Author’s response to reviews

Title: Patient and Public Involvement in designing and conducting doctoral research: the Whys and the Hows

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Author’s response to reviews:

Responses to reviewers:

Reviewer 1
This is an interesting article and sheds light on the experiences of four doctoral students in involving patients and public in their research. The paper provides an overview of key stages that PPI can be incorporated into doctoral research projects, there were a few points I felt could have been addressed further though to strengthen the paper a little more. Please find my suggestions below:

Comment
1. PPI stops at validating the findings here but we know that PPI can be usefully incorporated in dissemination, such as paper writing or developing ideas for dissemination strategies. I wondered whether the authors had considered this as PPI reps weren't co-authors on the paper and there wasn't really mention of dissemination - this might be interesting to pick up on, whether it's a limitation of the work and if so why it was omitted - it may be worth mentioning though and perhaps drawing on some literature if you've no experience of this personally.

Response
Thank you for raising this. At the time of the submission we had not conducted our analysis or dissemination activities with our PPI members so omitted these. We have now added in a section about the analysis work which is currently underway and our planned dissemination activities.
Comment
2. I also wondered about the generalisation of the PPI work you'd all done. I got the idea from the results that it may have involved older patients with long term conditions but was a bit unclear - would be interesting to have a little for context for each study. If it's quite select PPI characteristics, that's fine but worth mentioning perhaps in the limitations for example - would these approaches still be appropriate for PPI with young people? I think you do talk about this generally e.g. 'pg 20 - difficult to involve a diverse range of people in PPI' but not in the context of the work that you've done, so I think more detail in terms of your experiences of who you recruited would be good and whether you saw a bias.
Response
Thank you for highlighting this. It was important for our research projects to ensure our PPI members had experience of the topic under investigation – however this may limit the generalisability of our approaches as the reviewer suggests. We have added this as a limitation in our discussion. Also, we have included a new figure, Figure 1, which includes brief overviews of our projects and type of PPI members involved.

Comment
3. You talk in the discussion about the brief evaluations you did with PPI reps and question their usefulness but don't provide specifics as to why you question them? One thing that's missing from the paper is the PPI reps views on how you engaged with them? This would be useful to pick up on but if you don't have their feedback, perhaps mentioned in discussion that these are recommendations on your experience as researchers and that further work might be needed to ensure that these recommendations are appropriate are supported by their experiences too - this is one argument to include them in the paper authorship but appreciate this might be too late to do, so worth mentioning at least. For example, you talk about not having a long-standing relationship with PPI reps as a disadvantage in the discussion and in the tables - but is it a disadvantage - to whom? Are PPI reps bothered by this? I was unclear.
Response
Thank you for raising this. We questioned the usefulness of evaluation in small, longitudinal group settings as we believe bias is introduced. We have reworded this within the discussion. We have collected formal and informal feedback from our PPI members to improve the ongoing PPI activities, which are now discussed in the manuscript.
The 'relationship' was in the context of creating possible bias when completing evaluations. We have tried to make this clearer within the text. On reflection we do not believe that it is a disadvantage to the approach so we have removed this from the table.
We agree with the reviewer that PPI members can be included as co-authors, however we acknowledge that it is too late to do this. We have included a new section on dissemination in the manuscript and mention co-authorship of articles with PPI members.

Comment
Title
Patient and Public Involvement in designing and developing doctoral research: the Whys and the Hows … Maybe you could rephrase to 'designing and conducting'.
Response
Thank you for this suggestion which we have implemented.
Comment
Plain English Summary
- 'PPI is not a requirement of the award' This is typical but some awards may advocate it - maybe worth
saying 'not usually a requirement'
Response
Thank you for the clarification, we have actioned this.

Comment
Background
- Pg4 'within the community to improve practices' - do you mean PPI practices or more general?
Response
We have clarified the sentence - we meant to improve healthcare practices.

Comment
Defining and refining research questions with PPI
- Pg6 'not known' typo - think it should be 'know'
Response
We have corrected it.

Comment
- Pg6 'KM arranged to attend one of the group's regular meetings...' It would be great in this section to know how you all introduced PPI to the representatives? I think this would provide a lot of insight for students, especially as PPI could be a tricky concept to communicate to those who aren't familiar with research.
Response
Thank you for the suggestion. Information how KM introduced PPI concept to the patient support group has been added. We have also highlighted in the text, if approached PPI members had previous research experience or were familiar with the PPI concept.

Comment
Forming a patient advisory group
- Pg8 'A flyer was developed to facilitate recruitment' - study recruitment or PPI?
Response
Apologies for the confusion – we mean recruitment of PPI members into the group recruitment. This has now been clarified in the text.

Comment
Using an online patient panel
- Pg11 'No reimbursement was required to panel members in this instance' A few times in the paper, including in the subsequent tables you suggest that if the PPI rep doesn't have to travel to an event then reimbursement is unnecessary. I think INVOLVE guidelines that you have referred to suggest that PPI reps should be reimbursed for time on any task if possible, even if this is done remotely / online etc. I may have misinterpreted this but for example, the first row in Table 1 suggests that reimbursement is unnecessary for focus group participants.
Response
Thank you for highlighting the inaccuracy. No reimbursement for hospitality and transport was required for this instance (online panel in VC’s case). PPI members were reimbursed for their time as
an annual payment for their involvement by the local Trust and thus no additional payment was required by the researcher in VC’s and SK’s cases. We have now changed the wording in the text and the Table 1 to make it clearer for the reader.

Comment
Participant recruitment
-Pg18 'Important to note' - maybe change to It is important to note.... On the same line you also say that the approach requires ethical approval. I'm not sure I agree, there maybe variation across ethical committees - typically PPI does not require ethical approval, although researchers may require R&D approval to access patients via NHS trusts. Maybe worth checking up and whether there's lit on it.
Response
We apologise for this misunderstanding: we meant the recruitment of study participants (not PPI members) requires ethical approval. KM has clarified the sentence and moved to end of the paragraph where we discuss participants for the study recruitment to minimise the confusion.

Comment
Discussion
-Pg18 Typo 'demonstrated that doctoral researcher can' - should be researchers?
Response
This has been corrected.

Comment
-Pg20 'Creating tensions' - Suggestion that doctoral students don't do PPI as it can create tensions - maybe add a reference here. Did you find it created tensions because it's not formal research? I would have thought that the main issue is money and time?
Response
From our own experiences we have found that much more emphasis is given to ‘empirical research’ despite the benefits of engaging with PPI. We have reworded this section, removing the expression.

Comment
-Pg20 'On other hand' - Typo, on the other hand?
Response
This has been corrected.

Comment
Conclusion
-Pg22 Maybe mention the gaps in this work or next steps e.g. diversity of PPI, or PPI reps' perspectives on the methods you suggest.
Response
Thank you for the suggestion. We have mentioned limitations of our work in the discussion.
Reviewer 2

Comment
Reference 1 is used as an example of the positive impact on research yet in the article the authors confess that the 'impact remains weak'. Not sure therefore that it is appropriate to use in this instance
Response
We apologise for incorrectly citing this reference and have removed it from this sentence.

Comment
The 10 top tips for working with PPI in doctoral studies - inappropriate heading, 'working with PPI'. It would be far more appropriate to say working with patients and members of the public.
Response
Thank you for the suggestions, we have changed it as suggested.

Comment
For information, there are patient and public involvement organisations (INVOLVE in England, as mentioned and Involving People in Wales). These can help to recruit individuals for different studies according to their experience and interests
Response
Thank you for highlighting this. We have now signposted readers to this resource in the text (lines 132-134).

Comment
Otherwise a very useful article to help promote PPI and to give realistic expectations to others. The table with the summary of PPI activities with advantages and challenges is particularly useful.
Response
Thank you for the encouraging comment.

Reviewer 3

Comment
In this well written review article manuscript, four case studies are presented by doctoral researchers in health/social care field discussing in detail the approaches they used to incorporate patient and public involvement (PPI) at different stages of their research studies from study design to validating findings. The authors demonstrate beneficial impact on research project progression, researcher self-esteem and alleviated researcher isolation during doctoral studies.
Response
Thank you for the encouraging comment.
Minor essential revisions (General)

Comment
1. Insert "public and" before "patient involvement" throughout the Plain English Summary to make terminology consistent with rest of the manuscript
   Response
   This has actioned in the Plain English Summary.

Comment
2. Overall the Background is too lengthy and would benefit from being more concise
   Response
   The background has been reviewed and word count reduced.

Comment
3. Third paragraph of Background would benefit from some direct examples of how PPI has previously been applied to research in general
   Response
   Thank you for the comment. After the review, we feel that this would expand the background section too much. We have included references to studies and systematic reviews that give examples of how PPI have been applied to research. We have also developed Table 2 which gives direct examples of how we have applied our PPI members’ comments to our research projects.

Comment
4. There seems to be a great deal of overlap between table 1 & 2. Couldn't these be combined to save space?
   Response
   Thank you for the suggestion. Tables 1 & 2 have been merged to save space and prevent overlap (Table 1 in the revised manuscript).

Comment
5. Should there be a table detailing the evaluation of PPI in the four examples discussed here and the changes made given that this is such an important aspect of the article; This will definitely help others working with similar scenarios and add value to the field
   Response
   We have now included Table 2 (new table) to demonstrate some direct examples of changes made as a result of PPI comments.

Comment
6. How does PPI benefit the patients and the public? This aspect is missing from the conclusions.
   Response
   We have included reference to the individual benefits of taking part in PPI activities within our introduction. We have added a small section based on feedback from our advisory groups within the conclusion.
Minor essential revisions (Specific)

Comment
7. Line 87: Omit "together" before "joint decisions"
8. Omit Lines 110 & 111
9. Shift everything after "[2,5,6]...." in Line 128 Into a new paragraph
Response
These have been actioned.

Comment
10. Line 149: The reader would benefit from knowing how and in what format the open questions were asked from the atrial fibrillation local support group. The author responsible (KM) should comment on this
Response
The questions were asked verbally by the researcher in a small focus group setting. This has been added to the text.

Comment
11. Line 225-26: The author responsible (VC) should describe in greater detail the area of "medicines-related risks associated with hospital readmission of frail elderly patients". This is not clear currently
Response
This has now been clarified in the Figure 1 (new figure) with a summary of all the doctoral studies.

Comment
12. Line 231: The author responsible (VC) should better explain the term "home-based PPI activities". This is not clear currently
13. Line 234: The author responsible (VC) should better explain what they mean by "housebound"-patient's own house or a nursing facility? This is not clear currently
14. Line 276: The author responsible (VC) should better explain what they mean by "participant-facing materials". This is not clear currently
Response
These have now been clarified in the text.

Comment
15. Lines 276-77: The word "initial" should be inserted after "two weeks of the" and before "PIS"
Response
This has been corrected.

Comment
16. Lines 319-320: Omit "Although PPI can help ensure that patient-facing documents are written in plain English". Unnecessary information
Response
Comment
17. Line 320: Capitalise "translating" and omit "more"
18. Line 323: Omit ", as the " and replace with a ".'
19. Line 323: Capitalise "participant"
Response
These have been corrected.

Comment
20. Lines 366-68: Omit "Ways to manage this could be to pre-define the date and time of the meeting beforehand within the introductory email, although this may reduce the number of available members." Unnecessary information.
Response
This has been removed.

Comment
21. Lines 396-397: Omit lines
22. Line 398: Omit references and place them at the end of line 400
23. Line 402: Replace "are" with "were"
24. Lines 406-08: Omit "The group members decided to provide a brief overview of the study at their regular support group meetings and distributed the PIS."
25. Lines 409-11: Omit "Although the pool of eligible participants was small and they could be more informed about their condition and medicines than participants not attending patient support groups,"
26. Lines 425-27: Omit "The group was asked to discuss how those results resonated with their experience and if anything was missing."
27. Line 427: Omit "result of the" and replace "led to refining" with "refined"
28. Lines 430-32: Omit "(e.g. are patients pro-active in decision making consultations?). The same approach will be used in the analysis of patients' interviews"
Response
These have been actioned as per the reviewer’s suggestions.

Comment
29. Table 3 is a very useful resource but the heading needs to be on top otherwise it should be labelled as Figure 1
Response
Thank you. This has been corrected and labelled as Figure 2 now.

Comment
30. Lines 459-63: Omit "On other hand, undertaking this early work" and remove rest of the sentence.
31. Lines 487-88: Insert "(especially in the scenario of smaller groups)" after "challenging"
Response
These have been actioned as per the reviewer’s suggestions.
Discretionary revisions
Comment
32. The manuscript will benefit from a section on author credentials and research interests
Response
We have now included a Figure 1, which includes brief overviews of the doctoral research projects and brief credentials of doctoral researchers.

Comment
33. The section on "advisory group" should be before "online panel" for logical progression
Response
Thank you for the suggestion. The section “advisory group” has been moved before ‘’online panel’’ section.