Author's response to reviews

Title: Using the Nominal Group Technique to Involve Young People in an Evidence Synthesis which Explored 'Risk' in Inpatient Mental Healthcare

Authors:

Nicola Evans (EvansNG@cf.ac.uk)
Ben Hannigan (HanniganB@cf.ac.uk)
Steven Pryjmachuk (steven.pryjmachuk@manchester.ac.uk)
Elizabeth Gillen (GillenEC@cardiff.ac.uk)
Deborah Edwards (EdwardsDJ@cf.ac.uk)
Mirella Longo (LongoM1@cf.ac.uk)
Gemma Trainor (gemma.trainor@kcl.ac.uk)
Felicity Hathway (Felicity2.Hathway@live.uwe.ac.uk)

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Background page 4 line 53. The word co-production is mentioned first off here but does not feature in the abstract. Should it? I would suggest you have looked to co-produce decisions on the scope of your review and would be useful to say this in the abstract. Also on page 5 line 77 it is mentioned but not defined. Can you define what you mean by co-production in a research context?

We have taken the opportunity to be more precise in this revised version of our submitted paper.

We have refined the title to explicitly state from the outset that this is an application of the nominal group technique in this case, rather than an adaptation, because on reflection, the techniques was used as suggested, with some context specific modification.

We agree with the comments from the reviewers that terms such as involve, collaborate, engage were inappropriately used inter-changeably, so clearer attention has been paid to the terminology throughout.

L112 - Who were the young people you engaged with, what were their ages, gender and how did you recruit them? How representative were they of 'young people'?
There is clarity of this on p6 onwards in the paragraph entitled ‘involving young people’. Ages of the young people were not known.

L166 - why only one parent? How were they selected? Were they related to one of the young people involved? And why were they not physically present in the sessions?

This is clarified in the text now.

L170 - were the sessions recorded? Do you think that this would have been useful/detrimental?

Clarified in the section

L184 - what are your thoughts on getting one of the young people to facilitate the sessions? Would this have been useful? Are there any examples of people using this technique?

Thank you for this suggestion. I think should we use this approach again, inviting a young person to lead an advisory group will be considered, with appropriate training (if required) and preparation for the young person beforehand.

This now appears in the conclusion.

L235 - First paragraph of discussion does not read well - would rewrite L 285 - 'experts by experience'

Thank you for this. Much of the paragraph has been re-written.

L295 - do these really work? From my experience, young people (and adults) find them extremely annoying!

Interestingly I attended a training day facilitated by young people on involving young people in research, and they strongly advocated repeated use of ‘play’ to promote engagement.

L315 - did you conduct follow-up with all of the young people who were involved - if so, what were the overall opinions?

We invited all to respond.

One concern I have is that I have reviewed a few pieces for this journal and they tend to be about one off meetings, written up as research to build an evidence base around PPI. As with all research I think this paper needs a limitations section at the very least to acknowledge that best practice is for young people's voices to be found throughout the research process from bid development to research phases and dissemination. Working with Young Minds is excellent. But this paper presents a one-off input. More importantly there is no sense the young people's involvement stretches into phase2. Will the stakeholder group meet again to look at results out of the evidence synthesis? As far as I can tell this paper is written about a stakeholder meeting that had 2 young people in it and the young minds rep (who also brought the views of 7 people
not in the room). What is their influence outside of this one part of the research process? I do think it's important to situate what is a very useful piece of work in a wider context, because I'm not sure the recommendation would be to duplicate this as PPI, but instead as one component of it.

Thank you for this commentary. There was a further stakeholder advisory group for this study, and we have continued to consult with these young people and YoungMinds in the bid development for a follow-on study.

We have added to the discussion section outlining this.

Another general piece of feedback is I got confused in this paper about who the stakeholders were and how equality was created in a meeting of 14 people

Clarified in the text now

The exclusion of parents (or carer both terms were used) from the actual meeting, but the inclusion of other adults, and lots of research staff does need explanation. Explained in the text now

Throughout the paper I think you need to define terms used. The ones I picked out were:

a. Collaboration with young people
b. Engagement with young people
c. Co-production
d. Contribution of young people. Definition added on p 57.

NIHR INVOLVE defines ‘involvement’ as research being carried out ‘with’ or ‘by’

www.invo.org.uk

Rationalisation of terms throughout

PPI looks at engagement, participation and involvement. These are not the same things and should not be used interchangeably. Collaboration means something very specific in the INVOLVE guidance and acknowledging the limitations of your collaboration would be useful as described in the paper - there might be other examples in the study (but we don't know).

Thank you for highlighting this. We recognise the differences and have now rationalised our terminology.

To say nominal group technique might benefit from adoption isn't a very strong conclusion
Discussion section expanded and clarified

Also saying the technical aspects to adapt are warm up and ice-breaker (which are not mentioned anywhere else in your paper) again does not do justice to what you write in the main body if the text. I suggest you revisit your conclusions and revise this abstract

Thank you, abstract and discussion/conclusion have been edited.

Page 2 - plain language summary. Unclear what 'contribution' of young people means here

Clarified

Line 19. Might be better to say we wanted to include a contribution from young people alongside other stakeholders with expertise to guide the research team in decisions made setting parameters for the review.

Thank you, very helpful, now included

Background page 4 line 62. The phrase "informed" young people is used. Not sure what the definition is of an informed young person. Do you mean has experience of inpatient use, might be better to say that instead …

Thank you for this comment, it has been amended.

Background page 4 line 62. It says here that you wanted to ensure 'their perspectives' weren't filtered by adults but I think in the method section the two young people were supported to attend by practitioners. Apologies if I misunderstood. And only 2 young people were "in the room". So this seems contradictory to your actual methods?

The method you choose involved the young minds coordinator to be the spokesperson for the 5 people who provided consultative conversations. More discussion of that and reflection on it would be useful.

Page 7, nominal group technique. I am still struggling with the idea that the technique puts equal weight on views - but only 2 young people were in the room to express a view. Were decisions made in the group - or did research team make them later? Not sure the decision making part of line 43 is described anywhere .. Sorry if I missed this in the text.

We took advice from YoungMinds from the outset of this project how to involve young people. The detail is now added to the text (p5-6).

Background page 4 line 64. What does a contribution to 'crafting' this paper mean? Not a term you often see in an academic publication. Are they an author? Did they review a draft)? I think you need to state contribution

This sentence has now been reworded to improve clarity
Study overview pages 5 and 6, several mentions of stakeholders - I think its imp to be clear if this paper is about all stakeholders or really only the young people component (as per other comments above).

Thank you for this. Clarification has been added throughout the paper about the stakeholder advisor group composition.

Engaging young people, page 6. Line 113. Might be helpful to say what age range you are using when you say young people? 14-25 or ???. What is young!?

Although specific ages were not known, CAMHS services in the UK is up to 18 years, and this is now clarified in the text (introduction).

The paper is very descriptive in places, which has the advantage that others could replicate when you did, but could do with some editing so strategy and rationale come first followed by description of how you achieved that. Page 7 for example

Section re-written

why only one nominal group was held - is that standard practice? References to show that?

This was a limitation now acknowledged in discussion section

Page 8 step 1. Line 154. More detail would be helpful. How many people were in the stakeholder group? A quick tally shows:

a. 7 research team members

b. 5 practitioners (adults) plus young minds person?

c. 2 young people (would be useful to know ages of this 2 people as per definition of "young") Clarified in text.

Unfortunately we did not know the ages of the young people but they were users of CAMHS services and by definition were 18 or younger.

This is now included in the introduction and on page 8.

The strategy to not have a parent in the room would be usefully explained further as there were other adults. Why practitioners ok but parents not? Who might have been parents too of people with MH problems. Links to issue of identity and multiple identities and experiences that people bring into a room/ group or choose not to.

The parent was unable to attend, but was invited. Now explained in text.
Page 8 line 31 says 7 people were in the young minds consultation. But on page 7 line 127 it says 5. Which was it?

Clarified. 5 from YoungMinds plus 2 other young people

Page 9, the statement that young people might find silence uncomfortable I think is potentially discriminatory. Anyone might. Actually young people are used to silence - in their exams, in libraries studying in classroom working. I just think this needs removing. There are a few statements about young people in the paper that could be carefully reviewed to ensure they are not stereotyped.

Thank you for that comment, now edited.

Page 9, line 186 the term here is carer - I think you mean parent as that was used before - need to keep terms consistent. This process of absent voices being "presented" in the room by others - needs far more reflection. Changes the dynamics of a conversation. The way I am reading the paper is that young people and the parent voice is "equal" in the room as they are presented. I encourage that to be reflected upon as a method.

Amended terminology, and ‘equality’ issue in discussion section

Page 10, voting and ranking. Unclear if only those 'present' voted or if the people in the young mind consultation somehow voted too. How? Line 205. Also line 205 is the "person" here the 15 people in the stakeholder group - might be better to say this.

Page 11, table 1. Having read a lot of description we come to the voting data and the terms used in this paper seem unlikely to be those used in the room. Did the term dislocation come from young people? Why is this language used? Were young people comfortable with the concept of contagion to describe their experiences?

Line 275 - where are those themes in table 1 - education, friendships and relationships

Further description of the stages is now included and figure 2 has been added for clarity

Discussion from page 12 - first issue is need limitations section. Line 251 - wanting equal contribution - did your number impact on this?

Now included in discussion section

I think acknowledge the wider involvement of young people in your study is imp - how are they involved in stage2?

Section rewritten to improve clarity

There is a good description of the implementation of the nominal group technique in operation and I also agree that icebreakers in such situations could be helpful. However, I was not clear
whether ethical approval was provided for the nominal group technique involvement process, and if so this should be stated. If not, you need to say why this was not necessary and how you were able to ensure that all stakeholder interests were protected.

Now stated clearly no need for ethical approval

P7L132 missing word - invite 'other' young people to join him

L134 how were the young people prepared beforehand?

Section re-written

P11L219 dislocation - isolation from….social contact -even if in hospital young people would have social contact , should this be normal social contact?

Clarified as ‘existing social contacts’