Patient and Public Involvement in Research, Why Not?

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Kirsten Morgan joined McPin’s Public Involvement in Research team in October 2015, and worked on Resilience, Ethnicity, and AdolesCent Mental Health (REACH), a large cohort study of mental health among young people in south London, conducted by researchers from King’s College London and funded by the European Union. Morgan began her research career in 2009, facilitating the involvement of young people in Right Here, a five-year young people’s mental health and well-being programme developed and managed by the Paul Hamlyn Foundation and the Mental Health Foundation.

Since then, she has contributed to a wide range of research projects across a number of areas including self-management of severe mental illness, adult learning interventions for anxiety and depression, homelessness, and dementia. During this time, she has worked with multiple stakeholder groups across the public, private, and non-profit sectors and has demonstrated a strong commitment to the value of mental health lived experience in the design, delivery, and dissemination of mental health research.
About the talking point series

Almost everything to do with mental health has been, or is, sharply contested. Everything from understanding health experiences and diagnoses to appropriate treatments and approaches to managing distress to the language used to describe mental health problems has sparked ferocious debate. Mental health research is no exception. We still have a lot to learn.

To date, the majority of the discussions in mental health research have been framed from the point of view of mental health professionals and academics writing in medical journals or speaking at conferences. We welcome these platforms but are keen for discussions to broaden both engaging other disciplines in mental health research and other groups, particularly service users and families. We have therefore commissioned a series of Talking Point papers to encourage people to consider key issues in mental health research.

Involving patients and the public in research has become increasingly common. In part, this is due to major public funders such as the National Institute of Health Research (NIHR) requiring beneficiary stakeholder involvement in studies that they fund. But what do researchers and others think of patient and public involvement in research? Is this important? Does this make research better? Or beneath the surface of their acceptance, do people in the health research sector harbour objections?

A little bit of background about the McPin Foundation. We are a mental health research charity that wants to see expertise from experience involved in all aspects of research. We are committed to improving the quality of mental health research because we need to know a lot more about what works to improve the mental health of communities everywhere. We approach this by championing expertise from experience because we believe better mental health research is done collaboratively, including mental health service users and their families.

We are very pleased to present the second Talking Point paper, written by Kirsten Morgan, on a seldom discussed but important issue: What are the key objections to involving patients and the public in mental health research? Kirsten has been working in mental health research since 2009. Involving expertise from experience in research has always been at the heart of her work.

Join the discussion through our Facebook page or Twitter (the Twitter Handle is @McPinFoundation). You can also leave comments on a blog article we have placed on our website (www.mcpin.org) to announce the launch of this paper.

Talking point papers give people with expertise from experience the opportunity to discuss and debate under-discussed or particularly difficult issues in mental health research. We hope that these papers and the discussion around them will aid us in our mission to ‘transform mental health research’. The funding for the Talking Point papers is from the McPin Foundation, but the views expressed in the papers are the authors’ own.
Summary

Involving people in research using expertise from experience has grown over the past decade from something a few people do to a requirement by a major health research funder – the Department of Health. But does the public appreciate being asked to get involved in research? What do researchers think about sharing academic space with patients and lay people? This is what I set out to investigate in a paper on seldom asked questions in research. The McPin Foundation asked me to contribute to their new series of Talking Point papers, by people with lived experience of mental health problems. As a mental health researcher involved with public and patient involvement (PPI) in research projects for several years, I felt this was a great opportunity to bring these tricky issues to light.

I set out to explore some of the key objections to public and patient involvement in mental health research, but I mostly heard about barriers to involving services used and carers as lived experience experts in research studies. That might have been because people did not trust me enough to disclose their objections, that I was not able to speak to enough people, or because my questions and reading surfaced difficulties and challenges rather than firm views that PPI was a bad idea. What did I learn?

### Summary

- People are mostly supportive of the concept of PPI and recognised its benefits, talking most often about ‘how’, not ‘if’, to involve people in research. And the ‘how’ does vary greatly depending on the type of research – topic and methods. Opportunities for PPI in basic science are different to those arising in health services research projects.

- There are concerns about doing involvement well, creating a space for critical evaluation, and avoiding tick-box tokenisms.

- There was acknowledgement that professional researchers who have years of training and qualifications may feel threatened by critical evaluation from a lay perspective.

- There was a concern that a failure to engage the public in science more broadly may directly impact PPI in terms of accessibility and perceived relevance.

My conversations generated some interesting challenges to PPI. One concerned the democratisation of research. PPI is about academics and lay people working together, bringing different perspectives into a research study to improve the conduct and outcomes of research. This can bring a sense of ‘democracy’ to the research process. But is democracy always desirable in research? Could breakthroughs in research be missed if democratic methods are used? I am interested to know what other people think about this critique of a well-established principle of PPI.

I heard about practical challenges including payment issues, research time pressures, poor organisational support, lack of training and networks available for those interested in PPI, and finding appropriate people to work with – not the usual suspects, but a more diverse group of people who are interested in research. The conversations about representativeness were interesting, and I came away feeling we need to place greater emphasis on ensuring that varied perspectives are included in research teams – to better achieve the critical evaluation role – rather than trying to find representative patients or members of the public. We do need more people involved to advise research teams and develop their own ideas for projects. And
we need to be careful not to assume people are comfortable wearing the label “lived experience expert”. Mental health stigma impacts everyone, researchers and PPI team members included.

I have produced some tentative recommendations, and again I would be interested in other people's views on how to take PPI forward in mental health.

- Research institutions would be well advised to develop organisation-wide PPI strategies and implementation plans.
- Better sharing of learning and expertise across the whole health and social care research sector is needed, particularly training opportunities and peer support networks.
- The conceptual basis for PPI needs further development. Debates about what PPI looks like across a range of topics such as well-being, basic science, and child and adolescent mental health services research should be encouraged.
- Critical evaluation of PPI itself should continue, strengthening approaches to delivering involvement and growing diverse expertise across the mental health service user and carer community.
2. Introduction

In recent years, patient and public involvement (PPI) in research has grown exponentially. With increased political commitment to the concept and many funders now making it a requirement, an increasing number of research studies is involving expertise from experience for the first time.

For some, PPI has become somewhat of a buzzword, a catch-all term used to embody a wide variety of involvement activity in health research. Yet the concept remains poorly delineated and commonly misunderstood. We know little about researchers’ attitudes towards involving the public in their research. Are they convinced of its merits? Are there strongly held views against public involvement in research? Indeed, if there are objections to the concept, what are they, and how might these be addressed?

This paper is an exploration of this topic – an attempt to scratch the surface in an as-yet under-discussed area. It aims to bring some light to these issues and to stimulate an open dialogue of how they might be navigated.
3. Background

Recent decades have seen a substantial shift in approaches to health care, from paternalistic practice to that of shared decision-making and person-centred care. Accompanying this shift has been a drive for greater involvement of patients and other members of the public in health research – not only as research participants, but also as active partners in research design, delivery, and dissemination.

INVOLVE, the national NHS advisory group supporting public involvement in research, defines such research as being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’, or ‘for’ them. This can include, for example, involvement in choosing research topics, assisting in the design, advising on the research project, or carrying out the research (1).

The reasons for involving the public in research are twofold. First, there are the practical benefits: PPI helps ensure research quality, acceptability, and relevance. Second, the underlying reasons for involving members of the public in research are also informed by the broader democratic principles of citizenship, accountability, and transparency.

In addition to these principles, there is growing interest in PPI among research governance and support bodies (2;3) as well as the commitment to public involvement in health and social care policy (4;5). Increasingly, funders of health and social care research will only give research grants when it is clear there has been active public involvement.

There is significant support for PPI within the UK National Institute for Health Research (NIHR). Substantial investment has been made into infrastructure to promote and enable involvement, and researchers applying for NIHR grants are expected to involve the public in their projects,

We expect the active involvement of members of the public in the research that we fund. We recognise that the nature and extent of public involvement is likely to vary depending on the context of each study or award. (6)

This expectation has resulted in a large increase in the number of research projects that have involved the public in some capacity. Many more researchers and commissioners are working alongside the public for the first time. The United Kingdom is now considered one of the leaders in the field of PPI in health research.

Yet, despite a strong policy commitment, evidence for the benefits of PPI remains limited. While there is a small (but growing) body of literature examining the effectiveness and impact (7–10), there remains for many a significant gap between the rhetoric and reality of PPI in research. Support for the concept is far from universal. Knowledge of researchers’ attitudes towards involving the public is limited, and it has been suggested that some health professionals are unresponsive to involving the public (11).
4. Approach

While working for the McPin Foundation, I was invited to write a Talking Point paper exploring some key objections to PPI in mental health research. To do this, I worked with the McPin Public Involvement team to gather ideas and guidance on how best to approach the topic. To gather the views of the field, I conducted brief telephone interviews with eight people with experience of implementing, commissioning, or supporting public involvement in research. These people included active researchers, family carers, and people involved in policy. Not all were directly involved in mental health research, allowing for exploration of the issues across health research more broadly.

These individuals were identified by members of the McPin team because they represented a broad range of research expertise and role seniority. Efforts were made to ensure those interviewed represented different research backgrounds, from basic science to applied studies. In addition, I conducted a brief review of the literature and relevant web-based resources on the subject of PPI. This paper represents my own analysis of what I found and the view of the field towards PPI.

Given the Department of Health’s commitment to PPI in research, I recognised that some people may not feel comfortable openly discussing their objections. I reassured them that they were provided in confidence, and comments cited here are attributed according to the interviewee’s professional role. For instance, ‘clinician’ may include a number of health care professionals, from mental health nurse to psychiatrist. Other designations that I use include ‘academic researcher’, ‘PPI professional’, ‘service user’, and ‘carer’. ‘PPI professional’ refers to someone whose primary job is to involve members of the public in research.

A note on terms: I choose to use ‘mental health service user’ and ‘carer’ to describe members of the public who get involved in research using expertise from experience.
5. What did I find?

Within the McPin Public Involvement team, we discussed what we felt were likely to be some of the key objections to PPI in research, based on our experience of working in this field. These included:

- **Evidence/impact**
  - There is simply a lack of ‘evidence’ that PPI in research really makes a positive difference for research participants or research teams or affects the quality of research produced.

- **Knowledge/expertise**
  - The public (for example, mental health service users and carers) do not have sufficient ‘knowledge’ to contribute to research.
  - People who get involved in research become ‘semi-professionalised’ and lose their ‘lay’ perspective.

- **Representativeness**
  - People who get involved in research are ‘unrepresentative’ and have their own ‘agendas’.

- **Ethical issues**
  - Some people might say that it is unethical to burden people who are unwell with the work that involvement entails.
  - The health or ‘well-being’ of those involved might fluctuate, and involvement activities could (partly) lead to people becoming unwell.

- **Time/resources**
  - Involvement is quite resource intensive (both in terms of staff time and financial cost), and some could argue that it simply isn’t worth it.
  - Some may feel that although public involvement would be particularly helpful in the early stages of research (e.g., formulating research ideas), there is a lack of funding available at this stage, which prevents researchers from working in this way.

- **Lack of support/guidance**
  - Some may feel that they do not receive adequate support from research organisations to help them undertake involvement activities.

- **Poor past experience**
  - Some people may feel that they have had a bad experience of involving the public in the past.

I was interested in whether others raised the same or different points. This is what I found.
5. What did I find?

**Objections to involvement**

Interestingly, few of the people I spoke to expressed having come across fundamental objections to PPI in research. Instead, what I heard about were some of the difficulties associated with involving the public, the practical challenges of doing public involvement well and the inherent risks of a ‘tick-box’ approach to activities were common concerns.

“I think there is a slightly lip-service approach to it, but generally people see the point. I’ve definitely heard the, “Oh, it’s such a headache to do it”, and therefore “Is it worth it?” attitude, but I think that is about the practicalities. So I don’t know if anyone has fundamental objections to it in principle or can’t see the value in theory.”

**Academic Researcher**

**Culture shift: A new generation of researchers**

Importantly, a substantial culture shift in attitudes towards public involvement in research has taken place in recent years. One family carer reported that while the public had previously felt their contributions were undervalued due to a lack of expertise, the benefits of involvement were now more widely understood.

“So those concerns and worries people had years ago have gone, largely because public involvement has brought real benefits and I think most people now recognise that.”

**Carer**

In part, this progress was attributed to a new generation of researchers who were keen to understand how to do public involvement well. I heard that this presented a valuable opportunity for developing knowledge and practice in the field, although it was recognised that an element of resistance from some members of the research community was inevitable.

“I love the fact that nobody ever says, “Why do we have to do public involvement in research”, or “I think public involvement in research is rubbish”, or “I don’t see the point in public involvement in research”.

**Academic Researcher**

Whenever we run events for trainees and have the opportunity to talk to them, they just want to know how to do it well; they just want to be good at it... I guess there will always be people who don’t see the value... but I think that is a smaller and smaller community.”

**PPI professional**

“They may not quite understand the best way of approaching it, or the recognised ways of doing it... but they’re certainly more accepting of the principle of including the public in discussions.”

**PPI Professional**

**A ‘tick box’ approach – expectation without direction?**

Despite this perceived culture shift, one academic reported that while there did not appear to be ‘open’ objection to public involvement in research, its utility might still be questioned by those working in the field.

“All organisations are setting up their PPI departments because they don’t know how to meet the expectation. I have never seen anyone say, ‘Oh, I don’t want to do it’, so it is being done. Whether people think it is useful is another question.”

**Academic Researcher**

In this respect, the increased expectation of public involvement was understood to risk a ‘tick-box’ approach, particularly when there was insufficient support to do public involvement well or it was simply seen as a ‘means to an end’ to obtain research funding. Here, public involvement was seen to be something that some researchers felt they ‘had’ to do, regardless of whether it was a concept in which they were genuinely invested.

Often, public involvement was understood to be a last minute addition to funding applications, with little critical consideration given to how it might benefit the research more broadly.

“Well, I think sometimes researchers will have public involvement as a last minute addition. But they don’t have that as being at the heart of their research. At worst, it can just be a tick box exercise.”

**Academic Researcher**
Such concerns have been echoed elsewhere. While the emphasis on embedding public involvement from the NIHR has been immensely influential, there is still concern, even among those who are largely positive about public involvement, about having to be seen to be ‘politically correct’ and never question its rationale or value.

“It’s a complete nightmare because I’ve got to be really careful as to what I say and do. And as well as PPI’s really trendy at the minute, and I’m not saying it hasn’t got a place, but... it’s like, “Oh, brave new world”” \(^{(12)}\)

In the first systematic analysis of service user involvement in the mental health research arena in the UK, Patterson et al. found that ‘tokenism’ was reported by several respondents\(^{(13)}\).

Respondents typically observed a need to retain the traditional research hierarchies and uncertainty about the role of service user researchers and lived experience.

“I am very aware that service-user endorsement is valuable to academics and researchers. The smart ones have a bank of reliable service users they can call upon to advertise and support their own particular agendas. It is not uncommon to hear a researcher attempt to cover all sins by writing, “This was endorsed by our service-user steering committee”. Often this consists of researchers’ collaborators.”

Service User Representative\(^{(13)}\)
Few people I spoke to stated fundamental objections to public involvement, and most saw its merit, but there were concerns about doing involvement well and avoiding tick-box tokenisms.

There was a question of whether democratic approaches to research were desirable, or if we might lose scientific breakthroughs as a result. It is important to consider what democracy looks like in a research context, drawing on diverse perspectives to do so.

Consensus decision-making was challenged on the grounds that it may not always produce better research.

Providing a forum for these discussions is essential if progress is to be made.
Difficulties in patient and public involvement in research

While few specific objections to public involvement were reported, the people I spoke to brought up a broad range of difficulties associated with PPI. These difficulties can be broadly categorised into three areas: people; knowledge; and practical issues and resources.

Difficulty one: People (relationships, expectations, and representativeness)

Many difficulties I heard about concerned the people involved: their relationships, expectations, and representativeness. These difficulties were across the board, including both researchers and those contributing their lived experience expertise.

Recruitment and representativeness

I heard about ongoing problems with recruitment to public involvement activities. One researcher expressed frustration that despite having contacted local trusts to disseminate information about their studies and opportunities for involvement, public interest remained limited.

“You know they have a huge potential pool of people to draw from, but there just doesn’t seem to be a translation into people coming forward who are interested.”

Academic Researcher

A related concern was that of representativeness. It was difficult to ensure that a diverse range of people became involved and that they were sufficiently representative of a given population. This point is reflected in the literature (14). Existing systems of public involvement recruitment were problematic because they were generally self-selecting. Those who came forward were in some cases considered the ‘usual suspects’, and broadening opportunities for people could to be involved was seen as an ongoing battle.

“There’s a whole kind of argument about representativeness – whether we can ever get a fully diverse population involved. I think the whole diversity issue is one that is going to be high on peoples’ agendas for the next few years.”

PPI Professional

“When we’re recruiting people into helping us with the public involvement tasks, problems occur... in trying to recruit from a wide variety of people with different lived experience, coming from different parts of society. One of the inherent difficulties for us, in doing that, is because we’re asking people to conform to an existing system that ends up being quite a self-selecting group of individuals who might get involved.”

PPI Professional

“These patient reps are often bribed – bribed is a bit cynical – they are motivated by a little bit of money and some sense of influence or power, and are totally unrepresentative for the people they should represent.”

Clinician

There is a continuing need to recruit a range of people to public involvement activity, some of whom will have little or no previous experience of being involved in mental health research. It is particularly important to engage those with recent experience of using services. While engagement is pertinent here, so too is ensuring that teams are sufficiently resourced to support and enable this process, especially when those involved may have specific needs that must be supported for them to contribute meaningfully.

However, it may be that representativeness is the wrong issue. In research teams, we do not look for “representative” researchers, but for people with complementary skills and experiences to lead and contribute to science. Thus, it might be more appropriate to think about seeking patient ‘perspectives’ rather than worrying about ‘representatives’ (14). Thinking about the issue in this way goes some distance towards addressing an ongoing point of contention, finding representative ‘lay’ individuals, in a way that strengthens work by being clear about the role people are being recruited to undertake.
Stigma and mental health

I heard that some of the problems with recruitment to public involvement activities were linked to negative attitudes and stigma towards mental health. Those with mental health problems and their carers were believed to be reluctant to come forward for fear of discrimination. Such stigma was not perceived to be an issue in other types of health research, although it was noted that cancer had been subject to similarly negative attitudes in previous decades.

“I think the whole issue of stigma is a barrier for people coming forwards to get help, let alone say, ‘I want to be involved in this research’. So I think some of the things that are perhaps global issues for mental health care and treatment of mental health service users can play into the research going on.” PPI Professional

“Perhaps people are more willing to talk about their angina, or even their cancer. With cancer 30 or 40 years ago you might have found the same problem there... now, the attitude towards cancer is so much different, isn’t it? People are more willing to take part in all sorts of ways.” Carer

Perceived stigma, prejudice, and discriminatory behaviour have also been reported elsewhere as pervasive and as having a negative impact on the process and experience of involvement in mental health research\(^{(12)}\).

For instance, we know that some peer researchers find their dual identity difficult to navigate and are reluctant to be defined by their mental health ‘peer’ researcher status for fear of affecting job prospects in the future. Likewise, some academics may be resistant to public involvement on the grounds that it might challenge their professionalism and expertise by introducing further subjectivity.

Strongly held views – a barrier to public involvement?

It was noted by the people I spoke to that there are sometimes stark differences in opinion between people with lived experience of mental health problems and mental health professionals such as psychiatrists and psychologists. For example, some services users completely reject the medical model used by the vast majority of mental health academics. This has led to barriers to involvement not found in other areas of health.

Other issues can result in barriers. For instance, in mental health, there is often coercion that is not found in most other areas of health care that changes the dynamic of the relationship between patients/the public and academic clinicians, particularly psychiatrists. Mental health research is typically dominated by psychiatrists and psychologists, even though treating mental health holistically often involves a broad range of professionals, including social workers, mental health nurses, and peer support workers.

While on the one hand, strongly held views form the basis of a strong sense of identity and cohesiveness within the patient community, on the other, they were sometimes considered problematic in terms of perceived power imbalances and aggression in relationships with health professionals. While it was largely outside the experience of those I spoke to, it was recognised there was the potential for service users or carers to become involved because they had their own agenda.

“I think you have a very strong community identity around issues. And that’s community identity that I don’t know if you see in the kidney patients areas, for instance.” PPI Professional

“In mental health, there is always the power issue... or stronger power issues with different professionals. There tends to be more aggression in terms of the relationships. The atmosphere in chronic obstructive pulmonary disease is a bit more relaxed.” Academic Researcher

5. What did I find?
"I mean, there’s always that concern that that you’ll find people who are very anti-research and anti-psychiatry turning up, but I mean, to be honest, I haven’t come across that at all... I’m sure you get people with their own different agendas and things.” Clinician

Elsewhere, some health professionals are concerned that those involved have biased views of certain health issues, which may threaten the traditional academic impartiality of knowledge development, and that the public may exhibit different priorities compared to health professionals when health services are considered[14]. In my experience, these concerns should not be barriers to public involvement activity; this difficult terrain can be negotiated through careful planning and dialogue in the design stages of a research study. Importantly, biased views are not only held in patient communities, but in clinical communities too. The principles of research must be followed to produce high quality work, and often that means training patients and the public in basic research methods.

Clearly defined expectations for both researchers and the public

In light of these difficulties, the people I spoke to discussed how positive working relationships, built on trust and familiarity, were essential if research was to benefit from public involvement. This included clearly defined expectations on the part of both researchers and the public from the outset. Several researchers expressed a preference for designated advisory groups, rather than ad hoc consultation groups, to build productive relationships between researchers and the public over time.

One person described a service user and carer research advisory group that is well supported by academic staff, ensuring an ongoing dialogue with members and that expectations are realistic.

“There is some trust and familiarity, and I think then that scrutiny is very helpful. So I like to present my studies there, and there’s always helpful advice and feedback.” Clinician

- Recruitment systems that match people to role based on expertise and skills may address concerns about representativeness; we need diverse perspectives in research teams, not representative membership.

- Mental health stigma impacts the delivery of research. Some are cautious about doing work tied to expertise from experience due to mental health problems.

- Traditional power imbalances in relationships between mental health service users and health professionals continue to impact mental health research.

- Strong views can be held on how best to address mental health including medical versus social model of distress. This affects the type of research different stakeholders prioritise and how well individuals can collaborate in practice.

- More needs to be done to recognise bias in research – clinicians as well as patients and the public can import personal bias into a research study.

- Commitment to work on these difficulties is required, based upon positive working relationships that acknowledge differences in viewpoint.
Difficulty two: Knowledge

A second area of difficulty related to knowledge, specifically, a lack of research knowledge among the public, but also a lack of knowledge among researchers about how and when public involvement could benefit their research. Here, there was also the question of 'expertise' and how different types of 'expertise' were valued within research communities.

For some, there was still a considerable distance between the public and science or scientists. It was thought important to identify the motivations for people getting involved in research and to dispel preconceptions of elitism in the field.

“I think there is still some way to get people thinking about research as something that everybody can contribute to, rather than just the elite few.” PPI Professional

Training and the loss of the ‘lay’ perspective

It is clear that training is an important dimension to developing PPI in research. Here, I heard how training was a useful means to help the public understand how research outcomes were relevant to individuals in terms of treatments and services. Research needs to be made relevant to problems in everyday life.

“There is that whole thing about, if we don’t get our public awareness of research right, if people aren’t thinking of it in terms of how good research connects to good treatments and good services, then we’re going to struggle to get people involved.” PPI Professional

However, training was also seen as a double-edged sword. Recent research discovered a prominent fear for both patients and researchers that training would cultivate a researcher ‘mindset’, leading to an inauthentic patient perspective(15). Likewise, developing research expertise and credibility was described in one study as leading to exclusion from the service user community, whereas overexposure could lead to dismissal as a ‘usual suspect’ or a ‘non-representative professional user’ from the research community(13).

Ives et al. discuss this in terms of the ‘professionalisation paradox’(16). While the value of public involvement lies in the capacity of the person involved to be an ‘outsider, drawing on their own lived experience, who can reflect and comment, with relative objectivity, on the research process, through the process of formal training, those involved will necessarily undergo a degree of professional socialisation(16). As a result, people’s ability to act as ‘lay’ persons representing the public interest may be undermined by training. However, Staley contends that public involvement does not always involve the layperson acquiring the same skills as researchers, and even when it does, that person never loses his or her ‘lay’ perspective. Instead, the views of the layperson are complementary to those of technical experts(17).

The binary view of lay and professional is of course overly simplistic because people involved in research carry many identities into these activities, consciously and sub-consciously. Clinical academics can be carers and patients as well as parents, political activists, or members of faith communities, all of which impact their view of the world. In my experience, these identities need not be competing, but instead may help form the basis of the mutual trust and familiarity integral to positive working relationships.

The same concern was raised in terms of long-term involvement.

“There’s this specific group, this small number of people that after a while are less public involvement than another group of semi-professionals. The lay perspective depends on the selection of people coming forward. In mental health, you always find a technical group of service users. So people with severe negative symptoms of schizophrenia you won’t find. You always find a similar groups of service users or patients.” Academic Researcher

However, it has also been argued that people who get involved longer term become more effective at challenging, because they gain knowledge, confidence, and skills(18).
**Standardised research methods – a lack of critical evaluation?**

Linked to the concern that those involved could become semi-professionalised, one person I spoke to discussed problems associated with standardised research methodologies. Here, it was believed that those involved in public involvement activity are being encouraged to think in the same way as researchers, particularly at the design stages, resulting in a lack of critical evaluation. It is important for those involved to know the research process, but not to think of it too rigidly.

“We’re developing people to think along the same lines as researchers, and perhaps we need to think more broadly than that... we’re almost saying this is the best method – that randomised control trials come up with the best results, and this is the only way to go about it. So I think there would be some benefit in the way we develop learning opportunities for the public, to perhaps think more critically about how these studies are designed.” PPI Professional

From my experience, this is when group work is advantageous. If one only has one or two advisors, there is less potential to bring in a mix of expertise and experience. In public involvement advisory groups, one can have people who have never been involved in research alongside those who have lots of research committee experience. The crucial elements of a critical friend role in my experience are curiosity and interest in science and research, assertiveness and confidence alongside diplomacy and good listening skills, and being a team player.

When public involvement is incorporated from the very early stages of a research study, often before funding has been awarded, the insights afforded by the public on key design issues such as recruitment can play an important role in shaping the success of the study. Supporting and addressing questions raised by the public about specific research methodologies are integral to this process.

**A lack of understanding of PPI within the research community**

Despite an increased expectation of PPI in research, the research community still lacks understanding of how to do it well. Without a conceptual basis or knowing what good involvements looks like and how they could benefit their research, researchers naturally question the utility of something perceived as an additional pressure on time and resources.

“I think they... find it difficult to get their head around what public involvement is, and potentially how it can benefit them and their research. That is usually the first hurdle to get across... I think it’s a conceptual issue that they have.” PPI Professional

So, in this respect, learning for all parties was possible.

“There are some real issues around learning and development for both researchers, staff, and managers, but also patients, and the public, about bringing people together in a form of partnership that’s actually going to be beneficial.” PPI Professional

This lack of understanding has also been demonstrated elsewhere. For example, the second report of a joint INVOLVE and Health Research Authority (HRA) project to provide information on public involvement in applications to the National Research Ethics Service (NRES) found that for non-commercially funded studies applying for ethics approval (e.g., NIHR, medical research charities and research councils), 40% of researchers continued to misunderstand what the question about involvement was asking, instead describing plans for engagement and participation and not public involvement(19).

Elsewhere, fears have been expressed by researchers of being plunged into PPI without enough preparation, skills, and practical advice, even if they do want to do it and think it is important(12). Frequently, involvement is confused with engagement, particularly by those working in biomedical or laboratory research, reflecting the need for clearer, more accessible, and more
comprehensive information for researchers about involving the public in research(11).

**Expertise – a lack of research knowledge among the public?**

It was felt that while many researchers were now generally able to understand that they should be supporting PPI in research – attributing it to common courtesy – some were still suspicious or sceptical about what the public could actually bring to research in terms of expertise. How could someone who had not been trained in research have insight on the question of methodology? Would their ‘professional domain’ be eroded? To invite public opinion implied, in some sense, a loss of power. This was particularly the case with more senior research team members, for whom introducing the concept of public involvement involved the greatest shift in established ways of working.

“They feel as though they’re handing over some of the power, some of the decision-making abilities to others, and, traditionally, the senior research team had that power. And I think it’s handing over some of that power that some are finding difficult.” PPI Professional

“I had one very, very big research organisation approach me at a meeting and said, “Tell me one piece of research that’s been inspired by patients or members of the public that’s then gone on to a clinical trial.”... they can’t conceive that anybody who hasn’t been trained in the way they have could possibly do something that’s ground breaking.” PPI Professional

These feelings of apprehension suggest a possible attitudinal barrier to involvement. Involving the public in research could be seen to present a challenge to traditional scientific knowledge production and acquisition, because it suggests a move away from the positivist paradigm towards research that is driven by and grounded in expertise(11). In her blog, Cooper argues that in this respect, we come up against major philosophical questions about the function, purpose, and ownership of medical knowledge in society(20). The idea that expertise grounded in lived experience was not really valued and that different types of expertise were not accorded equal status were recurrent themes in a systematic review of service user involvement in mental health research; service user input was at risk of being discounted as non-academic or biased, or conversely, overvalued rather than subject to critical review(13).

For Wallcraft, one of the implications of collaborative research is a willingness to compromise and possibly carry out research in a different way(21). Researchers who fear involving service users may negatively impact the quality of research due to bias or subjectivity may need to be more flexible and open-minded in their approach.

**Knowing at what stage public involvement is most useful – a tailored approach**

There was a common concern among interviewees that due to a lack of experience, researchers might feel PPI had to be included at every stage – using a ‘blanket approach’ – resulting in an unrealistic expectation of researchers and inefficient use of the public’s time. Instead, it is important to focus on areas and levels in which public involvement could be most beneficial to a given research project. However, it was recognised that knowledge and confidence about how to implement PPI were incremental and could be accumulated as part of a learning process over time.

“Asking people to involve members of the public in absolutely every stage of research is quite an unhelpful approach... I think it makes a very unhealthy and unrealistic requirement, perhaps, on researchers, to create that kind of expectation.” PPI Professional

“I would like to think you could have some light course involvement in all studies, if that makes sense. But I’m a pragmatist and I know that actually on research teams, you have limited time and limited resources.” PPI Professional
"I worry slightly that it’s a bit of a tick box exercise, but more actually that people are just doing it because they have to – to include people everywhere. And I don’t think that’s actually the case. So there are some studies, voluntary committees, steering committees, and data monitoring that people are being asked to take part in all of those, and I’m not totally convinced that’s the best use of people’s time."

PPI Professional

It was considered important that each research project was taken on its own merit and for the public to be involved in these discussions about when public involvement would be most useful. It is important to realise that public involvement can be incorporated in a diversity of research, from basic science to epidemiological work or intervention studies. Looking to people with an interest in a certain type of research or research question is also important because not everyone wants to be involved in all kinds of research - public health, genetics, for example.

"I think it can be very helpful in all parts of the process. I think it’s more to do with... I could see how you take each research project or proposal on its own merits and then work out where public involvement has the most impact. So I don’t think you can make a general statement that it has more impact in one research cycle than another."

PPI Professional

There was general agreement that involving the public as early as possible was important, particularly at the research idea and question formation stages. However, it was often in these crucial developmental stages that funding was lacking. One PhD student described how the service user group involved in his project had helped shape the outcome measures used, thus ensuring the relevance of the research to its target population. Likewise, it is important to understand the subjective experience of being recruited to a research study when in hospital and how this might change over time.

"My research outputs are entirely pointless if patients and the public don’t find them acceptable or haven’t decided what they’re going to be."

Academic Researcher

"It’s really looking at people’s ability to make decisions when they’re unwell in hospital taking part in research. There’s potentially lots of issues around policy, around ethics, and recruitment of people, and also very much about what people feel
about being recruited into research when they’re unwell and how things can possibly change.” Academic Researcher

“Well, at the moment, for my research to support this beta trial, it’s at a reasonably early stage, but we are starting to get people involved, patients, for patient acceptance... at the moment we’re in the process of really wanting to engage and getting patient involved in telling us is this something that you find useful. I think it’s really critical at the early stage.” Academic Researcher

“Everything seems to point towards the fact that the earlier you have public involvement within a piece of research, the better that public involvement goes, and, I guess, the thing we don’t have the data on as yet is whether earlier involvement actually results in better research, as it were, overall.” PPI Professional

Importantly, it was noted that the research process is slow, which can impact the trajectory of public involvement. Likewise, the research might not come to anything, so managing the public’s expectations is important.

“Research is not moving very fast, so we’ve developed a drug discovery pathway for schizophrenia. It took us four years of just experiments, so there’s not much to discuss in the meantime whilst one makes a decision... four years of work just to develop the technology.” Academic Researcher

For one family carer, the initial stages of the research were the time at which those involved were most vulnerable, particularly if they were disclosing personal information to inform the research. It was especially important that this stage was well supported by researchers and that there were early discussions of potential issues that could arise.

“I suppose the most vulnerable stage is the statements that people give about their illness or ability, because it’s a very personal subjective statement that people make in order to help the research...” Carer

I also heard that recognising different levels of public involvement was essential. Targeting expertise appropriately was recommended.

“So obviously there are some very specific steps in a research study that people need specific expertise to do. So everybody having a go at multi-level modelling analysis probably isn’t all that helpful, but having said that, interpreting the findings of it – What does it mean? What does it mean for clinical services? It is very helpful to have PPI input.” Academic Researcher

“I think if you’re going to do some research into some gene therapy or some funky new anti-HIV drug, I think service user and carer involvement is going to look very different than if you’re doing research into the ethics of recruiting people in hospital. I think before you do anything, you need to really think about why you’re doing it and then what you want to get out of it.” Clinician

Biomedical and basic research – challenges of knowing where public involvement ‘fits’

Biomedical and basic research were areas in which public involvement was understood to be particularly challenging in terms of knowing how and when the public could contribute meaningfully. However, it was also noted that these were areas in which there is much discussion and development in terms of public involvement. These discussions were linked to public engagement work, and the possibility of providing increased scientific training to enable the public to better understand the language of the world of research scientists.

For example, to help identify the steps necessary for the public to be able to review a funding application that uses complex scientific terminology. Calls have been made elsewhere for open discussion of the needs and challenges of public involvement in these settings, among research scientists and those involved in public involvement activity(22).
"This is an area where I feel a lot of interesting and useful work is being done around collating public engagement, a way of starting relationships between us, researchers, and members of the public, and that then promotes relationship building, and understanding, and interest, which, potentially, then leads to public involvement in their work." PPI Professional

"I think for some of the more clinical lab-based studies, researchers often have a difficulty in identifying how patients, or a group of patients, could help them in their study. But then I think, they’re not thinking long term about what it is that they’re doing in the lab that may have clinical input at a later date." PPI Professional

For one person I spoke to, public health and social care research were also seen as lagging behind with respect to public involvement activity. This was partly attributed to lack of funding, but also to their distinct cultures and a perceived lack of dialogue about what public involvement could achieve.

"[public health and social care research] I feel in comparison to clinical research, and I just can’t quite work out why that should be so. I think partly it’s a funding issue, so it’s a very underfunded area of research and it has all sorts of particular sets of problems because of that, but it’s the context in which it’s happening. Public health is one of those places where public involvement should have a massive difference." PPI Professional

That public health is seen to be lagging behind in public involvement work may also be a result of being hampered by issues relating to identification of who the ‘patients’ are when the focus is the public – as is the case with much of the current work around well-being. Also, it is important to note that some areas of social care research do have well-developed public involvement traditions, such as disability studies, and that mental health, in my experience, is developing.

- Training is important – it is a way for the public to develop the skillset necessary to contribute effectively to mental health research, providing the expertise from experience but guarding against the creation of ‘group think’.

- There is concern that the public are being developed to think in the same way as researchers, resulting in a lack of critical evaluation. This was especially problematic when it came to standardised methodologies such as RCTs.

- It should be recognised that acquiring research skills does not necessarily invalidate the lay perspective; and we all carry with us multiple identities.

- Public involvement in research may challenge traditional notions of how ‘expertise’ is held within society, leading to some academics feeling undervalued. Attitudinal barriers to public involvement by the scientific community may be rooted in a perceived loss of power.

- There are types of research in which it has traditionally been difficult to see how public involvement ‘fits’, for example, biomedical and basic science. But these are growth areas for public involvement, and there is increasing discussion and interest based on engagement and training.

- Sharing of best practices, including how to work collaboratively and with a sufficient degree of flexibility, is needed to educate researchers in how public involvement can be incorporated in a diversity of research and at different stages of a study.
Difficulty three: Practical issues and resources

Funding – particularly at the development stage

Difficulty obtaining adequate funding to involve the public meaningfully in the initial formulation stage of the research appears to be a key concern. While public involvement is costed into funding applications, often the majority of the thinking has happened before the research reaches this stage.

“One of the stages that is obviously difficult is before you get funding. So, you know, we always cost in PPI, but really most of the thinking has happened before you get funding. And actually we’ve been really lucky that we’ve managed to get RDS [NIHR Research Design Service] funding for PPI at that stage, which I think is really important, because now to get the funding, you have to have written the protocol in so much detail that bringing people in after that... well, the horse has bolted, really.”

Academic Researcher

Our experience at the McPin Foundation, however, is that it is the commitment of research leaders that is crucial because research teams can often find resources if sufficiently motivated to involve people in the development stage of work. In August 2016, it was announced that ‘from today research funded by an NIHR research programme will be able to receive payments for start-up in advance of ethical approval’. This means that prior to ethical approval, funds will be available for service user and carer input. While this is progress, these funds will only be available once funding has been granted. At this stage, the design of a research study will very much have been decided upon.

Payment – challenges around status, benefits etc.

The people I spoke to described ongoing challenges around payment for involvement activity.

“It really frustrates me because we’re really keen to do PPI, and rightly, the funding bodies require you to do it, but then the practicalities of doing it have not been thought through.” Academic Researcher

“There are some of the practical issues in involvement around things like payment and institutional/organisational regulations... and national regulations and how they are interpreted, especially those around taxations, benefits – all those kinds of things.” PPI Professional

“It’s a nightmare – the university won’t pay people.” Academic Researcher

Issues relating to payment, benefits, and taxation cause anxiety and serve as barriers to people coming forward for public involvement activity. The benefits systems was described as a major stumbling block, particularly for service user representatives; respondents reported that participation in any activity could lead to assessment as having capacity to work and resulting in loss of benefits, whereas receipt of payment for research activity could involve convoluted reporting and net loss of income.

“I think in this culture where people are constantly assessed for whether they can have them, I think there’s a lot of anxiety about getting involved in anything where there’s a kind of legal, official process to go through which is linked to the tax man.”

Academic Researcher

Successful public involvement takes time

Public involvement work is time intensive (particularly in complex areas such as forensic settings or inpatient units) and requires adequate resourcing to be meaningful. The academic environment was not always seen as conducive to supporting this kind of activity, with researchers working in extremely pressurised environments.

“It’s quite interesting to me the level of pressure on them and researchers now to do things quickly and in a way that we probably would never have envisaged five years ago. And that pressure that they need quite controlled and complex questions about how
they find public involvement, seeing where they want to do research.” PPI Professional

“I would love to have people involved, but it takes time.” Academic Researcher

University environments described as competitive and outcome- rather than process-focused were considered particularly difficult to negotiate. In my experience, while the concept of public involvement is generally well supported, there is often variation in the degree to which public feedback is incorporated due to the need to meet deadlines for ethics submissions, etc. Likewise, feedback on which aspects of public feedback were incorporated and how these decisions were made can be lacking.

Maintaining contact can be challenging, particularly during the middle stages of the research

In some cases, involvement was seen to fluctuate throughout the research cycle. Much of the activity was peaks in the early stages (commenting on recruitment materials, etc., for research ethics committee applications) and analysis. In the middle stages, involvement waned because there were few opportunities for involvement during the data collection phase, for example.

“Often, what happens is people are involved in the beginning when you’re developing the tools and materials, and the recruitment strategy, but particularly for a trial, there’s then usually a very long period when actually it’s just happening, and I guess PPI can wane a bit.” Academic Researcher

Setting out expectations early on can help manage periods during which lower intensity input is required. Some studies produce newsletters to keep everyone on board and up to date. Again, this is not such a different challenge to that experienced by the economist or statistician on the team who is often not involved in all aspects of a project.

Involving those with mental health problems whose well-being may fluctuate

Interviewees were asked if there were any particular challenges linked to public involvement in mental health research. On the most part, such involvement was seen to be similar to other types of health research. Generally, there was a need to be flexible, to allow people to participate as and when was appropriate for them, particularly if their well-being was fluctuating.

“We have two models of service user involvement here. We employ a service user researcher, but for studies, we try to keep the reference group flexible, so that people can come in and out of it, and they’re paid for their input as and when they’re able to give it. And I think we’ve evolved to that because we’ve found that if you have a study and you employ a particular person and then they’re not well, and they’re off for a big chunk of it, it’s really difficult to back-fill it with any funding because obviously people are paid when they’re off sick.” Academic Researcher

- Insufficient funding being available for early development work was considered a significant barrier.
- There are also challenges of working with people who are in receipt of welfare benefits, ensuring they declare income earned through PPI; being on benefits can be a deterrent to wishing to get involved.
- The concern was raised that public involvement requires adequate resourcing of time, something that is not readily available in highly pressurised university environments.
- Involvement opportunities may wane at different stages of the research cycle; it is essential this is communicated to those involved to meet their expectations.
Where do we go from here?

I asked the people I spoke to what they felt would be helpful in moving past some of these objections and difficulties. What I heard was not revolutionary or particularly new, but it did emphasise areas that must be addressed for PPI activity to become more mainstream in mental health research.

Improving awareness of public involvement

Time was seen as an important factor. The Breaking Boundaries strategic review of public involvement was commissioned by the Department of Health and announced in March 2014. This review was the first, full-scale inquiry into how successful the NIHR has been in achieving its original strategic goals in public involvement.

It soon became clear that there was a palpable tension between those colleagues who advocated radical departures from the status quo and those whose preference is for continuity and steady improvement. Both are natural and symptomatic features of a social movement that is still relatively immature and underdeveloped in the NIHR\(^{(23)}\).

For one interviewee, there was no ‘magic bullet’, but raising the profile of public involvement using a campaign approach was essential to the future implementation of its principles. It was important to offer public involvement as a solution, not as a problem or challenge.

“So I think we have to go with public involvement actually as a bit of a campaign. And as a campaigner, we have to be three things. We have to be patient. You recognise that actually you’re actually not working within things that are straightforward –
organisations and people. They take time to change their highly regulated environments. I think you need to recognise that it’s going to take some time to change that. Second, I think you have to be persistent. And it really does take two, three, four, five decades before it becomes such a part of the culture and the way things are done that they are invisible. And we’re nowhere near that yet. And I think the third thing is you have to be positive.” PPI Professional

“There could be a much more vibrant discourse between the NIHR, charities and industry as to understand how to collaboratively act to develop the relationship between health research and its many publics.” PPI Professional

What has been clear throughout interviewing for this paper is the need to dispel preconceptions on the part of both researchers and the public for PPI to be a fruitful exercise and to make space for an ongoing dialogue. Too often it seems the two are pitted against each other in an ideological battle, when in fact we all manage multiple (sometimes competing) identities on a daily basis.

Creating Strong Leadership

Equally, strong leadership was identified as a key factor in the success of public involvement activity, now and in the future. INVOLVE’s publication NIHR Senior Investigators: Leaders for patient and public involvement (2014), referenced by one interviewee, identifies five examples of how senior investigators are involving patients and the public in their work, with a view to inspiring young researchers with a vision of what newly developed leadership roles could look like in the future by embedding a culture of public involvement in their work (24).

“I do think it’s a numbers game and gaining critical mass. At some point, it will be the majority of our leaders who just have public involvement embedded in everything that they do.” PPI Professional

“Whenever I see a successful example of public involvement, it’s usually been down to a key factor – not the only factor but a key factor – the leadership. So that means leadership from both the public involved, but also from the scientific community, from the PIs, from the specific organisations. You can’t have it led from the top, very small leadership from somewhere within is what we’re talking about what we’re talking about.” PPI Professional

Again, this may involve a changed cultural dynamic – a shift away from established ways of thinking or notions of where power lies within teams. It is an ongoing process, and development of leadership qualities must be sufficiently resourced to be effective in supporting this transition to more collaborative ways of working.

Innovation in public involvement

Despite recent progress, it was recognised that public involvement must not be carried out complacently; it is essential that the field innovates. For example, at a time when the advisory group format has become accepted and commonplace, the increasing role of digital technologies and social media must be considered. Likewise, strategies for increasing diversity, including commissioning processes, must be sufficiently flexible and creative to engage a more diverse audience in terms of research experience, use of services, ethnicity, age, and gender.

“Just as we are critical of and trying to break out of one culture, we also have to be mindful that we are ourselves creating our own culture... we live in a world where social media and new ways of working are increasing trends. So we have to recognise that. And while others say there’s a concern about diversity – and they’re absolutely right to call it out – we have to find new ways of making public involvement work in these new contexts. I don’t think we’ve done enough thinking in that area at the moment. And unless we do, then I think we are always in danger of being irrelevant or being seen to be irrelevant.” PPI Professional
“The models that we use work well, most of the time, but, actually, they don’t work in all situations and all contexts and settings, so how can we be more innovative, in a way that then allows us also to be more open and diverse and involving of a wider population... it is really challenging to identify opportunities to be innovative, to support different forms of public involvement in commissioning processes, when the deadlines and milestones of a commissioning cycle are so very solid.”

PPI Professional

In my experience, innovation and new ways of working in public involvement can be a daunting but equally exciting prospect for all parties, presenting the opportunity to acquire new skills and think in new ways. While creating sufficiently flexible ways of working can take time, once established, they can be used to demonstrate best practices in the field, providing a valuable opportunity for learning and development.

Acknowledgement that public involvement is not a panacea

It was thought important to acknowledge that public involvement is not a panacea that has weaknesses and limitations. It is important to focus on how public involvement might be most useful in a specific piece of research and to ensure the time of those involved was used effectively and in line with expectation.

“I think one needs to be very wise and savvy as to where patient and public involvement might be useful and framing involvement accordingly around that. There’s also a respect thing to be honest as well... it’s a waste of their time if you’re asking them to do things because it’s a tick-box exercise or because it’s a question that they can’t answer or you don’t even care what the answer is.” Academic Researcher

Support for the research community

In this respect, a need was identified for greater support for researchers on how to do public involvement well. This was both through practical support from relevant organisations and raising awareness of impact and best practices through case studies. Recruitment was a particular area in which support was needed, as well as advice on how to support those involved. The charity sector was considered a key source of support, but this support had not been forthcoming, because the sector was now under resourced to cope with increased demand for public involvement from universities.

“For the sceptics, for those who don’t see the benefits, I think it’s about sharing examples, case studies, evidence, to show where members of the public have had a valid contribution, a helpful contribution.”

PPI Professional

“It’s about supporting them in the process. So, if they’re perhaps kind of changing their mind and saying, ‘Well, ok, I’ve got to do this’, and albeit reluctantly putting their toe in the water, it’s about having resources and support out there for them, to enable them to find people, and to be able to support people as well.”

PPI Professional

“I think the more we talk about it, the more we share the nitty gritty of what we do and don’t do, and the nitty gritty of some of the things that work and don’t work, I think that’s really helpful.”

Public and Patient Involvement professional

“I’ve been emailing charities, and they say, “We’re doing too many studies, we are not interested”. The charities, the patient groups need to be open. We can’t improve if they don’t participate.”

Academic Researcher

One interviewee felt that it would be helpful to have a clear mechanism for the public to get involved with research if they were interested, facilitated by a national organisation.
“So I’ve recently got really interested in a physical health condition because I’ve been diagnosed with it. I have no idea where to go to see what research is happening, and how I could be involved on a panel or whatever. So that would be helpful – having an infrastructure for getting people involved.”
Academic Researcher

Addressing institutional barriers to involvement
Linked to the need for greater support for researchers was the need to address institutional barriers to public involvement, for example, issues relating to payment, indemnity, and public access. Some felt that while some of the problems relating to these issues were unavoidable, more often than not, the hurdles were manufactured. Here, a large role was seen for the education of institutions in how to facilitate public involvement activity; organisations such as INVOLVE offer helpful information for researchers, but there should be equivalent information for institutions and human resources departments supporting the process.

“The institutions do not do the involvement community any favours by highlighting or creating these issues and problems. So I think there’s a bit of work to be done with organisations and institutions. Some of these are valid questions about how these things should be done, but I think often its people looking to create hurdles where perhaps don’t exist.” PPI Professional

“It sounds awful, but sometimes the way to do it is without asking any officials about how you should be doing it. So just trying to get away with giving people vouchers or whatever. We do try and get round it by giving people ‘thank you rewards’ that pay for their time, because otherwise it just isn’t possible.” Academic Researcher

“I think people trying to set up that mechanism in different institutions where the institution has no understanding is just another headache you don’t need. It’s not really about educating the PIs – I mean obviously there is an element of that – but it’s more about educating institutions. So going to HR departments and explaining how to simply and easily set up a friendly way of employing people for PPI activity. I do think expecting the researcher to do it with their institutions is really hard. I mean, we do try, but often if feels as though you’re banging your head against a wall.”
Academic Researcher

Support mechanisms for the public involved – a national peer support network
I heard that supporting those involved in public involvement activity was sometimes problematic. It was felt that a national peer support network could be beneficial to those working as service user researchers.

“If you employ service users in a more long-term capacity as we do here, then they need a lot of support. And though we can give them support in terms of the research, I think they would really benefit from a peer support network. A national network of people working as service user researchers, so they can actually get some shared network support, because they must be facing very similar issues.”
Academic Researcher

This was felt to be particularly useful when it came to promotion, in which those working in service user researcher roles were seen to fall outside the recognised career trajectory in academia.

“The things that move you up the ladder are not the things that you bring in terms of expertise. But I don’t think that’s actually a battle that one person can have with an organisation, whereas if there was a network of people who were all facing similar challenge who could get together and come up with some proposals about how different levels of expertise can be valued in institutions, then I think it would be much more effective.” Academic Researcher
Professionalism of those involved

It was also noted that productive relationships and professionalism were integral to successful public involvement and to challenging some of the more negative attitudes toward public involvement.

“The patients or the carers themselves must be very professional in the way that they support the researcher. They have a duty to prove that they are value for money, that they’re making the effort to make sure their contribution is a valuable one. That is, that they attend, they keep on trying, they make a good contribution and prove their worth.”

Carer

Intellectual honesty – avoiding public involvement becoming a formality

Likewise, I heard from one person about the need for intellectual honesty when it came to public involvement to avoid it becoming a formality. It was felt that many researchers now saw public involvement as a tick-box exercise, something that was often only considered weeks before the submission of a funding application, and that the need for political correctness negated the benefits of public involvement and undermined our understanding of the way research ideas are formulated.

There was seen to be insufficient dialogue around public involvement, with the automatic assumption that public involvement is now the most important aspect of research and that consensus in decision-making processes was desirable.

“The lack of intellectual honesty, that doesn’t help. And if it goes on, then we’ll rather find – not necessarily resistance, because nobody would dare to resist, at least not openly – that nobody takes it seriously. And it’s just a tick box thing, like the ethics committee... they just simply see how they can get their application past the ethics committee... and I think PPI is moving in the same direction. A formality. And I think one has to get away from that. How, I don’t know.”

Academic Researcher

“Actual honesty goes back to the beginning – good research requires formal, new ideas – creativity and innovation and all that. And that’s not a democratic process. That may be a process involving many people, but not in terms of consensus in decision-making. I don’t know how many people Einstein talked to before Relativity Theory. Of course he wanted input, and then to come to a more appropriate understanding of where PPI sits – what it can do, what it can’t do – rather than having this current tick box exercise where three weeks before the submission of an application it’s – “Oh God, we’ve forgotten the PPI.”

Academic Researcher

“Learn how to fill that in – everyone knows how to do that now. This political correctness nonsense. So firstly, is it really the most important aspect of the research? The idea may be rubbish so long as a thousand people went for it. That’s number one. Number two, why does PPI necessarily have to change something? But you don’t get away with not filling it in.”

Clinician
In this paper, I set out to explore some key objections to public involvement in mental health research. Instead, the majority of people I spoke to talked about the more pragmatic, operational difficulties associated with public involvement activities. It seemed that people talked most often about ‘how’, not ‘if’ to involve people in research. While it may be that people felt unwilling to discuss their objections – believing my questions be in some way pejorative – for the most part, people were supportive of the concept of PPI and recognised its benefits.

An important point was that the political imperative to incorporate public involvement in research risks a ‘tick-box’ approach to it, in which public input becomes merely a formality of funding applications. This was particularly the case in highly pressurised academic environments in which public involvement often represented a last minute addition. To avoid falling into this trap, it is important to continue to discuss and debate the concept’s ideological underpinnings. Otherwise, there is the risk that researchers are increasingly being told to do public involvement with little understanding of its purpose and merit.

A democratic approach to research was challenged in my interviews. Does incorporating a wide number of views inevitably results in better research? Here, consensus decision-making can be seen to actively inhibit the creative process necessary for breakthrough ideas and progress in research by reducing research to the lowest common denominator of what can be agreed upon. I would like to know what other people think.

Public funders of health research have made PPI compulsory. But researchers need to be told more clearly why this is the case. Researchers need to understand why the public should be involved in research and what differences its involvement can make. Moreover, researchers need to understand how to actively involve the public and have the resources to ensure meaningful involvement, including the support of their institutions.

Addressing these issues may go some way towards reducing the difficulties faced by researchers, service users, carers and the broader public alike.

### I draw these conclusions:

- We need to do more thinking about what PPI perspectives are required in any one project, moving away from representation or charges of tokenism towards valued roles that are clearly developed and provide added perspectives into studies that are missing without the expertise from experience perspective.
- We need to develop PPI and the concepts behind it. In particular, democracy and the democratisation of research were raised. Is PPI weakening science by introducing co-production values to the process?
- PPI is valued and its potential value is recognised. How to do it well was the primary concern, not whether to do it at all.

An important point was that the political imperative to incorporate public involvement in research risks a ‘tick-box’ approach to it, in which public input becomes merely a formality of funding applications. This was particularly the case in highly pressurised academic environments in which public involvement often represented a last minute addition. To avoid falling into this trap, it is important to continue to discuss and debate the concept’s ideological underpinnings. Otherwise, there is the risk that researchers are increasingly being told to do public involvement with little understanding of its purpose and merit.

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Addressing these issues may go some way towards reducing the difficulties faced by researchers, service users, carers and the broader public alike.
A few recommendations:

- Research institutions need to plan how they will adequately resource PPI activity and support it. Creating an institutional strategy with support resources and opportunities for shared learning would help individual teams, which often feel they have little support to deliver PPI in their studies. Understanding institutional barriers to PPI in research and seeking solutions to them should be encouraged.

- There needs to be a more open debate about how PPI fits best in different kinds of research (e.g., basic research, well-being studies, and health services research) and how current ways of implementing PPI might be improved.

- There needs to be more training on PPI in health research for all stakeholders. The mental health sector should work with other areas to pool training and support resources.

- Efforts should continue to build a solid evidence base for PPI. The more evidence there is that involvement is beneficial, both for individuals involved and to the quality of studies, the easier it will be to convince people to include involvement and to resource it properly.

- We should continue to challenge and critically review current approaches, striving to improve and further develop ways of working to incorporate wider expertise from experience perspectives in mental health research.
References


5. Equity and excellence: Liberating the NHS, Cm 7881, Department of Health, (2010).


The McPin Foundation is a mental health research charity

We champion experts by experience in research so that people’s mental health is improved in communities everywhere.

- We deliver high quality user focused mental health research and evaluations
- We support and help to shape the research of others, often advising on patient and public involvement strategies
- We work to ensure research achieves positive change

Research matters because we need to know a lot more about what works to improve the lives of people with mental health problems, their families and communities. We believe better mental health research is done by involving experts by experience. We work collaboratively with others sharing our values.

About the talking point series of papers

Talking point papers are written by people with lived experience of mental health problems. Each paper is focused on a particularly under-discussed or difficult issue relating to mental health research. We hope that each paper will spark a constructive dialogue between a very wide range of people. We also hope that the Talking Point papers will influence the development of future research. The funding for the papers is from the McPin Foundation but the views expressed in the papers are the author’s own.

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