Reviewer's report

Title: What does it mean to engage consumers and communities in health care? A scoping meta-review

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Reviewer: Jessica N Mittler

Reviewer's report:

This manuscript aims to present and discuss the key concepts, terminology and activities in the area of engaging consumers and communities in health care based on a scoping review of materials published in 2010-11. The authors are on point in their assessment of this area as being unwieldy and unorganized, which contributes to difficulties in understanding and assessing consumer engagement interventions and their impact. However, this draft does not yet deliver on its promised purpose to present the state of the field and then bring some helpful discussion and organization of key concepts, key activities, key gaps in knowledge, and opportunities going forward. I see the potential to add to the field by presenting results from a scoping review, however, it may require a substantial amount of additional analysis and deep thought.

Note: My review is on the long side. There are actually only a total of 7 points, 3 of which I qualified as minor. These points are numbered and bolded. The length is due to my attempt to be helpful and constructive by providing insight into my thinking, the rationale behind my suggestions, and some examples to illustrate how I arrived at my points. The length and detail (and exclamation points) are representative of my enthusiasm for the CCE area and my sincere sympathies and support for tackling such a tough topic (and, frankly, no time to edit). I hope my review helps. Good luck.

Major Compulsory Revisions

1. Clearly and consistently state the purpose of this paper and make sure to clearly address all of the promised parts.

The aim(s) of this paper were inconsistently presented:

-- In the abstract, the purpose is to “explore the terms, phrases and types of activities currently used within this field with the aim of identifying and systematizing some of the key conceptual variation,” in order to provide “…new insight into the relationship of phrases and concepts related to CCE in health care. This identification of different types of activities and concepts will help to focus studies and initiatives.”

-- In the background section (4th paragraph), the aim is to “map out relevant types of activities and related phrases within this field, in order to: assist in clarifying the definition of CCE; assess the size of the challenge for the health care system and patients; identify ways to focus and tailor strategies and interventions; and identify the role that patients might adopt within these
strategies."

While related, the two presentations of the aims emphasize and promise different things. For example the second promises a definition of CCE and assess the challenge to the health care system, using an activities based approach. The first only discusses concepts and how they relate to one another. I kept getting confused about what the article was trying to do – come up with definitions? Come up with a framework of concepts? Come up with a way to characterize activities? Assess the evidence of what works? Some of the above? All of it?

The point is that the purpose has to be VERY clear and precise (i.e. what does “relevant types of activities” and “related phrases” mean?) Maybe it’s “map out activities called/referred to as CCE and amass the phrases used to describe these activities(?) and their purpose(?) in order to identify/characterize the different dimensions of CE currently being explored and the implications for ……”.

That’s a run-on sentence, but hopefully you get the idea. Be very specific and forthright about what I should expect to know when I finish the paper.

Then you have to deliver. One of problems I had with this paper is that several pieces promised up front were not delivered at all or insufficiently delivered. For example, there was almost no characterization or analysis of the systematic variation in key phrases and concepts or what the variation means – mostly concepts were just listed; no text/presentation of systematic variation in activities and their attributes; no presentation of clarification of the definition of CCE (and no definition really presented at all); no discussion of the “size of the challenge” (whatever “the challenge” is) for the system and patients; and no identification of ways to focus/tailor strategies or identify the role patients might adopt within these strategies. (This is all too much for one paper, I think. Focusing your aim will help with this).

2. Make new contribution and importance very clear and more compelling.

I think that the aim of this paper is important, but I wasn’t sold by the way it was presented. First, there is a lot of vague language “CCE has received growing attention over the last decade [1]. Yet CCE remains one of the most difficult areas of health care to define accurately. CCE can occur in different fields, in different ways, and for a variety of purposes.” I’m asleep. Attention by whom? For what? What do you mean by accurately? I don’t know what this means. Is it really one of the most difficult? Basically, choose your words carefully and be precise. Make it clear – who says? How do you know?

Another example, “The problematic nature of this melee of terms is well understood [9-12]...the use of common terminology for disparate activities can lead to controversy as the claims of and for such activities are contested.” (a) Don’t tell the reader it’s well understood – just get to what the problems are and why important (b) Present all the key, germane problems, not just one (without any explanation as to why this one is the only salient piece for this area/analysis.) (c) simplify language and connect explicitly to issue at hand. I think you are trying to indicate here that it’s hard to synthesize and evaluate evidence if it’s difficult to know if we are comparing apples or oranges. Just be more straightforward.

Second, the new contribution is problematic because of a couple of peer
reviewed and grey papers outside of the 2010-11 year that address similar questions (I list them below). I think that this manuscript must acknowledge this other work and point out how it is different/adds to the field. This manuscript’s potential advantages are (based on my remembrance of these articles):

--if/when the scoping review is more or less systematic then the others
--if/when the scoping review includes broader/different searching techniques
--the analysis is provides different kinds of information (for example, activity types or summary of evidence about what works)

The articles that immediately popped to mind are:


--This one talks concepts, terminology and has a framework.


--Intro in this one discusses some key concepts; differences between activation and engagement


--Has a framework to classify activities.

Third, the new insights from your analysis are not clearly presented (see #3 below for further discussion).

3. Clarify and revisit the methods

The authors’ description of their methods was insufficient to give me confidence in their findings. You know what you did, but I had trouble understanding exactly what happened. Too much hand-waving going on. The problems fall into two areas: (a) methods choices/approaches and why suitable for question at hand and (b) vague language/lack of detail,

(a) methods choices/approaches

First, selection of scoping review and definition of scoping review. The authors wrote: “it was deemed feasible and appropriate to undertake a scoping overview of existing systematic reviews on CCE in health care”. What is it? WHY is it appropriate? How exactly is this a scoping review rather than a review of systematic reviews? It was great that you cited (#18) the Levac, Colquhoun and O’Brien paper “Scoping Studies: Advancing the Methodology”, but you need to say a little more about what a scoping review is and how it is well-suited to your mission.

Second, although you say a scoping review is “wider” than (other?) systematic reviews, you appeared to select databases that are predominantly peer-reviewed, and you provide no rationale for why these databases. So I am unclear about what areas you are surveying and how wide you are going and if
you are including gray literature or not.

Third, as written it seems that you chose to limit the articles to 2010-11 to reduce the number of articles reviewed. This criteria for narrowing down the review does not make sense to me. You say that “a time limit of 2010-11 was set at the later stages of the review given the large number of systematic reviews identified.” I don’t follow. Wouldn’t the exclusion criteria then be to only review systematic reviews, and not the date?

In addition, this one year approach excludes important information (and seminal papers) from your analysis, which contributes to some misleading conclusions/statements. As I explain further in analysis below, conclusions like shared-decision making increases patient satisfaction but no effect is observed on clinical outcomes cites ONE paper and that paper’s focus is mental health. As written, it seems like the question has been settled; and it hasn’t. Another example is that the citations (four) for the impact of peer support are for AIDS/HIV, diabetes, mental health, foster children and neonatal care. These are very specific slices of this literature. Limiting to one year means you missed seminal work like Kate Lorig’s experiments with peer support among the chronically ill, which are touchstones for many in the field. I am very, very concerned that you are presenting your review as systematic (first sentence as methods) and wide, but it actually does not reflect the state of the field. The review of evidence of effect, in particular, is incomplete and overinterpreted (i.e. used to draw more general and widespread conclusions than a study or set of studies actually supports). [Aside, did you do any assessment/rating of studies’ methods? Or reviewed all comers? Ok either way, but just need to say and justify].

Fourth, the reliance on systematic reviews doesn’t make sense to me for your aims. If you are focused on describing the prevalence and types of terminology used, then the systematic reviews may be misleading since the reviewers are summarizing others’ work in their own words. In short, you aren’t seeing the original terminology. If prevalence is not important, then say so. And do the systematic reviews you identified provide the information you want anyway? I am not sure they do. Systematic reviews can be narrowly focused and may not include key pieces that are germane to your question at hand (e.g. areas where there isn’t a lot of existing work to synthesize or reviews that focus only on quantitative work). Plus, you selected items based on search terms that don’t include any of the particular activity names, so if the consumer engagement terms weren’t used in conjunction with the activity terms, you are missing evidence (this may not be a big issue, but because key evidence was missing, I thought it might be. I hypothesize that the missing evidence is probably more a function of limiting the year, but there may not be systematic reviews in some of your activity areas.) So, I am not convinced that this one year, systematic review centered approach is well-suited to the aims you outline, especially the discussion and use of terminology – you’ll need to convince me (the reader). [For example, explain/show that the reviews cover a broad time span, broad areas, cover the info/topics you are analyzing, etc. Just EXPLAIN your choices. Don’t hand wave and say “Trust me”. It’s totally ok not to do everything in one paper,
but just JUSTIFY what you are doing and how it suits the aim of this study and be forthright about limitations.

Fifth, quality assurance and reliability/validity is suspicious. After the selection of the articles, it seems that only one person was involved in extraction and analysis. Why should I believe what this one person found? Why is this sufficient? Also, the processes are not well described, especially after the article identification. (And even the selection of articles was a bit mystifying – what does “citations were first excluded based on title and abstract” actually mean? What were the criteria?). For example, the abstracting/extraction process is not well described – there is a PRISMA checklist in the appendix but it is not mentioned in the text, nor is its suitability or application explained. And what analysis and syntheses entails after the final set of articles is abstracted is totally missing. What did the author(s) do? What was the process? What subsequent decisions/criteria were made? I do not know how to evaluate the results because I don’t know how they were produced after abstracting the final set of articles. How does the analysis approach result in answers to the paper questions? Analysis and interpretation is not explained almost at all.

(b) vague language

Overall, there was too much vague language in the paper, but in the methods it was especially prominent. Scoping reviews are “wider”, meta reviews are “appropriate” when “adequate” systematic reviews on a topic are available. I don’t know what the words in quotes mean. “Citations were excluded by title” – passive voice masks what was going on – and the table was “cross-checked” is insufficient. What do you mean by cross-checked?. Be clear. Super, super clear. You don’t have to be perfect for me/the reader to believe you, you just have to be honest and clear and explain.

4. Revisit and enhance the analysis, conclusions and discussion (Results and Discussion)

The analysis and synthesis is poorly presented and in some cases missing.

First, the section variations and complexities in types of activities and terminologies near the beginning of the results section is two paragraphs long and has one sentence about terminology. If this is meant to be an introduction to the section, then make it short and straightforward. In this section we present the nine distinct (?) activity types followed by discussion of the terminology. Unless it’s the style of this journal, just saying, here are the figures and tables here is totally confusing. Present and integrate into the text where relevant. There is little evidence of systematic synthesis in the results regarding concepts and terms.

Second, the analysis of concept overlap and differentiation is essentially missing. There is one sentence in the intro that says “evaluation confirmed… that phrases like ‘community engagement’, ‘patient involvement’ and ‘consumer participation’ are used to describe different activities” but then the evidence is never presented or discussed after that. Figure 2 lists terms by activity, but there is no analysis of which terms are common or where points of overlap or distinction are. The table itself is not the final analysis – it’s a tool for the next step – where are the common points, or types of variation, and what’s important here. Results has to
highlight these things for the reader and then the importance and additional insight is drawn out in the discussion. The section on CCE related concepts never actually discusses how the concepts are related to CCE. As is, there is no analysis presented here that helps generate any insight. The bottom line as presented is: there are multiple terms. [I didn’t understand the purpose of Figure 2. What does this mean? Was this to generate the common terms or the list of activities? I was confused].

Third, and likewise, the activities are not systematically compared and analyzed effectively. It’s mostly description of activities. Where is the presentation of overlaps, differences? This is the analysis that is supposed to underlie the “new insights” in your discussion. It’s missing. I read the list of activities, but didn’t know what to do with the information and what to make of it. The list didn’t bring me any clarity or deeper understanding about the concepts or the evidence. Specifically, I couldn’t see how the information spoke to the paper aims (e.g. identifying and clarifying gaps, tailoring activities, and so on). The reader needs more guidance. Where is the actual analysis across activities (and even within)? What distinguishes them? What new insight does the list provide? At this point, I can’t say: it’s not discussed in results or discussion. Help the reader make sense of all this. For example, some activities are labeled by mechanism (e.g. peer support); some by level of focus (e.g. health care system design); and others by outcome target (e.g. health promotion, access to services). And some are a mix, like “community-based health promotion”. In the discussion on page 9 you refer to the these as 9 “forms” of activities. I don’t know what you mean by forms. Perhaps there is a way to organize these activities in some kind of logical way to help the reader follow. But above all, there needs to be analysis presented of these activities. It can be at the end of the section or integrated into the descriptive pieces for each activity but sense-making needs to happen in the paper. Most people can make a list of activities, but drawing out the key themes and what they mean is the tough part! This analysis is missing, and I think it’s a big part of why the discussion leaves me wanting. More research is too easy. Give me that new insight, even if it’s we couldn’t tell if X or Y.

Fourth, there as discussed in methods, your study sample of papers does not seem to be well-suited to assessing and presenting the breadth and evidence state for each of these activities. My skim of the references really concerned me because many of the papers were narrowly focused (i.e. mental health) and there was almost evidence that the authors took this into account and how it affected their interpretation and synthesis of data. Another example from p9 is the authors’ statement that “there is general agreement that more evidence is required for the success of interventions aimed at enhancing patient empowerment” -- but the citation is a review of web-based interventions. So is this conclusion just for web-based interventions or is it broader? General agreement among whom? Web-based interventions are just one way to try to improve empowerment. This conclusion is misleading as presented. Sharper presentation of what is known and not known will set up a more meaningful discussion. The vague conclusion that there isn’t enough evidence and more research is needed is, quite frankly, lame, and not new. Be specific! Interpret! You don’t have to know everything. This is complicated. But make some
interpretations and justify! For example, I am confident that the degree of knowledge across the activity areas identified is not equally bad. Or if you think it is, say so. You did the review, so you know. Present what exactly is missing, bad, good, and why it matters. Give us some ideas about where to go from here. What’s the new news? If keeping assessment of the evidence, authors need to be clear about what assessing exactly (i.e. effectiveness, populations studied, conditions studied, mechanisms, etc.) If identifying gaps or how to tailor is an aim, then need to address specifically. If evidence of effectiveness isn’t going to be thoroughly presented in this paper, then that’s fine, but be clear about what doing and what not doing. Don’t have to do everything in this paper, but what you do has to be clear and meaningful. This may mean cutting some parts, or additional analysis.

Minor Essential Revisions

5. Organization of the paper
The results and discussion are framed by the nine activities. This framing came a surprise to me after the up front part focused on general concepts and didn’t emphasize the different types of activities AND, perhaps more importantly, how digging into this area by focusing on identifying and comparing activities makes sense to meet the paper aims. Understanding CCE by identifying key activities, their characteristics, and how they are described actually makes sense to me. The key is to present and keep this thread throughout the whole paper (and make sure the connection to the aims is done somehow). An alternative is to organize the paper more clearly by key aim areas.

6. Tables and Figures
These should stand on their own. Titles, Source(s), key, and so on.
Also consider how to make Table 1 even more useful – maybe number of articles that mention activity; some sort of highlighting of terms to indicate which ones are most prevalent (and then might be able cut figure 2 and substitute in a figure or table that identifies the key conclusions/analysis themes); make aim part of table 1 more descriptive – instead of health “in general” maybe say population health?; and maybe dichotomize consumer role description into “active “ and “passive” ? “recipient “just seems odd. Or maybe participant and beneficiary?
Not all of the columns are discussed in the paper. When revisiting aims and analysis part, revisit which ones are key.

7. Precise, simple language and clear attribution of results and conclusions
Attribution is sometimes unclear and vague language is part of the problem. Specifically, watch the “they” “it” “we” and make it very clear when you are presenting your analysis/synthesis vs. others’. For example, on the top of page 7 the authors write, “the involvement of individuals needs to be implemented with caution…”. Who says? Is this your assessment or is it from a paper? Make it very clear when it is your analysis and give indication of how you weigh the data. You concluded this based on one study. Give indication of how trustworthy this study is. Plus, why should we be cautious exactly? And what do you mean by cautious? (Ok, so the why might go in discussion, but the point stands about
being precise and showing WHY you came to that conclusion.) SO terms like “it was appropriate” or phrases like (p6) “it is necessary to distinguish between these two types of involvement; and to be transparent about it” – what's the it? Transparent about the need to distinguish? Or transparent about …? You are thinking of something specific, so just tell the reader.

4. Participation in research vs. collaboration in research design and conduct – needs some refining.

As written, the two are not crisply distinguished. There is some language in “participation in research” that suggests some of the activities in “collaboration in design”. But then there is a sentence that says, in contrast to participation in research…. And I became confused because it seemed to me that they had some overlap, but it seemed like you were trying to say that these activities were mutually exclusive. So review and make sure that your language clearly conveys which of these possibilities you have in mind (is a research subject, is part of the research team (to some degree) or both).

Discretionary Revisions
N/A

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Not suitable for publication unless extensively edited

**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 below.