Reviewer's report

Title: ‘A group of totally awesome people who do stuff’ - A qualitative descriptive study of a children and young people’s patient and public involvement endeavour

Version: 0 Date: 11 Jan 2019

Reviewer: Max Williamson

Reviewer's report:

Plain English Summary: On the whole, superb. My only (small) query is the beginning of the fifth sentence, "As not much is published about about PPI with young people...". The literature on Teenage and Young Adult PPI has been growing vastly over the last ten years, and has seen a recent boom with the completion of BRIGHTLIGHT, so I would perhaps reframe this sentence. The methods used in this paper are novel, so I would perhaps state "Including young people in PPI is a quickly growing area in healthcare research, as are the number of different ways that Clinical Research Facilities {} use PPI."

Abstract: Excellent.

Background: Very clear. I would include the median age of the Children's board along with the age range. The objectives are set out brilliantly.

Definition: Superb to see a section like this in a PPI paper. A short but real highlight.

Aim: Excellent.

Methods and People Involved: Unclear in paragraph 1, sentence 4 as to whether "dyads" implies parents and children were interviewed together (as I think it does), or between a single interviewer and interviewee. For the former, 'at request, parents and children were interviewed together' should be sufficient.

Stages and Levels of Involvement: Very clear overall, and I agree with the author's decision to not involve the Children's Board as researchers directly in this instance.

Measurement of PPI impact: No need to have the semi colon in the first sentence. The summarisation of how the impacts were derived from the interviews and tabulated is clear. From
a design perceptive, I think colour-coding the table itself may be useful, to improve it's readability.

Study Results: very clear.

Context/Process of PPI: In general, I think this section should be shortened; it covers 11 pages, and could be cut down dramatically. I would argue that the quotations from the interviewees would be better placed in an aggregated way, rather than being integrated in the text. Personally, I would like to see a supplementary table with each of the 12 descriptive summaries and their corresponding quotations in a second column, and the interviewee who said them in the third. For descriptive summaries where more than one quotation is used, additional sub-rows within each could be used for multiple comments. The discussion could then cite the quotations from this table to simplify the data presentation. If the current format is preferred, I would use quotation marks.

Discussion: I would like to see the authors discuss how this issue of 'late' involvement could be improved further; what options could/should the CCRF take as a result of this paper to improve the output of the group? In relation to the next paragraph (which is persuasively argued), would the 'Hub and Spoke' model of involvement also improve the timing, as well as the remit, of patient involvement in this area?

The Learning as reciprocation paragraph is excellent.

Surprise, underestimation and self-selection: I think the language in the second sentence could be more precise. It strikes me from the examples included in the paper that we aren't seeing a "power imbalance between adults and young people" so much as one between health professionals and their patients, which is compounded further by age difference. This interpretation may be wrong of course, but I think the authors may wish to argue their case (that age differences are the primary factor in competence judgement) a bit more precisely. Otherwise, this paragraph is very strong.

Reciprocity, incentivisation and participation: well argued.

Regular meetings, contact and feedback/ expectation setting and ground rules: The paragraph is well argued and I agree with the sentiment that the idea of organising informal contracts of work in PPI is a difficult one. I would replace the word 'dichotomous' with 'contradictory' or 'paradoxical'. I also recommend changing the title of this section to 'Flexibility vs. Rigour in PPI', or something along those lines, to neaten the wording.

Culture of PPI: Superbly argued.

Practicalities, timing and barriers, event structure; Again, no comments to be made for this.
Parents as gatekeepers, motivators, regulators, assurance: I would stress to reduce the length of this title to "The role of parents" or something similar. Otherwise, I agree with the authors' comments.

Reflections / Critical Perspective: Use Reflections only here. The authors are right to question the methods of the research, and I think they approach the issues very well.

Implications and Conclusion: I would agree that boards and committees are not also the most appropriate setting for PPI, but the authors must state that their data is only relevant to paediatrics and TYA. Other than that, the conclusions are clear and well thought out.

References and documentation: Reference 13 contains a comma between Gibson and AJ. All other aspects are good.

Overall, I think the paper describes, in excellent detail and with great insight, the issues and importance of the CCRF well. The writing is very clear and the authors should be commended for their ability to synthesise interview data with the current literature to create a really persuasive paper. However, I think the sheer quantity of interview data and conclusions thereafter necessitates some reductions to make the paper more accessible. I have proposed reducing the quotations used to a table, as I think aggregating these, and then combing the results and discussion sections, will significantly reduce the amount of work the reader needs to do to follow the argument. Overall, however, I think this is a really strong foundation on which to build a very high quality, succinct paper to add to RIE, on the lessons from the CCRF.

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