Author's response to reviews

Title: The impact of patient advisors on healthcare outcomes: A systematic review.

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Author’s response to reviews:

Re: Manuscript submission # BHSR-D-17-00694 (BMC Health Services Research)

Title: The impact of patient advisory councils on healthcare outcomes: A systematic review

Authors: Anjana E. Sharma, MD MAS; Margae Knox, MPH; Victor L. Mleczko, MD; J. Nwando Olayiwola, MD, MPH, FAAFP

Dear Editors of BMC Health Services Research,

Thank you for your review of our manuscript. We have numbered the reviewers’ thoughtful comments and added our responses below. We have reviewed the Editorial Policies and believe we have addressed all requirements including Declarations and Availability of Data. We hope we have addressed the recommendations satisfactorily. Thank you for the opportunity to work with your editorial team.

Best regards,

Anjana Sharma and coauthors.

Comments from Reviewers

Reviewer 1:

1) It is strongly recommended that the authors use the PRISMA checklist to report the review.
We appreciate the recommendation and have included a PRISMA checklist with page numbers to report the review in our supplemental materials/appendix.

2) The objectives are clearly stated, however, "patient satisfaction", and "patient experience" are used interchangeably in the manuscript. Please clarify.

We have revised the manuscript to use the term “patient satisfaction” consistently. We use the term “experience” now only in the context of “experience-based codesign,” which was a distinct patient engagement strategy that arose in our results, in order to avoid confusion to readers.

3) Systematic reviews should be included in the background, and not in the results section.

We have listed two systematic reviews within our results, as they were unknown to us prior to conducting this review and were uncovered within our review process. We had followed the convention of another systematic review of patient engagement in safety (Hall J, Peat M, Birks Y, et al. Effectiveness of interventions designed to promote patient involvement to enhance safety: a systematic review. Qual Saf Health Care 2010;19:e10) which did include systematic reviews within their results.

4) The results section is confusing as the grey literature is reported with the peer reviewed literature (for example p. 8 news article) making it hard to understand the impact on the outcomes.

We agree the evidence base is quite heterogeneous with regards to study quality. Grey literature is now more explicitly identified in the “article type” column section of Table 4. We have also specified in results text which articles were grey literature.

Reviewer 2:

5) (Abstract) In the first sentence of the conclusion, you highlight the included studies demonstrate promising results, but don't mention that they also indicated some impact on client outcomes.

We have edited the first sentence of the abstract’s conclusion section to mention the client outcomes.

6) (Background) Are PCMHs a US / UK term? BMC Health Services Research is an international journal, and terms such as this need to be placed in context or explained, as do any national standards referred to.
We have added additional explanation in the Background about the PCMH concept for readers outside the US.

7) (Background) In Australia, consumer consultant positions are also available in mental health services, who often contribute to committee as part of their role.

We appreciate the additional example and have added this to our Background section.

8) (Background) The end of the final sentence - 'and other changes to the healthcare setting' is a bit vague - please write more clearly.

Sentence has been edited for clarity.

9) (Methods) You should state you have followed the PRISMA guidelines at the beginning of this section.

PRISMA guidelines noted and the checklist is now added to our supplemental materials/appendix.

10) (Methods) When was your search undertaken?

The search was undertaken September 2015 – May 2016, which is now noted in the Methods section.

11) (Methods) How did you adapt the initial search strategy in PUBMED - did you change terms or anything?

The syntax was slightly adapted for each search engine. Exact search terms are provided as an appendix.

12) (Methods) You haven't really addressed how you searched for grey literature and what types of grey literature was included (you mention white papers and foundation documents, but was anything else considered) - this is the main weakness in the paper at the moment and needs more clarity.

We included grey literature based on reference list reviews and through the organization websites IFPCC (Institute for Patient and Family Centered Care) and PCPCC (Patient Centered Primary Care Collaborative); these are the two best-known resources to our knowledge for advocacy and research on patient engagement strategies. This has been clarified on page 5.
13) (Methods) Your definition of PAC’s (currently in the study selection section) could be in the section about search terms.

There is a definition of PACs in our Background Section. The “Study selection” section includes detailed discussion of our search terms and inclusion/exclusion criteria.

14) While the exclusion criteria may seem self evident, it would be good to include them in Table 2 for the sake of clarity in two columns (inclusion / exclusion) - at present they seem to be listed under the inclusion criteria but in the negative.

A column of Exclusion criteria has been added to Table 2.

15) The inter-rater agreement for abstract screening were both in the good range - add in this interpretative detail for the convenience of the reader.

We have added the interpretation of our inter-rater agreement for readers.

16) (Methods) What were the secondary outcomes related to PAC impact - provide some examples. You could also delete the following sentence as it is repetitive.

We added examples of our secondary outcomes in the “study selection” section. We have deleted the repetitive sentence.

17) (Methods) Terms such as Accountable Care Organization are not universal and require explanation - see comment in background.

We appreciate the reminder to add more clarification. We have added a brief explanation of ACOs to the background.

18) (Methods) While rating the articles in terms of risk is appropriate for quantitative, scientific studies, the nature of your included studies limits its application. Did you consider alternative means of assessing rigour which may have been more suitable to the body of articles you were reviewing - for examples the Mixed Methods Appraisal Tool (http://mixedmethodsappraisaltoolpublic.pbworks.com/w/page/24607821/FrontPage) would enable you to give standardised star ratings to both quantitative and qualitative studies and could also be suitable for some of your case studies. I think that would provide a more comprehensive understanding of the rigour of the evidence base overall.

The reviewer makes a valuable point. We were not previously familiar with the MMAT tool. We have added a quality score using the MMAT to the final studies (Table 4) in order to improve our assessment of the rigor of final studies.
19) (Results) I'm not clear on why you eliminated the two studies around community leadership councils in the community - how are they distinct from PACs.

We appreciate the reviewer’s question. The two studies in question discussed interventions designed to increase community interaction with regional public health leadership. Our group concluded that while there was discussion of community member participation in regional health care governance, these interventions were quite diverse, were not clearly “patients” serving in an advisory role, and the community participation was not discretely tied to a healthcare setting. We have clarified the exclusion rationale in our Results section.

20) (Results) Your findings that the primary mode of Patient Advisor intervention was a PAC wasn't surprising as this was the focus of your search terms and aim of the study - I'm not sure if you need to report this as a finding.

While we initiated this review due to our group’s interest in advisory councils, we selected an expansive range of search terms designed to include any modality of patient engagement, not necessarily only PAC (see search terms). Our search terms included studies that either matched a group of “patient engagement” terms or “patient advisory” terms. To this end, we intend to explain to readers that while PACs were a common modality, we also found different modalities of patient engagement such as evidence-based codesign. In order to improve clarity we have also amended the title so it reads “The impact of patient advisors,” rather than “patient advisory councils.”

21) (Results) What were the "other" activities you mention specifically ... provide some examples.

We have added an example of “other” patient engagement activity in our results section.

22) (Results) US abbreviations for states need to be written in full - for example, WA could also stand for Western Australia.

We have corrected the abbreviation.

23) (Results) Type in first sentence under patient satisfaction - case based, not cases based.

We have corrected the typo, thank you.

24) (Results) Final paragraph - This study could also be acknowledged in the background section as an important prior review of the topic, before being described in full here.
We have added a mention of this other systematic review which only included the UK within the background section.

25) (Discussion) The group of quasi-experimental studies from one initiative should be acknowledged as being geographically bounded - this is a limitation for them, despite their number and findings.

We have added this acknowledgement to the Limitations section and additional clarification in the text that these studies were from the same research group.

26) (Discussion) The description of the single cluster randomised trial is quite brief - what was your critique of this article.

We have added the most notable critique of the article, which is the fact that the study could not verify whether patient advisor recommendations would be implemented by local primary care officials. Overall the study design and methods were quite rigorous.

27) (Discussion) Sometimes you use the abbreviation PAC and sometimes it is written in full - please be consistent in your use of the abbreviation.

We apologize for the discrepancies; the acronym PAC has been consistently spelled out as patient advisory council.

28) (Discussion) A knowledge translation perspective could also be very useful in regards to future research in this area, as you've acknowledged that there is very little information about how they actually work in practice.

Thank you for highlighting the knowledge translation perspective. We have added the following to the discussion section: “Patient advisory councils and similar patient engagement approaches are ripe for knowledge translation approach, i.e., a close, interactive relationship between researchers and health systems to accelerate evidence and improve health systems.”

29) (Discussion) CG-CAHPS - This abbreviation doesn't appear to have been introduced in full previously.

CG-CAHPS (Clinician & Group – Consumer Assessment of Healthcare Providers and Systems) is a commonly collected survey among US clinics. We have replaced the term with “standardized patient satisfaction surveys” for applicability to settings outside the U.S.
30) (Discussion) Typo in paragraph beginning 'Our study limitations ....' - Another limitation of is possible (remove of).

We have corrected the typo.

31) (Discussion) Please expand a little on the need for analysis which takes confounding variables into account - I think this is an important point for future research in this area

Our group feels that cluster randomization is one of the best approaches to address confounders in this type of work; we have added as such in the discussion section: “by utilizing randomization, the study addressed the many potential confounders involved in clinic-level interventions.”

32) Table 2, Final row - do you mean the protocols were used to find studies when you refer to snowballing?

We have deleted the line as it caused additional confusion and “snowballing” does not have a consistent definition. What we meant to convey was that in our full text review, if we found relevant papers that were actually perspective pieces, we would earmark their reference lists for potential papers for inclusion.

33) Table 3, Remove the location section, as this is also reported in Table 4 and you have already addressed this in the text.

We reported summaries of the location settings in Table 3 so that readers can see summaries/totals of our included papers to review the countries/settings where patient engagement literature is most active.

34) Figure 1, Are the 38 other records identified the grey literature - could be good to flag that.

Our PRISMA diagram wording has been modified to clarify that additional records were identified through our reviews of reference lists.