WITHDRAWN: Evaluating Patient and Public Involvement (PPI) in NHS Talking Therapies for Anxiety and Depression: A Framework Analysis of PPI Experience and Development of Good Practice Guidelines

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Research Article

Keywords: Patient and Public Involvement, Talking Therapies, Evaluation, Guidelines

Posted Date: September 18th, 2023

DOI: https://doi.org/10.21203/rs.3.rs-3328022/v1

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Additional Declarations: No competing interests reported.

EDITORIAL NOTE:
The full text of this preprint has been withdrawn by the authors while they make corrections to the work. Therefore, the authors do not wish this work to be cited as a reference. Questions should be directed to the corresponding author.
Abstract

Background

Patient and public involvement (PPI) in research is increasingly growing. Despite the potential benefits of receiving service-user feedback within healthcare services, PPI remains limited in the context of psychological therapies services. Six PPI meetings, aiming to improve treatment engagement, were held in an NHS Talking Therapies service in Northwest England. The aim of the study is to evaluate the PPI experience and to develop good practice guidelines, hoping to encourage PPI activity within Talking Therapies services.

Methods

The study adopted a qualitative focus group design using a semi-structured topic guide. Five participants were recruited from the PPI meetings, all of whom were ex-service users. Framework analysis, incorporating both inductive and deductive coding, was applied to the transcript. The National Institute of Health Research (NIHR) INVOLVE standards were used as the predetermined themes, namely, respect, support, transparency, responsiveness, fairness of opportunity and accountability.

Results

The members reported an overall positive PPI experience. Acknowledgement of PPI contribution, receiving adequate guidance and flexibility, and acquiring new knowledge increased members’ feelings of empowerment. It was also emphasised that being provided with detailed information about the process and role expectations, as well as enabling inclusivity, encouraged engagement and active participation. The members also offered some suggestions for future involvement, such as ensuring diverse recruitment and discretion. In addition, a new standard was added, “Safe Space”, underscoring the importance of creating a welcoming environment when involving people with past or present mental health difficulties.

Conclusions

To the best of our knowledge, this is the first study presenting good practice guidelines to facilitate the recruitment, engagement, empowerment, and impact of PPI activity in Talking Therapies services. By providing this guidance, we hope that researchers and clinical staff will be encouraged to involve service users in the decision-making of Talking Therapies service improvement.

Plain English Summary
Patient and public involvement is when patients and the public offer their feedback to help shape research so that it is carried out with or by patients rather than to or for them. Despite the many benefits that PPI has to offer in healthcare service decision making, it is not common practice within psychological therapy services. For our study, six PPI meetings were held with service users of NHS Talking Therapies service to explore ways to improve treatment engagement. Our aim is to evaluate the members’ experience of being involved and to develop recommendations for other services to conduct similar PPI groups.

Our analysis showed that members found the experience positive overall. They reported that feeling acknowledged for their input, being provided with guidance and support when needed and learning new things helped them feel more encouraged and empowered. It was important for the group members to be given clear information about what was expected of them to feel more confident in contributing. However, PPI members reported that PPI groups should be more diverse and include trigger warnings for any sensitive information shared. The members also spoke about the importance of creating a “safe space”, feeling comfortable taking part and in sharing their experiences of the services.

Using their feedback, we developed good practice guidance to help and encourage clinical staff and researchers with the recruitment, engagement, empowerment, and impact of PPI activity in psychological therapies services.

**Background**

Involving the public in research and service-related decision-making offers unique insight into patients’ priorities, ensuring that service improvements and development are aligned with their needs (1). Patient and public involvement (PPI) in research is research “carried out ‘with’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (2). The extent of public involvement depends on the members’ level of influence, ranging from consultation to collaboration to coproduced research (3).

There is an increasing drive for PPI in healthcare research (4), with charitable and national funding bodies, such as the National Institute of Health Research (NIHR), setting PPI activity as a requirement for obtaining research funding (5). In addition, to ensure public engagement in the context of service quality improvement, PPI activity is now at the forefront of the NHS Long Term Plan priorities (6). Incorporating PPI has proven to be beneficial to the research itself by informing research priorities and ensuring that research design is participant friendly (7, 8), as well as to the members involved, by increasing feelings of empowerment and acquisition of research knowledge (9). However, one must also acknowledge the emotional labour that may arise from PPI contribution, given the discussion of potentially distressing topics (10).

Despite its benefits, PPI activity remains limited in the context of mental health services, where patient input primarily contributes to the development of clinical trials rather than the formation of service-related strategies and improvements (11). Furthermore, researchers often do not feel adequately equipped to chair PPI groups and have previously reported challenges such as communication barriers, fear of
upsetting patients, lack of predefined budgeting routes and limited guidance documents related to the ethical responsibilities of public involvement (1). Therefore, evaluating the PPI process and developing practical guidelines for involvement appears essential to reduce uncertainty and to further encourage PPI activity that will contribute to the development of psychological therapy service delivery (12).

Relevant frameworks have been developed to facilitate the evaluation of PPI activity by assessing the level of its impact and identifying potential challenges faced during the process (13). NIHR has published INVOLVE, a PPI evaluation framework that includes a set of values and principles promoting good practice when embedding public involvement in research (14). However, a systematic review reported that of the 65 available PPI frameworks, only very few can be transferred to a different context (15). The importance of evaluating PPI within a specific context, namely, for participants with a severe mental illness, was highlighted by Richmond et al. (16), who found that many of their values of good public involvement also mirrored those of the INVOLVE principles. More specifically, they emphasised the importance of creating a meaningful and beneficial relationship with PPI members, aiming to protect them from any harm (16). However, as seen in this example and vastly in mental health research, the majority of PPI guidance and toolkits refer to public involvement in clinical trials (17), making the guidelines difficult to implement in the context of healthcare service development.

*NHS Talking Therapies: for Anxiety and Depression* (previously known as IAPT: Improving Access to Psychological Therapies) was nationally established in 2008 to provide evidence-based psychological therapies for people with anxiety and depression (18). In 2021/22, 1.8 million people were referred into the service nationally (19). Despite the projected increase in prevalence and future service expansion (20), there are limited opportunities for service users to contribute to the improvement of Talking Therapies service delivery. Within services’ standard practice, clients are invited to complete the Patient Experience Questionnaire (PEQ; 21) at discharge to provide feedback on their experience of treatment provision. However, the PEQ is only administered to the proportion of clients who had a planned discharge, omitting the potentially illuminating views of a high proportion of clients who drop-out, approximately 31% (22), before completing treatment. An example where patient involvement has been proven fruitful is the steps2change service in Lincolnshire, which runs monthly patient involvement groups, encouraging service users to share their views to support the modernisation of the service (23).

Aiming to gain a deeper understanding of client needs and experiences with Talking Therapies, to ultimately increase engagement with treatment, we set up PPI meetings with ex-service users from four Talking Therapies services in Northwest England. Groups that are frequently underrepresented in Talking Therapies services (24), namely, males, younger and older adults, people from a non-white ethnic background, and people from the LGBTQ+ community, were prioritised for inclusion in the PPI groups.

Fourteen (n = 14) PPI members were recruited using advertisements within the Trust. The group was separated into two smaller PPI groups (n = 6 and n = 8, respectively). The meetings were conducted remotely using Microsoft Teams, chaired by three members of the research group. Each group met a total of 3 times over a 3-month period for 2 hours per meeting. A member of the research team kept in
occasional contact with the group members between the meetings to answer any queries, to provide them with any necessary support and to facilitate their overall experience. All group members were reimbursed for their time in line with INVOLVE Guidelines (25).

Each meeting followed a similar structure, beginning with a brief presentation, followed by group discussions. The topics covered included the structure and operation of the Talking Therapies services, insights on how to better understand research, and the client characteristics that act as barriers when accessing and engaging with the services. The PPI group discussed their views and suggestions in smaller breakout rooms before providing feedback to the whole group. Any group members who did not wish to contribute verbally were able to use the chat function.

After the completion of the PPI meetings, we conducted a focus group to evaluate the members’ overall experience. To our knowledge, there is no previously published evaluation of the PPI process in the context of IAPT or Talking Therapies.

Therefore, the aim of this project was to evaluate the PPI activity that took place in Talking Therapies services using the NIHR INVOLVE values and principles as an evaluation framework. Given that implementing meaningful PPI can be challenging without the relevant support structures (17), our secondary aim is to develop a set of good practice guidelines to facilitate clinicians and researchers with PPI recruitment, engagement, empowerment, and impact upon Talking Therapies services.

**Methods**

**Design**

This study adopted a qualitative focus group design using a semi structured topic guide. Further details on reporting are presented on the GRIPP tool (26; Appendix 1).

**Participants**

Participants were recruited as part of a service evaluation of NHS Talking Therapies in an NHS Trust in Northwest England. PPI members who had attended at least two PPI meetings were invited to a focus group (n = 13). At the end of the last PPI meeting, the potential participants were provided with a brief overview of the purpose of the focus group, were informed about their right to withdraw at any point and had the opportunity to ask questions. Eligible and interested participants were then sent a copy of the Participant Information Sheet and a Consent Form via email to complete prior to their participation.

The inclusion criteria were as follows:

- Attended at least 2 PPI group meetings as part of the NHS Talking Therapies for Anxiety and Depression service evaluation.
- Aged 18 years or over.
- Able to speak and read in English.
The final focus group consisted of five (n = 5) PPI members (see Table 1).

[Insert Table 1]

Data Collection

A semi structured online focus group was held on Microsoft Teams. To avoid response bias, the focus group was led by two members of the research team who had no prior involvement in the PPI meetings. The focus group meeting was audio recorded and transcribed verbatim. The group lasted 70 minutes and was transcribed in a 21-page transcript. The participants received £30 as reimbursement for their time in participation.

To structure the focus group and support the evaluation of the PPI experience, a topic guide was developed, informed by the INVOLVE framework. Although the INVOLVE framework does not exist in the form of a validated instrument, we used its six domains to form the main questions included in our topic guide (see Table 2 for further details).

[Insert Table 2]

Analysis

We analysed the focus group data using a framework analysis method incorporating both inductive and deductive coding. The analysis was completed by ILV, HF and AB. This method was deemed appropriate, as it allowed us to consider both predetermined themes from the INVOLVE values and to discover new emergent data-driven themes (27). We followed the five stages of framework analysis as outlined by Ritchie & Spencer (28). After our familiarisation with the transcript, we organised our data and developed framework categories that offered the best fit for our data and research questions. We added a category to code emerging issues that did not fit with any of the preexisting categories. Following the process of indexing and charting the data, three of the researchers independently organised the transcript into the framework categories. After independently highlighting text that best matched the framework categories, the reviewers exchanged views until they reached consensus. All data were then organised into a more manageable format by summarising the indexed data for each category to facilitate the final stage of mapping and interpretation. The research team developed ‘bottom-up’ explanations based on the explored patterns and produced the final themes and subthemes.

Development of PPI Good Practice Guidelines

Based on the subthemes derived from the PPI evaluation, the research team developed four good practice guidelines to be considered when planning and conducting PPI groups in NHS Talking Therapies services. Our goal was to guide and facilitate future researchers and practitioners with the recruitment, engagement, empowerment, and impact of PPI groups in the context of psychological therapies services. Iterative discussions took place among the research team to correspond to the emerged subthemes within each guideline. This involved each researcher individually reading through the evaluation and
emerging themes to ensure that all data were incorporated. To integrate public involvement throughout our research process, the focus group participants were presented with the guidelines and were asked to give their feedback. We discussed whether the content was reflective of their comments and experiences and made necessary amendments.

**Reflexivity**

Reflexivity is intrinsic to qualitative analysis. Throughout the analysis process, the relationship between the researchers, participants, and the analysis itself were explored (29). Above wanting to understand more about the PPI experience in NHS Talking Therapies, the research team had no prior expectations for the data analysis. Various strategies were also employed to ensure transparency of data, such as the transcripts being independently coded by ILV, HF and AB, who then met after to agree with their coding. Interpretations of the analysis were also shared and discussed with the wider research team to ensure that the data analysis was not biased to the individual members of the research team.

**Results**

Our analysis resulted in seven themes and fourteen subthemes, as outlined in Table 3.

[Insert Table 3]

**RESPECT**

**Appreciating PPI Contribution**

The members appreciated that throughout their involvement, the researchers expressed their gratitude for the group's feedback. The researchers clearly communicated the importance and necessity of PPI input to better understand service users' needs and priorities.

It felt like they were learning as much as we were in a way, which was nice as well. I mean, that's what it was all about. As I say, as soon as you made any comment at all, they did take it on board.

The researchers informed the group that the views and suggestions shared offered unique insight into the service user experience, facilitating the shaping of future strategies to improve access to mental health services.

But they said to actually get to speak to the people in a live setting and get that feedback, they really seemed to be getting a lot from it.

**Respect for Lived Experience**

As a result of researchers’ acknowledgement of PPI contribution and expertise, the group felt valued and empowered. The members were happy to be involved in the decision-making process for service development purposes and appreciated the opportunity to provide both positive and negative feedback.
And also, they really made us feel valued, because they said that it was like a dream come true, because they said they’re normally studying research notes or whatever.

In addition, the group recognised the importance of involving people from different backgrounds. All members agreed that different perspectives were respected and that the researchers were seeking to acquire a representative view of service users’ experiences.

So, from the researchers’ point of view, they’re getting all that benefit of all these different people and obviously different people with different conditions, different backgrounds, different experiences of the service. So, I think it was a good thing to have a group of people.

**SUPPORT**

**Learning opportunity for members**

PPI members were happy to share their concerns and suggestions based on their experience with the services. The group appeared to enjoy exchanging views and knowledge with others.

And also, from my...I would call them my peers, other fellow participants, (I have increased my knowledge) on how they were perceiving the service that was given to them, and other things that I would never think about how to improve.

In addition, the researchers ensured that all PPI members had access to the necessary learning and development opportunities by presenting important information about the services and previous research findings. This supported the groups’ involvement, as they gained a better insight into how the services operate and increased their knowledge on research methods and outcomes.

I learnt a lot about how this kind of research is conducted. And it was a new experience for me. It probably was the second time, these sessions where you give feedback on a mental health service, but it was carried out in a different way and I think on this occasion, I learned much more, even about how to share views on the service. And I learned from the researcher about how to conduct these kinds of things.

**Flexibility and Guidance**

Before the initial PPI meeting, to offer flexibility and encourage participation, the researchers provided the members with the option of choosing the modality of the meetings. All PPI members agreed that online meetings were preferred due to practical reasons, such as time and location flexibility.

I was quite happy with online, I felt it worked quite well and saves people the hassle of having to travel. Because I’m aware of we all might live in vastly different places around Greater Manchester, so it kind of made sense to me.

Since the meetings were conducted online, the researchers checked the members’ digital literacy and provided clear guidance on how to use the basic features of the online platform used for the meetings.
At the beginning of the session, they did a: this is where everything is on your screen, so how to press mute, how to put your hand up, where the chat was.

A member stated that they felt less anxious and more confident using technology due to the support offered.

I’m not very computer literate and I felt a bit overwhelmed and a bit anxious the first time, but I was made to feel at ease, and it wasn’t too bad. It was better than I expected it to be because I was supported.

**Reimbursement**

All members were informed in advance about the reimbursement to be received for their contribution. However, the payment was often delayed, which occasionally acted as a deterrent for some people, especially for those who relied on the funds.

> “I appreciate the public sector has some challenges in doing finance but for me that would be a good improvement, particularly for those where money may be more significant, given the cost of living. For some people, £20 is the difference between putting food on the table.”

**TRANSPARENCY**

**Expectation of PPI Role**

The members noted the importance of being provided with detailed information about the PPI process prior to and during their involvement. Transparency on the purpose of the PPI role helped them manage their expectations and feel more confident contributing in a group setting.

...and when we asked for clarification on if there was anything unclear in what we were about to discuss, they made it easier for us to understand and to guide us in what we were expected to do and discuss about.

One of the participants recalled that during a small-group (i.e., break-out room) discussion, the focus of the conversation lacked clarity. Although the facilitators provided prompts beforehand to guide the conversation, e.g., ”How do you think we could improve access for people from the LGBTQIA + community?”, they were not present in the break-out rooms.

> “We were sent out into a breakout room, and I didn't feel...we weren't that sure what to say or what to discuss. I think a couple of other people agreed actually”.

**Availability and Commitment**

Despite planning meeting dates in advance, there were occasions where PPI members could not attend. One of the members who could not attend appreciated the catch-up call that followed the missed
meeting, as they had the opportunity to share their views and hear the group’s input on the topics discussed.

I had to miss one of the sessions and [researcher] was brilliant. She set up a...I can’t remember if it was a call or a Teams meeting, to bring me back up to speed and to get my input on that as well, just to make sure that I hadn’t missed out.

**RESPONSIVENESS**

**Inclusive Participation**

The facilitators actively supported all PPI members in contributing by providing an open space for the group to offer their insight, irrespective of their level of confidence.

*“they specifically made sure the quieter members of the group were able to speak, but not in an uncomfortable picking on them way, but making sure their voices were heard.”*

To facilitate engagement for all, the PPI members were provided with the option to participate with their camera and/or microphone deactivated and using the chat box as a suggested alternative. For individuals who contributed their ideas in written form, the researchers ensured that their ideas were voiced and were part of the group discussion.

*“We had someone in our group who wasn’t comfortable speaking on mic, so he had his camera on but didn’t want to talk. So, he was putting messages into the chat, and they were making sure that all of those were included in the discussions.”*

One of the PPI members raised concerns that PPI meetings and all supporting information provided were solely in English, excluding individuals who do not speak English as their first language.

If I was pondering on how to engage other people, I did wonder about language. Information is written in English, so I don’t know how we make it accessible for people whose first language isn’t English, or if you struggle reading.

**Responding to PPI Input**

The PPI members felt reassured, as the facilitators appeared to actively listen to and respond to their concerns and views. Fostering a collaborative and equal relationship, the researchers encouraged the PPI members to openly contribute their thoughts, feeling acknowledged and understood.

And the feedback felt like they were listening and responding to, so it wasn’t like you gave a statement and they just carried on.

During the PPI meetings, the group recognised that the facilitators made relevant adaptations when suggested. For example, after the first session, two members expressed the need to have the presentation
slides in advance of the next meeting to feel more prepared. The researchers subsequently made this amendment for the process going forward.

So, I’ve obviously heard that...you were saying it would be better if the slides could have been sent on the first session, and then subsequently they were.

Evidence of taking PPI recommendations and input onboard was continued after the meetings were completed. The PPI group recognised that the facilitators had successfully incorporated their feedback in the final reports that were shared with senior management, contributing to service improvement.

because when [researcher] shared the report with us, reading through it, you could see things in there that had come out of our group within it. So, it was very clear that they’d been listening and taking on board what we’ve been talking about.

**FAIRNESS OF OPPORTUNITY**

**Diversity**

Overall, the PPI members felt that the group was diverse and representative of the NHS protected characteristics, including people from different ethnic backgrounds and a wide age range.

I don't know what effort they went to, but our group was a pretty mixed age group, almost from teenagers up to quite a lot older. There was a mixture of nationalities... It’s tricky when people are kind of self-selecting to come into it.

Although the group acknowledged the facilitators’ attempts for diversity, concern was expressed by one member in their ability to appropriately cover all topics, as there was nobody present in the group who had the necessary lived experiences.

we got asked questions about LGBTQ + residents and other groups, and I’m not sure we had enough of a representation in our group to adequately represent them.

In addition, one of the members recalled feeling lonely, as they were the only black person present in the PPI group setting. In being the only individual from their community, they felt isolated and feared that the other members would not understand or empathise with their lived experiences and thus became more reluctant to share their insights.

"I was the only Black African in our group and I felt a bit isolated, the only one. A bit lonely, actually. And I just wondered if other people will see things from my perspective as a black person...."

The group agreed that including more than one person from the same community should be taken into consideration to promote diversity and togetherness.
When the services reach out, reassuring them that there will be someone in the same condition that is from the service... They might be encouraged, so there will be someone who really understands what I’m going through, where I come from.

**ACCOUNTABILITY**

**Peer Support**

When the researchers asked the group to reflect on their initial intention behind their involvement in PPI, most members perceived the invitation as a unique opportunity to provide their feedback and contribute to the improvement of service delivery.

“I think it’s always very good to give feedback on something, on a public service, because we really don’t want other people to have the same issues as ours.

When reflecting on the overall PPI experience, the group agreed that it felt reassuring to hear other members having similar experiences, feeling motivated to contribute further.

I felt like there were points where that happened for everybody in our group on different topics, but just hearing from other people’s views. And I think that was really interesting. It wasn’t what I was thinking about particularly when I signed up to do it, but to hear other people’s stories, and commonality, sometimes, going, oh, other people have had that too. Oh, that’s not just me. I thought that was unexpected, I hadn’t anticipated that happening.

**Continued involvement**

After the last meeting, the researchers contacted the PPI members to ask about their interest in getting involved further, including reviewing the final report, becoming co-applicants and discussing future research ideas. Most of the group opted to be contacted in the future, as they felt they could impact the future of the services.

I think it’s really important that users are consulted on things, because, generally, the state that people are in when we’re trying to access these services, we’re not at our best for obvious reasons. And so actually getting input as to how the services should be shaped and should be made accessible, things like that. If I feel, and I don’t know if everyone else feels the same, but if I feel that I’ve helped improve that for someone else, then that’s enough for me.

**SAFE SPACE**

**Comfortable environment**

The PPI facilitators helped the members to feel comfortable in the group setting by being approachable and gentle, establishing a safe space for all members. This was especially important for people who
suffer from or have previously struggled with mental health issues, especially when showing vulnerability and sharing personal experiences.

I think they probably got the best out of us because of their approach and their gentleness in a group where people are sharing quite private things.

Offering a secure and relaxing environment was appreciated by the PPI members, as they may have previously been reluctant to contribute and provide feedback due to stigma and fear of judgment.

I do think mental health is something, as much I’d like to say there isn’t a stigma, there is, and I do think this is part of the organisation helping address that…This is a very protected, I feel, safe way for us to say, this is our positive and negative feedback.

The PPI meetings offered a space for the members to socialise with people who had experienced similar challenges. The experience of sharing and being vulnerable created feelings of empowerment, with some members observing a boost in confidence and self-esteem.

you get to interact with other people and speak to people, it can only be a good thing for most people. It’s a form of socialisation, I suppose, if it’s someone who’s lonely or... It might help to boost somebody’s confidence.

**Discretion**

For some service users, participation may have felt intimidating due to the novelty of the experience and the sensitive nature of information being shared in a group setting.

I think they communicated it well, but it still felt daunting going and doing it. If you haven’t done something like that before or, in my case, it was...you’re talking about something quite personal in a group.

The group suggested identifying triggers preparticipation. When conducting a PPI group with individuals who are currently or have previously struggled with mental health issues, some experiences might bring up feelings of distress. Sharing any potential triggers prior to the meeting and avoiding deviating to personal stories would help prevent potential distress.

it might be something to consider, that you would inform privately each participant that there might be something they should be more careful about, because there’s someone in the same group who is very sensitive about...

**Discussion**

This is the first study evaluating the PPI experience in NHS Talking Therapies services. Applying the INVOLVE values as the overarching framework for the analysis allowed us to further develop the
standards and increase their relevance in the context of PPI for service improvement. In addition to the six INVOLVE standards, we recommend an extra theme to highlight the importance of a ‘safe space’ when conducting PPI. Furthermore, as summarised in Table 4, to best achieve the involvement of service users in the development of Talking Therapies services delivery, we identified four key questions to consider when planning and conducting PPI in this setting: 1) What to consider when recruiting PPI members? 2) How to engage PPI members? 3) How to empower PPI members? 4) How to facilitate PPI impact? In response to those questions, we developed four good practice guidelines based on the emerged subthemes to encourage the development of PPI activity in Talking Therapies.

We hope that by providing practical recommendations for involvement, we will inspire and facilitate more services to work collaboratively with service users, actively involving them in the service development and improvement process.

Summary of PPI experience

The PPI members described their overall involvement as a positive experience. They valued being in an equal relationship with the researchers, who actively listened to their perspectives and feedback, as made evident in the final reports. In addition, the members appreciated and felt reassured by hearing and learning from the experiences of their peers. They commented on the importance of being provided with sufficient information to manage their expectations and to support their involvement. Although most of the members thought that the PPI groups were diverse and representative, it was acknowledged that more than one person from the same community should be present to avoid feelings of isolation and to encourage contribution. The members also suggested sharing triggers preparticipation to avoid deviating to distressing conversations during the meetings.

What to consider when recruiting PPI members?

People from different ethnic groups are often underrepresented in healthcare research and clinical trials (30) due to communication barriers, stigma, and unfair access to mental health services (31). In the context of psychological therapies, evidence indicates that ethnic minority groups are less likely to be referred (31) and engage with Talking Therapies treatment (24) and thus less likely to recover (33). As reported in our findings, inadequate representation of different ethnic groups within a PPI setting can often lead to feelings of isolation and exclusion (34). It is therefore essential to consider effective recruitment strategies and reach out to communities, facilities, and faith-based organisations to ensure that all perspectives are considered and contribute to psychological therapies service development.

A lack of awareness about the concept of research can be a barrier to public involvement, especially among ethnic minorities (34). Clarifying the purpose of PPI, the role of PPI members, and the benefits of PPI activity is crucial to successful recruitment. As indicated in our focus group, clients with mental health difficulties might feel intimidated and reluctant to take part due to underlying anxieties and the
novelty of the PPI experience. It is therefore important, when advertising PPI opportunities, to briefly communicate the focus of research and the members’ level of involvement and to describe how their input could bring change in the local and wider community (35). It would also be beneficial to contact the PPI candidates prior to the first meeting to discuss further details and potential concerns about their role and expectations. This might alleviate any distressing thoughts and will establish a good rapport between the research team and patients.

Given that participation in mental health research is oftentimes stigmatised, ensuring discretion will help potential candidates to trust the process and become more willing to share their honest views (34). Potential PPI members should be reassured about confidentiality and reminded that they are not expected to disclose any personal details or sensitive information. Last, all PPI members involved need to be reimbursed in acknowledgement of their contribution, skills, and expertise (36). Resources, such as the INOVLVE calculator and budget guidance, can be helpful tools to calculate the appropriate payment (25).

How to engage PPI members?

In addition to the challenges faced during the recruitment process, attendees might drop out immediately before or after the first meeting (37). Hence, engaging PPI members throughout the PPI process is critical. Practical issues such as timing and location, mobility restrictions and caring responsibilities have been previously reported as potential barriers to face-to-face PPI activities (37). On the other hand, a lack of digital literacy and technological devices might prevent members from engaging in online PPI activity (38). Subsequently, offering both in-person and online meetings, with relevant guidance where necessary, provides PPI members with the flexibility to increase their readiness to engage. In addition, to enable inclusive participation during the PPI meetings, members should be encouraged to participate either verbally or orthographically, with the option of having their camera and/or microphone off, depending on their desired choice.

Regarding availability and commitment, the group discussed the importance of conducting catch-up calls when a PPI member had missed a meeting. Researchers’ effort to record everyone’s views and experiences irrespective of members’ availability helps the PPI group feel valued and thus more engaged with the process. Baxter et al. (37) suggested that fluid membership, i.e., flexible participation, should be considered for members with more severe physical and mental health issues to help reduce time burden and manage commitment.

In line with previous literature, service users suggested that language should be carefully considered, particularly when developing information packs and research materials. Previous studies reported that written materials need to be communicated in an easy-to-read format to overcome language barriers and lower literacy levels (39). Last, essential to PPI engagement is a relaxed atmosphere, where everyone feels comfortable sharing their experiences and views. Researchers’ attitudes and well-developed facilitation skills will significantly contribute to an enjoyable environment and subsequently increase members’ willingness to participate and engage. Being kind, authentic and curious towards the PPI
members’ input will enhance the level of rapport and trust gained between the research team and the members.

How to empower PPI members?

To aid engagement and active contribution, PPI members must feel empowered and adequately supported. Their expertise and contributions need to be acknowledged and conveyed by the research team both verbally, via words of affirmation and positive feedback, as well as practically, by proceeding to make changes in response to their input. Previous evidence has shown that power imbalances between researchers and patients during the PPI process can act as a potential barrier to an equal partnership (40). To reduce this perceived gap and increase relatability and empowerment, PPI facilitators need to adopt an encouraging and respectful attitude towards the participants, indicating that their opinions and lived experiences count.

Incorporating training, mentoring support and learning materials to increase knowledge of the research topic has also been proven beneficial in promoting a sense of empowerment and motivation (35). In our PPI groups, providing insight into the structure and operation of Talking Therapies services appeared useful and enjoyable to most participants, while research skills training increased their confidence and understanding of the PPI value. Peer support and sharing experiences might be equally empowering, given that they feel met and acknowledged while also gaining new insights into different perspectives and experiences.

How to facilitate PPI impact?

The impact of PPI has been proven to be challenging to measure and thus is often omitted (41). However, the first step to achieve effective PPI activity is to be responsive to the members’ input throughout the PPI process. Acting on the feedback received and clearly demonstrating the changes that were made following the public input is critical. PPI recommendations should be evidenced in final reports, and members should be encouraged to review and comment if necessary. PPI is a collaborative process, and it is therefore important that feedback to participants, communities, stakeholders, and anyone relevant to the implementation of the findings should be part of the dissemination strategy (1).

After the completion of PPI activity, it is strongly suggested to evaluate the PPI experience using tools and guidance from NIHR (42). Reflection and feedback from PPI members can provide invaluable information on how to achieve better engagement and improvement of public involvement to encourage future contributions.

Clinical Implications for Talking Therapies Services

Talking Therapies services have been developed to meet enormous societal needs. One in six adults report experiencing common mental health problems (33), with depression and anxiety accounting for 23% and 18%, respectively, of the NHS mental health costs (43). The original implementation of IAPT
emphasised the importance of evidence-based treatments, the external monitoring and internal governance arrangements of services, and the development of new training courses and new psychological professions. However, this process was implemented in a top-down ‘professional gift’ approach (44). Carefully analysing where the services are going wrong, including participative decision making to generate solutions, could significantly improve the acceptability, efficiency, and outcomes of Talking Therapies services. For example, it is estimated that nationally, 12% of all appointments for these Talking Therapies are missed, and 40% of first appointments are not attended (45).

Barriers to access and engagement experienced by some groups within the population lead to missed appointments and disengagement. As previously commented, the available PEQ feedback questionnaire comes predominantly from those who have attended and worked towards a planned ending. Adequately understanding the variety of reasons for failure to initially attend or for early disengagement, which may vary as much as the population who could benefit from access to Talking Therapies services, is vital. Incorporating a collaborative research approach such as PPI may ensure that the voices of the service user shape the development and delivery of Talking Therapies. The fact that the change in service name (from IAPT) in itself comes from a national public consultation is perhaps a positive sign that the time is right.

**Limitations**

Our findings should be considered in light of the study's limitations. As a result of the PPI groups being relatively small (n = 14), our focus group consisted of only five PPI members. However, small groups are often suggested to help participants feel comfortable and prevent them from being overwhelmed (46). Due to the small sample size, a lack of diversity in terms of ethnicity and age might also limit the generalisability of our findings. To gain a more holistic understanding of the public involvement experience, future research should aim to account for heterogeneity within PPI recruitment and evaluation.

In addition, to gain better insight into the overall PPI experience, further feedback from the PPI facilitators and researchers could contribute to a more inclusive PPI evaluation and the refinement of the PPI good practice guidelines. PPI members had the opportunity to provide us with their feedback throughout the development of the guidelines, yet they did not contribute to the data analysis. Although the involvement of PPI in analysing data is commonly recommended (47), this is rarely the case. Future studies may use the best practice framework for collaborative analysis with PPI developed by Jennings et al., (48) who reviewed the current evidence and identified the principles and challenges entailed in collaborative data analysis when conducted in the setting of mental health research.

**Conclusion**

Despite some limitations, the current research provides an initial understanding and structure of how PPI can be implemented within the context of NHS Talking Therapies services. Developing this guidance is
only the first step in the journey. To support the development of public involvement initiatives in Talking Therapies, the guidelines need to be tested within services to explore their feasibility and acceptability, making any necessary amendments, ensuring suggestions from lay members are incorporated. Furthermore, evaluating the impact of the guidelines requires further exploration to understand how PPI in Talking Therapies services can help inform service priorities and decision making.

Abbreviations

GRIPP
Guidance for Reporting Involvement of Patients and Public (checklist)
IAPT
Improving Access to Psychological Therapies
NIHR
National Institute of Health Research
PEQ
Patients Experience Questionnaire
PPI
Patient and Public Involvement

Declarations

Ethics approval and consent to participate

Ethical approval for the study and all documented procedures was received from West London & GTAC Research Ethics Committee (Reference: 22/PR/0775). Focus group participants gave written informed consent.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and analysed during the current study available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

This study was supported by the Research & Innovation Office (GMMH, NHS) [grant number SRF008].
Authors’ contributions

ILV and HF drafted the main text, which was then revised and reformatted by AB. DH contributed to the introduction and discussion. HB facilitated the focus group and reviewed the draft before submission. All the authors have read and approved the final manuscript.

Acknowledgments

We would like to thank the PPI members who gave their time to attend our PPI groups and provide their invaluable insight throughout the research project.

References


Tables
**Table 1.** Participants Demographics

<table>
<thead>
<tr>
<th></th>
<th>P1</th>
<th>P2</th>
<th>P3</th>
<th>P4</th>
<th>P5</th>
</tr>
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<tbody>
<tr>
<td>Age (years)</td>
<td>50</td>
<td>74</td>
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<td>32</td>
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<td>Gender</td>
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<td>Female</td>
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<td>Male</td>
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<td>Black British</td>
<td>White British</td>
<td>White Other</td>
<td>White British</td>
</tr>
<tr>
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<td>Sick Leave</td>
<td>Student</td>
<td>Employed</td>
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**Table 2.** Framework Analysis using INVOLVE standards

<table>
<thead>
<tr>
<th>Values</th>
<th>Definitions</th>
<th>Questions to support analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect</td>
<td>Researchers, research organisations and the public respect one another’s roles and perspectives</td>
<td>Did PPI members felt that researchers recognised the importance of their knowledge and the impact of including people with different perspectives?</td>
</tr>
<tr>
<td>Support</td>
<td>Researchers, research organisations and the public have access to practical and organisational support to involve and be involved</td>
<td>Did PPI members felt adequately supported throughout their PPI involvement?</td>
</tr>
<tr>
<td>Transparency</td>
<td>Researchers, research organisations and the public are clear and open about the aims and scope of involvement in the research</td>
<td>Was clear information given about public members’ role, involvement, and outcome?</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>Researchers and research organisations actively respond to the input of public members involved in research</td>
<td>Were all PPI members able to input their opinion and contribute to discussion?</td>
</tr>
<tr>
<td>Fairness of Opportunity</td>
<td>Researchers and research organisations ensure that public involvement in research is open to individuals and communities without discrimination</td>
<td>Was the PPI group diverse and did everyone have the opportunity to get involved?</td>
</tr>
<tr>
<td>Accountability</td>
<td>Researchers, research organisations and the public are accountable for their involvement in research and to people affected by the research</td>
<td>Were the PPI members given the opportunity to reflect on their experience of involvement?</td>
</tr>
</tbody>
</table>

INVOLVE (2015) Public involvement in research: values and principles framework, INVOLVE: Eastleigh
<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect</td>
<td>Appreciating PPI contribution</td>
</tr>
<tr>
<td></td>
<td>Respect for lived experience</td>
</tr>
<tr>
<td>Support</td>
<td>Learning opportunity for members</td>
</tr>
<tr>
<td></td>
<td>Flexibility and guidance</td>
</tr>
<tr>
<td></td>
<td>Reimbursement</td>
</tr>
<tr>
<td>Transparency</td>
<td>Expectation of PPI role</td>
</tr>
<tr>
<td></td>
<td>Availability &amp; commitment</td>
</tr>
<tr>
<td>Responsiveness</td>
<td>Responding to PPI input</td>
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<td></td>
<td>Inclusive participation</td>
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<tr>
<td>Fairness of Opportunity</td>
<td>Diversity</td>
</tr>
<tr>
<td>Accountability</td>
<td>Peer support</td>
</tr>
<tr>
<td></td>
<td>Continued involvement</td>
</tr>
<tr>
<td>Safe Space</td>
<td>Comfortable environment</td>
</tr>
<tr>
<td></td>
<td>Discretion</td>
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</table>
Table 4. Good practice guideline for increasing PPI activity in Talking Therapies services

<table>
<thead>
<tr>
<th>Guidelines</th>
<th>Subthemes</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>Expectation of PPI role</td>
<td>Clear communication of the purpose of PPI role, including members’ responsibilities and expected outcomes</td>
</tr>
<tr>
<td></td>
<td>Diversity</td>
<td>Promote PPI opportunities to underrepresented groups</td>
</tr>
<tr>
<td></td>
<td>Discretion</td>
<td>Reassurance about confidentiality and management of sensitive information</td>
</tr>
<tr>
<td></td>
<td>Reimbursement</td>
<td>Skills and expertise of PPI members are recognised and rewarded accordingly</td>
</tr>
<tr>
<td>Engagement</td>
<td>Flexibility &amp; guidance</td>
<td>Offering flexibility on medium of communication and ensuring understanding of the information provided</td>
</tr>
<tr>
<td></td>
<td>Comfortable environment</td>
<td>Create a comfortable and warm atmosphere to enable vulnerability and trust</td>
</tr>
<tr>
<td></td>
<td>Inclusive participation</td>
<td>Support members’ contributions irrespective of their level of confidence and extroversion</td>
</tr>
<tr>
<td></td>
<td>Availability &amp; commitment</td>
<td>Have regular catchups to ensure all members up to date and have their needs met</td>
</tr>
<tr>
<td>Empowerment</td>
<td>Appreciating PPI contribution</td>
<td>Acknowledgement of members’ valuable feedback and communication of the benefits acquired</td>
</tr>
<tr>
<td></td>
<td>Respect for lived experience</td>
<td>Encouragement of involving people with lived experiences and respect their input</td>
</tr>
<tr>
<td></td>
<td>Learning opportunity for members</td>
<td>Increase of knowledge on the topics discussed and relevant training provision</td>
</tr>
<tr>
<td></td>
<td>Peer support</td>
<td>Encouraging PPI members to share experiences with each other in a reflective way</td>
</tr>
<tr>
<td>Impact</td>
<td>Responding to PPI input</td>
<td>Actively response to PPI feedback during and after the group meetings</td>
</tr>
<tr>
<td></td>
<td>Continued involvement</td>
<td>Reflection on PPI experience and offering opportunities to further contribution</td>
</tr>
</tbody>
</table>

**Supplementary Files**

This is a list of supplementary files associated with this preprint. Click to download.

- Appendix1GRIPP2.docx