Author's response to reviews

Title: 'Practical' Resources to support Patient and Family Engagement in Healthcare Decisions: A Scoping Review

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Author's response to reviews: see over
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Dear BioMed Central Editors:


The author team has reviewed and addressed each of the comments made by each Referee. Responses follow and include reference to any related text and/or tracked revisions made in the manuscript. Based on the suggestions or comments from the three Referees, the authors have rewritten portions of the manuscript to ensure that the scientific rigor is captured for this scoping review and to also ensure clarity. We have also shortened the title to ‘Practical’ Resources to support Patient and Family Engagement in Healthcare Decisions: A Scoping Review.

For ease of responding to the concerns or suggestions made by the three Referees, we have responded to each concern or suggestion made by each Referee separately, as follows:

Referee 1:

“... other than a few typos (bottom of pages 13 and 17)....”

These typos have been corrected and are identified on pages 14 and 26, respectively (in the tracked changes version).

Referee 2:

Major concerns

“...concerns about the scientific quality of the paper.”

Scoping review is an accepted scientific method recognized in health research, and recognized by health research funders (e.g. Canadian Institutes of Health Research). References are provided. The text has been further clarified around the approach in the methods section. The approach is used to explore diverse sources of literature (i.e. quantitative, qualitative, mixed and general unpublished reports or guidelines) in terms of identifying or refining the research question(s), using specific search terms and screening criteria, worksheets for final article review and analysis, and summary tables to present results. This paper describes the scoping review of a specific area of patient engagement which is to identify tools, guides, and other information to inform the content for a patient engagement resource kit.

“First, the research question is vague and very/too broad described. Due to this an answer cannot be formulated in the discussion and conclusion section of the paper.”

The research questions posed in the introduction (bottom page 3 and top of 4) are fitting for a scoping review as per references, and are actually quite specific to our inquiry about what existing approaches, preparation, models, tools and guides can be found and used or adapted for engaging patients and families in health services decisions. The focus of these questions is pursued in the methods section and is continuously referred to in the results section through the thematic analysis of published and grey literature. We have reframed the ‘Discussion’ section to strengthen the focus back to the original questions (starting page 16 of the revised manuscript). Answers to our questions were found through
the scoping review and were categorized under patient engagement themes with the clustering of types of articles/items as tools, education and infrastructure. The themes are described in the results, and the themes and clustering are further explained in the discussion section. The conclusions summarize all findings back to the research questions posed (starting on page 26) and the intent of the scoping review which is to inform the contents of a Patient Engagement Resource Kit. To ensure we have addressed the reviewer’s concern, and to ensure there was continuity of the research question and focus through the methods, results, discussion and conclusions sections, we made revisions to the manuscript text.

“Second, the methodology used is unclear and lacks a sound scientifically (transparent) description of how the study was carried out. It is unclear why papers were in- or excluded. No clear criteria were being described, nor was the rating procedure clarified. The authors just mention that articles were selected 'if deemed relevant' to the project. This is by far insufficient to claim any scientific method used. Moreover, no inter-reviewer procedure to discuss the papers chosen, was described.”

We have gone over the methods section of the manuscript and revised it to ensure that the steps in the scoping review were clearly described. The specific search terms used to identify the published and grey literature for the questions posed, as well as the inclusion and exclusion criteria for selecting or rejecting literature, are clearly identified in Table 1. The published and grey literature in a scoping review are screened, reviewed and either rejected or selected based on the search terms specific to patient engagement tools and guides and on the inclusion/exclusion criteria as listed. Figure 1 shows the flowchart for the numbers of articles selected or rejected using these criteria to refine the search and selection of articles for the research questions posed. The articles selected are not ranked or rated as they would be in a systematic review for their quality or the science, but rather, each article or item is selected or rated based on the search terms and set criteria as per a scoping review (reference provided). Each item selected is reviewed in detail using a review sheet designed for this scoping review of the published and grey literature which could be quantitative, qualitative, mixed methods or merely a report or practical guide used in some way with patient engagement. This is the accepted scientific approach for a scoping review as per description and reference. We have removed any reference to ‘if deemed relevant’ or ‘relevant to’ to avoid confusion with the scientific application of the search terms and inclusion/exclusion criteria. We do describe the inter-reviewer or inter-rater process followed in this scoping review, on page 5 under ‘Article Review and Selection’. We had three reviewers/raters as part of the process described. We made a revision to the text to ensure we captured this process clearly.

“Last, seven key findings were presented, some based on arguments with a literature reference, others lacking a reference, but it remains completely unclear on the basis of what these key findings were chosen and why.”

In the methods section we revised the last paragraph to include and clearly describe the thematic content analysis of all of the information gathered in all of the worksheets from the published and grey literature selected for review. Reference is also provided. This was originally in the results section as a lead into the emerging themes but is more appropriately situated in the methods section. The themes were selected as a result of the coding of the content information contained in each of the literature review worksheets. The codes from all of the worksheets were then clustered and these clusters were categorized by themes. Through the coding, clustering and categorizing process, we ended up with seven main themes. We did not invent these themes ourselves as they are based on the concepts coming out of the specific literature reviewed and analyzed. This description should now be captured in the revised ending to the methods section and the introduction to the results section.

Additional Remarks:
1. “An abstract is missing.”
We apologize but we had submitted an abstract as instructed through the manuscript submission site; so we are not sure what might have gone wrong with the upload of the abstract. We have now included the abstract with the manuscript text, so it is not a separate document. The abstract is structured into Background, Methods, Results and Conclusions. There are also Key Words provided.

2. (p2) skills, knowledge, tools and resources could fill ANY resource kit. What are specific problems encountered. Where are we looking for and why? We have described the issue or problem in the background starting on page 2, along with the questions we posed for exploration through the scoping review (pages 3 and 4). Our intent was to locate specific content items for a patient engagement resource kit that would provide skills, knowledge, tools, guides, and resources for targeted groups within healthcare service organizations (healthcare providers, leaders/administrators and patients/families) to use for effective engagement of patients in health services decisions. So, this is not just any resource kit but one that would be specifically developed for patient engagement. This rationale and the questions posed lead into the reason why we selected the scoping review method to locate the resource kit content items.

3. “The methodology paragraph starts with what belongs to the introduction paragraph.” This paragraph has been moved into the Background section as the paragraph preceding the methods section. A revised paragraph introduces the methods section.

4. “STARs are highly unappealing, can be anything” We have taken the initiative to remove STARS from the manuscript and replace it with simply ‘tools and guides’.

5. “(p4) Unclear of only English literature was included or other languages as well” This was stated in the Inclusion Criteria for both published and grey literature in Table 1, but we also included this in the Methods section (page 7).

6. “The rating procedure was not described” This was previously addressed as part of the second concern above. We have indicated that the rating procedure was described in the methods section, and we have gone through this section again and revised the text to ensure clarity on the rating procedure.

7. “Why a paper was classified relevant remains a complete mystery.” This was previously addressed for this reviewer under the second concern, and essentially, we removed this reference in the manuscript to avoid confusion with the application of search terms and screening criteria as identified in the text and Table 1.

8. “(p5) Once again: 74/193 articles/items were deemed relevant. Please indicate why and based on what” This was previously addressed for the reviewer and also corrected in the manuscript.

9. “On p6 the authors state in the last paragraph that defining patient engagement is confusing and hardly possible, whereas they presented a clear definition in the introduction paragraph of the paper.” Under the ‘Definition of Patient Engagement’ we clearly describe the situation discovered in the literature which is that there are many different terms and definitions provided for patient engagement,
which does make things confusing for the general reader of this literature, and makes it impossible to choose or decide on one definition. But we also explain how subjective some aspects such as meaningful engagement or effective engagement are, and this relates to stakeholder interpretation and expectations. People define patient engagement relative to their context rather than using a generic definition. Hence, we do state a definition used by Alberta Health Services in the Introduction paragraph, as this is the context for this review and need for a patient engagement resource kit. We feel this has been clearly described in the manuscript and noted for the reader so there are no surprises with the terminology used for searching or describing the findings from the literature.

10. “Whereas on p6 patient engagement was said to be confusing, on p7 the authors state that it is meaningful and successful...”
Again, this needs to be interpreted within the context it is written as we do explain these concepts on both pages. We do not state that patient engagement is confusing but that because there are many different terms and definitions for the same thing, it does become confusing to the reader to decide what is the best term and definition to use. We do not compare the confusing nature of the multiple definitions of patient engagement with how meaningful and successful it is – the Referee refers to a quote on page 11 which suggests that while we are accepting of the fact that there are diverse interpretations of what patient engagement is by stakeholders, there is still a common challenge around what is meaningful patient engagement. We think this quote is important as it shows the dichotomy in thinking about not only one definition for patient engagement, but also one for what is meaningful. This is important to consider when reviewing literature for content within a resource kit, as there are many approaches to patient engagement and different tools, models etc. We have clarified this in the discussion section.

11. “After stating that patient engagement is confusing, it is an open door to conclude that stakeholders differ in their explanation of what patient engagement is/ consists of.”
I think we addressed this in concerns 9 and 10 above.

12. “P8 Interventions are mentioned, it would be nice to know what these interventions are.”
We could not locate ‘interventions’ on page 8 of the paper, but we did have ‘interventions’ mentioned in the Background, first paragraph in which “‘best practice’ or evidence-based interventions” is mentioned in context with patient- and family-centred healthcare, and referenced accordingly. We do not have specific interventions in this instance as it is not part of the scoping review nor is it in the results, discussion and conclusions sections. We have left this term in the opening paragraph as referenced, as it is important to the principles of patient centred care.

13. “Topics and themes come out of the blue, it would be nice to justify the use of these based on literature”
The process for deriving the themes is a qualitative approach identified as content thematic analysis. We have tried to clarify this in the methods section on this thematic analysis, and have also inserted appropriate references for this. We think this concern has now been better addressed in the method section to clarify that there is a process for deriving the themes from the literature.

“I hope that the authors will be able to sharpen the research question, afterwards they will be able to answer the question making use of a valid scientific method to do so. They now possess a lot of
literature they already categorized, so they for sure will succeed in re-writing this paper in a way it can be considered for publication."

The authors have reviewed the entire manuscript with reference to this concern. We believe the research questions in the Background are the appropriate ones for this manuscript and scoping review study. The scoping review is a valid scientific review method and we attempted to clarify this in the manuscript as well. The findings from the scoping review provide answers to the original questions and informs the content for a Patient Engagement Resource Kit. We have attempted to address each concern raised by this and other referees and have revised the manuscript accordingly.

Referee 3:
Major compulsory revisions

• The scoping review is based on the methodology such as outlined by Akrsey and O’Malley. Given that well-established systematic review methodologies do exist, especially within the Cochrane collaboration, the authors must provide a good rational why they did not use a standard systematic review method. For example, why did they not rely on Grades of Recommendation, Assessment, Development and Evaluation Working Group (GRADE) for assessing the quality of the available evidence?

We have included a statement as to why the review method and working sheets are unique with scoping reviews. This review involves a comprehensive search of diverse literature in published and grey literature sources, and we are not assessing quality of any study or process, but rather gathering information on different tools, guides, and resources (inserted in pages 7 and 8).

• In the result section subchapter 4, the barriers to patient engagement are nicely outlined in a bullet list. As importantly as the barriers are also the enablers for increased patient and family engagement. In consequence, the scoping review should also add the results of the enablers.

The barriers and benefits are derived from the literature, and we explain in the manuscript that by addressing the barriers we should then be looking at enablers of patient engagement. But the literature does not reference enablers, only barriers and benefits. So, we will need to maintain this latter terminology but include a clarification on enablers.

• Not much is said that across the manuscript that one of objectives of increased patient engagement is behavioural change of patients (e.g. within smoking cessation activities or diabetes control). Please extend on this aspect.

The focus of the scoping review is really on tools, guides and resources to facilitate/implement patient engagement. Some of our search exclusion criteria included patient engagement in their own care decisions and personal health outcomes, so we did not explore personal healthcare decisions. Instead, we focused on patient engagement in broader organizational healthcare service or program decisions. Behavioral changes of patients did not appear in the articles or items identified and selected. Behavioral change was also not one of the benefits identified in literature on general patient engagement in health care service decisions. As a result, we cannot include this in the results we have without compromising the selection terms and criteria set out originally.

• The result section is structure along 7 themes. The authors should strongly consider to restructure the organisation of these themes along: Inputs, Process, Outcome. If this logic is followed, the sub-chapter 6 in the result section on engagement resourcing is to be considered as input to patient and family engagement and should come at the beginning of the result section)
The themes are derived through a scientific qualitative process from content thematic analysis of the published and grey literature (as referenced) and we cannot replace them with generic terms of inputs, process and outcomes. We have tried to rewrite the methods section to reinforce the qualitative analysis as important to the identification of the themes described in the paper. The authors do not feel it is appropriate to use the generic terms to replace the themes found and described in the results and discussion sections. The scientific approach used and described in this paper (i.e. scoping review) is credible for determining the themes and terms we have used in this paper, and therefore justify our reasons for staying with what we have in the paper.

- **The discussion section is somehow not well tied to the result section. In other words the discussion section is not used to discuss the 7 themes identified in the results section and the strength and the weaknesses of the results found by the scoping review but rather provides a discussion on topics such tools used for patient engagement. Please align the discussion better to result section thereby eventually used the logic mentioned above (inputs, process outcome for/of patient engagement).**

  We have gone through the discussion section and aligned it more appropriately with the results section. As previously explained, we still need to use the themes coming out of the literature, and the use of inputs, process outcome for/or are too general or generic for the results of this scoping review which will inform the content of a patient engagement resource kit. We hesitate on including terms which might confuse the results of the scoping review with a logic model where inputs, process outcomes and outcomes/outputs are found.

- **There is no abstract. This has to be added**

  We noted this concern and cannot say why our abstract was not included. But we have now included it with the manuscript text as per the guidelines provided.

**Minor compulsory revisions**

- **On page 2 there is the sentence “The actual resource kit, its pilot and evaluation within AHS, are described in other manuscripts.” Either drop this sentence or add the references.**

  We have deleted this statement as the manuscript is in review.

In conclusion, we have attempted to address each and every concern raised by the three referees, as best as possible for a scoping review. We have revised the manuscript accordingly and where we felt we could not make changes as they would alter the actual method or possible meaning of this scoping review process or findings, we indicated that in our responses. In some cases we removed terms if they were not that important to the meaning of the manuscript. We hope these responses and clarification as well as revision of the manuscript address the concerns.

We look forward to your response to our covering letter and revised manuscript. We have attached the manuscript with the tracked changes and a separate title page and figures.

Thank you again for the review and consideration of our manuscript for the journal.

Sincerely,

Katharina Kovacs Burns
Corresponding author