**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:** 17 Feb 2019

**Reviewer:** Carlin Rafie

**Reviewer's report:**

I appreciate the opportunity to review this manuscript. It describes the formation and initial evaluation of a service user/caregiver advisory group as a mechanism for providing Patient and Public Involvement in data linkage research. The application of stakeholder engagement in this type of research is timely and important, as the issues related to linking various data sets for research, including the protection of personal health information, should consider the perspectives of patient stakeholders.

Although the authors make clear that this was a pilot project, the manuscript could benefit from increased description of the process, and program evaluation methods. I have outlined my recommendations below:

**ABSTRACT:**

You highlight the single result of breaking down barriers between service users/carers and researchers. The abstract would benefit from adding findings from the Advisory focus groups and researchers in this section.

**PLAIN ENGLISH SUMMARY:**

Line 38 - 39: You state this conclusion in several locations in the document, yet the results, as presented, do not specifically demonstrate this. I recommend including a stronger discussion of how the results establish the conclusion of barriers being broken down between researchers and patients/carers.

**BACKGROUND:**

* You provide a general description of the reason for PPI in data linkage research. What is not discussed is the importance of engaging stakeholders in research question development and
design to the relevance of the research to the people who will ultimately be impacted by it? Could you include information about this.

METHODS:

The methods section is lacking some information that will be of interest to the readers. I have highlighted some points below:

* Provide more information about the consent process for participants. Were they compensated?

* Can you provide more detail on what researchers were told about the function of the advisory group.

* Training:
  o You provided a description of the training the advisory group received about data linkage. Can you provide information on what they were told about their role as an advisory group.

* Frequency of Meetings:
  o Did you document what happened during the researcher presentations?
  o Did you evaluate if the group's recommendations to the research being discussed was acted upon? Was this communicated to the advisory group?

* Evaluation:
  o Provide more detail about the focus group: Detail the lines of questioning (particularly interested if you asked about their perspectives on the researchers acting upon their advice). Who led the focus group. Was it recorded and transcribed? Notes taken? How was the data analyzed?
  o Provide more information about the research survey contents.

RESULTS:

* Need more description of the people that composed the Advisory group - how many service users and carers, age, etc.

* Line 214, should this read "…aware of the OBJECTIVES (rather than objections)…"?
* I am wondering if you had some a priori expectations for what the information coming from the advisory group would be used for by researchers? Did this align with what they indicated they used it for in the survey?

DISCUSSION:

* Line 303 - 307 - This summary statement is not based on any information in the results sections. Can you provide a little more detail in the results that substantiates this statement. Providing more detail about the questions asked during the focus group in the methods section would also help the reader understand the source of this conclusion.

* Line 345 - 347 - I am not sure that you have adequately substantiated this statement. On what basis are you concluding that setting up this advisory group broke down barriers between these two groups, or "improving" perceptions of data linkage research. This might be inferred by the fact that the two groups talked to each other, and each felt they got something out of the interaction, however, you have not outlined what the "barriers" were initially and how you measured them to know that you have broken them down. The trainings certainly did increase the advisory group's understanding of data linkage research, but I am not sure you have demonstrated that participants improved their "perceptions" of data linkage. You provide no information about what their perceptions were before and after the project.

CONCLUSION:

Line 350 - I am not sure that this paper provides much of a description of the groups experience with setting up the Advisory Group. Rather, it presents a description of how the Advisory group was set up operationally, and the experience of group members and researchers.

Line 356 - 357 - Theoretically, an Advisory group whose opinions are sought and applied can maximize legitimacy of research designs and priorities. This project, however, has not provided evidence that the information gathered from the Advisory group was actually applied to the research design. Can you add further specific evidence that the engagement actually impact the research design or methods such that it increased its legitimacy.

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

**Declaration of competing interests**
Please complete a declaration of competing interests, considering the following questions:

1. Have you in the past five years received reimbursements, fees, funding, or salary from an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?

2. Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?

3. Do you hold or are you currently applying for any patents relating to the content of the manuscript?

4. Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript?

5. Do you have any other financial competing interests?

6. Do you have any non-financial competing interests in relation to this paper?

If you can answer no to all of the above, write 'I declare that I have no competing interests' below. If your reply is yes to any, please give details below.

I declare that I have no competing interests.

I agree to the open peer review policy of the journal. I understand that my name will be included on my report to the authors and, if the manuscript is accepted for publication, my named report including any attachments I upload will be posted on the website along with the authors' responses. I agree for my report to be made available under an Open Access Creative Commons CC-BY license (http://creativecommons.org/licenses/by/4.0/). I understand that any comments which I do not wish to be included in my named report can be included as confidential comments to the editors, which will not be published.

I agree to the open peer review policy of the journal