Reviewer’s report

Title: Patients’ and researchers’ experiences with a patient board for a clinical trial on urinary tract infections

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Reviewer: Rachel Hemphill

Reviewer's report:

This article presents a qualitative analysis of patients’ and researchers’ experiences with patient involvement in a clinical trial conducted in Germany. The findings have the potential to add to the literature on patient and public involvement (PPI), particularly because little research has been conducted on PPI in Germany, and research about challenges and facilitators of PPI is needed to identify effective practices and inform recommendations. However, a number of issues need to be addressed or acknowledged to improve this manuscript and provide adequate information for readers to be able to judge the strength and relevance of the findings.

1. More information is needed about the way the qualitative analysis was conducted.
   - Could the authors say more about what they mean by "textual work with each case and our focus group guides" and how that informed the development of the primary categories?
   - The analysis description indicates that analysis of the focus groups was done by two of the authors, but it is unclear if the texts were double-coded and then reconciled, or if the two analysts coded different texts. Please also indicate if/how the two analysts reached adequate intercoder agreement.
   - On page 7, line 173, the authors state that "Interpersonal perception was reviewed through discussions within the author team." What does interpersonal perception mean? Is this referring to intercoder agreement?
   - In the introduction, the authors mention taking patients' and researchers' views on their motivations and expectations into consideration, seemingly in reference to an earlier study they conducted. It is unclear how the authors took participants' motivations and expectations into consideration, as this is not mentioned in the methods. Please clarify.

2. Better explanations of the overarching qualitative themes and categories are needed, or perhaps reorganization of some of the results to enhance clarity. The overarching themes do not always clearly match up with the categories under them. To give some examples:
   - It's not intuitive to me that "building up a patient board," "atmosphere and communication," and "roles and aims" all group together to reflect "Social
issues and culture." "Roles and aims," in particular, seems to be more about facilitation of PPI. I'm not really sure what "Social issues and culture" is intended to mean.

- The "Benefits" theme includes results about researchers benefiting more from attending meetings than from reading minutes. This finding seems to be more about methods of PPI (under the "Organization and conduct" theme) than about how PPI benefited or affected the researchers.

- It is unclear why the "Benefits" theme has no subtopics under it, unlike the other 3 themes. The results that are presented within this theme could be organized in a number of ways, such as:

  ♦ benefits to the research; benefits to the people involved

  ♣ experienced benefits; uncertainty about benefits

At a minimum, the authors should add brief descriptions of each overarching theme to explain what it's about. That would make it easier for the reader to understand the authors' views about how each theme relates to the categories under it and how the categories hang together. The authors may also want to consider regrouping some of the categories or specific findings.

3. The authors need to acknowledge the limited attendance/experience of some of the board members, especially the researchers. This study's findings are based on transcripts and notes from board meetings and from focus groups about patients' and researchers' experiences on the board. It is therefore very important to note that only 3 researchers participated in the focus group, and 2 of those researchers had only attended one board meeting. Thus, this study's findings about researchers' experiences come from a small number of people, most of whom had limited experience with the board, and the findings may overrepresent the experience of the one researcher who attended all board meetings. The authors do note this limited attendance in the Results section, but they do not discuss it as a limitation or how this may have affected the themes that were identified and the generalizability of the results.

4. Also related to generalizability, the authors should provide more information about the activities of the patient board as important context for understanding this study's findings. Since the patient board was created after the study had been designed, what types of activities did the board members engage in? What was their intended role? How was their input asked for and incorporated into the study? Were they involved in decision-making? More information about the activities and level of involvement of the patient board would be helpful context because it likely influenced patients' and researchers' experiences with PPI and the challenges they perceived. A research team using a different approach to PPI may experience different challenges.

- The authors may want to consider using a framework from prior literature to describe their patient board along a continuum of engagement. See Carman et
al., 2012 (doi: 10.1377/hlthaff.2012.1133) and Forsythe et al., 2019 (https://doi.org/10.1377/hlthaff.2018.05067) in Health Affairs. Using such a framework could help the authors speculate in their discussion about how their approach to PPI may have influenced patients' and researchers' experiences and how PPI could be approached or structured differently to avoid or lessen some of the challenges they experienced.

5. The authors’ conclusions not always clearly tied to results. For example, the authors conclude that adequate structures and resources are needed to facilitate effective PPI. While I agree with this statement, it's not clear which part of the results gave rise to that conclusion. Perhaps the authors can more clearly articulate the implications of particular findings and the conclusions drawn from them.

6. Similar to the previous point, the authors could sharpen their discussion section to more clearly emphasize key take-aways. The discussion section is quite long, and it's hard to keep it all in mind and come away with a clear sense of the overall findings and their implications for engagement strategies. A table summarizing the key findings from each theme, perhaps broken down into engagement challenges and strategies that worked well, would help the reader digest all of the findings and would make the article more impactful.

7. I appreciate that the authors define what they mean by the terms 'PPI' and 'patients' and acknowledge related terms in this field. I wish more articles did this! Thank you.

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