Reviewer’s report

Title: User-involvement in a Cochrane systematic review: using structured methods to enhance the clinical relevance, usefulness and usability of a systematic review update.

Version: 1 Date: 22 December 2014

Reviewer: Nathan Shippee

Reviewer’s report:

Major compulsory revisions

I. Overall contribution

Several other papers exist implementing (and in some cases assessing the effect of) stakeholder involvement in research. I like this paper on many counts but am not sure what it adds other than another piece of vaguely supportive evidence. The authors could do more to make clear up front what their approach does or does not add to the literature.

I don’t believe that “successfully” involving a stakeholder group (e.g., in the Abstract) is unique or novel, nor am I sure how one would measure successful versus, and I don’t believe this paper needs it as a contribution anyway.

I actually believe that there was a great deal more “behind the scenes of this paper,” which was described briefly (such as a doodle poll on a title, discussion points, etc.) but could be better and more systematically presented to bring out the true contribution of the paper. Otherwise, as a takeaway, we’re mainly looking at the fact that there were meetings, that there was some manner of input by stakeholders, and that there was consensus. I believe systematically laying out themes discussed, results of any non-reported votes, collated feedback from stakeholders (lines 243-44), and so on would make this paper more novel and useful. Consensus by a very few on some relatively broad statements is good to report, and is a step in the right direction beyond some of the vague descriptive articles that are out there, but ultimately lacks “bite.” Drawing a bit more on the richness of stakeholder input, or systematically and more specifically presenting more pieces of information from this obviously long-term stakeholder involvement process would greatly strengthen the paper.

As an example, findings from the evaluation end of meeting 3, if presented more fully, would be particularly useful in indicating that the involvement had an impact (which has often been omitted, or weakly made as a case, in other papers on the topic). See also my last comment at the bottom of the review for another example.

II. Methods

A. Reimbursement
Prior experience with willingly involved patients (line 113-115) doesn’t guarantee against or address the possibility that not providing some compensation for time will impact disadvantaged survivors and others disproportionately, or have other potentially biasing effects. This may (though I can’t tell) foreshadow what some of the stakeholders seemed to say later re: representativeness of the group members (line 288). The authors may have a rebuttal to that, but not using prior anecdotal personal experience is a relatively weak justification for this choice.

B. Ethical issues and participant status

The authors seem to imply that stakeholders in this group were involved in the process of research, but not participants (see line 125). I’m glad the authors acknowledged this distinction, and this might be splitting hairs, but since the authors present tables with individuals’ perceptions, I would argue that they are involved in one research process (updating the review), but that for the purposes of this paper (which is not a Cochrane review itself but an assessment of a process of producing one), they are participants whose data were used for research. Imagine if a quantitative research team reported their statistical results in one study (Study A), and assessed their meeting procedures to producing study A in a separate paper (study B). Study A would not require any informed consent of research team members, but Study B could. Acknowledging both aspects by study, rather than implying that the stakeholders somehow might not be participants, is probably a good idea.

C. Recruitment

At 131: why was the 8-12 number chosen? No justification is given. Also, why were physiotherapists the only ones intended to receive purposive selection (lines 132-33)?

D. Consensus

It was a stated goal of the meetings 1 and 2 to reach consensus/agreement (lines 151-55). Also, the entire point of the stakeholder involvement was to provide input into how to update the review considering the recommendations of the previous review—implying that the current topics, etc. were insufficient. Might the two together not have predetermined the fact that we’d see consensus in early meetings? The pre-determined statements are pretty broad, so I’m not sure how remarkable it is that we see general consensus- could we feasibly have found it to be not the case?

E. Consensus methods

How is it that the review authors’ attending of the meetings and taking part in the discussions, regardless of whether they voted, helped “ensure that the results of the voting was not biased by the opinions of the review authors”? Would it not have been a better design for them to not participate, and/or to attend in a number smaller than the next smallest group (survivors/carers)?

III. Results
A. Stakeholder group composition

If this group only had four survivors/carers volunteer (line 210), why should I not be concerned that marginal or disadvantaged voices (who might be less likely to consent in a more stringent process) were not self-selected out completely? I’m likewise concerned by the fact that survivors/carers had only four to their group compared to nine physiotherapists, which with four researchers in their groups, comprises 13 clinical and/or research experts to four “lived experience” experts. Other than anonymous voting, I’m not sure I see anything in the methods that assures me that issues of power and interpersonal or professional politics were kept to a minimum.

IV. Discussion

A. Impacted substantially on the review?

While some of the impacts listed seem convincing, some do not. The inclusion of international studies, for instance, seemed to be something the researchers might do anyway given that one of the reasons for the update was because many of those international studies were still in progress at the time of the last update, and the authors suggested including them (at least as far as I can see from this manuscript). I would suggest being a bit more circumspect about the impacts of the stakeholder input, acknowledging that some of these “changes” might have been made anyway, etc.

B. Lines 315-317

Is it true that this update was unique owing to the older version having highlighted several limitations, helping to determine the issues to be addressed? Don’t many reviews do that? I’d rather think the issue is how those questions are presented to stakeholders (i.e., in a leading or non-leading fashion) if one is interested in the impact of stakeholder input per se.

C. Paragraph beg. line 360

I believe the authors to be sincere, but aren’t there more systematic and structured ways to ensure stakeholder empowerment than simple verbal reassurances? Is the use of only verbal reassurances and anonymous votes, therefore, a potential limitation?

D. Lines 367-374

“Handing over control” and its alien feel is great transparency. A couple of things: First, I feel that the authors’ involvement in discussions may have limited the degree of this “handing over”, which might be noted as a limitation. Second, with the mention that this added “value” and “validity”, I think that very concisely noting how/why that was the case—i.e., distilling how it actually strengthened the usefulness, validity, etc. of the review other than representing peoples perceptions—would go a long way toward addressing my overall comments on the contribution of this paper (above). I’m suggesting something as simple as a list of what things were different than how they would have been without
stakeholders to make it clear for readers like me who might have lost something in the descriptive language.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have not competing interests.