

PPI workforce career recognition and training

Funded by NIHR Centre for Engagement and Dissemination



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in collaboration with the project team

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BACKGROUND

A range of difficult situations can arise during PPI activities but it is often challenging to find appropriate forums to address these. At the end of 2021 the NIHR Centre for Engagement and Dissemination (CED) put out a call to address the theme ‘Learning from and strengthening regional infrastructure for involvement, engagement and participation in health and care research’. Spurred on by a – then – recent challenging incident we submitted a proposal on ways of resolving such difficult situations. The incident in question had been one of poor behaviour but as we were working on our proposal other scenarios and concerns came to mind, including lack of support for PPI, the challenges of carrying out PPI activities online, and the significant administrative burden.

We were awarded funding to hold a workshop to capture the range of difficult situations experienced by PPI staff, researchers and public contributors, from their differing perspectives. Our overall aim was to prioritise support and resources required to address such issues in the future.

Due to the conditions of funding (less than three months for the project) the workshop needed to be planned and delivered rapidly which was challenging – everyone involved was doing this in addition to their day jobs – and ironically meant that on the day, we were presented with our own difficult situation as a result of one facilitator feeling inadequately prepared.

While planning the workshop, we liaised with colleagues at the Centre for Primary Care in Manchester who had done a similar piece of work a few years ago. We were keen to ensure that our workshop did not duplicate what they had already done and rather that it would complement their work.

The workshop brought together researchers, public contributors and PPI staff at an Oxford college. The day began with context-setting using some examples of difficult situations from the point of view of

each stakeholder group; this was followed by break-out sessions to discuss other issues that we had come across, along with any ideas of how to address these; after lunch there was a group discussion and a 'dot democracy' exercise to establish priorities for work.

Together, we developed three main themes from the day:

- Systems and processes eg setting codes of conduct; pre-meetings with contributors to ensure expectations are understood; a procedure to follow if something goes wrong.
- Culture and expectations eg all parties having the right motivations for doing PPI; the importance of feedback; the need for senior support and endorsement for PPI.
- Training.

The need for and lack of training for everyone involved with PPI was clearly the most important priority for people attending our workshop (the full report is available to read [here](#)).

The work done by our colleagues in Manchester had focused on improving processes and increasing support for public contributors and researchers through training and mentoring. Through our discussions we agreed that what is missing and not being addressed is any sort of career recognition or training for PPI staff. A clear message from the workshop – including from public contributors – was that PPI staff need to be well-equipped and supported in order to do their role well and effectively. There needs to be appropriate support and systems in place to properly involve members of the public in research. Even as public involvement has evolved extensively, and the PPI workforce has developed a wealth of experiential knowledge in this area, we noted that such knowledge is not in itself enough, and that systems and support are also required to guide solutions when difficulties come up. This reflects findings previously highlighted in 2016 at an INVOLVE event for PPI leads, and again in 2018 in the PPI workforce survey.

Additional funding was awarded to pilot resources to provide recognition for the key skills required by PPI staff for their role, as per the recommendations. This would be done through training and the establishment of a career pathway that acknowledges the experience and knowledge that PPI staff develop.

COLLABORATING PARTNERS

A small group of colleagues who had been involved in the original project were keen to take this work forward. We sought out other colleagues, in addition to those in Manchester with whom we had already been in contact, who we knew were doing similar work and invited them to contribute. We wanted to ensure that we did not duplicate existing work but rather built on it. At this point, Stan Papoulias joined the project team as a service user researcher working with NIHR ARC South London.

Further information about the related work being done by Stan and others is available in appendix 1.

PPI WORKFORCE SURVEY

To gather further evidence a survey of the workforce was planned to determine what training they felt would be useful, and what skills and abilities are needed for PPI staff roles. We developed a short, anonymous survey which asked about these areas, as well as questions about how long people had worked in PPI, what percentage of their role was allocated to PPI and whether their PPI post was funded by NIHR. We did not ask what FTE people worked in total as we felt this could compromise anonymity. All questions were optional, and we sent a separate demographic questionnaire.

The survey was distributed widely across multiple NIHR networks and beyond to ensure the resources were as widely applicable as possible.

The full survey and accompanying background text are in appendices 2 and 3.

General survey findings

In total 82 people responded to the main survey with 36 completing the demographic information. Slightly more than two-thirds of respondents were wholly or partly funded by NIHR for their PPI role – many people said that PPI was only part of their job; a noticeable number said that PPI was not in their job description at all.

The data we obtained was rich and wide-ranging, with respondents being very generous with what they shared. The responses were quite consistent with similar issues and themes being raised numerous times. It is worth noting that while nobody on the project team was surprised by the survey findings, nevertheless we were all aware that the issues, challenges and skills identified are not well understood beyond the PPI workforce itself.

Some key themes from the three main questions are summarised below.

What do you wish you had known?	What skills/experience have been useful?	What training/knowledge would help?
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<p>The time required to do PPI well</p> <p>Difficulties and lack of clarity or consistency around how to do things eg payments, but also bureaucratic constraints</p> <p>How broad the job is, but also how it can 'creep' and gradually encompass more and more tasks</p> <p>Tokenistic PPI, lack of senior support, how it can be seen as a bit 'frivolous'</p>	<p>Communication skills</p> <p>Facilitation/chairing experience</p> <p>Being a good listener</p> <p>Organisational skills</p> <p>'People skills'</p> <p>EDI awareness</p> <p>Understanding of research (process)</p>	<p>Facilitation</p> <p>Leadership/influencing</p> <p>Capturing and measuring impact</p> <p>Diversity literacy</p>
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COMPETENCIES FRAMEWORK

There were many recurring themes and issues, and members of the project team individually did a broad thematic analysis of the responses. We then came together to compare them and identify competency areas. We also looked at a competencies framework co-created by Cancer Research UK a few years ago for PPI staff working in that organisation (see appendix 4), and drew on findings from work done by INVOLVE around the needs of the PPI workforce.

A framework of five competencies emerged which was broken up into different levels of experience: developing, capable and proficient. These reflect the competencies needed in job descriptions for public involvement leads and also provide a framework for capacity development and career progression.

The project group met with our colleagues from Manchester and three public contributors to discuss and refine the framework. That meeting led to some competencies being split into 'essential' and 'desirable'; there was also discussion around how many of the skills in the framework are regarded as 'soft' which can be hard to measure or show their impact because there are few tangible outputs. For example, trust (ie between PPI staff and public contributors) is a key measure but difficult to demonstrate.

It was agreed that the framework could be further developed and adapted over time, but had already had considerable input and we had to recognise the limits of this project in terms of time and resource. However, we are keen to seek NIHR support for it and would like to see a plan for its implementation

across NIHR, ideally supported by the NIHR Academy.

The current version of the framework can be seen in appendix 5.

FACILITATION TRAINING WORKSHOPS

Concurrent to the framework development, a mapping exercise was done of existing training that would address the areas identified in the survey responses, and the broader competencies that emerged (appendix 6). While we recognise that the mapping may not have been completely exhaustive, it was clear that there is a gap in appropriate facilitation training for PPI staff, particularly in managing potential difficult situations.

It was suggested that forum theatre, which had been used for a training session by the team in Manchester, could be an effective format for such training. Forum theatre encourages audience interaction and considers different options for dealing with a problem or concern, allowing participants to work through issues and explore solutions.

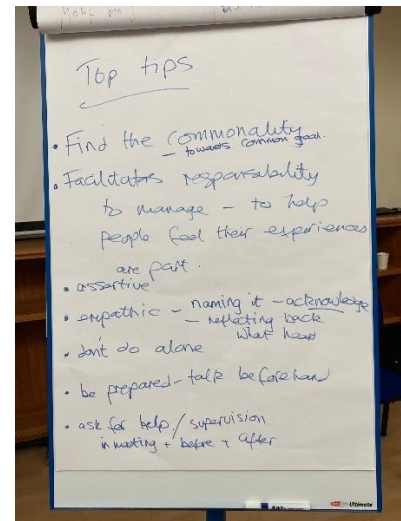
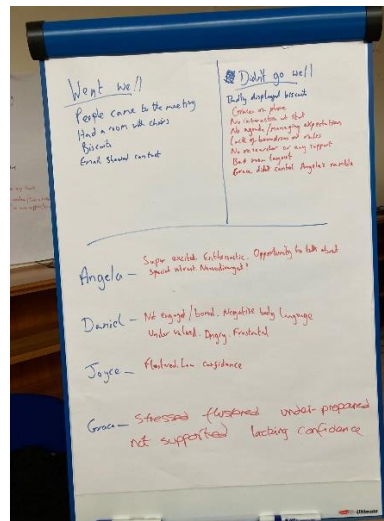
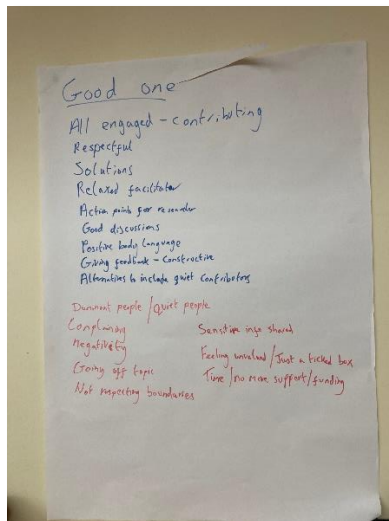
We worked with Janet Allison, a clinical educationist with experience in PPI in medical teaching, to develop two training sessions, one in-person and one online, considering difficult scenarios that can occur in PPI. To ensure that these were as realistic as possible, Janet spoke separately with both public contributors and PPI staff to hear about their experiences, such as people arriving late, one person dominating a discussion, rude or offensive comments being made, struggling with technology. This meant that the scenarios which were written for the training were rooted in real-life situations, although they were adapted for the training, and at all times anonymity was maintained.

It was decided by all involved, including our collaborating public contributors, that the workshops would only be for PPI staff, so they could feel fully at ease.

The in-person training session took place in Oxford and was attended by 20 local PPI staff, most of whom had met each other before. The online one took place the following day attended by 20 people from across England, a minority of whom knew each other. In both groups there was a range of experience of working in PPI from a few months to several years. This format enabled those with more experience to share solutions and practice, showing that having multiple levels of experience in the workshop was beneficial, and also helped to strengthen peer support networks beyond those sessions.

Both workshops followed a similar structure beginning with some background, introductions and context-setting. Two specific scenarios were presented: the first featured the start of a meeting of a new PPI group and the second enacted a challenging situation erupting in the course of a PPI group meeting. Professional actors played the roles of PPI contributors while Janet took the role of a relatively

inexperienced PPI staff member. The purpose of the forum theatre approach is to actively involve the audience in the scenarios and enable them to suggest different possible solutions to the problems shown, which are then acted out. This set-up enabled PPI leads to work together, learn from each other and reflect on how to best prevent such challenges from arising in the first place. The workshops ended with some recommendations which included asking for support before, during and after a meeting if needed, and the importance of empathy.



EVALUATION

We asked attendees to complete a short feedback form after taking part. The workshops were

evaluated mostly positively and there were rich suggestions for refinement and improvement – a summary of the feedback is available in appendix 7. It was noticeable that there was clearly a need for this training and that nobody in either session had ever taken part in anything at all similar.

The workshops mainly addressed the ‘facilitation’ competency but also covered elements of ‘communication/influencing’, ‘organisational’ and ‘diversity literacy’ demonstrating a broad applicability. It is important to recognise that this form of training was new to most attendees and, as cited by some in the evaluation forms, offered the opportunity for experiential learning in a safe environment.

RECOMMENDATIONS

In collaboration with our colleagues doing work in this area, we have come up with some recommendations which we would push for NIHR to take forward.

- Support increasing the visibility of the PPI workforce.
- Recognise the range and depth of skills required for the role.
- Approve the competency framework and begin implementation across NIHR.
- Support the creation of a PPI career pathway.
- Develop a recognised training programme.
- Consider PPI fellowships.

NEXT STEPS

This work was presented on 30th November 2023 along with three other presentations by NIHR funded PPIE colleagues at a ‘necessary conversation’ meeting hosted by CED and to which senior NIHR staff were invited. The overall theme of the meeting was the hidden labour of PPI and our presentations supported our argument that we are now reaching a tipping point where the field has evolved hugely but without the necessary support and resources keeping up.

A number of actions were identified from the meeting including following up with NIHR Academy to discuss a training programme, and a pledge to establish a definitive list of NIHR PPI leads.

We have contacted Sophie Staniszewska at the University of Warwick about work she is planning on a PPI framework for PhD and post-doc researchers. We will share the work we have done to ensure these projects are aligned. In addition, we asked Sophie, in her role as Editor of *Research Involvement and Engagement*, about a special issue on the topic of ‘hidden labour in PPI’ and this is planned for 2025.

Based on the feedback we received, we are now developing four further training workshops with the same acting team, to be delivered online and in-person in March: the two in-person ones will take place

in London through Stan Papoulias and NIHR ARC South London. These will follow a similar format to the pilots but be shorter and specifically aimed at PPI staff with different levels of experience.

Please see our logic model for this work in the separate document.

This project builds on an issue that has been identified previously, and brings together work that evidences its importance. We have proposed solutions and are keen to see NIHR take these up and support their implementation.

ACKNOWLEDGEMENTS

Project team

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Training workshops team

Janet Allison, Krage Brown, Karen Ford, Elizabeth Hughes

With great thanks for their input to:

Douglas Findlay, Sally Giles, Moira Lyons, Georgina McMasters, Rebecca Morris, Claire Planner, Jo Welsman

APPENDICES

1

It is important to give credit to the colleagues whose work has contributed to this project, and which we were keen to ensure was built on rather than duplicated.

Tracking the labour of the NIHR PPI workforce

Stan Papoulias, Deputy Theme Lead for PPI Research, NIHR ARC South London

Background

Workers tasked with specific responsibilities around PPI are now routinely part of the organisational landscape for applied health research in the UK. The NIHR has played a key role in establishing this workforce in order to both facilitate the embedding of public contributions in research projects and – increasingly – to deliver PPI strategy across research centres, NHS trusts and other stakeholders regionally. However, there is currently little research investigating the challenges and concerns of PPI staff. More attention to these is necessary to optimise PPI, especially as expectations on inclusive practice and engagement with underserved communities are now the norm for NIHR and other major health research funders.

Methods

Qualitative study with participatory elements, co-designed with PPI practitioners and public contributors working with the NIHR CLAHRC and ARC South London. Using purposive and snowball sampling and attending to regional and institutional diversity, we conducted 21 semi-structured interviews with individuals holding NIHR-funded formal PPI roles across England. Interviews were analysed through reflexive thematic analysis with coding and framing presented and adjusted through two workshops with study participants.

Results

We generated six overarching themes which signal a growing tension between expectations put on staff in PPI roles and the structural limitations of these roles: a blurring between supporting and undertaking PPI; PPI leads perceiving PPI as moral obligation rather than ‘just’ work; “doing the PPI” as a conjuring act where the labour involved is invisible to others; PPI leads being held accountable for outcomes they cannot control; PPI leads expected to deliver institutional change in name only.

Conclusions

We conclude that a clearer role demarcation and better resourcing for PPI staff is necessary. However, we also argue that better resourcing is not sufficient: meaningful integration of the expertise that both the PPI workforce and patients/service users bring to applied health research can only be achieved through a broader transformation in research institutions and systems.

Managing difficult situations in public involvement: a co-production event

Claire Planner, University of Manchester Centre for Primary Care

A blog about the work done by PPI colleagues at the University of Manchester Centre for Primary Care is available here: <https://www.spcr.nihr.ac.uk/news/blog/managing-difficult-situations-in-public-involvement-a-co-production-event>

Exploring the emotional labour experienced by patient and public involvement professionals when working with public contributors in health and social care research environments

Jo Welsman, Strategic Lead for Patient and Public Involvement, NIHR Research Support Service, University of York

Liz James, freelance qualitative researcher

(This work was supported and funded by NIHR Research Design Service South West)

Background

The role of the PPI professional is unique and brings with it expectations to create an environment where patients and public contributors feel safe to share their experiences. These experiences can be painful, traumatic and deeply personal. Managing your own and others' emotions whilst carrying out professional responsibilities entails "emotional labour". Emotional labour describes the work involved in dealing with other people's feelings. It also relates to the regulation of one's own emotions during that work. We were interested in hearing about the experiences of PPI professionals and how they cope personally with emotional labour. We were also interested in identifying sources and examples of emotional labour within PPI work, the impact of this on the PPI professional and how individuals cope within a complex and demanding role. We were also keen to identify what training, support or supervision is currently provided and what PPI professionals identify as needed to support their work.

Methods

Qualitative study co-designed with a stakeholder group of PPI professionals and public contributors. Using purposive and snowball sampling to reach PPI professionals working in NIHR, NHS or University departments across England, we conducted 21 semi-structured interviews during Summer 2023. Interviews were coded and themes and subthemes identified by the two researchers. Initial thematic ideas were shared, and further interpretation informed by our stakeholder group.

Results

Data analysis and interpretation is ongoing but key sources of emotional labour came from the complex relational work undertaken by PPI professionals, largely in an unregulated space with little or no training, or support. PPI professionals drew on their experiences and training in previous more regulated careers such as teaching, nursing and social work to set and navigate boundaries and develop policies and processes for managing relational work, difficult situations and their own emotional triggers. Peers, families and partners provided necessary emotional support in the

absence of professional supervision although there were examples of good practice provided in teams having other professional backgrounds (e.g. social work). Managing safeguarding issues without appropriate support was not unusual. National priorities such as efforts to promote the involvement of underserved communities without training or infrastructural support were noted as a source of considerable emotional labour. Participants clearly articulated extensive policy, training and support needs to underpin the profession.

Conclusions

PPI staff work often in isolation with little understanding from other staff of the hidden complexity and emotionally demanding nature of their role. There are many challenges of working in an unregulated space with people who may well be “at risk”. The role urgently needs a national regularised underpinning with training, supervision and policies that meet the needs of PPI professionals.

2 Survey for PPI leads – see separate document

3 Additional background information to accompany survey

We would like to invite you to complete a short, anonymous survey on the challenges and support needs in your role as part of the PPI workforce. This survey is part of a larger piece of work, the aim of which is to create a competencies framework alongside relevant training, some of which already exists. This can be used nationally to raise the profile of PPI and recognise it as a career, with opportunities for learning and development.

This survey is being carried out by PPI staff in Oxford with input from colleagues across England. Although funded by NIHR Centre for Engagement and Dissemination (CED), it is not being led and no data is being collected by them.

The NIHR region of Oxford and Thames Valley was awarded funding through the NIHR CED call for proposals on ‘Understanding and strengthening regional infrastructure for involvement, engagement and participation’ to carry out a workshop to consider how to manage difficult situations when they arise in PPI (see workshop final report [here](#)).

A key outcome of this was the need to develop accreditation, with accompanying training, for PPI staff, and NIHR CED have provided additional money to fund this work.

In order for this to be successful and able to be implemented, we need input from you as PPI staff. We would be grateful if you can answer this [short, anonymous survey](#) by Thursday 1st December. We are also, separately, collecting [demographic information](#) – although providing this is optional, it will help us to understand the demographics of the PPI workforce, and to better tailor the training that is offered.

We would like this work to be applicable to all PPI staff, not just those working for NIHR organisations. We are keen to hear from a range of organisations (in terms of eg geographical area, size of PPI team, amount of funding) so please feel free to share this survey with PPI colleagues. This work is specific to PPI in the research context, but we know that many people's roles span service delivery as well and it may not be possible to separate these.

Public contributors took part in our initial workshop and are also being surveyed about their expectations of the role of PPI staff.

Thank you very much for your input. For more information about this project, please contact polly.kerr@phc.ox.ac.uk

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4 CRUK Patient Involvement Core Competencies Framework – see separate document

5 Current PPI competencies framework informed by this work – see separate document

6 Mapping of existing relevant training – see separate document

7 Summary of feedback from forum theatre workshops

Overall impressions

Responses were very positive and enthusiastic. Both online and in-person sessions were greatly appreciated – while online participants were very positive about an in-person session, it is clear that a virtual session is also needed as many PPI meetings are online and have specific challenges.

At the in-person workshop there was a feeling of positivity and energy in the room – lots of chat, everyone spoke, it was a 'safe space to share and discuss', it felt very warm and there was lots of laughter.

At the online workshop there was good use of the chat function, most people spoke and break-out rooms seemed to be successful.

Overall participants' responses show that the workshop tapped into a genuine need for the PPI workforce.

Positives

- Forum theatre: it provided people with practical hands-on training (rather than sitting through more lectures, tips etc), they enjoyed the 'experiential, interactive learning', 'working together to change the outcome'.
- Hearing tips and suggestions from others' experience: 'getting practical advice', 'being with 'experienced [PPI] facilitators'.
- Being together in a 'safe space' where difficult issues could be discussed openly.
- Training was original, creative and fun.

Attendees listed a range of benefits – a lot of them tangible, practical actions – that they would take away:

- increased awareness of complexities of facilitating
- the importance of asking for help
- prep with public contributors
- acknowledge and hear all voices, show empathy
- manage expectations
- be assertive – creates safety and confidence
- confidence and techniques to put into practice for managing challenging PPI situations
- strategies to de-escalate

Unanticipated benefits

By foregrounding the skill of facilitation, the workshop also demonstrated to PPI staff their value and skills, which was empowering.

By making the need for good preparation visible, the scenarios vividly brought to the fore how much hidden labour there is in PPI.

Challenges

The IT problems at the in-person workshop were very stressful and led to the organisers and external facilitator feeling stressed and anxious. It also meant the videos that had been carefully prepared could not all be used. Lots of learning here for organisers!

Timing – always hard to get right, some would have liked longer to discuss the scenarios.

It was felt by some that there were dominant voices in the online workshop discussions. There was also mention of some jokes that could be insensitive (around mental health conditions). This shows that considerable challenges may still arise even for very skilled facilitators, further demonstrating the need for such training.

Furthermore, some observed that since facilitation scenarios often include potentially upsetting content (by necessity) perhaps a prior warning could be helpful 'might be helpful to also consider how dealing with people who have been harmed/are grieving day in day out might affect PPI leads?'.

Suggestions for improvement

The workshop was perceived by many as two-level, with the first scenario being more appropriate for new PPI staff and the second for more experienced staff (although one participant felt that the whole thing was too introductory!!).

A couple of participants felt uneasy about the conventions of forum theatre: having the 'improved' scenario stop and start and hearing the characters' feelings (diary room).

Generally participants would have preferred:

- the content to have been different levels potentially 90 minutes each or longer (some spoke of a longer 'module')
- more scenarios
- time for discussion and reflection at end
- two facilitators for the online version ie one person to be responsible for comments in chat
- someone suggested putting subtitles on videos

Word cloud of words used to describe the in-person workshop

