



**The  
10 for 10  
Project**

Celebrating 10 Years  
of McPin



# Public involvement in mental health research

Reflections and learning over 10 years

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**October 2023**

# Foreword

**Welcome to our resource on public involvement in mental health research. This is one of ten resources we've produced to celebrate ten years of the McPin Foundation.**

For those new to us, we are a small mental health research charity that has been delivering on our mission to *transform mental health research* by placing lived experience at the centre of research since April 2013. In this time, we have changed and grown from a six-person team to a network of staff, collaborators and partners covering the UK, with friends across the globe.

To mark our anniversary we have produced a collection of ten resources that explain our approach to working in collaboration with lived experience expertise to lead and shape research, evaluations and public involvement work.

The '10 for 10' resources showcase our learning and reflections from working across a wide range of projects. They are not 'how to' guides but instead present our thinking and learning to date. Two years in the making, this collection has encouraged us to navigate differences of opinion, even amongst co-authors. We value the conversations this process sparked, and we believe the results are a collection of resources with more depth and nuance.

Now that we've published these resources, we'd like to continue that conversation. We don't have all the answers. At McPin, we are continuing to develop our expertise in co-production, public involvement in research, peer research and supporting lived experience roles in the workplace. By sharing how we approach these issues and what we have learnt over the decade we hope the resources spark passionate conversations amongst the wider mental health research community, and beyond.

We do hope you find this resource on public involvement and others in the series useful, and we welcome feedback.

Turning to this resource specifically, we begin by highlighting the history of public and patient

involvement (PPI), acknowledging the work that came before us. We explore what we have learned as an organisation delivering PPI in publicly-funded studies, covering the roles and skills in PPI, the case for carrying out PPI work, and more. We hope that our learnings can help you embrace public involvement in research.



**Vanessa Pinfold**

Co-founder and Research Director

## The resources in our 10 for 10 collection are:

1. Using lived experience in the workplace: How staff lived experiences are shaping work at McPin
2. Co-production at McPin: Reflections and learning over 10 years
3. Peer Research at McPin: Our approach, reflections and learning over 10 years
4. Public Involvement in mental health research at McPin: Reflections and learning over 10 years
5. Research Involvement Groups: McPin's models and learning, and linked resource on 'recruiting for diversity'
6. Working as a co-researcher at McPin: Shaping young people's mental health research
7. Young People meeting guide
8. Wellbeing at work: What does it mean at McPin? and linked resources: Mentors and mentees (podcast); Neurodivergent meeting guide: A McPin lived experience perspective
9. McPin's journey towards antiracism
10. An Ode to Peer Research at McPin: You got the Power!: Dedicated to those who have crafted their pain into power (video)

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## Acknowledgments

We would like to thank all the people who have worked with us both on projects and shaping this resource. We would specifically like to thank staff at McPin (current and past) who have commented, including our Communications team and the lived experience partners who wrote sections and fed in ideas. We also recognise and remember the influence on our work from colleagues since departed, including Janey Antoniou and Ruth Chandler. Raj Hazzard, Senior Researcher at McPin, to whom we owe a particular thanks for the care and kindness brought to this project, has co-ordinated the production of all 10 resources in our series.

Illustrator and visual storyteller Kremena Dimitrova and 10 for 10 project lead Raj Hazzard collaborated to create two visual metaphors that captured the essence of McPin's work. 'Bridge Between Worlds' speaks to McPin's commitment to connect the knowledge, experience and expertise from a variety of differing and overlapping communities and spaces. 'Valuing Vulnerability' speaks to McPin's commitment to nurture and empower the knowledge and skills embedded in mental health experiences. Design work is by Mark Teagles at White Halo.

# Setting the scene

This resource introduces our public involvement in mental health research work, also known as PPI (Patient and Public Involvement). We have approached this by focusing on our learning from over 40 studies commissioned by the two largest public funders of research in the UK: the National Institute for Health and Care Research (NIHR), and UK Research and Innovation (UKRI). They have embraced PPI and made it a core condition for gaining health research funding over the past 15 years. Involvement in mental health research takes many forms. Our intention is to acknowledge the work that came before us and describe some of what we have learnt as an organisation delivering PPI in publicly-funded studies. We aim to share our learnings and generate conversations about PPI in publicly-funded mental health research. We are keen to hear from others about what they do and have learnt delivering PPI in research, so please get in touch.

## Survivor-led research

Before the development of PPI there was rapid progress in mental health, and disability and social justice, both in the UK and overseas. These established survivor-led research teams and lived experience methods, including Mad Studies courses, *Asylum* magazine, (a radical mental health publication) and some major survivor-led research programmes. We list some key organisations and projects shaping the survivor research discipline below:

- 🕒 **Shaping our Lives** – which started as a user-controlled project in 1996.
- 🕒 **User Focused Monitoring** at the Sainsbury Centre for Mental Health, developed in 1996.
- 🕒 The **Strategies for Living project** at the Mental Health Foundation (1997–2003) which set up the **Survivor Research Network**.
- 🕒 **National Survivor User Network (NSUN)**, a user-led, membership organisation of people with lived experience of a mental distress, ill-health and trauma launched in 2007.

- 🕒 The **Service User Research Enterprise (SURE)** based at Kings College London was founded in 2001.

Survivor-led mental health research is very different from PPI – philosophically and practically. Many have produced useful critiques of PPI practices and public research funders (such as **Rose et al 2018**). We would like to acknowledge how the survivor research discipline has helped PPI to develop a more critical focus and reflect on its practices and impacts. We recognise the expertise and knowledge from all those connected with survivor research and thank them. It has been a critical influence at McPin.

## What is Patient and Public Involvement (PPI)?

Perhaps the most common definition of PPI in health research comes from the NIHR: when research “is carried out ‘with’ or ‘by’ members of the public who have a stake in the research, rather than ‘to’, ‘about’, or ‘for’ them” (**NIHR glossary**). McPin also uses this definition.

Not everyone considers themselves to be a patient in a research context. At McPin we invite people to describe their role in ways that reflect the type of work they will be doing and makes sense to them. This has included public contributor; service user advisor; lay member; expert by experience; lived experience co-applicant or co-investigator; PPI co-ordinator; peer researcher; survivor researcher; Lived Experience Advisory Panel (LEAP) member; and Young Person Advisory Group (YPAG) member.

We try to emphasise the importance of centring lived experience in research through meaningful involvement roles. There are other terms that get used in the PPI space including research engagement and research participation (see **Health Research Authority definitions**). We have tried to show the differences between three of these core concepts in Table 1.

**Table 1: Comparing key features of research involvement, engagement and participation**

Key features	Research involvement	Research engagement	Research participation
<b>Role description</b> Are role requirements clear?	<b>Yes</b> Most involvement roles are clearly defined with responsibilities and expectations outlined in a role description.	<b>Yes</b> Each engagement opportunity is likely to be advertised with a clear summary of what to expect.	<b>Yes</b> An information sheet will outline what is required of a research participant.
<b>Open recruitment</b> Are people selected through an application process?	<b>Depends</b> Most opportunities involve an open advert and clear process to select individuals to roles.	<b>No</b> Most people self-select to attend an event, or sign up to a newsletter. They may be selected on a first come first served allocation, depending on the opportunity.	<b>No</b> Research participants are often selected and invited to take part in research, such as through NHS database searches.
<b>Time commitment</b> Is it a regular, long term role?	<b>Yes</b> Involvement opportunities are mostly regular and over a long period of time. They can be full- or part-time employment or regular meetings and occasional tasks.	<b>Depends</b> Might be a one-off opportunity or a longer-term engagement with a project or research team.	<b>No</b> This is usually 1-2 hours to complete a data collection process, although will be longer if using participatory action research methods.
<b>Payment</b> Are people paid?	<b>Yes</b> The current McPin rate is £25 per hour (as of Summer 2023). This often includes preparation time as well as meeting or task-specific time.	<b>Depends</b> Often opportunities are not paid, but they might be. Research engagement can also be rewarded through non-monetary exchanges such as networking or training opportunities.	<b>Depends</b> Payment is usually a token 'thank you' voucher after each data collection point.
<b>Role status</b> Are people viewed as members of the research team?	<b>Yes</b> Most research involvement work is integral to the project and those involved are viewed as part of the team.	<b>No</b> Mostly people engaged in research are doing specific isolated and ad hoc tasks.	<b>No</b> A research participant voluntarily participates in the research after giving informed consent, rather than becoming a member of the team. A few exceptions: when participatory methods are used the boundaries between team and research participants changes.

## Research involvement

### You might be:

- ④ A member of a research advisory group
- ④ Reviewing a research proposal
- ④ Doing interviews
- ④ Reviewing transcripts as part of the collective analysis process
- ④ Writing a blog about research findings
- ④ Talking at a conference.

## Research engagement

### You might be:

- ④ Taking part in a research consultation workshop prior to funding
- ④ Joining a study mailing list to receive project updates
- ④ Attending a conference or webinar as a member of the public
- ④ Speaking at a study launch event from a lived experience perspective but with no other links to the study.

## Examples of tasks and activities

### You might be:

- ④ Taking part in research after consenting to do so, such as going in an MRI scanner
- ④ Filling in surveys
- ④ Sharing experiences in a research interview
- ④ Providing data (information) to the research team for analysis in the study, including personal sensitive data.

## Research participation

# A short history of Patient and Public Involvement (PPI) in research

We have created a timeline to document some of the key milestones that came to shape PPI in publicly-funded health research (see Figure 1). This started in 1974 with a Labour-led government interested in a patient-led NHS and accompanying bodies to provide spaces for patient voices to be heard (Hogg et al 2007). The work of Consumers in Research/INVOLVE influenced us. So much of what was written by INVOLVE and the NIHR Mental Health Research network influences our approach to PPI at McPin.

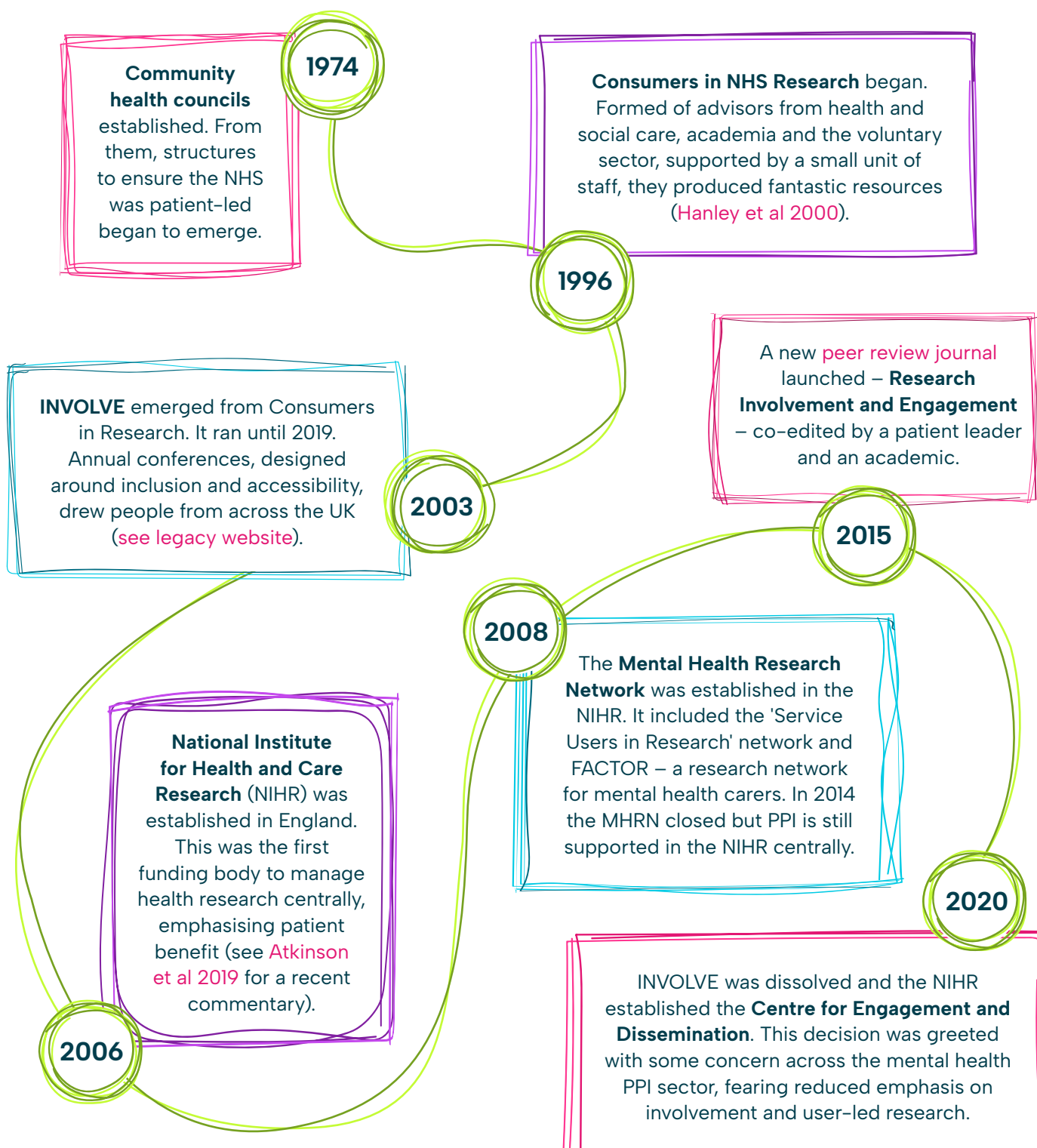
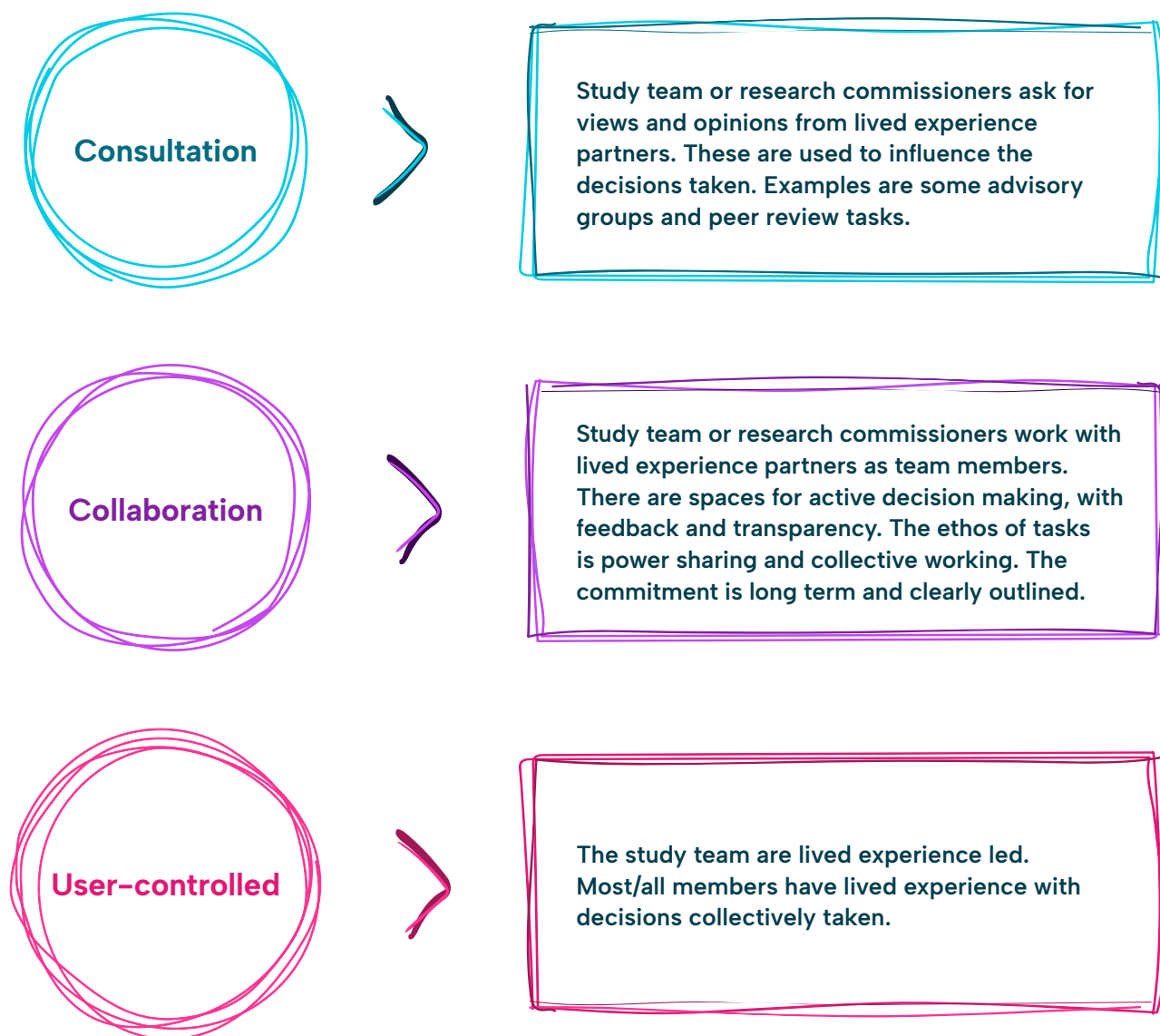


Figure 1: Key milestones in the development of PPI in publicly-funded health research

A legacy from early PPI work is the continuum of involvement in research which tended to have three stages: consultation, collaboration and user-controlled. Each stage involved different levels of power sharing with lived experience partners. This model was something NIHR and INVOLVE promoted, with researchers identifying on application forms which stage of the involvement continuum they were following.

We summarise and provide our own explanations in Figure 2 below. This approach draws inspiration from Sherry Arnstein's *Ladder of Citizen Participation* (1969), widely described as a foundational model for public engagement. For McPin, these key models provided grounded starting points for our own PPI work.



**Figure 2: A continuum of research involvement**



# Why do Patient and Public Involvement (PPI)?

In recent years, PPI has been formalised in health and social care research. Most health research funders in the UK require applicants to demonstrate patient and public involvement in their proposal and plans for project delivery, either through individuals or community organisations. Although PPI comes in many different shapes and sizes, the case for PPI tends to follow social justice and technical reasoning:

- ⑥ **Rights-based approach** underpinned by the United Nations Convention on the Rights of Persons with Disabilities.
- ⑥ **Epistemic justice approach** recognising the expertise and knowledge of those typically marginalised or oppressed.
- ⑥ **Democratic approach** where people with lived experience should have a say in research that directly impacts them: 'nothing about me without me'.
- ⑥ **Harm-reduction approach** where PPI can provide checks against practices that will negatively impact research participants, attending to harms carried out in mental health research for decades.
- ⑥ **Evidence-based approach** expands the potential evidence base by including the impact PPI can have on the quality of research and research outcome.

We recognise all these reasons but emphasise epistemic justice and a democratic approach in our work. Most PPI tends to take place within dominant structures of academia. It simultaneously seeks to be creative, inclusive, and innovative whilst being pragmatic about the amount of change that is possible in academic systems. Thus, PPI methods are often characterised by compromise, between an ideal and the practical. Such an approach risks lived experience being used in an extractive and tokenistic way. We work hard to mitigate the risks and develop PPI models of best practice.

We place a huge emphasis on how we work in research studies. How we work is as important as the topics we focus on because team ethos and approach shapes research team culture, which in turn influences the quality of research produced. Projects that work in partnership with the public using their lived experience to shape and deliver studies provide many opportunities for reciprocal support and learning between clinical, research and experiential experts. Why do PPI? In short, because it is a rewarding to all those involved and a better way of working.

Most PPI tends to take place within the dominant structures of academia. It simultaneously seeks to be creative, inclusive and innovative whilst being very conscious and pragmatic about the amount of change that is possible in academic systems. Thus, PPI methods are often characterised by compromise, between an ideal and the practical, and they carry the risk of being tokenistic and extractive. We work hard to mitigate the risks and develop PPI models of best practice. Here we reflect on how PPI at McPin has developed, through three staff member's recollections.



## McPin staff reflections



I was a member of the INVOLVE advisory group 2004–2012, and I learnt so much from members outside of the mental health community. It was a very unique space. My lasting sense of INVOLVE was kindness, compassion and inclusivity; everyone was welcome and all contributions were valued in meetings and at their excellent conferences.

Our work at McPin has been shaped considerably by this ethos and key authors of their resources including Bec Hanley, Kristina Staley and Alison Faulkner.” Vanessa Pinfold, Co-founder and Research Director



I coordinated the national service user involvement arm of the NIHR-funded Mental Health Research Network (MHRN) 2008–2014 which supported in some way most publicly-funded mental health research. This gave me a great overview of involvement in mental health research at the time.

I was lucky to have been in contact with so many people with lived experience across the country, and to be able to propose and commission resources that proved to be a help for the entire PPI community, networks and knowledge I’ve been able to bring to McPin. I was particularly proud of the ‘budgeting for involvement guide’ which became one of the most frequently accessed resources on the NIHR Involve website and the principles are still relevant and used at McPin today.” Thomas Kabir, McPin Deputy Director – Public Involvement until August 2023



I was Research Information Officer for the NIHR Maudsley Biomedical Research Centre (BRC), working across all of the mental health research themes, and linking with communications and PPI teams. Through this I learnt of and became involved with several of their PPI initiatives including being a member of the Service User Advisory Group (SUAG). This was a group of people with lived experience of mental health issues, and an interest in mental health research, that would provide feedback on researchers’ study ideas.

I continue to be a member of the Feasibility and Acceptability Support Team for Researchers (FAST-R), who provide fast turn-around reviews of a wide range of study documents before they are submitted for ethical approval e.g. protocols, participant information sheets, consent forms, advertisement/recruitment materials, questionnaires. It was refreshing in an academic environment at the time to meet and work alongside other individuals and researchers using their lived experience to help shape mental health research. Being a part of these initiatives gave me much of my foundational knowledge in PPI.” Annabel Walsh, Public Involvement in Research Manager

## McPin's stance on PPI

It's not just what you research but how you do it that matters. This is why PPI is important. It brings lived experience partners into projects – to do things differently. We believe PPI, and other lived experience approaches, are essential requirements for high quality mental health research. As important as governance and ethics, training, supervision, team leadership and project planning. We believe that a role in research teams should always be given to people with lived experience in the same way doctors, psychologists, nurses, and others (including statisticians, economists and trial specialists) are invited into research teams – so they can share their expertise.

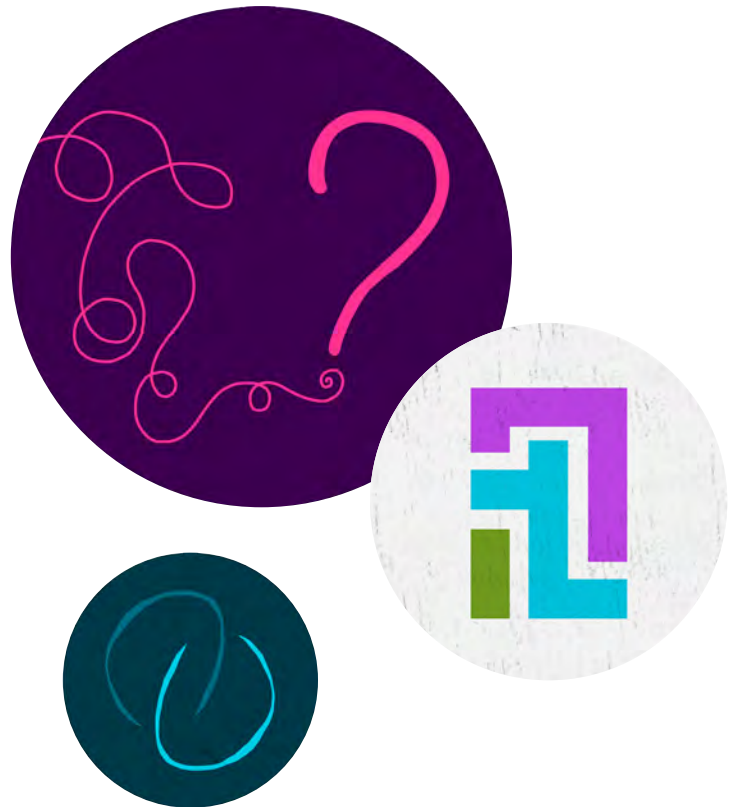
Thinking about PPI specifically, lived experience roles can be applied to many different aspects of the research process. Roles include lived experience coinvestigator, PPI co-ordinator, lived experience advisory group member and peer researcher.

We advocate that the different structures in the research ecosystem should all include people with lived experience and the expertise they bring, for example:

- Research funding panels including people with lived experience as decision-makers.
- Peer review processes run by journal publications and funders, including people with mental health issues or family/carers as reviewers.

Overall, we strive for meaningful involvement for PPI partners, as a strategy to counter the risks of tokenism. Having the influence to shape decisions in any PPI role is essential. In our experience, this work should be based on clear expectations, trusting relationships and a commitment to reciprocity where all partners are valued and given opportunities to develop.

We believe involvement should lead to change. PPI contributors often question whether their academic and emotional labour will be put to good use: "What is the point of this?", or "Is this research project important enough for the time and resource commitment required of me?".



Sense checking how well an opportunity aligns with ones values and the likelihood of the research achieving positive results can be important points of reflection for lived experience contributors. We do know that much research is poorly implemented and slowly translated into practice, if at all.

Research can be a frustrating endeavour and it is incremental change that often occurs in order to increase understanding and build our knowledge-base on how best to support mental health issues in different populations. It can also be a positive experience: an opportunity to work with a group of experts, to challenge thinking, and progress personal goals. PPI is not something that appeals to everyone but it is one way to attempt to achieve incremental system change.

### Learn more

Other McPin 10 for 10 resources you might be interested in are *Peer Research at McPin*, *Co-production at McPin* and the *Research Involvement Groups*. Find them on our website: [mcpin.org](http://mcpin.org)



**I came to PPI by accident. I had a job where I was coordinating a randomised controlled trial, and doing a part-time (opportunistic) PhD about how research participants understood the process of being involved in the trial.**

**As someone who was collecting all the trial data and meeting all the participants, it was obvious to me that the trial would have benefitted from input from participants before key decisions were made (such as choosing the right outcomes to measure and how to measure them).**

**Once I had finished my PhD, I went to work for a mental health charity and learnt about the existence of PPI, i.e. the mechanisms in which people with lived experience are involved in shaping research. This felt like a good fit for me at the time. It still does. I like being able to communicate complex information in ways that feel intuitive, which is one of the pillars of good PPI alongside relationship-building and administrative skills."**

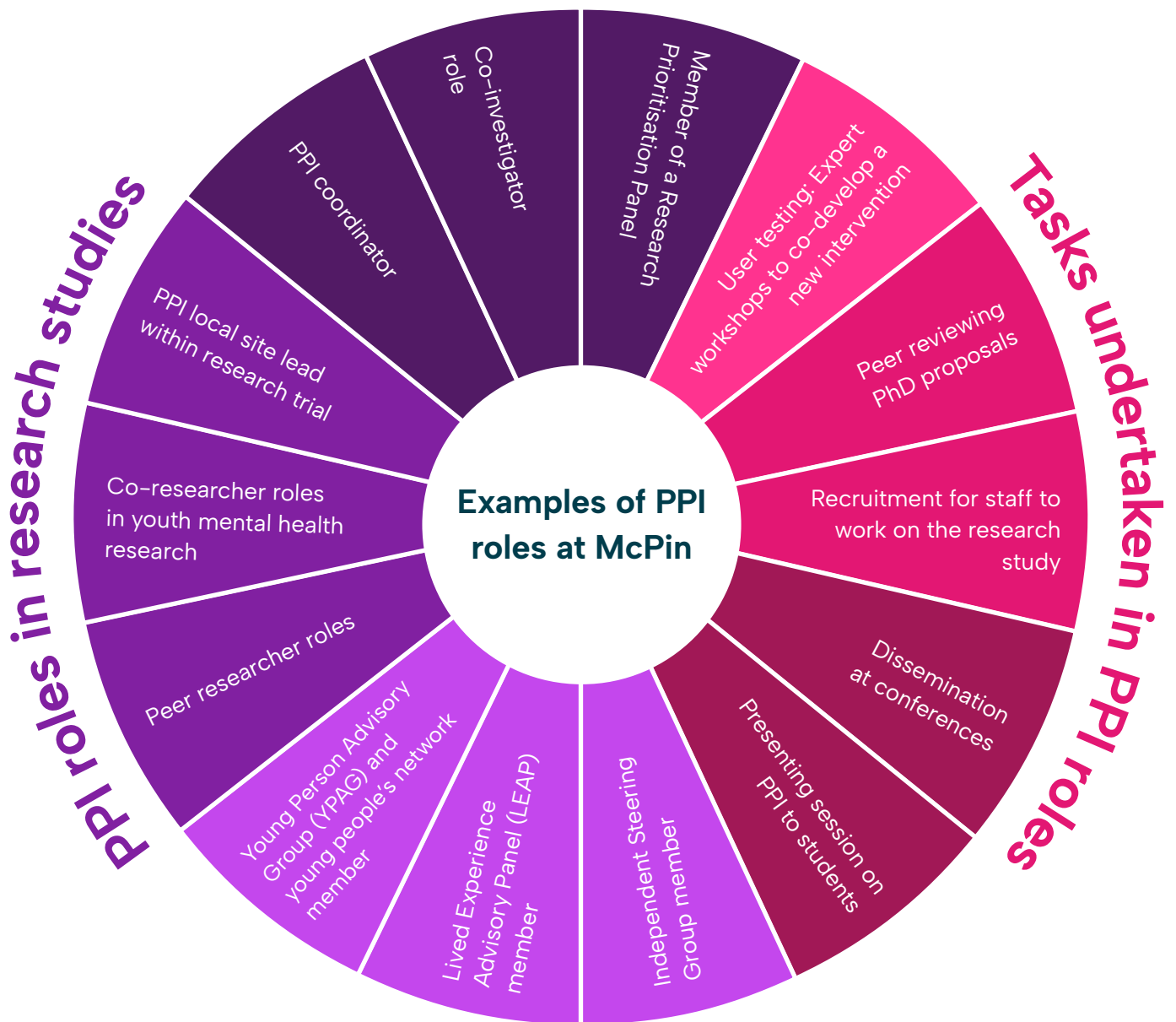
Dan Robotham

McPin Deputy Director – Research and Evaluation until June 2023

# PPI roles and skills: summary

In this section we present fourteen descriptions of PPI roles and associated tasks that people working with McPin have undertaken. The roles range from leadership in large studies to part time roles that students can take on alongside education. The reflections exemplify the vast range of skills PPI requires and are all written from the role holders personal perspective.

A note on skills. The case studies identify various skills that are required in each role. Some of these skills, such as empathy with the research topic and research participants, are derived from having lived through similar mental health or other experiences – a form of experiential expertise. Other skills, such as diplomacy, are developed through the work itself, training and other professional roles



# 1

## Co-investigator role in the STOP study

by Thomas Kabir



I see my role as a co-investigator as being the person who has to hold that overall responsibility for making sure there is lived experience involvement in the study – and that it happens well.

I have been working with a team of researchers from Kings College London for around nine years now. The team has been developing an approach to help people with paranoia based on something called Cognitive Bias Modification. I was a co-applicant on a small study funded by the NIHR called CBM-pa. I am now a co-investigator on a much larger study funded by the Medical Research Council with the same team called **STOP**.



I was heavily involved in developing the funding applications for both studies. This involved developing an involvement plan, influencing the design of the study, and putting together a budget for our work. Of course, I also arranged for people with lived experience to be involved in the process. To do any of this I needed to have an understanding of the proposed research and the design of the study (in this case a randomised controlled trial).

I see my role as a co-investigator as being the person who has to hold that overall responsibility for making sure there is lived experience involvement in the study – and that it happens well. I have a responsibility of maintaining relationships with both the study team and the STOP Lived Experience Advisory Panel (LEAP). Sometimes I have to advocate for an opinion from the LEAP that I may not agree with, or put the LEAP's point of view to the wider study team. This is not always easy, but a fundamental aspect of being a lived experience co-investigator. You really do need to be willing to advocate for the opinions of others (alongside your own) no matter what they are.



### Skills

**Diplomacy**  
in managing differences between the study team and the LEAP.

**Responsibility**  
for ensuring lived experience is included in the study.

**Advocacy**  
to support or argue LEAP members' opinions articulately.

# PPI coordinator on the CONNECT study

by Alex Kenny



In this role I created recruitment content, and advertised for and hired a Lived Experience Advisory Panel and Involvement Network to work on the **CONNECT study**, particularly focussing on communities who are marginalised by ethnicity and economic status. During recruitment I took a personalised approach, phoning each potential member, getting to know them and assessing the mutual suitability for the role. With a background working in research I am used to recruitment and talking with people on the phone.

To keep engagement and motivation high I maintain regular contact with the LEAP members. I share relevant aspects of my own experience that resonate with them; for example, feeling ignored by professionals. I feel this has empowered and encouraged people in our group to be more open; it feels like a form of mentoring

I do wonder, who am I to offer this support? I have previously worked as a peer support worker which gives me experiential expertise – particularly in how I approach disclosure. In this role I considered what was appropriate and helpful, and when was it not necessary to share. I did not want to feel exposed.

In the study I have built a relationship with academics and clinicians who work in different systems. In one of these systems. What was this like when I come from a marketing and business background? One example is that I learnt being very responsive to their emails is not as important as how I now work on an equal playing field, and can spend time formulating a response.



**I share relevant aspects of my own experience that resonate with them [LEAP members]; for example, feeling ignored by professionals.**



**Careful** disclosure keeping myself and others safe.

**Mentorship** to advisory members to engage and motivate.

**Trustworthy and collaborative relationships** built with academics.



## Skills



## PPI local site lead within the EYE-2 research trial: facilitator of a group as part of the intervention and running local lived experience advisory group



I think this group worked because each member found a space where they could be themselves with no judgement, and they empowered each other naturally.

As the PPI lead on the **EYE- 2 research project** at the Psychosis Research Unit in Manchester I facilitated peer groups. The groups were part of the research trial which aimed to see if peer support would help people in early intervention services from relapsing. I was massively interested in the benefits of peer working and, before applying, had been a peer mentor in an in-patient environment. I also offered my experiential expertise in the advisory group attached to the trial and supported the write-up of outputs.

I was responsible for setting up and facilitating the peer support groups, which ran weekly in the research trial. The group was socially orientated. We would talk about all sorts, including our diagnosis and medications. I think my lived experience of schizoaffective disorder made these conversations possible and, at the same time, normalised them. I am a recovering alcoholic with many years of AA wisdom. This helped me share my experiences, as opposed to giving professional advice.

The group had four regular members and we maintained a weekly get-together via telephone during lockdown. I think this group worked because each member found a space where they could be themselves with no judgement, and they empowered each other naturally. Everyone's recovery journey is different and at a different pace. Having 25 years' experience as a service user, and a similar time as a recovering alcoholic, I like to think that sharing my experience and my recovery journey inspired the group to continue their own recovery journeys with hope and trust for the future.



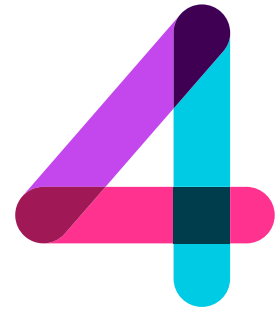
### Skills

Work with **respect and mutuality** to build trusting relationships.

**Empathic listening** supporting a deeper understanding of the group.

**Selective disclosure**, sharing lived experience when appropriate.





# Co-researcher roles in youth mental health research

by Georgia Naughton

Whilst studying for my masters, I applied for a role as a co-researcher on the **Blueprint project**. I was excited and intrigued by the role as it described using your own lived experience of mental health to shape the research – something I hadn't heard of before. I applied and succeeded, alongside five others.

We were trained by researchers at the Universities of Manchester and Cardiff, where the project was based. The training focused on qualitative research techniques, such as interviewing and analysis. We went on to co-interview alongside the study researcher, which involved working together to interview young people, their parents and people who work in the mental health services. We collaboratively developed a framework analysis of the interview transcripts. We also co-analysed reflective diaries of our experience on the project, to form a paper focusing on the co-research methodology.



**Working on the Blueprint project led to my first three journal publications, more co-researcher work on different projects and then to a full-time peer researcher role.**



Working on the Blueprint project led to my first three journal publications, more co-researcher work on different projects and then to a full-time peer researcher role. I am immensely grateful for having had this initial opportunity, and the ability to learn and progress, which will hopefully lead to a long-term career in lived experience-based research. The skills and knowledge I learnt from this role are ones I believe I could not have learnt elsewhere.

**Empathetic listening** in research interviews.

**Reflective approach** including keeping a research diary.

**Fresh insight** from a young person's perspective, not available to academics.



## Skills



# Peer researcher roles – working as a service user researcher on PARTNERS2

by John Gibson

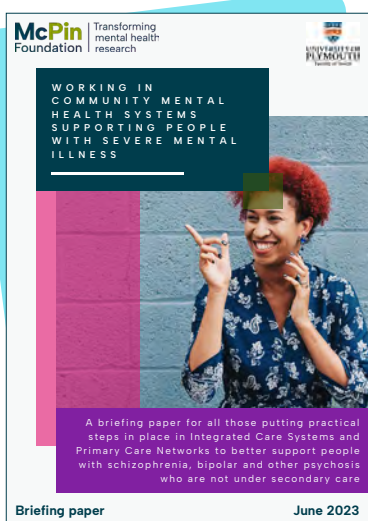


**As a peer researcher, I had the opportunity to choose my role title, opting for service user researcher because it best fit my personal experiences.**

My role as a peer researcher on **PARTNERS2** evolved from first being a Lived Experience Advisory Panel (LEAP) member on the study. The study itself involved developing a collaborative care intervention for people with schizophrenia, bipolar and other psychoses, based in GP practices. Lived experience of one of the diagnoses was central to being accepted as a LEAP member – in my case as a service user with a diagnosis of bipolar. I have also been a carer for a parent who shared the same mental health issues. This has given me the invaluable experience of two different, often challenging, perspectives.

As a peer researcher, I had the opportunity to choose my role title, opting for service user researcher because it best fit my personal experiences. I acted as a 'bridge' between the LEAP and the rest of the study team. I was someone with whom the LEAP could identify. As a service user researcher, I was much closer to day-to-day decision making and, in theory, had greater opportunity to shape the project; however, as a LEAP member I felt freer to express opinion and the collective voice potentially afforded more influence.

The LEAP and I worked together on diverse aspects of the study: developing recruitment materials; and building the study website and choosing outcome measures. I was responsible for: recruiting participants; contributing to workshops with role play bringing to the fore experiential knowledge; co-designing and co-delivering conference presentations at dissemination stages. In meetings I took many roles, giving progress updates to study partners and co-chairing. The role requires a mix of experiential, administrative and research skills gained at degree level – a unique blend! I've since put this experience to good use on other studies as well – I'm currently working as a peer researcher with researchers at the University of Cambridge.



## Skills

### Perspective taking:

Empathy, active listening and taking the time to understand someone else's experience.

### Administration, accuracy and efficiency

to keep on top of seven work streams and multiple teams, keeping to tight deadlines.

### Strong research skills

such as interviewing, data analysis, understanding of randomised controlled trial methods, writing for publication, and presenting at conferences.

# Young Person Advisory Group and young people's network member



When looking for roles related to mental health and research, most opportunities I found were voluntary, or aimed at people with more experience and qualifications. However, the **McPin Young People's Network** stuck out. They offered paid opportunities, accessible to someone with no professional background in mental health. What counted was my lived experiences of mental health struggles. The Young People's team showed how much they valued people's insights from this perspective by offering support, training, and financial compensation.



As a Young Person's Advisory Group (YPAG) member, I have reviewed research proposals; helped design how studies are conducted and assisted in interpreting findings. Many of these projects have been brilliant and inspiring, but some I've been less impressed with. Sometimes, a project can be unhelpful, stigmatising, or miss the point. McPin constructively facilitates conversations around these issues in a valuable way – making sure lived experience is brought into research meaningfully, even when this might be difficult.

It's hard to name what it is about my experience of mental distress that I bring to the YPAG work. I can think of my diagnoses, my neurodivergence, and also my social privileges – the multiple ways these things have shaped my experience of mental distress. Drawing upon lived experience isn't simple. I would never assume that my experience will be shared by everyone else. I think it's about empathy and expression.

I draw upon my experiences to reflect, open up conversations, and hopefully offer insight. Often, it's a gut instinct – a judgement based more in my values than my knowledge – that guides my work in the YPAG.



**What counted was my lived experiences of mental health struggles. The Young People's team showed how much they valued people's insights from this perspective by offering support, training, and financial compensation.**

**Critical thinking:** Ability to think critically about research proposals.

**Reflectivity:** Ability to draw upon personal experiences reflectively to offer feedback to researchers.

**Empathy** with other young people in the group or potential research participants in studies.



## Skills

# 7

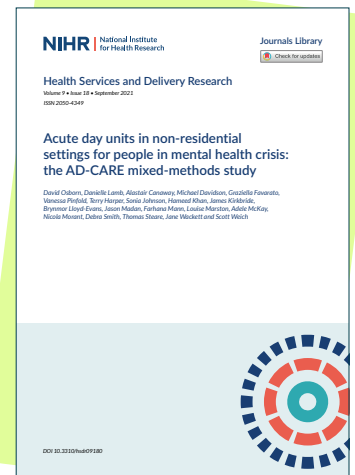
## Lived Experience Advisory Panel member on the Ad-Care study

by Hameed Khan



**As a British Pakistani Muslim man I represent, through my voice, different intersections who are marginalised but not forgotten.**

I was a study advisory group member for Ad-Care, which explored the nature of acute day units, the services they provided and how they reduce inpatient admissions. We held LEAP meetings in the acute units across the country. In the role, I, with other LEAP members spoke with service users and observed the activities provided, such as arts and fitness. As a former user of services, I felt comfortable visiting these units. I also have professional experience as a support worker in a mental health setting, so the environment was not unfamiliar.



As a British Pakistani Muslim man I represent, through my voice, different intersections that are marginalised but not forgotten. This is one of the things that makes me passionate about this kind of work. My role as a carer for a parent adds yet another perspective to my experiential knowledge and skills. These professional and personal experiences helped me understand the project from multiple perspectives. Ad-Care was a very unique project, special for me, as it was hands-on and face-to-face.

I was part of a large team that consisted of academics from different Institutions. Although I was a small fish in a big pond, exposed to the different work environments, I learnt a lot in the role and held knowledge that others around the research table did not. It was like yin and yang with two different sides complementing each other. I felt an expert – it was great to be there, I was making a valuable contribution. I did not feel tokenised in my role.



### Skills

#### Insider perspective

My own lived experience of accessing mental health service in-patient settings and acute day unit.

#### Research skills

My skills in understanding mental health research learnt from being a PPI member in a previous project.

#### Intersectional perspectives

My in-depth personal experience of marginalised intersectionality gave me a unique perspective on equality diversity and inclusion.

# Independent Steering Group member

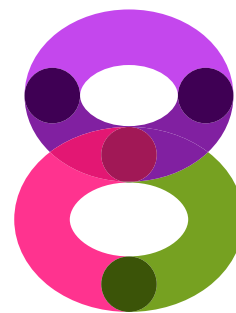
by Gill Grimshaw

Steering Groups are drawn from a pool of research experts and those who live with the condition, or circumstances, being researched. The latter breathe fresh air into the process and ground research in the service user's perspective.

I have cared for someone who has a severe psychotic illness for nearly 25 years. We have lived through many episodes of drug resistance, acute illness, social disfunction and disruption. I have witnessed a heroic climb back to a stable and worthwhile life – but that is only half my story. During this time I was a health services researcher and academic, working with the very colleagues treating my family.

Who better to sit, as a person informed by lived and professional experience, on a steering group? In this role we met regularly to review progress, support and advise the study team. I provided possible solutions to design challenges, reflected on the results and commented on the interpretation. There was not always agreement, especially when a research 'expert' and a 'lay person' placed differing emphasis on an issue.

My role required an ability to be critically engaged; to listen, read and reflect, and a willingness to speak up when something wasn't clear or didn't seem right. This was, mostly, valued by the research team. It takes confidence and a preparedness to "ask the silly question" in an appropriate, calm manner. Researchers can become immersed in the detail, sometimes needing a fresh perspective on their work. This role continued up to the presentation of the final report.



**My role required an ability to be critically engaged; to listen, read and reflect, and willingness to speak up when something wasn't clear or didn't seem right.**

## Confidence

A willingness and confidence to speak up from a lived experience perspective.

## Multiple perspective-taking

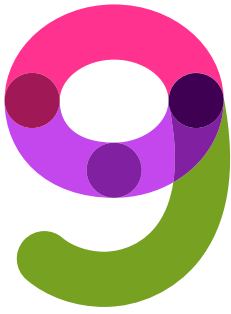
To be able to see things from both a research and lay perspective.

## Managing conflict

Being calm and respectful when disagreements arise.



# Skills



# User testing: Expert workshops to co-develop a new virtual reality intervention

by Beverley Chipp



**Being around other mental health service users for so long it was not only my own lived experiences but many others' stories that I could bring to the table.**

A diverse group of us met at the Royal College of Art to come up with the **gameChange** virtual reality environments. I have two decades of co-production experience, and working on gameChange was particularly enjoyable. Being around other mental health service users for so long it was not only my own lived experiences but many others' stories that I could bring to the table. In the testing stage it was interesting to actually put on the headset and try out the programme that we had designed. We had a whole wall as our whiteboard, and this became busy with sticky notes. Tech team members were present so they would let us know if suggestions were too difficult to write code for, such as moving background outside the bus windows. It was good learning what could and couldn't be done and find solutions to that together.

We designed the avatars together, giving feedback on how they should look and sound. We identified when things didn't look quite right – usually something missing or a problem with unrealistic scales and proportions of one set of things to another, or disjointed body parts.



We were reminded that this would be used by people in many places and so we had to look beyond a city-scape view of the world and make sure it was relatable to those who lived in rural areas. We replaced the iconic London bus for a single decker, and we made sure the buildings were not too grand. This made it more inclusive and relatable to a wide range of service users.



## Skills

**Extensive co-production experience** which was brought into this co-design task.

**Broad knowledge – drawing on own and others experiences** in the user-testing process.

**Problem solving** to find solutions together, working constructively.

# Member of a Research Prioritisation panel

by Lucy Power

The Right People Right Questions (RPRQ) project was a priority-setting partnership, bringing together young people, parents and professionals to uncover the top ten unanswered questions about young people's mental health. My role on the advisory group involved attending regular steering group meetings and helping co-create the public survey of important unanswered questions. I was involved in the collection and analysis of survey responses, which built upon the skills I gained in research method and design at McPin. I also helped to create a video which summarised the project's objectives and encouraged wider involvement.

The main driver for my involvement was a desire to make a positive impact. My own lived experience with mental health and as a service user taught me that there isn't always enough knowledge, or funding, to provide the best information and treatment for those with a mental health condition. Previous experience in PPI has also highlighted the power dynamic which forms a researcher/clinician/service user relationship is often skewed. I hoped to help change this, in whatever small capacity.

My involvement was really rewarding, and an opportunity to use my lived experience for good and not see it as a problem to overcome. I was one of a diverse group, adding value by contributing to an anthology of unique experiences. The project's co-production ethos meant that its findings were relevant, accurately reflecting young people's concerns.



RESEARCH INTO YOUNG PEOPLE'S MENTAL HEALTH



**My involvement was really rewarding, and an opportunity to use my lived experience for good and not see it as a problem to overcome.**

## Collaboration

The work is group-orientated and it helps to be receptive to different opinions and experiences.

## Critical thinking

As a young person involved in research, I got to apply training I received in research skills into a project framework immediately. This requires being able to implement critical thinking skills quickly.

## Insight

Personal experience and knowledge of systemic shortfalls meant I could identify gaps and potential solutions better.



# Skills



## Peer reviewing PhD proposals



**This was a really rewarding opportunity that brought a huge sense of togetherness with other young people.**

I've been working with The McPin Foundation since 2017, when I was enrolled as part of their Young People's Advisory Group (YPAG). At that point in my lived experience, I was still very much struggling with various aspects of my disordered eating. McPin provided a space where I could use those experiences to better inform the public – and amongst the whirlwind of my own mental health, this was a really rewarding opportunity that brought a huge sense of togetherness with other young people. We would discuss at length our experiences, using our understanding of mental health needs to enhance research.

Since then I have progressed into a peer reviewer role, reviewing PhD proposals that have come via McPin. This work, unlike my previous YPAG involvement, is primarily remote, which is very suited to my current circumstance and allows me to contribute regardless of my personal schedule. The reviewing includes critiquing the research focus, reviewing proposed research methods, and contributing relevant lived experience that may strengthen the proposal. Having been a part of the YPAG, I have witnessed first-hand how lived experience can inform research, and so any way I can advocate for this to happen I willingly do so.

I came out as non-binary in 2021 and have since thrived as my true self within the trans+ community. This has provided an additional perspective when peer reviewing, which I'm very proud to contribute. I grew up in a single parent household, struggling with anxiety and anorexia nervosa for several years. McPin has always provided a safe and supportive space to explore these issues – and this has continued as I have discovered my true queer, non-binary self.



### Skills

**An openness to share my lived experiences.**

Enthusiasm to share a trans+ and queer perspective.

**Attention to detail** when reading large amounts of text.

**Providing constructive feedback** on proposals.





# Recruitment of staff to work on a research study

I was involved in the recruitment process of a study designed to support people with chronic depression and/or anxiety. The process took a co-production approach. The panel was made up of people with lived experience, academic partners involved in the study, and clinicians working in the community mental health teams where the trial was running. I was involved from the start, designing and implementing the recruitment process alongside others. We were recruiting Community Navigators to support participants on the study to take steps to address loneliness associated with their mental health.

Collectively, the panel represented a diverse spectrum of experiences. We used this to inform the role description and co-design the interview process. The most innovative part was developing a series of interactive scenarios that we 'role-played'. We used our own experiences of service use – uplifting and motivating ones, as well as ones that set us back. I enjoyed the creativity of this task, coming up with real-life situations and then adding possible challenges or unexpected twists. Our intent was to see how candidates would problem-solve whilst keeping the needs of the person they were supporting front of mind.

Our lived experiences provided vital insights into the suitability, skills and personal characteristics of potential Community Navigators. The decision for selecting suitable candidates took a collective approach. Multiple perspectives were taken into account, particularly from an experiential perspective. On a personal level, I was able to use previous experiences of recruitment in professional situations, championing processes that were fair, inclusive, and humane.



**Our lived experiences provided vital insights into the suitability, skills and personal characteristics of potential Community Navigators.**

**Creativity** in how to approach tasks to be more engaging and inclusive.

**Listening** to other viewpoints and perspectives in the group.

**Balancing different perspectives** when making decisions.



## Skills



## Dissemination at conferences



**All our experiences count in a PPI role. We can use the skills that we have learned across our lifetimes because we are so much more than our mental health situations.**

I was a peer researcher on the [Viewpoint study](#) and was mainly involved in interviewing and analysing data. As part of this I was asked to speak at a conference on stigma and discrimination. I was terrified by the idea and my first instinct was to refuse. However, at the time, I was doing therapy work and was challenged to 'face the fear and do it anyway!'. My son was also being asked to perform at school and, to help him overcome his fears, I realised that I must practice what I preach and speak at the conference!

It helped to focus heavily on mindfulness and hone the skill of watching my catastrophic thoughts, while not paying too much heed to them or accepting them as actual 'truth'. The truth that really mattered was how best to represent the people I had interviewed. Finding confidence was important, but if there's one thing that I am confident about it is the fact that I have experienced both stigma and discrimination – which was the subject of the presentation.

I drew on so much more than my mental health experiences. For example, many years ago, I worked as a receptionist and had to learn to become comfortable with greeting and speaking to strangers – public speaking was simply an extension of that. All our experiences count in a PPI role. We can use the skills that we have learned across our lifetimes because we are so much more than our mental health situations.

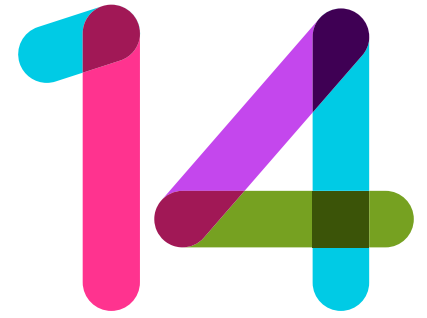


### Skills

Have **courage and confidence** to speak about difficult emotive subjects in a public space.

**Mindfulness techniques** learnt in therapy used to support anxiety of public speaking.

**Insight and boundary setting** give the ability to reflect deeply on how much one wants to share when giving a presentation.



# Presenting session on PPI to students

by Davino Beckford

I co-presented a session on 'Patient and Public Involvement (PPI) in Research' for masters students at University College London. In the presentation, we explained terms such as 'expertise from experience', 'public advisory work' and 'collaborative research', which are all central to McPin's work. We expanded on the different dimensions of PPI work, including co-production and peer research methods.

We offered students a hypothetical scenario, inviting them to devise a PPI plan for a research project and engage in critical reflection, asking themselves: What would you prioritise for PPI involvement and why? How could people with lived experience be involved in the study? How would you recruit to ensure diversity in the PPI?

I used my knowledge as a Peer Researcher to provide real life examples of the work I do. Having worked with various different groups of people such as the Black community and queer communities, I have gained insight on some of the needs and adjustments that can be made to enable equity in research. I highlighted the crucial role recruitment plays in representation of the target demographic.

As a Black Queer person, I know that marginalised voices are routinely left out of research. Sharing my lived experiences and emphasising the importance of diversity felt particularly important.



**Having worked with various different groups of people such as the Black community and queer communities, I have gained insight on some of the needs and adjustments that can be made to enable equity in research.**

**Confidence** to present and share learning with others.

**Experience of doing peer research** and working with the Black community and queer communities.

**Knowledge of how to share and use lived experience in research.**



## Skills

# Key ingredients of PPI

In this section, we highlight the main ingredients for PPI in mental health research based on our own work. The application of these dimensions will depend on role, with some being relevant in all roles, such as payment and power sharing, and others depending on context, like being a critical friend. We have found four key ingredients, each with three elements.





## Applying lived experience expertise

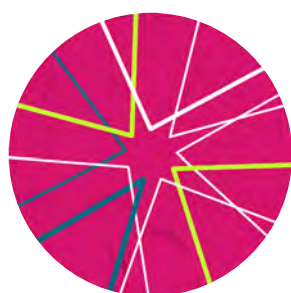
**Lived experience expertise** is core to PPI. As we are a mental health charity, most of the experiences in our work relate to mental health in some way, but other experiences overlap with these and are also important. These include experiences of gender, sexuality, heritage and race, age, where you live, and/or migration, trauma, discrimination, and poverty. Involvement work brings intersecting life experiences into conversations and projects, and these can be vital.

Central to lived experience work is disclosure. At McPin, disclosure; choosing to share, or not share, one's lived experiences, is a personal choice. Working out what feels safe and comfortable to share, and when is central to acknowledging and respecting the emotional labour attached to disclosure. It can change over time and depend on context. At McPin, we provide training, support and guidance on disclosure from staff whom themselves have experiential expertise.

Lived experience sits alongside other forms of knowledge, skills, and experience in PPI work. It can be combined with academic, clinical and practitioner experience and qualifications, as well as skills from other work such as communication and graphical design. People may wear more than one 'expert hat' in a study team.

### Learn more about working with lived experiences and disclosure

Other McPin 10 for 10 resources you might be interested in are *Peer Research at McPin* and *Using Lived Experience in the workplace*. Find them on our website: [mcpin.org](https://mcpin.org)



An important consideration in projects and activities is what type of lived experience expertise is required. This is often shaped by the focus of the work. It might be that the study is looking at in-patient experiences – so experience of mental health in-patient stays in the recent past are going to be useful and relevant. If the study is comparing two medications for a specific health condition, for example bipolar, then experience of taking medication for mental health needs related to bipolar are important. The matching maybe around experience of homelessness, job loss, mental health stigma, racial discrimination, mental health support in schools. A study might require people with experience of managing mental distress, seeking GP support for mental health issues, experience of self-harm or feelings of suicide. It will depend on the topic – but it is useful to consider this question even if there are not always clear answers.

We tend to write role descriptions and run open recruitment processes for most of our involvement opportunities. Some roles require lots of previous research involvement experience, others none. Some require research qualifications and training. PPI work needs diversity of relevant lived experience in projects and must find different ways of continuing to promote opportunities, working with new people and learning from each other. A tricky part of selection processes is that often all applications are suitable and have relevant lived experience expertise. In those situations, we look at intersectional characteristics to build diversity in teams. Intersections such as age, gender identity, sexual orientation, educational backgrounds, ethnicity and geography. This is not a rejection of individuals lived experiences but a validation of how overlapping forms of oppression can marginalise some people and communities even more than others in the creation of research knowledge.



## Being a co-investigator on a trial from a lived experience perspective

I am a co-investigator on a trial that is exploring the use of peer support to alleviate the self-stigma associated with experiences of psychosis. I was put forward for the role because of the shared experiences I had with the project's focus and the people working on it. I have experienced self-stigma because of my mental health and worked as a peer supporter in an NHS setting. My role is structured and demands a mix of professional and personal skills. Here I explore how I have used my lived experiences in the role.

I co-designed and delivered a training session for the peer support workers. In it, I included a segment on the history of peer support, paying homage to its activist roots, which I have admiration for. This was a small way of injecting experiential knowledge into a clinical and academic space. I also shared a very personal story of a watershed moment in my life – the unmasking of self-stigma. I drew on it because it was relevant to the trial. It was a part of my personal history I have not shared in other spaces at McPin. I find disclosing to people with whom I won't have regular contact easier than with people I work with week to week. Learning my personal boundaries with disclosure is something I did through testing the waters over time; or, in other words, through the trial and error of over-sharing! I am also supporting the analysis of primary data. The years spent introspecting on my mental health – the 'why me?' questions – have all been beneficial to the reflexive approach the analysis is taking. I can join the dots between people and systems and am adept at questioning my own biases.

I call my role a respectful rebellion. I am working alongside academics embedded in traditional institutions, flying the flag for experiential knowledge along with my own strong motivation for social justice. Being assertive in expressing opinions that flow counter to the prevailing current is important, but how far I can go depends on the context. Maintaining a respectful demeanour is important as I am representing my organisation and not on a personal protest. Also valuable is maintaining a pragmatic attitude. I am a small fish in a big pond – sometimes my suggestions lead to change and sometimes they got lost in a larger process. This is not the 'fault' of anyone but a system reality.

## Good communication

The most important priority in PPI work, as an organisation, is establishing and maintaining good quality, **respectful relationships** with individuals and across teams. This responsibility is often held by one or two people at McPin. In some studies, this means developing working relationships with several teams in different sites and managing these over years. Relationship building among PPI contributors, so tasks can be done well, takes time. We have found it is important to take the time to get to know all our PPI partners, such as peer reviewers or advisory group members: understanding personal motivations, preferences, communication and learning styles, and working out how to ensure that each person can contribute to the research project in meaningful ways. Lived experience contributors also seek to understand other team members' motivations, preferences, learning and communication styles. Shared understandings are a priority in this type of work, particularly because allocation of tasks tend to happen in group meetings.

McPin often takes on the role of co-ordinating lived experience contributions within a wider research group, led by a university. The role of the lived experience contributors can be framed as '**critical friends**'. This involves giving honest, transparent feedback, which can sometimes challenge and critique the design and processes of a study. The intention is to be supportive; to improve and maximise the impact of the study.



People in PPI roles are partners with viewpoints, and like other team members can agree or disagree with proposals. This can lead to providing opposing views, standing firm in doing so, suggesting changes or bringing fresh perspectives to a study design. Being a critical friend is a set of skills. It can also require a level of resilience and ability to deal with discomfort and rejection of suggestions, as well as positive feedback.

McPin staff working in PPI leadership roles will give robust feedback and stand firm in our opinions. That means lived experience involvement roles can be challenging – emotionally and practically. We have found it is important to **establish trust** within teams to be able to give **honest feedback**, particularly if it is against the current flow of opinion in a project. That takes time and effort. Lived experience contributors may hold differences of opinion amongst themselves as well as with other team members in the study team. How far teams take on ideas and feedback from PPI contributors very much depends on the set-up of PPI involvement. If the set up of the PPI group is peripheral, the take up of advice offered may be ignored. If the PPI group is valued as a project partner respected to have an equal voice and influence, the take up of ideas may be greater.

**PPI co-ordination** involves managing the expectations of all involved to assist with positive communication. So can keeping everyone updated on decisions being taken, study progress, and celebrating individual and collective successes in the team. Investing time in team building and paying attention to supporting and inclusive team culture makes integrating PPI members and work into studies far easier.



## My experience of being on a fellowship interview panel

by Gillian Samuel

I was welcomed onto the top floor of the British Library by a group of academics, over coffee and pastries. My home for the next 1.5 days. In the board room, we gathered around the table. I was placed at one end.

*I was suddenly the patient, in a ward round, with psychiatrists, social workers, nurses, therapists, junior doctors. Pens in their hands, ready to write down the answer to the question they had once asked me: 'do you hear voices?'*

Question 6 was 'the PPI question', a rather general, not so challenging question, which I was to ask each of the candidates. Back-to-back interviews ensued, with what seemed to be a never-ending swirl of information gathered and noted. That I was to be part of the decision-making process as to who would be offered the fellowships suddenly felt overwhelming. Over a buffet lunch, I was reassured by the team. I was looked after, looked out for.

*I was in the hospital canteen. A man acutely unwell dropped his tray on purpose. I saw him do it. The noise was horrific sending the other patients into despair. Chaos.*

Inside, the unrest grew. I came to believe that my one pre-ordained question was in some ways a question for show. All the candidates demonstrated at least a basic understanding of PPI even before I asked my question. So, my question felt benign and therefore the reason for me being there felt opaque.

Next year must be different. I found my voice and with confidence, I fed back both verbally and in writing, describing ways to improve public involvement in the interview process.

I have come a long way. Further than they know.



## Power sharing and decision making

A crucial part of PPI is influence and shaping or making **decisions**. Ensuring that the work of lived experience contributors is meaningful means changing how decisions are made in research studies. This can range from individualised decision-making to collective processes. This is not easy in research, with statutory regulations driving key processes or funder requirements shaping decision making. It is easier in studies with fewer partners and research methods that are naturally more democratic – such as participatory action research or when adopting a co-production approach.

We have found ways to **share power** in university-led research studies, including:

- ④ lived experience contributors running meetings or determining how agendas are set
- ④ sharing conference presentations to jointly own the narrative over research findings
- ④ asking lived experience contributors to co-author papers, including as lead author
- ④ involving PPI partners in project management spaces where team decisions are made and minutes taken
- ④ providing the PPI team with resources to run a dissemination event
- ④ employing peer researchers and PPI co-ordinators, embedding them within the central research team so they can shape the day-to-day running of the project.



There are some challenges. Academic **research hierarchies** – with leadership in professorship roles or support structures like a Clinical Trials Unit – do make it very hard to equalise ways of working and share decision making. Hierarchies are found in most organisations, including McPin, so navigating these carefully and opening up how decisions are made is important.

Budgets tend to be small for PPI work (10% or less of total budget is typical) but larger for other aspects of a project. PPI roles are often part time or ad hoc, with the ‘core’ university-based research team working full time, providing another potential distortion in ways of working (and thus influence). Involvement should be meaningful: people’s contributions are not tokenistic or poorly valued additions; they should be a vital part of project delivery. For McPin this means we need to be clear on the limits of decision making, be careful to **manage expectations**, and strive for a culture of transparency in projects.

We also push and seek out opportunities for more involvement throughout a project because often, as research studies progress, new ideas arise for how lived experience expertise can help the knowledge-generation process.



## Championing youth involvement in a research study as a co-applicant

by Rachel Kimberley Temple  
Young People's Involvement Manager, McPin

"I joined the **Agency project** as a young person PPI co-applicant. It was my first time as a co-applicant and co-investigator, so naturally I didn't know what to expect. My job was to ensure that PPI was embedded throughout the entire course of the project and in the most meaningful ways possible. It's not easy coming into a leadership role alongside brilliant professionals and academics, and it was no easier for me, a young person with pretty intense social anxiety at the time. It made speaking up challenging.

Despite this, the other co-applicants could not have been more welcoming and supportive. I felt safe enough to be upfront about my anxieties with them early in the project, and together we established a way of working where I felt I could be of value. As a co-investigator, I was invited to all the project management meetings and encouraged to have my say. I soon learned the true value of my expertise on this project. I was able to make suggestions about the directions of the project, the approaches we took in communicating with young people working on the project, and in shaping key decisions.

The team truly listened to me. They asked regularly for my opinion, and whenever I felt bold enough to challenge something or make suggestions, these were addressed. We all seemed to be on the same page about the importance of high-quality youth involvement and what this would bring to the project. The trusting relationship we built as a leadership team and with the young people was the making of the project and all of its successes."

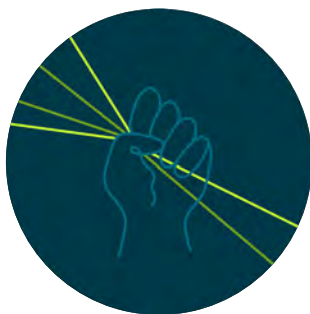
## Payment and reciprocity

PPI work is **remunerated** at McPin. Our principle is that lived experience expertise should be paid for – and not in vouchers (unless specified for a good reason). PPI work can be demanding, as well as personally rewarding. As of September 2023, the hourly rate recommended by the NIHR is £25 per hour. This can cause problems for people on welfare benefits, and a **NIHR advice service** exists to support anyone concerned about receiving income from PPI activities.

We are aware of the **emotional labour** involved in carrying out work using lived experience expertise. We have tried to ensure people are supported with supervision and mentoring for co-researchers, peer researchers and PPI co-ordinators. For people working in advisory groups, we try to speak with members regularly and have debrief sessions after meetings. Developing people within their role is a priority and peer support is part of this, with members supporting each other and sharing skills.

### Learn more

Other McPin 10 for 10 resources you might be interested in are our *Wellbeing at work resource* and a *podcast on mentoring and coaching*. Find them on our website: [mcpin.org](https://mcpin.org)



A good way to ensure that PPI is a two-way exchange of ideas and skills is to focus on training and development. There has always been a lack of research training and development specifically aimed at people with lived experience. However, more recently there have been courses made publicly available online (see [here](#) for an example). Training courses are often valued by people with lived experience. At McPin we have seen people develop and progress into both contractual paid work and formal educational course such as doctorates, partly due to this.

Our sense is training should always be seen as a two-way reciprocal process. Just as training can be offered to someone with lived experience, someone with lived experience can offer training to the wider research team. Training and development at its best is always mutually beneficial, with reciprocal learning opportunities.

### Learn more about reciprocity

Other McPin 10 for 10 resources you might be interested in are *Working as a co-researcher* and *Research Involvement Groups*. Find them on our website: [mcpin.org](https://mcpin.org)



## My experience on the TYPPEX-LEAP and its qualitative research training programme

by Annabel Walsh

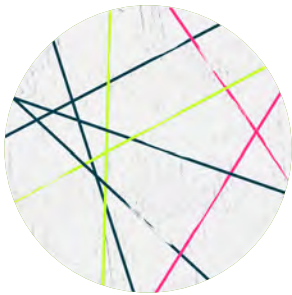
“When I became aware of the McPin Foundation, the involvement of people with lived experience in research was a relatively new concept to me. With my own lived experience, my first foray (of many more to come) into the world of PPI was to apply to be a LEAP member on the “Tailoring evidence-based psychological therapy for people with common mental disorder including psychotic experiences” (TYPPEX) study in 2017 and I have been involved ever since. The TYPPEX study, led by the University of Cambridge and the Cambridge and Peterborough NHS Trust, aims to develop and test a training package for therapists within Improving Access to Psychological Therapy (IAPT) services, so they are equipped and empowered to better meet the needs of individuals with psychotic experiences. As part of this, the study team is currently undertaking a process evaluation, including qualitative interviews with the IAPT therapists that received training, and the service users under their care.

Throughout the course of the TYPPEX LEAP, we have been encouraged to express interest in training and development opportunities, and this was the perfect opportunity for us to learn more about qualitative research. Under the Qualitative Research Training Programme, we received three interactive training sessions covering everything we needed to know to contribute to the development of a coding framework and the coding of actual transcripts from the qualitative interviews. It was a thoroughly interesting process and I have gained new skills, expanding my knowledge of mental health research methodology.

Additionally, over the now six years I have been a TYPPEX LEAP member, I have learnt a huge amount about the world of PPI, watching and learning from the fantastic PPI co-ordinators, and see this as a significant part of why I am where I am today – employed at the McPin Foundation as a Public Involvement in Research manager myself!”

# Problems in PPI

Critiquing PPI is a task in itself, which we can't do full justice to here. There are problems with lack of diversity, equity and inclusivity of practice, inadequate levels of funding and time to do it well, too few opportunities for lived experience leadership and problems of tokenism. We cover four problem areas below and offer some suggestions to make progress against each challenge.



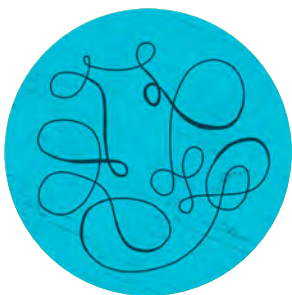
## 1. Non-diverse

Mental health issues can affect everyone, with some groups disproportionately impacted. PPI in research does not always reflect this and is known to be non-diverse in terms of gender, ethnicity and education attainment. As a sector, we are currently not engaging communities that need to be involved so there are groups of people who are 'seldom-heard' in academic research.

We seek diversity of perspectives, however, it is often a challenge to recruit people that reflect varied experiences and expertise, and more outreach and proactive efforts are required by us.

### Suggestion

**Work harder at inclusive research to ensure it is more accessible and engaging. Learn from others and create support networks to build a diverse community and stay in touch with everyone, paying community groups for their expertise and help; community engagement with a focus on reciprocal relationships.**



## 2. Tokenism

In PPI work, there is a risk of tokenism. It is rare to have lived experience-led research funded by NIHR or UKRI. People with lived experience may not be in formal full-time employed positions. This can lead to frustrations for those with expertise to share but limited potential for influence. When PPI is included in research proposals, it is often underfunded. It can also feel extractive – that people with lived experience are only there to 'tell a story' rather than use lived experiences alongside other skills and interests to shape projects, equally alongside researchers and clinicians. When lived experience expertise is marginalised into small roles, and separate spaces, it can feel like a token tick box exercise rather than a genuine partnership to improve research methods and co-develop new solutions, understandings and knowledge. We do our best to rally against tokenism but unfortunately it does still happen.

## Suggestion

**Attempt to align expectations from an early stage of the project and accept the limits of what is possible together. Work hard to prevent tokenism, with team members holding themselves to account, including by seeking feedback from lived experience contributors. Good communication keeping everyone up to date with progress, including where funding is unsuccessful.**



## 3. Activism and pragmatism

Part of the problem for PPI in mental health research comes from its foundations. If we look to the grassroots mental health community and survivor researcher pioneers, this work has roots originating in activism and protest. However, a lot of PPI has been co-opted by mainstream systems and adapted for a national health research agenda. In some ways this co-opting was needed to begin to open up spaces in the mainstream – but with gains come (unintended) consequences and losses. It is important we retain the activist and challenging aspect of involvement.

We have found that, in order to work in harmony within teams, compromise becomes a key skill for those working in PPI. But the problem is, how far should we compromise? In our experience it is at least necessary for people to be able to voice opinions with honesty and in good faith to try to get as full a response as we can from the research team.

## Suggestion

**The right to formally record disagreement should additionally be offered to everyone. In some more extreme cases it may be necessary for someone to end their involvement in a study – and this does happen. Such endings need to be handled extremely sensitively, with compassion. In some instances, people actively working with their lived experiences of mental health and intersecting experiences that face societal and/systemic oppression and marginalisation, may experience the leaving of a project as distressing. It may be experienced as another form of marginalisation or rejection for speaking out. Respecting such feelings is important when ending a relationship.**

**Openly talk about how compromise can be achieved with the study team and provide training and support to those in PPI roles to prepare for compromise and conflicts. Recognise emotional labour involved in involvement work. Use an impact log and complete the feedback circle, recording what could and couldn't be implemented and why.**



## 4. Respecting people's lived experiences

There is a danger that PPI work can be too focused on individual-level lived experience which diminishes the sense of equity in the team. Asking people to share 'their mental health story' does not recognise the broader value of lived experience contributions of systems, other intersecting lived experiences and professional. The commodification of lived experience expertise is a huge risk in public involvement work.

How expertise is requested and applied can feel extractive and undervalued; a tick-box exercise linked to tokenism. This tends to happen more where researchers are less familiar with PPI, and less confident in working with lived experience partners.

### Suggestion

**Keep developing the skill and conceptual basis for PPI work. Work on strategies for integrating lived experience expertise and skills/knowledge into mental health research. Don't expect people to share part of their story if you aren't willing to share part of your own personal life story. Encourage lived experience leadership and establish well-paid research positions for lived experience experts.**



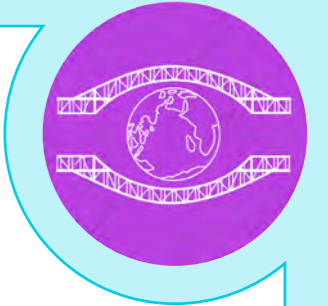
## 5. Power dynamics

All health research involves the negotiation of power dynamics within teams because research is a hierarchical enterprise by nature, often with research groups led by professors overseeing or mentoring the work of early career researchers. The equity of roles in teams is hard to achieve when you have partners that traditionally hold a lot of power; NHS trusts, universities and large well established voluntary sector organisations. Systemic power can extend beyond the organisation, to individuals within them too.

In mental health we also see positioning of roles and professional rivalries including within psychiatry, psychology, nursing, social work and allied health professions. It can make for an intimidating environment to carry out PPI.

### Suggestion

**Openly discuss how to achieve collaborative leadership and shared decision making. Seek strategies to reduce power dynamics in teams whilst respecting the skills and experiences of all contributors.**



# 10 tips for patient and public involvement work

We have collated below a few summary learning points from our work delivering PPI in NIHR- and UKRI-funded studies. These tend to be complex mental health research studies, across multiple sites, spanning 2–5 years. They cover a range of topics including developing new treatments such as digital mental health (virtual reality), new roles (**Community Navigators**), evaluating parts of services (acute day units), exploring young people’s mental health (**the importance of agency in decision making**), understanding issues that may impact mental health (sleep) and understanding lived experiences (inequality and mental health). See our [website for details](#).

## 1 Develop a PPI strategy

Each research project will need a bespoke PPI strategy. You may borrow from things you have done before, but it is best to create new plans collaboratively and review them over time. It is important to think carefully about the tasks you are going to be allocating, as well as the personnel required.

## 2 Invest time and money

All partners need to invest time to do PPI well. There are no short cuts. It needs resources, money to pay people for involvement work – including core staffing – and time to create the conditions to do it well. We always recommend offering payment to people for their contributions.

## 3 Ensure early involvement

It is never too early to involve people in your idea for a research project. The sooner the involvement starts, the better. The earlier that you involve people the bigger the changes they can make to the research. Building a small team of people with lived experience, with different skills and experiences, to work alongside you on several research projects can work well.

## 4 Think diversity

PPI work needs diverse perspectives and thus a plan to achieve and put this into practice is vital. Invite people new to research as well as those with more experience. Working with community groups to promote opportunities takes time so build reciprocal partnerships for the long term.

## 5 Think intersectional

‘Patient’ and ‘public’ are very broad terms. Which characteristics and experiences are you interested in seeking to shape the research and support project delivery? Aside from mental health experiences, this might include age, gender identity, ethnicity, heritage, sexual orientation, geographical location, class, migration history and experiences such as poverty, discrimination or detention under the Mental Health Act. Individuals will draw on their own and collective experiences, thus their knowledge is deep and grounded, and will most likely draw on intersecting identities and experiences.

## 6 Research team culture

Following on from points 4 and 5, build an inclusive team so all research team members, including people contributing their lived experience within roles, feel valued and supported. Create a team ethos and culture that prioritises respect for each other’s expertise and knowledge, and the different ways we may need to work to help each other thrive and best contribute.

## 7 Embed training and feedback

We have found more emphasis needs to be placed on reciprocal learning opportunities. Work in ways so that people who have lived experience can develop within the project, and you learn from them. This may require training and support structures to be set up, as well as mentoring and other development opportunities such as work experience placements. Core members of the academic and research team may need training to facilitate and engage in PPI work. Seek regular feedback from the entire research team and act upon it.

## 8 Track your impact and influence

Maintain a sense of what difference PPI is making to the research. Perceived benefits can be gathered from everyone in a research team, not only public contributors. Impact logs are commonly used. Produce case studies and use reflective practice as a way to generate information. Setting up systems such as regular newsletters to share progress and impact to all team members is helpful.

## 9 Involve the wider research team in whatever you do

Invite members of the wider research team to PPI meetings and involve them as much as possible. This can help avoid misunderstandings, build a ‘team’ ethos, and help people with lived experience to be more aware of the wider context of your project or study.

## 10 Be as flexible as you can

Different people will have different preferences and needs. Some people prefer face-to-face meetings; others virtual meetings. Some people do not like meetings at all and could provide input via email, text messages or phone calls. The point is to try and be as flexible as possible.

### Get in touch

**Thank you for visiting this resource on our reflection on PPI in publicly-funded studies over the past 10 years. There are ten in the series, please do check out our other resources.**

**We are always keen to hear from others doing PPI work – you can write a guest blog at McPin or collaborate with us on a new project. Do get in touch and share your journey with us too: [contact@mcpin.org](mailto:contact@mcpin.org)**



# Other resources



## Funder guidance

- ④ NIHR resources on PPI including national standards:  
<https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437>
- ④ NIHR Research Design Service (South Central) collated PPI resources:  
<https://www.rds-sc.nihr.ac.uk/ppi-information-resources/>
- ④ UKRI resources on stakeholder involvement and engagement:  
<https://www.ukri.org/what-we-offer/public-engagement/public-engagement-mrc/>



## Peer review papers

(not cited in the main resource)

- ⑥ Beresford, P. (2020). PPI or user involvement: taking stock from a service user perspective in the twenty first century. *Research Involvement and Engagement*, 6(1), 1-5.
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- ⑥ Sales, C. M., Martins, F., Alves, M. M., Carletto, S., Conejo–Cerón, S., da Silva, L. C., ... & Edbrooke–Childs, J. (2021). Patient and public involvement in youth mental health research: protocol for a systematic review of practices and impact. *Frontiers in Psychology*, 12, 703624.
- ⑥ Staniszewska, S., Brett, J., Mockford, C., & Barber, R. (2011). The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. *International journal of technology assessment in health care*, 27(4), 391–399.
- ⑥ Staniszewska, S., Denegri, S., Matthews, R., & Minogue, V. (2018). Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future. *BMJ open*, 8(7), e017124.
- ⑥ Rose, D. (2014). Patient and public involvement in health research: ethical imperative and/or radical challenge?. *Journal of health psychology*, 19(1), 149–158.



# McPin Foundation | Transforming mental health research

We want mental health to be better understood. Our mission is to improve everyone's mental health through research informed and directed by lived experience expertise. We want the value of lived experience of mental health issues to be upheld and embraced, which is why we put it at the heart of all our work.

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