Author's response to reviews

Title: Patient Engagement in Research: A Systematic Review

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Author's response to reviews:

Dear Editor,

We thank you and the reviewers for the time, effort and excellent advice that we followed and will hopefully make this manuscript more explicit and helpful to the readership of the journal.

Our responses to the reviewers’ comments are listed below.

MH Murad and co-authors
Reviewer 1: Alex Pollock
1. It would be preferable if the review protocol could be made available (? As an electronic/additional file?)

Response:
The protocol is added as appendix 1.

2. Overview of existing systematic reviews – the authors only discuss 3 of the 8 included reviews. I think it is essential to clearly state in this section that 8 reviews were identified. It may well be appropriate to just to describe 3 – but as a
reader I need to know why this decision has been made and why you are not discussing the remaining 5.

Response:

As suggested by reviewer, we briefly described the 8 systematic reviews and reference a supplemental table that has more details.

3. Results of search. “142 met the eligibility criteria and were included. Studies reported a spectrum of engagement. Studies described patient engagement in research preparation phase (24), execution phase (64) and translation phase (21).” Could the types of studies be described in relation to the total number of included studies (i.e. 142). The list above only adds up to 109, so I don’t know about the remaining 33. I realize that there will be a reason for these 33 not being included in the list of ‘phases’ (e.g. some of the 33 will be systematic reviews etc)….but it would be nice if all of this could “add up” so that the reader gets a complete picture of the study results. [Figure 2 is a great addition to this paper – ideal!]

Response:

The number of studies were reviewed and verified to be consistent with the figure. Please note that the numbers do not add up to the total because some of the studies described patient engagement in more than one phase. To clarify this, we added this sentence immediately after the relevant text:

“Some studies contributed to our understanding and definition of more than one phase.” We added the breakdown of study design as suggested by reviewer.

4. Discussion. Is the heading “comparisons with other systematic reviews” in the right place? It seems to relate to the paragraph below.

Response:

We thank reviewer for pointing out the typo.

5. Supplemental table 2: systematic reviews. It would be helpful to add a column detailing the aims of the review.

Response:

The column with Aim is added to the table.

Reviewer 2: Gro Jamtvedt

1. A total of 142 studies are included. There are 7 RCTs and 8 systematic reviews and the authors have classified the remaining majority as qualitative studies. However, according to the supplemental table 1 and Figure 2 more than 20 studies are classified as cohort studies, cross sectional, case studies etc. These studies are definitely not qualitative research and should be outlined as such in the text.

Response:
In the revised manuscript, we separated the qualitative studies from other types of observational studies. Supplemental table 2 now has these two separate subcategories (observational studies and qualitative research). We thank reviewer for the suggestion.

2. The aim of the review is now clearly divided into four sub questions. The included studies are not classified according to these questions. How many, and which of the 142 included studies address questions one, question two and so on. Which questions are addressed in the systematic reviews included and which questions are addressed by the RCTs? In the result part the description of findings related to each question should include the number of studies addressing each question.

Response:
As suggested by reviewer, in the revised manuscript we report on the number of studies contributing to our understanding of each of the 4 questions (second paragraph, results section). Please note that the numbers will not add up to 142 because most studies contributed to our understanding of more than one question. A sentence was added to clarify to reader such overlap so that readers don’t expect a total of 142.

3. According to the 5S concept systematic reviews should be presented first followed by RCTs and other design. Please include presentation of the included systematic reviews within the questions instead of presentation in a separate paragraph in the result part.

Response:
As suggested by reviewer, in the revised manuscript we present the systematic reviews (in the text and in the tables) before studies with other designs; to be consistent with a 5S concept. The systematic reviews had aims and goals that spanned across the 4 key questions and cannot be clearly separated; therefore, we kept them in their own dedicated section.

4. In Supplemental table 2: Systematic reviews: please include a column addressing the question or aim of the review. This would also help classifying which question the evidence contributes to.

Response:
A column indicating the aim of each review has been added to table 2.

Associate Editor's comments:
1. Abstract: the four questions should be placed in the final part of the Introduction. Please also expand the Methods part with more concrete information about methods.

Response:
We revised the abstract accordingly and thank the Associate Editor.
2. Introduction: please place the four questions in the last part of the Introduction. Explain shortly the need for this review, based on current knowledge (added value to 8 reviews that already exist)

Response:
We revised the introduction section accordingly by adding the 4 key questions and the rationale of the review and how it was commissioned by PCORI to answer specific questions not answered at the present time.

3. Methods: describe what environmental scan means

Response:
This text is added:
“We complemented the database search with an environmental scan and a manual search. The environmental scan includes searching the Internet using various search engines for recent and ongoing activities, initiatives, white papers and websites to identify key players and trends in the field. It helps provide content from grey (unpublished) literature and from fields other than medicine. We also searched the scientific search engines Scirus and Sciverse, which contain scientific journal content, scientists’ homepages, courseware, pre-print server material, patents, and institutional repository and website information. In addition, we contacted experts in the field to identify other relevant documents (e.g., dissertations, scientific reports).”


Response:
As suggested by the Associate Editor, we add a supplemental table with quality evaluation and commented on it in the text.

5. Results, question 1: I lack a better description of possible methods to identify patients, and the theoretical justification for each of them. In research, the random method would in principle be the better one - is this different in this setting? Why? Some elaboration is needed, preferably in the Discussion part.

Response:
We added to the discussion section a brief suggestion on choosing a method although this is purely theoretical as there is no comparative evidence available.

“In terms of identifying patients for engagement, random sampling is the least biased way although considering that the number of patients chosen for engagement is very small, random sampling can fail. This approach is also challenging in rare diseases. Most of the included studies used volunteers which
is a more practical method despite the potential for having a sample of patients that are not truly representative of the targeted population. Volunteers may be more educated and motivated and engage more effectively, yet they may have personal agendas. At the present time, we suggest that researchers chose their method of selection based on the availability of subjects and the research topic at hand."

6. Results, question 2: many of the methods to engage is rather passive (for instance surveys), see also the conceptual division you make in the Introduction (passive vs active, the latter reflecting engagement). Could you clarify the theoretical starting point in relation to these more passive methods? Preferably in the Discussion.

Response:
We added to the eligibility criteria:

". In general, we sought studies in which patients were actively engaged in designing research. Participation in surveys was only considered to be research engagement when the main purpose of the survey was to obtain patients’ values and preferences that relate to research prioritization or research design."

7. Results, question 3: please also include type of control groups in the studies you describe.

Response:
The control interventions added as suggested.

8. Results, question 4: in question 1 and 2 you write that "We found no comparative analytic studies..." Is this also the case for question 4?

Response:
The Associate Editor is correct. The suggested sentence is added to question 4 as suggested.

9. Discussion: It would be very useful if you could elaborate about the type of research you want in this field, and relate it to all the questions you have in this review. What would be the main features of such a research agenda? Possible to give an example? Any differences in research design regarding the questions "who", "when" and "how"?

Response:
A paragraph is added to the discussion section proposing various study designs and future research ideas in this field.

10. References: please check reference 5 and 6 - are they correctly referenced?

Response:
References have been reviewed and edited as needed.