Author’s response to reviews

Title: EXPLORING EXPERIENCES OF PEOPLE PARTICIPATION ACTIVITIES IN A BRITISH NATIONAL HEALTH SERVICE TRUST: A SERVICE USER-LED RESEARCH PROJECT.

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Author’s response to reviews:

Dear Editor

Many thanks for the opportunity to revise our manuscript in light of the helpful comments of the reviewers.

We have provided response to the reviewers’ comments below and have highlighted in yellow all the changes to the manuscript as a consequence of the comments. We have also provided a clean version of the revised manuscript (without highlights).

We hope that our paper may now be acceptable for publication in your journal.

RESPONSE TO REVIEWERS

REVIEWER 1

Firstly, at the start of the background section you mention PP groups across the UK to include the public as well as service users and carers, however the public are then excluded from the rest of the article (as this opportunity to research wasn't open to them). Although I can guess the rationale behind this, for me it would have helped for it to be clearly stated. I run a PP in research
group for mental health and I find that my members of the public contribute equally to service user and carer members and may be joining because of historical situations that hold personal meaning to them.

Authors: We have now clarified that this specific activity was focused on people who were service users and particularly aimed to evaluate the activities which involved service users within a People Participation team (see Page 4).

Secondly, in the service user recruitment section you state your recruits but there is no information about these three people, are they male or female, are they all the same age. You have broken down the demographics of the participants that were interviewed but for me knowing this information whether this was likely to hold any bias or not in terms of the interviews would have been very helpful to know.

Authors: The three service user researchers were one male and two females and all have been involved in PP activities (Page 5). We commented in the discussion that their positive experience of previous involvement might have caused a bias towards a positive interpretation of service users’ experiences (Page 14).

Thirdly, with the first service user led interviews, you state that these were overseen by Giacco, again, how might that have affected responses in these sessions, I wondered here again about possible bias.

Authors: Giacco attended the first interview of each of the service user researchers. This may have somewhat influenced the setting of the first interview, the behavior of the interviewers and participants and consequently the material. However, it was strongly felt within the preparatory workshops that attendance of an experienced researcher during the first interview would be important to increase the confidence of service user researchers (who had never interviewed people for research) and to provide an opportunity for direct feedback. This was added on Page 7.

Fourth, in the discussion section a key output is that these findings are the first in providing insights about PP in NHS Trusts. This may be the first journal article but if definitely isn't the first output. In 2014 for example my PPI group displayed a poster on this very topic at the INVOLVE conference. I think this needs to be framed more clearly.

Authors: We clarified as follows: “One important output is that its findings were among the first ones providing insights on experience of People participation activities in NHS Trusts. This is a
still understudied topic and our paper, to our knowledge, is the first contribution to the scientific literature, although the debate on how to carry out PP activities has been going on for a long time in conferences and fora dedicated to service user involvement (Page 13).

Fifth, in the limitations sections (p14) I would have again expected something around researcher bias in terms of who your researchers were and also in terms of the service user researchers not being completely independent.

Authors: We added a discussion on the potential bias of the researchers as they had been part of the People Participation Team in the past (Page 14). Service user researchers were supervised by Giacco but we have no reason to believe that this has modified their views about the data substantially as Giacco is not a member or stakeholder of the People Participation Team.

REVIEWER 2

I recommend the paper for publication, however, I would like the authors to briefly discuss the age range of participants and how their findings are specific to the older generation but may not be applicable to young people. There is little mention of this but it is an important consideration.

Authors: Thank you for the interesting suggestion. Looking into specific subgroups (i.e. younger service users) was not an aim of this project, but we added as an implication for future research that young people using mental health or other health services should be a focus on future dedicated studies in this area (Page 15).

REVIEWER 3

This seemed a very worthwhile study, and brought up some interesting insights, into the benefits PPI can have not just for the trust, but also for the participants involved, I am a firm believer that for the right person and when it is the right time, being involved in such studies can be highly beneficial to someone with Mental Health Issues, certainly increasing self belief and esteem, and giving you the confidence back that someone values your opinion and that it is actually worth something again.

I can also see how participation in this study would help to reduce feelings of isolation and improve social connectedness, in building up trust and rapport with others and recognition of your own personal value.
It seemed in general from reading the comments in this article, that those who had taken part in this study had had a very positive experience, and it had been a Win -Win situation for both the participants and the trust.

I agree that great care must be taken when selecting clinician staff for the interview process for these studies, and that the right people must in place.

When supporting and advocating for service users or friends, I have encountered too many people in professional roles such as a Psychiatrist or clinician, who have possessed a 'God Complex' or a 'I know best attitude', and have dismissed or not even listened to their patients, thoughts, views or concerns.

I cannot even begin to imagine the damage, this could do to someone with Mental Health Issues, if this is the first thing they encounter, when they have made that huge brave step out of their comfort zone, it would be devestating, and this would most likely make them not want to ever engage in PPI again.

We must start from the point of recognising patients as being experts in their own condition and care, and the unique experiences and information that they can bring to a study from their valuable lived experience.

Proper renumeration to study participants is essential, as this shows, we value their unique skills and experience and their views and time involved.

Finally I do agree aftercare is important after a study, as we don't know what issues, doing the study could of brought to the surface, it will also help those who wish to continue to develop either their Personal or professional skills.

Authors: We did not identify any critical comments. We wish to thank the reviewer very much for the nice words and for the positive evaluation of the study.

REVIEWER 4

Scientific Abstract:

The abstract could be strengthened by a slightly clearer explanation of the people participation schemes (this is done well in the lay summary where examples are given for what the scheme involves).
Authors: We have added a brief explanation of people participation schemes in the scientific abstract (Page 2).

It may also be important to adapt the language to suit an international audience, so talking about 'British National Health Services' or something rather than NHS Trusts.

Authors: We have changed to British National Health Services (NHS) at the beginning and then to NHS throughout.

I have reservations about stating the specific trust this was evaluated in, in terms of whether this may reduce participants anonymity. It might be worth reflecting on whether referencing the location as London might be enough.

Authors: We have removed references to the specific Trust with the exception of the Methods section where we felt such details should be specified.

The conclusion needs to relate to the aims of the project and the implication of these for People Participation and similar schemes, rather than reflecting on the methods.

Lay summary:

Again, the conclusion needs to stick to the main aim of the study, and it would be strengthened by being more specific.

Authors: We rewrote the conclusion section of both the scientific and lay abstract focusing on findings rather than methodology.

Introduction:

As someone who doesn't work in mental health, talking about whether People Participation is good for 'recovery' didn't quite make sense to me at first. It might help to either talk about benefits to health in broader terms, or if these schemes tend to sit within mental health it might be helpful to make this clearer in terms of context.

Authors: Our expertise and experience is in mental health settings, which we specified in the text (Page 4). This is not to deny that People Participation activities can be helpful in other health services, but just to clarify the limit of our expertise and direct knowledge, as we referred to anecdotal reports.
The authors state there is 'little systematic evaluation' of these schemes - if there is some please refer to this in the introduction.

Authors: As per previous comment by a reviewer, there is an active debate within conferences and online and offline networks but this is, to our knowledge, the first scientific paper on evaluations of people participation schemes (this was mentioned on Page 13).

Some of the language needs balancing - for example the authors talk about exploring potential benefits, but I assume they were also interested in potentially negative outcomes too.

Authors: We had originally framed our research question in terms of “suggestions for improvement”. However, the participations’ suggestions were all around the themes of increasing access. We have now gone back to the original phrasing of the question (“suggestions for improvement”).

Where the authors start to introduce their user-led approach, it would help to understand why this approach was chosen. Similar to the editor's previous comments I'm less sure about calling the methods novel, but rather 'emerging' or something like that.

Authors: Thanks for allowing us to clarify this. Having a research team almost entirely including service users (although with supervision from more experienced professionals) was in line with the ethos of the people participation scheme. We aimed to create an absence of any perceived power dynamic and hierarchy between the interviewers and participants and allow participants to feel more comfortable in expressing their views (Page 5).

The final question of the evaluation talks about suggestions to make it more attractive - but this is a little tricky as this sort of assumes benefit. It might be better to talk about 'suggestions for improvement' to avoid this judgement.

Authors: We changed to “suggestions for improvement”. This is explained in more detail in our response to a similar query above.

Methods:

Please double check the paper for abbreviations that are not explained (e.g. ELFT).
Please review where very short paragraphs / single sentences may be able to be combined into a paragraph, as this may help the flow for the reader.

Authors: Thank you. The manuscript was checked in view of both suggestions and amended as required.

In line with focusing on the evaluation, I wonder if the details about recruitment of the service-user researchers could be placed in a box and referred to briefly in the text.

Authors: We would prefer to keep the process of recruitment as part of the text as for us it is a very important part of the project and ay be of interest if other teams would wish to replicate a similar methodology.

I found the bit about the training materials a little hard to follow - at first I thought they were to train the service-user researchers but then it seems like they helped adapt it. Please can this section be clarified? If again this is part of the induction of the service user researchers, this could sit with the recruitment details - whereas if this was for the workshops it sounds like they are part of the evaluation methods.

Authors: We have provided more explanation on the procedures by which, starting from a pre-existing training, we removed jargon and over-technical terms with the help of our service user researchers and through discussion in team meetings (Page 6).

I'm not sure it is helpful to measure the quantitative component - it might be helpful either to state the aim of this other component (to make it clear why it is being completed and written up separately) or not mention at all.

Authors: We removed references to the quantitative component of the study as we agree that they may be misleading for the readers of the current paper.

Overall the description of the qualitative methods requires some strengthening, and would benefit by being written in line with the COREQ reporting guidance for qualitative studies. It would be useful to understand whether the work was underpinned by any particular theory or approach, and if this was definitely using content analysis or actually thematic analysis (as the presentation of the results seems like the latter). It is important to know whether the analysis was completed deductively or inductively, whether there was consideration of saturation, divergent
cases, reflexivity, etc., and whether there were procurers in place to improve rigour (e.g. dual coding). Please also mention the sampling method.

Authors: We explained methods used more in detail on Page 7. We used an inductive content analysis approach. The inductive approach was chosen because of the relative novelty of the area. Saturation of themes was agreed upon in group meetings. A consideration of reflexivity issues is given on the last eight lines of Page 7. No dual coding was carried out, as it is explained in the data analysis paragraph but the analysis was carried out by all group members in meetings in order to reduce subjectivity.

Results:

I wonder if more detail could be given in regard to the participants' ethnicities, as 40% are currently not reported.

Authors: We provided more detail on participants’ ethnicities (Page 8)

Please attached anonymised ID numbers to the quotes, to help the reader see if a mixture of participants are represented.

Authors: Anonymised ID numbers were attached to the quotes.

Although the principles or qualitative research are not focused on numbers, it would be helpful for the narrative to give some indication of how prominent or minor some of the themes were - it seems unlikely that they were all equally as salient.

Authors: Given the small number of participants, and the exploratory nature of the study we would prefer to avoid making statements about recurrence of themes, but rather offer a comprehensive report of the themes identified.

If possible, I would avoid abbreviating People Participation to PP, just to make it a little easier for the reader.

Authors: We have now reported People Participation in extenso throughout the paper.
Discussion:

As mentioned about, this is where it is important to be reflecting primarily on the findings in relation to the aims of the study - rather than focusing too much on the methods. The discussion should summarise the key findings, then relate these to existing literature.

Authors: We agree that the main results’ sections, focused too little on actual findings so we added more detail on them. As we mentioned earlier, to our knowledge, this is the first study in the published literature on our research questions, so we focused on implications of our findings in the discussion (Page 14).

I think that the lack of formal evaluation of the service-user led approach is not a weakness of the study (as it was not what you aimed to do), but is an important area for future research.

Authors: We have now mentioned on Page 15 that the service user led research model should itself be evaluated with systematic methods, which was beyond the scope of our research.

Within the implications, be careful not to overstate the potential benefits of People Participation, especially if the current study is the only evidence. It might be worth tempering the language (e.g. our results suggest people participation can reduce social isolation).

Authors: We specified that our results are to be considered initial and need to be confirmed in larger scale studies (Page 15).

Please add further reflections on this project in relation to existing work, including potential international relevance (baring in mind not to take this too far, as this was a service evaluation rather than research).

Authors: We have now cautiously suggested that the service user led research model might attract interest in international research as it is in line with the ethos of recovery focused mental health services (Page 15).

Please change the conclusions to primarily reflect the study findings in relation to your aims, rather than the service-user led approach.

Authors: We have now focused the conclusions on the findings, although we still mentioned the relevance of the used methodology (Page 16).
Kind regards

The authors