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: 28 Feb 2019

Reviewer: Yamile Jasau

Reviewer's report:

The article describes the set up an advisory committee for data linkage in mental health research projects. The advisory committee was composed of 6 people with lived experiences in mental health (patients and carers) who had used NHS services. The aim of advisory group was to support researchers and their studies by providing service user/carer feedback and advice in order to create more relevant projects, promote dialogue between service users/carers and researchers, and identify research priorities. The authors found that both, service users/carers and researchers, valued the meetings and benefited from the shared knowledge and constructive criticism.

General comments

- In general, the article is easy to understand and the concepts are explained clearly. However, the authors need to review article for long sentences, grammar, and punctuation. Some sentences, which will be pointed out below, need to be modified to facilitate the understanding of the ideas that the authors are trying to convey.

- Considering the PPI nature of this article, was the GRIPP2 checklist criteria used? If it was, please add it to the Introduction and References. (Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ (Clinical research ed). 2017;358:j3453).

- The word "appropriateness" used in the Abstract, Introduction, Discussion, and Conclusion is a very subjective term and lends itself more towards ethical considerations of the research project. The word should be removed or exchanged for another word such as "relevance".

Abstract

Background:
- The aims need to be described here.

Method:
- Describe the steps followed to achieve your aims.
- Briefly describe how the advisory was set up and how the service users and carers were recruited.

Results:
- What barriers were broken down? It would be easier to follow if it said, for example, "the group promoted dialogue between service users/carers and researchers".

Conclusion:
- "Pool" does not fit a group of 6 people.
- Is it an "expert" group? If I were to read only the abstract, I would think of a group of experts in data linkage (i.e. professors, researchers) and not service users/carers.

Introduction
- The introduction is easy to follow, going from general to more specific aspects of PPI and data linkage and ending with the aims.
- The rationale for the advisory group is well explained, outlining the lack of resources and guidance for setting up PPI groups in data linkage.
- Line 87-89: the flow of the sentence seems interrupted at "and a systematic review". For example, this part could be written as "... contributes to feelings of empowerment and value"
- Line 88: I suggest the authors add "awareness" before "acceptance of research". It is very difficult for the public to accept research they are not aware of or implications/science not properly understood.
- Line 93: A new sentence can begin at "for example, health data..."
- Line 98: Remove "public acceptance". It is PPI in data linkage which ensures legitimacy rather than public acceptance.

- Line 119-123: This sentence is too long and not easy to follow. It could be broken down into 2 sentences.

- Line 126: Following "service users,..." the sentence would be clearer if it said "with their perspectives being considered..."

Methods

- A description of the demographic information of advisory group is needed. Of the 6 service users/carers how many were men and how many were women? What was the age range? Which mental illnesses did the group have experience with (either as patient or carer)? How many years of experience did they have as service users/carers in mental health?

- The authors need to restate that the data linkage research projects were in the area of mental health. For example, sentence 177 just mentions "data linkage projects" which might lead to confusion in terms of data linkage projects in other areas. Similarly, did the email newsletter feature only mental health data linkage research (line 188)?

- The methods successfully address aims i, ii, and iii, however, the authors do not mention how or if the group assisted in designing studies, preparing grant applications, disseminating findings, or identifying research priorities.

- If research priorities were identified, what methodology was used to identify them?

Results

- Please provide examples of:

  - Questions, feedback, or opinions from the advisory group to the researchers.

  - Other frequent questions that the researchers asked the group.

-Please provide 1-2 more examples of the research projects presented to give the reader a better idea of the type of studies reviewed by the advisory group. For example, did the researchers present new studies or were some of these ongoing studies with researchers seeking ideas for improvement?

- Line 214: "objections (objectives) and purpose of the group".
Discussion

- Line 328: What are possible ways to measure the group's impact on research studies? Could it be measured, for example, by the number of accepted ethics applications or grants won?

- Line 335: Very briefly explain the reasons why a formal qualitative evaluation was not conducted.

- Line 345: Include specific barriers between researchers and service users/carers identified in the literature.

Summary

Overall, it is a very interesting article, which provides insight into the development and feasibility of service users/carer advisory group for data linkage research.

As the authors mention, guidance for the set up of PPI groups for research studies is lacking. This paper offers one way an advisory group can be created and the benefits it provides for its members and researchers. The experiences of the researchers with the group need to be highlighted to other researchers in order to promote additional advisory groups in different research areas.

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