Author’s response to reviews

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

Authors:

Faye Forsyth (fc349@cam.ac.uk)

Caroline Saunders (caroline.saunders@addenbrookes.nhs.uk)

Anne Elmer (anne.elmer@addenbrookes.nhs.uk)

Shirlene Badger (sb491@cam.ac.uk)

Version: 1 Date: 01 Mar 2019

Author’s response to reviews:

18 Feb 2019

Dear Editor

Re: Point by point response to the reviewers

Please find appended point by point responses to the reviewers whom we would like to thank for their detailed and helpful comments.

Yours Sincerely,

Faye Forsyth

Reviewer #1

The beginning of the fifth sentence, "As not much is published about about PPI with young people...". The literature on Teenage and Young Adult PPI has been growing vastly over the last
ten years, and has seen a recent boom with the completion of BRIGHTLIGHT, so I would perhaps reframe this sentence. The methods used in this paper are novel, so I would perhaps state "Including young people in PPI is a quickly growing area in healthcare research, as are the number of different ways that Clinical Research Facilities {} use PPI."

Above changed as per reviewer’s suggestion.

I would include the median age of the Children's board along with the age range.

Above changed as per reviewer’s suggestion.

Methods and People Involved: Unclear in paragraph 1, sentence 4 as to whether "dyads" implies parents and children were interviewed together (as I think it does), or between a single interviewer and interviewee. For the former, 'at request, parents and children were interviewed together' should be sufficient.

Above changed as per reviewer’s suggestion.

Measurement of PPI impact: No need to have the semi colon in the first sentence. The summarisation of how the impacts were derived from the interviews and tabulated is clear. From a design perceptive, I think colour-coding the table itself may be useful, to improve it's readability.

Above changed as per reviewer’s suggestion.

Context/Process of PPI: In general, I think this section should be shortened; it covers 11 pages, and could be cut down dramatically. I would argue that the quotations from the interviewees would be better placed in an aggregated way, rather than being integrated in the text. Personally, I would like to see a supplementary table with each of the 12 descriptive summaries and their corresponding quotations in a second column, and the interviewee who said them in the third.
For descriptive summaries where more than one quotation is used, additional sub-rows within each could be used for multiple comments. The discussion could then cite the quotations from this table to simplify the data presentation.

Above changed as per reviewer’s suggestion but split into 2 tables.

I would like to see the authors discuss how this issue of 'late' involvement could be improved further; what options could/should the CCRF take as a result of this paper to improve the output of the group? In relation to the next paragraph (which is persuasively argued), would the 'Hub and Spoke' model of involvement also improve the timing, as well as the remit, of patient involvement in this area?

Addition of sentence on how this could have been improved. The Children’s Board has now been incorporated into a larger project across the BRC so would not be able to test the Hub and Spoke model in this group.

Surprise, underestimation and self-selection: I think the language in the second sentence could be more precise. It strikes me from the examples included in the paper that we aren't seeing a "power imbalance between adults and young people" so much as one between health professionals and their patients, which is compounded further by age difference. This interpretation may be wrong of course, but I think the authors may wish to argue their case (that age differences are the primary factor in competence judgement) a bit more precisely. Otherwise, this paragraph is very strong.

Changed as per reviewer’s suggestion – this is an important facet that we had not considered. Not all the facilitators were healthcare professionals but the majority were and at some meetings, the nurses wore uniform which would have accentuated this differential.

I would replace the word 'dichotomous' with 'contradictory' or 'paradoxical'. I also recommend changing the title of this section to 'Flexibility vs. Rigour in PPI', or something along those lines, to neaten the wording.
Above changed as per reviewer’s suggestion.

Parents as gatekeepers, motivators, regulators, assurance: I would stress to reduce the length of this title to "The role of parents" or something similar. Otherwise, I agree with the authors' comments.

Above changed as per reviewer’s suggestion.

Use Reflections only here

Critique now added

Implications and Conclusion: I would agree that boards and committees are not also the most appropriate setting for PPI, but the authors must state that their data is only relevant to paediatrics and TYA. Other than that, the conclusions are clear and well thought out.

Above changed as per reviewer’s suggestion.

References and documentation: Reference 13 contains a comma between Gibson and AJ. All other aspects are good.

above changed as per reviewer’s suggestion.

Reviewer #2

It would be helpful to understand further why content analysis was used; justifications are made clear for the use of QD, and further clarity around why content analysis was chosen would be welcomed.
Further detail regarding the rationale for using content analysis has been added.

Noticed a typo in lines 121-122.

Above corrected

Long sentence in lines 409-414, consider re-working to aid comprehension?

Above reworked

Line 460 was unclear.

Above reworked

Lines 538-545 might work better in the methods section rather than towards the end of the article. I think it would make the methods process more transparent to the reader at an earlier point.

Changed as per reviewer’s suggestion.

Reviewer #3

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.

above revised in line with the reviewers suggestions
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.

Above revised in line with the reviewers suggestions

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.'

above revised in line with the reviewers suggestions

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

Revised throughout

Revised in line with reviewers suggestion

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

Removed

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.'

Above revised in line with the reviewers suggestions
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

Wording and additional file 1 revised to make this more explicit

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.)

Revised to reference all points

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

Change made to CYP throughout, definition from United Nations Convention now incorporated.

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.

References to papers that demonstrate the challenges of engaging CYP have now been included.
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.

This has not been changed as the authors wish to adhere to the GRIPP 2 checklist structure.

2. What is the PPI mandate? This could be referenced.

A link to the website has been included

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

This has been clarified and ‘staff’ added

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.'

Revised in line with reviewers recommendations

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

Revised throughout

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!?

Details and context have been added;
Line 77: Present these as a list

Revised in line with reviewers recommendations

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

Revised in line with reviewers recommendations

9. Line 83: INVOLVE should be capitalised.

Revised in line with reviewers recommendations

10. Line 85: Change : to ;

Revised in line with reviewers recommendations

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'.

Removed reference to participant

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

This has been revised for clarity and reference to training removed.

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

This has not been changed due to the authors wish to adhere to the GRIPP2 checklist

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.

Revised in line with reviewers recommendations

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

Simplified as per the reviewers recommendation

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

Removed and relocated as suggested.

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

Some revisions made however have kept in line with GRIPP2 checklist

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.5

As before, this has been revised for clarity.

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'.

Revised in line with reviewers recommendations

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.

Revised in line with reviewers recommendations

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

Revised to add more detail and context
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.

This has been revised, and we have highlighted in the methods section why we included numerical counts in order to enable readers to see how ‘representative’ the themes are of the collective interviews in terms of the sub-groups.

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.

Revised in line with reviewers recommendations

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

Revised in line with reviewers recommendations

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

Relocated as per the reviewers recommendation

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

This has not been changed to ensure adherence to the GRIPP2 checklist
1. Some narrative is needed in this section. E.g. Contextual factors included: [list]. Process factors included: [list].

Revised in line with reviewers recommendations

2. I have some reservations about the results, particularly ix 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.

The authors are very conscious of the small, diverse and unequally distributed sample and have endeavoured to be as transparent as possible by labelling, adding numerical counts and where possible presenting a quote from each of the sample groups (CYP, staff and parents). Bold statements and interpretations have also been avoided and the data has principally been compared and contrasted to the current literature base.

3. Line 347 - should read parental involvement?

Corrected

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

Corrected

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.

Corrected

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

Corrected

NIRH should read NIHR

Corrected

2. Person's should have an apostrophe

Corrected

Consent for publication: Participants should have consented to having their data published anonymously. This should be mentioned here.

Added

Reviewer #4

Please add a couple of lines to summarise the 'findings'. It explains what you did, but not the key findings

Previously highlighted by reviser 3, now corrected
Page 3, lines 49-62 contain a set of statements without references to support them, such as line 53-55, line 55-56, line 56-57 and line 59-61. Please expand on your sentence from line 61 about adult PPI methods not translating to young people - why is that?

Previously highlighted by reviser 3, now revised

Practical details were missing about how the Children's board operated - these are details that are often missed in PPI publications, yet are crucial to readers' who wish to know more about how things are done. Please add some detail about the board - e.g. when did you hold the meetings? details on timing etc that enabled young people to attend. Details on Budget - how were the meetings funded? How did you manage the parent-child dyads in the Board - did you use break outs or were you always in one group? If word count is an issue perhaps consider using a summary table

Context and details has been added

I am not familiar with QD methodology so can not comment on the quality of the research conducted. Line 112 on Page 6 - it would be helpful to explain that seven interviews with nine people was as a result of paired interviews in some instances, as this is not explained until later.

Previously highlighted by reviser 3, now revised

A quick summary of the QD method would be helpful again this could be in a 'box' or table, but something to explain the method briefly. Page 6, line 116 - the plan was to invite everyone to interview - how many people was this?

Revised in line with Reviewer 3 and Reviewer 4’s recommendations.

Page 6 line 119 - I'd like to know more about the dyads - did you consider doing separate interviews? Why did you choose dyads? What steps did you take to reduce inhibition in the children?
Context and detail added here, the intention was to undertake separate interviews in the CYPs own home, however all participants selected to be interviewed in their own home.

Page 6 line 122 - a word is missing here.

Corrected

Page 7 line 133-135 - The staff perspective is more extensively represented. It is disappointing that the child perspective is so limited. Perhaps worth commenting on why this was the case? Did you hope to interview more children. The title of the paper led me to think there would be more from the child's perspective.

Revised in line with Reviewer 3 and Reviewer 4’s recommendations. The intention was to interview all of the CYP who attended meeting 1 and 2 however there was a very low response rate and the maximum number of contacts, set out in the IRAS form, had been reached.

Page 19. Parents: This was interesting, I wondered if parents as enablers came through? I imagine for most children they can't physically get to the meeting without their parents, which is different from being a motivator.

Source data rechecked, the term enabler did not come through. In population terms, Cambridge is not likely representative of other regions, moreover, the CYP/parents had been attending the CCRF to participate in a research trials. There is multiple data demonstrating how trial samples are not representative. It is highly possible this did not come out during interview as it was not perceived to be problematic; this might be different in other less socio-demographically privileged areas/populations.

I also wondered if there was anything about inhibition in the parent's as regulators description. The quote here seems to touch on the parent as a barrier to getting the 'pure children's perception' this seems to be a different thing to 'regulator' which speaks more to behaviour.
Detail and context has been added, CYP and staff did mention the ‘possible ‘inhibition from parental presence during discussion but no specific examples of inhibition were given

I think this section is strong. There is a clear link between the findings and the way the discussion progresses. P 23. The section on reciprocity is very interesting. To further enhance the clarity please indicate in lines 456-463 whether the views reported here are researcher views on what is valued or derived from young people. For example Kirby 2004 - who thinks participation is valuable on a CV - the young people or someone else?

Revised in line with reviewers recommendations


Thank you for this reference.

Culture of PPI, Page 24-25. This section discusses organisational culture but I had expected to read something about the culture created within the meetings - perhaps from the child/parent view point as well - by this I mean what was it like in the meeting, how was the PPI experienced - were the meetings fun? Was there laughter? Or were they serious and formal? What was the style of the meeting? This 'local' culture can be what keeps people coming back - is there anything to unpack here or nothing in the data?

Context and detail added, all CYP, parents and staff felt the meetings were fun. The DVD, although professionally edited, is available on the CCRC website and does, in our view, demonstrate the ethos/ambience. The overarching drive for the CYP being involved in the board was altruism (both has taken part in a life changing study).
I think it would be helpful to reflect here on the child/parent dyads and how this may or may not have affected participants' ability to speak freely, as you do for staff inline 534-536.

Revised in line with reviewers recommendations

Something seems off with the reference sequencing - please check throughout the manuscript

Corrected throughout.