Reviewer’s report

Title: ‘A group of totally awesome people who do stuff’ - A qualitative descriptive study of a children and young people’s patient and public involvement endeavour

Version: 0 Date: 24 Jan 2019

Reviewer: Simon Stones

Reviewer's report:

Review comments to authors

Thank you for the opportunity to review this interesting article on the important topic of patient and public involvement with children and young people. While the authors present an interesting study of their Children's Board, there are a number of issues with the manuscript in its current form, which I’ve addressed below in the order of sections to aid subsequent interpretation by the authorship team.

The manuscript would benefit from a clearer, more cohesive narrative, particularly within the results and discussion section, which could be married together to improve the flow for the reader.

Plain English summary

A reasonably good Plain English language summary is provided; however, I think this could be improved by removing some unnecessary points, and adding in a few extra areas, such as key overarching findings, since the summary doesn't touch on those, and these are fundamentally the main things to take away from the article.

Abstract

The abstract succinctly described the study undertaken. However, the results section is somewhat lacking in results! A brief summary of findings would be very useful here.

1. The aim seems somewhat long-winded and difficult to read on the first occasion. It would read better as 'To explore the views and experiences of young people, parents and staff involved within the Children's Board at CCRF.'

2. This point relates not only to the abstract, but generally throughout the manuscript. 'Children' and 'young people' are used interchangeably throughout (even within the manuscript), and so I would suggest referring to 'children and young people' which could be abbreviated to CYP.
3. I would suggest moving the reference to the GRIPP2 checklist to the methods section. This would enable you to provide a very brief results summary of content.

4. The first centre of the discussion paragraph is quite long-winded and difficult to interpret. This could be simplified to 'Mechanisms by which CYP are involved in research should be considered from the outset; considering appropriateness and contextual features with each group.'

5. The abstract doesn't explicitly state the number of interviews undertaken - Line 36 suggests it could be 9 (5+2+2), yet the results sub-section of the abstract states 'twelve descriptive summaries', and the methods section later on in the manuscript states 7 - so some clearer more explicit definitions would be good.

Introduction

1. The introduction is sparse on references to the existing literature and needs amending (e.g. progression of PPI, commitment from external bodies, aim of PPI, early papers on value, latter papers on impact, legal statements about rights of young people etc.)

2. I made a point in the abstract section about the use of children and young people. Here the term adolescent is used (though suggesting hereafter that young people covers all of these terms). I would suggest identifying one term and sticking with it (which means consistent use in the abstract). I would also suggest that you define who you are classing as children and adolescents, referencing appropriate literature from bodies such as the World Health Organisation (WHO). Young people up to 16 years? Or according to WHO, children and young people refers to those up to 24 years (while adolescents typically refers to those 10 to 19 years old). Very clear definition as to what you mean will help the reader interpret 'who' you are referring to.

3. Brief description as to 'why' PPI methods/techniques effective for adults cannot be translated for CYP would be useful for the reader - a simple list could be effective.

Background

1. The inclusion of 'background' as a header is confusing, given that introduction and background are more or less the same. I'd suggest the use of a more appropriate sub-title here, such as 'The Children's Non-Executive Research Board' or something similar.
2. What is the PPI mandate? This could be referenced.

3. Who did the response spark an idea with - CYP? Staff?

4. End the sentence of line 71 at group. Creating a separate sentence which says (something along the lines of) 'Subsequently, a survey canvassing opinions from CYP was conducted.'

5. Again, please consistently use the correct term for children, young people, CYP etc (line 71).

6. Line 74/75: That's quite an age range for one board! How were the younger CYP (particularly that the 5-year-old age group) supported and engaged!?

7. Line 77: Present these as a list.

8. Line 78: Amend to 'the suitability of a metabolic measurement kit for paediatric use.'

9. Line 83: INVOLVE should be capitalised.

10. Line 85: Change : to ;

11. Line 87: This is the first time you use 'participant' - are you referring to CYP? Keep things clear I would suggest. Also when you begin to start using participant, people can often think away from PPI to more traditional forms of research where CYP are merely viewed as research participants. This seems the case on line 88, 'explore children's views of research participation' - great if that was also the case, but then that changes the tone of the overall paper, given that this was to look at 'PPI'.

12. Line 89: It feels a little confusing having the aim of CHEER here and then also the aim of the research in this paper (also CHEER) - with not all the same things mentioned. Inclusion of 'training in primary research for CCRF staff' also doesn't seem to be related at all to the tone of the paper on PPI?
Definition

1. This section would be really useful further up in the paper, before some of the terms are used.

2. Line 97: I'd also suggest changing this to: 'the Children's Board could be viewed equivalent to a Young Person's Advisory Group', referencing the GenerationR YPAG Framework which were the first of their kind established in the UK.

Aim

1. See comment made about the aim in the abstract - this could be simplified so that it is easier for the reader.

2. Line 105: Reference to the GRIPP2 checklist shouldn't be in the aim section; rather in the methods section.

3. The last sentence of the aim points towards another methodological approach that isn't mentioned in this study. 'What works, for whom, why, and in what circumstances' is a classical quote related to realist evaluation/synthesis, which has not been undertaken in the current study.

Methods & People Involved

1. This section should be simply labelled 'Methods' (& people involved isn't necessary), with subsequent sub-sections following.

2. Here you clearly state 7 interviews with 9 people (see comment earlier in the abstract to make this clear). Also, listing the number of participants usually comes in the results section during the opening paragraph.

3. Re-word the section of 'the recruitment plan was to...' - since this has already been done. I would suggest changing to 'Everyone who had participated in the first and/or second Children's Board meeting were invited to take part in the study'.
4. Line 122: Needs checking. Suggest 'the collection of this data was deemed too intrusive and unnecessary in addressing the aims of the study'. Reference to only collecting relevant data that will be used in the study is an important ethical consideration which could be referenced here.

5. There is no mention of who/how many people conducted interviews, and the location of these?

6. While analysis can only be done with the given data, it is a little disheartening to read on line 134/35 that much of the analysis comes from staff interviews (simply because more staff were interviewed), especially given the focus of the paper! This for me stands out as a methodological issue with the conduct of the study.

Stages and level of involvement

1. The end of the first sentence should go on to say that other CYP were involved in shaping the study, such as reviewing the protocol, participant information sheets and so on.

2. What would be useful to describe on line 140 is what the recommended changes were… reporting of these would be useful.

3. Line 142/43 - this is something for the discussion section.

Measurement of PPI impact

1. From line 148 onwards, these would be best placed in the results/discussion, since these are still the methods section.

Study results

1. Some narrative is needed in this section. E.g. Contextual factors included: [list]. Process factors included: [list].

2. I have some reservations about the results, particularly in Reciprocity, incentivisation and participation, given the first section on payment seems to come only from staff. It begs
the question as to how representative is your study of both the staff and children/families? Clearly you can only report on the data you've collected, but the findings must be interpreted carefully and clearly.

3. Line 347 - should read parental involvement?

Discussion / reflections

1. Some nice references to the existing literature, critiquing the findings and approach of the CCRF Children's Board.

2. The authors clearly identify limitations with their research.

3. Some may argue that quantifying statements as alluded to on line 541 goes against the methodological approach taken in this qualitative study, particularly with such a small sample size. I would be cautious of using this as a positive of the study because I feel there's limited merit.

4.

References

1. The reference bibliography needs updating, as they are not in ascending numerical order in place of the text.

2. References need to be formatted in the correct journal style. The current references are inconsistent (e.g. year sometimes in brackets, sometimes after author list, sometimes after journal name).

3. Each reference also needs to be checked that all of the relevant content is present. For example, 2-Bate et al has no year date.

4. References with hyperlinks need to be properly formatted with the correct information.
List of abbreviations

1. NIRH should read NIHR

2. Person’s should have an apostrophe

Consent for publication

Participants should have consented to having their data published anonymously. This should be mentioned here.

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Please indicate how interesting you found the manuscript:

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