Author’s response to reviews

Title: EXPLORING EXPERIENCES OF PEOPLE PARTICIPATION ACTIVITIES IN A BRITISH NATIONAL HEALTH SERVICE TRUST: A SERVICE USER-LED RESEARCH PROJECT.

Authors:

Adrian Curwen (adrian.curwen@gmail.com)
Jane Fernandes (fernandesjane141@yahoo.co.uk)
Rachael Howison (Rachael.Howison@nhs.net)
Paul Binfield (paul.binfield@nhs.net)
Frank Röhrich (frank.rohrich@nhs.net)
Domenico Giacco (d.giacco@qmul.ac.uk)

Version: 1 Date: 01 Oct 2018

Author’s response to reviews:

1/10/2018

Dear Editorial Team

I have modified the manuscript in order to incorporate the editorial requirements as per your email received on 25/09/2018.

Many thanks

Domenico Giacco
24/09/2018

Dear Editors

Many thanks for your interest in this paper and for your helpful comments, which gave us the opportunity to clarify some points in the paper. Please find below our response to your comments. The related modifications to the paper are highlighted in yellow in a submitted version of the paper. We also submitted a clean version of the paper.

There appears to be no patient/user involvement in the paper itself, nor in the design of your research, despite the use of patient co-researchers to deliver it. How was it decided what training the user researchers needed, and how was it decided what themes they would explore? It is quite legitimate for any piece of research to be carried out entirely by professional researchers, but in a journal such as ours, the reasons for not involving patients in a study explicitly exploring patient viewpoints do need to be covered. The most obvious question for the reader is why are the patient co-researchers not co-authors? Or if they are, then we would urge you to state this clearly in the paper early on, and clearly (if not early) in the abstract and the lay summary - and quite possibly in the title too?

Authors’ response:

We would like to clarify that most of the authors, i.e. Curwen, Fernandes, Howison and Binfield have lived experience of mental health problems and of using secondary mental health services, whilst having no experience of conducting research before carrying out this study and no professional research qualifications.

Descriptions of the active role of service users have now been added to the text in several points: a) Abstract, lines 10 and 13-14; b) Lay summary, lines 4-7; Methods, page 5, lines 1-4; page 5, lines 30-31; page 6, lines 1-10).

As now specified in the text, all decisions on how to adapt a previous training to research interviewing to the needs of service users with an interest in research, but no work experience or formal qualifications to carry out research, were made by the research team (involving these members with lived experience) and discussed and agreed with a larger group of service users (N=15) in workshops. The topic guide which informed the interviews was developed entirely during these workshops and based on theme suggested by service users. Curwen, Fernandes and Howison carried out the practical research activities, the interviews and the analysis of data under the supervision of Giacco and Rohricht.
The title of the paper is not reflected in either the professional abstract or the "lay" summary, both of which are vague about what the research sought to find or explore. That in turn means that the lay abstract needs sense-checking from someone not involved in the study and not aware of what it was about. This is a role that may sometimes be assigned to a patient/public co-author, although it is not a requirement, and does in itself qualify a patient to be listed as a co-author. However the lay summary at present seems to be rewrite of the academic abstract (which as already noted, lacks some precision and clarity), rather than a fresh approach at writing a summary, hence the need for sense-checking from an external viewpoint (ie a lay reader's perspective). On the whole the paper itself is not always clear whether the work of the co-researchers has been evaluated and/or validated - can the academic community trust these results?

Authors’ response:

We have completely revised the lay summary and the abstract to clarify aims of the project and service users’ involvement. The lay summary was sense checked by a groups of service users who are currently working with the PP team.

The service user researchers received weekly and ad-hoc supervision of their research activities by Giacco and Rohricht. Giacco was present during the analysis and coordinated the paper writing efforts. We believe that the presence of experienced academic researchers and the close supervision has made sure that the findings can be trusted and are sound from a methodological point of view.

However, due to funding and time constraints for this project, there was no formal evaluation or validation of the work of the service user researchers. This was cited as a limitation of the project (page 14, lines 19-21).

Lastly we would suggest that the methodology is not especially "innovative." For example, the Macmillan Listening Study in the UK used a very similar methodology (although for a different topic), and that was in 2004-05. As we wish to encourage genuine patient involvement in research, we are biased in making this suggestion, but perhaps "under-used" (or "rarely-used") might be less debatable (and more useful in the wider picture) than "innovative"? The reality that user co-researchers have been employed on other studies is one reason why we as Editors feel that this study is valid and the findings can be trusted, but we are not sure that the paper itself makes this clear or address specifically this issue - although that is perhaps an area where peer review could generate useful discussion.

Authors’ response:
As suggested, we have specified that this methodology is rarely used in health care research rather than suggesting that it is completely innovative (see page 14, lines 4-7). We have referenced the paper describing service user involvement in the Macmillan Listening Study [14].

We hope that our responses to your comments and the related modifications to the text have improved this paper enough to warrant consideration of external peer review.

Please do not hesitate to contact us in case there is a need for further clarifications.

Kind regards

Domenico Giacco

On behalf of all authors