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: 26 Sep 2019

Reviewer: Isabel Boyer

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The findings of this small qualitative study highlight the importance of providing support for parents who have had distressing experiences with prenatal diagnosis and/or terminations.

This paper appears to be a by-product of another qualitative research project in which the same "research partners" ie parents worked in focus groups and workshops to "explore and develop interventions that offer informational and emotional support to expectant parents presented with a prenatal diagnosis". The paper I am now reviewing is the result of further research through semi-structured interviews with those parents about their experience of working on that project. I will continue on that assumption though the structure of the paper confuses what I regard as two projects.

It is only the Data collection section that describes the interviews with the research partners on which this paper seems to be based. Are the findings of the activities in Table 1 being reported separately?

The sample size is very small, arguably too small to reach valid conclusions. The sample group was 10 at the start, but it appears that one person could not continue so 9 completed the study. It is also implied that these were partnered parents, so represented only 5 diagnoses.

Some of the aims of the project and the terminology is confusing to the English reader for example line 125 "We commissioned a PPI research project"; this phrase does not make sense in English.

There a substantial number of minor errors of English grammar eg in line 327 "A need for building and establishing trust between collaborators were seen as necessary" and line 355 "Indeed, research report that these persons appreciate peer support…”

Despite the flaws in this write-up, the authors make an important point about the need for sensitivity when involving public and patient representatives in studies which they may find upsetting because their prior experience. The wellbeing of these research partners must be paramount, with support in place in advance and contingency plans both for the individual and for the PPI work of the project.
Level of interest
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An article of importance in its field

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

Not suitable for publication unless extensively edited

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