Author’s response to reviews

Title: Patient-Oriented Research Competencies in Health (PORCH) for Researchers, Patients, Healthcare Providers, and Decision-makers: Results of a scoping review

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Responses to reviewer comments:

Reviewer 1:

Reviewer comments on the variability of terms used, and addresses the issue of interpretation and meaning of terms used by authors we reviewed.

RESPONSE: We appreciate the comments on meaning of terms. We present our competencies using the terms of the authors. However, we can note and reflect on the fact that because there is no global consensus of meaning or what terms are best used in what settings, there is no way to assure we and published authors are using words to relate a common message. We can surmise that ‘patient-oriented’ research in Canada is similar to ‘patient-engaged’ research or to ‘patient involved research’ elsewhere. We have added a section on terminology and meaning of terms in our discussion section (expanding what we already had in that section) to address this issue.
We also expanded the discussion on our search terms to add this dimension of the challenges of working in this field.

We agree that such a discussion is crucial to moving the science and work in this field forward.

Reviewer 2 Comments:

Re Abstract:

reviewers asked us to list at least some competencies found for the clinician and decision-maker stakeholder groups.

RESPONSE: A sentence was added to present competencies for these groups.

Re Introduction:

• questioned lack of mention of ‘co-production

RESPONSE: We added ‘co-production’ to the list.

• asked US to address the diversity of activities that service users undertake under the umbrella term of PPI

RESPONSE: Our project did not set out to look at ‘service users’ or those who might be considered ‘consumers of service’ in North America or other locations. Our focus was directed only on the competencies (knowledge, skills and attitudes) needed for members of a research team that is undertaking patient-involved research. [We use the term ‘patient-involved’ as an overarching, generic term to include research teams having a patient or community partner as a member of the research team – more on this below]. As such, service-users was not a search term/phrase relevant to our scoping review.
• requested we add a statement to explain why POR is important

RESPONSE: We added statement of POR’s importance (in producing different knowledge or in providing a different perspective in looking at research priorities and interpretation of data).

On Page 7

Questioned why did the author team not include patients?

RESPONSE: We added additional information about both our scoping review method and the ways in which we as ‘scoping reviewers’ involved patients and other stakeholders in our work:

"The purpose of a scoping review is to examine literature as widely as possible and to report clearly what the literature on the topic states. A scoping review does not interpret, prioritize, or filter the information presented in the literature in any way. Our author team was comprised of a group of individuals with background and expertise in conducting such reviews and included an experienced health librarian who could guide the search process. Our methods section and our scoping protocol detail our process in finding, retrieving, and reporting literature. Our belief was that patient-partners as well as members of each of the other stakeholder groups could best contribute by assisting us to interpret and evaluate the competencies reported in the literature. Therefore, in the second part of our work where we looked at and reflected on our data, we asked members of our Advisory Group to examine what we found, tell us if they believed the competencies reported were important, resonated with their experiences, and ‘fit’ with their views of what members of patient-involved research teams needed."

We have rewritten the methods section to make clear that we have conducted this work in two steps, first the actual scoping review and the second the reflection on what we found. We have also noted the makeup of the Advisory Group for clarity.
Additionally, at the beginning of the ‘Data Analysis and Findings’ section we have added a sentence to make it clear that the competencies reported come directly from the literature with references provided for each competency. We have cautioned the reader to understand that any one of the competencies might be ‘disputable’ -- in our report of what is in the literature, we did not filter, change, or omit any idea that appeared. Keeping to our goal of presenting a complete scoping review, the competencies presented are a summary of what we found. The discussion section provides the comments on the relevance, usefulness and interpretation of those competencies. Input from patients and other stakeholders was critically important in this part of our work.

Reviewer comment: Expected to see terms of ‘service user’, ‘survivor research’, ‘peer research’, ‘community participation’, or ‘community engagement’

RESPONSE: In our search and reading of literature (that brought us to 2,414 articles) we were focusing on competencies needed to conduct patient-involved research. Initial searches in phase 1 of our search process documented that searching the literature for terms/phrases such as ‘patient participation’ led to literally hundreds of papers that did not address research competencies. Thus the terms suggested, while they may be useful in understanding the full range of ways that individuals participate in the health system (or the health and social care system), were not directly related to our search questions.

On Page 11

Reviewer questioned about how our data (competencies reported) were ‘grouped’ and asked about the skills of those team members who completed this work.

RESPONSE: Where we reference ‘conventional content analysis’ in our section on data analysis, we have explained how this process is used to group data into themes. We also noted that members of our author team were highly experienced in undertaking this work, having used this method multiple times in other projects.

Further, we added comments to make it clear that all of the raw data from this project are available to the public through our university’s open-source repository. As such our data is transparent, such that anyone can look at the data and draw their own conclusions about the competencies reported.
Reviewer asks if the statements in the results section are from the 35 papers reviewed. . . wasn’t clear if the competencies reported are from the literature.

RESPONSE: We’ve revised the introductory statement to the presentation of the competencies:

"We present the themed competencies of knowledge and skills for each stakeholder group, followed by the attitude competencies, which were not grouped into themes. Additionally, our findings yielded a set of attributes, related to – but distinct from – attitudes. We report these in the ‘attitudes’ section. We supply the references from both the academic and grey literature for every competency listed. The competencies under each theme are organized so that the competency that was noted most frequently is reported first. In keeping with our purpose of presenting findings from a complete scoping review, a competency that may have been noted only once is still reported as part of the data we reviewed. The reader is cautioned to understand that the competencies are data from our scoping review and reflect published statements from persons writing on the topic. These do not necessarily represent a global consensus of the knowledge, skills or attitudes/attributes needed for patient-involved research. The interpretation and sense of appropriateness or usefulness of these competencies is addressed in our discussion section."

Reviewer noted that the competency of ‘researchers are expected to understand participatory research is an approach to research and not a method’ could be contested.

RESPONSE: We agree, any one of the competency statements could be contested. This one is a statement that came from reference #52: Reed J, Weiner R, Cook G. Partnership research with older people - moving towards making the rhetoric a reality. Journal of Clinical Nursing. 2004;13(3a):3-10.
We realize that this statement was made by only one author group, published in 2004 and may or may not find agreement by all in the field. It is reported as our means to present ALL data related to research knowledge that was found in literature.

ON Page 13

Reviewer raised several questions on use of words: involved, engaged, partnership, community, patient-involved researcher. . . .

RESPONSE: For each competency, we report our findings using the terms used by the authors of the publication(s) reviewed.

Because these authors come from many geographical locations, the meaning of such terms lacks the clarity anyone would like, as we are working without a common global consensus of meaning for any of the terms.

Following the related comments from Reviewer 1 we have expanded our discussion section to address the complex issue of terminology and the fact that there is no common agreement or consensus about what terms like ‘community’ ‘partnered research’ ‘involved’ or ‘engaged’ mean. We recognized early on that this lack of common terms presented a challenge to even conducting a literature search; we can reflect on our findings to see that that meaning of the published work lacks the clarity one would like if we are to move the science of patient-involved work forward. We urge researchers/authors to define the terms they use and to move toward a global recognition of terms and their meaning. (see section 4.5)

Re Page 23

Reviewer asks: who are the expert group of advisors?
RESPONSE:

This information has been added now in the section on describing the phases of this work and the use of the Advisory Group – see page 7 comments

On Page 26

Reviewer asks us to consider the use of 'critical friend' when discussing dissent.

RESPONSE:

- The notion of ‘critical friend’ has been incorporated in the discussion section.

Reviewer asked: Did literature pick up on the debate about the term ‘lay’?

RESPONSE: No, our literature did not pick up this term. It is another term that lacks clarity in the field. Note that we define patient partners and including patients, family members and community members. Given that some patients take on the researcher role, the term lay is confusing. We've added a comment about patients taking on this role in the discussion section.