Author’s response to reviews

Title: Using Qualitative Health Research Methods to Improve Patient and Public Involvement and Engagement in Research

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Author’s response to reviews:

In response to Reviewer #1:

• The term ‘patient engagement’ has been clarified to include ‘patient and public involvement’ to reflect differences in terminology between North America and the UK. As well, the issues regarding the use of the term patient are considered and addressed in the section entitled “A note about language” – starting on line 597.

• Only bold text and underlining has been used to differentiate section heading levels. Other italics have been removed.

• Integrated knowledge translation is defined and referenced on lines 349-351.

• The paper has been reviewed and changes have been made to improve readability. Qualitative health research is now briefly described in the Plain English Summary (lines 48-49), the Abstract (lines 213-215).

• There is not a lay author on the writing team.

• We are in agreement that the terms ‘co-creation’ and patient engagement were used interchangeably and this may be confusing to readers. We have removed terms related to co-creation of research, including within the Abstract.

• The identified sentence within the Abstract (What is missing from the recent proliferation of resources and publications detailing the practical and experiential aspects of patient engagement, however, is a recognition of how existing research theories and methodologies that have an established history of public and patient involvement can inform current patient engagement initiatives.) has been revised – see lines 211-217.
In response to Reviewer #2:

- The concern that engaging patients may lead to emotional distress has been addressed by including the recommendation that, as with many qualitative health research studies, considerations are made to provide brief counselling support should the sharing of patients’ experiences result in emotional distress. See lines 527-529.

- The Plain Language Summary has been revised to be easier to read and more engaging.

- Tokenism is discussed in detail beginning at line 613 and is also now briefly explained on lines 43-44 of the Plain English Summary.

- The final paragraph (“Conclusion”) has been revised for clarity and simplicity.

In response to Reviewer #3:

- References have been edited and Accessed dates have been added where appropriate. Reference 17 has been double checked, but we believe is accurate. The date for Reference 54 has been added, and the duplicate doi for Reference 56 has been removed.

In response to Reviewer #4:

- The reviewer’s important point about confusion in using qualitative methods in PPIE has been seriously considered. This has been addressed previously in line 633, but we have made an additional comment on lines 424-425 that the use of qualitative methods for PPIE does not infer that PPIE is research or that information collected for PPIE is data.

- The section entitled, “Rigour: Interpreting and incorporating patients’ experiences into the design and conduct of research” has been revised for clarity to ensure that the use of qualitative research methods in PPIE are not misconstrued as qualitative research data collection. As indicated in the previous point, lines 424-425 reiterate that information gathered as part of PPIE is not data, but can be systematically analyzed to increase the rigour of PPIE initiatives. To be clear, we are not intending to suggest that engaged patients (e.g., for a Delphi or JLA exercise) are research subjects.

- The reviewer’s concerns about dense description of engaged patients are valid. We have addressed this issue on lines 468-471 to suggest that research teams use discretion when describing engaged patients, whilst not omitting this information altogether.
• We believe that it is beyond the scope of this commentary paper to provide greater discussion related to ethics and participatory research, these issues are addressed and the reader is referred to relevant references in the section entitled “Tokenism”, the Abstract, and on lines 394-395.

• The typo in the abstract has been addressed – see line 208.

In response to Reviewer #5:

• We agree with the assertion that qualitative research and PPIE have different purposes. However, without attending to evidence-based approaches to gathering and interpreting information about patients’ lived experiences with health and the healthcare system, PPIE remains ripe for unethical practices. It is this concern that has compelled us to write this paper. That being said, we appreciate the need to ensure that researchers engaged in PPIE need to seek further knowledge and training in qualitative research as a paradigm and practice. As such, we have made this suggestion/caveat in the revised paper on lines 55-57, 375-376, 379-384, and 394-395.

• We also agree that PPIE is not an essential requirement for sound and rigorous qualitative research, and that the skills for PPIE are different than those required for sound qualitative research (or even integrated knowledge translation research). However, rather than to suggest that sharing power and decision making, working at a strategic level, or being flexible or accessible to public contributor (patient) needs is a new or unique aspect to the conduct of health research fails to acknowledge the foundation for this type of research that has been developed by many qualitative and/or participatory researchers over many decades. As a result, these are posited as new skills/concepts to be mastered by PPIE professionals or researchers new to PPIE, without looking to include experienced qualitative and participatory health researchers on projects or teams involving PPIE to which they would bring great skill. The hope is that this commentary also brings this issue up for consideration by readers. Again, the suggestion that readers seek further training and information on qualitative research (rather than relying solely on this commentary paper) is made clearer in the revised paper, as described in the previous point.

• We are in agreement that the terms ‘co-creation,’ ‘involvement’ and ‘patient engagement’ were used interchangeably and this may be confusing to readers. We have removed terms related to co-creation of research, including within the Abstract. Of note, is the fact that distinguishing between engagement and involvement is specific to the UK, and the term ‘engagement’ is the accepted term in North America. By clarifying that the terms differ based on geography, we hope that readers will appreciate that in this paper, we are using these terms to refer to the process rather than a level of engagement as part of the spectrum of engagement that is described for example by the IAP2 Spectrum of Public Participation.

• The Plain English Summary has been revised to better reflect the Abstract.
• Integrated knowledge translation is defined and referenced on lines 349-351.

• The GRIPP reporting guidelines were not available when this manuscript was drafted, and thus are not reviewed therein. References 6 and 27 do direct readers to the wealth of resources and expertise provided by the NIHR.

• Constant comparative analysis is indeed not appropriate for ongoing collaboration with patient partners. It is relevant for researchers to consider this approach in particular contexts, however, for example to refine research objectives, outcomes or process as planning and conduct of the study progresses (depending on chosen methods). We have attempted to clarify the context in which constant comparative analysis is appropriate, as well as to describe more clearly that PPIE is an iterative rather than a linear process (see lines 480-490).

• We feel that the issues of power sharing and shared decision-making in the coproduction of research require the initial step of reflexivity. For this reason, this issue is discussed in the section entitled, “Reflexivity: Ensuring meaningful and authentic engagement”, and power sharing discussed in the second paragraph. While it is beyond the scope of this commentary paper to delve deeply into these issues, an introduction to reflexivity as a practice is a more concrete, evidence-based discussion to address tokenism than many beginner guides to PPIE provide.

• The reviewer’s thoughtful and critical assessment of the paper, its merits and weaknesses has been very thought-provoking and has led to, what we hope, an improved version of the original article. Based on our understanding of the journal’s publication types, an ‘opinion’ piece is not an option, but we have submitted this originally and in this revision as a ‘Commentary’. The hope is that this evidence-informed but opinionated perspective will encourage greater discussion and debate about the relative merits and challenges of applying qualitative research methods to the practice of PPIE, and hopefully strengthening the theoretical foundations of PPIE.

In response to the Associate Editor:

• The term IKT has been defined and replaced with ‘integrated knowledge translation’ throughout the paper.

• Clarification about terminology of PPIE has been made in the Abstract and Plain English Summary (see also response to Reviewer #1, point 1).

• Constant comparative analysis is indeed not appropriate for ongoing or all collaboration with patient partners. It is relevant for researchers to consider this approach in particular contexts, however, for example to refine research objectives, outcomes or process as planning and conduct of the study progresses (depending on chosen methods). We have attempted to clarify the context in which constant comparative analysis is appropriate, as
well as to describe more clearly that PPIE is an iterative rather than a linear process (see lines 480-490).

• The grammatical error in “Conclusions” has been revised: see line 648.

In response to the Editors-in-Chief:

• We hope that we have adequately addressed the issues and concerns raised by Reviewer #5, and addressed the issues of terminology that caused concerns for several reviewers.

• We sincerely appreciate the critical review and feedback of all reviewers and editors and feel that the revised manuscript is much improved from the original submission.