

Using cartoon vignettes to understand and better resource patient and public involvement and engagement (PPIE) labour in research

Stan Papoulias Alison Faulkner



Table of contents

Plain English summary	3
Why this work is needed	4
What we set out to do	6
What we aimed to achieve	6
What we did	6
What we found: shared challenges	7
What we found: changes needed	15
What it all means	27
What next	29
Acknowledgements	30
References	30

Using cartoon vignettes to understand and better resource patient and public involvement and engagement (PPIE) labour in research
© 2026 by Stan Papoulias and Alison Faulkner is licensed under CC BY-NC 4.0. To view a copy of this license, visit <https://creativecommons.org/licenses/by-nc/4.0/>

Plain English summary

This project aimed to better understand the challenges facing the patient and public involvement and engagement (PPIE) workforce and find out what needs to change to address them. In a previous study we found that the PPIE role is poorly understood and undervalued and our findings fed into recommendations to strengthen sustainable support, provide better resourcing and encourage 'fit for purpose' reporting and learning. A series of graphic images was produced to communicate our findings. These images were used as the starting point for the conversations that took place for the present project.

We carried out eight focus groups between July and October 2025. We reached 37 participants; all had experience of working in PPIE; some had lived experience and some were senior academics. Interviews were transcribed and analysed by the project team.

Challenges found: 1. Limited agency in research systems: UK research systems prioritise academic researchers, while PPIE is often left to professional services' staff whose work is short-term and reactive, and who have few opportunities for career progression. 2. Feeling stuck in the middle: PPIE workers are caught between the researchers and the public contributors or community organisations. This can result in significant emotional costs. 3. Disconnect between PPIE work and academic work: the complexity and time consuming nature of PPIE work is not understood and PPIE workers can feel isolated and deskilled. 4. Institutionalisation of PPIE: top down mandates from funders for PPIE have contributed to tokenism, along with a weakening of the patient/public voice for change.

Changes proposed: 1. Recognition of PPIE worker roles/profession: PPIE work to be better costed, availability of robust training and support for career progression. 2. Firming role boundaries – managing relationships: guidelines, support and training to manage the emotional costs of being stuck in the middle. 3. Embedding PPIE work across research systems: PPIE work to be better distributed and embedded across research systems, teams and departments. 4. System transformation and power redistribution: Research structures and funding plans need a longer-term vision, substantial provision for community engagement and stronger PPIE leadership built in.

In conclusion, our study highlights the urgent need for long term investment in the PPIE workforce, for the skills and the work of PPIE workers to be valued and recognised, and for PPIE to be better integrated within research work and teams. The negative impact of such barriers is likely to grow as the expectations on delivering PPIE also grow. Addressing these barriers now by investing in long term systems' change is urgent.

Using cartoon vignettes to understand and better resource patient and public involvement and engagement (PPIE)¹ labour in research

Why this work is needed

The PPIE workforce are increasingly considered a key ‘ingredient’ for the successful embedding of PPIE, yet the working conditions and on-the-ground experiences of this workforce have not received much attention and are not often the focus of research. Given the specialised knowledge of this workforce and its important role in embedding PPIE activities across health research, a more robust understanding of the challenges they may encounter is called for (Crowe, 2017; NIHR, 2019). Such an undertaking is particularly crucial at a time when UK funders are increasingly preoccupied with assessing PPIE impact (Lammons et al, 2025; Brady & Preston, 2020; Brett et al, 2014; Russell et al, 2020; Staley, 2015), with establishing more inclusive PPIE practice, and with conducting research in sustainable partnership with underserved communities (DHSC, 2021): in 2024 the NIHR published five strategic commitments in public partnerships emphasising the need to work with underserved communities to establish more inclusive models for PPIE (NIHR, 2024a). At the same time the funder has mandated that the needs of those facing the sharpest health inequalities should be explicitly addressed in all funded research and that public involvement and engagement work should progress to reflect this (NIHR, 2024b).

The present study builds on our earlier work on the PPIE workforce also funded by the NIHR Applied Research Collaboration South London. In that earlier work, we found that PPIE workers’ role remains poorly understood, that the proliferating instruments and reporting mechanisms through which this work is managed and evaluated may be ill equipped to capture its specific quality and strengths, moreover that PPIE workers may be held accountable for institutional failures that they have little power to address (Papoulias & Brady, 2024). Findings from our earlier study played a key part in a [Necessary Conversation](#) on the ‘hidden costs of PPIE’ between PPIE leads, researchers with senior NIHR leads held in November 2023 and which led to recommendations on improving the work of PPIE. These recommendations can be summed up as: strengthening sustainable support, providing better resourcing and encouraging fit for purpose reporting and learning (See Table 1). The present study sought to understand how current PPIE workforce concerns relate to these recommendations, how the workforce has responded to current expectations on delivering inclusive research, what challenges they may have encountered and what pathways may be proposed to address these.

¹ We use the acronym PPIE throughout this document rather than the NIHR mandated ‘public partnerships’ both because it is a more widely used term and so that we can reflect the current importance of community engagement in research. When quoting statements from participants, we leave their preferred acronym in place.

Table 1

Recommendations for addressing the hidden costs of PPIE

● Strengthen and develop sustainable support for the NIHR public partnerships workforce

- 1.** Articulate the core competencies and skillset needed for impactful and meaningful public partnerships by encouraging organisations and individuals to use the framework;
- 2.** Develop and strengthen public partnerships leadership in the NIHR through training programmes, fellowships, and convening spaces for the public partnerships workforce;
- 3.** Provide more visible leadership for the NIHR public partnerships workforce, including and beyond the forthcoming strategic commitments for public partnerships 2025-2030;
- 4.** Enable public partnerships workforce to input into the design of funding calls, including deciding timelines for applications.

● Provide and encourage better resourcing for public partnerships

- 1.** Commit ring-fenced national or regional funding for public partnerships initiatives, including through specific funding calls;
- 2.** Provide clear messaging to NIHR-funded individuals and organisations that public partnerships require cross-organisational commitment and action, including through accurate and transparent budgeting and allocation of funding;
- 3.** Establish specific roles for the public partnerships workforce (in addition to public contributors) on panels that review and award funding applications, and evaluate how these work.

● Encourage accurate reporting of, and learning from, public partnerships

- 1.** Amplify regional examples of approaches to public partnerships and share learning of what works, for whom and why;
- 2.** Encourage funding and award holders to share learning from what has not worked, including through questions the NIHR may ask through funding monitoring processes.

What we set out to do

We used the findings of our earlier study on the labour of the PPIE workforce to produce a series of visual vignettes (in the form of a webcomic) representing different challenges of PPIE work. We wanted to use these vignettes as visual prompts for group conversations, to help us develop a robust understanding of the challenges faced by PPIE workers, assess how such challenges might be experienced differently across different kinds of institutions and by different segments of the workforce.

What we wanted to achieve

- Use the cartoons in a group setting in order to support open and honest discussions around potentially controversial or difficult situations
- Foster collaborative work in devising potential solutions to these situations
- Raise awareness of the social complexity of PPIE and the power relations underpinning its implementation
- Help to advocate for change

What we did

We carried out eight focus groups between July and October 2025, reaching 37 participants with experience of working in patient and public involvement and engagement and having been responsible for PPIE within large NIHR grants, centres or organisations. Five of the focus groups involved mostly professional services staff although a minority were on research contracts; two involved people with lived experience; and one focus group engaged with senior academics.

We approached each focus group in a similar way: sharing the comic vignettes in advance and asking the following questions:

- Do you see something from your own experience here?
- Is there anything that you think is missing from these stories?
- What do you think causes the challenges presented here?
- What would need to change to address these challenges?

Focus groups lasted for two hours, were held on Microsoft Teams and recorded. Recordings were transcribed and transcripts fully de-identified. For the purposes of this report, we undertook a rapid thematic analysis of the transcripts as follows:

- Immersive reading of transcripts
- Generation of summaries with main points focusing on what the challenges are and what needs to change

- Use of summaries (with ongoing cross-checking with transcripts) to generate codes and themes collated on Excel spreadsheets, one for challenges and one for proposed changes
- Revisions of themes
- Setting up equivalences/connections between themes related to challenges and themes related to proposed changes

What we found: shared challenges

1. Limited agency in research systems

Several conversations discussed the powerlessness of PPIE workers within what appears to be an immovable system or set of systems. Participants related this to the relegation of such roles to academic adjacent people who lack the agency and prestige of academics, others to the add-on status of PPIE while some pointed to the immovable nature of systems themselves.

Lack of career progression for those in PPIE roles

Participants mentioned the ill-defined nature of the role, the lack of opportunity for career progression and the scarcity of more senior roles to aspire to

“I think there’s loads of PPI officer roles and then there’s really not a lot above that, ...if we are really valuing it, there should be senior positions within that as well that recognise the expertise and the wide range of knowledge and capabilities that you have to have to do this job well, and I don’t think currently there’s enough....opportunities for development and progression.”

For some, this stagnation was in part a consequence of the broader organisational lack of understanding and therefore of valuing what PPIE workers do – the variety of roles they are made to occupy.

“we’re very much glass ceilinged in the organisation, because unless you diversify your portfolio [it is hard to get promoted]... there is no way to diversify and it does get very frustrating, that that is people’s perspective. ...It’s like it’s all the stuff that we have to do to make our jobs work is not necessarily seen and valued in the same way as if you had a role that was fulltime, permanent”

Confinement of PPIE to professional services

Locating the majority of dedicated PPIE roles within professional services led to a very real divide between PPIE workers and their academic colleagues, with the former having much less power to influence change despite being expected to make an impact.

“Generally, in the area that we work there can be that under-recognition of professional, managerial workers or clerical workers over clinical academic workers as well. And this [vignette] speaks really loudly to that as well I think, the culture that we work within.”

This relative powerlessness of professional services staff within research organisations was also noted by those on academic/research contracts. One

such participant suggested that in fact assigning PPIE work to professional services staff became a way of suppressing the potential for such work to create meaningful change in the organisation and ensuring that it remains an add-on

“It’s a bit like that’s a way of oppressing PPI [...] of keeping it down because those people will only have so much agency within an academic context. So it’s a very effective way of creating a repressed system that does not create the change it then is demanded that it does.”

PPIE work as always reactive

People expressed frustration at the short-term nature of PPIE work, the expectation that they were meant to automatically respond to demands, with a consequent inability to think ahead and plan.

“That idea that someone just comes and says, ‘Oh, do you mind just joining that meeting or sitting on that group or being involved or supporting that researcher?’ It’s small in itself but the cumulative impact is quite massive.”

This frustration was at its most intensely felt when it came to participating in applications for funding: several participants reported that they did not feel organically connected to the process and were not treated as part of a team. A typical experience was PPIE staff finding out that they have been added in bids at the last minute:

“We’ve got this [bid] that’s going in at midday today and I’m sending it to you at 9am. Can you add the PPI bit in, and there’s a little box for PPI...I get that we’re all under pressure and deadlines and stuff but everyone else has received this application, you’ve already met about it and discussed it and discussed the approach and the bid and whatever it is”

Some participants argued that the reactive nature of much PPIE work and workers’ experiences of not being an integral part of the research team was connected to broader systemic issues: research institutions’ ongoing reliance on external funding, the short term nature of the funding itself and the tight timelines of funding calls which, combined, allowed little time for longer term planning or capacity building in PPIE:

“...so you end up with this very reactive thing where you put something in a bid that you know NIHR will like and then you get the funding and you scrabble around, trying to get together some kind of an advisory group which has relevant lived experience and then the project ends and those people go off.”

Even those in research/academic roles and in relatively senior positions, reported feeling powerless to influence the system towards a more holistic incorporation of PPIE and related this powerlessness to the same systemic issues:

“...because of the academic challenges we’ve all been talking about, our future job security depends on getting funding. So it’s very hard as an individual researcher to challenge and to push back and to say, ‘I don’t think you’re doing this right.’”

Indeed, those on primarily research/academic roles pointed to the requirements for their own career progression as academics as a systemic barrier to delivering better and more meaningful PPIE.

“there is this whole structural context which causes this mismatch that makes it really difficult, actually, for researchers because of [...] publications, all of those sorts of things – forms of academic currency that you can’t ignore if you want to progress in your career and then the requirements of public involvement – time, all of those things that we discussed.”

2. Feeling stuck in the middle

The role of PPI/E coordinator or lead is essentially a mediating, brokering role between an organisation or a team of researchers and public contributors or community organisations. PPIE workers themselves frequently experience this role as being pulled in different directions, by having to represent and seeking to align actors whose interests, values, language and priorities may be in conflict

Emotional costs of representing both sides

People talked of the emotional costs of managing the expectations of public contributors, feeling a need to protect them from academic demands and potential exploitation, whilst at the same time encouraging them to participate. Some felt uneasy about their impulse to protect public contributors from institutional harm while others reflected that, despite their best efforts in mediating, they could still be perceived to be upholding the interests and priorities of such potentially harmful institutions.

“[I almost feel] like I am the funnel, making sure that what comes through from one side to the other is not harmful to that other side, and then catching myself at times and thinking why am I feeling so protective; I don’t want to be parenting a group, and that’s not healthy for the group, but equally I don’t want them to be exposed ... or exploited even.”

“sometimes being the face of the organisation works against you because people see you as the personal embodiment of a health and research system that is failing to make the impact that it’s perceived to have.”

Participants strongly argued that the emotional costs of being stuck in the middle are qualitatively different for those with lived experience, that they cannot be reduced to something like workplace related stress but might have a more existential dimension

“So there’s more than just stress, there’s more than just burnout. It’s total inner turmoil that these jobs can give you if you’re involved in systems that have harmed you and you see them harming other people.”

For some PPI/E coordinators such compromise was intensified when they could see that the public contributors had been repeatedly treated tokenistically or even dismissed within organisations:

“people come in thinking that they’re going to be valued, thinking that their stories are going to matter, often quite traumatised, thinking for the first time ever their voices are going to be heard, listened to, respected, and that their contribution will be meaningfully accepted and held, and they often have a really terrible awakening around their function and their role in that process.”

Emotional costs of dealing with harm/deprivation

Several participants talked of the emotional cost of hearing people’s stories: the trauma, distress and histories of harm that people can bring to the PPIE space. This was particularly difficult to bear since participants reported feeling powerless and unable to respond to practical issues and unsupported in coping with the emotional burden.

“It is distressing to hear about people’s lived experiences, so negative sometimes, and you’re taking on the burden of their emotion and their distress. A lot of the time there’s nothing there for people like us who are leaving work feeling drained and sad and hopeless when you’ve taken on other people’s experiences and you feel like you should be able to do something, but you haven’t been able to give them the support that they need.”

Ongoing risks of negotiating trusting relationships with public contributors

The maintenance of relationships with public contributors was an important concern. Many PPIE workers worked with flexible boundaries in the interest of forming trusting relationships.

“You only get that openness by making people feel safe and trusting and that involves you putting yourself out there as well.”

However, developing flexible boundaries could open up additional challenges: one challenge that was particularly difficult to discuss was the rise of ‘fraudulent’ contributors, that is people who were dishonest about their lived experiences or made nefarious expenses claims. One participant linked the rise in such claims to the increase in social and economic deprivation since the pandemic:

“I think since COVID it’s a really difficult time and I think some people have realised that there is money to be made in PPI. I don’t say that with any judgement at all, but in the past few months I have had an entirely faked invoice of [expenses] we completely acknowledge we can always do better, but we’re being asked things that we cannot say yes to and in some cases they are very obviously fraudulent”

Other participants suggested that the mandatory nature of public involvement might lead some public contributors to make unreasonable demands which PPIE workers then must try to accommodate, thus putting additional pressure on them:

“they know that we’re required by the government to do this thing and therefore they also know that we have to accommodate their needs and their wishes and everything as far as possible, which of course we’re happy to do but not when it’s used as a shield and a sword against us.”

3. Disconnect between PPIE work and academic work

Several conversations addressed a lack of connection between the academic working environment and the role of PPIE colleagues. For some people, PPIE was poorly understood amongst researchers; for others, it was devalued as a necessary add-on with poor recognition of the specialist knowledge and skills necessary to undertake it. This left people themselves feeling devalued and unskilled.

PPIE as an add on to academic work

Many participants reported that researchers and academics did not engage with PPIE nor understand it and did not see it as integral to their work

“most of the time the researchers in my group, they’re more worried about their data, they’re more worried about their publications, they’re not really tuned in to what relevance PPI has to them until they really need it”

While such discussions often revolved around a distinction between ‘researchers’ and ‘professional services PPIE staff’, some participants were keen to point out that in fact those relatively new to research work were particularly receptive and enthusiastic and that this disconnect was more evident in the case of senior academics and those leading large programmes:

“it’s actually the more senior [...] that are more like ‘this is a tick-boxing exercise and this is what funders want to see and we’ll bring you in at the last minute and just shoehorn it in’. And the number of times we’ve said, ‘Involve people from the start,’ again and again and again and it just doesn’t seem to be getting through to people! Apart from the early-career researchers, who seem to be really wanting to do this well”

Those participants who were themselves both senior researchers and PPIE specialists argued that this disconnect could be traced to funders’ relative lack of investment on research on PPIE as a form of knowledge. This lack of investment and paucity of funding calls for research on PPIE has meant that researchers and academics are less likely to connect with PPIE work since they struggle to see this work as an organic part of research

“there’s a disconnect between academic knowledge and PPI knowledge and NIHR really struggles to think, ‘How can that be connected and how can it be brought together?’ So it’s fine just to do a bit of doing but to capture that, to learn from it, to publish on it, it really struggles with that idea”

Scope creep

The broader lack of recognition and understanding of the skillset and responsibilities constituting PPIE as opposed to academic work was linked to what one participant called ‘scope creep’, that is, the ongoing addition of new responsibilities which might make the role increasingly difficult to sustain:

“we’re expected to be experts in information governance; we are expected to be experts in ethics; we are expected to be experts in involvement and then you add co-production to it and there’s just this urgh, [...] And we do it [...] we become these experts and it’s amazing that we have this absolute wealth of skills that makes us amazing people, right? And yet, when it comes to our organisations, they don’t see that.”

Funders’ heightened expectations around PPIE ‘delivery’ and, more recently, the emphasis on research inclusion, were seen to have exacerbated this, with participants experiencing researchers passing on such expectations to them, seemingly without consultation.

“a lot of the time in PPI, you get the ‘E’ thrown on the end...and the engagement does actually take so much time and effort to build relationships with different people and organisations. A lot of the time it’s just an afterthought, in reality I do think it can be a whole role in itself and takes years to build those relationships up to a meaningful point”

Participants were particularly exercised about being constantly written into applications for funding, often without their knowledge. For some, this was interpreted as a result of funders and researchers being wedded to a certain model of time allocation that was more appropriate for research management and delivery rather than PPIE:

“I think the major issue is because the NIHR have this academic model of putting 5% onto people’s time. I have had one with 2% and I’ve never had anything to do with this project but they put my name down.. they’ve taken this academic model and put it onto PPI and expected it to work. So then that workload is mounting up for people so much..... When people say, ‘Oh,[name] is full-time’ – well no, I’m full-time on about a million projects because of that academic model.”

When discussing the causes of ‘scope creep’ some participants reached beyond a disconnect between PPIE work and academic work and spoke of the overarching models of cost-effectiveness underpinning PPIE work and academic work alike

“I think it’s a system, it’s keeping costs low, we introduce new things, we have to dig deeper and deeper into the communities, but that’s all supposed to happen in the same time with the same amount of money”

Valuing and reporting outputs rather than relationship building

Another conversational thread concerned the lack of opportunity to present and report PPIE work adequately. The outward facing and visible outputs required and expected by academic systems prohibited reporting the more process-oriented PPIE work, such as building and maintaining relationships and supporting people

“soft skills like networking aren’t recognised as much. I’ve had people who don’t usually work with me attend a community function with me and go, ‘Oh, wow! You’re really good at this! You know everybody in the room, you network really well.’ I’m like, ‘Yeah, but you wouldn’t know that if you hadn’t been here today, and you don’t appreciate that as a skill <laughs> because I can’t write it into a report.”

In addition, several participants discussed not only the invisibility of relationship building work in reports but the fundamental alien-ness of such relational work for those professionalised in time-pressured research institution environments

“I think there is a deep lack of understanding; unless you’ve worked in this field I don’t think you will realise how long it takes. and I don’t think [researchers] can appreciate, especially if you’ve always worked in quite a fast-paced turnover, very professional world...people cannot fathom how relational the nature of the work is, and how that relationship takes a long time and how people that you build those relationships with have a lot of other priorities”

Some participants reported that this emphasis on outputs versus process had compromised the quality and depth of their work. Overworked PPIE staff might opt to concentrate on what they know will look good on the report and drop what might be necessary in order to build sustainable networks

“[researchers and those overseeing reports to funder] get to decide what is important in my workload so then when I’m looking at my workload, I’m trying to think what is gonna look better on the report, rather than what needs done. So in some ways, that steers what I do”

4. Institutionalisation of PPIE

Several people talked about the unintended consequences of mandating PPIE throughout the research funding landscape, but particularly in the NIHR. The adverse consequences of the institutionalisation of PPIE, particularly the way it has been instrumentalised within NIHR were discussed by senior academics but also elsewhere, including in the lived experience groups.

Depoliticisation of patient voices

Some participants spoke of the potential of patient activism and health movements to transform research which, in some cases, had inspired them to enter the field of PPIE:

“I had seen the difference that patient power has in reducing stigma around HIV and increasing or improving care in HIV care and treatment and drug development. So I know the power that people can have in research and pushing research forward and using their lived experience to do that”

Participants who have been in the PPIE world for a longer period of time reported that Involve, the Department of Health funded advisory and advocacy group which, between 1996 and 2020, led nationally in shaping, conceptualising, promoting and resourcing PPIE, had carried forward some of the legacies of patient activism in that one of its roles

“[One of Involve’s roles] was also about challenging, about speaking truth to power. I think that’s missing now”

For those participants the institutionalisation of PPIE has led to a forgetting of the principles underpinning PPIE, such as legitimising, valuing and embedding experiential knowledge within research systems:

“...it’s the instrumental doing of [PPI] that has become the valued thing rather than, ‘We want to create the best knowledge for the best impact for society that creates the best healthcare or the best outcomes,’ or whatever, and to do that, we have to have public contributors as part of the picture because it’s integral, it’s embedded, it’s bringing together different forms of knowledge.”

Other participants recounted that, in their experience, researchers and academics can be wary of public contributors whom they might perceive to be too political:

“Politicised PPI is seen as a bit of a threat has been my experience.... So I think if someone’s seen as having an underlying political agenda, or [appears to be an activist], I think people switch off”

PPI as mandate lacking connection to organisational change

Participants also argued that the voices of patients, service users and those with lived experience had been neutralised as a force for change through PPIE activities becoming mandatory by funders, thus creating more work for PPIE staff.

“ what happens is that [research inclusion] comes down as a policy directive from the top to everybody else’s surprise, and then all of a sudden they’re going, ‘oh [expletive] we need to be inclusive now,’.... And all of a sudden there’s this added burden, which of course ends up with the PPI leads”

As another participant pointed out, because mandates are top down, they can preclude any in depth understanding of the kinds of organisational changes that may be necessary to reach that goal. In the absence of a long term vision and coherent plans for organisational change, the new mandates may result in further embedding tokenism:

“...the mandated nature of public involvement introduces a whole array of problems in terms of how they define public involvement, the timeline of public involvement, all of that. ... it is a double-edged sword and it just seems that to get the benefits, inevitably you will have the negatives as well – tokenism is created by mandating public involvement.”

What we found: changes needed

1. Recognition of PPIE worker roles/profession

All participants called for higher valuing of PPIE roles: that meant fit for purpose costing, recognition of the distinct skillset required to undertake these roles as well as availability of robust training. For several, that recognition crystallised into a distinct professional identity and the need for career progression. A requirement for PPIE experts to be part of funder and institutional decision making was also proposed

Appropriate costing for PPIE work

The need to cost the PPIE workers' labour on a research project, programme or institution authentically was discussed across all groups: participants argued that such costing would be crucial for enabling PPIE colleagues to manage the demands on their time

"...budgeting is done to cover contributors' time and expenses but there's no workers time often costed in to do all that stuff that's needed - sending all the emails, arranging the meetings, doing the follow up, and that tends to get forgotten, and I think that undermines the profession - and I would call it a profession as well."

Capacious budgeting for PPIE would mean larger teams. In particular, several participants discussed the need for administrators since the pressures of administrative work constrained sustained relationship building:

"I wondered if more costed admin support would be helpful to take some of the things like dealing with payment forms or the logistics of hiring a venue and things like that. If we weren't trying to cram that into the time we're also trying to build relationships and come up with PPI activities, I think that would go a long way. Also you'd feel less on your own."

People proposed a number of different ways of managing this, from simply refusing to be costed in a project at 5% to ensuring that a new PPIE role is created in larger projects.

"We have what's called a rolling call for funding, so different researchers from the themes can apply to me for up to £1,000 to help with their PPIE activity. Within that, I am part of that, so although I'm not costed into normal grants, this is coming from me, so anybody who needs support will automatically get my support through this funding."

Clarity of skill set and career progression

Most participants called for identifying a clear skill set as a way of establishing a professional identity and countering 'scope creep'. A few people referred to the competency framework currently publicised on the NIHR website and developed by PPIE leads for the PPIE workforce.

"I think it is a profession, it is a set of skills, and I think it needs to be recognised as such, and then I think that it makes it much clearer to then advocate for ourselves."

In this context, people specifically called for a recognition of so-called soft skills which need to be made legitimate as proper 'skills' in their own right

"I think building trust and relationships like that is so, so vital for this area and it's a massive crux of what we do but there's nowhere to demonstrate it or talk about it."

"soft skills are not valued, and actually calling them soft skills ... denigrates them"

A few participants pointed out that one way of recognising relationship building as a distinct and important skill is to explicitly seek out such expertise in job descriptions and prompt for it in interviews particularly in relation to community advocacy and engagement.

"I think there needs to be a real respect for what we do and how it's done and I think that that comes from, where possible, only hiring people that work within this field or have come from grassroots organisations, and two, the people that aren't from those worlds being given the support and time and guidance to venture into those worlds and be curious and learn and it needs to be a deliverable for them."

Several people mentioned the need for funders and research institutions to invest in PPIE workers and enable visible pathways for career progression in PPIE roles, to act as a positive incentive to people coming into the roles.

"I think as this field starts to grow, if we are really valuing it, there should be senior positions within that as well that recognise the expertise and the wide range of knowledge and capabilities that you have to have to do this job well"

"There isn't the investment in it by institutions or funders like the NIHR, so investment in PPI workers and career progression, but also training and [...] building the evidence."

A robust training infrastructure for PPIE workers

The availability of consistent and reliable training was a central demand across all groups. Many participants expressed concerns about their difficulty in locating training for the complex skillset of the role, a problem that was particularly serious since they were then expected to train others:

"So when people are like, 'We need training for contributors,' it's like, 'Ha! That's a funny joke - I'm not even trained!' So I think that's probably a challenge in different areas with different skills that people need because you are like a jack of all trades and a master of none but you're not trained in anything at all. You just pick it up as you go along because you don't have a team either; If there was just different ways to learn some of these skills, I think that would be really helpful and it would give - I can't speak for other people - me a lot more confidence in what I'm doing, rather than feeling like I'm just stumbling through stuff."

Those who had identified appropriate training agreed that what is currently on offer is neither systematic nor easily accessible and that it requires a lot of self-directed work from them to seek out, which may increase their sense of isolation:

“there’s no systematic way of receiving training. It’s been quite a lonely journey for me to try and upskill because I am essentially seeking out my own training plan and joining these individual interest groups So in terms of the role and the training provided, it all seems to be bitty and all over the place, all online, nothing in person.”

Specifically, the provision of training on facilitating and managing relationships with public contributors was singled out as an urgent issue requiring immediate attention, while participants also expressed a need for robust safeguarding protocols:

“I know the structural problems are really important, but right here, right now, I would say we need support and training and guidance on boundary setting with people who are volunteers, and this is not always a very safe space; safety, safeguarding, facilitation. There needs to be something that is a national offer, a good offer, a solid offer, designed by people who get the role.”

Others interpreted this lack of consistent training provision as a sign of the funder’s considerable under-investment in developing an infrastructure which is fit for purpose in developing PPIE. They argued that the lack in training provision shows a fundamental mismatch between what is currently expected in the ‘delivery’ of PPIE and the resources available to facilitate this delivery:

“when we talk about infrastructure and NIHR, if we did a review of infrastructure for public involvement, it would probably be quite shocking – huge gaps in training and all sorts of things. People have to make up their own infrastructure, so there’s a huge diversity of what people end up doing... compared to the performance expected, the infrastructure is appalling, actually, for delivery at a system level.”

Increasing PPIE worker agency in systems

There were conversations about ways in which PPIE workers could be made more visible within the overall systems: for example, on decision-making or governance panels alongside PPIE contributors. Additional reasons given for this were that PPIE workers had more experience of those same systems, but could also support the PPIE contributors to participate. Whilst this might add to their workload, it could also increase their influence in the system:

“I’ve always found this weird, that on the funding panels we have public contributors, which is great, but the public contributors are not the ones organising the PPI, and so I think sometimes there’s a bit of confusion about our role, and I think we need PPI experts on those panels to properly assess the PPI plans.”

Those with PPIE expertise in funding panels would be able to discern and identify more quickly whether PPIE plans in applications are fit for purpose and could therefore limit or alleviate some of the bigger challenges of implementing such plans which are typically faced by other PPIE workers downstream

2. Firming role boundaries – managing relationships

Participants spoke of various tactics they had adopted in their different working environments to manage or contain scope creep and some of the emotional costs of ‘straddling both worlds’ in the absence of consistent institutional support. These were practical suggestions, some of which were directed at managing role expectation and improving relationships: those between PPIE leads and other work colleagues, between PPIE leads and public contributors, and between PPIE workers themselves.

Mapping responsibilities – managing institutional expectations

Most participants argued that institutional and team expectations far exceeded the resources available to them. In this context some had suggestions for gatekeeping the demands from other research colleagues and teams. Participants in three groups mentioned mapping their various activities as a relatively quick way of presenting researchers and other colleagues with clear evidence of the plurality and complexity of responsibilities. It was hoped that such evidence could facilitate understanding, potentially ward off excessive demands and, in some cases, might even lead to better resourcing in the future:

“tracking where our time is spent [...] quite down to the nitty gritty detail of splitting it all up into different categories of emails, relationship building, admin, finance, all that kind of stuff and having that quantitative evidence base of what we’re doing [...] to basically get more capacity or support”

However, another participant pointed out that such tracking is itself laborious and can therefore exacerbate the challenges of overwork rather than alleviate them:

“would be great, if you had time <laughs> to do that but you don’t, or I don’t, so I struggle.. I started my role doing that and then it dropped off but I think if I could do that practice, it would be really helpful then when I am asked to do something else, if I can share that.”

Another tactic suggested was producing documents which stratified different levels or tiers of ‘support’ work, thus clarifying what researchers and teams can expect from PPIE staff

“We came up with these three tiers of support that we can offer and the first one is just signposting to resources, [...] and then the second level is that you’re costed in 5% and you’re supervising a researcher to carry out the public involvement, and then the third level is actually leading the public involvement yourself on a project and doing that innovative public involvement that really, at least for us, that really excites us and that’s why we want to do the job.”

Given the diversity and complexity of skills that are required in PPIE roles, some participants discussed quick ways of gaining some knowledge in those areas where they were lacking in confidence: one proposal involved mapping the expertise of PPIE colleagues or indeed of colleagues from other institutional fields (finance, HR) in order to be able to reach out for advice when presented with challenging or overwhelming tasks:

"[It might be useful] to map out our skills and strengths and perhaps each one of us in some sense focus on something specific...if I know that [name] is really good at facilitating focus group discussions, then I can go to [name] and ask, 'Can you tell me, I have this difficult situation ...' If [name] is good at writing impact reports, I could ask [name] how best to write them... Not delegating work, but having an internal point of contact"

Regulating public contributors

Numerous conversations engaged with the tensions that can emerge through working with public contributors in the absence of contracts and formal regulatory frameworks. As well as noting an urgent need for robust facilitation training, participants discussed more localised solutions: some participants had put in place guidelines and codes of conduct to act as a non-contract-based set of regulations which could assist them in managing relationships with public contributors. One person described their experience of doing this - they had found the code helpful but also acknowledged its limitations in consistently preventing difficult situations:

"linked to that code of conduct is what we call a problem-solving procedure because they're not staff so we needed a way of saying, 'Right, if this happens you go to this step and then you do this step and this step and this step.' We're in the process of testing it and it hasn't worked as well as we'd hoped but some of the things we put in that code of conduct didn't even cover some of the stuff that's now happening."

Another participant had supplemented a code of conduct with training which would enable public contributors to acclimatise to institutional ways of working:

"I think the codes of conduct are a really good idea and there needs to be like what we have in ours - we do a role descriptor and we've done something similar because I did work with the Chair of one group who every meeting was completely off on a tangent and derailed quite a lot of things. So what we did was we provided training and support for them on how to get their point over in what they were trying to say."

However, other participants, especially those with lived experience, argued that regulating and managing behaviours could be uncomfortably close to policing public contributors, by discouraging statements and attitudes which are perceived to be too political. Other participants suggested that such regulation should not aim to silence those who challenge the institution. Instead it should facilitate group cohesion and collaborative practice through supporting the development of shared values within the group itself.

"we should be open to challenge so it's not necessarily about the 'right' people, it's the wrong word, but then equally [we should be making sure] that ... there are group values in terms of the way that different people treat each other, and in terms of the importance of the commitment that people are making to a project, when they get involved, because they are working on something which is publicly funded as well"

Developing support / mentoring / learning networks

In addition to calling for specialised and consistent training, participants valued the importance of learning from peers through mentorship, coaching or specialised supervision schemes. Noting the importance of connection

and community in the PPIE space (a key reason many had come to the focus groups), participants called for opportunities to establish learning networks and communities of practice – while acknowledging that setting these up and maintaining them also adds to their workload

“Communities of practice, yes, it’s an add-on to my role but actually, I’ve learnt so much and I suppose it’s not about attending training all the time but it’s about saying, ‘So-and-so’s doing that already. How can we learn from that and how can we adapt our models?’”

“I’m a big believer in the value of networks. So, like [name] was talking about, the BRC network and I’m part of another NIHR cross-infrastructure network. And even just soft networks within organisations, I think, can be really helpful where you can talk about the different problems you’re having and different solutions or approaches you’ve come up with together.

3. Embedding PPIE work across research systems

This change was proposed as a means of addressing many of the challenges PPIE workers experienced with workload and demands on their time and resources, as well as to mitigate the stresses associated with being ‘stuck in the middle’. Participants called for an understanding of PPIE practice to be distributed more evenly and effectively within the research systems, teams and departments, so that those with specialist PPIE roles would still lead and support but without also being held responsible for doing all the work themselves

Redistribution of PPIE responsibilities across teams

The starting point for many participants was redistributing the responsibility for PPIE across different research team members so that they can conducting involvement work locally. Some participants recounted cases where a whole-organisation involvement culture had been implemented because of the commitment and long term presence of highly experienced PPIE staff:

“My predecessor... has done a really nice job of trying to get a good culture of involvement in the organisation, [...] a lot of my colleagues do the involvement themselves in their jobs and they have patient contributors and they manage those relationships and I’ll provide some support but really they’re the ones who are driving and doing the involvement and engagement which is great.”

Notably, much of the discussion around such redistribution implicitly relied on the PPIE workers themselves as instigators. Some participants saw this as a process of empowering others through sharing their skills

“And maybe we need to release some of the ownership that we feel for PPI and actually empower [researchers], so we’re increasing our workforce and not just keeping it as, ‘We’re the PPI leads, we’re the specialists,’ but sharing our knowledge, empowering other people and building it up from the bottom again. I think we need a bit more of that.”

Participants noted the importance of senior academic buy in when attempting to implement organisation-wide receptiveness to PPIE work. While it was

recognised that the support of sympathetic senior staff would be enormously helpful in encouraging such receptiveness, this was still likely to require considerable influencing work by the PPIE workers

“I do think having a senior champion someone who is senior in the academic structure, who believes in PPI [is crucial] Even if you’ve had to be the one to convince them of it and show them and get them involved and get them in the room, or whatever. It is annoying because it is pulling up the hierarchy but I do think it can help you make your case”

PPIE skills become part of researcher training / formal education

Almost a partner to the previous suggestion was the idea that, as well as those in specialised PPIE roles, all other staff, researchers and academics should receive consistent training in PPIE. Participants presented different ways in which they already had spearheaded or were proposing to spearhead training in their own institutions. Some spoke of costing for training as part of applications for funding

“I always build in a PPI training budget into all the applications to be co-delivered with the co-applicant or another PPI member, so that when we start off at the beginning of a study the research team... know what PPI is and what it’s not.”

Others mentioned the advantages of setting up comprehensive training programmes with sessions (e.g. on community engagement, payment, facilitation) taught by independent specialists and attended by researchers, PPIE leads and public contributors. They argued that embedding such a programme can considerably lessen PPIE staff workload and leave them freer to pursue support and mentorship roles

“we are coordinating a free to access programme of PPIE training ... there’s sessions for researchers but also public contributors who are wanting to develop themselves or feel a bit more confident in being part of that.....[there are good examples already of] PPIE leads not delivering any [training] and just purely operating in a mentorship model, and in order to access that mentorship, setting a standard that researchers needed to access at least an introduction to PPIE session that they run”

Still others argued for the importance of embedding PPIE training in earlier stages of academic education, including in undergraduate degrees. Such early embedding could help normalise PPIE as an integral part of the ‘doing’ of research

“I think when people get to the grant application stages and PhDs and all that kind of stuff they just have never had... they don’t know how to do it, are terrified of it, all this kind of stuff. I think embedding training modules at undergraduate level just familiarises people with it and it gives people the opportunity to get more involved if they connect with the message and the value of PPI”

Fit for purpose reporting

Another potential solution to the visibility of PPIE was for reporting to be adapted so it can better reflect this work. Here again, some participants suggested techniques which could help them raise the visibility of their work, for example by explicitly and consistently connecting their work in relationship building to what researchers would recognise and value as outputs:

“But I’ve had a bit of a win recently because again, it’s about, ‘Don’t just describe what you’ve done, describe what outputs have resulted in thatNot just, ‘Oh, I’ve sat on three mock panels, or done this, done that.’ No, ‘I’ve done this and this is what’s resulted from this,’ and I’ve got the researchers to give me some feedback to say if I wasn’t there, what would’ve happened.”

However, others recognised that such connections cannot always be made, so they called for a broader shift in reporting and presentation conventions to centre the process of relationship building, and highlight it as a distinct achievement in itself, even when it does not lead in what researchers might recognise as tangible outputs

“It would just be really great for [researchers] to say, ‘Actually, we love that you’ve submitted this as the annual report but instead of putting it in a spreadsheet and talking numbers, could you actually give us an example of a really special connection you made this year, even if it’s not outwardly led to a piece of work.’I think building trust and relationships like that is so, so vital for this area and it’s a massive crux of what we do but there’s nowhere to demonstrate it or talk about it. So that would be really helpful, and just acknowledging the so-called “soft skills” somewhere.”

Finally, participants recognised that, over the years, NIHR expectations on reporting involvement activities have increased, which means that the visibility and value of such activities within their workplaces have also increased. However, for many, this appeared to be an uneven process, therefore participants called for more consistency and clarity of expectations in terms of both the what and the how of reporting

“I guess I’ve been working on NIHR grants for ten years and in that time I have... it feels like they’re starting to check up on me a bit more. Which is to say they do want to know about the progress on the patient and public involvement. I think that can sometimes come down to the manager who you’re assigned to from the NIHR so I don’t know that that happens consistently across everything. But I agree that it feels inconsistent in the NIHR about what they want you ... to write about”

4. System transformation: power redistribution

This theme had particular resonance for the lived experience and senior academic groups. Participants argued that when PPIE workers/lived-experience staff feel that they are not up to the task, it is in fact the institution itself that is not up to the task

“that’s actually why we’re being brought in, to change systems, it’s literally in the role description, change our systems, coproduction means structural change. It doesn’t mean send it to [participant’s name], it comes back coproduced, voila! It means ask [participant’s name] how the system should change and then change it.”

For several participants what is needed for PPIE work to change is for funders to set up plans and a long-term vision for changing research structures rather than expect that isolated activities undertaken by individual workers can somehow lead to such change

“research funders need to hold a mirror up against themselves and think how can we be more inclusive, what needs to change at this level for this work on the ground to have an impact up here? those structures aren’t inclusive and we don’t have the ability to make those structures inclusive. We can make our activities inclusive. Can’t make those things inclusive”

Setting up robust and independent leadership for PPIE

Calls for stronger and better resourced national leadership on PPIE were prominent in most groups. Participants who have been in the PPIE world for a longer period of time referenced the importance of Involve, the Department of Health funded advisory and advocacy group which, between 1996 and 2020, led nationally in shaping, conceptualising, promoting and resourcing PPIE. Participants who mentioned the need for an organisation to lead on PPIE, also highlighted the different needs such an organisation would serve. While the ability to influence was mentioned by all, for some a firm understanding of research cultures and the nature of academic work was crucial if the purpose of such an organisation was to change research:

“So I think we’ve got an empty space where we should have an influencing organisation or society or something but rooted, actually, in an academic context as well as links to funders”.

Others saw that the main function of such a leading organisation would be to nourish support, enable community and provide a holding space for all those working in PPIE so they would have the resources to come together, understand that their challenges are shared and find ways to address them:

“We don’t have an organisation that holds us. We don’t have support. We’re all individuals working in a ... and you occasionally bump into somebody that ooh, fantastic, yeah, you’re working same area, can you help me? ... And I get this all the time, people calling me, [name] do you know, have you seen, is this something you’ve experienced? What do I respond?’ And also we have our own difficulties and stresses, but we don’t have any underpinning, we don’t have a national conference where we come together.”

Another valued dimension of Involve that was seen as a crucial ingredient for leadership in PPIE was its relative independence from both funders and specific research institutions. This independence enabled Involve to uphold transparency, to challenge, rather than simply follow, institutional priorities and to advocate for change

“before it was badged as NIHR, [Involve was originally] a semi-independent critical friend, that’s how it was set up....there was a webpage saying, ‘These are the people in our advisory group, these are the minutes of our meetings,’ everything was open and transparent” and I think that...dialogue, that...ability to challenge and speak truth to power is also really important.”

Changing the values and processes of knowledge creation

Both senior researchers and lived experience workers argued that the separation between academic and PPIE work stems from a forgetting of the original mission of PPIE which was to change the knowledge base for research and make research

more likely to attend to people's real needs. They therefore called for re-investment in that original mission. Some described this re-investment as funding research on transforming knowledge through PPIE

"The NIHR really struggles to think, 'How can [academic knowledge and PPI knowledge] be brought together?' [It's about] funding research that allows us to create ways of working that embed public involvement conceptually and methodologically within what people do. It doesn't have to be so prescriptive that it's, 'Do this, do that,' but it's the values and the philosophy that underpins it, which I think has diminished over the last five to ten years."

Participants noted that while funding calls for such research have appeared, these have been sporadic and inconsistent and did not speak of long-term commitment:

"I think there needs to be some strategic work but also some investment by NIHR in research on public involvement. I think that's not happened, or it's happened in those little, 'Oh look, here's a call that suddenly pops up out of nowhere,' and then it's not repeated again, it's not embedded."

Changing the models for research and knowledge production also means changing the workforce. Here lived experience workers were particularly vocal in highlighting the need for more lived experience and peer researchers to be embedded in and supported by the system

"I want to support peer researchers into the study, and coproduction and that kind of thing, and if that's in there then I'll put my name to it and I'll be running that side of it. And across the board I'm seeing increasing peer researchers and incorporating them into the system a wee bit, in that developing NHS job descriptions, so they're not outliers, they're part of ... and there's progression and there's supervision and it's meaningful"

Long-term investment in making research systems more inclusive

Many participants agreed that only a change in funding patterns and a willingness to address exclusionary institutional structures could effectively address the pressures experienced by PPIE staff. As one participant pithily put it:

"... How are we gonna manage [community engagement], when our system doesn't support long-term relationship development, doesn't support spaces where we're reciprocal and we say, 'What can we do for you?'"

Calls for a coherent payment policy which would be integrated within institutional structures and across institutions were prominent across all groups. Several participants pointed to the need for a wider systems reform so that community organisations could be embedded from the start rather than being approached belatedly as outsiders:

"...the academic institutions need to change their systems so they can integrate these voices within all of the governance structures, HR, finance, because this will solve a lot of the issues on how we actually connect with communities or with people who are outside of the department."

Participants also argued that, in order for such reform to be possible, a broader recognition of the power dynamics embedded in institutions would be necessary, rather than an attempt to only deal with such dynamics when it comes to doing PPIE:

“One is addressing those power dynamics and working in a more cooperative, coproduced way, which is what we’re asked to do with communities. I think that needs to come from inside and I think that... management need to start doing that more.”

The redistribution of resources was seen as an essential part of tackling power dynamics: funding patterns would need to be adapted with some funding redirected away from research institutions so that sustainable community engagement could be possible. As another participant put it, what is needed are “mechanisms to put our money where our values are”. Some people pointed to the NIHR Reaching Out Initiatives as good examples of this, as these initiatives had led to minoritised communities and organisations receiving funding over several years to collaborate on research. However, such initiatives have been scarce, testifying to a lack of consistency from the funder:

“it basically just needs to be this ring-fenced [pot of funding] if you really want to be able to do authentic involvement and engagement, in the initial phases, which is the places where we can have the biggest impact and can really change the temperature on how involvement is working, you have to put the resourcing there and there has to be that type of access to it and the time to do it”

Building collective power in the workplace

While most participants called for networks for mutual learning and support, participants in the lived experience groups spoke more explicitly about the need to build a collective voice in order to advocate for change

“We just don’t know what’s going on, we don’t know what impacts different Ministers are having or what’s happening in the higher echelons of NIHR. So we’re sitting in our own little boxes in our own little worlds, reinventing wheels....how do we create a collective response ... [Those working in engagement] are facing the same challenges, so having the same conversations.... we just need to create a bigger [push]....we need more voices”

For some, this collective voice could take the form of a lived experience workers’ trade union capable of identifying, promoting and fighting for participants’ rights and recognition in the workplace

“There was a lot of work around people with lived experience and mental health working in the industry, and one of the things that came out of that was that we should have a union.... I think the idea is not new. It’s been explored but we’re not quite getting there, so it might be something we need to ... whether it’s a union...as a political entity or something else that isn’t political I don’t know, but I think it might be something that we look at and air”

Others pointed to the work of social movements and the activism of minoritised groups to argue that change does not come through asking those in power to change, but through coming together to collectively fight for change:

“... maybe that’s not a union, but we need to come together, we need to learn from disability, critical disability as a framework....disabled people have had to go and fight for everything they’ve got; they didn’t get it by going oh please include us. They went and fought for it, and I think we need to come together, ‘cause together we’re stronger, and advocate, not just advocate but basically demand the things that they say they want”

Table 2

Shared challenges	Changes needed
<p>Limited agency in research systems</p> <ol style="list-style-type: none"> 1. Lack of career progression 2. Confinement to professional services 3. PPIE work always reactive 	<p>Recognition of PPIE worker roles</p> <ol style="list-style-type: none"> 1. Appropriate costing for PPIE work 2. Clarity of skill-set and career progression 3. A robust training infrastructure 4. Increased PPIE worker agency in systems
<p>Feeling stuck in the middle</p> <ol style="list-style-type: none"> 1. Emotional costs of representing different sides 2. Emotional costs of dealing with harm/deprivation 3. Ongoing risks of negotiating relationships with public contributors 	<p>Firming role boundaries – managing relationships</p> <ol style="list-style-type: none"> 1. Mapping responsibilities – managing institutional expectations 2. Regulating public contributors 3. Developing support/mentoring/ learning networks
<p>Disconnect between PPIE work and academic work</p> <ol style="list-style-type: none"> 1. PPIE as an add-on to academic work 2. ‘Scope creep’ 3. Valuing outputs rather than relationship building 	<p>Embedding PPIE work across research systems</p> <ol style="list-style-type: none"> 1. Redistribution of PPIE responsibilities across teams 2. PPIE skills embedded in researcher training/formal education 3. Developing fit for purpose reporting
<p>Institutionalisation of PPIE</p> <ol style="list-style-type: none"> 1. Depoliticisation of patient voices 2. PPIE as mandate – lacking connection to organisational change 	<p>System transformation – power redistribution</p> <ol style="list-style-type: none"> 1. Setting up robust & independent leadership for PPIE 2. Changing the values and processes of knowledge creation 3. Investing long term in creating more inclusive research systems 4. Building collective power in the workplace

What it all means

Participant discussions strongly suggest that there is

- a lack of broader institutional understanding of PPIE work,
- an ongoing emotional cost in attempting to bring together institutions and members of the public and communities with different priorities, values and social position
- a real dissonance between the slow processes of relationship building and the accelerating rhythms dictated by funder timelines, short contracts and demands for performance indicators and research deliverables.

Faced with these challenges, all participants presented several examples of local teams producing creative and workable solutions. These solutions relied on individual expertise, individual actions and a receptive institutional context. However, these solutions are often temporary and fragile (be they codes of conduct for public contributors or mandatory training programmes at the start of new projects). Recognising this, participants who were senior academics and those with lived experience called for a broader and more comprehensive transformation of the power relations and working conditions that underpin research systems.

Participants underlined a need for long term investment in the PPIE workforce, for the skills of PPIE workers and the complexity of PPIE work to be recognised, and for both to be more holistically integrated within research work and teams. As one participant pithily summed it up:

“So the big thing for me is PPI needs to be embedded and the workforce needs to be invested in and there’s that infrastructure funding that I think is really, really needed.”

Our findings strongly resonate with the existing recommendations on addressing the hidden costs of PPIE work currently on the NIHR website. However, our findings reach beyond these recommendations: they suggest that many of the pressures experienced by PPIE staff may be symptoms and fallout from higher level structural problems which need to be addressed on the level of the research organisation and the funder. We therefore bring three cautions to the existing recommendations:

Individuals and teams with expertise in delivering PPIE cannot be expected to resolve wider systemic issues

Often it is PPIE workers themselves or senior academics who become agents of change by working towards a broader recognition of the value of PPIE work in the organisation. However such change cannot be sustained long term without further resourcing, nor can it effectively address what might be symptoms of broader institutional problems.

Training is not sufficient for addressing wider systemic issues

Establishing clarity in PPIE roles and responsibilities and a better understanding of the skill set needed to undertake these (such as that provided by a competencies framework), as well as developing comprehensive training for both PPIE specialists and research staff more generally, are essential for the consolidation of PPIE work in research. However, skilling up the workforce does not in itself address some of the barriers to PPIE work that research environments present – in particular the dissonance between tight project timelines and lengthy trust building processes. Addressing this dissonance requires considerable adjustments in funding timelines, in contracts, in how outputs are presented and in how impact is defined.

Boundary setting and support structures cannot by themselves repair wider systemic deficiencies.

The consistent provision of safeguarding frameworks, institutional and peer support via the establishment of mentorship schemes, peer networks and communities of practice is essential for preventing isolation and burnout in the PPIE workforce. However the impact of such measures may be limited if the PPIE workforce is dealing with fallout from higher level organisational and structural failures (be these related to the NHS or to research harms or to exclusionary institutions). Indeed, current funder mandates for more inclusive research and PPIE and for higher engagement with minoritised and under-served communities can exacerbate these problems, since it is these same underserved communities which are more likely to have experienced organisational failures and inequities.

We conclude that a long term investment in the PPIE workforce also requires a long term investment in making research systems more inclusive. This further investment means

- Recognising and addressing the central and complex role of trust and relationship building in PPIE work
- Understanding how research systems, institutional priorities and funding timelines may constitute additional barriers to trust building
- Understanding how the widening of social and economic inequalities may constitute additional barriers to trust building
- Recognising that working collaboratively with those most affected by social and health inequities requires a change in institutional priorities, working patterns and timelines for deliverables
- Investing in developing organisational readiness for inclusive PPIE and research
- Moving away from top-down mandates to more bottom-up approaches to policy making

What next

Focus group discussions facilitated through the visual prompts provided by the cartoons/vignettes have unearthed some of the larger and more difficult tensions that may block meaningful PPIE work. Structural and organisational barriers can militate against building and sustaining partnerships with public contributors and minoritised communities and those under-represented in research. The negative impact of such barriers is likely to grow as the expectations on delivering PPIE also grow. Addressing these barriers now by investing in long term systems change is urgent. In the words of one PPIE worker:

“coproduction means structural change. It doesn’t mean send it to [Ann] and voilà: it comes back coproduced”



Acknowledgements

Stan Papoulias is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) South London at King's College Hospital NHS Foundation Trust. The views expressed are those of the author and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. Alison and Stan would like to thank Savi Hensman, Kabelo Murray and Will Lammons for supporting and helping steer this work, Krini Kafiris for her helpful thinking on prompts and on the initial topic guide, the 37 participants for their incredible generosity along the way.

References

- Brett J, et al. (2014) Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations* Oct;17(5):637-650.
- Crowe S, Wray P, Lodemore M. (2017) NIHR Public Involvement Leads' Meeting November 25, 2016.
- Crowe, S., Adebajo, A., Esmael, H. et al. (2020). 'All hands-on deck', working together to develop UK standards for public involvement in research. *Res Invol Engagem* 6, 53 .
- Department for Health and Social Care (2021). *Best Research For Best Health: The Next Chapter*.
- Lammons, W., Buffardi, A. L., & Marks, D. (2025). Measuring impacts of patient and public involvement and engagement (PPIE): a narrative review synthesis of review evidence. *Research involvement and engagement*, 11(1), 76
- NIHR (2019) Taking Stock – NIHR public involvement and engagement. Available at: <https://www.nihr.ac.uk/documents/taking-stocknihr-public-involvement-and-engagement/20566>.
- NIHR (2024) Definition and role of the designated PPI (Patient and Public Involvement) lead in a research team. ; Available at: <https://www.nihr.ac.uk/documents/definition-and-role-of-the-designated-ppi-patient-and-public-involvement-lead-in-a-researchteam/>
- NIHR (2024a) Renewing the NIHR's commitment to public partnerships. <https://www.nihr.ac.uk/news/renewing-nihrs-commitment-publicpartnerships>
- NIHR (2024b) Inclusion now a key condition for NIHR funding. <https://www.nihr.ac.uk/news/inclusion-now-key-condition-nihr-funding>
- Papoulias, S., & Brady, L.-M. (2024). "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 / BioMed Central*, 22(1), Article 118.
- Russell, J., Fudge, N. & Greenhalgh, T. (2020) The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it?. *Res Invol Engagem* 6, 63
- Staley K. (2015) 'Is it worth doing?' Measuring the impact of patient and public involvement in research. *Research involvement and engagement*;1(1):6.