Reviewer’s report

Title: Public involvement could usefully inform ethical review, but rarely does: what are the implications?

Version: 0 Date: 08 Jun 2017

Reviewer: Raksha Pandya-Wood

Reviewer's report:
This is a useful article which highlights a unique contribution to the field of ethics and public involvement. I enjoyed reading its content and commend the authors for their work on the article. I have some suggestions for improving the article and increasing its use to the readership of the journal. Please see my suggestions below - they are mainly concerned with adding further referances to make a stronger point.

Pg 5-6
1. In the methods section, where 'Cohen's Kappa ...' is mentioned I think it needs a reference with date and a brief description of what that is.

2. Also in the methods section a reference is needed where you mention 'experiential knowledge' along with a brief description of what you mean by it (do you mean professionally in public involvement work that you both do? is it your understanding of ethics or are you referring to your current jobs - this is important as it offers grounding to the reader.

Pg 6
3. In the overall findings section, a reference is needed when you discuss that it was reported that there was a mismatch between communicating findings and understanding what public involvement was. There are plenty of references that refer to this and stating it here will strengthen your paper.

4. Third paragraph last line: could you find a reference to back the point that there is always a list of pros and cons between 'free text' and 'tick box' (lots of research text books would
reference this). This would strengthen the point you are making by showing the reader you are familiar with the implications this has on appreciating the different results the two views offer (qualitative v's quantitative).

Pg 7
5 - Under involvement in design, first paragraph, can you find a reference to show that there is a wider issue here of burden to participants.
6 - Second paragraph can you referance how public involvement in the design stage has elsewhere in other studies shown that ethical issues are improved as a result of public involvement.

Pg 11
7 - First paragraph, could you end that useful first paragraph with a reference to show that public involvement in the dissemination process can lead to better ideas for implementation and translation.
8 - Second paragraph, could you reference the importance of accessability of information in dissemination processes.
9 - The rationale given for no involvement - could you add a reference to show that finding people from extremely rare diseases for involvement is hard.
10 - A reference needed for the broad issue of technical knowledge.
11 - Also a reference is needed for the point that children can act as researchers.

Pg 12
12 - A line with a reference is needed were you discuss that data saturation was not reached. (second paragraph).
Conclusions - Fist paragraph, could say a little about how lay REC members could help with appreciating the issues you address in the paper?

Pg 13
13 - Fifth line down - 'Lay friendly' could be replaced with 'plain english' (in line with the language used in the NHS/NIHR) but this is just my view.
Thank you for letting me review this paper. I think it makes an important and much needed contribution to the expanding field of public involvement and ethics.

Level of interest
Please indicate how interesting you found the manuscript:
An article of importance in its field

Quality of written English
Please indicate the quality of language in the manuscript:
Acceptable

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