer them peer support.

Conclusion

There was a clear expression of interest to be part of relevant, on-going networks for mutual learning, signposting, and access to resources. A particular gap appears to be opportunities for public advisers and peer researchers to access support and share their experiences in groups set up specifically for them and their learning and development needs.

We recommend that NIHR and other research funders prioritise funding for public involvement infrastructure.

This is needed for:

- Public involvement in research interest groups, facilitated over time.
- Development of easy-to-read resources and participative learning about public involvement, drawing on evolving expertise.
- Communication about public research involvement opportunities via social media channels.
- Segmented learning opportunities for people with different levels of experience may be useful.

1 Background and introduction

The National Institute for Health and Care Research (NIHR) Children's Health and Maternity (CHM) National Priority Programme leads the development of research in children's and maternal health to drive meaningful change and improve services across England. It aims to enhance both organisational and individual capacities by building and collaborating with experts from diverse backgrounds to generate new insights, identify areas for improvement, and plan for the future.

The CHM National Priority Programme is deeply rooted in a commitment to involving the public and working together collaboratively. Naomi Morley (NM) coordinates public involvement in the CHM National Priority Programme and started a Public Involvement Community of Practice (CoP) as a way for programme partners to share experiences of public involvement, support individual goals and build partnerships to create new learning. Strong relationships were established with members of the public and patient groups, particularly those involved with the ARC South London Maternity and Perinatal Mental Health theme. The CoP highlighted the need to build capacity for effective involvement and engagement of the public in research (PPIE). It noted that the culture of public involvement is still developing, with PPIE efforts often feeling fragmented and disconnected. Both early career and experienced researchers feel that existing guidance does not fully address important practical questions. Additionally, both public members and researchers seek more resources and support for conducting PPIE effectively.

At the annual ARC South London Maternity and Perinatal Mental Health PPIE Strategy Group, in November 2022, members explored ways to strengthen leadership capacity in PPIE and empower community members to take on more active roles in research.

Mary Newburn (MN) and Naomi met through the CoP and the webinar series came about as a result of Mary contacting Naomi in her capacity as CHM Patient and Public Involvement coordinator. They discussed capacity and infrastructure for public involvement, along with Rachel Plachcinski, an experienced freelance public involvement lead with a National Childbirth Trust ([NCT](#)) education and research background. Rachel had spoken at the annual PPIE Strategy Group meeting of the ARC South London Maternity and Perinatal Mental Health theme, about the need for more transparency in public involvement processes and resources, such as network support, accessible training and relevant resources. And while online NIHR resources were considered valuable, people expressed the need for support at

regional and local levels. This included development networks for specific areas such as women's health, or maternity research.

Exploring the problem

There is much intellectual and practical work to be done in taking forward public involvement in research. Greenhalgh and colleagues' review of frameworks for public involvement demonstrated the multiplicity of approaches to PPIE, shaping different ways it is conceptualised and done. They begin by stating that "It is a truth universally acknowledged by policymakers, researchers and research funding bodies that patients and the public should be "involved" in research, though there are different perspectives on what such involvement should look like and why it should happen."¹ They conclude that there are five categories of approaches to public involvement in healthcare research. This degree of variation of perceived purpose and approach may contribute to uncertainties and mixed expectations, as well as a sense of outright conflict or isolation for some. And anecdotally we know that public involvement work and opportunities can feel siloed, with limited resources available to help embed it culturally. MN and NM share a view that adequate infrastructure support is necessary throughout research from the generation and prioritisation of research ideas and application writing stages onward.² The NIHR has published guidance on the role of the PPIE lead in general, emphasising the need for "a named person with appropriate skills and experience".^{3,4} The PPIE lead is responsible for ensuring that public involvement is carried out to a high level of quality and must have "authority to be accountable, represent, manage and embed patient and public involvement in all aspects of the research study/programme". The guidance specifies areas of activity and core values to inform and enable public involvement. Yet, aspects of the PPIE leadership roles can be invisible and lack power typical of gendered, traditionally female, caring roles.⁵ Tensions experienced by PPIE leads can include the complex demands of a role that is administrative, facilitative and involves emotional work,

¹ Greenhalgh T, Hinton L, Finlay T, et al. Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. *Health Expectations* 2019;22:785-801. <https://onlinelibrary.wiley.com/doi/epdf/10.1111/hex.12888>

² Staniszevska S, Jones N, Newburn M. User involvement in the development of a research bid: barriers, enablers and impacts Health expectations: an international journal of public participation in health care and health policy, 2007-06, Vol.10 (2), p.173-183

³ National Institute for Health Research. Definition and role of the designated PPI (Patient and Public Involvement) lead in a research team. 2019. <https://www.nihr.ac.uk/documents/definition-and-role-of-the-designated-ppi-patient-and-public-involvement-lead-in-a-research-team/23441>

⁴ NIHR now encourages use of the longer phrase, Patient and Public Involvement and Engagement (PPIE), which is an extended focus, encompassing both PPI functions and sharing of research findings 'engagement'.

⁵ Mathie E, Smeeton N, Munday D, et al. The role of patient and public involvement leads in facilitating feedback: "invisible work". *Research Involvement and Engagement* 2020;6:40. <https://researchinvolvement.biomedcentral.com/counter/pdf/10.1186/s40900-020-00209-2.pdf>

plus the top-down pressures of expected deliverables inherent in institutional performance managerial systems.⁶ Just as there are many different frameworks for supporting public involvement, multiple approaches to PPIE leadership are needed, reflecting a range of experiences. The role remains under-theorised and little researched; with no recognised qualification.⁵

MN has lived experience as a PPIE leader from a community, third sector, and non-academic background, and was particularly interested in exploring the needs of current and potential of this role. Working closely with academic researchers as an independent freelance PPIE consultant she is aware of the high demand for PPIE advice, executive leadership and facilitation of PPIE groups. She recognises that there is limited capacity but sees huge potential for further development. For this to be realised, awareness must be raised about the different ways that people come into public involvement work, their strengths and their unmet needs.

The jointly planned webinars were intended to bring people together to share good practice, consider practical questions and challenges, and to explore unmet needs. We therefore wanted to engage a diverse group, including established academics, early career researchers, public advisers on individual studies and PPIE leads from different backgrounds, to hear from their experiences and inform our call for further development of mechanisms to provide accessible, relevant information and learning support.

Language and terminology

It is evident that many different words and phrases are used in relation to public involvement in research. We have provided a glossary (page 40) to be clear and transparent.

NIHR used to refer frequently to 'patient and public involvement', abbreviated frequently to 'PPI'. In recent years, however, the funding body has encouraged the use of the longer phrase, Patient and Public Involvement and Engagement (PPIE). This encompasses all PPI functions and sharing of research findings, 'engagement' (see Glossary). We have used the longer abbreviation in this report, however, we generally avoid overuse of abbreviations which can be a barrier for many people. We have therefore used full words as much as possible and tend to use 'public involvement' as an active way of talking about PPIE.

⁶ Papoulias S, Louca-Mai B. ["I am there just to get on with it": a qualitative study on the labour of the patient and public involvement workforce](#). Health research policy and systems, 2024-09, Vol.22 (1), p.118-13.

2 What were the aims?

The Children's Health and Maternity Programme agreed to host a short, cross-ARC, series of online public involvement webinars, led jointly by Naomi Morley (NM), a public involvement researcher and facilitator at PenARC, and Mary Newburn (MN), a public involvement lead with ARC South London

The webinar series was designed to be collaborative, allowing participants to raise questions and to learn from one another. Its goals were to 'build connections, share solutions and create opportunities'. We set out to:

- Create a safe and inviting space for a wide range of contributors.
- Build capacity by promoting knowledge exchange.
- Build networks and create new opportunities.
- Explore the needs of those working in public involvement to improve sharing of learning, access to valued resources and support to solve practical issues, and
- Identify needs of current and potential PPIE leaders from community, third sector and non-academic backgrounds.

3 Webinar planning

Planning meetings were held online with NM and MN agreeing what they could each contribute. NM undertook this project as part of her role as the Children's Health and Maternity Programme Patient and Public Involvement and paid MN's as a freelance service user researcher from the CHM programme budget. PenARC hosted the webinars and NM made the marketing and booking arrangements. The aims, themes, programmes and messaging were co-designed with support from the communications teams at both PenARC and ARC South London who also promoted the events.

What did we do?

We began by agreeing on the number and timing of the webinars, and the broad theme for each of them. We discussed and agreed on the intended audience and how we would publicise the events.

The titles of the three webinars would be:

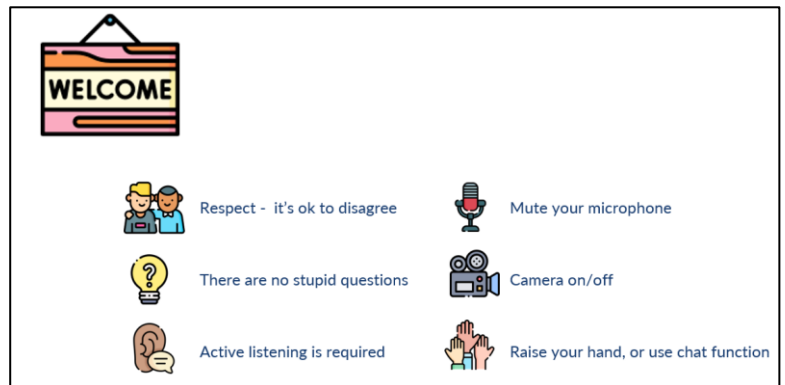
- Building capacity in Patient and Public Involvement (PPI) leadership
- Equity, ethics and budgeting for public involvement in research
- Emotions in public involvement

They would be held in the middle of the day, on the same day of the week, monthly for three months, starting on Wednesday 13 September (12.30-2.00).

We decided on a format of three presentations per webinar with each presentation having a maximum of 20 minutes, the last few minutes of which could be used for questions and answers. Some of the presentations were enriched by having speakers with diverse backgrounds and perspectives, such as an academic researcher paired with a public partner or peer researcher. When two speakers presented together, we asked them to decide how to divide the time between them.

The three presentations were to be followed by 20 minutes discussion in small breakout groups with predetermined questions from a facilitator. Speakers and organisers were asked to facilitate the groups, so each consisted of 6-8 people. Over time, the format was simplified to include only one question for discussion.

We wanted to ensure equity, diversity and inclusion informed the design of the webinars. As part of this approach, we felt the tone and style of the start of the events really mattered. We set out to ensure they were welcoming, fun and that ways of working together were established. We wanted to support public members and researchers who were relatively new to public involvement in research and considered how to communicate the learning culture we intended to create to the speakers and potential delegates.



Icons made by [Freepik](https://www.freepik.com) from www.flaticon.com

Intended audience

The intended audience for the webinar series was people with an interest in public involvement in research and services: community members and activists, experienced and early-career researchers, public involvement leads, peer researchers, third-sector organisations, public partners and any other individuals. The speakers tended to work in maternity and child health topics but not exclusively so.

4 Three webinars - an overview

The presentations of each webinar can be accessed here [NIHR Children's Health and Maternity National Priority Programme - Public Involvement webinar series](#).

Webinar 1: Building capacity in patient and public involvement (PPI) leadership



Illustration by [Storyset](#)

The first webinar in the series focused on enhancing leadership skills in public involvement. The session covered the importance of involving patients and the public in healthcare decisions and offered strategies for effective leadership in PPIE. The speakers shared practical insights, best practices, and strategies to build capacity in PPIE leadership, emphasising inclusive and effective

engagement. The webinar highlighted practical tools and frameworks to support capacity building and foster collaboration, aiming to improve health outcomes and research relevance through active public involvement. One way of embracing public involvement is to create opportunities for 'peer researchers' (see Glossary). The first talk in the series gave an insight into this approach.

Developing a peer research community of practice

Felicity Shenton, NIHR ARC Northeast North Cumbria (NENC)

Felicity presented how she and her colleagues from Fuse, Centre for Translational Research in Public Health at Newcastle University, identified a need for better organisation and

training in peer research. They observed good practices but also noticed duplication due to a lack of coordination. To address this, they aimed to create a peer research community of practice to share knowledge, create new learning, and leverage existing resources. This community is founded on principles of openness, honesty, lack of judgement, and confidentiality.

The community's first event brought together various stakeholders involved in peer research, using the "Six thinking hats" model for discussions. This approach was valuable for a diverse audience of public contributors, researchers, and practitioners. Participants highlighted the benefits of enhanced community involvement and insights from people with lived experience, while also acknowledging challenges and the importance of learning from unsuccessful projects. There was a call for more peer research, clear definitions, standardised training, and improved communication between funders and researchers.

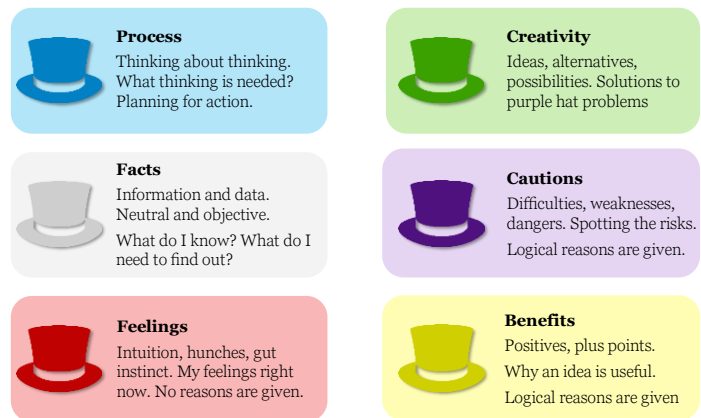


Illustration adapted from [Slideegg](#) - Edward Bono's Thinking Hats

Future plans include more events, expanding the repository of resources, and ongoing projects like the Autism in Schools Project, delivered by young peer researchers, which exemplifies practical peer research applications.

Key learning

Felicity emphasised the importance of shared learning and collaboration, inviting webinar participants to use the ARC NENC and FUSE learning resources and contribute if anything important is missing (See Resources below). A Peer Research Repository is hosted on the [ARC NENC website](#).

Being a public member co-applicant on research applications

Kristin Liabo, NIHR ARC South West Peninsula (PenARC) and Lynne Wright, Public collaborator, Peninsula Public Engagement Group (PenPEG, PenARC)

The second talk was a conversation between Kristin, a public involvement lead, and Lynne, a public partner, about the role of a public co-applicant on research applications.

Kristin explained that the research process is complex, often involving various groups like researchers, steering committees, and co-applicants. Co-applicants, including public contributors with lived experience, play a significant role in planning and delivering a study. Kristin highlighted the importance of involving public partners in the research team and providing the necessary support for their roles, for example form-filling and understanding complex terms.

Lynne shared her personal experience as a first-time co-applicant, discussing the challenges of feeling underprepared and uncertain about her role. She highlights the need for confidence and clear, two-way communication. Despite initial difficulties, she found the experience rewarding and valued the recognition she received for her contributions. Lynne also stressed the importance of seeking help when needed and understanding the research project to contribute effectively.

Key learning

Kristin and Lynn emphasised the need for structured support and mentoring, especially for new co-applicants. Advocating for clear communication, defined roles, and clarity on how one's lived experience will be integrated to build effective public involvement leadership. Overall, their presentation stressed the value of thorough planning, continuous support, and collaboration to create an inclusive environment for public partners in research.

Building capacity in patient and public involvement leadership – the Listen2Baby project

Rachel Rowe, National Perinatal Epidemiology Unit, University of Oxford and Rachel Plachcinski, Independent parent, patient and public involvement consultant

Rachel and Rachel presented the "Listen2Baby" project as an example of building capacity in public involvement leadership. Rachel Rowe emphasised the importance of involving public partners in research, considering ethical aspects and diverse perspectives. She highlighted the challenges public partners face in understanding complex research methodologies and systems, stressing the need for mentoring and support to help public partners effectively navigate their roles. In the Listen2Baby project, the lead researcher was taking the public involvement lead role to ensure that there was strong advocacy for public involvement within management and design. This also established strong structural positions for public members new to planning and monitoring research activity. In addition, funding was included in the

budget for mentoring by Rachel Plachcinski, an independent experienced public involvement leader.

Rachel Plachcinski discussed her role in mentoring two public partners in the “Listen2Baby” project, helping them build confidence and understand their responsibilities. She highlighted the necessity of clear communication and practical support for meaningful contributions from public collaborators. Drawing from her experience, she stressed the importance of simplifying complex information and making public contributors feel valued and supported.

Key learning

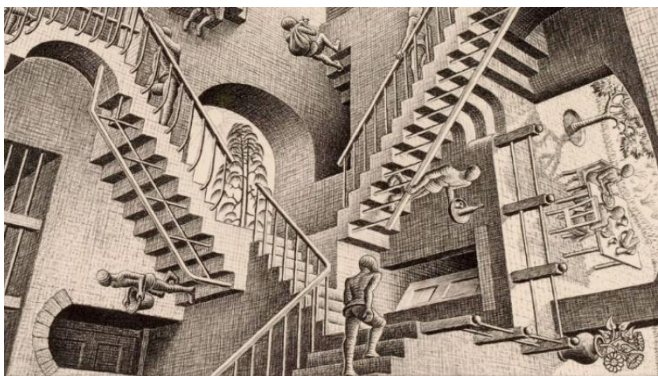


Image: M.C Escher, Relativity (1953). The M.C. Escher Company - Baam, The Netherlands

Rachel Rowe concluded by underscoring the importance of openness to continuing learning for both researchers and public contributors, emphasizing the need for continued support for shared learning, the value of innovation - such as employing experienced public involvement mentors - and broad collaboration to build capacity in public involvement leadership.

Discussion

Workshop delegates discussed the presentations in small breakout groups and identified several key challenges in building capacity.

- **Commitment and leadership:** Public partners need to lead research in various ways while balancing other commitments.
- **Training and Support:** Both public partners and researchers often lack adequate training and support to enable optimal public involvement, designed-in and well implemented.

There was consensus that capacity building is essential for effective public involvement and inclusive research and that funding and support are necessary to provide flexibility and support for public partners. Practices to facilitate capacity building in public involvement include several key strategies:

- Prioritising relationship building by allowing adequate time for mutual understanding is crucial, e.g. Research teams need to allow time for team building activities, and make specific plans for researchers, PPIE lead and public advisers or peer researchers to find out about each other's perspectives and priorities.
- Ensuring clarity of roles and support involves providing clear role descriptions and creating supportive environments. Adequate planning and budgeting for public involvement, treating public co-applicants as equal team members, and scheduling regular meetings and one-on-one discussions between public partners and academics are essential.
- Recognising and including public partners from the outset, providing feedback and expressing gratitude, and involving public co-applicants in all necessary meetings and planning phases are critical steps. Ensuring researchers fully understand the role of public co-applicants, providing timely reimbursements to prevent financial burdens, and employing adaptable communication methods further enhance effective collaboration. These practices collectively support the development of robust partnerships and enhance the impact of public involvement in research processes.

Webinar 2: Equity, ethics and budgeting for public involvement in research



Illustration by [Storyset](#)

The second webinar in the series addressed some of the challenges of, and strategies for, incorporating ethical, equitable, and well-funded public involvement in health research. Key points included the importance of creating safe and inclusive spaces for diverse communities, building trust with marginalised groups, and addressing power imbalances to ensure meaningful involvement. Speakers emphasised the importance of careful planning and budgeting to ensure sufficient funding. This includes costs of training, and support for public partners from the project's inception. The webinar highlighted the need for continuous learning and adaptation, encouraging reflection and feedback to improve public involvement strategies.

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

Agnes Agyepong, community advocate, and Mary Newburn, Public involvement lead, Abigail Easter, researcher, ARC-SL

Agnes and Mary gave a presentation developed collaboratively with Dr Abigail Easter, as a three-way researcher, PPIE lead, public adviser commentary. They highlighted the

importance of involving diverse communities in research and addressed challenges related to equity, ethics, and budgeting in public involvement. Their presentation emphasised careful planning, ethical considerations, and overcoming barriers to conducting inclusive research. They emphasised the need to involve black and other marginalised communities in research, given their historical mistrust and underrepresentation. To do this, they stressed the importance of balancing community

safety and the right to be heard. Adequate funding, they said, was necessary but not sufficient for ensuring good community relations and engagement. Building trust through liaison with community leaders and building in the principle of reciprocity was vital.

A case study was shared of a co-produced training event in South London addressing black community members' and researchers' perceived barriers to more integrated, inclusive research. The event used participatory appraisal methodologies, including the interactive techniques of spider diagrams and H-forms, to explore barriers and solutions. Key themes included prioritising community-focused research questions, clear communication, detailed planning and budgeting, and building trust through demonstrating respect and sharing power.

Key learning

Agnes and Mary concluded by stressing the need for a positive focus on equity and diversity in health research, calling for intentional efforts to include Black communities who experience poorest perinatal health outcomes, and other communities, by addressing systemic barriers. They recommended

How we can all play a role in bringing about change
Questions for introspection

- Are our leadership teams reflective of the types of audiences we are trying to reach?
- What Black researchers are we working with on this project?
- What Black networks are we reaching out to and co-producing with?
- Are we funding our partners adequately?
- Is our approach transactional or relationship led?
- How are we collaborating with and amplifying the voices of those who are already doing the grassroots work within the community?

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We need to prioritise research questions which are important to local communities... not just driven by funding bodies
(workshop participant)

Recommended actions:

- Ask the community: "What is important?"
- Budget for a PPIE lead
- Think reciprocity
- Advocate for community-led research

aiming to ensure diverse ethnicity in research teams to mirror the ethnic make-up of communities being studied, fostering empowering relationships, adequately supporting public partners, and relationship-building work to maintain continuous engagement throughout projects.

Overcoming challenges in public involvement: learnings from the RIVA study

Jill Domoney, researcher, King's College London and Tania Sutedja, public involvement, ARC-SL

Jill and Tania presented on the challenges and strategies of public involvement in the RIVA study, which is an evaluation of the implementation of the Independent Domestic Violence Advisors (IDVA) service in maternity settings to advise women, midwives and other staff directly. They discussed how public partners were involved as critical friends and co-researchers, providing feedback and conducting interviews. The study emphasised trauma-informed practice, ethical engagement through the Survivors' Voices Charter, and maintaining research integrity. Practical challenges had included complex administrative processes in NHS trusts and obtaining all necessary ethical approvals. The presentation also emphasised the importance of flexible roles, inclusivity, and collaboration, particularly in the choice of language when discussing sensitive subjects like domestic abuse.

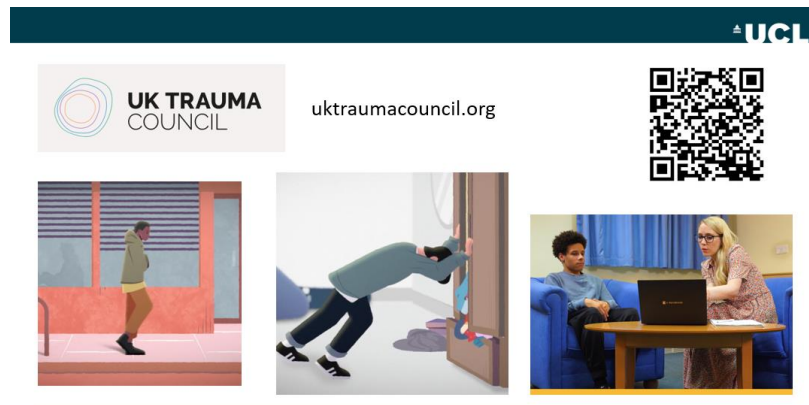
Tania shared her experience as a public partner, highlighting the valuable support and training she had received, including role playing before carrying out a research interview. Conducting interviews was challenging but rewarding, and she felt empowered by the experience and valued by the research team.

Key learning

Jill and Tania concluded by emphasising the importance of a supportive and inclusive environment for public involvement, and the role that peer researchers can play in conducting sensitive research. They underscored the need for clear communication, adequate support, and how public partners can improve a study's impact and relevance.

Ethical and Equitable Social Care Research: Involving care-experienced advisors to help reduce barriers to research participation for care-experienced youth receiving trauma-focused mental health support

Rosie McGuire, researcher, University College London, and Kane Wilton, lived experience adviser, ADaPT study



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Images: [UK Trauma council](https://www.uktraumacouncil.org/)

Rosie and Kane presented their work on the ADaPT project, which aims to improve mental health outcomes for care-experienced young people through trauma-focused cognitive behavioural therapy (CBT). They discussed the challenges and

successes of involving these young people as advisors and co-researchers. The project trained over 200 mental health professionals in trauma-focused CBT across 11 NHS trusts and collected data on screening, treatment provision, professionals' views, and young people's experiences and mental health outcomes. The advisory group, including Kane, provided crucial insights on recruitment strategies, consent procedures, and the overall approach to involving young people, helping develop accessible animations and sensitive consent procedures.

Future research plans include extending support to those over 18, addressing the transition out of care, and ensuring continuity of support. Kane highlighted the positive experience of being involved, appreciating the freedom to express ideas and the genuine value placed on his contributions.

Key learning

Rosie emphasised the importance of listening to and validating young people's ideas, even when faced with practical constraints. The presentation underscored the need for ongoing support and flexible, sensitive approaches to involving care-experienced young people in research, ensuring they feel empowered and appreciated.



Discussion

Workshop delegates were asked to discuss the presentations in small breakout groups and reflect on their experiences to consider ethical approaches to public involvement that promote diversity and inclusion. Delegates highlighted the need for clear guidelines, consistent safeguarding standards, transparent budgeting, and practical support for public involvement in research.

Ethics

Delegates noted the confusion between ethical considerations and formal ethics approval. They emphasised that ethics approval is needed only for research participation and can be restrictive when trying to work inclusively and flexibly with the public. However, they stressed that even though formal ethics approval is not required for public involvement, it is still essential to think and behave ethically, consistently applying ethical standards and safeguarding measures.

Budgeting

Delegates stressed the importance of transparency and open conversations about constraints in budgeting such as institutional policies. They also highlighted the necessity of budgeting that is fair and responsive to people's circumstances and needs. This includes for example grassroots involvement of community groups and practical considerations like acknowledging people's time that cannot receive bank transfers and paying for childcare.

Challenges

Discussions highlighted the need for flexible involvement to promote diversity and ensure safety. Delegates pointed out that current PPIE models lack guidance for involving vulnerable groups, and researchers often lack the necessary support. They emphasised the importance of regular check-ins with public partners to ensure their comfort and the appropriateness of practices. Additionally, delegates noted a lack of understanding and resources for involvement, making it difficult to justify actions to ethics committees, such as working with peer researchers to conduct data collection.

Webinar 3: Emotions in public involvement



Illustration by [Storyset](#)

The final webinar of the series focused on the emotional impact of public involvement in many research studies. This affects both public partners and researchers working together in research. Service users' experiential knowledge, or lived experience, is fundamental to public involvement and is often deeply anchored to emotions. It emphasised the need to create space for emotions, recognising that personal experiences shared in public involvement may be about deeply moving experiences including

experiences of fear, anxiety, powerlessness, loss and pain. The speakers highlighted the critical need to acknowledge and work with emotions when involving public partners, advocating for supportive and inclusive practices that promote emotional well-being. The presentations encouraged ongoing feedback and the continuation of learning communities to share this complex work and strategies for doing it safely and sensitively.

Reviewing the literature on the role of emotions in public involvement

Lauren Asare, Research assistant, Patient and Public Involvement Team, Exeter University, PenARC

Lauren presented learning from a [conceptual literature review](#) which had been inspired by an emotional PPIE meeting that highlighted the significant impact of emotions on research discussions. Lauren emphasised the crucial role emotions play in public involvement, advocating for practices that support emotional well-being and enhance the contributions of public partners. The review's insights were drawn from various disciplines, including sociology, literature and psychology, and relevant theories for understanding the role of emotions in public involvement.

From the 18 studies included in the review, key themes included: challenges of managing emotions in public involvement, for example that emotions could impact group dynamics and expose vulnerabilities; and positive impact stemming from emotional relief and bonding with peers.

Key learning

Lauren suggested ways forward, including the importance for projects to:

- use emotionally supportive facilitators,
- record emotional contributions in meeting minutes to capture the importance of this phenomenon,
- create comfortable physical environments to make emotional sharing easier, and
- provide clear role descriptions for public contributors to reduce uncertainty and related anxiety.

In summary, make space for emotions in public involvement by creating supportive and equitable research environments and focus more on learning and adaptation to explicitly incorporate emotions into public involvement practices.

Giving birth mothers a voice: examples of meaningful research engagement from the MUMS@RISC study

Kaat De Backer, Research midwife, King's College London, and Cassandra Newall, lived experience public adviser, ARC-SL

Annually, approximately 3,000-4,000 babies are removed from their mothers within a week of birth in England. Kaat and Cassandra presented the MUMS@RISC study, focusing on the maternity experiences and outcomes for mothers who have had to face removal of their baby due to social care proceedings. The study explores maternity care, mental health, and emotional impact for these mothers. Motivated by Kaat's personal experiences as a midwife, the study involves a panel of mothers with lived experience and collaborates with third sector partners to provide support and guidance. The study's public involvement panel has co-produced agreement on how to work together, resulting in a written [charter for research engagement](#). The charter emphasises confidentiality, respect, empathy, and safety. It also establishes values like being heard, trauma-informed approaches, accountability, and poverty-proofing the research.

Kaat shared practical measures included in the study such as well-being checks, grounding techniques, and ensuring ongoing support from third sector partners. Independent reflective supervision for the researcher has been arranged. Feedback from the panel has significantly shaped the study design, and participants receive transcripts of their story as shared during

interviews to maintain control over their narratives. Cassandra shared her personal reflections, highlighting how involvement in this project has given her a voice, hope for positive changes, and had contributed to her healing journey.

Key learning

Reflective supervision can support researchers in processing the emotional impact of their work. The presentation concluded with a call for kindness in research and a commitment to creating positive changes in the treatment and support of mothers facing infant removal.

Emotions in Public Involvement: feeling our way in research

Mandy Cheetham, researcher, Northumbria University/ARC NENC Research Fellow

Mandy Cheetham presented her study on the mental health effects of being on Universal Credit (UC), a UK benefit for working-age adults and people on low incomes. Mandy emphasised the importance of integrating emotions into public involvement and research practices, advocating for supportive structures and recognising the political dimensions of welfare and social issues research. Public involvement in the study was viewed as a human right, with diverse involvement opportunities that value the skills and experiences of public partners.

"We certainly see a lot of emotions during our PPI sessions"

- Feelings are a welcome and important part of the research / PIE process
- Public partners *and* researchers have feelings which affect research
- Sometimes we need support from others to help identify / manage these
- We should be honest about the values underpinning our approach to PIE

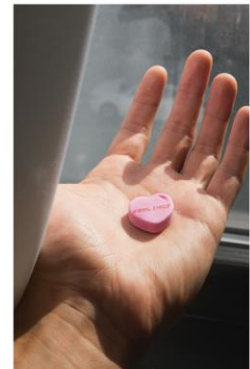


Photo by Joseph Frank on Unsplash
<https://unsplash.com/s/photos/feelings>

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Activities included the "UC Creatives Project", a co-produced participatory arts project involving seven public partners with experience claiming Universal Credit, which resulted in an online and touring exhibition. Another initiative was the theatre production "Credit," which was based on the study's findings and adapted into a filmed reading due to COVID-19 restrictions. Recognising the political nature of their public involvement, the study team implemented safeguarding and distress protocols, encouraged peer support, and created spaces for open discussions about emotions.

Key learning

Mandy emphasised the importance of flexibility in adapting involvement opportunities to meet participants' individual needs. She highlighted the importance of self-care, supportive team meetings, and empowerment as an outcome of public involvement. She also acknowledged the challenges in measuring impact of public involvement, like subtle relational changes made possible by emotional awareness and focus. Further research is needed to explore the role and value of engaging with emotions in research and ways to support well-being to enhance public partners' contributions.

Discussion

The presentations were received enthusiastically and they stimulated researchers and public members to talk about their own experiences around emotion work in research. Some of the key points were:

1. Emotional support in virtual meetings:

One of the breakout groups particularly focused their discussion on the challenges of attending to emotions and emotional needs when working via online groups rather than face-to-face. Some of the shared practical tips were:

- **Mood:** Use smiley face mood indicators, or a traffic light system for people to give an indication of their mood, before and after sessions.
- **Support:** Have plans in place to manage responses to any 'red' indicators with follow-up and assistance, while maintaining group dynamics.
- **Emotional support:** Assign facilitators, held on standby, to offer a breakout room for emotional support.
- **Light endings:** Acknowledge emotions in the room and conclude sessions on a lighter note to alleviate emotional heaviness.

2. Support for PPIE staff:

Another discussion focused on the needs of researchers and group facilitators when demanding emotional work was being done. Suggested tips were:

- **Supervision and debriefing:** Implement regular supervision and debriefing meetings - as a team or one-to-one - for staff to manage emotional impact.

- Intrinsic role of emotions: Recognise the importance of acknowledging and integrating emotions and its impact within research teams.

3. Budgeting and remuneration challenges:

It was recognised that some of the most vulnerable groups with the poorest health outcomes may be on state benefits or unable to receive payments. Attendees had experience of working within these constraints and also regarded them as significant barriers to involvement. They advised the following.

- Issues with payments: Use guidance from NIHR and the Citizens Advice Bureau to address challenges related to payments due to benefits/tax implications.
- Asylum seekers and vulnerable groups: Explore alternative remuneration options, e.g. in-kind support, and seek procedural guidance from organisations working with refugees.
- National discussion: Engage with HMRC and Department for Work and Pensions (DWP) on remuneration issues and share examples of barriers with NIHR for better advocacy.

4. Practical ways to engage with emotions in public involvement:

Discussion also focused on processes and methods researchers could use to address emotional needs, particularly when marginalised groups are engaged as research partners, and stigmatising or sensitive subjects are being researched. Two areas of work were recommended.

- Create a group agreement: Use initial contact and meetings to make people feel comfortable and respected. Discuss important values and form agreed key principles through participant input.
- Seek advice on best practice for inclusion: Seek guidance from experienced organisations on involving and supporting diverse and vulnerable groups.

5 Who attended?

Overall, after advertising on social media through our networks and with the help of PenARC and ARC-South London communications teams, around 180 people attended across the three events. This includes some people who attended more than once as each attendance is counted separately.

Number attending - Around 50 people, including speakers and facilitators, attended the first webinar. The following events were attended by around 70 and 60 respectively. Each time, this was half-to-three quarters of the number who registered for a free place.

Inclusion and diversity - NM and MN had rather different views on the value and potential unintended consequences of attempting to record some of the characteristics of those who attended the events. There was a concern that asking monitoring questions can be intrusive and be perceived to imply judgement. Also, that simple closed-answer questions can be reductive and fail to see the individual holistically. If more questions are posed to find out more, there is a greater burden on the person being asked to share their personal data and fill in the form. So for the first and second webinars no such questions were asked. However, those who completed a feedback form were asked about their role, so it was possible to determine of those who responded how many were public individuals and what number were researchers. In advance of the third webinar, we agreed to ask some socio demographic questions at registration, and 61/81 of registrants provided details.

The information presented below is for the third webinar only.

- Age - there was a good age range; most were aged 30-49 (41%) around a quarter were aged under 30 (23%; all 25-29) and rather fewer aged over 50 (18%).
- Ethnicity - the majority (60%) were white British, followed by white other (10%) including Polish; there were five Asian or Asian British participants with Pakistani, Indian, Bangladeshi and other heritage (8%), and three Black or Black British participants (5%) including both Caribbean and African heritage, and six recorded being mixed White British and either of Asian, Black including Trinidadian, or Australian/Croatian heritage (10%). Some preferred not to disclose their ethnicity (7%),
- Disability – Seventeen said they had a disability (28%). Of these, nine ticked 'mental health/cognitive impairment', other conditions referenced were 'mobility/manual dexterity', 'dyslexia', 'hearing impairment', 'other' and 'prefer not to say'.

- Roles – registrants’ primary roles in terms of research involvement included being a service user or community member (public), an academic researcher, or in a public involvement leadership role. Some reported multiple roles.
 - 12 (20%) were ‘public members’ who named themselves variously as ‘PPIE adviser’, ‘expert by experience’, ‘peer researcher’, ‘public co-applicant’, among other descriptions.
 - 18 (30%) were academic researchers with varying levels of experience and seniority. Details provided included ‘PhD student’, ‘research fellow’, ‘senior trial manager’, ‘senior statistician’ and ‘senior lecturer in social science’. We included in this group those who said they were a ‘programme manager’. 24 (39%) had a public involvement leadership role. They used a wide variety of names and titles: ‘PPIE manager’, ‘PPIE Lead’, ‘PPIE facilitator’, ‘PPIE coordinator’, ‘engagement lead’, ‘policy officer’, ‘communications and engagement officer’, and ‘head of research and involvement’.
 - Other roles included ‘administrator’, ‘public health registrar’, ‘SASCI coordinator’ (presumed to be Supporting Adult Social Care Innovation) and ‘research facilitator’.

In summary, the 61 people who provided details have enabled us to share an indication of the audience that has been reached by the webinar series, in terms of sociodemographic characteristics. The data shows a varied age range, ethnic diversity, a notable presence of individuals with disabilities, and a mix of roles including public members, academic researchers and public involvement leads.

6 Participants’ feedback

Those who took part were asked to provide feedback to the organisers by completing a short online questionnaire. We wanted to learn more about people’s needs and the extent to which they had been met, plus what we - and others - might do differently in the future. Those who had attended were each sent an email with an embedded link.

A minority of those who participated sent a response but there was rich detail from those who did reply. Across the three webinars we received 34 completed feedback forms. Only two individuals responded about webinar 1. The link to the feedback questionnaire was

circulated around a week after the event and we realised this was too late to motivate most people to share their views and reactions. After webinars 2 and 3, the link was circulated promptly and 16 people responded each time. Questions were presented in neutral terms; closed questions had a scale of possible responses and there were several open questions.

Webinar 1

The two who responded to webinar 1 were a health professional and a professional PPIE lead. They valued aspects of the event, one flagged 'Hearing from PPIE contributors and their experience', the other mentioned how hearing a public member's experience of being a co-applicant had provided useful insight. Both had some criticisms. One felt the facilitation of their breakout could have been better. They said that there was too much focus on individual public involvement experiences and difficulties in receiving public involvement payments. Overall, each of them felt the webinar was only 'a little relevant' for their needs. Both said they were already a member of a 'community of practice (or interest group) related to public involvement in research' and they expressed interest in a new community of interest group on public involvement in research. Along with others responding to the later webinars, they ticked many areas of information and learning support that they would like to be able to access. We have identified these as public involvement in research community 'infrastructure needs' (see table 1).

Webinar 2

Feedback after the second webinar came equally from those working professionally in research and public members of various kinds. The multiple boxes that people selected to describe their roles in research made it clear that there is considerable cross-over between academics, health professionals and those coming primarily from a service user or community background in the public involvement in research community, for example, there were people studying for a PhD in both groups.

Almost all (15/16) found the webinar 'relevant' or 'highly relevant' to their interests. The positive elements emphasised were opportunities for learning; space and stimulus for reflection on practice; seeing how other researchers and projects tackled practical issues and challenges; hearing from experts by experience; and an opportunity to focus on diversity of involvement and ethics. The ARC South London co-production training event presentation (Agyepong and Newburn) was commended by one person, and the opportunity to 'attend such a well-run and professional webinar' by another.

Overwhelmingly, the aspect of the webinar that participants most felt could usefully be done differently was scheduling more time. More time for discussion, and for Q&A. More focus on budgeting for PPIE was asked for and, specifically, 'a crib sheet or checklist (on PPIE budgeting) would be a great resource'. Though, everybody's constrained time was also acknowledged.

Those with a particular interest in working with children or young people were keen to explore this in-depth with others who had related experience, within an ethical and inclusive framework. One said:

"I would really like some more practical answers on how to work with young people. I understand all the "woolly" stuff about PPI but I would have loved to hear more about ethical challenges, [...]. Is there precedent on this? I really need practical answers and nobody seems to have them or know them. It was nice to hear in the breakout room that everyone shared my frustrations but it did point to a real need for work in this area."

Webinar 3

Once again, feedback was provided by attendees from all backgrounds. All 16 attendees giving feedback said they felt the webinar, 'Emotions in public Involvement', was 'relevant for their interests', with a large majority saying 'highly relevant' (13/16).

Participants explained what they had found most useful. Two said "All of it!" or a similar phrase. The topic itself was felt to be highly important, a rich focus for learning and an opportunity for articulation of shared values and concerns. One person said: *"The range of presentations was excellent; each one was so helpful and insightful. I especially appreciated hearing practical examples of how to give space for emotions in PPI events."* Another, *"Talking about sensitive topics including child removal and benefits."*

As in previous webinars, participants valued *"getting the patient perspective"* and hearing lived-experience presenters speak and share their views and reflections firsthand.

Some attendees particularly valued the scholarly aspects of the session, making comments such as: *"liked the literature review"*. The webinars were seen as opportunities to hear *"excellent presentations and (obtain) really useful tools & resources"* and resolve or further consider possible ways of tackling practical challenges. Positive feedback included acknowledgement of the *"non-judgmental space"*. The high calibre of the presentations was commented on repeatedly; they were *"all really informative and delivered in an engaging and genuine way. The audience was talked to, not at."*

Once again, time was the thing everyone wanted more of. Time for more Q&A with speakers and for discussion in breakout groups. However, overall, across the series, there was a positive feeling. Attendees appreciated the chance: *“To hear about best practice of the sector and have the feeling of a community.”* Plus, *“hearing approaches used by others; hearing a value-base that reflects my own.”*

Independent public PPIE leads

Seven of those providing feedback were independent public involvement leads. In keeping with other attendees, most of them found the webinars ‘highly relevant’ to their needs and two felt they were relevant. Their comments included a need for *“More discussion time – MUCH more!”*. They valued opportunities to hear about the experiences of others involved in research. Comments about what this group found ‘the most useful for you’ were:

“A chance to see how one’s own experiences fit into a bigger picture.”

“Being able to hear about best practice, particularly from Experts by Experience.”

“Practical suggestions for providing emotional support /acknowledgment.”

“I especially appreciated Lauren (Asare) & liked the literature review as that gave me ideas of things I can do practically. It would have been great to spend a bit more time picking her brains. I also liked hearing others’ stories (realising you are not alone; others doing even more difficult work).”

Regarding what would have improved the webinars:

“Great to have a focus on inspiring/good practice today, but perhaps some more acknowledgement of just how hard this stuff can be in practice might have been helpful, including tips on how to manage that if you’re not working in a ‘dream team!’”

A further six of those providing feedback indicated that they were doing public involvement work giving advice on a study. One person expressed a preference for further explanation in the webinars:

“Maybe in the introduction to include a very basic explanation of what ethics, equity and budgeting means and how its relevant. Unless I missed it, I did get confused by some of it. I don’t have an academic background on these things and some really basic explanations would be really helpful...”

Generally, they seemed to gain benefit from attending:

“Great to hear about the problems and solutions that other teams are encountering. (I would have liked) more time for networking and discussion.”

“(I most valued) to hear real-life examples of how other studies are handling PPIE ethically. (I would have liked) maybe a little more time? We ran out at the end in our breakout rooms just when we were getting into some really good chat!”

Membership of a Community of Practice

We asked those attending for their feedback about Communities of Practice, to identify who already had access to one and what their unmet desires and support preferences might be. The concept of ‘Community of Practice’ comes from learning theory, and has been defined as:

“groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly”.⁷

Some of the key characteristics are learning through practice and reflection, and the ‘creation of a system for collective critical inquiry in which knowledge and awareness is developed over time’.⁸

The attendees were asked ‘Are you currently a member of any Community of Practice (or interest group) related to public involvement in research?’ We did not however provide a definition of that phrase, so it may have been interpreted differently by different attendees.

Most people who responded to the question stated that they were currently in a public involvement in research Community of Practice (68%) and provided details as requested. Examples included the National Coordinating Centre for Public Engagement (NCCPE); Co-production Collective; Oxford PPI Leads Group; Health and Care Research Wales Public Engagement and Involvement Alliance; School for Primary Care Research PPIE Leads Group; NIHR Child Health and Maternity Programme Community of Practice and the ARC North East and North Cumbria Public Involvement and Community Engagement (PICE) Special Interest Group.⁹

⁷ Wenger-Trayner, E; Wenger-Trayner, B. Introduction to communities of practice: a brief overview of the concept and its uses. 2015. <https://www.wenger-trayner.com/introduction-to-communities-of-practice/>

⁸ <https://www.communityofpractice.ca/background/what-is-a-community-of-practice/>

⁹ <https://arc-nenc.nihr.ac.uk/news/public-involvement-group/>

In addition, some advisory groups were referenced. While these forums may further good practice in public involvement in research, about a third of those who had said they were members of a Community of Practice were referring to a time limited, individual study (or programme) public involvement group, rather than a broader community of practice spanning various institutions or independent studies.

The information provided was useful as it made clear that any research on access to a public involvement in research Community of Practice needs to define what is meant by a Community of Practice. Currently, both professionals working in research and public advisors seem to have a range of understandings of what the term may mean. Also, it is possible that a range of very different groups and organisations may fulfil some, but perhaps not all, of the functions of a Community of Practice.

Attendees shared information and described groupings in their area, such as:

'[Name of university] have just set up a CoP for Participatory Action Research',

'We have a group of people locally (across two trusts and two universities) for whom PPI is the main or whole part of their job, and we meet once every two months'.

In contrast, one public contributor to research involved in a PPIE advisory group said *'I really don't know how to best engage locally on this!'* It seemed that those who were further away from big institutions or funding bodies were least likely to know of Communities of Practice and how they might join one or obtain funding to set one up.

The Northeast and North Cumbria Public Involvement and Community Engagement (PICE) Special Interest Group, seems to demonstrate the characteristics of a Community of Practice for public involvement in research. The meetings provide a forum for collaborative learning. Dr Felicity Shenton, Public Involvement & Community Engagement Manager, NIHR ARC NENC, says it exists *"for ARC members in the Northeast and North Cumbria - including researchers, students and public contributors - to ask advice, share good practice, or share obstacles and barriers to public involvement and community engagement."* Now the group is well established, she says. *"There are currently 106 members from across the region. We hope the discussions help to improve practice, and generate evidence of the impact of meaningful public involvement and community engagement in research. We also have a North East North Cumbria Peer Research Community of Practice that is coordinated jointly by the ARC & Fuse."*¹⁰

¹⁰ [NIHR ARC NENC Peer Research Community of Practice repository - ARC.](#)

Interest in joining a community of practice

In response to the question 'Would you be interested in joining a (new) Community of Practice around public involvement in research?' there was a lot of interest. Around two-thirds (21/34) said they would like to become part of a Community of Practice related to public involvement in research, Others said 'maybe' (7) or 'don't know' (2); only one person said 'no'.

Attendees then provided feedback on eight listed examples of kinds of information, support or signposting they would like to be able to access. Both professionals and public contributors expressed high levels of interest (see Table 1). There was a further, 'Other, please explain' option. Every attendee providing feedback expressed interest in at least two listed items.

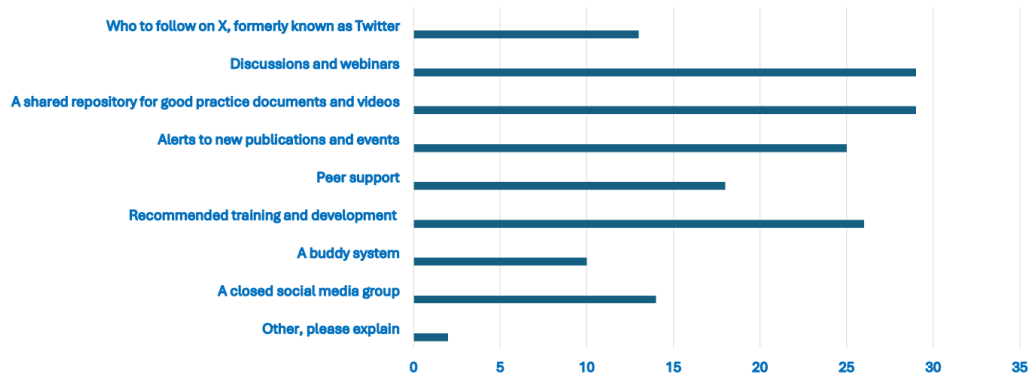
As many as 29/34 (85%) wanted access to a shared repository for good practice documents and videos and expressed interest in a means to hear about up-coming discussions and webinars related to public involvement in research. A large majority also wanted access to recommended training and development initiatives (76%) and to receive alerts about new publications (reports, videos, events, journal articles, etc) related to public involvement in research (74%).

Around half of the group were interested in the opportunity to have peer support (53%) with 29% wanting a buddy system. Six of the ten wanting a buddy system seemed to have a public, rather than a professional background or primary identification, but as there was considerable overlap in roles this is not clear cut.

In terms of social media, well over a third were interested in becoming a member of a closed social media group on public involvement or specific, related, topics such as emotions in research (41%) or to have guidance on relevant people and institutions to follow on X formerly known as Twitter (38%) for public involvement in research postings. Two people made other suggestions. One simply said they wanted "a network," another said they'd like to have access to:

"(A) message board not on social media - not connected to any social profile as work and volunteering don't always mix with social identities (e.g. you might be out as Queer in one space but not another)."

Table 1: Public involvement in research – expressions of interest in forms of information and support



There was communication after the webinar series from a postdoctoral researcher which also demonstrates a need for further infrastructure to support public involvement in research, saying:

“I am writing a training and development plan and would like to include PPIE courses/workshops for myself and my PPIE group members to attend. ... There seems to be a real gap; I know my PPIE group would love to receive more in-depth training but I just can't find anything to offer them. The one thing I have been able to think of is costing in people who are very experienced in PPIE to mentor my group members, (as) for many it is their first time (doing) PPIE.”¹¹

7 Discussion and lessons learned

The webinars were planned to provide a journey around the islands of public involvement practice and expertise; to shine a light on the aims, values and approaches, and encourage shared learning. The quality of the nine presentations and the breadth of topics explored demonstrated the range of knowledge and skills in public developed and provided a platform to discuss key questions.

Our aim of creating a collaborative, inclusive space for all contributors was largely fulfilled, despite the limited time and multiple speakers. However, had there been further time for Q&A and small group discussion these ambitions would have been taken further.

¹¹ MB to MN, quoted with consent. Emails: 20 November 2023.

As organisers, were aware of the isolation some participants felt and gathered feedback to understand how best to support those working in public involvement, including different groups who work in this field: early career researchers, health professionals doing research, public contributors and PPIE leads. There was a high level of interest in the webinars, a good attendance rate, and detailed feedback from a large minority of attendees.

Attendees suggested examples of further information and support which interested them, indicating that the current infrastructure for supporting public involvement in research development is seen as lacking by those working in the field, whether professionals or public contributors. There seemed to be a need among researchers and public members for accessible interest groups, such as a Community of Practice, for collaborative learning, improved access to resources and training opportunities, and showcasing of innovative practice. Having a sense of community with shared values also mattered; being 'part of something bigger' and knowing that other people wrestled with related questions and challenges. Communities of Practice on public involvement are still relatively new and may be difficult to find. It seemed that those who were outside of universities or funding bodies, like independent community organisers and self-employed PPIE leads were less likely to know of Communities of Practice and how they might join one or obtain funding to set one up.

There was a lot of learning for the organisers in the process of hosting this webinar series. Positive achievements included the collaboration between two ARCs to host the events with support from both communication teams to market and promote the events. Contributions from other ARCs and relevant units enabled expertise to be shared and ideas generated. It seemed to work well to bring together the child health and maternity services research communities to address public involvement issues together. The last webinar in the series, focusing on emotions in public involvement, was especially well received. This is perhaps a topic that is less covered, so had novelty as well as being a fundamentally important consideration, especially for work with vulnerable groups and on sensitive health topics or traumatic life events. Another time, we would allow more time for discussion and Q&A by focusing each webinar on a single topic, and potentially offering people the opportunity to select a breakout group based on their level of experience, or key aspects they would like to discuss.

Summary points

1. Online public involvement webinars for attendees from a mix of backgrounds worked well as an accessible, safe learning forum.
2. The webinar feedback indicated that there is a need for investment in more infrastructure to promote the practice of public involvement in research, including more interest groups such as Communities of Practice and better access to resources via well-run and well promoted repositories or libraries.
3. Having three presentations at each webinar stimulated a lot of interest and enabled many people from service user and research perspectives to contribute, share their approach and insight. However, we felt that some of the webinar themes were too broad and there was insufficient opportunity to explore specific questions and points of good practice in depth.
4. Some of the attendees would have liked to question speakers about aspects of their work and approach to problem solving. In future events, we would allow more time for this, as well as having break-out group discussion after each presentation for maximum participation.
5. Some public advisers wanted time to discuss their frustrations or share their personal unmet needs, rather than step back and consider a question collaboratively. Planning for these different functions and signposting clearly the purpose of each space would be useful.
6. Online webinars are almost certainly one of the ways of fulfilling the need for low-cost, time-efficient opportunities to learn about public involvement using different methods, and problem solving with colleagues.

8 Conclusion

There are many aspects of methodology to consider when planning for and doing public involvement in research. Being able to learn with and from others is important, partly to build on and benefit from the successes of other teams and disciplines, also to avoid 'reinventing the wheel' or making the same mistakes. It is important that public contributors are treated well and researchers can work effectively. From considerations of ethics and capacity-building, unless the community of people - researchers and public - who value and are committed to involvement is grown, there will be continued waste of resources, slow growth in knowledge and arrested development of culture and good practice.

Several groups, including academics, early career researchers, health professional researchers, PPIE leads and individual public advisers valued the opportunity that the webinars provided. There was a clear expression of interest to be able to participate in relevant, on-going groups for mutual learning, signposting, and access to resources. For example, some academic and early career attendees wanted to discuss methodological questions and ethical issues with their peers around doing research with children in care or care-leaving young people, and maternity service users including those with a history of trauma and distrust.

A particular gap appears to be opportunities for public advisers and peer researchers to get support and share their experiences in groups set up specifically for them and their learning and support needs. Some of those who become involved in research as a service user or community representative may wish to move into public involvement leadership in future, and may have the kinds of personal characteristics, community knowledge and contacts that are valuable in making research more relevant and democratic. Enabling career progression within public involvement is important and it can be addressed in concert with valuing participatory and peer research, implementing equity, diversity and inclusion strategies, and tackling the barriers experienced by communities which lead to exclusions from research and the body of clinical and health research evidence. Thus, facilitating multiple paths into public involvement leadership should be supported.

We recommend that NIHR and other research funders prioritise funding for public involvement infrastructure.

This is needed for:

- Public involvement in research interest groups, facilitated over time.

- Development of easy-to-read resources and participative learning about public involvement, drawing on evolving expertise.
- Communication about public research involvement opportunities via social media channels.
- Segmented learning opportunities for people with different levels of experience may be useful.

9 Useful resources for public involvement in research

- Recordings of each of the webinar presentations are available [online](#).
- The ARC NENC hosts the Peer Research Repository [NIHR ARC NENC Peer Research Community of Practice repository - ARC](#)
- Fuse hosts a [list of resources](#) to support public involvement in research. They say: *“Please let us know if there are any great resources that we might have overlooked so that we can continue to share examples of public involvement and engagement good practice and ways of undertaking more inclusive public health research. You can email Ella, Fuse Public Involvement and Engagement Manager at eleanor.anderson@ncl.ac.uk.”*
- ARC South London have curated [Resources to support involvement in research](#). They are suitable for public contributors, researchers or anyone wanting to support public involvement in research (with or without research training).
- NIHR [Public co-applicants in research- guidance on roles and responsibilities](#)
- [Public involvement workforce career competencies framework](#) © 2023 by Polly Kerr.
- McPin Foundation's guide on involving young people in research. <https://mcpin.org/wp-content/uploads/2021/12/Involving-young-people-in-research-work-guide.pdf>
- [Nuffield Foundation's ethical principles for co-production with young people](#).
- [Emotion in public involvement: A conceptual review](#).
- Kaat De Backer and the MUMS@RISC service user advisory panel created a [Charter for research engagement](#), trauma-informed approaches to research engagement.
- ARC-SL Maternity and perinatal mental health (MPMH) theme [Public involvement blogs, papers, reports and presentations](#) All the MPMH research is underpinned by the principles of diversity and inclusion which are central to the ARC's Involvement Strategy.
- [How do peer researchers make a difference?](#)

- [“I’m making it up as I go along!”](#) Why we need to build capacity for community involvement and service user-led PPI in research.
- ARC South London [Involving diverse communities in research – learning from a co-production training event](#)
- [‘Conjuring PPI’ - the unseen labour of patient and public involvement](#). In this blog Dr Stan Papoulias and Dr Louca-Mai Brady discuss the invisible labour of patient and public involvement and how institutional systems can exclude public contributors.

About the authors

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Glossary

Many different words and phrases are used when discussing public Involvement in research. Some words and phrases can be used interchangeably, others may sound similar but have distinct meanings. It is important to choose language that is clear and conveys a defined meaning.

We use the NIHR definition in this report for involvement in research and make a distinction between this and engagement or participation in research. These terms are each defined as follows:

Involvement – members of the public are actively involved in research projects (e.g. planning, deciding, reflecting, reporting) and research organisations.

Engagement – information and knowledge about research is provided, shared and explained, including sharing (disseminating) the findings of completed research studies.

Participation – where people take part in a research study.¹²

Other terms of relevance to public involvement in research are listed in alphabetical order below. Those registering to attend the third webinar described in this report were asked to describe their public involvement role. One or more people used the terms marked with an asterisk below.

Community - a group of people living in the same place or having a particular characteristic in common. Sometimes ‘community’ is used in research about areas with high levels of deprivation or groups of people who are marginalised or have less power than the majority, or the most powerful, in the population. See, for example, this discussion about Della Roberts’ community-based participatory research with Harperville’s African American

¹² National Institute for Health and Care Research Cambridge Biomedical Research Centre. Patient and Public Involvement, Engagement and Participation (PPIE) Strategy 2022-2027. <https://cambridgebrc.nihr.ac.uk/public/patient-and-public-involvement-engagement-and-participation-ppie-strategy-2022-2027/>

neighbourhoods that didn't have access to healthy food.¹³ Community 'is frequently based in place and so is local, although it can also represent a community of common interest, purpose or practice'.¹⁴

Community leader - a person widely perceived to represent a community. Leadership in, for and by the community.

Community of Practice (CoP) - a group of people who share a common interest or concern. The group helps to build networks, share knowledge and support both individual and group goals.

Consultation - the action or process of formally consulting (seeking information or advice from) or discussing. The person consulted expresses their ideas and views but is not a decision-maker.

Co-production - '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.'¹⁵

Expert by experience - has a meaning similar to the phrase 'lived experience' but emphasises that this creates expertise. It is used by the Care Quality Commission, for example.¹⁶

Lay member - comes from 'laity' meaning people who are not members of the clergy. It means a person without professional knowledge of a subject, e.g. research. It is used here in a NICE blog¹⁷ but is perhaps used less frequently than other terms as it emphasises the absence of knowledge rather than expertise by lived experience.

Lived experience - implies first-hand, direct, personal experience (of a health condition or behaviour), in the context of health services as a patient, service user or carer, rather than as a clinician with professional knowledge of patients or a researcher with academic knowledge.

¹³ <https://ctb.ku.edu/en/table-of-contents/evaluate/evaluation/intervention-research/main>

¹⁴ Anderson L., O'Loughlin P. & Salt A. (2001). *Community leadership programs in New South Wales*, UTS Shopfront, for the Strengthening Communities Unit, NSW Premier's Department, Australia December 2001 cited by Wikipedia https://en.wikipedia.org/wiki/Community_leader Accessed 26 April 2024.

¹⁵ INVOLVE. Guidance on co-producing a research project. March 2018. Accessed 26 April 2022.

<https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/>

¹⁶ Care Quality Commission. Experts by Experience. Updated July 28 2022. Accessed 25 April 2024.

<https://www.cqc.org.uk/about-us/jobs/experts-experience>

¹⁷ Farooq A. Hearing the voices of young patients. National Institute for Health and Care Excellence (NICE).

<https://www.nice.org.uk/news/blog/hearing-the-voices-of-young-patients> Accessed 26 April 2024.

It is now used widely and is often not defined explicitly, such as 'lived experience of self-harm or suicidality'.¹⁸

Patient and Public Involvement and Engagement (PPIE) - patient and public involvement in research is research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.¹⁹

Peer researcher - a community member, or person with relevant lived experience, who carries out research, often with some training and support from academic researchers.²⁰

Public - NIHR uses the term 'public' to include patients and potential patients, people who use health and social care services, carers, and people from organisations that represent people who use services [such as registered charities and community interest companies].²¹ We would add to this pregnant women and people, partners, parents of babies and toddlers, children and young people.

Public co-applicant - 'will help to develop, approve and sign the research application ahead of submission for funding.' They have 'the same level of responsibility as other co-applicants and should be considered an equal member of the team'.²¹

Public partners - as 'public' above.

PPIE adviser - this noun is sometimes used for those doing public involvement work, particularly at the consultation end of the involvement spectrum, rather than as a partner in co-production.

Service user - a person who uses health or social care services.

¹⁸ National Institute for Health Research. How to generate inclusive and diverse mental health patient and public involvement and engagement. July 2021 <https://www.nihr.ac.uk/blog/how-to-generate-inclusive-and-diverse-mental-health-patient-and-public-involvement-and-engagement/28061>

¹⁹ National Institute for Health Research. Patient and Public Involvement and Engagement Resource Pack. August 2022. <https://www.nihr.ac.uk/documents/patient-and-public-involvement-and-engagement-resource-pack/31218>

²⁰ See, for example, the presentation by Felicity Shenton, NIHR ARC North East North Cumbria, in our [first webinar](#).

²¹ NIHR Public co-applicants in research – guidance on roles and responsibilities. Accessed 26 April 2024. <https://www.learningforinvolvement.org.uk/content/resource/public-co-applicants-in-research-guidance-on-roles>