Reviewer's report

Title: Patient engagement in Patient-Centered Outcomes Research: A Meta Narrative Systematic Review

Version: 2 Date: 25 October 2013

Reviewer: Alex Pollock

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MAJOR COMMENTS

1. Analysis.
   Figure 1 clearly defines the questions of interest and it is stated that a “meta-narrative approach” was used to analyse the data. Although a reference is used to support the use of this “meta-narrative” approach, the authors have failed to state or explain what they actually DID in order to analyse the results. What data was collected, by whom, and how was it categorised?? Was this done by one reviewer, two reviewers, by consensus? Was a particular method of analysis used – was the aim to aggregate or configure data? With the sort of data that the reviewers are synthesising I would have anticipated that they would have used some sort of thematic analysis to identify and collate the key themes and subthemes arising from the identified studies.

2. Results.
   This point relates to point 1, above. The questions of interest laid out in Figure 1 have not been answered comprehensively or systematically. Figure 3 summarises the types of engagement and the method with which this was explored; but there has been no attempt to explore the “best” methods, to compare methods, or explore issues such as the timing of engagement. While I appreciate that there were no comparative studies, I believe that you have synthesised substantial evidence relating to how different methods were implemented etc. The lack of systematic or comprehensive analysis of this evidence means that you have failed to adequately answer your questions of interest, despite having synthesised data which should be able to provide some answers if explored systematically.

3. Systematic reviews.
   The authors state that they have identified 11 systematic reviews relating to public involvement in research. Each of these systematic reviews presumably summarises the results of a number of primary research studies, each answering a specific question relating to public involvement. Unfortunately the authors have simply “lumped” these reviews in with the other studies, commentaries and opinion pieces. The authors have missed the opportunity to provide an overview of these reviews. Such an overview would provide an opportunity to assess the risk of bias within the individual reviews, as well as the quality of evidence
included in the reviews.

4. Assessment of quality of included studies

The authors have not made any attempt to assess the quality of the studies that they have included. This is an essential component of any systematic review, and is crucial to enable appropriate interpretation of the results of the included studies. The authors state that “Studies reported design feature to assess the risk of bias for their primary and secondary outcomes; however, we found insufficient data to assess the risk of bias as it pertains to patient/informant engagement.” However there are several tools available for the quality assessment (critical appraisal) of studies, whatever their methodological design, and assessment of the quality of the included studies I believe is essential within any systematic review.

5. Environmental scan.

I applaud the reviewers for attempting to identify the grey literature. However I am perplexed by the decision to report all evidence identified through this searching as separate from the electronic search results. The authors identified systematic reviews and papers within their ‘environmental scan’ – surely this evidence ought to be synthesised and reviewed alongside the studies identified in the electronic searching? Just because it has been identified through a different route does not mean that it is of any lesser quality, or of any less relevance (and this would be formally assessed if you did a quality assessment as refered to in point 4 above). I appreciate that the websites and organisations are very clearly a different ‘type’ of evidence (perhaps more an information resource rather than ‘evidence’?) and agree that these ought to be synthesised separately from the research studies.

DISCRETIONARY COMMENTS

1. A lot of work has clearly gone into systematically identifying evidence and information sources relevant to public involvement. However in its current form I feel that the authors have not adequately addressed many of the essential components of a systematic review (i.e. assessment of study quality; systematic analysis of results). I feel that the authors have 2 choices:

a) Revise the paper so that it is presented as a systematic identification of evidence and information sources relating to public involvement. i.e. the aim is simply to identify and list studies and information sources (which is what is currently done). This would meet the stated aim (page 4) of “synthesising the existing evidence about patient engagement in research” (but not the questions within Fig 1).

b) Do additional work to appraise the quality of the evidence and systematically analyse results. In doing this I would recommend that the authors group their evidence according to the ‘type’ of evidence, which will enable them to select appropriate quality assessment tools and methods of analysis dependent on the type of study. This will help the authors reach informed conclusions based on the quality of the evidence that they have synthesised.
2. The authors have chosen to include studies where the informants’ role was as a participant. One could argue that these studies are investigating participation in research, rather than true “involvement”. I think that it would probably be impossible to identify all primary studies that have reported some degree of feedback from their participants, and I don’t believe that the search strategy will have comprehensively identified all studies where the experience of participation has been explored (due to inconsistencies in the reporting of this, rather than due to any failures of the search strategy). Since the authors’ questions are really about “engagement”, rather than “participation”, I do wonder whether one way to make this review both more manageable (in terms of its size) and more useable (in terms of the usefulness and accessibility of presented information) might be to exclude studies that are exploring participation, and concentrate on studies of user-engagement, collaboration and co-production?

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

Quality of written English: Acceptable

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.