Author's response to reviews

Title: Evaluation of patient involvement in a systematic review and meta-analysis of individual patient data in cervical cancer treatment

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Version: 2 Date: 16 March 2012

Author's response to reviews: see over
Response to Reviewers’ reports

Reviewer 3: Rebecca Smyth
Reviewer’s report:
Thank you for providing me with the opportunity to review this manuscript. This is an interesting manuscript which provides insight into patient involvement in a systematic review and meta-analysis. The title provides a clear and accurate description of the manuscript. The manuscript reads well and is easy to follow. The aims and methods are clearly described and the approach seems sound. The results from the questionnaires identified some interesting findings, in particular those relating to survivor issues, and the importance of identifying patient centred outcomes that would not have normally be collected. Both the Discussion and Conclusion are balanced and supported well by the data.

Discretionary Revisions - I have just a couple of points for the authors:

Background – 1st paragraph: I presume the authors are stating that they did not identify any published examples of reporting patient experience in involvement of quantitative meta-analysis. It reads as though there are no SR’s that have patients / public involvement - Cochrane Pregnancy and Childbirth Group have many.

• I have now clarified the statement in the paragraph to indicate that there are only few published accounts that aim to describe or evaluate patient involvement in the review process.

I would be interested in knowing a little more about the ‘mixed feelings about participation at the Collaborators Meeting’ as only one positive quote was provided – or is this included in 4.ii?

• The more negative comments on the participation at the collaborators’ meeting are included in section 4.ii. I have added a signpost to this in the text at the appropriate point (i.e. Results section 3.iv paragraph 2)

Reviewer 1: Jonathan Boote
Reviewer’s report:
I thought this to be an interesting and worthwhile paper, describing the involvement of patients in a systematic review and meta-analysis, together with a report of an evaluation from the perspectives of researchers and the patients themselves. There are few published accounts of patient involvement in the systematic review process, so this paper is to be welcomed.

I recommend that the journal accepts the paper for publication, subject to the authors addressing the following relatively minor issues:

1. in the background section of the abstract on line 2, I think the words 'to be involved' should be deleted
2. In the results section of the abstract, second to last line, the words 'which was generally positive about the experience' is unclear and should be rephrased to state if those who took part in the evaluation were positive about the process and/or the outcome of the involvement exercise
3. second to last line of the first paragraph in the methods section, an 'a' is needed between 'of' and 'job'
4. page 6 of the manuscript, last paragraph, line 2, the word 'provided' is needed between 'they' and 'input'
5. page 7, 2nd paragraph, lines 5 and 6, I think 'help' to 'should be replaced with 'held to', and a comma and an 'and' be added after 'points'
6. page 7, 1st paragraph in the results section, line 2, the second 'from' should be changed to 'at'
7. page 8, first line under survivorship issues, I don't think the apostrophe after researchers is needed
8. page 10, line 4 under the 'being of value' heading, 'affects' should read 'effects'
9. page 15, paragraph 2, line 3, 'the' is needed between 'that' and 'disease'
10. page 15, 3rd line from the bottom, 'researcher's' should read 'researchers'
11. page 16, line 4, 'studies' should read 'study'
12. page 16, is the INVOLVE guidance on public involvement in systematic reviews out yet? I couldn't find it on the INVOLVE website
13. page 16, last paragraph, the Boote et al. review looked at patient involvement in health and social care research, so the words 'and social' need inserting between 'health' and 'care'.
   • I have made all the changes indicated above. These are annotated by track changes in the revised manuscript

Reviewer 2: Bridget Young
Reviewer's report:
This paper reports on a study of patient involvement in a systematic review of cervical cancer treatment that involved meta-analyses of individual patient data. There are a few previous reports on patient involvement in the context of systematic reviews, and none that involve individual patient data. The topic addressed is therefore a new one and of interest to researchers conducting similar systematic reviews.

Major compulsory revisions
1. In the background section it would be helpful if the authors could outline a) the findings of previous studies of patient involvement in systematic reviews and b) what they anticipate to be the specific issues that arise in involving patients in systematic reviews and particularly systematic reviews that include meta-analyses of individual patient data i.e. what issues arise that do not arise in other types of research. This would help the reader to identify how the findings of this paper add to the existing literature.
   • I have included extra sentences at the end of the first paragraph of the Background section describing the findings in relation to the contribution of patient involvement to reviews from a recent review of patient involvement in systematic reviews. However, I think that to include information on what issues may arise in reviews that do not arise in other research areas pre-empts some of the findings of our evaluation, so I have not included this in the background, but details of such issues as we encountered are included in the results and discussion sections.
2. There is currently no description of the methods used to analyse the data for this study. The data are qualitative, comprising participants’ free text responses to a questionnaire and their contributions to a meeting ‘held to discuss further key points’. The authors need to describe the approach they took to the data analysis, how the data were analysed, and what steps were taken to help ensure the rigour of this qualitative study. A particular issue here is the interdependence of the researchers and the Patient Research Partners - given the relationship they built up over the course of the systematic review, to what extent were each able to say what they really thought of the process? The authors need discuss how this was managed and how the researcher-partner relationship may have influenced the data. Furthermore, the study participants are also its authors. It would be helpful to include a discussion of how this was handled and the implications for the data collected. It would also be helpful if the authors could supply a copy of the questionnaire and indicate the topics covered in the meeting. Finally, any changes to the methods in the main text of paper also need to be reflected in the abstract.

3. The study involved only five participants. The authors need to discuss the adequacy of the sample and the implications for theoretical saturation.

4. There needs to be a section in the discussion reflecting on the limitations of the study’s methods.

- All of these points relate to the conduct and reporting of qualitative research, however whilst we intended to evaluate the patient involvement in our review, this was not conducted as a prospectively designed piece of qualitative research but a simple evaluation intended to inform us (and we hoped, others) with regard to involvement in similar future research projects. I have now added a statement to this effect in the methods section. There are inevitably limitations – as with any findings based on a retrospective evaluation rather than prospectively designed research. Therefore, I have now better described in the methods section how these data were obtained; the processes by which we extracted themes (from written responses to a short questionnaire) and how these themes were explored further in a follow up meeting. I have also added a section detailing limitations to the discussion (paragraph 2).

**Minor essential revisions “Minor issues not for publication”**

1. The term ‘reference group’ appears in the methods subsection of the abstract. This needs to be explained as readers may not be familiar with its meaning.

- I have replaced reference group with the term advisory group, which I think is more transparent. The methods section of the main manuscript however, where the group is fully described retains the term reference group.

2. In results section 3 iv) paragraph 2, consider indicating that the ‘mixed feelings’ (briefly mentioned here) are further discussed below.

- See comment to reviewer 1 above.

3. In results section 4 iii) the third sentence was unclear to me. Consider
rephrasing to clarify.

- I have now rephrased this section and hopefully improved its clarity

4. Remove ‘/!’ from the end of the first paragraph in the discussion.

- I could not find this punctuation in the text. Perhaps it was an anomaly with the reviewer’s copy?

5. Discussion paragraph 5, sentence 3, consider rephrasing as ‘A similar model may benefit researchers who are new to patient involvement’

- I have rephrased this statement

**Discretionary revisions**

1. Several of the points highlighted in the findings and discussion appear to relate to patient involvement in research generally. It may be helpful to elaborate more on the issues that are specific to involving patients in a) systematic reviews and b) systematic reviews with individual patient data.

- I think that based on our experiences and also the findings of the Boote et al review of involvement in systematic reviews, many of the issues do overlap with involvement in research in general. The one main issue that was raised with regard to individuals having potentially less influence in shaping a review than might be the case with primary research is raised in the results and discussion.

2. In section 5i) of the results, the authors write ‘the researchers felt that they could only commit to a similar approach to patient involvement in systematic reviews based on IPD’. It would be helpful if they could expand on this to explain their reasons.

- I have added a sentence to explain what was intended by this in the results section. There is also some discussion of this point in the discussion section.