Reviewer’s report

Title: The Maudsley Biomedical Research Centre (BRC) Data Linkage Service User and Carer Advisory Group: Creating and Sustaining a Successful Patient and Public Involvement Group to Guide Research in a Complex Area

Version: 0 Date: 13 Mar 2019

Reviewer: Albine Moser

Reviewer's report:

Review Research Involvement and Engagement

Dear authors,

The paper describes the process of setting up a data linkage service user and carer advisory group. Participants were service users (focus group discussion) and researchers (survey). The manuscript is relevant and provides a good example of pioneering Patient and Public Involvement (PPI) in 'new' scientific developments. Please find below the suggestions for improvement.

ABSTRACT AND PLAIN ENGLISH SUMMARY:

The Abstract and Plain English Summary are the same. The abstract should be written in scientific terms, e.g. method: goal, design, participants, data collection and analysis. In the results section the main categories should be provided. Concerning the Plain English Summary the conclusion should be simplified.

BACKGROUND

The authors refer to very few systematic reviews about the positive impact of PPI. However, there have been more than 20 systematic reviews on PPI in research. It would strengthen the background to cite more of them (or at least most cited ones), for example Shippee and colleagues (2015) Patient and service user engagement in research: a systematic review and synthesized framework, HEX, Domecq and colleagues (2014) Patient engagement in research: a systematic Review, BMC Health Service Research. Also the following review might be suitable to cite Manafo and colleagues (2018) Patient engagement in Canada: a scoping review of the 'how' and 'why' of patient engagement in health research. Health Research Policy and Systems.
There should be reference to the theoretical background of PPI such as the ladder of participation by Sherry Arnstein (1969).

The authors might also provide a definition of PPI so that it is clear for an international readership.

Line 112, page 2, the authors state that there is very little guidance on how to set up and sustain PPI groups concerning data linkages. This statement is barely supported by the literature. There should be a strong identification of the knowledge gap. If there is no literature on PPI in data linkage research - this is great to do new research - but there should be a review of proxy literature to provide the current state-of-the-art of scientific knowledge which should lead to the knowledge-gap. Then the research question should follow - which is missing. Please add it.

METHOD

In the method the process of PPI is in detail described. However, this should be one heading within the method section. It improves the manuscript if you follow the authors guidelines.

Please start with aim, design and setting.

Continue with the characteristics of participants. As it is written now a lot of information is provided on recruitment but only patients are described not the researchers who participated in the survey. What were the inclusion and exclusion criteria for participation in this study?

Process and data collection. Here the authors might want to integrate the working process with the advisory group (in a shorter way). As I understand it there is a qualitative (patients/focus group discussion) and a quantitative part (researchers/survey) please provide all relevant information timing, construction of questioning route for the focus group discussion, construction and validation of the survey, etc. Please provide the focus group questioning route and survey in a box. How did you deal with data saturation/recording/transcription/data entry?

Information about the analysis and trustworthiness is completely missing. How do you secure credibility and transferability and validity?

There is little information about research ethics. Was it reviewed by a research board, did participants sign informed consent etc.

I was also wondering what was the involvement of the group, especially patients and carers in writing this manuscript? Where they involved besides providing information?
RESULTS

This section should start with a description of the participants in the study.

The first heading does not really cover the meaning of the results. It might be helpful to work with a main category and sub-categories. Next, it is a summary but not really a description of experiences. Short quotes or only words are used, but they are used as result and not to illustrate results. The quotes used should be longer and context rich to provide meaningful information.

The second heading is about a survey with researchers. The survey instrument and analysis is not explained, as a consequence, it is not easy to understand the quotes. It seems that in the survey open questions were used and no measurements, right?

Since there is fragmented information about data collection, data collection tools and no information about the analysis it is very hard for the reader to 'get' the results.

DISCUSSION

The discussion should start with the goal and then summarize the main results. As the first paragraph it is written now it seems a kind of conclusion. Line 303, page 12 the sentence 'From the perspective of the group members, the factors….' This sentence is not supported by the results. Is it a new results or already conclusion? Line 328 0 340 - it seems new results are presented because it is not positioned in current scientific literature.

The findings of the survey are rarely discussed and positioned in current scientific literature. Please add.

The authors make an interesting difference about the monetary costs and non-monetary benefits. However, the benefits as stated here are not supported by the results - please add the missing data in the results section. It would be interesting to reflect on what the literature says about value of PPI to bridge costs and benefits?

It might strengthen the manuscript if the authors reflect on the level of actual participation in research about data linkage using Arnsteins ladder of participation and what might be the theoretical implications of this study to develop the ladder further. In addition, the authors should reflect about what is necessary to move to the partnership or control level and is it necessary?

A methodological reflection is missing: what is the strengths and what are the weaknesses of this study and how did you compensate?

It would strengthen the discussion if the authors show what is the 'new scientific knowledge' and how does it contribute to advance PPI. Also recommendations for research and for researchers, who want to start PPI in a complex scientific area would improve the discussion.
The last sentence of the conclusion might be left out since it has already been proven in many publications. It reads as a personal commitment.

REFERENCES

Be aware that no [ ] should be used when citing the assessment date of online data.

Level of interest

Please indicate how interesting you found the manuscript:

An article whose findings are important to those with closely related research interests

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Please indicate the quality of language in the manuscript:

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