Author’s response to reviews

Title: Understanding patient engagement in health system decision-making: A co-designed scoping review

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Version: 1 Date: 08 Feb 2019

Author’s response to reviews:

To Whom It May Concern:

Thank you for your insightful comments and the opportunity to revise and resubmit our manuscript. Please find a point-by-point response to the reviewers’ comments.

Sincerely,

Tamara L. McCarron
*A table of responses to each reviewer comment has also been submitted in the file upload area.

Reviewer #1

Although the James Lind Alliance and HTAi do not provide investment opportunities such as training they do provide resources (HTAi online) and JLA (handbook). EUPATI is an excellent example of the focus of this review and it will be exciting to see the results of these efforts. We have added the following

Any studies these organizations may have published either did not meet our inclusion criteria or were published after our review was completed. Grey literature was also not included. However, given the national focus and ability to impact this area, we added an acknowledgement of all three organizations in the discussion section. Thank you for this observation!

Lines: 296-303

Reference to Arksey and O’Malley has been removed from the methods portion of the abstract.

Line 53

The methods section has been rewritten to provide additional clarity. We removed the definition provided by Colquhoun to improve clarity. Thanks for this suggestion.

Lines: 109-111

We have updated the title to reflect the domain of patient engagement. The title is now: Understanding patient engagement in health system decision-making: A co-designed scoping review.

This domain specification has also been made clearer in the background information by indicating participation in healthcare decision-making across the entire health system.
This domain of patient involvement been made clearer.

See previous response.

At the time of submission, there were no reviews. There are now two – one systematic review and one narrative review. We have listed these reviews in the background section.

Removed the research question in the method section and further clarified the background section.

The steps identified in Lines 117-119 are the enhancements as per Levac et al. There is current debate in the academic literature about whether a quality assessment should or should not be conducted in a scoping review. We did conduct a quality assessment and since it is not part of Levac’s suggestions for a scoping review, it is included separately.

We have omitted “in addition, some researchers…” and rewrote the justification.
PRISMA ScR guidelines suggests several different frameworks including PICO but we
determined that a modified SPICE approach was more appropriate to our research question.

Lines: 115-117

These two sentences have been moved to the co-design and co-investigators section.

Line: 129-135

We indicated that the search strategy was designed in collaboration with a librarian.

Line: 141 and again on Line: 144
We reorganized the eligibility criteria and study identification sections. We have refined and
further clarified.

Lines: 150-157
Moved and great comment.

Lines: 180-191.

*Please note: the table numbers have also been updated to reflect this move.
Data extraction worksheet has been provided in Appendix 1.

This section has been updated to describe how items were identified, selected, and calibrated.

Lines: 195-197
Synthesis header added to data extraction header. Added a paragraph to describe synthesis process.

Lines: 199-205

Omitted bullets. See Table 3 (Formerly Table 1).

Added column for study design.

Added column for description of themes

Added a description for each theme

Added column for outcomes.

Instead of domain, purpose of study was already included which we believe provides domain information and focus of study.

**please note: this is now table 3.

Added a column for study theme.

Thank you for identifying this oversight. We have address this.

Lines: 220-225

We feel we have adequately described the four themes and are unsure how to proceed. We would be happy to receive further comment and guidance about how best to address this comment.
We have addressed this, please see table 3 (formerly table 1).

Although the James Lind Alliance and HTAi do not provide investment opportunities such as training they do provide resources (HTAi online) and JLA (handbook). EUPATI is an excellent example of the focus of this review and it will be exciting to see the results of these efforts. We have added the following

Any studies these organizations may have published either did not meet our inclusion criteria or were published after our review was completed. Grey literature was also not included. However, given the national focus and ability to impact this area, we added an acknowledgement of all three organizations in the discussion section. Thank you for this observation!

Lines: 296-303

Reviewer #2

We no longer have 2 difference research questions. We have changed the title as per the other reviewer’s comments and the questions now better align with the objectives and methodology.

Lines: 103-105

Investment was defined in two ways: the traditional definition and the act if devoting time, effort or energy to something. LINE: 131-135

As a result, these studies are not considered out of scope as they illustrate the patient/family member investing in building the knowledge and/or understanding of the medical/dental student and these studies expand our definition of investment to include an investment of time, as in providing patients with the opportunity and space to participate in health care delivery/health system improvements through participation in student training.

We have also further clarified this nuance in the study theme section and hope this satisfies your comments.
We aren’t suggesting a cohort of patients represent all patient groups. We are suggesting the importance of building a group of patients who have the skills, confidence and ability to engage in all aspects of health system decision-making. We believe this requires the active training and development of these individuals and we were curious to see how this was currently occurring in the literature.

The background section has been further clarified:

This requires a critical number of qualified patients and family members who not only want to engage, but who are who also qualified and confident to work in partnership with healthcare professionals and other stakeholders. This involves harnessing the skills and further building the capabilities of patients to support their participation in healthcare decision-making across the entire health system.

We have slightly revised this statement so we are no longer implying that in order to make engagement meaningful it is necessary to educate patients. It now reads:

This area of patient engagement is not well defined, and it is unclear what strategies are currently being implemented to promote the active engagement of patients in building their skills and capabilities to support their involvement in healthcare decision making.

Training healthcare professionals is also an important concept, just out of the scope of this paper.

We further clarified why we think this line of inquiry is important:
Research has demonstrated that patients who take part in their healthcare decisions are likely to also have better health outcomes [15]. Following this line of logic, we can assume patients who actively engage in opportunities to improve healthcare decision making may have gaps in the education and the training required to participate as an equal partner.

Lines 85-89

Thank you for this very thoughtful comment and observation. The authors agree, using and reporting the benefits of codesign is a very important concept. We are currently publishing this in a separate publication.

We added informal feedback into the discussion section on the patient involvement in our study.

Lines: 307-310

The text has been revised to include the study number as opposed to the percentage. In addition, a new table 1 of study characteristics have been added to further clarify. Thank you for your suggestion.

Lines: 212-217 and Table 1.

Thank you for this observation. We have restructured as per your suggestion.

Lines 253-265

We have further clarified how the gaps were identified.

Line 275-279