Author’s response to reviews

Title: Supported and valued? A survey of Early Career Researchers’ experiences and perceptions of youth and adult involvement in mental health, self-harm and suicide research

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Response to reviewers

Reviewer #1: The article deals with an interesting and important topic, the engagement and involvement of young people. The authors chose to use the term involvement rather than PPIE and it is not clear whether they understood the distinction between involvement and engagement. I also had some concerns about the use of the term ‘general public involvement’ to denote adult involvement in health research. Again, I wondered if they appreciated the distinction between patient and public involvement and engagement.

- Thank you for this feedback. We have attempted to clarify our use of terminology throughout the manuscript, guided by INVOLVE (see particularly the first paragraph of the introduction, p.5 line 98 onwards)

The summary and background stated that the study was focusing on youth involvement in self harm and suicide research but much of the focus was on the engagement of mental health service users and research more generally. It felt that the intended focus on self harm receded into the background. I felt that a clearer focus was needed on the primary objective of the study although the survey questions suggested the purpose was more general.
- We agree that as a result of the research interests of our survey respondents, the focus is on mental health research more generally. We have redrafted the manuscript throughout to reflect this (including changing the title). The primary objective of the study should now be clearer to the reader (see for example the ‘Present Study’ subsection, p.8 line 171 onwards).

It was also unclear whether the young people engaged in the reference group for the symposium development had lived experience of self harm and suicidal behaviour as well as more general mental health experience. Similarly, had the group been involved in generating the research topic, the research design or anything other than the symposium development? If they were, had they been clearly told the purpose of the symposium and its relationship to the research?

It would be useful to know if the authors reflected on their own PPI and the impact it had on the study.

- We appreciate that more detail regarding the young person’s advisory group is needed. We now provide further details in the subsection ‘Youth Involvement in this Study’ (p.9, line 197 onwards). Due to the ethos and way in which the youth group operated, we cannot confirm precisely what lived experience of mental health the young people had. The youth group were involved in the symposium development as described and we now reflect that it would have been useful if the young people could have attended the symposium in person. Unfortunately, this group has now disbanded with the closure of the department so they have not been able to be involved in the study any further.

I didn't feel that the paper really explored what it set out to do i.e. the challenges of involvement work with young people with experience of self harm and suicidal behaviour. the risks of engaging with this group were referred to on more than one occasion but not explored in any depth nor did the researchers reflect on their own experience of engagement with this group within their own project.

- Hopefully with clarifying our primary objectives, and considerable revisions especially to the qualitative section, these comments have been addressed.

The literature on involving young people in co-design wasn't particularly explored. There are several other papers where young people have been involved in setting research questions and in research design. There is also literature from other fields e.g. alcohol and drugs, which may also be perceived as 'risky' areas of work, demonstrating how to engage young people in research and also setting out why conventional approaches to research and involvement may not work.
- Thank you for these suggestions. Whilst mindful of manuscript length we have now added some references to this literature in the introduction (p. 7-8) and discussion (p. 21).

Exploring the term value, which could be interpreted in different ways, and expanding on how cultural barriers such as value and power impact on involvement would strengthen the paper.

- Apologies, but we are not clear on what is required here. Our data do not directly address meanings of ‘value’, cultural barriers or power relationships – and these did not emerge in the qualitative analysis of the free response sections. We did not provide definitions of the terms ‘value’ etc to the respondents, as now stated in the notes to Table 1. We note that lack of funding to support PPI group members can exacerbate potential power imbalance between group members and researchers (p.22, line 509).

Reviewer #2: This is good work and I am sorry that I do not think it is of much interest to the readers. You have excellent research and fine methods. My response is the feeling that most older researchers know of similar struggles when they were young in all research fields and organisations. It is also well known of the perceived barriers to involve young persons in research studies. Therefore I believe that you have not found anything unexpected or new in your research.

- We would counter that the very fact that this situation has not improved for younger researchers, despite the widespread acceptance of the need for good PPI, is a very good reason to explore ECRs’ experiences, barriers and facilitators in a research study at this point in time.

- The paper has been strengthened considerably following the reviewers' comments. It is clearer in terms of its objectives and take-home messages.

Reviewer #3: The authors present a useful and valuable addition to the literature on Patient Involvement as well as Mental Health and Self-harm research.

The authors may wish to consider the following:
On a more general note, results from the survey show that the majority of respondents (n=25; 61%) answered the questions reflecting on their involvement on mental health research. Self-harm and suicide research were reported less frequently. Therefore, the title of the manuscript is misleading, and I believe Mental health should come prior to self-harm and suicide given that the majority of reflections and answers from participants came from mental health research.

- Thank you for this feedback. We agree that as a result of the research interests of our survey respondents, the focus is on mental health research more generally. We have redrafted the manuscript throughout to reflect this (including changing the title). Similarly, ‘mental health’ is listed first throughout the manuscript now. The primary objective of the study should now be clearer to the reader (see for example the ‘Present Study’ subsection, p.8 line 171 onwards).

Similarly, results from the survey report participants reflecting primarily on public involvement rather than youth involvement. Therefore, the title should be amended to reflect which concept is being predominantly reported.

The title could be changed to this: 'Supported and valued? A survey of ECR experiences and perceptions of public and youth involvement in mental health, self-harm, and suicide research'

- We have changed the use of the term ‘public involvement’ to ‘adult involvement’, in response to feedback from the associate editors. In doing so, we believe we have also addressed this comment.

In the Introduction (page 5), the authors define Patient and Public Involvement and briefly touch on how there are other terms used interchangeably when referring to Engagement. The emphasis on Engagement is not strong, as well as the clarification made. I would suggest the authors consider re-visiting the term Public Engagement (knowledge disseminated) and apply this to their results so that their study reports on the entire NIHR cycle of Patient and Public Involvement and Engagement.

- Thank you for this feedback. We have attempted to clarify our use of terminology throughout the manuscript, guided by INVOLVE (see particularly the first paragraph of the introduction, p5. line 93 onwards).
Despite reading the manuscript several times, I struggled to understand why youth and public involvement were presented separately in the introduction. Once reading the results, it became clearer why the authors separated the concepts given that participants reported differences in involvement with youth and the public. I am not sure whether these two concepts should be separated from the introduction or rather from the presentation of results. Also defining the age criteria for public involvement to be considered youth involvement would be helpful (e.g. 16-25).

- As we have changed the use of the term ‘public involvement’ to ‘adult involvement’ – this should be clearer to the reader.

- We now state that no specific age criteria for ‘young people’/’youth’ was given to the survey respondents (p.10, line 223). This reflects the broader lack of consensus on the definition of ‘youth’.

The authors draw on terms such as self-stigma (introduction page 6). It would be useful for them to include a definition of self-stigma (as opposed to enacted stigma for instance).

- We now give a definition of self-stigma (p.6, line 134).

Participants: The authors state the study was designed for ECRs researching mental health, self-harm and suicide. There is no mention of geographical location of ECR’s and if this was a UK based study or was open worldwide to ECRs in the field. The authors do argue that because of the relatively small research field, no further information was requested from participants such as gender, institution, age. However as mentioned, inclusion criteria with regards to geographical location is missing and I believe this is important to give the reader context when interpreting results given that some countries prioritise PPIE more than others (e.g. funding for PPIE). Also, if this is a worldwide survey, despite agreeing with the authors that this is a small research field, more participants would have needed to be included.

- We now state that the respondents were UK based (p.8, line 185). We focused on capturing characteristics like length of research experience/ current contract/ job title as this tells us far more about the characteristics of the ECR group than knowing their age/ gender would. Furthermore, due to the small research field and familiarity of those working in this area, we judged it appropriate not to collect potentially identifiable information (e.g. age, gender, current institution).
Despite the authors stating participants included came from a convenience sample, the authors fail to report how many people were invited and how many participated in the study. Knowing the participation rate is essential when judging the study's methodological quality.

- As our recruitment strategy involved social media, the total number of potential participants reached is unknown (p.9, line 193). We now note this as a limitation (p. 23, line 523)

Once again, this study is a valuable contribution to the literature on PPIE and mental health and suicidal behaviour research. Findings could be better reported taken into consideration the above suggestions.

- We are grateful for these comments and believe the manuscript has been strengthened considerably.

Associate co-editors’ comments

We welcome mixed methods papers, but these need to include sufficient quality in both methods and results sections as would be expected of stand-alone qualitative and quantitative studies. For instance, qualitative data excerpts need to include sufficient data to judge context. (e.g. “Collaborations with experienced colleagues”).

- Thank you for this feedback. We have undertaken considerable reworking of the qualitative analysis section in an attempt to address the co-editors’ concerns (p.13, line 303 onwards). We have included more data excerpts as evidence of the presence of the themes, which should also provide the additional context required. As a result of this reworking, and in the interests of parsimony, the themes have been streamlined – with a couple of the weaker (less well evidenced) subthemes being dropped. This has, we believe, strengthened the qualitative aspect of the manuscript.

The authors may also wish to make changes to improve readability, for instance including the questionnaire items as a box, or description of respondents in a table.

- We now include the survey questions and response options in a table (Table 1).

- We now include a description of the respondents (in terms of research experience and interests) in a table (Table 2).
Please make clear your paper’s geographical country setting. The publication is international and readers will want to know the country in which you have worked.

- We now state that the respondents were UK based (p.8, line 185).

Please justify your use of “public” instead of “adult”. As the reviewers have pointed out, it is confusing terminology for those who are more familiar with the use of “public” being anyone (not necessarily adult) who is a member of the public.

- We have changed our use of ‘public involvement’ to ‘adult involvement’ throughout (although we have not highlighted these changes throughout)