Author’s response to reviews

Title: Ensuring young voices are heard in core outcome set development: international workshops with 70 children and young people

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Author’s response to reviews:

Dear Professor Staniszewska,

Re. RIAE-D-19-00066

Ensuring children and young people are heard in core outcome set development: suggestions from international workshops with 70 children and young people Frances C Sherratt; Heather Bagley; Simon Stones; Jenny Preston; Nigel J Hall; Sarah L. Gorst; Bridget Young; Research Involvement and Engagement

Thank you for sending the comments from the reviewers and for inviting us to submit a revised version of the above manuscript. We outline our revisions and responses to the reviewers’ comments below and have submitted both tracked and clean versions of the revised manuscript.

REVIEWER 1

COMMENT 1: It is an interesting manuscript with a valid point. It is fair to include the opinion of those who will 'affected' by the outcomes (COS) despite their age. And this study should be the first step towards this goal. Further studies should be done about the subject.

RESPONSE: Thank you for your encouraging comments.
COMMENT 2: There's no mention about any difference on the feedback received from children of age 10-14 and those of age 15-18. Would you consider that their understanding, interaction, involvement, and interest were at the same level? Was there any inconvenient about the vocabulary used?

RESPONSE: We are unable to comment on age differences. As this was a consultation rather than a research project, we did not collect data that would allow us to comment on the links between to delegates’ ages and their comments.

COMMENT 3: I believe this wasn't mentioned: What was the role of the parents/guardians during the workshops? Completely quiet or they helped with the tasks? What were the instructions that they received?

RESPONSE: Parents did not take part in the workshops as our focus was on the views of children and young people. We have now noted this point in the revised manuscript (see page 7).

COMMENT 4: Despite the suggestion given by the CYP about not including their parents/guardians during the workshop I would consider for further studies to include a survey for parents/guardians that should be completed after the workshop. It could even send online. They can be asked what they think about this kind of workshop and do they think their children were relaxed/confident about the activities and the environment? Parents know their children best.

RESPONSE: Thank you for this comment which has helped us to reflect a little further. The children and young people at the iCAN workshop were very clear in their view that it would be preferable to separate children and parents during consensus meetings. However, we acknowledge this may reflect the high levels of confidence among delegates at our workshops and their previous experience of voicing their perspectives in similar events. We also acknowledge that other children and young people may feel differently. For example, children and young people who do not have such experience or are less confident might find the presence of their parents helpful. We have amended the manuscript accordingly.

REVIEWER 2

COMMENT 1: The article was of great interest to the reviewer and the planning, delivery and commentary of the results was well executed and understandable to the reader.

RESPONSE: Thank you for your comments – it is good to hear you that found the article interesting.

COMMENT 2: I would have liked to have seen that the participants were offered follow-up or signposting to relevant agencies if they felt distressed at participating and/or after the event.
RESPONSE: The workshop discussions focussed on the rather abstract topic of research methodology rather than on delegates’ personal experiences of illness or treatment. Therefore, we feel it is unlikely that they would have experienced distress afterwards. However, the iCAN conference organisers were available throughout the summit and are highly experienced in providing support to children and young people when needed. We have amended the manuscript to note this (see page 7).

COMMENT 3: I would be interested to see if the results from this article then would lead to the development of the core outcomes for children and young people and a recommendation for this in the article. Overall the article was clear, concise and of interest to the reader and fits well within the selected journal audience.

RESPONSE: We are also interested to see if our article helps towards the inclusion of young people in COS development. As we comment in the conclusion on pages 12-13 (and as reviewer 3 also notes), the hope is that our article lays some the groundwork for future studies to include younger participants in COS development, although research evidence on suitable methods is still much needed.

COMMENT 4: Please consider very minor grammar correction for first sentence of abstract 'Researchers working on different research studies often measure different treatment outcomes, despite investigating the same health condition.' The use of 'different' twice in one sentence could be improved.

RESPONSE: Thank you – we have now amended the sentence to read ‘Researchers working on different research studies often measure inconsistent treatment outcomes…’

REVIEWER 3

COMMENT 1: This paper provides useful insights into using a modified Delphi technique with children and young people, as well as for PPI with children and young people more generally. It contributes to filling a gap in research in this area and lays the groundwork for future studies involving younger participants as experts in areas of health relevant to them.

RESPONSE: Thank you – we appreciate your encouraging comments.

REVIEWER 4

COMMENT 1: The topic of the article is interesting, and the timing is good given that young people's voices are being questioned in the current debate on the global environment crisis worldwide, with arguments that we can not listen to them because of their age or lack of college degree. This is of course nonsense. Therefore, it feels very comforting to read this Commentary.
It is my opinion that the article in general is very well-written and easy to understand. I can only add a few comments on some unclarities I have identified and would also suggest the authors have a look at the paper for editing as there are a few typos. Should these minor things be addressed, I would be happy to make the recommendation to publish.

RESPONSE: It is good to hear of your support for the overarching point of our article regarding the importance of providing young people with the opportunity for their perspectives to be heard. We hope we have responded satisfactorily to your comments.

COMMENT 2: Throughout the paper the authors use the term and abbreviation CYP, but they never state whether this means CYPs in general or those with the condition, i.e. patients. This I find problematic as for adults it is normally patients or patient representatives that are invited to participate in COS, not any adults in general or 'the general public'. I would suggest this to be explained early on in the manuscript, as now it is unclear to the reader, even still at the end of the paper.

RESPONSE: Thank you for this comment. While COS are often developed for patients who have particular conditions or undergo particular treatments, some COS are developed to assess interventions (such as healthy lifestyle promotion) that are implemented in community or social care settings rather than in healthcare settings, or are intended for children/young people for whom the term ‘patient’ is not appropriate or contested (e.g. disabled children and young people, or those who use mental health services). We have added a brief explanation of this to the manuscript (see page 6).

COMMENT 3: The title is very long, anything that can be done to shorten it, would be good.

RESPONSE: We agree and have now shortened the title to “Ensuring young voices are heard in core outcome set development: international workshops with 70 children and young people”.

COMMENT 4: "Main text" seems out of context and should be removed.

RESPONSE: This is a required heading for Commentary articles in Research Involvement and Engagement, which is the category that we think our article is most suited.

COMMENT 5: In the first paragraph under Main text, the authors introduce iCAN, however this introduction is way too short and gives the reader almost no information about this network. I am left with many questions. How come iCAN was chosen? Are there other networks like this one? Who are their members? From what countries? Can anyone become a member? How? Is iCAN only concerned with health matters? Given the topic of this paper, I think a whole paragraph only introducing iCAN is justified and is needed for readers to understand the context.
RESPONSE: We have revised the manuscript to explain why we selected iCAN, provided further details about the organisation where available and added links to the iCAN website and a brochure about the 2018 Edinburgh Summit. However, there are a few questions that we are unable to answer as we are not part of this organisation and the information is not readily available.

COMMENT 6: In the final sentence of this paragraph, the authors state that they "are unable to provide demographic details on delegates". This is very unsatisfying and I wonder if there is really no information at all? Do they for example know, which one might expect, if the majority of those participating was male or female? Sick or not sick? Closer to age 10 than age 18? Surely there must be some more information we could get here, especially as the authors later in the manuscript draw the conclusion that "the iCAN delegates we consulted were typically from high-income backgrounds and countries". Either the authors do not have this information and can therefore not draw such a conclusion, or they do have information which in that case should have been presented much earlier.

RESPONSE: Thank you for raising this point. We have revised the manuscript to explain that because the workshops were a consultation activity, rather than a research activity, we did not formally collect demographic data on the characteristics of delegates (beyond doing ‘head count’ of the number who attended the workshops). Regarding the reviewer’s specific query about how this squares with the information that we do present, we have revised the manuscript to clarify that the contextual information on delegates came from the iCAN organisers. Specifically, the iCAN organisers advised us that: delegates were aged between 10-18 years; were mostly from high income socio-economic backgrounds within countries across Europe and North America; included healthy CYP and those with experience of acute and chronic conditions; that some delegates had been motivated to join CYP advisory groups and attend the summit because they had an interest in undertaking health-related educational courses and careers, while others attended to share their voice and experience.

COMMENT 7: In the next section under the heading "How were the workshops organised and facilitated?" the authors describe their methods. It is however unclear to me how their method is different from focus groups - which I suppose it must be as this term is not mentioned at all.

RESPONSE: We use the term ‘workshop’ because the term ‘focus group’ refers to a qualitative research method. Although the latter term is often also used more broadly, our article is reporting on a consultation activity, and using ‘focus group’ may confuse readers, or lead them to think we are reporting research findings.

COMMENT 8: In the 2nd paragraph it is stated that "…all had experience of patient and public involvement (PPI), COS development, or both with CYP". But did they have any experience of leading discussions in focus groups or in moderating workshops or other events?
RESPONSE: We confirm that all facilitators had experience of leading discussions with children and young people in similar fora. We have amended the manuscript accordingly (see page 8).

COMMENT 9: It would have been good had there been page numbers to refer to, this needs to be added.

RESPONSE: We apologise for this omission – we have now added page numbers.

COMMENT 10: List of abbreviations should be presented earlier, preferably at the beginning of the paper rather than at the end of the document, which is too late.

RESPONSE: We have moved the list of abbreviations to the beginning of the paper.

COMMENT 11: Language generally very good but needs to be checked as on several places as words are missing, for example line 15, same page as Main text starts, is an incomplete sentence. Another example: in Box 2, in the 4th bullet item in the 2nd section an "of" is missing. I therefore recommend the authors to have the paper proof-read.

RESPONSE: Thank you, we have amended the above errors and proof read the revised paper and made a number of minor improvements to the writing.

COMMENT 12: Difficult words for non-native English speakers - hover, deter, interspersing - please explain or change these words.

RESPONSE: Thank you - we have now used alternatives for these words.

I hope that we have provided satisfactory answers to the reviewers’ comments and look forward to your response.

Yours sincerely,

Bridget Young