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: 29 Jan 2019

Reviewer: Kate Boddy

Reviewer's report:

Thank you for the opportunity to read this manuscript. I enjoyed it and found the discussion section particularly, to be interesting and well written. My comments are aimed at increasing clarity and understanding for RIE readers.

Plain English Summary:

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

Introduction:

Page 3, lines 49-62 contain a set of statements without references to support them, such as line 53-53, 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?

Background:

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.

Methods:

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.
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?

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?

Page 6 line 122 - a word is missing here.

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.

Results:

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.

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.

Discussion:

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?

P 23, line 463, this is a great Ref about the importance of reimbursement from the person involved's perspective: Richards, Dawn P.; Jordan, Isabel; Strain, Kimberly; and Press, Zal
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?

Reflections:

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.

References:

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

Review ends.

**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:

Acceptable
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