Reviewer’s report

Title: Patient Involvement in Guidelines Remains Poor Five Years after Institute of Medicine Standards: Review of Guideline Methodologies

Version: 0 Date: 23 Jun 2017

Reviewer: Liz Avital

Reviewer’s report:

The paper covers an important topic i.e. the identification that the involvement of patients in guidelines remains poor. There is clearly variability in the US and this needs to be improved, which is the essence of the paper. However, there are a number of elements that need to be addressed to ensure this message is clearly conveyed as at present, sections are unclear to the reader. For ease, I have outlined the areas that need attention by section.

1. The abstract: the background section needs editing for clarity; the sentence "disagreements were resolved by discussion" is not explanatory. Suggest changing to "where the researchers differed in opinion on ... discussion was held for resolution" (this sentence is later repeated in the main document, further expansion can be given here). The background notes that it is US guideline developers but this is not restated in the rest of the abstract. As practice varies internationally, please state in all sections that this pertains to US guideline developers.

2. Background: second paragraph: unclear why reference is made to only these 3 organisations. If a systematic review was carried out, please identify. Internationally other organisations do involve patients in guideline development such as the National Institute for Health and Care Excellence (NICE).

Identify when referring to IOM fifth paragraph; a reference re the consensus is needed. Identification of how many guideline developers were surveyed should be provided in order to contextualise the percentages. The following overview of percentages of the study lacks clarity.

3. Methods: Please state what IRB is. Reporting of participants is confusing between what is an organisation guideline developer and what is an independent guideline developer. Unsure as to what a producer of a 'rare guideline' is. Does this mean an organisation that does not frequently produce guidelines? The methodology used is not stated.

4. Data extraction: second paragraph, third sentence is unclear and confuses the process.

5. Results: the use of the term 'at least sometimes' is very ambiguous. How is this quantified? There is an assumption that the term 'post' is clear, expand to state posted online / on their website. When making statements such as 'only half of US guidelines developers ...' please refer this back to the research 'only half of US guideline developers in this study...’ The last sentence
of the results section is confusing; this new information was subsequent to what? Consideration should be given to whether this should be in the results section of in the discussion. This section would benefit from clearer reporting.

7. Discussion: second paragraph again the number of organisations participating in the 2008 survey need to be stated. Fifth paragraph discusses known barrier to use of PPI, yet this was not outlined as an aim of the study. If it was it should be included. If not, then this paragraph may sit better in the background section.

From a presentation perspective, the following needs to be addressed; a grammar and spelling check is needed; there is a confusion of tenses, with the past being used and then the present when reporting results; abbreviations should only be used once the term has been written in full (IOM, CPG); consider using Institute of Medicine in the title for clarity; there is a confusion of terms such as public friendly or patient friendly; definitions would be more easily accessible if listed

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