Reviewer’s report

Title: Being involved in research as a collaborator with experience of a prenatal diagnosis of congenital heart defect in the fetus: a qualitative study

Version: 0 Date: 08 Oct 2019

Reviewer: Raksha Pandya-Wood

Reviewer's report:

Abstract

Thank you for offering me the opportunity to review this interesting paper which raises ethical issues arising from PPI work.

This study explores the experiences of nine parents who were interviewed. The focus of the subject area is ethical issues which arise out of PPI work.

Parents were involved for over a year and this paper shares their experiences of why they participated but I am struggling to understand if they were simply participants or whether they were the public involved in helping with the study or both. As I read on, I could see that they are indeed talking about public involvement motivation but this needs to be clearer and stated in the abstract and the plain English Summary.

The study is not describing patient and public involvement UK readers might understand it, in the abstract in my opinion, it is discussing participation. The language is confused and I found it hard to follow how it was public involvement. This would be fixed with a simple definition of public involvement in research.

The article confuses PPI with qualitative research and I find it hard to understand, apologies if I am missing something here. For example they use the following terms interchangeably:

- Respondents,
- patients and the public,
- Public involvement,
- research partners,
- peers,
- participants

I just can't understand why all the different terms are used. I also struggled with the term 'prenatal diagnostics'.

Plain English Summary

I struggled with the same sorts of issues in this section too. Are the patients and the public, the parents
involved or are they participants or research partners in the sense of PPI or both? This is such a central part to the paper and I feel it needs to be absolutely clear so that readers can see the value of what is to come. Scholars in the field of PPI work already know that there is a lot of inconsistency in the language used to describe patient and public involvement (PPI) work and research. This journal's main readership concerns those working in PPI roles so this is essential to get right.

Page three line 65, are the patients and the public conducting the research as well? Have the researchers adopted a participatory action research methodology? This is not clear.

Is this paper trying to share the experiences of parents as participants in the research study or are they asking parents to share their experiences of involvement in research (as patients and the public involved). If it's the latter, they will need to define what they mean by involvement. They say they have used the GRIPP checklist and Oliver et al. (2008) but do not offer a definition of what involvement means to them.

Some of the text from Oliver and GRIPP needs to be described in the actual paper and not in the supplementary files - please add these important details so that the reader can see how they relate to the paper content.

Page seven and eight. The same sorts of issues are coming up. Are the research partners respondents/participants/research partners? They need to explain/define the terms they have used and then use them consistently. These issues are making it very hard for me to read and understand the thread of the story about what they did or the focus of the paper.

Page ten - line 199. If this study is reporting on patient and public involvement then I am unsure why they have ethical approval? If the study is interviewing people after the main study ended, then is that not then a new study? Maybe my question here stems back to the focus of the paper, is it PPI or research? I am confused.

The quotes are too long especially page thirteen-fourteen and they are not succinct. It needs to be explained that the research was carried out in a different language, if it was, and then that it was translated.

I likely the data that was presented, that people are emotionally connected to their PPI role which comes from their experience. Many researchers in the field of PPI work, would resonate these findings. Could the researchers reference another study that had similar findings? This would validate this paper's findings in the context of PPI studies.

I liked the conclusion in the sense that they acknowledged their limitations.

General message.

Please restructure the paper, using consistent language and resubmit. I would be happy to read it again once these fundamental aspects are clearer.

There are too many typos.
Level of interest
Please indicate how interesting you found the manuscript:

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

Quality of written English
Please indicate the quality of language in the manuscript:

Not suitable for publication unless extensively edited

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