Reviewer’s report

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

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Reviewer: Diego Villalón

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RESEARCH INVOLVEMENT AND ENGAGEMENT

Patient Involvement in Guidelines Remains Poor 5 Years after IOM Standards: Review of Guidelines Methodologies

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Review: Diego Villalón (June 9th, 2017)

This review article is really valuable to understand PPI strategies in guideline development in the real world practice. The text is very comprehensive and provides a good quality information about the different types of collaboration between guidelines developers and patients and also about the level of compliance among clinicians to accept patients as a relevant stakeholder to contribute in these guidelines.

After reading this article, I want to highlight the need of updating the data about how many guidelines developers actually involve patients and consumers and explore resistances and obstacles. These obstacles may be come from personal attitudes, certain mistrust about the value of patient contribution, lack of resources or unexperienced working with patient advocates. But it's important to identify not only the level of PPI in this guidelines but also to explore deeper the reasons of counting on (or not) patients.

Even when there is an international consensus, we need to make progresses and measure benefits and risks of PPI in practice. Collecting data about these involvement initiatives will let us to know best practices to get the best results when involving patients in these processes. But this analysis requires time and money so it must be included on the planning.

Engaging patient requires training and education from both sides. Advocates needs a high knowledge about the disease and the patient journey, and guidelines developers must be aware about how to work with patients and adapt the process for an effective contribution.. I like the idea I read about using a public-friendly language in the draft research plan, despite only once of 101 did it. Also, patients need more patient versions of guidelines or guidelines summaries for a better contribution.
I have only one change to propose to authors. I think that discrepancies between the views of patients and physicians must not be considered in the article as a barrier (this is said in page 13). PPI in guidelines development implies potential discrepancies between them because both represent different perspectives of the disease and may be have different perceptions and expectations. Therefore, in my opinion, these must be understood as a consequence and a result of the review, not as barrier for PPI. To examples: If scientific community feels this is a barrier, probably it is because of their own resistances. And if these discrepancies are consequence of a lack of knowledge of patient about this process, the barrier would be the lack of training of patients.

In summary, I want to congratulate Melissa J. Armstrong and Joshua A. Bloom for this excellent review and work. This article encourages patients to advocate to get an effective involvement in these guidelines development.

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