PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	Facilitating and inhibiting factors for long-term involvement of patients at outcome conferences - Lessons learned from a decade of collaboration in OMERACT.
AUTHORS	Wit, Maarten; Abma, Tineke; Koelewijn-van Loon, Marije; Collins, Sarah; Kirwan, John

VERSION 1 - REVIEW

REVIEWER	Bie Nio Ong, Professor of Health Services Research, ARUK Primary Care Centre, Keele university, Keele UK. I have no competing interests.
REVIEW RETURNED	30-May-2013

THE STUDY	I have answered 'no' to some of the questions because they are not relevant to the type of study reported in the paper. The paper is a qualitative study discussing a process rather than an outcome.
GENERAL COMMENTS	P.6. line 18-23. The two sentences state different issues and are not linked. This needs to be written more clearly. P.7. line 5-16. It may be better to first explain the rationale behind inviting patients to the 2002 conference, and how this has incrementally grown over time until the level of 2010. Insert reference to figures 1 and 2 P.7. It would be helpful to give dates of the first and second qualitative studies in the text. P.8. line 7. I would not use the term anecdotal as that tends to have a negative meaning. P.8. line 26-27. Rephrase this sentence because a lot has been written about lay knowledge, but more needs to be understood about its role within research and scientific conference contexts.

REVIEWER	Amye L. Leong, MBA President & CEO, Healthy Motivation Director of Strategic Relations, Bone and Joint Decade, the Global Alliance for Musculoskeletal Health USA
REVIEW RETURNED	20-Jun-2013

THE STUDY	* Generous use of the word 'they' makes the author's reference point confusing throughout the document. * Article focus: use of the term 'structural involvement' is unclear, and could be better explained as developing an organizational infrastructure (not structure) to facilitate the engagement of partners in discussions. * Study does not address the long-term or over-arching process of partner engagement in between the conference that occurs once every 2 years, thus the study must be confined to at-conference participation only. Would have been helpful to know how these tactics are carried forward. * Needs better description of diversity of partners besides gender, country . . . such as age, years with the disease, patient or family member, etc and to compare this to the general conference participants. * Some partners participated in the leadership group of other working groups besides the Patient Perspective. This was lost in this study, and as mentioned above, did not speak to the patient engagement process between the bi-annual conference. However, overall, this subject is important, the qualitative study methods sound, but needed more comparators to offer up the difference in backgrounds, skills, experience that these partners bring to a research discussion. Use of language is inconsistent, and grammatical errors throughout.
RESULTS & CONCLUSIONS	* Was not clearly explained why generalizability of communication principles cited would not be transferable to other situations of patient engagement in research discussions, even though authors cite their study confirming a diabetes study in their conclusion. * Generalizations were made without further explanation (eg, "An important barrier was the exhausting conference program" but no details were provided to substantiate what that means to a partner with the disease. * Suggest removing "It was kind of serendipity" from the barriers section. Inappropriate editorial comment for a research paper reporting results. * Results do not show the aggregated evidence of the thematic analysis, the priorities, or the relational items. * Unable to decipher if the interpretation and conclusions are derived from data since this was not provided.
REPORTING & ETHICS	All is fine in reporting and ethics.
GENERAL COMMENTS	The authors address an important subject and offer up good qualitative data reflecting recent OMERACT partner engagement and the evolution of partner engagement since 2002. Minor revisions are suggested to enhance this article in these areas: use of pronoun "they"; distinguish concepts as those identified and activated during actual bi-annual conference with no mention as to how they concepts are employed in work groups between bi-annual conferences; incorporate summary of data analysis of themes to show priorities, relative weighting, and from whence the authors are led to their conclusions.

VERSION 1 – AUTHOR RESPONSE

Response to the reviewers' comments on our submission

Reviewer 1

1. P.6. line 18-23. The two sentences state different issues and are not linked. This needs to be written more clearly.

We have adjusted both sentences and clarified the distinction between our knowledge of the role of patient research partners and the role of patients as conference partners.

2. P.7. line 5-16. It may be better to first explain the rationale behind inviting patients to the 2002 conference. Insert reference to figures 1 and 2.

We have changed the text according to this suggestion and inserted references to the online fig. 1 to 5.

3. P.7. It would be helpful to give dates of the first and second qualitative studies in the text.

With the first and second qualitative studies we mean two publications that focus on different aspects of patient involvement in OMERACT conferences. The first study explicitly deals with the experiences and expectations of new patient participants. The second study describes the impact of a decade of patient involvement in OMERACT conferences. The present study describes the factors (conditions) that have been beneficial or obstructive for the success of patient participation in OMERACT. These studies have taken place in parallel with this study and have been recently published (2013).

4. P.8. line 7. I would not use the term anecdotal as that tends to have a negative meaning.

We agree that in the dominant scientific discourse ‘experiential’ and ‘lay knowledge’ are more accepted terms then anecdotal knowledge. Patients often express the knowledge that is based on their daily experiences with a chronic disease, limitations and the use of health care, in stories. An important condition for engaging with patients is the competence of researchers and health professionals to respect and listen to these patient stories and distill the meaningful components that are relevant to drive research forward. We have therefore changed the word to ‘personal experience’

5. P.8. line 26-27. Rephrase this sentence because a lot has been written about lay knowledge, but more needs to be understood about its role within research and scientific conference contexts.

We agree with the reviewer and have nuanced this sentence.

Reviewer 2

1. Generous use of the pronoun 'they' makes the author's reference point confusing.

We have tried to explain more clearly who is ‘they’ in the text and where possible replaced this pronoun by the name of the group that is meant.

2. The term 'structural involvement' is unclear, and could be better explained

We have given a description of the term structural involvement in the last sentence of the paragraph “challenges” (page 8).

3. Study does not address the process of partner engagement in between the conference.

The reviewer is correct that our focus has been on the at-conference participation. Where appropriate we have stated this more clearly in the text. At the time of the data collection (2010) we were aware of a small number of working groups that had started to engage with patients between conferences. Some have reported on this. In the paragraph about 'remaining challenges' of our previous BMJ open article about the impact of patient participation in OMERACT (2013;3:e002241), we have emphasized the importance of including patient in working group activities between conferences. Based on the findings from the interviews we have in the current manuscript again emphasized that 'early participation in working groups will best prepare partners for the participation at the conference' (page 18). In the discussion paragraph we elaborate on future research that should focus more on the role of patients in working groups between conferences and included two references that have already provided experiences of patient involvement in the OMERACT working group on flares and the working group on fatigue (page 23; ref 15 and 16). The additional comments of the reviewer contain valuable topics and questions for future (follow-up) research: The role of patients in working groups; the tactics of engaging with patients in working groups; whether concepts of patient participation employed in working groups are similar or different from those at the conference. These do not derive directly from the work reported in this paper or follow on from the discussion, and they have been mentioned in our previous paper.

4. Needs better description of diversity of partners and to compare this to the general conference participants.

Table 1 contains the information about the characteristics of the 32 interviewees such as gender, country of origin, professional background (professionals only) and rheumatic condition (partners only). Online figures 1 till 5 provide additional information about the characteristics of the patient delegates over the period 2002-2012 such as rheumatic condition (fig.1), country of origin (fig. 2), number of OMERACT conferences attended (fig. 3), balance between new and experienced delegates (fig. 4) and gender (fig. 5).
Neither for OMERACT conference 10 (2010), nor for the previous conferences do we have information on the characteristics of the general conference participants. Therefore we are not able to describe differences in background, skills and experiences of partners and those of professionals. Only for the eight new partners at OMERACT 10 do we have information about their professional background. These have been published (see ref. 21)
In the paragraph 'Composition of patient group' we reflect on the representativeness of the patient group according to the interviewees. There are different views on the composition of the patient group based on the expected input of patients (page 20-21). In the discussion section we critically comment on this issue (page 23).

5. Use of language is inconsistent, and grammatical errors throughout.

Editing of the revised main text has been outsourced to a native-English speaking professional working for a proof reading agency.

6. Suggest removing "It was kind of serendipity" from the barriers section. Inappropriate editorial comment for a research paper reporting results.

The statement about 'serendipity' has been literally derived from a quote of one of the interviewees who has been involved in OMERACT from the onset. This paragraph does not contain editorial comments of the authors. The statements are based on the memoires of four interviewees (2010; RA, RD, RE, RF) who attended the conference in 2000. Their recollections form a kind of oral history. They were unanimous in their perception that the decision to invite patients was not impulsive but based on extensive discussions in the Executive Committee. We have adjusted the text and emphasized, according to one of the interviewees, the iterative nature of the decision to start with patient involvement.

7. Incorporate summary of data analysis of themes to show priorities, relative weighting, and from whence the authors are led to their conclusions; Results do not show the aggregated evidence of the thematic analysis; Unable to decipher if the interpretation and conclusions are derived from data since this was not provided.

For a better understanding of the data analysis we have expanded this paragraph in the Methods section and gave a more detailed description of the process. We provided also some evidential quotes for the sub-categories in the supplementary data: In appendix 1 we gave an example of an audit trail, partly illustrated for the main categories ‘conference design´ and ‘scepticism’. In table 2 we already provided an overview of the 8 main categories and the 36 sub-categories that came out of the extensive team meetings. In qualitative research it is difficult to use the concept of ‘relative weighting’ since the process of synthesizing common meanings is based on a careful exchange of arguments and interpretation by the team members and not by counting numbers of respondents that have mentioned an item. As stated in the manuscript, the Result section is entirely based on the combined review of the data (‘evidence’) that came out of the thematic document analysis and the qualitative interviews.

8. Was not clearly explained why generalizability of communication principles cited would not be transferable to other situations of patient engagement in research discussions, even though authors cite their study confirming a diabetes study in their conclusion; Generalizations were made without further explanation (eg, "An important barrier was the exhausting conference program") but no details were provided to substantiate what that means to a partner with the disease.

Qualitative research is not based on statistical generalization of a random sample to the whole population, but works toward ‘naturalistic generalization’ based on pattern matching (Abma & Stake, 2001). Readers may on the basis of a ‘thick description’ of the context and meaning of patient involvement in OMERACT recognize patterns and transfer them to other than the study context. Knowledge from qualitative research is context-bound. That means that the findings of this study are relevant and valid for the context of OMERACT, a world-wide initiative in the field of rheumatology centred around outcome research. Whether the same facilitators and the same barriers will be important to study the inclusion of the patient perspective, for example, in the field of cancer research, when conducting Health Technology Assessments or at an annual conference of a national society of cardiology, cannot be concluded from our study and needs further research in other contexts. In the Discussion section we refer to a study in the field of diabetes that confirmed the important role of the leadership in implementing structural patient involvement. We have adjusted the text to limit the generalizability (in the traditional sense of statistical generalization) of the next sentences by emphasizing the context in which we developed our findings.
Finally, the category “exhausting conference program” has been raised by a large majority of the patient respondents. It is explained in the paragraph “intensity of the program” (page 18).