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Involving the public in mental health and learning disability research: Can we, should we, do we?

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Abstract

Introduction

Patient and public involvement (PPI) is integral to UK health research guidance, however implementation is inconsistent. There is little research into the attitudes of NHS health researchers towards PPI.

Aim

This study explored the attitude of researchers working in mental health and learning disability services in the UK towards PPI in health research.

Method

Using a qualitative methodology, semi-structured interviews were conducted with a purposive sample of eight researchers. A framework approach was used in the analysis to generate themes and core concepts.

Results

Participants valued the perspective PPI could bring to research, but frustration with tokenistic approaches to involvement work was also evident. Some cultural and attitudinal barriers to integrating PPI across the whole research process were identified.

Discussion

Despite clear guidelines and established service user involvement, challenges still exist in the integration of PPI in mental health and learning disability research in the UK.

Implications for Practice

Guidelines on PPI may not be enough to prompt changes in research practice. Leaders and researchers need to support attitudinal and cultural changes where required, to ensure the full potential of PPI in mental health and learning disability services research is realised.

Relevance Statement

Findings suggest that despite clear guidelines and a history of service user involvement there are still challenges to the integration of PPI in mental health and learning disability research in the UK. For countries where PPI guidelines are being developed, attention needs to be paid to cultural factors in the research community to win ‘hearts and minds’ and support the effective integration of PPI across the whole research process.

Introduction

Involve (2012) define public and patient involvement (PPI) as “…research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (p. 1). PPI activity is encouraged in all stages of the research process from planning to dissemination. The underpinning principle across the literature is that PPI is about shifting the balance of power between the research participant and the researcher (Brett et al. 2012). Working in this way may challenge some long-standing conventions in the research process.

Involving the patients and the public in health research is relatively new; however, it draws from well-established traditions in disability and mental health services (Beresford 2005). Similarly, the growth of PPI in health research echoes these antecedents. Barnes and Cotterall (2012) suggest emancipatory research, user-led research and participatory action research have all contributed to moving from the 'expert view' of researchers to practice that includes more collaborative ways of working.

The arguments for PPI improving the quality and outcomes of health research fall into three categories; methodological, moral and political (Ward et al. 2009, Mathie et al. 2014). Boote et al. (2011) highlight the methodological rationale. Consequentialist in its focus, it is mainly concerned with how PPI impacts on the research itself. The moral case is grounded in democracy (Thompson et al 2013, Ward et al 2009) with the final political argument for PPI linking to the broader agenda of involving the public in decision-making and health policy development (Mathie et al. 2014).

There is a debate within the research community about the value of PPI to health research and Forbat et al. (2009) conclude there is little agreement how PPI works in practice. Some commentators such as Beresford (2005) question the genuineness of involvement work while for Thompson et al. (2009) and Hayter (2011), researchers taking a 'tick box' approach to PPI have led to suggestions of tokenism. Within the academic community, varying degrees of support, ambivalence and resistance to PPI have been reported by Liabo and Stewart (2012) and Thompson et al. (2009). Some studies have identified a concern about the potential 'professionalisation' of people in PPI roles in health research (Thompson et al. 2012) as well as unrepresentative and tokenistic approaches to patient involvement in mental health service development (Enamy et al. 2013) and in individual care planning (Grundy et al. 2015). To muddy the waters further, Rose (2015) draws attention to a recent Involve document that "… completely conflates involvement, engagement and participation in the sense of recruitment" (p. 360). This is a departure from Involve's previous, longstanding position on PPI as a separate activity from recruitment. Rose suggests this reduces the integrity and clarity of PPI as an activity distinct from research participation.

Although the benefits of PPI in health research have begun to be evaluated (Gillard et al. 2012, Staley 2009, Minogue and Girdlestone 2010, Williamson 2014) it is recognised that evaluation methods need to improve. Edelman and Barron (2016) suggest the existing approaches to evaluation have contributed to the weak evidence base and call for researchers to use more consistent and robust methods. Few studies explore the extent of PPI in research and those that have, found implementation was inconsistent (Forbat et al. 2009, Barber et al. 2011), although Brett et al. (2012) suggest there has been a recent shift towards PPI being included in empirical research. Although there is growing evidence of the impact of PPI in health research (Gillard et al 2012, Williamson 2014) there is little on the negative effects of PPI (Boote et al. 2011).

In light of the benefits of PPI; increasing the range of research topics, more ethical research design, enhancing recruitment (Barber et al. 2011b) and positive impacts on both lay members (Williamson 2010) and researchers (Gillard et al. 2012), it raises the question why, even in the context of policy guidance, more researchers do not involve the public in their work. As noted by Greenhalgh et al. (2004) and Kontos and Poland (2010), the struggle to translate policy into practice is a common experience in health care, even when a strong evidence base exists. Evidence of the impact of PPI is weak which may be a contributory factor to the low uptake (Staley 2009). Positive staff attitudes and the alignment of the intended adopters' values, norms and perceived needs with those of the organisation is a strong predictor of adoption (Greenhalgh et al. 2004, Brookes et al. 2011).

There is very little literature exploring the attitudes of health researchers to PPI (Mathie et al. 2014), though attitudes are identified as an important contextual factor for successful involvement work (Brett et al. 2012). The concepts of citizenship and altruism emerge as the main motivations for involvement by PPI participants (Thompson et al. 2012, Williamson 2010). In some studies, working collaboratively led to positive shifts in attitudes to PPI by researchers and PPI participants (Brett et al. 2012, Calden et al. 2010, Gillard et al. 2012, Williamson 2014). Thompson et al's (2009) work is the only study that directly explores researchers' attitude towards PPI. The researchers used telephone interviews with a purposive sample of 15 university based health researchers. Their findings indicated general support for involvement on policy grounds; however, a number of participants revealed feelings of apprehension, suggesting an attitudinal barrier to involvement. The authors suggest that researchers who simply 'follow the rules' risk not realising the full potential of PPI activities.

The UK has the most stringent PPI requirements in health research internationally; despite this policy imperative there are challenges to implementation. Given recent calls to demonstrate the impacts of PPI in research, it seems particularly important to understand what supports some researchers to embrace PPI whilst others may not. No previous studies have investigated the attitudes of researchers working in mental health and/or learning disability services towards PPI even though service user involvement has a long history in clinical practice. This study was an opportunity to gain insight into how this translates into research activity and what role, if any the organisational context plays in the uptake of PPI.

Aims

To explore the attitude of NHS researchers working in mental health and learning disability services towards PPI in health research.

To gain insight into what motivated, supported and hindered participants in involving patients and the public in their research.

Method

Study design

This is an exploratory, qualitative study. This type of research can generate rich descriptive accounts from participants, which is appropriate to the aim of this study to explore personal attitudes, beliefs and experiences. Qualitative research seeks depth rather than breadth (Mason 2002) and the sampling strategy reflected this. A purposive sample representative of relevant demographic characteristics was used to collect in-depth data (Ritchie & Lewis 2003).

Ethical approval and conduct

Approval was granted through the Health Research Authority, Integrated Research Approval Process. Ethical conduct was maintained throughout utilising an opt-in process. Written consent was obtained from all participants and confidentiality maintained in all aspects of the study, including dissemination. Data were collected, managed, stored and disposed of in accordance with the Data Protection Act 1998.

Sample

A purposive sample of eight staff actively involved in research within a mental health and learning disability NHS Foundation Trust in the UK. The National Health Service (NHS) is the publicly funded national healthcare system for England. A Foundation Trust is an NHS health provider, serving a defined population. The Trust provides mental health and learning disability services across two cities in the north of England, UK. An opt-in process was used to ensure no coercion was used. Twenty active researchers were emailed by the Trust Research Governance Manager. A participant information sheet was shared and a request they email the Chief Investigator (CP) directly if interested in participating in the study. Potential participants were also asked to provide information about each inclusion criteria in their initial response. Fifteen responses were received. Based on the findings in the literature, and to ensure a degree of diversity, a sampling frame was used with the following inclusion criteria:

- participant's research role
- type of research study they were involved in
- length of experience of working in health research
- professional background

The final sample included participants that worked in either mental health or learning disability services, or a combination of both.

The sample is summarised in Table 1.

Table 1: Sample Frame

Data collection

Data were collected by an experienced mental health clinician (CP) with training in qualitative research methods, using face to face, semi structured interviews. The interviewer (CP) had no working relationship with any participant. The interviews took place in a confidential venue in the participants' workplace. They varied in length, lasting between 21 and 58 minutes with a mean length of 35 minutes. Good practice guidelines as suggested by Arthur (2006) were followed to develop the topic guide to give consistency to the areas covered. The final version was reviewed by both authors.

The interview began with clarification of terminology to ensure participants were clear about the definition of the term Public and Patient Involvement (PPI) in research. The areas covered in the topic guide are summarised in Table 2.

Table 2: Interview topic guide

The interviewer asked for practical examples to illustrate individual thoughts and opinions during the interviews. All data were collected before data analysis commenced and to ensure reflexivity a research diary was kept throughout.

Data analysis

The interviews were audio recorded and transcribed verbatim. Data were analysed using the framework. Initially both authors selected two transcripts, read and analysed them independently. Descriptive comments summarised or paraphrased from the text were sorted into initial categories. The authors then compared the two lists of categories and agreed an initial coding matrix, with categories grouped into themes. As the analysis progressed, themes were modified and re-categorised. A number of new categories and themes emerged and were included in a revised coding matrix. Author (CP) returned to transcripts that had already been analysed when new categories emerged and continually revisited participants' accounts to maintain a connection between the data and the coding matrix. All data from all transcripts were coded. The final coding matrix (table 3) identified nine themes, with a number of categories within each theme.

Table 3: Coding matrix

Following Smith and Firth (2011), the next stages in the analytic process were to synthesis the data and identify core concepts. The raw data were scrutinised to confirm meanings and associations between themes. Key dimensions of the data were then developed into three core concepts that appeared to reflect the attitudes of participants to PPI in research.

Reflexivity and rigour

The purposive sample was appropriate to the aims of the study and the opt-in process enabled potential participants with a range of views on the topic being investigated to participate. The framework approach strengthens rigour and dependability of research by emphasising transparency in data analysis and the links between the stages of analysis (Ritchie and Lewis 2003). Furthermore, using two researchers to complete the analysis, including one very experienced researcher (JH) strengthens the rigour of the data analysis. Quotations from participants are included to illustrate the findings. The lead researcher (CP) kept a research journal during the data collection and analysis process which ensured reflexivity was incorporated into the study.

Results

Three core concepts were developed; Valuing the PPI perspective, Constraints and Culture. Data analysis revealed some overlaps between the concepts, each but each core concept captures the key dimensions of a group of themes; illustrated below.

Fig 1: Themes and core concepts

Valuing the PPI perspective

This concept encompassed the themes Get it right, What will work? Collaboration and Ownership and Empowerment. Participants described the positive impact PPI could have on setting research priorities and on research design. Working in partnership with patients and the public was a recurring theme. However, some frustrations with implementing PPI were also expressed, as were difficulties in some aspects of collaborative working.

An interesting observation was that the majority of participants requested clarification when asked about the purpose of PPI, typified by the following response;

"What it [PPI] should be or what it really is?"

Many participants made a clear distinction between policy and their experience of PPI in practice. There was strong awareness of the consequentialist arguments for PPI; citing the improvements PPI could make to the research itself. The majority of participants emphasised the validation function of involvement activities. Only one participant described a service user led research process. Ethical and moral arguments for patients and the public influencing research priorities were cited by a number of participants.

"…if we're doing publically funded research then the public have a right to steer that I think" (Participant 3).

Alongside the role PPI could have in setting the research agenda, the practical impact of PPI on research design was described by all participants. Examples were given of PPI improving data collection instruments, documentation and interventions. There was a strong sense the PPI perspective could help to ensure research was accessible, acceptable and feasible to participants. Tension between fidelity to research methods and the practical feasibility of projects were often highlighted. The PPI perspective was noted as an important support in negotiating the inclusion, exclusion or revision of specific measures or interventions. One participant explained

"…well I can't imagine how the trial would have run without it [PPI] because there were so many things we overlooked…we're so focused on methodology and how things are going to work statistically…but their priority was what is actually going to work" (Participant 2)

Collaborative processes where PPI members worked as co-applicants, co-researchers or members of research steering groups were described by some participants. The need for researchers to work differently to ensure meaningful involvement activities often highlighted. For example, adjusting language;

"Yeah, not using jargon all the time and fancy scientific terms when there's plain English to do the same job" (Participant 4)

Many participants spoke about the value PPI could have on the individual PPI member or the groups they represented. This account described the potential for PPI to contribute to personal recovery;

"It can almost be a beneficial part of recovery as well because it's turning what was probably something quite negative about their lives into something quite positive because they feel like actually this is something that's valuable about me, you know, this experience is worthwhile sharing and does mean that I can bring something. It's not a part of their life they have to write off" (Participant 2).

However, participants also extensively offered less effective examples of consultation and collaboration which will be explored in the following section outlining the concept of Constraints.

Empowerment was also an important aspect of PPI. There was recognition that some groups may not ordinarily be afforded opportunities to influence, design or lead research and that PPI could be one way to achieve this.

"It's about giving a voice to, especially groups that are typically quite marginalised… they're a group that don't always get included in all sorts of things. Generally they're excluded from all sorts of research studies" (Participant 7).

In sum, all participants identified the value of PPI to health research. A consequentialist construction of PPI was most commonly described. The findings suggest there is may be a gap between the participant knowledge of PPI and implementation in practice.

2. Constraints

The core concept Constraints overarches the themes Resources and Tokenism which speak to participants' accounts of the barriers to effective PPI in research Participants highlighted the need for more time and funding, as well as providing examples of external mechanisms hampering PPI work. A recurring issue was the existence of tokenistic approaches to PPI that reduced the integrity and meaning of PPI activities.

It was widely recognised that to involve patients and the public in a meaningful way took time and effort by researchers. Many participants described operating in an environment where capacity within research teams was limited. The availability of funding for PPI activities was noted as a difficulty, though one participant felt that funding often was available, but that researchers were rarely aware of it.

The local promotion of PPI opportunities for patients and the public, including the provision of training was commonly described as ineffective. Participant 2 suggested this was in part due to organisational research priorities.

"…if you've got patients who are interested in research we automatically presume that that means "lets find a trial that fits their diagnosis", we don't think, would you be interested in other aspects?" (Particpant 2).

One of the most pervasive themes to emerge was the description of tokenistic approaches to PPI in health research. All participants were aware of the political imperative to include PPI in research grant applications and this was identified as a motivating factor for researchers to complete PPI activities. Many participants articulated how this could lead to a tokenistic approach that reduced the meaning and integrity of involvement. The term 'tick box' was frequently used to describe this process, leading to dissatisfaction and frustration.

"… it feels distasteful calling [the PPI group] a bit of a tick boxy event" (Participant 8).

"…whether it's real or tokenistic, and if it's real you get, you get a level of involvement that actually very rewarding because you know it's real …rather than a tokenistic involvement

which might well tick the requirements of the Research Ethics Committee but doesn't provide a feeling of that personal validity I suppose" (Participant 6).

The perceived overuse of a limited number of individuals in PPI activities was also highlighted. Concerns about over-burdening individuals, representation and professionalisation were raised in relation to this way of working.

To summarise, participants described feeling constrained in implementing PPI in practice in a number of ways. It is worthy of note that a number of participants identified the positive impact that the governance requirements for PPI in research could have in the promotion of and learning about PPI in practice.

3. Culture

This final core concept speaks to the context in which participants worked and encompassed the themes Knowledge, Caution and Moving Forward. Cultural factors in the research community and in the organisation were identified as important in both supporting and complicating involvement work.

Many participants described challenges in integrating different types of knowledge in the research process, with the concept of expertise central to the theme. The value placed on experiential knowledge, versus knowledge held within the research community emerged as a particularly complicated aspect of PPI in practice. Participants described a complex process of working with different stakeholders in the research process. Tensions between academic, clinical and PPI perspectives were evident. The dominance of research knowledge was seen to inhibit some involvement work. However, relying on experiential knowledge to support clinical research priorities was described as problematic when these perspectives were judged to be misaligned.

"Sometimes people aren't experts …the public don't see [the clinical condition] as a priority because they don't get it" (Participant 3)

Although all participants identified the value PPI could bring to research, caution was also expressed in some areas. The challenges to researchers of including PPI in an already demanding process were typified by the following quote.

"…what is it going to throw up and its probably going to make things more complicated, more tricky" (Participant 1)

However, another participant appeared to be energised by relinquishing control in the research process;

"Its, you lose control of some of it really. I think probably quite an exciting; provoking process and it is hard work if you're going to do it meaningfully" (Participant 7).

Different research designs were identified as being more open to PPI than others, with co-led or participatory research approaches described as more challenging than consultative PPI models in clinical trials for example.

Managing expectations of PPI members was the final area in which a degree of caution emerged. It was suggested it could be impractical to give PPI members free reign in terms of generating research ideas.

"…there are a lot of questions that the public and patients would like to ask and its very difficult to do that methodologically or operationally… on the one hand you want to

encourage people to take up the opportunity of talking and developing their idea… but then, you know, there are things that are actually very impractical, may be unethical… so we don't want to give people unrealistic expectations I suppose" (Participant 6).

Although caution was a clear theme, optimism about PPI going forward also emerged. A process of sharing and learning from experience was identified as having the potential to positively influence researchers' practice. Calls for more organisational and strategic support for PPI activities were frequently made. Interestingly, in contrast to the tokenism identified earlier, some participants identified a positive function in the requirement to include PPI in their work.

"…so those nudges and those requirements…make sure you have thought about it" (Participant 7).

Connected to this was the idea that momentum could build over time and create more meaningful involvement through cultural change. A key aspect of the support participants felt would make a difference was the development of networks and more resources to draw upon to make PPI work more meaningful, which echo the frustrations outlined in the resources and tokenism theme.

"…it would be helpful to be a bit more strategic because otherwise its just down to individuals really that have little time and resource to encourage and facilitate it" (Participant 6).

In summary, some tensions emerged in incorporating the PPI perspective across the research process. Some optimism also emerged, alongside calls for more organisational support to embed more meaningful involvement work.

Discussion

The core concept 'Valuing the PPI perspective' indicates that participants' awareness of the benefits of involvement work in research was high. The examples of PPI in practice outlined in What will work? theme, focused on activities such as inputting to research design or interventions. This is in line with the findings of Thompson et al. (2009); participants frequently described PPI in terms of its validation function. Despite this, a clear distinction was made between what "should" happen and the reality. The 'shoulds' centred mainly on moral arguments for the public setting the research agenda. However, only one participant provided an example of a service user-led process. This finding suggests the dominance of consultative models of PPI, giving weight perhaps to Ross et al's (2005) argument that the equation; PPI equals consultation, is still prevalent in the health research community.

There was however, more consensus on participants' construction of PPI in research than Thompson et al. (2009) found. There was no reference to the role PPI may have in improving the social acceptance of research. This is not surprising given the research setting, as these arguments tend to be more prevalent in biomedical research (Thompson et al. 2009). In this study, the value of PPI was often described in terms of ownership and empowerment. Perhaps the cultural context of mental health services contributed to participants being particularly attuned to these aspects of PPI work. Staff working in mental health services are very aware of issues of stigma and social exclusion for the population they work with. This finding may also reflect the participants research interests; for example working with minority or marginalised groups. Giving a voice to such groups through PPI work may also be a reflection of the emancipatory traditions within mental health and disability research (Barnes and Cotterall 2012). Enamy et al. (2011) suggest that patient involvement in mental health service development can have therapeutic purposes – one participant made reference to the role PPI could have in personal mental health recovery for patients.

It was apparent that participants felt constrained in the implementation of PPI in practice. Working in the context of tight deadlines and with limited resources is in line with the findings from Thompson et al. (2009). Scarce resources are frequently identified as a barrier to PPI (Williamson et al. 2010) and Brett et al. (2012) specify the availability of funding and resources as a key condition for successful involvement work. Participants' frustration with starting involvement work too late suggested some dissatisfaction with this way of delivering PPI and an investment in working in more meaningful ways. This may, in part, reflect the research interests of participants and the mental health setting. In contrast to Thompson et al. (2009) where tokenistic approaches to PPI were inferred from participants' accounts, the researchers in this study were keen to share explicit examples of what were frequently called 'tick box' processes.

The limited pool of PPI participants used within the Trust provided further evidence of tokenistic approaches and may indicate some professionalisation of members of PPI groups in the trust (Thompson et al. 2012, Enamy et al. 2011). The need for more effective PPI networks was clearly articulated and further confirmed the importance of resources. It was interesting that a number of participants advocated for the provision of PPI training for members of the public. This is a contested idea in the research community (Staley 2009, Ives et al. 2012) and serves as another example of the complicated landscape of PPI in health research.

The caution expressed towards some aspects of PPI suggests there may some attitudinal barriers to PPI work locally and is aligned with the findings of Thompson et al. (2009). This supports the view that researchers may accept PPI as a "good" thing (as evidenced in the Valuing the PPI perspective theme), but that it may not always be translated operationally (Forbat et al. 2009). Some participants had particular reservations about including the public in the analysis of data. Health policy (DOH 2005) clearly outlines the need to include PPI in all stages of the research process and Brett et al. (2012) describe involvement in analysis as a key indicator of meaningful PPI work. These findings indicate there may still be some distance to travel before PPI is truly integrated across the research process.

The caution expressed in relation to integrating different types of knowledge and expertise within the research process could indicate different value being placed on experiential knowledge and professional knowledge (Abma et al. 2009, Gillard et al. 2012). This corresponds to the debate about the place of 'lay' knowledge (Ives et al. 2012) in the research process and to the presence of "epistemological dissonance" described by Ward et al. (2009 p 75). Some participants' accounts indicated a reluctance to relinquish control of research by inviting public involvement, suggesting the power base of academics and researchers may still be dominant (Ross et al. 2005, Gillard et al. 2012). These cultural aspects of the research community are long-standing and can hinder PPI work (Ward et al. 2009).

The fact that some participants expressed some optimism for the future, suggested they were invested in PPI and were keen to make it more meaningful. The positive regard for the requirement to include PPI in research and to share learning suggested participants felt some individual agency in moving the work forward. This positive staff attitude is a good basis for partnership working such as PPI (Brookes et al 2011). However, reflecting on Greenhalgh's (2004) ideas on adoption of innovations, it appears that researchers' values can be both aligned (Valuing the PPI perspective) and misaligned (Knowledge and Caution) with those of PPI and therefore serve to support and inhibit the uptake of involvement work. These tensions illustrate the complex nature of PPI work and the challenges to truly integrating different perspectives in the research process (Farrell 2004).

Some hope was evident that over time more effective ways of involving patients and the public locally would emerge. However, participants called for more strategic support, indicating that organisational context is also important. Participants identified an organisational role in promoting more PPI networks locally and in encouraging a more research active culture. This underlines Brett et al's. (2012) concept of the 'Architecture of PPI', in which context is paramount. The responsibility for establishing the conditions for effective PPI in research involves individual and organisational commitment. Strategic leadership may be an important component in shifting from the current position to one where PPI is consistently delivered and the full potential of involvement work in the local mental health research community realised. These findings may be challenging to those leading research locally, as it questions the veracity of some involvement processes within the trust.

Limitations

The study was small scale and the findings specific to the research site. The data revealed large areas of consensus across participant accounts with few outlying or deviant views expressed. It may be that the opt-in process appealed more to supporters of PPI. It was difficult to measure the effectiveness of the measures taken to minimize this effect. However, frustration and dissatisfaction with various aspects of involvement work was also evident, as well as some caution towards PPI, which suggests participants were not simply recounting an organisational position.

Implications for practice

There is increasing interest in the literature about the part contextual factors play in the effective implementation of health policy on PPI in health research (Morrow et. al. 2010, Brett et al. 2012, Staley 2013). The individual attitudes of stakeholders are an important aspect of this context, but there has been little investigation of researchers' attitudes towards PPI in practice to date (Thompson et al. 2009). This is the first study to explore the attitudes of researchers working in mental health and learning disability services towards PPI. This study provides a timely contribution to research in this area by providing valuable insight into the reality of PPI in a NHS research setting.

The findings indicate that participants were very aware of both political and moral arguments for involving the public and patients in their work. The potential for PPI to function as a tool of collaboration and empowerment was evident; however, consultative models of PPI emerged as most prevalent. The findings suggest participants experienced a number of structural barriers that led to tokenistic approaches to some involvement work. Many participants expressed frustration with "tick box" approaches to PPI and wanted to make involvement work more meaningful. This presents an opportunity for research leaders to harness the enthusiasm and motivation of local researchers to improve the effectiveness of PPI. Successful strategies should be shared locally, nationally and internationally.

Whilst optimism was expressed for the future, several attitudinal barriers, coalesced around knowledge, expertise and control of research appeared to hinder the translation of positive constructions of PPI into practice. The findings illustrate the complexities of involvement work in health research and suggest, even in a service context with long established service user involvement, challenges still exist in the integration of lived experience knowledge in research.

Embedding PPI across the whole research process in a meaningful way takes commitment to create the right conditions for involvement work to thrive (Brett et al. 2012). For countries where PPI guidelines are being developed, attention should be paid to cultural factors in the research community to win 'hearts and minds' and ensure a policy-practice gap does not emerge. Strategic leadership may be an important component in shifting from the current position in the UK to one where the full potential of involvement work is realised.

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Participant	Years of experience	Research Role	Type of study/Client Group	Professional Group
1	4	Clinical Studies Officer	RCT and observational study/MH and LD	None
2	4	Research Manager	Various/ MH and LD	None
3	21	Principal Investigator	RCT and feasibility study/MH	Medicine
4	6	Clinical Trials Co-ordinator	RCT/MH and LD	None
5	4	Clinical Trials Co-ordinator	RCT/MH and LD	None
6	17	Principal Investigator	RCT/MH and LD	Medicine
7	0.5	Principal Investigator	Qualitative/LD	Clinical Psychology
8	4	Clinical Studies Officer	RCT and Observational study/ MH and LD	None

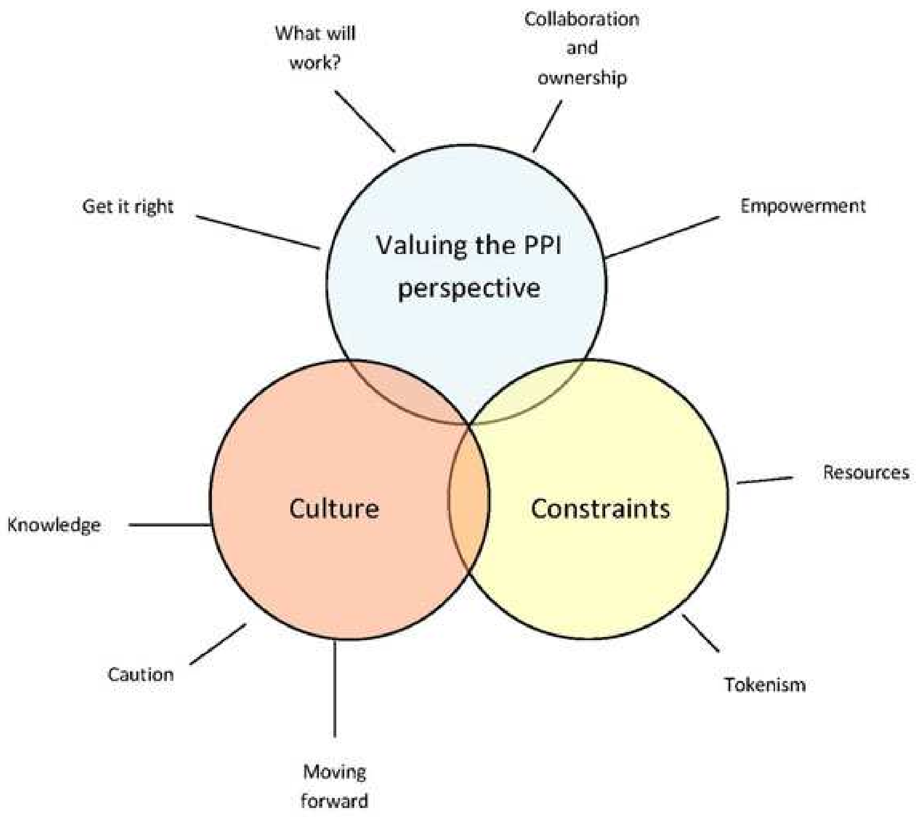
MH – Mental Health

LD – Learning disability

Thoughts on the purpose of PPI in research
Awareness of the arguments for and against PPI in research
The scope and limitations of PPI in research
Exploration of experiences of PPI in practice, both positive and negative
Exploration of the factors that support and hinder PPI
The impact of PPI on the researcher and on the research itself
Thoughts on the future of PPI in a local context

Categories	Theme	Core Concept
• Asking the right research question • Validating the research – giving it credibility • Ethical and moral responsibilities • Researching what is important/relevant/meaningful to patients and the public • Benefitting the research community	Get it Right	**Valuing the PPI perspective**
• Keeping the researchers grounded • Responding to minority groups' needs • Preventing participant burden • Making research designs practical • Promoting effective recruitment • Making the research accessible	What will work	
• Being open to feedback • Recognising differences in power • Researchers working differently • Partnership working • Shared ownership of research • User-led research	Collaboration and ownership	
• Feeling valued and included • Feeling listened to • Giving a voice to marginalised groups • Challenging stigma • Personal recovery	Empowerment	
• Limits on time and capacity in the research team • Limited funding for PPI activities • Lack of awareness of PPI opportunities • Difficulty in sustaining PPI activities • Training opportunities for patients and the public	Resources	**Constraints**
• Ticking the box for funding applications • Using the same PPI group repeatedly • Starting PPI too late • No opportunity to integrate PPI feedback	Tokenism	
• Tensions between academic, clinical and lived experience knowledge • Dominance of expert research knowledge • Developing research knowledge for PPI members	Knowledge	

• Complicating the approvals process • Focus on PPI in certain aspects of the research process/designs • PPI putting the research at risk • Limits of working with specific groups • Retaining control of the research • Managing expectations	Caution	**Culture**
• Strategic support for PPI activities • Strategic support for co-led research • Learning from positive experiences of PPI • Developing local PPI networks • Making PPI meaningful	Moving forward	


What will work?
Collaboration and ownership
Get it right
Empowerment
Valuing the PPI perspective
Culture
Constraints
Resources
Knowledge
Caution
Tokenism
Moving forward