Difficult Situations in Public Involvement Workshop Report

NIHR | Applied Research Collaboration Oxford and Thames Valley

NIHR | Oxford Health Biomedical Research Centre

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NIHR | Community Healthcare MedTech and In Vitro Diagnostics Co-operative

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NUFFIELD DEPARTMENT OF **PRIMARY CARE** HEALTH SCIENCES
UNIVERSITY OF OXFORD

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NIHR | National Institute for Health and Care Research

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Foreword

For the most part, anyone who has anything to do with patient and public involvement (PPI) does so because they believe in it, and the value it brings to research. But there are times when we all want to walk away for any number of reasons – disappointing behaviour, lack of support, an absence of continuity, the mountains of administrative tasks to name a few. And, sadly, there is a small minority of people participating in PPI who do not have appropriate motivations or behaviours, which is another cause for uncomfortable or distressing situations.

Recently, several upsetting experiences brought the issue of what to do in difficult situations in PPI discussions to the front of our minds. This led to our group agreeing that this would be a highly relevant topic to address through the NIHR Centre for Engagement and Dissemination 'Learning from and strengthening regional infrastructure for involvement, engagement, and participation in health and care research' funding call, which we were funded to deliver.

The planning and implementation of this workshop highlighted how very needed this piece of work was. It was both apposite and unfortunate that the event itself brought up its own difficulties, but this made the topic all the more real and relevant for us. The workshop produced clear next steps and practical deliverables to support our community. What we are undertaking is significant both in terms of actual work and in the potential for what it can achieve; it is crucial for working towards a situation where everyone concerned with PPI feels that it is worth the time, energy and emotion that they commit. **– Polly Kerr, PPI Manager, Nuffield Department of Primary Care Health Sciences, reflecting the views of the organising group.**

Difficult Situations in Public Involvement Workshop – 31st March 2022

What were the aims? To host a workshop to capture the range of difficult situations that have, and can arise in public involvement, from a local perspective. The overall aim was to prioritise the support and resources required to address issues in the future.

Why this is important? To effectively involve members of the public in research there needs to be appropriate support and systems in place. As public involvement has evolved so extensively, there are increasing cases of difficulties with only experiential knowledge to guide solutions. All of this equates to many people experiencing upset, frustration and distress, which needs to be addressed.

What did we do? We rapidly created a community of stakeholders, including public contributors, public involvement staff, and researchers to develop and deliver an interactive workshop.

What were the outputs? A list of priority areas to take forward with the remainder of the funding from the Centre for Engagement and Dissemination. The Land of Research Map visually representing the successes and perils of public involvement from the workshop to aid further discussions and actions. A logic model to guide next steps.

What are the next steps? To develop an accredited training programme for public involvement staff. We will also share effective resources, templates and produce practical guidance to reduce the difficulties in involvement.

> *"The vast majority of the time public involvement activities are constructive, valuable, reciprocally beneficial and critical to effective research. However, sometimes things don't go to plan and the impacts can be distressing for all involved. Support is needed to prevent these situations arising in the first place and practical tools to guide individuals to manage and resolve issues if they do arise."*

Funding was awarded by the National Institute for Health and Care Research (NIHR) Centre for Engagement and Dissemination (CED) to run a project to support and improve regional working in public involvement. The Oxford and Thames Valley region has a strong collaboration for involvement with several groups including the Working Together group, Department of Primary Care Health Sciences Patient and Public Involvement (PPI) group and the NIHR Infrastructure PPI Leads Group. There is considerable overlap with the membership of these three groups all three elements build to provide an agile infrastructure to support public involvement in the region. For this project predominantly the NIHR Infrastructure Leads came together to identify a key area of focus for the project and to then develop the application. Funding was awarded to deliver a three phased project:

Phase 1: Host a workshop to discuss difficult situations in public involvement (March 2022).

Phase 2: Develop and pilot training and resources to support the prevention and management of difficult situations (April - December 2022).

Phase 3: Roll out the interventions developed and disseminate through CED's Learning for Involvement website and other mechanisms (January- March 2023).

Purpose of the Workshop

The aim of the workshop was to capture the full range of difficulties experienced or known about in our local public involvement community. The other focus of the workshop was to see what works well to identify processes, resources or experiences that could be shared. As this can be a challenging subject to discuss the workshop was designed with sections for individual stakeholder group discussions and whole community discussions to help all perspectives to be heard but shared. It was also suggested by one of the planning group members that a research illustrator may be a

way to bring some light into the discussions and create a resource that could be shared and prompt further discussions.

The outputs of the workshop were to be shared with Claire Planner and colleagues in Manchester who had hosted a similar workshop in 2018, to bring together the findings and plan the work needed in the next phase of this project.

Workshop planning

An organizing group was formed with a public contributor, a researcher and the NIHR infrastructure leads. The group;

- developed the agenda and timings for the day,
- chose the venue,
- suggested and linked with the illustrator,
- reviewed scenarios, provided from the Manchester event, and provided additional ones,
- identified need for photography and consent forms,
- co-facilitated the event,
- debriefed following the event and
- planned next steps.

Discussions with the illustrator led to the idea of a map, with images to annotate and support capture of the breakout groups' discussions and suggestions.

Scenarios (Annex 1) and workshop information was shared with participants in advance of the event.

Workshop overview

The workshop was hosted at Lady Margaret Hall in Oxford on the 31st of March 2022. Participants on the day included 7 Researchers, 10 Public contributors, and 7 public involvement staff.

The workshop started with an introduction and background to the piece of work and then some scenarios were presented to set the scene and give attendees a chance to reflect on situations they might have experienced. This was followed by break-out sessions which aimed to provide a 'safe space' for each group (public contributors, researchers, and public involvement staff) to talk about the difficult situations they have been in or know of. After lunch, the group came back together to share and discuss some of the topics that had come up, and to start to make recommendations

for handling these. Finally everyone had the opportunity to vote for the areas that they felt were most important to address first.

Figure 1 Collage of the photographs taken during the workshop

Workshop Outputs

The key points raised in the discussions were captured through the map which was built through the breakout sessions and the feedback discussion.

Figure 2 The Land of Research - coproduced mapping of research involvement - successes and perils. Final map produced following the event with the recommendations and priorities included.

Key: Flowers and Trees – Things to keep hold of, nurture and grow; Mountains – Challenges; Volcanoes – Frustrations; Boats – Ideas; Sea Monsters – Barriers; Houses – Community; Bridges – Ways forward.

The final session of the day looked to capture the key next steps, recommendations and things to share. These are listed below and the participants then voted on them in the dot-democracy session.

Key Themes

Training

The need for and lack of training for everyone involved with PPI was voiced loud and clear throughout the day. There needs to be a baseline for everyone that is consistent

and rigorous, and provides clarity over what the role of a PPI contributor is. Training in the following areas was suggested (tailored as appropriate):

- Communication/interpersonal skills
- Legal/ethical frameworks (including GDPR)
- Research landscape
- How to read and write proposals
- Working with under-served communities
- How to handle difficult situations and/or conflict resolution

The overwhelming consensus was that PPI training with proper recognition/accreditation would be highly valuable.

Systems and processes

One suggestion was that researchers should have 'pre-meetings' with potential PPI contributors to ensure that what is being expected and offered is understood by both sides. Everyone would then be able to agree to roles, responsibilities, and a code of conduct which would hopefully go some way to preventing difficult situations arising, and providing a mechanism for resolution if they do.

There needs to be a clear, known process for managing difficult situations, with a reporting process for when things go wrong, who to speak to, and a procedure for how to escalate issues.

It would be helpful to have better communication between the PPI contributions and ethics approval processes, so that if there are differences of opinion, researchers are not caught in the middle.

Culture and expectations

Researchers need to have the right motivations for doing PPI – there needs to be mutual respect and more transparency around why PPI is being done. PPI contributors also need to be responsible for self-regulation and calling out unacceptable behaviour – this ties in with the importance of them having the right motivation for PPI.

PPI contributors need feedback so they can develop – this is something that is consistently mentioned as missing and shows a lack of courtesy but also a lost opportunity to help contributors to learn and develop.

There is a general lack of senior support/endorsement for PPI in academic departments, and the wider infrastructure is often not conducive to easy and straightforward PPI.

PPI is maturing and needs to be done appropriately.

Recommendations for improved public involvement

Better system for feedback.

Value – public involvement is as important a part of research as any other element.

Sign up for code of conduct.

Better communication and feedback between ethics committees and PPI input.

Development of mutual respect.

Self-regulation – call out unacceptable behaviour.

Learn from others (need a mechanism).

Build support for PPI (e.g. from ethics committees, senior staff).

Recognition of skills – PPI leads need qualification.

PPI modules for students.

Pre-meetings (i.e. informal chat before starting PPI work with someone).

Things to share

Biomedical Research Centre's code of expectations and escalation (who and how).

Good experiences.

Terms of reference.

Modules developed for PPI, for health and care students (Nottingham example).

Ben Goldacre experience.

Training examples (Share Bank).

Dot Democracy

The potential areas to focus on were listed and attendees asked to vote for their top two for prioritisation – results are shown below.

Training was the clear priority with nine votes. Further discussions clarified that the first step would be to provide an accredited training course for public involvement professionals.

It is worth noting that as well as being the top issue by some margin, training was included in some of the other points.
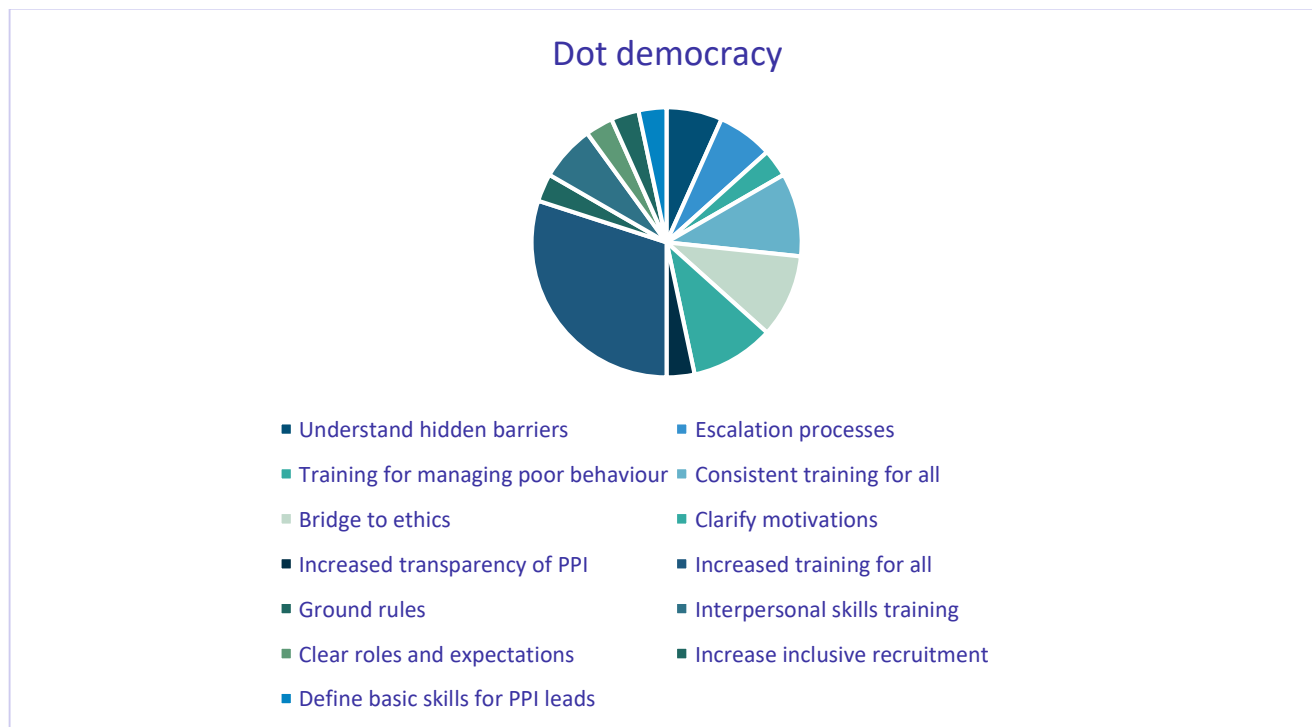

Dot democracy

- Understand hidden barriers
- Escalation processes
- Training for managing poor behaviour
- Consistent training for all
- Bridge to ethics
- Clarify motivations
- Increased transparency of PPI
- Increased training for all
- Ground rules
- Interpersonal skills training
- Clear roles and expectations
- Increase inclusive recruitment
- Define basic skills for PPI leads

Figure 3 Summary of the voting results from the dot democracy exercise.

Logic Model to Guide Next Steps

Following the workshop the organising group met to debrief and share outputs, learning and priorities with the team in Manchester. The key areas of focus were around the organisation of the event and similar events, training and the need to get the systems and processes in place first before we start to look at broader areas. The main thing from the group's perspective was to provide some accredited training for public involvement leads and staff, relevant to the position they are in, entry, intermediate or senior level. This would provide recognition for the skills required to be a public involvement member of staff as the roles vary considerably but there are

key skills required including: community engagement skills, pastoral support, people management, organisational, management, and strategic.
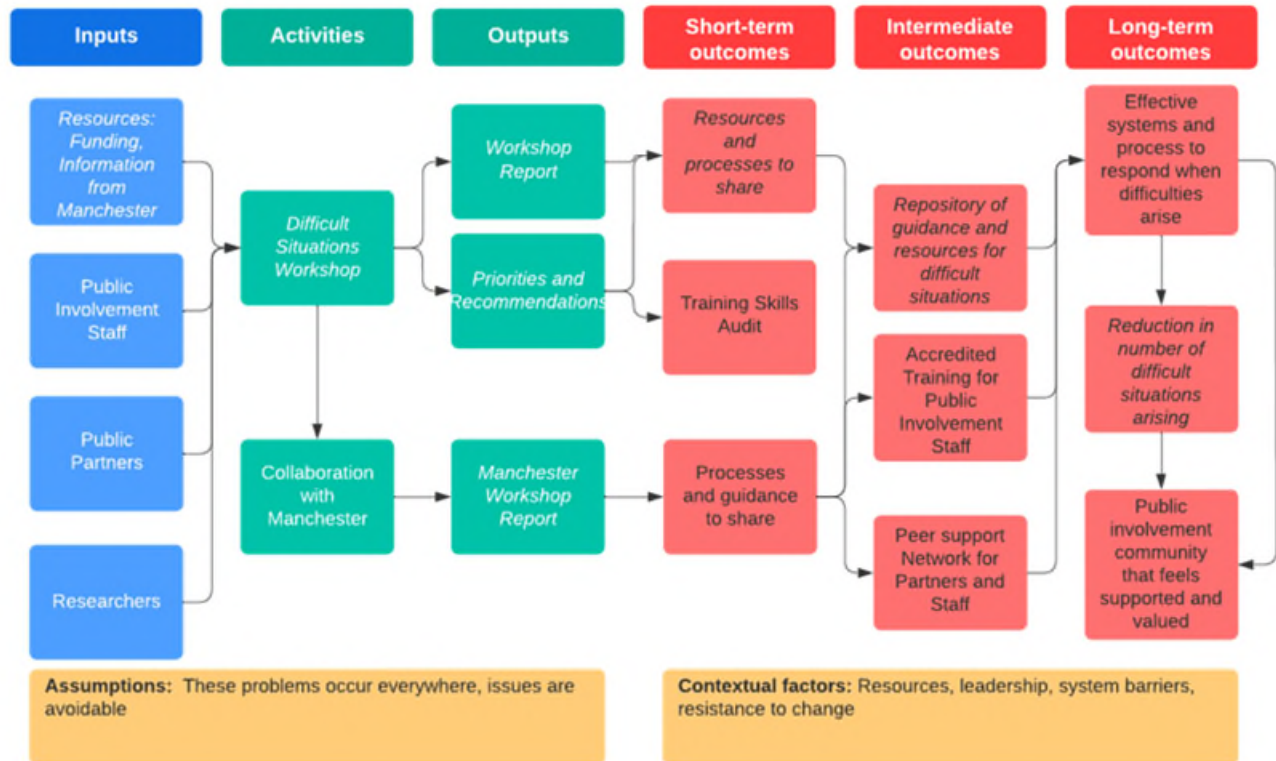

Figure 4 Logic model generated from the prioritised list of next steps and discussions with Manchester.

A skills training audit will be carried out to capture the full extent of the skills required at each level. The complexity of these positions are not readily recognised in the system and there is currently no clear career trajectory for staff. Our public contributors felt that by achieving an accreditation and being formally trained to be a public involvement lead would better equip staff and instil a level of authority and recognition which is often missing. This work will be led by the group in Oxford and Manchester will share their guidance on event planning to ensure genuine co-production, discussions and processes they have implemented locally, including human resources support from the institution.

Many of the other areas flagged by the group already have available resources to support so we will gather these together to produce a resource repository which will

be openly shared through the Learning for Involvement website and other mechanism, to reduce future duplication and improve consistency in approaches.

Lessons Learnt and Workshop Feedback

Reflections on the process and day from the organizing group
What didn't work well? The rapid nature of the development of the workshop (less than one month from start to delivery) produced its own constraints and difficulties. While we worked collaboratively to plan the workshop it was not truly co-produced with tasks having to be delegated and often actioned in isolation. The issues this raised included:

- Selection of partners to shape the day (public partners and researchers).
- Venue choice was limited; there was only one date for the workshop which limited the attendance.
- There was not time to visit the venue in person and this meant that there were no discussions about allocation of breakout rooms, no understanding of the acoustics in the rooms or other factors. On the day there was confusion as to which group was in which room and where the rooms were.
- Access to external facilitators was hindered by the short timescale, but fortunately we found a facilitator who ran the event incredibly well. However, we felt it would be best to have a peer facilitator for each of the breakout sessions and that responsibility fell to the organizing committee group which meant that as we only had one public partner and one researcher that that role fell to them. In hindsight this wasn't particularly fair and independent facilitators for each of the breakout rooms would have been more appropriate. Facilitator briefing notes where created but on the day because of the layout and the arrangements things became much more fluid and therefore the facilitation of the public group changed. This was incredibly disorientating for our public partner and caused distress which was the last thing we wanted.
- A disruptive participant caused difficulties for the facilitator and other members of the breakout group, with inappropriate comments and little interaction with the discussions. When the facilitator sought support to manage the individual, the organisers were not aware of the extent of the issue so were unable to effectively support. Other PPI contributors attempted to 'self-regulate', this

clearly did not work. Despite expectations being shared ahead of the workshop and reiterated in the introduction there was no clear resolution at the time. On reflection, all agreed that PPI contributors should be asked to state 'why they wish to attend an event, what they hope to take away from it, and what they hope to contribute on the day."

What worked well? Overall the response to the event was very positive and we had sufficient numbers from each stakeholder group from which to draw our insights.

- Accommodations were made for participants with the use of a hearing loop, onsite parking, dietary requirements and providing space for Friday prayers during the breakout session.
- The atmosphere was positive for the duration of the workshop and there was good contribution from participants.
- We captured a lot of information and some additional issues that will be raised with NIHR directly as pertain to funding panels.
- People were enthusiastic as it was the first in-person event since the pandemic and the social interaction was appreciated.

Workshop Feedback Summary

Everyone who responded (12 participants) said that they had the chance to say everything they wanted to on the day, and they were confident that action would happen as a result although one person thought there were some barriers that would need more high level input.

Among the things gained from the workshop, respondents cited getting insight and understanding into the challenges facing other groups, as well as the chance to meet other people and listen to their needs. Attendees had also welcomed the opportunity to reflect on PPI and its value – and the importance of doing it well.

A couple of people said they would have liked longer in the break-out rooms and a clearer briefing of the purpose of those sessions. There was also some feedback that people would have liked to hear more fully about what was discussed in the other break-out rooms. Overall there was a feeling that the workshop was much needed and well run, and people are enthusiastic about next steps.

Participant Feedback Quotes:

'It feels as if the gaps are beginning to be filled and that there is a real desire and feeling of empowerment to make positive change.'

'Really impressed by all the constructive comments received from all contributors.'

'Insight into issues facing PPI leads and researchers.'
'Much needed excellent session – thanks to all!'
'Good identification of issues and common purpose towards solutions.'

Acknowledgements

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Thank you to Esther van Vliet for her excellent facilitation of the workshop and bringing support for this project from the School for Primary Care Research.

Thank you also to Carmen Byrne, freelance visual artist and researcher (narrative specialist) for her creative input and fabulous artwork which will provide a useful record of the day and facilitate future discussions.

Thank you to Claire Planner, Rebecca Morris and Sally Giles for their insights and outputs from their 2018 workshop in Manchester.

Finally we would like to thank all the participants on the day for their contributions and ongoing support for this work.

If you have any queries about the content of this report please contact:

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Annex 1 Scenarios

Managing expectations
PPI contributors agreeing to the proposal before submission, but then wanting to change direction of research once received funding. Anticipating a one-and-a-half/two-hour max read time, but PPI contributor asks for 8 hours for payment. The expectation on public contributors that they will know how to give feedback on academic work or review lay summaries/ papers. Expectations placed on role of co-applicant vs public contributors being volunteers and how much can be asked from volunteers. Lack of boundaries – egg public contributors phoning regularly, seeing PPI staff as friends. PPI not seen as a priority – maybe delegated to more junior (female) researchers. Many demands on researchers' time. Public members misinterpreting discussions which leads to assumptions being made egg offer of a job assumed when all that was said was 'it would be great to work with you' to conclude an initial conversation. Understanding that it is all right to agree – some public contributors feel they have not done their job if there are no tangible changes so changes are added for the sake of it, not out of a genuine need – we need to value validation.

Finance
PPI contributors wanting to be paid beyond the CED/ INVOLVE rates. Public contributors refusing to complete the paperwork required by university policy to be completed to allow for payment, but still demanding payment. Finance systems being inflexible and payment taking a long time. Public contributors with experience of abuse felt coerced into agreeing with the researchers because they were being paid for their involvement. Public contributor taking advantage of the system, offering lived experience and requiring first class travel and accommodation for him and his caregiver (his wife) then always fell ill on the day of presentation but still claimed fee. This was happening across multiple charities and projects including international travel to

present at conferences – when challenged he threatened legal action on grounds of discrimination. Caused very serious distress to multiple staff members. Not able to share experience as open up to legal challenge so others were then hurt in the same way.

Virtual working

People not turning camera or microphone on, and not interacting.

Activities having been done virtually for some time have enabled broader geographic reach but how to now do things in-person that don't exclude those living further away?

Technical difficulties – less functionality egg on Teams.

Inappropriate comments in chat.

Inclusion

Difficulty with recruiting patients who are extremely unwell.

From PPI lead perspective; working with positive discrimination where you choose public contributors solely because of their EDI data, actively excluding people who comply to "the usual profile"

Perception of very experienced PPI contributor being too specialist/ too much a researcher to still give PPI input, making experienced PPI contributors feel like they don't have a place.

How to deal with letting people go from PPI groups (as budgets limited) to allow space for new people, avoiding making people invalidated etc.

Fear of upsetting public contributors by using the wrong terminology.

Meetings

PPI contributor repeatedly fails to respond to emails (not completing requested tasks), but still turns up to meetings (disrupted meetings as several steps behind other members).

PPI contributors developing a deep dislike of other PPI contributors...more for early career researchers who aren't sure how to deal with this communication.

a public contributor struggled with an online event as they saw there was a public contributor there with whom they had a very difficult experience and they were very

anxious about being in the same meeting and potentially put in the same break-out room (in this case, organisers didn't know about previous relationships in place).

Use of acronyms that are particular to Oxford, as well as to research.

Bringing personal/emotional issues to meetings egg COVID trial where people had experienced great trauma and approached the PPI meeting as though it was a therapy session.

Researchers pitching presentations inappropriately (i.e. for academic rather than public audience) despite briefing beforehand.

Researchers recognising that challenge is positive not a threat.