Reviewer's report

Title: Patient engagement in Patient-Centered Outcomes Research: A Meta Narrative Systematic Review

Version: 2 Date: 4 November 2013

Reviewer: Gro Jamtvedt

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General comments

In this paper the authors summaries information about patient engagement in research. Involving consumers in all steps of research is of great interest to the research community, funders and policy makers and there is a need both to increase awareness, understanding and practice of involvement. This paper might contribute to this.

The authors have conducted a “meta-narrative systematic review”. I am not familiar with this type of review and suggest the authors define the study type. They should also clarify whether the review includes a meta-narrative approach in the analysis of data, or whether the study type is a “meta-narrative systematic review”.

It might be understandable that all research and other types of information within an area need to be mapped and disseminated, but a journal article publication might not be the best format. A systematic review is defined as a review that addresses a clear question and is carried out through systematic and transparent methods, including search, quality assessment and summarizing the evidence. Even though the authors refer and report according to some criteria from the PRISMA statement there is a strong need for improvement and clarification of the review process, as well as narrowing the research question.

Major Compulsory Revisions

1. The review question is extremely broad. It intends to summarise “evidence about patient engagement is research” and to include studies of any design. Comments, opinions, letters and editorials are also included as evidence, as well as reference to organizations and websites. These are publications without empirical data and would normally not be classified as “evidence” or “studies”. The authors should consider excluding information without empirical data and clarify this both in methods and results.

2. The unclearness of the research question brings further confuse into both methods and results. One way to clarify might be to address the four questions identified within the analytic framework (Figure 1) into the aim of the review. Preferably I would like to see each question addressed in separate papers and with separate methods.
Alternatively, if the authors still want to address them all, the questions must be addressed within the aim of the study. In the method section through the eligibility criteria each question needs to be outlined and specified for type of studies (design) to be included, assessed and summarized. Finally the result part should follow the same pattern by reporting findings according to each of the four questions and for each design.

3. Since this topic already has been covered in published systematic reviews, an alternative solution for this paper could be to perform an overview of reviews only. Alternatively the authors could address the questions not summarized in published systematic reviews. This approach could also allow for assessment of risk of bias or other quality criteria depending on design. The rationale for not including risk of bias/quality assessment is not clear. This is an essential part of a systematic review.

Minor Essential Revisions

4. According to the eligibility criteria this review looks at studies in which patients took part in design, conduct and dissemination of research. Patients should be involved in every step of the research circle. The important step of “prioritization” is not included or mentioned and should be addressed.

5. In Additional table 1 the included studies should be sorted according to their research question or their design rather than in alphabetical order.

6. Please define “non-original” as publication type in the eligibility criteria part.

7. Please clarify the aim of the environmental scan and Additional table 1. Was this scan carried out to identify more studies only, or to describe relevant organizations and sources for user involvement? Did the scan result in more studies included? If yes, how many studies?

8. The title could be revised and shortened into “Patient engagement in research ..” leaving out “Patient Centered Outcome”. This phrase is not needed to address the topic.

9. In the abstract the aim of the study is missing

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 no competing interests