



**Facilitating and inhibiting factors for long term involvement of patients in outcome conferences - Lessons learned from a decade of collaboration in OMERACT.**

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3 **Facilitating and inhibiting factors for long term involvement of patients in outcome**  
4 **conferences - Lessons learned from a decade of collaboration in OMERACT.**  
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9 **Abstract**

10 **Objective:** Several studies have provided insights into conditions for successful patient  
11 involvement in health research. Recently we have showed that long term engagement with  
12 people with arthritis in international outcome research has made a significant change in the  
13 research agenda in the field of rheumatology. In this article we explore facilitating and  
14 inhibiting factors for long term involvement of patients as collaborative partners during 5  
15 Outcome Measures in Rheumatology (OMERACT) conferences.  
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24 **Design:** A responsive evaluation, starting with a thematic document analysis of conference  
25 proceedings and grey literature, followed by 32 qualitative interviews. Interview transcripts  
26 were subjected to an inductive content analysis.  
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31 **Setting:** Five international OMERACT conferences between 2002-2012.  
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33 **Participants:** Patient delegates (n=16) and professional delegates representing researchers  
34 (n=14), pharmaceutical industry and regulators (n=2).  
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38 **Results:** Combined review of the document analysis and interview data revealed 5 main  
39 facilitators and 3 main barriers. Engagement of patients as full participants at OMERACT was  
40 enhanced by: strong commitment of the leadership and the presence of change agents; a clear  
41 selection procedure; an inclusive consensus based conference design; individualized and self  
42 organized support; an interactive and encouraging moderation style during discussion groups.  
43 Barriers were related to the intensity of the conference program, scepticism among  
44 researchers and doubts about the representativeness of the patient group.  
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53 **Conclusions:** This study concludes that developing a sustainable structure of funding,  
54 selection and support of patient delegates, and adjusting conference design and moderation  
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3 style, enable a direct dialogue between all stakeholders and enhance mutual understanding  
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5 and a successful inclusion of the patient perspective in an outcome conference such as  
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7 OMERACT.  
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For peer review only

## Article Summary

### Article focus

- The bi-annual conference on Outcome Measures in Rheumatology (OMERACT) has extensive experiences with structural involvement of patients as collaborating partners in outcome research.
- Through a systematic document analysis and 38 qualitative interviews with all stakeholders we explore the facilitators and barriers of long term participation of patients in outcome research.

### Key messages

- Making patient participation an integral part of the vision, structure and program of the conference enables an effective and efficient inclusion of the patient perspective.
- Adequate introduction and personalized training and support of patients are important conditions for a successful engagement with patients.
- The role of moderators in small group discussions is pivotal for enabling patients to contribute to research and to foster mutual learning processes of all participants.

### Strengths and limitations of this study

- OMERACT has provided a unique opportunity to evaluate the conditions of long term involvement of patients as conference partners in a highly scientific environment.
- Generalizability and transferability of the result findings to conferences on national and local level and to other disciplines is limited and require additional research.

**Keywords**

patient participation; OMERACT; outcome research; qualitative research; research conference; responsive evaluation; rheumatology; user involvement

**CONTRIBUTORSHIP**

MW, JK and TA conceived the idea of the study and were responsible for the design of the study. MW carried out the document analysis and all interviews. MW and MK were responsible for the coding of the interview transcripts. All authors provided input into the phase of cross-code checking and data analysis. The initial draft of the manuscript was prepared by MW and then circulated repeatedly among all authors for critical revision. All authors read and approved the final manuscript.

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3 The last decade has seen an increased involvement of patients in health research based on a  
4  
5 widespread transition towards empowered health consumers and acknowledgement of the  
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7 right to influence research that will affect their daily life. Patients aspire to more horizontal  
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9 and deliberative partnerships with researchers resulting in a variety of patient roles.<sup>1-4</sup>  
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11 Patients can be committee members, reviewers of protocols or grant applications, advisors,  
12  
13 panel members or commissioners of research. Each patient role implies different tasks and  
14  
15 different kinds of contributions, and can be performed at different levels of involvement.<sup>5,6</sup>  
16  
17 Most case studies observe a power shift between patients and researchers. Because there is  
18  
19 still little evidence about the effectiveness of these new patient roles, participative research  
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21 still needs to be justified.<sup>7</sup>  
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24  
25 A new role in health research is that of the patient as conference partner. In this new role  
26  
27 patients do not participate as patient advocates or representatives of a patient organisation.  
28  
29 Nor do they attend a conference for networking or for learning about new developments  
30  
31 regarding their condition. Rather, they are invited to collaborate with researchers as equal  
32  
33 partners with the purpose to provide the patient perspective. This is the case for the Outcome  
34  
35 Measures in Rheumatology conferences called OMERACT. Here patients have been  
36  
37 successful in changing the research agenda, contributing to the development of core outcome  
38  
39 sets and helping to devise new measurement instruments.<sup>8</sup> To our knowledge there is no  
40  
41 literature that explores the tasks, contributions and challenges of patients as collaborating  
42  
43 partners at scientific conferences. However, we do know more about patient research partners,  
44  
45 a role that shows similarities with that of patients as conference partners. The term patient  
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47 research partner has been coined in the context of rheumatology<sup>9</sup> and can be defined as  
48  
49 “persons with a relevant disease who operate as active research team members on an equal  
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51 basis with professional researchers, adding the benefit of their experiential knowledge to any  
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53 phase of the project”.<sup>10</sup> Patient research partners have actively contributed to the development  
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3 of research agenda's for people with spinal cord injuries,<sup>11</sup> intellectual disabilities,<sup>12</sup> and  
4  
5 chronic kidney diseases.<sup>13</sup> Patient research partners can also be involved in developing  
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7 research designs, collecting data, and the development of patient reported outcomes.<sup>14</sup> At the  
8  
9 department for rheumatology of the University of Bristol patient research partners have  
10  
11 contributed to the study of fatigue.<sup>15</sup> On an international level they were involved in the study  
12  
13 of flares in rheumatoid arthritis (RA)<sup>16</sup> and in the development of a new patient derived  
14  
15 quality of life measure for RA.<sup>17</sup>

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18 Although there is some evidence that active involvement of patient research partners  
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20 brings several benefits to research<sup>18</sup> there is little information about the conditions for their  
21  
22 effective involvement at research conferences. OMERACT is the first series of international  
23  
24 research conferences that has successfully engaged with patients as collaborating partners  
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26 over a substantial period of time.<sup>19</sup> However, it is unknown what factors have been supportive  
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28 to this success, how the organization, structure and procedures have facilitated patients to  
29  
30 contribute effectively, or how reported barriers have been removed. The objective of the  
31  
32 present study is to describe how OMERACT has organized structural collaboration with  
33  
34 patients in its conferences over the last decade and which factors have been supportive or  
35  
36 inhibiting to this process. Furthermore we analyze how this process has changed perceptions  
37  
38 and beliefs of OMERACT delegates regarding patient involvement.  
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#### 45 **The context: OMERACT**

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47 OMERACT started in 1992 to achieve consensus on a core set of outcome measures for  
48  
49 clinical trials in rheumatoid arthritis. Based on the success of the first conference, it developed  
50  
51 into a worldwide, data driven working conference known for its interactive conference design  
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53 and high scientific rigor. It brings together a large variety of professionals with an interest in  
54  
55 the methodology of clinical trials in the field of rheumatology. The objective is to build  
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3 consensus regarding core outcome sets and appropriate measurement instruments for clinical  
4 trials. At OMERACT 10 (2010) 172 persons participated, 152 professionals and 20 partners.  
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6 Since 2002 OMERACT has invited patients as full conference participants based on the  
7  
8 belief that outcomes for clinical trials need to be derived from “the lived experience of  
9  
10 arthritis” and from “concepts which can be readily communicated to patients to help with  
11  
12 therapeutic decision making”.<sup>20</sup> During the period 2002-2012 58 patients in total have taken  
13  
14 on this role.  
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17  
18 An initial qualitative study explored the expectations and experiences of patients who  
19  
20 participated in OMERACT for the first time.<sup>21</sup> They reported barriers to full collaboration  
21  
22 with professionals . These were, among others, related to the preparation, moderation style of  
23  
24 professionals and lack of individual support onsite. They believed that they did not contribute  
25  
26 significantly to the breakouts and that their experiential knowledge was not optimally used.  
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28 Nevertheless they believed that their involvement had been valuable and meaningful. They  
29  
30 confirmed personal learning curves and felt their contribution would be more effective at the  
31  
32 next conference.  
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36 In a second qualitative study, including the opinions of all stakeholders in OMERACT,  
37  
38 researchers confirmed that the involvement of new as well as experienced patients had been  
39  
40 successful and had significantly influenced the conference outcomes.<sup>8</sup> Patients had enriched  
41  
42 the research agenda with new topics such as well-being, flares, sleep disturbances and, most  
43  
44 illustrative of all, fatigue. A substantial amount of work in the area of fatigue in rheumatoid  
45  
46 arthritis has been published<sup>22 23</sup> and OMERACT participants have almost unanimously  
47  
48 confirmed that this research would not have been vigorously carried out or even identified  
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50 without the presence of patients at the conferences.  
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## 55 56 **Challenges** 57 58 59 60



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3 In this study we will address some of the challenges that we know from earlier studies that  
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5 have looked at the role of patients as research partners. One of the most important challenges  
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7 is the fact that anecdotal or lay knowledge is not accepted as a valid source for scientific  
8  
9 research. It is often perceived as inferior compared to the evidence based knowledge of  
10  
11 professionals.<sup>24</sup> Therefore patients find it hard to create a basis for trust and equal  
12  
13 collaborative relationships.<sup>25 26</sup> Caron-Flinterman studied 23 cases of active patient  
14  
15 involvement in biomedical research and argued that the deliberate use of experiential  
16  
17 knowledge of patients needs additional research.<sup>27</sup> Recent studies have demonstrated that  
18  
19 starting with dialogue and deliberation among patients in collaboration with patient research  
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21 partners is an effective way to strengthen their voice and develop a shared knowledge base  
22  
23 grounded in the experiential knowledge of individuals.<sup>18 26</sup> However, further understanding of  
24  
25 the nature and significance of lay knowledge is still necessary.  
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30 A second challenge is that some researchers are reluctant to engage with patients or  
31  
32 involve patients as a kind of tokenism.<sup>28</sup> They have difficulties adjusting their language and  
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34 communication style, perpetuating an important barrier for collaboration. Elberse studied the  
35  
36 effectiveness of inclusion strategies to incorporate patients' perspectives in the development  
37  
38 of a research agenda for people with congenital heart disease.<sup>29</sup> This study concluded that  
39  
40 verbal communication is an important inhibiting factor and additional inclusion strategies are  
41  
42 needed to realize an effective partnership between patients and professionals.  
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45  
46 A last recurring challenge is the lack of knowledge required to implement structural  
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48 involvement of patient research partners.<sup>6</sup> The evidence base underpinning the assessment of  
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50 effective conditions for patient involvement is relatively weak, primarily because of poor  
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52 documentation, analysis and reporting.  
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## 55 56 **Method** 57 58 59 60

### *Data-collection*

Data collection was based on a document analysis and 38 interviews with representatives of all stakeholders involved in OMERACT. The thematic document analysis included OMERACT conference proceedings and grey literature such as OMERACT policy documents, correspondence, invitations, session reports and e-mails. The document review focused on the objectives and structure of the conference, number of patient delegates, their selection, preparation and support, and the rheumatic conditions and countries represented. We were particularly interested in the explanation and arguments given for the way OMERACT created, changed or improved operational procedures and the way participants accepted or adjusted these.

After this document review the first author started a responsive evaluation<sup>30</sup> by conducting qualitative interviews with representatives of all stakeholders before, during and within four weeks after the conference in 2010. Finally the opinions and experiences of 16 professionals and 16 patients were collected (table 1). Of the 8 patient delegates that attended OMERACT for the first time 3 were interviewed on 3 different occasions during the five-day conference. This was done to obtain accurate insights into occurring changes in expectations, experiences and contributions.

All interviews were recorded, transcribed by an independent secretariat and subjected to a responder check. The average duration of the interviews was 52 minutes. The interview protocols differed for professionals, new patients and experienced patients. The topics dealt with the expected role of patient participants, their selection, preparation and support, and their experiences in discussion groups, in particular those belonging to the workshops on remission and flares. All participants gave their informed consent prior to the interview. For this study no ethical approval of the MEC was needed.

### *Selection of interviewees*

Selection of interviewees aimed at maximum variation and followed an emergent purposive sampling approach, based on stakeholder's background, opinion about patient involvement, gender, geographical spread and number of OMERACT conferences attended. The selection strategy took into account the limitations inherent in a five-day worldwide conference.

Potential candidates for face-to-face interviews should be willing to dedicate some of their time for the interview during this conference. Directly after the conference preliminary analyses of the first interview data revealed an unexpected response shift. The attitude towards patient involvement of professionals that were presumed to provide a critical perspective, had significantly changed. Their scepticism had made place for a more positive assessment of collaboration and its benefits. For this reason we identified two new interviewees who were known for their critical perspective. Also the perspective of a research fellow and a post-doc researcher was missing and subsequently added to the list of interviewees. After analyzing the additional transcripts saturation was achieved.

[table 1]

*Data analysis* – Interview transcripts were subjected to an inductive thematic content analysis focusing on conditions and barriers for patient participants to contribute to the process. The analysis concentrated on those aspects of the actual conduct of the conference, the preparation and the breakout sessions that have a direct influence on the ability of patient delegates to contribute. The documents and the interview data were analyzed with the purpose of ascertaining what structural arrangements were provided by OMERACT that facilitated the integration of patient knowledge in the conference. All team members – representing different

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3 perspectives and professional backgrounds - were involved in the abstraction process to distil  
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5 relevant conditions for organizing structural involvement of patients.  
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### 8 9 *Quality procedures*

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11 Triangulation took place by synthesizing interview data and results from the document  
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13 analysis. To increase the relevance and quality of the analysis and interpretation of the data a  
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15 patient who attended OMERACT 10 for the first time (SC) joined the research team. She was  
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17 actively involved in the coding and analysis of the data, team meetings and writing this  
18  
19 manuscript. To increase the inter-rater reliability of the coding an external expert in  
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21 qualitative research (MK) who had never worked with conference partners before,  
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23 participated in all phases of the study, starting from the phase of transcript coding. To protect  
24  
25 the anonymity of the participants all quotes in this manuscripts are exposed in the “she”-form.  
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29 Quotes of professionals are indicated by ‘R’ and those of conference partners (in short:  
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31 ‘partners’) by ‘P’.  
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### 36 **Results**

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38 During the combined review of the document analysis and the coding of the interview  
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40 transcripts the research team grouped 1,563 open codes into 44 meaningful generic categories  
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42 of which 29 were descriptors of facilitators and 15 descriptors of barriers. In a second review  
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44 round, 8 main categories emerged that characterized the features of the conference that were  
45  
46 supportive or inhibitory to the contributions made by partners. Finally the team defined the  
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48 content of these categories and divided them into 5 main facilitators and 3 main barriers  
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50 (Table 2). The 5 facilitators were the role of the leadership, selection procedure, conference  
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52 design, moderation style and support. The 3 barriers were the intensity of the program,  
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3 scepticism among researchers and representativeness of the patient group. Each one is  
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5 described below with examples from the data.  
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9 [Table 2]  
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## 12 13 14 **Facilitators**

### 15 16 17 18 *Leadership*

19  
20 Long term commitment and support of opinion leaders is key to the success of new initiatives.  
21  
22 The organizing committee of OMERACT was intrinsically motivated to foster patient  
23  
24 engagement in the conference: “We believe their input is essential to decide on the right  
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26 measurement tools”.<sup>31</sup> According to one of the members of the organizing committee the  
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28 decision to invite patients was not taken lightly. It was discussed during several planning  
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30 meetings and the group was daunted by the question “how to organize patient  
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32 participation?”[RD]. When the decision was taken, the leadership was determined to do it  
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34 properly. They gave full support to the patient perspective workgroup leader who took on the  
35  
36 role of a change agent, and provided funds for patient partners to attend the conference. These  
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38 costs were calculated for an amount over \$ 80,000 in 2012. They also acknowledged the  
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40 repeated contributions made by partners: “Their dedication to the process is an example for us  
41  
42 all” (ibid). Based on the positive experiences of two conferences attended by partners, in 2006  
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44 OMERACT formulated basic principles for patient engagement: “OMERACT policy on  
45  
46 including the patient perspective in rheumatology outcomes assessment” [internal document].  
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48 This document represented a milestone by making patient participation part of the vision of  
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50 OMERACT, embedded in a set of operational procedures. After three further conferences the  
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3 Executive Committee decided on the principle that active patient involvement would be a  
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5 prerequisite for working groups suggesting themes in the OMERACT program.<sup>20</sup>  
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7 The leadership recognized the value of a mixed group of new and experienced partners  
8  
9 and was committed to providing opportunities for experiments and long term learning. They  
10  
11 confirmed that a learning curve is a requisite to becoming productive.  
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### 14 15 16 *Selection*

17 From the start it was clear that patient participants were not expected to represent any group  
18  
19 or organization. Although partners might be active in patient organizations, they should adopt  
20  
21 a strict individual role at OMERACT. Their contribution is valuable because of their personal  
22  
23 experience: “a living knowledge of their long term conditions” and “the unpredictable nature  
24  
25 of their illness” [internal report, 2008]. Their input is not related to advocacy for resources or  
26  
27 attention to a particular disease. Recruitment is done through the clinic of participating  
28  
29 physicians “to ensure that people were invited who could make a contribution in unfamiliar  
30  
31 circumstances”.<sup>32</sup> In practice physicians proved to be ideally positioned to identify eligible  
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33 patients because they were familiar with the patients and with the requirements of  
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35 OMERACT.<sup>20</sup> Since 2004 OMERACT has aimed for 10% of patients with a mixture of  
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37 conditions [online figure 1], geographical spread [online figure 2] and OMERACT experience  
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39 [online figure 3].  
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45 Selection of partners is still an issue of concern, especially with regard to the dual  
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47 relationship between the individual partner and their physician. Participants reported  
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49 significant advantages with the current system: This personal relationship leads to a strong  
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51 motivation to collaborate, makes researchers feel responsible for appropriate guidance and  
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53 funding of the partners, and avoids the selection of patient advocates. Some respondents  
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55 pointed out the risk that partners might not dare to speak openly about their opinions in the  
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3 presence of their treating physician. In one case a partner admitted that “pleasing” or  
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5 “identification” with her own consultant had happened when she felt she had to defend the  
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7 consultant’s point of view against criticism from other delegates that the patient perspective  
8  
9 was insufficiently incorporated in the data the consultant had presented:  
10

11 As the result of structural involvement, the relationship between partners and researchers  
12  
13 has developed into an equal collaboration in many parts of the conference. Participants have  
14  
15 tended to raise the level of required competencies: Partners are expected to speak up, provide  
16  
17 the patient perspective, compartmentalize their clinical relationship<sup>9</sup> and carry out tasks like  
18  
19 all other delegates. Most of the participants confirmed that partners must be able to  
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21 understand basic principles of research, contribute to discussions and receive criticism.  
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### 27 *Conference design*

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29 OMERACT started as an informal gathering of researchers interested in outcome  
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31 measurement in rheumatology<sup>33</sup> and evolved into a biannual five-day working conference  
32  
33 with a multi-stakeholder approach. Participants confirmed that the small size of the  
34  
35 conference, the attitude of the delegates and the spirit of OMERACT as an open and inclusive  
36  
37 initiative have been beneficial for a positive reception of partners: “I think that most of the  
38  
39 researchers and clinicians that go in here are rather open minded” [RB]. Partners felt welcome  
40  
41 at the conference: “You do feel like you’re part of the family” [PH] and “OMERACT is  
42  
43 probably the most patient inclusive meeting” [PI].  
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47 The conference layout and the strong focus on active interaction and debate in small  
48  
49 groups, including pre- and post-workshop meetings, have been specifically arranged to serve  
50  
51 the need to integrate a diversity of perspectives and to avoid the dominance of one single  
52  
53 voice: “At times discussion on topics may be strongly influenced by key opinion leaders, but  
54  
55 holding more meetings of smaller concurrent interest groups has partially remedied this  
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3 problem”.<sup>34</sup> The breakout discussions also “support the patient contributions in what might  
4  
5 otherwise be a very professionally oriented forum” (ibid.).  
6

7 Partners were officially invited to participate as full delegates with voting rights and  
8  
9 access to all sessions, discussions and events. Some of the experienced partners felt equal to  
10  
11 professionals and acted as co-researchers by co-moderating, reporting back or becoming co-  
12  
13 author (Online table 1). A majority of the partners saw their role as giving information or  
14  
15 advisor, sometimes even as an observer. In particular new partners regularly felt the same  
16  
17 disparity towards professionals as is experienced in clinical practice. The interviews revealed  
18  
19 that also new researchers and research fellows sometimes experienced this disparity.  
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#### 25 *Moderation style*

26  
27 The breakouts during OMERACT form the heart of the conference. Although the moderation  
28  
29 is part of the conference procedure and has been described in separate guidelines [internal  
30  
31 document], the quality of the moderation emerged as of utmost importance: A facilitator can  
32  
33 help partners contribute to their full potential or degrade partners to unvoiced observers. From  
34  
35 the perspective of partners a facilitative moderation style and creating an environment that  
36  
37 fostered mutual learning through open dialogue, were seen as important conditions to  
38  
39 empower partners to make their voices heard and to contribute fully to the objectives of the  
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41 session. One of the partners described what made her feel confident to contribute:  
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47 “Just simple things, like at the start: we had something like a semi-circle [for the  
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49 seats] rather than in rows. So we could all interact and see each other. Basic stuff like  
50  
51 that. Especially for somebody like me with hearing disability it is important to see all  
52  
53 the faces”. And the moderator “did thank everybody for coming, made us all feel  
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55 welcome and stopped a couple of times through the session to say ‘what do the  
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3 patients think?’ We were all given the opportunity to speak, and weren’t cut off or  
4  
5 being manipulated or something like that, it (...) all really felt equal.” (PC)  
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10 At times partners were confronted with an apparently patronizing attitude of a  
11  
12 moderator or other delegate. Occasional comments such as “That is quite obvious” were  
13  
14 experienced as disqualifying their competences or disease experience. As a result  
15  
16 partners sometimes felt ignored, frustrated or unable to contribute. Also the language  
17  
18 was a barrier for those whose first language is not English. This factor was  
19  
20 underestimated and partners tended to hold back when they were afraid of not using the  
21  
22 right words or expressions.  
23

24  
25 Good moderators used the dynamics of a dialogue to articulate partners’ opinions:  
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28  
29 “Because one patient can say something which facts up the other patients in the room to  
30  
31 say ‘yes, this is very important and I haven’t thought about it but now that’s been brought  
32  
33 up: absolutely’. I’ve seen examples of that many times at OMERACT and you almost  
34  
35 hear the penny drop, it was all of a sudden a big light bulb goes up and everyone says  
36  
37 ‘yes, absolutely!’“ (PH)  
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43 Moderators behaviours were sometimes considered unethical or poor approaches to  
44  
45 sensitive issues. For example, at one occasion a discussion on a rare rheumatic disease  
46  
47 caused distress for one of the partners affected by that disease when mortality rates were  
48  
49 presented. The researcher mentioned in a rather dismissive way that this was not of  
50  
51 importance in relation to the topic under discussion. The off-hand dismissal of the  
52  
53 scientific importance of mortality in relation to the discussion topic could not easily be  
54  
55 separated in the partner’s mind from a dismissal of the importance of mortality for  
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3 patients in general and her in particular. Table 3 offers an overview of strategies  
4  
5 moderators have found useful in reducing partner reported barriers.  
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8  
9 [Table 3]  
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### 12 13 14 *Support*

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16 According to the organizers of OMERACT the first conference with patient involvement was  
17  
18 actually the most easy and successful because no one involved had any expectations. Partners  
19  
20 formed a homogeneous group and the program was not demanding. Despite the fact that  
21  
22 support was limited and there was a minimum of organization, patients felt welcome and  
23  
24 accepted.<sup>35</sup> During subsequent conferences partners were extremely motivated to learn the  
25  
26 OMERACT way and started to organize themselves. They formed a patient liaison group that  
27  
28 became responsible for communication between the patient group and the organizing  
29  
30 committee. Experienced partners developed information modules to bring newcomers to a  
31  
32 basic level of understanding of the scientific purpose of OMERACT. Where necessary they  
33  
34 approached professionals for assistance.  
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37  
38 In 2010 partners received a pre-conference pack containing information about the  
39  
40 program, lay-summaries of the objectives of the workshops, and a participants list. New  
41  
42 partners were matched with an experienced partner who took on the role of a buddy. After  
43  
44 arrival at the conference partners gathered for their own dinner and had an introductory  
45  
46 meeting. The second day, before the start of the official program, partners followed a half day  
47  
48 training session moderated by the Chair of the liaison group. Workshop leaders provided  
49  
50 disease-specific patient update sessions, prior to the workshops. To better understand the  
51  
52 discussion topics important terms, questionnaires or issues were explained. Experienced  
53  
54 OMERACT partners coordinated the production of a glossary<sup>36</sup> which has been so useful that  
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3 researchers as well as partners were supplied with a copy. Every conference the glossary is  
4  
5 updated with input from the workshop leaders.  
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7  
8 Nowadays it is the intention of OMERACT to optimize support by tailoring it to the  
9  
10 individual needs and competencies of partners. To overcome the barrier of an exhausting  
11  
12 program, the patient liaison group developed personalized programs that helped new partners  
13  
14 to pace themselves by making informed decisions about which sessions they should attend as  
15  
16 a minimum, and which sessions they should attend when their condition allowed. Other  
17  
18 suggestions were related to the OMERACT pre-conference work. It is now expected that  
19  
20 early participation in working groups will best prepare partners for participation at the  
21  
22 conference.  
23

## 24 25 26 27 **Barriers**

### 28 29 30 31 *Intensity of the program*

32  
33 OMERACT is an overwhelming experience for all partners attending the conference for the  
34  
35 first time.<sup>21</sup> An important barrier was the exhausting conference program. Physically  
36  
37 challenging were: the (intercontinental) travelling and climate change; accessibility of the  
38  
39 conference venue; early and late starting times of sessions; and the duration of the conference.  
40  
41 New partners in particular often participated far beyond their physical capacities. They were  
42  
43 not able to discriminate which sessions were most relevant and consequently tried to  
44  
45 participate in all. Mentally challenging were: the use of medical or methodological jargon;  
46  
47 uncertainty about the expected role and contributions; and dealing with hierarchical power  
48  
49 relations and strongly opinionated professionals. A recurring difficulty was the invisibility of  
50  
51 the importance of one's own provided contribution. In sessions dedicated to their own disease  
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53 partners were more confident about their contributions than in sessions dealing with topics  
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3 that were more remote to them. The barriers experienced by new partners have been reported  
4  
5 in detail in a previous study (ibid). Experienced partners coped better with the requirements of  
6  
7 the conference and reported fewer barriers.  
8  
9

### 10 11 *Scepticism*

12  
13 The notion of including patients as participants in OMERACT reached its tipping point at the  
14  
15 final voting session at OMERACT 5 (2000). It was a kind of serendipity: Although the  
16  
17 organizers had discussed the issue before, the proposal to invite patients at the next  
18  
19 conference occurred spontaneously from the audience. A majority was indifferent and did not  
20  
21 object to the notion as a principle of OMERACT.  
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24  
25 Initially some respondents were not convinced of the added value of partners and  
26  
27 attributed extrinsic motives to the leadership: promoting patient involvement for reasons of  
28  
29 political correctness. Others did not believe that partners were able to think beyond their own  
30  
31 condition or to understand the rigor of the methodological discussions. They perceived the  
32  
33 unconditional endorsement as a kind of tokenism but did not object as long as it would not  
34  
35 affect their own research; one respondent admitted not feeling confident to express politically  
36  
37 incorrect opinions out of fear of disapproval by her colleagues.  
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40  
41 After OMERACT 6, researchers slowly started to see and experience the benefits of  
42  
43 patient involvement and changed their perceptions.  
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46  
47 “At the start I was not optimistic and I saw several objections. First, patients don’t  
48  
49 understand clinometric issues. Secondly, I did not see any potential contribution of  
50  
51 patients. But I got convinced when they started to organize themselves, the glossary, the  
52  
53 training modules... Patients proved to be good organizers to lift themselves to a higher  
54  
55 level... Patients were professional and very motivated, which was different for other new  
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3 researchers entering OMERACT and not having much interest in the methodology of  
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5 outcome research.” (RE)  
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10 In 2010 a few respondents still believed that the disadvantages did outweigh the benefits.  
11 They judged the influence of partners out of balance and feared less interest in solving  
12 methodology challenges and a negative impact on the variety of topics on the research  
13 agenda. They felt forced to engage with partners in areas of research where they hardly saw  
14 any added value, such as imaging and biomarkers. Most of the partners confirmed this  
15 opinion and thought that domains that are distant from their daily life were less likely to  
16 benefit from their input. They were in particular keen to contribute to areas of research such  
17 as work, remission, flares, doctor-patient communication, adherence and non-  
18 pharmacological interventions such as self-management. They believed that they could  
19 contribute to research focused on their own condition but were uncertain about providing  
20 meaningful input to other rheumatic conditions. To a great extent physicians agreed on this.  
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### 36 *Composition of patient group*

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38 Institutionalization of patient involvement gave rise to a debate regarding the  
39 representativeness of professionalized partners. The OMERACT policy welcomes partners to  
40 provide the ‘naïve’ dimension based on the assumption that what has been achieved in the  
41 past is the result of a balance between new and experienced partners [internal report; 2008].  
42  
43 However there has been a tendency to raise the selection criteria in order to recruit partners  
44 that are aware of the methodological issues at stake. Some respondents objected to the  
45 participation of partners who do not understand the rigor of scientific research, slow down the  
46 process and hence cause irritation during breakouts. They argued that partners should be  
47 selected according to stringent criteria such as an academic education and preferably a  
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3 professional background in medicine or health care: “It makes the conversation run more  
4 smoothly”. The patient perspective is important but should be obtained during the pre-  
5 conference research work.  
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9  
10 Other participants emphasized the irreplaceable value of new partners for generating new  
11 ideas and a ‘real’ patient-oriented perspective. They reported potential risks of experienced  
12 partners becoming too professional, adapting their language, identifying themselves with  
13 researchers, and finally losing touch with their peers. And some respondents warned that  
14 partners who started acting as patient advocates might compromise the outcomes of  
15 OMERACT as a data-driven evidence based conference.  
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## 25 **Summary**

26  
27 Through this empirical study we have obtained insights into the factors for successful  
28 collaboration between patients and professionals in a scientific conference. Building the  
29 involvement of patients as equal partners directly into the program is an effective way to  
30 incorporate the patient perspective in outcome research. The experienced benefits and the way  
31 it is organized, have changed the perception of researchers in favour of a structural integration  
32 of partners in all parts of the conference. Factors that stimulated this process were long term  
33 commitment of the leadership; selection of partners through participating physicians; and an  
34 inclusive conference design. A facilitative moderation style and the personalized support of  
35 partners were essential. Barriers were often the negativity of the facilitators and related to the  
36 intensity of the conference program, scepticism among researchers, and the competencies and  
37 representativeness of the patient group.  
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## 51 **Discussion**

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3 OMERACT has provided a unique opportunity to evaluate the conditions of long term  
4 involvement of patients as conference partners in a highly scientific environment. Our  
5 evaluation showed that structural collaboration, fostered by a consensual leadership, is  
6 essential for successful engagement with partners and confirms the finding of a case study in  
7 the area of diabetes.<sup>37</sup> The current study has increased our knowledge and understanding of  
8 the challenges of structural involvement and might serve as an example for other conferences.  
9 Key opinion leaders could take a pro-active lead in this. Just by starting to invite patients and  
10 by providing adequate training and support, scepticism and resistance to change, elsewhere  
11 identified as important barriers for implementation,<sup>28</sup> transform into a supportive attitude. In  
12 our study we found that scepticism is often based on prejudices regarding the benefits and  
13 fear of tokenism. However, the evolution of engaging partners in OMERACT has been a  
14 process of empirical learning: Improving and adjusting inclusion strategies as the result of a  
15 continuous process of reflection. Participants lost their scepticism when partners started to  
16 organize themselves and when they saw their positive influence on the flow and content of the  
17 conference. Concerns that were expressed in the beginning, turned out not to be the case:  
18 Patients came with an open mind and without any agenda; they were able to transcend their  
19 own individual experiences and to understand the objectives of OMERACT. All these  
20 experiences convinced most of the participants that inviting patients is inevitable to address  
21 the ongoing challenge of developing outcomes that reflect the interests of people with  
22 arthritis.

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47 Although the impact of patients at OMERACT has been substantial, it is difficult to  
48 summarize how the experiential knowledge of partners is actually utilized during the  
49 OMERACT breakout sessions. Researchers are not used to taking notes about the particular  
50 contributions made by partners, and journals do not expect authors to report on the input of  
51 partners. And when patient involvement is an integral part of the conference, it becomes  
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3 almost impossible to distil individual contributions. Apart from this, there are hidden  
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5 contributions: impact that is not noticed by the researcher nor the partner. And finally patients  
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7 tend to underestimate the value of their own experience. More sophisticated methods are  
8  
9 required to articulate and evaluate their experiential knowledge.  
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12 Some researchers in the field of rheumatology have started to describe how they have  
13  
14 involved partners<sup>15 16</sup> which is necessary because patient involvement is not yet fully  
15  
16 understood. Also OMERACT participants still believe that the patient expertise is not fully  
17  
18 utilized and conditions to facilitate the contributions of partners are still suboptimal. A  
19  
20 remaining challenge is the development of full involvement in all phases of OMERACT by  
21  
22 engaging partners in the pre- and post-conference working groups, and by exploring  
23  
24 categories and phases of research where patient involvement is expected to be most  
25  
26 beneficial. Future research will enhance our body of knowledge of the feasibility and  
27  
28 effectiveness of different strategies to include patients in conference sessions and of our  
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30 understanding of the nature and significance of lay knowledge.  
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33  
34 Another challenge that requires further research is the representativeness of patient  
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36 research partners.<sup>14</sup> Partners have mostly been educated, white, middle class and socially  
37  
38 skilled persons able to collaborate with professionals in a critical though constructive manner.  
39  
40 Therefore important perspectives from other groups might be missed. Most professional  
41  
42 participants believe that – despite the lack of representativeness - partners are an asset for the  
43  
44 conference because of their personal contributions based on the reflection on their own patient  
45  
46 journey and the intense contact with other partners during several conferences. New and  
47  
48 experienced patients provide different kinds of contributions at different moments, finally  
49  
50 resulting in a kind of aggregated and synthesized expert-input.  
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54 In projects that follow the dialogue method, a stepwise, multi-stakeholder approach for  
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56 identifying priorities for health research,<sup>38</sup> patients develop and articulate their experiential  
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3 knowledge in a structured process of enclave deliberation; by exchanging and discussing  
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5 personal experiences in a homogeneous group, anecdotal stories – also called ‘being familiar  
6  
7 with’ – are subsequently transformed into practical knowledge (‘knowing how’) and expert-  
8  
9 knowledge (‘knowing that’).<sup>18</sup> For the OMERACT conference all types of knowledge are  
10  
11 important although there is a tendency to explore and utilize the anecdotal and practical  
12  
13 knowledge during the pre-conference activities and the expert-knowledge during the  
14  
15 conference. Relying on the input of *expert-patients* only, constitutes the risk of pseudo-  
16  
17 professionalism that is reported elsewhere.<sup>39</sup> Are partners empowered by their new role in  
18  
19 research or do they lose their naivety as a patient and align easily with professionals?<sup>40</sup> The  
20  
21 effect may be that they operate apart from their peers and try to ease collaboration by  
22  
23 suppressing their experience-based knowledge. Due to the dual relationship, partners may feel  
24  
25 uncomfortable to express a personal and independent voice if this contradicts the view of their  
26  
27 own physician. It is still not known whether partners sometimes try to please their physician  
28  
29 by avoiding disagreement.  
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34 The self-organized training and support empowered not only the individual partners, but  
35  
36 strengthened the mutual relationship with professionals too, a process that can be described as  
37  
38 relational empowerment.<sup>41 42</sup> The structural collaboration in OMERACT, fostered by regular  
39  
40 meetings during other conferences, sensitized both parties to the importance of beliefs and  
41  
42 priorities of the others. Partners obtained a better understanding of the methodological  
43  
44 challenges of outcome research and researchers learned about new domains that are relevant  
45  
46 from a patient perspective. Through mutual discussions and exchange of personal experiences  
47  
48 partners gained more confidence to speak up and to confront researchers with their own  
49  
50 opinions. Researchers met partners that were able to raise their voice without reservations and  
51  
52 experienced partners as a reliable ally. Structural involvement facilitated a mutual learning  
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54 process and a better understanding of the perspectives of others. In this context relational  
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3 empowerment might contribute to a sustainable inclusion of the patient perspective in  
4  
5 OMERACT activities without a total reverse of power<sup>43</sup>. OMERACT has created solid  
6  
7 partnership relations that, in the longer term, may result in the integration of different sources  
8  
9 of knowledge, also known as a melting of horizons. The characteristics of this process require  
10  
11 further exploration.  
12

### 13 14 15 16 **Funding**

17  
18 None  
19

### 20 21 **Competing Interests**

22  
23 None  
24

### 25 26 **Contributorship**

27 MW, JK and TA conceived the idea of the study and were responsible for the design of the  
28  
29 study. MW carried out the document analysis and all interviews. MW and MK were  
30  
31 responsible for the coding of the interview transcripts. All authors provided input into the  
32  
33 phase of cross-code checking and data analysis. The initial draft of the manuscript was  
34  
35 prepared by MW and then circulated repeatedly among all authors for critical revision. All  
36  
37 authors read and approved the final manuscript.  
38  
39

### 40 41 **Data sharing**

42  
43 No additional data are available.  
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Table 1 Characteristics of interviewees

	Professionals	Patient Research Partners	Interview Code
Sex (M:F)	12 : 4	7 : 9	
Professional background or Diagnosis	10 practicing rheumatologists 3 full time researchers 3 other professionals	10 rheumatoid arthritis 2 vasculitis 2 ankylosing spondylitis 1 fibromyalgia 1 gout	
Number of OMERACT conferences attended			
1	5	8	PA to PF, PO, PP
2	0	3	} PG to PN
3	1	1	
4	4	4	
≥5	6	0	
Interview in relation to OMERACT conference			
Before	2	1	
During	8	16	
After	6	5	
Geographical spread	6 countries 2 continents	7 countries 4 continents	
Research	10 Senior Researchers		RA to RG, RJ, RK,



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Background	1 Research Fellow	RY
	1 Post-doctoral researcher	RH RI
	2 Pharma representatives	DA, DD
	2 Staff members	DB, DC

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For peer review only

**Table 2****Facilitating and inhibiting factors for structural involvement of patients**

Facilitating factors	Inhibiting factors
<p><b>Strong leadership</b></p> <ul style="list-style-type: none"> <li>• Endorsement by key opinion leaders</li> <li>• Long term financial and organizational commitment</li> <li>• Ambassadors of participative research</li> <li>• Acknowledgement of contributions</li> </ul>	<p><b>Intensity of the program</b></p> <ul style="list-style-type: none"> <li>• Physically challenging</li> <li>• Intercontinental travelling</li> <li>• Accessibility</li> <li>• Mentally challenging</li> <li>• Language &amp; terminology</li> <li>• Remote themes</li> </ul>
<p><b>Selection procedure</b></p> <ul style="list-style-type: none"> <li>• Recruitment through clinicians</li> <li>• Proportional representation</li> <li>• Selection criteria</li> <li>• Learning curve</li> </ul>	<p><b>Skepticism</b></p> <ul style="list-style-type: none"> <li>• Doubts about added value</li> <li>• Risk of tokenism</li> <li>• Imperceptibility of contributions</li> <li>• Lack of continuity</li> </ul>
<p><b>Conference design</b></p> <ul style="list-style-type: none"> <li>• Multi-stakeholder approach</li> <li>• Spirit of OMERACT</li> <li>• Full &amp; equal participation</li> <li>• Interactive breakouts</li> </ul>	<p><b>Composition patient group</b></p> <ul style="list-style-type: none"> <li>• Lack of representativeness</li> <li>• Pseudo-professionalism</li> </ul>

- 
- Structural involvement

### **Facilitative moderation style**

- Open dialogue
- Deliberate encouragement
- Respect of confidentiality
- Clear communication
- Sensitivity to patient values

### **Individualized support**

- Pre-conference information pack
  - Training
  - Personalized programs
  - Buddy system
  - Glossary
  - Pre-conference involvement
-

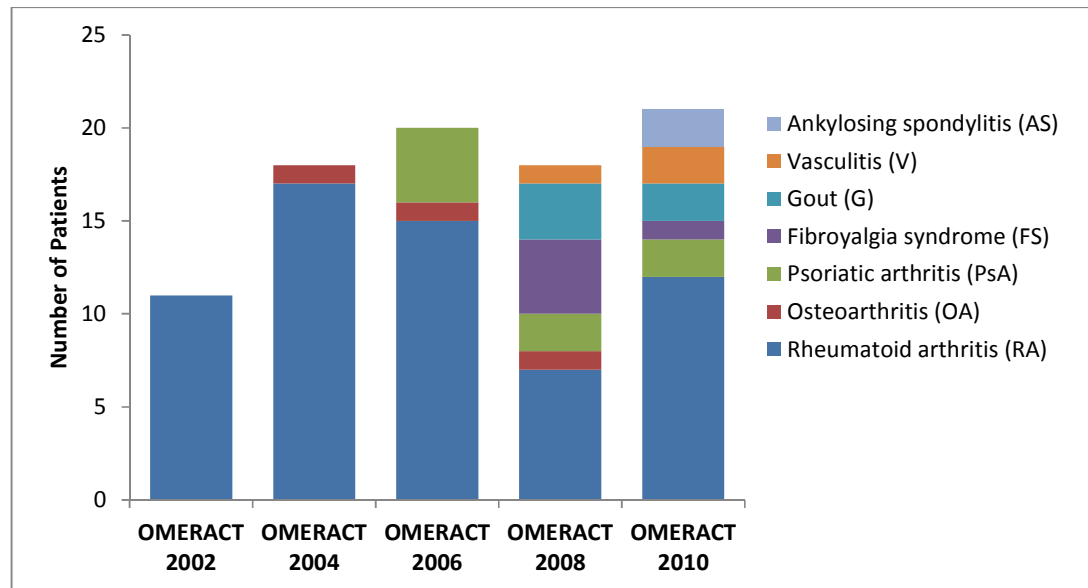
**Table 3****Patient reported barriers to collaboration and strategies to reduce these barriers**

<b>Barriers to contribute identified by partners</b>	<b>Helpful tools, responses and points to consider to encourage partners to contribute</b>
<p><b>Feeling an observer in the conference, rather than a colleague</b></p> <ul style="list-style-type: none"> <li>• Not involved from the beginning</li> <li>• Lack of information</li> </ul>	<p><b>Involve partners right from the start</b></p> <ul style="list-style-type: none"> <li>• Provide background information in understandable language (research protocol)</li> <li>• Treat all team members equally</li> </ul>
<p><b>Inadequate introduction</b></p> <ul style="list-style-type: none"> <li>• Not knowing what is expected</li> <li>• Feeling not prepared for the job</li> <li>• Unaware of the aims of the conference</li> <li>• Why me?</li> </ul>	<p><b>Discuss mutual expectations in a face-to-face meeting before the start of the conference</b></p> <ul style="list-style-type: none"> <li>• What kind of contribution is expected from the partner?</li> <li>• Has the partner affinity to the research topic(s)?</li> <li>• In which phase or activities will the partner be involved?</li> <li>• Who takes the initiative for contact and how?</li> <li>• How will the partner be informed and supported along the way?</li> <li>• What are specific needs of the partner?</li> </ul>
<p><b>Doubts about their added value</b></p> <ul style="list-style-type: none"> <li>• Feeling shy to tell personal stories</li> </ul>	<p><b>Encourage partners deliberately</b></p> <ul style="list-style-type: none"> <li>• Adapt to a patient-centered communication style and promote open dialogue, attentive listening and</li> </ul>

<ul style="list-style-type: none"> <li>Assumption that experiences are obvious and already known to professionals</li> <li>Low status of anecdotal knowledge</li> </ul>	<ul style="list-style-type: none"> <li>authentic contact</li> <li>Invite partners to share their perspectives</li> <li>Ask open-ended questions and probes</li> <li>Give feedback on contributions</li> <li>Emphasize the importance of personal experiences and provide reassurance</li> </ul>
<p><b>Feeling unable to contribute</b></p> <ul style="list-style-type: none"> <li>Lack of knowledge about research and statistics</li> <li>Problem with medical jargon</li> <li>Problem with English language</li> <li>Hierarchy of professions</li> <li>Power imbalance</li> </ul>	<p><b>Tailor support to the competencies of the partners</b></p> <ul style="list-style-type: none"> <li>Provide lay summaries</li> <li>Create a learning environment: provide training opportunities</li> <li>Distribute reading materials before meetings</li> <li>Explain jargon without being asked</li> <li>Provide glossaries, journals and websites</li> <li>Help partners access and judge scientific literature</li> </ul>
<p><b>Feeling disqualified, not listened to</b></p> <ul style="list-style-type: none"> <li>Feeling muddled about inappropriate disclosure</li> <li>Feeling dismissed when an initiative to contribute is ignored</li> </ul>	<p><b>Be alert for sensitive issues</b></p> <ul style="list-style-type: none"> <li>Partners want to be regarded as individuals, from a holistic perspective</li> <li>Try to be inclusive</li> <li>Respect confidentiality and apply to ethical rules</li> <li>Acknowledge contributions</li> </ul>

**Online Table 1****Overview of tasks carried out by patient participants at OMERACT 6-10**

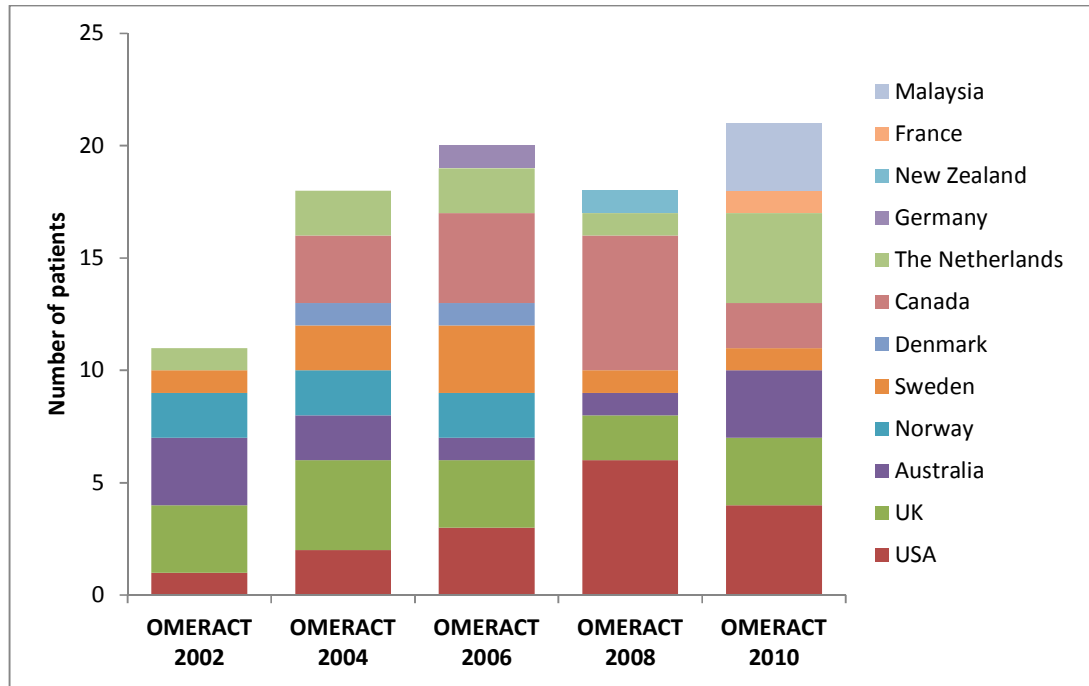
- Act as co-chair of the patient participation workshop;
- Moderate break-out sessions
- Formulate questions for the workshop(s)
- Give a presentation at plenary sessions
- Weight different measures and domains
- Participate in different meetings as full delegates
- Provide input on pre- and post-conference documents
- Participate in workshops on fibromyalgia, gout, psoriatic arthritis, RA, AS and vasculitis
- Edit or contribute to the OMERACT patient newsletter
- Compile and edit the patient information pack and the OMERACT glossary
- Assist researchers to produce summaries suitable for lay participants
- Co-author scientific publications
- Promote topics from the research agenda on a national level
- Guide, support and inspire new patient research partners
- Disseminate the outcomes outside OMERACT.

**Online figure 1****Rheumatic conditions represented at OMERACT meetings between 2002-2010**

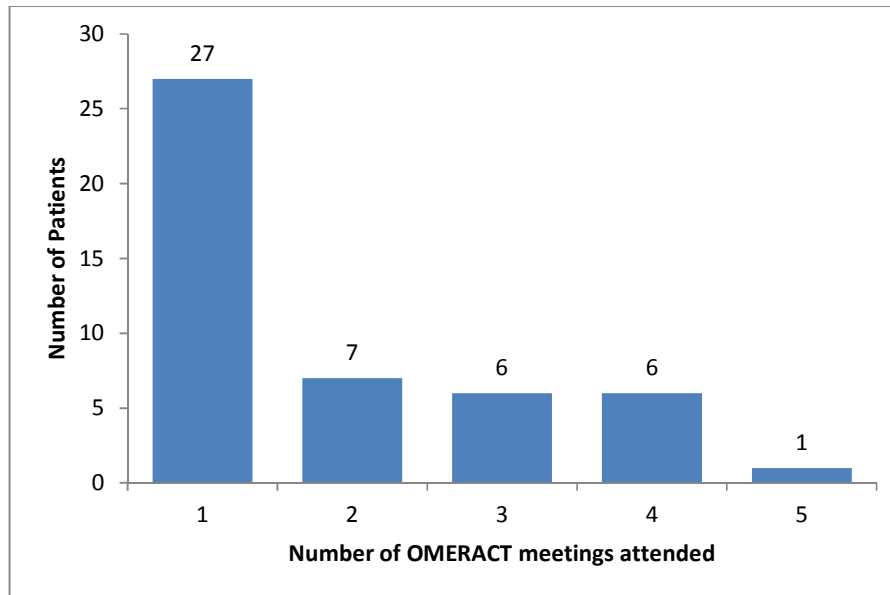
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**Online figure 2**

**Countries represented at OMERACT meetings between 2002-2010**



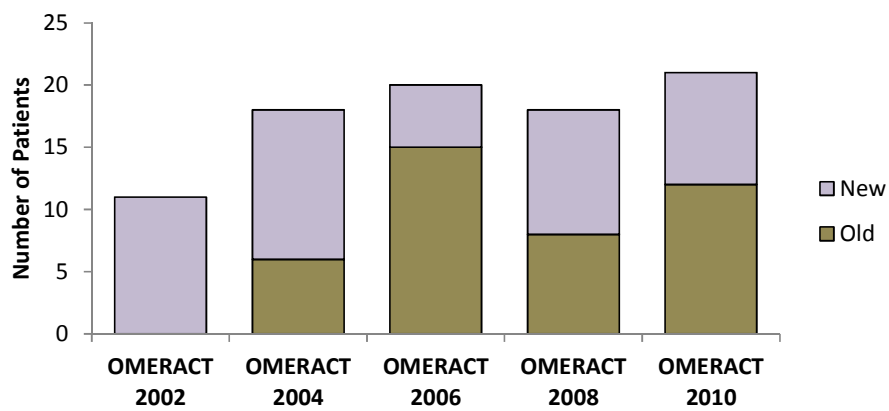


**Online Figure 3****Number of times partners attended OMERACT between 2002-2010**

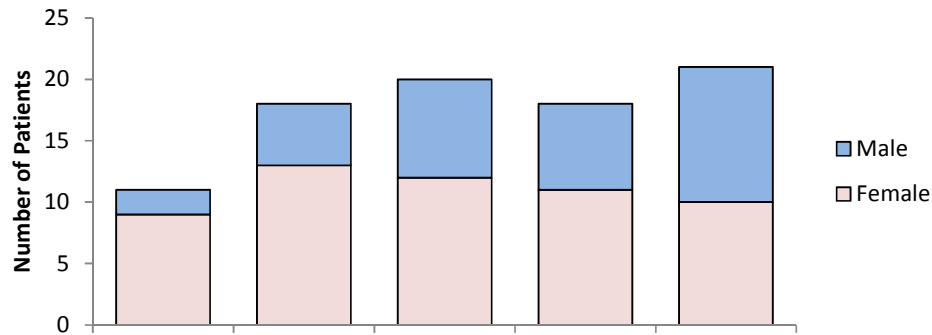
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**Online figure 4**

**Number of new versus experienced patient participants between 2002-2010**



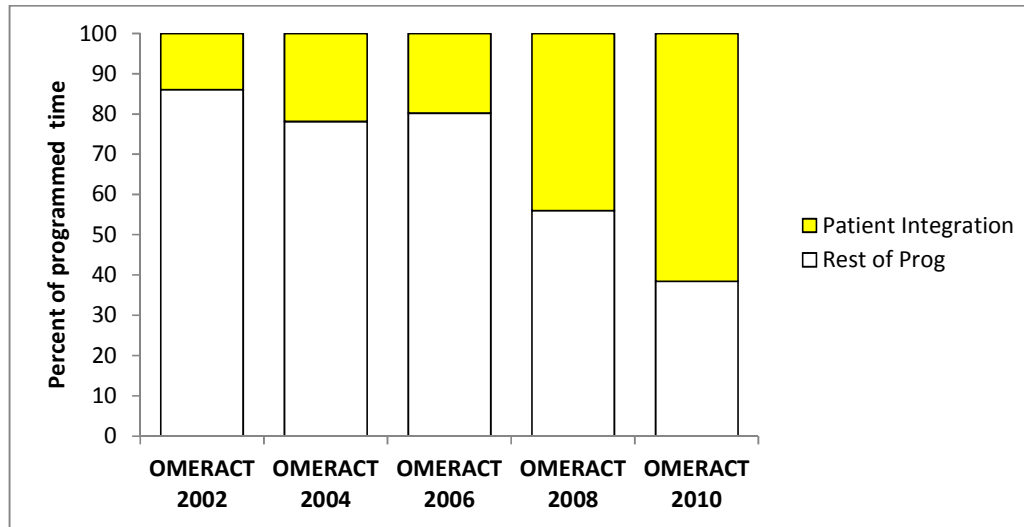
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**Online figure 5****Gender of the 47 patient participants between 2002-2010**

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**Online figure 6**

**Programmed patient integration at OMERACT meetings between 2002-2010**





**Facilitating and inhibiting factors for long-term involvement of patients at outcome conferences - Lessons learned from a decade of collaboration in OMERACT.**

Journal:	<i>BMJ Open</i>
Manuscript ID:	bmjopen-2013-003311.R1
Article Type:	Research
Date Submitted by the Author:	17-Jul-2013
Complete List of Authors:	Wit, Maarten; VU Medical Centre , Metamedica Abma, Tineke; VU Medical Centre, Metamedica Koelewijn-van Loon, Marije; CAPHRI School for Public Health and Primary CareCentre, Department of General Practice Collins, Sarah; Patient Research Partner, Kirwan, John; University of Bristol, Rheumatology
<b>Primary Subject Heading</b>:	Rheumatology
Secondary Subject Heading:	Rheumatology, Qualitative research, Patient-centred medicine
Keywords:	QUALITATIVE RESEARCH, RHEUMATOLOGY, SOCIAL MEDICINE

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3 Facilitating and inhibiting factors for long-term involvement of patients at outcome  
4 conferences - Lessons learned from a decade of collaboration in OMERACT.  
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11 Abstract  
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14 Objective: Several studies have provided insights into the conditions for successful patient  
15 involvement in health research. We recently demonstrated that long-term engagement with  
16 people with rheumatic conditions in international outcome research led to significant changes  
17 in the research agenda in the field of rheumatology. This article explores facilitating and  
18 inhibiting factors for long-term involvement of patients as collaborative partners at five  
19 Outcome Measures in Rheumatology (OMERACT) conferences.  
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28 Design: Responsive evaluation, starting with a thematic document analysis of conference  
29 proceedings and grey literature, followed by 32 qualitative interviews. Interview transcripts  
30 were subjected to inductive content analysis.  
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36 Setting: Five international OMERACT conferences between 2002 and 2012.  
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39 Participants: Patient delegates (n=16) and professional delegates representing researchers  
40 (n=14), pharmaceutical industry and regulators (n=2).  
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44 Results: Combined review of the document analysis and interview data revealed 5 main  
45 facilitators and 3 main barriers. Patient engagement as full participants at OMERACT  
46 conferences was enhanced by: strong leadership commitment and the presence of change  
47 agents; a clear selection procedure; an inclusive consensus-based conference design;  
48 individualized and self-organized support; an interactive and encouraging moderation style  
49 during discussion groups. Barriers were related to the intensity of the conference programme,  
50 scepticism among researchers, and doubts about the representativeness of the patient group.  
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3 Conclusions: This study concludes that developing a sustainable structure for funding,  
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5 selection, and support of patient delegates, and adjusting conference design and moderation  
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7 style, contribute towards facilitating direct dialogue between all stakeholders and towards  
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9 enhancing mutual understanding and the successful incorporation of the patient perspective in  
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11 an outcome conference such as OMERACT.  
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## Article Summary

### Article focus

- The bi-annual conference on Outcome Measures in Rheumatology (OMERACT) has extensive experience with the structural involvement of patients as collaborating partners in outcome research.
- Through a systematic document analysis and 38 qualitative interviews with all stakeholders we explore the facilitators for and barriers to long-term participation of patients in outcome research.

### Key messages

- Making patient participation an integral part of the conference vision, structure and programme enables the effective and efficient inclusion of the patient perspective.
- Suitable introduction and personalized training and support for patients are important conditions for successful engagement with patients.
- The role of moderators in small group discussions is pivotal for enabling patients to contribute to research and to foster the mutual learning processes of all participants.

### Strengths and limitations of this study

- OMERACT is a unique opportunity to evaluate the requirements for the long-term involvement of patients as conference partners in a highly scientific environment.
- Generalizability and transferability of the result findings to conferences on national and local levels and to other disciplines is limited and additional research is required.



**Keywords**

patient participation; OMERACT; outcome research; qualitative research; research conference; responsive evaluation; rheumatology; user involvement

**CONTRIBUTORSHIP**

MW, JK and TA conceived the idea for the study and were responsible for the study design. MW conducted the document analysis and all interviews. MW and MK were responsible for coding the interview transcripts. All authors provided input for the cross-code checking and data analysis phases. MW prepared the initial draft of the manuscript, which was then circulated a number of times for critical revision among all authors. All authors read and approved the final manuscript.

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3 The past decade has seen an increase in the number of patients becoming involved in health  
4 research. The background to this is the general trend towards empowered health consumers,  
5 and an acknowledgement of patients' entitlement to influence research that will affect their  
6 daily life. Patients aspire to more horizontal and deliberative partnerships with researchers,  
7 which has resulted in a range of different patient roles.<sup>1-4</sup> Patients may be: committee  
8 members; reviewers of protocols or grant applications; advisors; panel members or research  
9 commissioners. Each patient role implies different tasks and different kinds of contributions,  
10 and roles can be performed at different levels of involvement.<sup>5 6</sup> Most case studies observe a  
11 power shift between patients and researchers. However, participative research remains to be  
12 justified since there is still little evidence as to the effectiveness of these new patient roles.<sup>7</sup>

13  
14 One new role in health research is that of the patient as conference partner. Patients in  
15 this new role do not participate as patient advocates or representatives of patient  
16 organizations. Neither do they attend conferences for networking purposes, or for learning  
17 about new developments related to their condition. With a view to providing the patient  
18 perspective, patients are invited to collaborate with researchers as equal partners. This is the  
19 case with OMERACT: the Outcome Measures in Rheumatology conferences. Here patients  
20 have successfully changed the research agenda, contributed towards developing core outcome  
21 sets, and helped to devise new measurement instruments.<sup>8</sup> As far as we are aware, there is no  
22 literature that explores the tasks, contributions and challenges of patients as collaborating  
23 partners at scientific conferences. We do however know more about patient research partners,  
24 a role that is similar to that of patients as conference partners. The term patient research  
25 partner was coined in the context of rheumatology<sup>9</sup> and can be defined as 'persons with a  
26 relevant disease who operate as active research team members on an equal basis with  
27 professional researchers, adding the benefit of their experiential knowledge to any phase of  
28 the project'.<sup>10</sup> Patient research partners have actively contributed towards developing research

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3 agendas for people with spinal cord injuries,<sup>11</sup> intellectual disabilities,<sup>12</sup> and chronic kidney  
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5 disease.<sup>13</sup> Patient research partners can also be involved in developing research designs,  
6  
7 collecting data, and in the development of patient-reported outcomes.<sup>14</sup> Patient research  
8  
9 partners at the Department for Rheumatology at the University of Bristol have contributed to  
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11 the study of fatigue.<sup>15</sup> Internationally, patient research partners have been involved in the  
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13 study of flares in rheumatoid arthritis (RA)<sup>16</sup> and in the development of a new patient-derived  
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15 quality of life measure for RA.<sup>17</sup>

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18 There is some evidence that the active involvement of patient research partners brings  
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20 with it several benefits to research<sup>18 19</sup> but there is little evidence or consensus about the  
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22 factors that facilitate or constrain effective involvement. OMERACT is the first series of  
23  
24 international research conferences that has successfully engaged with patients as collaborating  
25  
26 partners over a substantial period of time.<sup>8</sup> However, it is still not known which factors  
27  
28 support this success, how the culture, structure and procedures have facilitated patients to  
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30 contribute effectively, and how previously reported barriers have been removed. The  
31  
32 objective of the present study is to describe how OMERACT has organized structural  
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34 collaboration with patients in its conferences over the past decade, and to examine which  
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36 factors have supported or inhibited this process. We also analyse how this process has  
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38 changed OMERACT delegates' perceptions and beliefs on patient involvement.  
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#### 45 **The context: OMERACT**

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47 OMERACT started in 1992 to achieve consensus on a core set of outcome measures for  
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49 clinical trials in rheumatoid arthritis. Based on the success of the first conference, it went on  
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51 to become a worldwide, data-driven working conference known for its interactive conference  
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53 design and high scientific rigour. The conference brings together a wide range of  
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55 professionals with an interest in the methodology of clinical trials in the field of  
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3 rheumatology. The objective is to build consensus on core outcome sets and appropriate  
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5 measurement instruments for clinical trials. Since 2002 OMERACT has invited patients as  
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7 full conference participants based on the belief that outcomes for clinical trials need to be  
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9 derived from 'the lived experience of arthritis' and from 'concepts which can be readily  
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11 communicated to patients to help with therapeutic decision making'.<sup>20</sup> A total of 58 patients  
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13 took on this role between 2002 and 2012. Of the 172 conference participants at OMERACT  
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15 10 (2010) there were 152 professionals and 20 partners. Partner characteristics are given in  
16  
17 the online figures 1-5.  
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21 In a separate case study we explored the expectations and experiences of patients who  
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23 were participating in OMERACT for the first time.<sup>21</sup> They reported a number of barriers to  
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25 full collaboration with professionals, and such things as preparation, the professionals'  
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27 moderation style, and the lack of individual support on site. They believed that the  
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29 contributions they made to the breakouts were not significant, and that their experiential  
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31 knowledge was not optimally used. They believed, nevertheless, that their involvement had  
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33 been valuable and meaningful. They confirmed they had experienced personal learning  
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35 curves, and felt that they would be able to contribute more effectively at a subsequent  
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37 conference.  
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41 In a previous publication in which we reported on the impact of patient participation in  
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43 OMERACT, researchers confirmed that the involvement of both new and experienced  
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45 patients had been a success, and that this had significantly influenced the conference  
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47 outcomes.<sup>8</sup> Patients had enriched the research agenda with new topics such as wellbeing,  
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49 flares, sleep disturbances and, most illustrative of all, fatigue. A substantial amount of work  
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51 on fatigue in rheumatoid arthritis has been published<sup>22 23</sup> and OMERACT participants have  
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53 almost unanimously confirmed that this research would not have been rigorously conducted  
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55 or even identified without patients being present at the conferences.  
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## Challenges

In this study we address a number of challenges that we are aware of from previous studies that have examined the role of patients as research partners. One of the most important challenges is the fact that personal experience or lay knowledge is not accepted as a valid source for scientific research.<sup>24</sup> It is often perceived as inferior compared with professionals' evidence-based knowledge.<sup>25</sup> This means that patients find it hard to create a basis for trust or for equal collaborative relationships.<sup>18 26</sup> Caron-Flinterman studied 23 cases of active patient involvement in biomedical research and argued that the deliberate use of patients' experiential knowledge requires additional research.<sup>27</sup> Recent studies have demonstrated that starting with dialogue and deliberation among patients in collaboration with patient research partners is an effective way to strengthen their voice and develop a shared knowledge base grounded in the experiential knowledge of individuals.<sup>18 19</sup> However, further understanding of the nature and significance of lay knowledge in the context of medical research and research conferences is still necessary.

A second challenge is that some researchers are reluctant to engage with patients and believe that involving patients amounts to some kind of tokenism.<sup>28</sup> Other researchers may have difficulty adjusting their language and communication style, which only perpetuates a significant barrier to collaboration. Elberse studied the effectiveness of inclusion strategies to incorporate patients' perspectives in the development of a research agenda for people with congenital heart disease.<sup>29</sup> This study concluded that verbal communication is an important inhibiting factor and additional inclusion strategies are needed if an effective partnership between patients and professionals is to be achieved.

A final recurring challenge is the lack of knowledge required to implement the structural involvement of patient research partners.<sup>6</sup> Structural involvement means that the initiative to engage with patients is not incidental, and dependent on the goodwill of one or two

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3 individuals. In contrast, it is a long-term commitment to engage with patients by making  
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5 patient participation an integral part of the vision, structure and practices of the organization.  
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7 The evidence base underpinning the assessment of effective conditions for patient  
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9 involvement is relatively weak, due primarily to poor documentation, analysis and reporting.  
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## 12 13 14 **Method**

### 15 16 17 *Data collection*

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19 Data collection was based on a thematic document analysis and 38 interviews with  
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21 representatives of all stakeholders involved in OMERACT. The document analysis included  
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23 OMERACT conference proceedings and grey literature such as OMERACT policy  
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25 documents, correspondence, invitations, session reports and e-mails. The document review  
26  
27 focused on the objectives and structure of the conference, number of patient delegates, their  
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29 selection, preparation and support, and the rheumatic conditions and countries represented.  
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31 We were particularly interested in the explanation and arguments given for the way  
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33 OMERACT created, changed or improved operational procedures and the way participants  
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35 accepted or adjusted them.  
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41 Following the document review the first author performed a responsive evaluation<sup>30</sup> by  
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43 conducting qualitative interviews with representatives of all stakeholders before, during and  
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45 within four weeks following the 2010 conference. Finally, the opinions and experiences of 16  
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47 professionals and 16 patients were collected (Table 1). Of the 8 patient delegates who  
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49 attended OMERACT for the first time, 3 were interviewed on 3 different occasions during the  
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51 five-day conference. This was done to obtain accurate insights into any changes that occurred  
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53 in their expectations, experiences and contributions.  
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3 All interviews were recorded, transcribed by an independent secretariat and subjected to a  
4 responder check. The interviews lasted an average of 52 minutes. The interview protocols  
5 differed for professionals, new patients and experienced patients. The topics covered the  
6 expected role of patient participants, their selection, preparation and support, and their  
7 experiences in discussion groups, in particular those during the workshops on remission and  
8 flares. All participants gave their informed consent prior to the interview. No ethical approval  
9 from the MEC was needed for this study.  
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### 20 *Interviewee selection*

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22 Maximum variation was the aim when selecting interviewees, and the selection was made  
23 using an emergent purposive sampling approach, based on stakeholder's background, opinion  
24 about patient involvement, gender, geographical spread and number of OMERACT  
25 conferences attended. The selection strategy took account of the limitations inherent in a five-  
26 day international conference. Potential candidates for face-to-face interviews should be  
27 willing to dedicate some of their time for the interview during the conference. Preliminary  
28 analyses of the initial interview data conducted immediately after the conference revealed an  
29 unexpected response shift. Professionals' The attitude towards patient involvement of  
30 professionals who were initially assumed to be critical, had changed significantly. Their  
31 scepticism had made way for a more positive assessment of collaboration and its benefits. For  
32 this reason we sought out two new interviewees who were known for their critical  
33 perspective. The views of a research fellow and a post-doc researcher were missing and  
34 subsequently added to the list of interviewees. Saturation was achieved after the additional  
35 transcripts had been analysed.  
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5 *Data analysis* – An inductive, content analysis of all the data was performed. The entire  
6  
7 interview transcript was read first to identify emerging themes and subthemes related to the  
8  
9 research topic of facilitators for and barriers to patient participation in OMERACT  
10  
11 conferences. All text fragments were given a descriptive label or code relating to a specific  
12  
13 theme or subtheme. For example: ‘there is still an undercurrent that questions the issue of the  
14  
15 added value of patient input’ was labelled as ‘(low) expectations of patients’ contribution’.  
16  
17 Each interview was first analysed separately. Any new emerging theme was added to the  
18  
19 process of labelling and analysis, and also adopted for the interviews previously analysed.  
20  
21 This is referred to as open coding. In the subsequent, axial coding step, the data from the  
22  
23 different interviews were compared (cross case analysis) and grouped into clusters based on  
24  
25 the main emerging (sub)themes. The descriptive labels were removed by interpretive codes  
26  
27 that refer to the meaning of an experience. In our example the labels were placed under the  
28  
29 subtheme of ‘doubts about the added value’ and ‘resistance to change’. In the final step we  
30  
31 concluded that both themes were strongly related to ‘scepticism among researchers’ which  
32  
33 was identified as one of the three main barriers to implementing structural patient  
34  
35 participation. An example of the audit trail of some of the text fragments can be found in  
36  
37 Appendix 1.  
38  
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43 The quotations of the different interviewees were compared and example citations were  
44  
45 identified per cluster and theme. A further understanding of the facilitating and hindering  
46  
47 factors was obtained by comparing the themes among those participants who were satisfied  
48  
49 about the conference as opposed to those who were more critical.  
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51

52 The analysis concentrated on those aspects involving how the conference was conducted,  
53  
54 the preparation and the breakout sessions that have a direct influence on the ability of patient  
55  
56 delegates to contribute. The documents and the interview data were analysed with a view to  
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ascertaining what structural arrangements OMERACT made to facilitate the incorporation of patient knowledge in the conference. All team members – representing different perspectives and professional backgrounds - were involved in the data analysis and interpretation.

### *Quality procedures*

Triangulation was done by synthesizing interview data and results from the document analysis. In order to improve the relevance and quality of the analysis and interpretation of the data, a patient who attended OMERACT 10 for the first time (SC) joined the research team. She was actively involved in the data coding and analysis, team meetings and in drafting this article. To increase the inter-rater reliability of the coding an external expert in qualitative research (MK) who had never worked with conference partners before, participated in all phases of the study, starting with the transcript coding phase. All quotes in this article are presented as if made by female participants in order to preserve participant anonymity. Quotes by professionals are indicated by ‘R’, and those of conference partners (in short: ‘partners’) by ‘P’.

### **Results**

During the combined review of the document analysis and the coding of the interview transcripts the research team grouped 1,563 open codes into 44 meaningful generic categories, 29 of which were descriptors of facilitators and 15 descriptors of barriers. In a second review round, 8 main categories emerged that characterized the conference elements that either supported or inhibited the contributions made by partners. The team finally defined the content of these categories and divided them into 5 main facilitators and 3 main barriers (Table 2). The 5 facilitators included: the role of leadership; selection procedure; conference design; moderation style, and support. The 3 barriers were the programme intensity,

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2  
3 scepticism among researchers, and representativeness of the patient group. Each barrier is  
4  
5 described below with examples from the data.  
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8  
9 [Table 2]  
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## 12 13 14 **Facilitators**

### 15 16 17 *Leadership*

18  
19 Long-term commitment and support of opinion leaders is key to the success of new  
20  
21 initiatives. The OMERACT organizing committee was intrinsically motivated to foster patient  
22  
23 engagement in the conference: ‘We believe their input is essential to decide on the right  
24  
25 measurement tools’.<sup>31</sup> According to one of the members of this committee, the decision to  
26  
27 invite patients was not taken lightly, and was discussed at several planning meetings. The  
28  
29 committee was daunted by the question: ‘how to organize patient participation?’[RD]. When  
30  
31 the decision was taken, the leadership was determined to do it properly. They gave full  
32  
33 support to the patient perspective working group leader who took on the role of a change  
34  
35 agent, and provided funds to enable patient partners to attend the conference. These costs  
36  
37 amounted to over \$ 80,000 in 2012. They also acknowledged the repeated contributions made  
38  
39 by partners: ‘Their dedication to the process is an example for us all’ (ibid). Based on the  
40  
41 positive experiences of two conferences attended by partners, OMERACT formulated basic  
42  
43 principles for patient engagement in 2006: ‘OMERACT policy on including the patient  
44  
45 perspective in rheumatology outcomes assessment’ [internal document]. This document was a  
46  
47 milestone because it made patient participation part of OMERACT’s vision, embedded in a  
48  
49 set of operational procedures. After three further conferences, the Executive Committee  
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3 agreed on the principle that active patient involvement would be a prerequisite for working  
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5 groups to put forward themes for the OMERACT programme.<sup>20</sup>  
6

7 The leadership recognized the value of a mixed group of new and experienced partners  
8  
9 and was committed to providing opportunities for experiments and long-term learning. They  
10  
11 confirmed that a learning curve is a requisite for being productive.  
12  
13

### 14 15 16 *Selection*

17  
18 It was clear from the outset that patient participants were not expected to represent any group  
19  
20 or organization. Although partners might be members of patient organizations, their role at  
21  
22 OMERACT should be strictly personal and individual. Their contribution is valuable purely  
23  
24 because of their personal experience: ‘a living knowledge of their long-term conditions’ and  
25  
26 ‘the unpredictable nature of their illness’ [internal report, 2008]. Their input is not linked at  
27  
28 all to advocacy for resources or to attention for a particular disease. Recruitment is done  
29  
30 through the clinic of participating physicians ‘to ensure that people were invited who could  
31  
32 make a contribution in unfamiliar circumstances’.<sup>32</sup> In practice physicians proved to be in an  
33  
34 ideal position to identify eligible patients simply because they were familiar with the patients  
35  
36 themselves and with the OMERACT requirements.<sup>20</sup> Since 2004 OMERACT has aimed for  
37  
38 10% of patients with a mix of conditions [online figure 1], geographical spread [online figure  
39  
40 2] and OMERACT experience [online figure 3].  
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45 Partner selection is still a cause for concern, particularly as regards the dual relationship  
46  
47 between the individual patient partner and their physician. Participants reported that the  
48  
49 current system had a number of significant advantages: this personal relationship clearly  
50  
51 motivates patients to take part; it makes researchers feel responsible for the appropriate  
52  
53 guidance of and funding for the partners, and precludes the selection of patient advocates.  
54  
55 Some respondents pointed out that there might be a risk that partners might not dare to speak  
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3 openly about their opinions in the presence of their own physician. In one case a partner  
4  
5 admitted that ‘pleasing’ or ‘identification with’ her own consultant had played a role when  
6  
7 she felt she had to defend her consultant’s point of view when delegates criticized her for not  
8  
9 having incorporated the patient perspective sufficiently in the presented data.  
10

11  
12 As the result of structural involvement, the relationship between partners and researchers  
13  
14 has developed into equal collaboration in many aspects of the conference. Participants have  
15  
16 tended to raise the level of competencies required: partners are expected to speak up; provide  
17  
18 the patient perspective; compartmentalize their clinical relationship<sup>9</sup>, and carry out tasks just  
19  
20 like all other delegates. Most participants confirmed that partners must be able to understand  
21  
22 the basic principles of research, contribute during discussions, and receive criticism.  
23  
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26

### 27 *Conference design*

28  
29 OMERACT started out as an informal gathering of researchers interested in outcome  
30  
31 measurement in rheumatology<sup>33</sup> and evolved into a biannual five-day working conference  
32  
33 with a multi-stakeholder approach. Participants confirmed that the modest size of the  
34  
35 conference, the attitude of the delegates, and the spirit of OMERACT as an open and  
36  
37 inclusive initiative, have all been beneficial for a positive reception of the concept of patient  
38  
39 participation: ‘I think that most of the researchers and clinicians that go in here are rather  
40  
41 open minded’ [RB]. Partners felt welcome at the conference: ‘You do feel like you’re part of  
42  
43 the family’ [PH], and ‘OMERACT is probably the most patient inclusive meeting’ [PI].  
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47  
48 The conference layout and the strong focus on active interaction and debate in small  
49  
50 groups, including pre- and post-workshop meetings, have been specifically designed to serve  
51  
52 the need to integrate diverse perspectives, and to avoid one single dominant voice: ‘At times  
53  
54 discussion on topics may be strongly influenced by key opinion leaders, but holding more  
55  
56 meetings of smaller concurrent interest groups has partially remedied this problem’.<sup>34</sup> The  
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3 breakout discussions also: ‘support the patient contributions in what might otherwise be a  
4  
5 very professionally oriented forum’ (ibid.).  
6

7 Partners were officially invited to participate as full delegates with voting rights and  
8  
9 access to all sessions, discussions and events. Some of the more experienced partners felt they  
10  
11 were on a par with the professionals and acted as co-researchers by co-moderating, reporting  
12  
13 back or becoming co-authors (online Table 1). The majority of partners believed it was their  
14  
15 role to give information or advice, but found themselves sometimes in the role of an  
16  
17 observers. New partners in particular often felt the same disparity towards professionals as is  
18  
19 experienced in clinical practice. The interviews revealed that new researchers and research  
20  
21 fellows sometimes also experienced this disparity.  
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### 27 *Moderation style*

28  
29 The breakouts during the OMERACT conferences lie at the heart of the conference. Although  
30  
31 moderation is part of the conference proceedings and has been described in separate  
32  
33 guidelines [internal document], the quality of moderation was considered to be of the utmost  
34  
35 importance: A facilitator can either help partners contribute to their full potential, or relegate  
36  
37 them to the sidelines as silent observers. The partners considered a facilitative moderation  
38  
39 style and an environment that fosters mutual learning through open dialogue to be critical  
40  
41 conditions for empowering them to make their voices heard and to contribute fully to the  
42  
43 objectives of the sessions. One of the partners described what made her feel confident enough  
44  
45 to say something:  
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51 ‘Just simple things, like at the start: we had something like a semi-circle [for the  
52  
53 seating] rather than in rows. So we could all interact and see each other. Basic stuff  
54  
55 like that. Especially for somebody like me with a hearing disability it is important to  
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3 see all the faces'. And the moderator: 'did thank everybody for coming, made us all  
4  
5 feel welcome and stopped a couple of times through the session to say "what do the  
6  
7 patients think?" We were all given the opportunity to speak, and weren't cut off or  
8  
9 being manipulated or something like that, it (...) all really felt equal.' (PC)  
10  
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12  
13  
14 Partners were at times confronted with what seemed like a patronizing attitude on the  
15  
16 part of a moderator or other delegate. Occasional comments such as: 'That is quite  
17  
18 obvious' were felt to undermine their competences or disease experience. As a result  
19  
20 partners sometimes felt ignored, frustrated or unable to contribute. The language was  
21  
22 also a barrier for some whose first language is not English. This was something that had  
23  
24 been underestimated and partners tended to refrain from saying something when they  
25  
26 were afraid of not using the right words or expressions.  
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29  
30 Good moderators used the dynamics of a dialogue to articulate partners' opinions:

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34 'Because one patient can say something which facts up the other patients in the room to  
35  
36 say "yes, this is very important and I haven't thought about it but now that's been brought  
37  
38 up: absolutely". I've seen examples of that many times at OMERACT and you almost  
39  
40 hear the penny drop, it was all of a sudden a big light bulb goes on and everyone says  
41  
42 'yes, absolutely!' (PH)  
43  
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47  
48 Moderators' behaviour was sometimes considered unethical or to be a poor approach to  
49  
50 sensitive issues. For example, on one occasion a discussion on a rare rheumatic disease  
51  
52 caused distress for one of the partners affected by that disease when mortality rates were  
53  
54 presented. The researcher mentioned somewhat dismissively that this was not relevant  
55  
56 for the topic under discussion. The off-hand dismissal of the scientific importance of  
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3 mortality in relation to the discussion topic could not easily be separated in the partner's  
4  
5 mind from a dismissal of the importance of mortality for patients in general and for her  
6  
7 in particular. An overview of the strategies moderators have found useful for reducing  
8  
9 partner reported barriers is given in Table 3.  
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11  
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14 [Table 3]  
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### 16 17 18 *Support* 19

20 According to the OMERACT organizers, the first conference that included patient  
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22 involvement was actually the easiest and most successful because none of those involved had  
23  
24 any expectations. Partners formed a homogeneous group and the programme was not  
25  
26 demanding. Despite the fact that support was limited and there was a minimum of  
27  
28 organization, patients felt welcome and accepted.<sup>35</sup> Partners at subsequent conferences were  
29  
30 highly motivated to learn in the OMERACT way and started to organize themselves. They  
31  
32 formed a patient liaison group responsible for communication between the patient group and  
33  
34 the organizing committee. Experienced partners developed information modules to bring  
35  
36 newcomers up to a basic level of understanding of the scientific purpose of OMERACT.  
37  
38 Where necessary they approached professionals for assistance.  
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42  
43 In 2010 partners received a pre-conference pack with information about the programme,  
44  
45 lay summaries of the workshop objectives, and a participant list. New partners were teamed  
46  
47 up with a more experienced partner who took on the role of buddy. On arrival at the  
48  
49 conference, partners gathered together for their own dinner and an introductory meeting was  
50  
51 held. Before the official programme started on the second day, partners also followed a half-  
52  
53 day training session moderated by the Chair of the liaison group. Workshop leaders provided  
54  
55 disease-specific patient update sessions prior to the workshops. And for a better  
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3 understanding of the discussion topics, important terms, questionnaires or issues were  
4  
5 explained in more detail. Experienced OMERACT partners coordinated the production of a  
6  
7 glossary<sup>36</sup> which turned out to be so useful that both researchers and partners received a copy.  
8

9  
10 The glossary is updated for every conference with input from the working group leaders.

11  
12 The current intention of OMERACT is to optimize support by tailoring it to the individual  
13  
14 needs and competencies of partners. To overcome the barrier of an exhausting programme,  
15  
16 the patient liaison group drew up personalized programmes that helped new partners pace  
17  
18 themselves by making informed decisions about which sessions they should attend as a  
19  
20 minimum, and which sessions they should only attend if their condition allowed it. Other  
21  
22 suggestions were related to the OMERACT pre-conference work. It is now expected that  
23  
24 early participation in working groups is the best way to prepare partners for taking part in the  
25  
26 conference.  
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## 32 **Barriers**

### 33 *Programme intensity*

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38 OMERACT is an overwhelming experience for all partners attending the conference for the  
39  
40 first time.<sup>21</sup> One significant barrier was the exhausting conference programme. The following  
41  
42 were physically challenging: (intercontinental) travel and change of climate; accessibility of  
43  
44 the conference venue; early and late starting times of sessions; and the duration of the  
45  
46 conference. New partners in particular often participated far beyond their physical capacities.  
47  
48 They were not able to decide which sessions were most relevant and they consequently tried  
49  
50 to go to all of them. The following were mentally challenging: the use of medical or  
51  
52 methodological jargon; uncertainty about their expected role and contributions; and dealing  
53  
54 with hierarchical power relations and highly opinionated professionals. A recurring difficulty  
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3 was the invisibility of the importance of one's own contribution. In sessions dedicated to their  
4  
5 own disease partners were more confident about their contributions than in sessions that dealt  
6  
7 with topics they were less familiar with. The barriers experienced by new partners have been  
8  
9 reported in detail in a previous study (ibid). Experienced partners coped better with the  
10  
11 requirements of the conference and reported fewer barriers.  
12  
13

### 14 15 16 *Scepticism*

17  
18 The notion of including patients as participants in OMERACT reached a tipping point at the  
19  
20 final voting session at OMERACT 5 (2000). Interviewees at this conference were unanimous  
21  
22 in their recollection of how the decision to invite patients was not impulsive but based on  
23  
24 extensive debate among the organizers. They confirmed that it was somewhat serendipitous:  
25  
26 although the proposal to invite patients to the next conference came spontaneously from the  
27  
28 audience, the organizers had, in fact, discussed the issue beforehand. The majority was  
29  
30 indifferent and did not object to the notion as an OMERACT principle.  
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34 Some respondents were not initially convinced that partners would have any added value,  
35  
36 and suggested that the leadership had extrinsic motives i.e. to promote patient involvement for  
37  
38 reasons of political correctness. Others did not believe that partners would be able to think  
39  
40 beyond their own condition or understand the rigour of the methodological discussions. Some  
41  
42 researchers saw the unconditional endorsement as tokenism, but did not object as long as it  
43  
44 would have no bearing on their own research; one respondent admitted she did not feel  
45  
46 confident enough to express politically incorrect opinions out of fear of being disapproved of  
47  
48 by her colleagues.  
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51  
52 After OMERACT 6, researchers gradually started to see and experience the benefits of  
53  
54 patient involvement and changed their views.  
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3 'At the start I was not optimistic and I saw several objections. First, patients don't  
4 understand clinometric issues. Secondly, I did not see any potential contribution of  
5 patients. But I got convinced when they started to organize themselves, the glossary, the  
6 training modules... Patients proved to be good organizers to lift themselves to a higher  
7 level... Patients were professional and very motivated, which was different for other new  
8 researchers entering OMERACT and not having much interest in the methodology of  
9 outcome research.' (RE)  
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20 In 2010 a few respondents still believed that the disadvantages still outweighed the benefits.  
21 They considered that the influence of partners was out of balance, and feared there would be  
22 less interest in solving methodological challenges, and that there would be a negative impact  
23 on the range of topics on the research agenda. They felt compelled to engage with partners in  
24 areas of research where they barely saw any added value, such as imaging and biomarkers.  
25 Most partners confirmed this opinion and admitted that domains that are far removed from  
26 their daily life would be less likely to benefit from their input. Some partners were  
27 particularly keen to contribute to areas of research such as work, remission, flares, doctor-  
28 patient communication, adherence, and non-pharmacological interventions such as self-  
29 management. They believed that they could contribute to research focused on their own  
30 condition but were uncertain about providing meaningful input to other rheumatic conditions.  
31 Physicians agreed with this to a considerable extent.  
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#### 49 *Patient group composition*

50 Institutionalization of patient involvement gave rise to a debate on the representativeness of  
51 professionalized partners. OMERACT policy welcomes partners to provide the 'naïve'  
52 dimension based on the assumption that what has been achieved in the past is the result of a  
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3 balance between new and experienced partners [internal report; 2008]. However, there has  
4  
5 been a tendency to raise the selection criteria in order to recruit partners who are aware of the  
6  
7 methodological issues at stake. Some respondents objected to the participation of partners  
8  
9 who do not understand the rigour of scientific research, who tend to slow the process down  
10  
11 and hence cause irritation during breakouts. They argued that partners should be selected in  
12  
13 accordance with stringent criteria such as academic education and preferably a professional  
14  
15 background in medicine or health care: 'It makes the conversation run more smoothly'. The  
16  
17 patient perspective is important but should be obtained during pre-conference research work.  
18  
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20  
21 Other participants emphasized the irreplaceable value of new partners for generating new  
22  
23 ideas and a 'real' patient-oriented perspective. These researchers reported the potential risks  
24  
25 of experienced partners becoming too professional, adapting their language, identifying  
26  
27 themselves with researchers, and finally losing touch with their peers. And some respondents  
28  
29 warned that partners who started acting as patient advocates might compromise the outcomes  
30  
31 of OMERACT as a data-driven evidence-based conference.  
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### 34 35 36 **Summary**

37  
38 Through this empirical study we now have a better understanding of the factors for successful  
39  
40 collaboration between patients and professionals in a scientific conference. Integrating the  
41  
42 involvement of patients as equal partners in the programme is an effective way to incorporate  
43  
44 the patient perspective in outcome research. The way the conference is organized, and the  
45  
46 benefits as experienced by researchers have changed their perception in favour of structurally  
47  
48 integrating partners in all parts of the conference. Factors that stimulated this process were the  
49  
50 long-term commitment on the part of the leadership; partner selection through participating  
51  
52 physicians; and an inclusive conference design. A facilitative moderation style and the  
53  
54 personalized support of partners were essential. Barriers were often the negativity of the  
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3 facilitators, the intensity of the conference programme, scepticism among researchers, and the  
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5 competencies and representativeness of the patient group.  
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## 8 9 **Discussion**

10 OMERACT has provided a unique opportunity to evaluate the requirement for the long-term  
11 involvement of patients as conference partners in a highly scientific environment. Our  
12 evaluation showed that structural collaboration, fostered by consensual leadership, is essential  
13 for successfully engaging with partners and confirms the finding of a case study in the field of  
14 diabetes.<sup>37</sup> The current study has increased our knowledge and understanding of the  
15 challenges of structural involvement at an international research conference and might serve  
16 as an example for other conferences. Key opinion leaders could take a pro-active lead in this.  
17 By starting to invite patients and by providing adequate training and support, scepticism and  
18 resistance to change, elsewhere identified as important barriers for implementation,<sup>28</sup>  
19 transform into a supportive attitude. In our study we found that scepticism is often based on  
20 prejudice surrounding the benefits and a fear of tokenism. However, the gradual engagement  
21 of partners in OMERACT has been a process of empirical learning: improving and adjusting  
22 inclusion strategies as the result of continuous reflection. Participants became much less  
23 sceptical when partners started to organize themselves and when they saw the positive  
24 influence partners had on the flow and content of the conference. Concerns that were initially  
25 expressed, turned out to be unfounded: patients came with an open mind and without an  
26 agenda; they were able to transcend their own individual experiences, and to understand the  
27 objectives of OMERACT. All these experiences convinced most participants that inviting  
28 patients is inevitable if the ongoing challenge of developing outcomes that reflect the interests  
29 of people with arthritis is to be addressed.  
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3 Although the impact of patients at OMERACT has been substantial, it is difficult to  
4  
5 summarize how the experiential knowledge of partners is actually utilized during the  
6  
7 OMERACT breakout sessions. Researchers are not used to taking notes about the particular  
8  
9 contributions partners make, and journals do not expect authors to report on input given by  
10  
11 partners. When patient involvement is an integral part of the conference, it is almost  
12  
13 impossible to distil individual contributions. There are, moreover, hidden contributions: an  
14  
15 impact that is not noticed either by the researcher or the partner. And finally patients tend to  
16  
17 underestimate the value of their own experience. More sophisticated methods are required to  
18  
19 articulate and evaluate their experiential knowledge.  
20  
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22  
23 Some researchers in the field of rheumatology have, in fact, started to describe how they  
24  
25 have involved partners<sup>15 16</sup>, and this is necessary because patient involvement is not yet fully  
26  
27 understood. OMERACT participants also still believe that patient expertise is not fully  
28  
29 utilized and conditions to facilitate the contributions of partners are still far from optimal. A  
30  
31 remaining challenge is to develop full involvement in all phases of OMERACT by engaging  
32  
33 partners in the pre- and post-conference working groups, and by exploring categories and  
34  
35 phases of research where patient involvement is expected to be the most beneficial. Future  
36  
37 research will enhance our body of knowledge on the feasibility and effectiveness of different  
38  
39 strategies to include patients in conference sessions and of our understanding of the nature  
40  
41 and significance of lay knowledge.  
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44  
45 Another challenge that requires further research is the representativeness of patient  
46  
47 research partners.<sup>14</sup> Partners have generally been educated, white, middle class and socially  
48  
49 skilled people capable of collaborating with professionals in a critical though constructive  
50  
51 manner. This means that important perspectives from other groups might be missed. Most  
52  
53 professional participants believe that – despite the lack of representativeness - partners are an  
54  
55 asset to the conference because of their personal contributions based on introspection,  
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3 reflection on their own patient journey, and the intense contact with other partners at several  
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5 conferences. New and experienced patients make different kinds of contributions at different  
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7 times, finally resulting in a kind of aggregated and synthesized expert input.  
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10 In projects that follow the dialogue method: a stepwise, multi-stakeholder approach for  
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12 identifying priorities for health research,<sup>38</sup> patients develop and articulate their experiential  
13  
14 knowledge in a structured process of enclave deliberation; by exchanging and discussing  
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16 personal experiences in a homogeneous group, anecdotal stories – also called ‘being familiar  
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18 with’ – are subsequently transformed into practical knowledge (‘knowing how’) and expert-  
19  
20 knowledge (‘knowing that’).<sup>19</sup> All types of knowledge are important for the OMERACT  
21  
22 conference, although there is a tendency to explore and utilize the anecdotal and practical  
23  
24 knowledge during the pre-conference activities and the expert-knowledge during the  
25  
26 conference itself. Relying solely on the input of *expert* patients runs the risk of pseudo-  
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28 professionalism that is reported elsewhere.<sup>39</sup> are partners empowered by their new role in  
29  
30 research or do they lose their naivety as a patient and align easily with professionals?<sup>40</sup> The  
31  
32 effect may be that partners operate separately from their peers and try to ease collaboration by  
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34 suppressing their experience-based knowledge. Due to the dual relationship, partners may feel  
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36 uncomfortable expressing a personal and independent voice if it contradicts the view of their  
37  
38 own physician. It is still not known whether partners sometimes try to please their physician  
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40 by avoiding disagreement.  
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45 The self-organized training and support empowered not only the individual partners, but  
46  
47 also strengthened the mutual relationship with professionals, a process that can be described  
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49 as relational empowerment.<sup>41 42</sup> The structural collaboration in OMERACT, fostered by  
50  
51 regular meetings at other conferences, sensitized both parties to the importance of beliefs and  
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53 priorities of the others. Partners benefited from a better understanding of the methodological  
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55 challenges of outcome research, and researchers learned about new domains that are relevant  
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3 from the patient point of view. Through mutual discussion and the exchange of personal  
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5 experiences, partners gained more confidence to speak up and confront researchers with their  
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7 own opinions. Researchers met partners who were able to have their say without reservation  
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9 and recognized partners as reliable allies. Structural involvement facilitated a mutual learning  
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11 process and a better understanding of the perspectives of others. In this context relational  
12  
13 empowerment might contribute to a sustainable inclusion of the patient perspective in  
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15 OMERACT activities without a total power reversal<sup>43</sup>. OMERACT has created solid  
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17 partnership relations which, in the longer term, may result in the integration of different  
18  
19 sources of knowledge, also known as a melting of horizons. The characteristics of this process  
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21 require further exploration.  
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#### 24 25 **Funding**

26  
27  
28 None  
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#### 30 31 **Competing Interests**

32  
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34 None  
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#### 36 37 **Contributorship**

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40 MW, JK and TA conceived the idea of the study and were responsible for the design of the  
41  
42 study. MW carried out the document analysis and all interviews. MW and MK were  
43  
44 responsible for the coding of the interview transcripts. All authors provided input into the  
45  
46 phase of cross-code checking and data analysis. The initial draft of the manuscript was  
47  
48 prepared by MW and then circulated repeatedly among all authors for critical revision. All  
49  
50 authors read and approved the final manuscript.  
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#### 53 54 **Data sharing**

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57 No additional data are available.  
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Table 1 Characteristics of interviewees

	Professionals	Patient Research Partners	Interview Code
Sex (M:F)	12 : 4	7 : 9	
Professional background or Diagnosis	10 practicing rheumatologists 3 full time researchers 3 other professionals	10 rheumatoid arthritis 2 vasculitis 2 ankylosing spondylitis 1 fibromyalgia 1 gout	
Number of OMERACT conferences attended			
1	5	8	PA to PF, PO, PP
2	0	3	} PG to PN
3	1	1	
4	4	4	
≥5	6	0	
Interview in relation to OMERACT conference			
Before	2	1	
During	8	16	
After	6	5	
Geographical spread	6 countries 2 continents	7 countries 4 continents	
Research	10 Senior Researchers		RA to RG, RJ, RK,

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Background	1 Research Fellow	RY
	1 Post-doctoral researcher	RH
	2 Pharma representatives	RI
	2 Staff members	DA, DD
		DB, DC

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For peer review only

**Table 2****Facilitating and inhibiting factors for structural involvement of patients**

<b>Facilitating factors</b>	<b>Inhibiting factors</b>
<p><b>Strong leadership</b></p> <ul style="list-style-type: none"> <li>• Endorsement by key opinion leaders</li> <li>• Long-term financial and organizational commitment</li> <li>• Ambassadors of participative research</li> <li>• Acknowledgement of contributions</li> </ul>	<p><b>Intensity of the programme</b></p> <ul style="list-style-type: none"> <li>• Physically challenging</li> <li>• Intercontinental travel</li> <li>• Accessibility</li> <li>• Mentally challenging</li> <li>• Language &amp; terminology</li> <li>• Remote themes</li> </ul>
<p><b>Selection procedure</b></p> <ul style="list-style-type: none"> <li>• Recruitment through clinicians</li> <li>• Proportional representation</li> <li>• Selection criteria</li> <li>• Learning curve</li> </ul>	<p><b>Scepticism</b></p> <ul style="list-style-type: none"> <li>• Doubts about added value</li> <li>• Risk of tokenism</li> <li>• Imperceptibility of contributions</li> <li>• Lack of continuity</li> </ul>
<p><b>Conference design</b></p> <ul style="list-style-type: none"> <li>• Multi-stakeholder approach</li> <li>• Spirit of OMERACT</li> <li>• Full &amp; equal participation</li> <li>• Interactive breakouts</li> </ul>	<p><b>Composition patient group</b></p> <ul style="list-style-type: none"> <li>• Lack of representativeness</li> <li>• Pseudo-professionalism</li> </ul>

- 
- Structural involvement

### **Facilitative moderation style**

- Open dialogue
- Deliberate encouragement
- Respect of confidentiality
- Clear communication
- Sensitivity to patient values

### **Individualized support**

- Pre-conference information pack
  - Training
  - Personalized programmes
  - Buddy system
  - Glossary
  - Pre-conference involvement
-



**Table 3****Patient-reported barriers to collaboration and strategies to reduce these barriers**

<b>Barriers to contribute identified by partners</b>	<b>Helpful tools, responses and points to consider to encourage partners to contribute</b>
<p><b>Feeling like an observer in the conference, rather than a colleague</b></p> <ul style="list-style-type: none"> <li>• Not involved from the beginning</li> <li>• Lack of information</li> </ul>	<p><b>Involve partners right from the start</b></p> <ul style="list-style-type: none"> <li>• Provide background information in understandable language (research protocol)</li> <li>• Treat all team members equally</li> </ul>
<p><b>Inadequate introduction</b></p> <ul style="list-style-type: none"> <li>• Not knowing what is expected</li> <li>• Feeling not prepared for the job</li> <li>• Unaware of the aims of the conference</li> <li>• Why me?</li> </ul>	<p><b>Discuss mutual expectations in a face-to-face meeting before the start of the conference</b></p> <ul style="list-style-type: none"> <li>• What kind of contribution is expected from the partner?</li> <li>• Has the partner affinity with the research topic(s)?</li> <li>• In which phase or activities will the partner be involved?</li> <li>• Who takes the initiative for contact and how?</li> <li>• How will the partner be informed and supported along the way?</li> <li>• What are specific needs of the partner?</li> </ul>
<p><b>Doubts about their added value</b></p> <ul style="list-style-type: none"> <li>• Feeling too shy to relate personal stories</li> </ul>	<p><b>Encourage partners deliberately</b></p> <ul style="list-style-type: none"> <li>• Adapt to a patient-centred communication style and promote open dialogue, attentive listening and</li> </ul>

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<ul style="list-style-type: none"> <li>• Assumption that experiences are obvious and already known to professionals</li> <li>• Low status of anecdotal knowledge</li> </ul>	<ul style="list-style-type: none"> <li>• authentic contact</li> <li>• Invite partners to share their perspectives</li> <li>• Ask open-ended questions and probes</li> <li>• Give feedback on contributions</li> <li>• Emphasize the importance of personal experiences and provide reassurance</li> </ul>
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<p><b>Feeling unable to contribute</b></p> <ul style="list-style-type: none"> <li>• Lack of knowledge about research and statistics</li> <li>• Problem with medical jargon</li> <li>• Problem with the English language</li> <li>• Hierarchy of professions</li> <li>• Power imbalance</li> </ul>	<p><b>Tailor support to the competencies of the partners</b></p> <ul style="list-style-type: none"> <li>• Provide lay summaries</li> <li>• Create a learning environment: provide training opportunities</li> <li>• Distribute reading materials before meetings</li> <li>• Explain jargon without being asked</li> <li>• Provide glossaries, journals and websites</li> <li>• Help partners access and judge scientific literature</li> </ul>
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<p><b>Feeling disqualified, not listened to</b></p> <ul style="list-style-type: none"> <li>• Feeling muddled about inappropriate disclosure</li> <li>• Feeling dismissed when an initiative to contribute is ignored</li> </ul>	<p><b>Be alert for sensitive issues</b></p> <ul style="list-style-type: none"> <li>• Partners want to be regarded as individuals, from a holistic perspective</li> <li>• Try to be inclusive</li> <li>• Respect confidentiality and apply to ethical rules</li> <li>• Acknowledge contributions</li> </ul>
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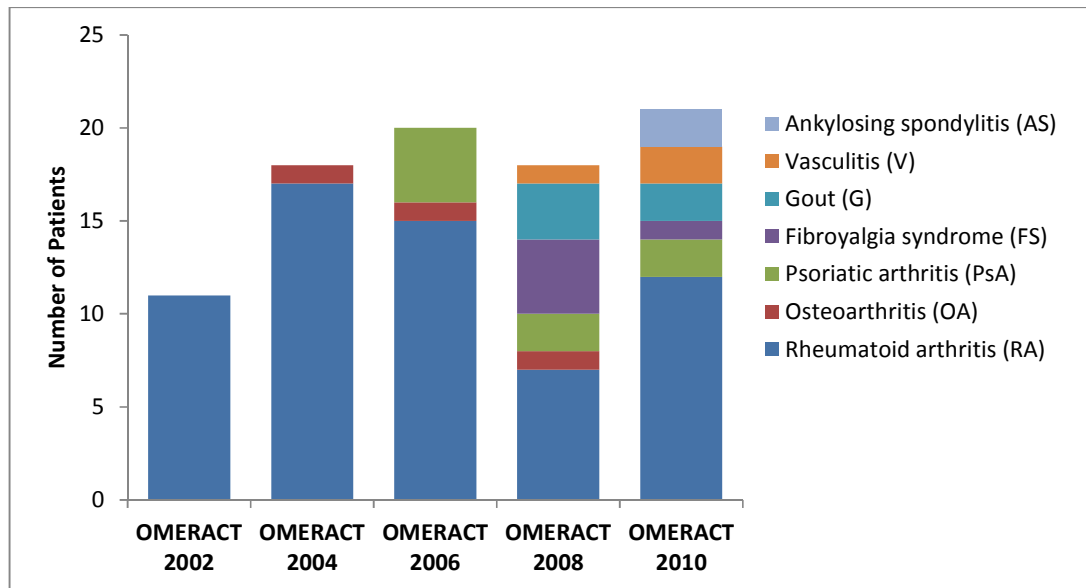
## Online Table 1

### Overview of tasks carried out by patient participants at OMERACT 6-10

- Act as co-chair of the patient participation workshop;
- Moderate break-out sessions
- Formulate questions for the workshop(s)
- Give a presentation at plenary sessions
- Weight different measures and domains
- Participate in different meetings as full delegates
- Provide input on pre- and post-conference documents
- Participate in workshops on fibromyalgia, gout, psoriatic arthritis, RA, AS and vasculitis
- Edit or contribute to the OMERACT patient newsletter
- Compile and edit the patient information pack and the OMERACT glossary
- Assist researchers to produce summaries suitable for lay participants
- Co-author scientific publications
- Promote topics from the research agenda on a national level
- Guide, support and inspire new patient research partners
- Disseminate the outcomes outside OMERACT.

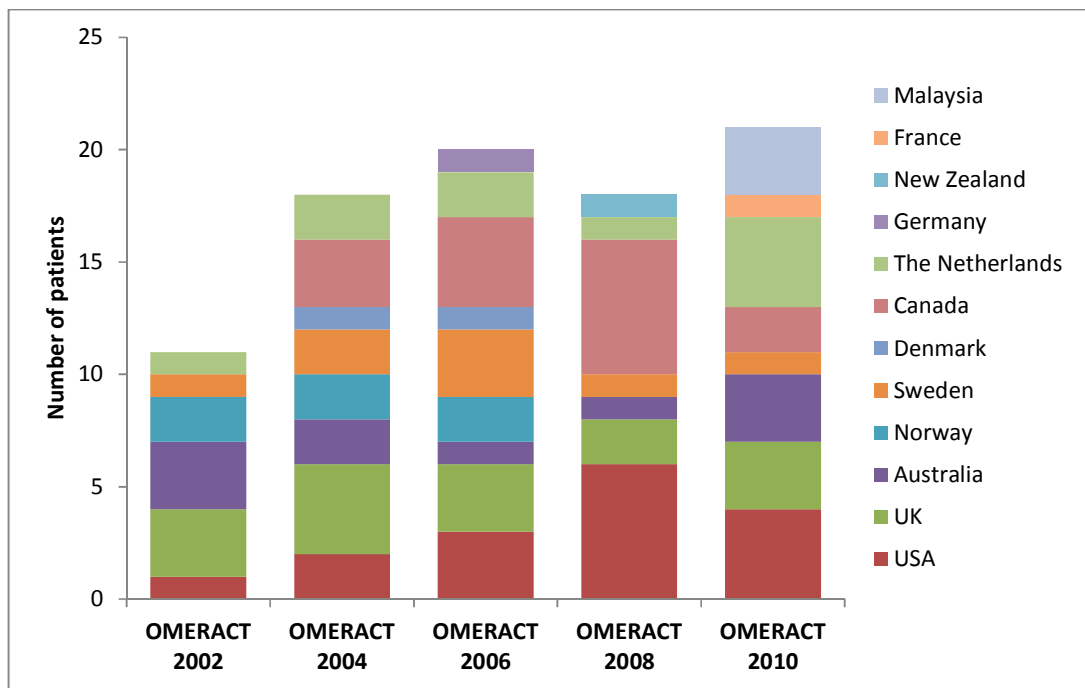
## Online figure 1

## Rheumatic conditions represented at OMERACT meetings between 2002-2010



Online figure 2

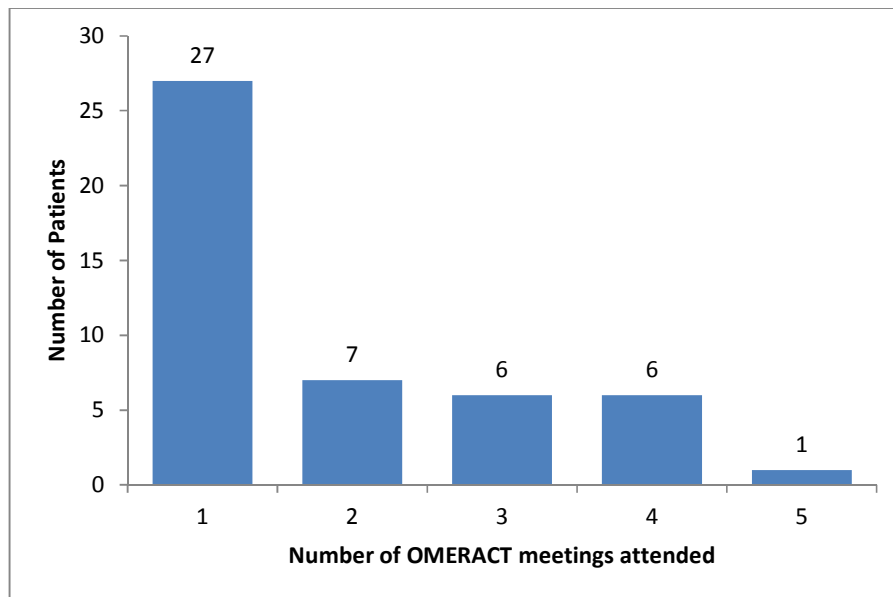
Countries represented at OMERACT meetings between 2002-2010



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**Online Figure 3**

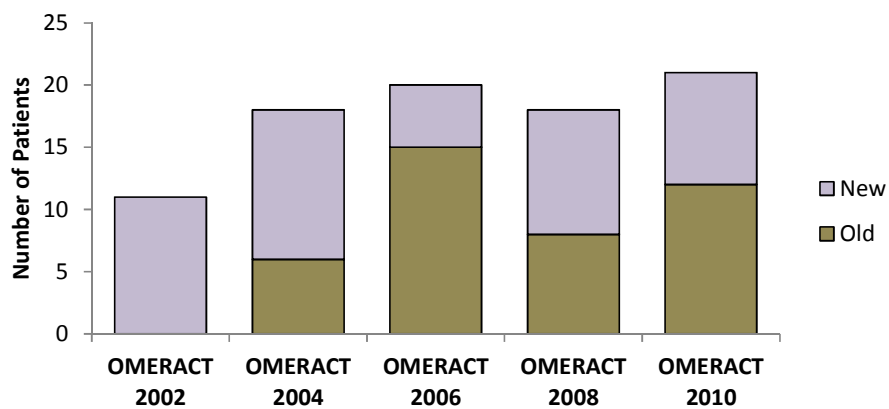
**Number of times partners attended OMERACT between 2002-2010**



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Online figure 4

Number of new versus experienced patient participants between 2002-2010



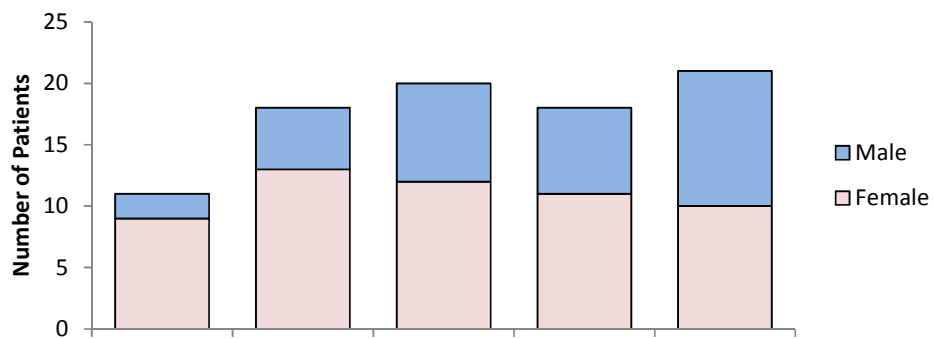
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**Online figure 5**

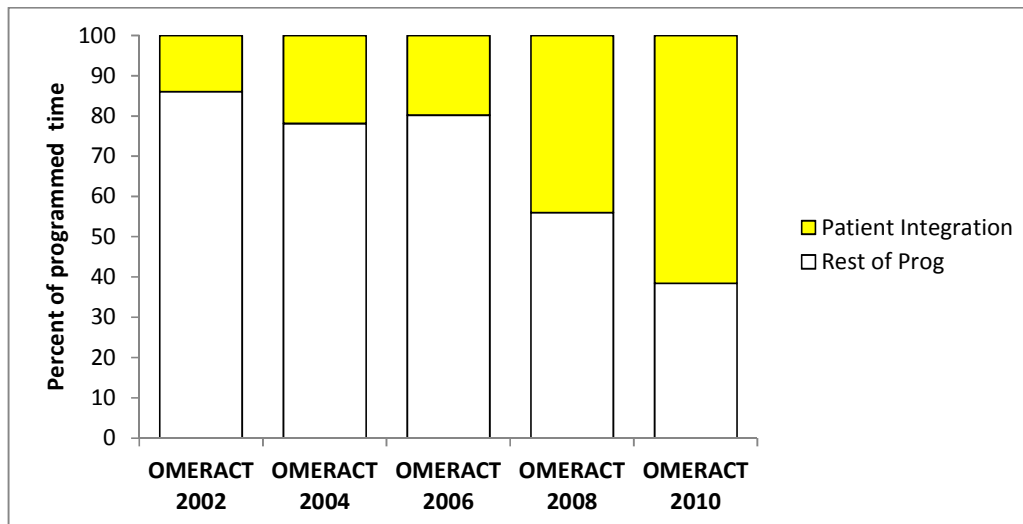
**Gender of the 47 patient participants between 2002-2010**





Online figure 6

Programmed patient integration at OMERACT meetings between 2002-2010



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**Appendix 1 Example of an audit trail:** Main categories (column 5) derived from the thematic content analysis, partly illustrated for the main categories ‘conference design’ and ‘skepticism’.

Text fragment	Open coding	Axial coding	Sub-categories	Main categories	
<ul style="list-style-type: none"> <li>• “as soon as you invite a collaborator, you are on the same team” [RL]</li> <li>• “I felt equal to all others and I was stimulated to participate” [RH]</li> <li>• “as part of the team I was considered an equal co-researcher” [PG]</li> <li>• “I don’t remember feeling us and them” [PM]</li> </ul>	<ul style="list-style-type: none"> <li>• Co-researcher</li> <li>• Equality</li> </ul>	<ul style="list-style-type: none"> <li>• Participation ladder: partnership</li> <li>• Co-creation</li> <li>• Equality</li> </ul>	<ul style="list-style-type: none"> <li>• Multi-stakeholder approach</li> <li>• Spirit of OMERACT</li> <li>• <b>Full &amp; equal participation</b></li> <li>• Interactive breakouts</li> <li>• Structural involvement</li> </ul>	<ul style="list-style-type: none"> <li>STRONG LEADERSHIP</li> <li>SELECTION PROCEDURE</li> <li><b>CONFERENCE DESIGN</b></li> <li>MODERATION STYLE</li> <li>PEER SUPPORT</li> </ul>	FACILITATORS
<ul style="list-style-type: none"> <li>• “New stakeholders often don’t have knowledge about clinimetry” [RE]</li> <li>• Clinicians who do not accept patients’ influence, are difficult to change [PI]</li> <li>• “there is still an undercurrent that questions the issue of the added value of patient input” [PN]</li> </ul>	<ul style="list-style-type: none"> <li>• (low) expectations of patients’ contribution</li> </ul>	<ul style="list-style-type: none"> <li>• Resistance to change</li> <li>• Perspective on potential contributions of patients</li> </ul>	<ul style="list-style-type: none"> <li>• Risk of tokenism</li> <li>• <b>Doubts about added value</b></li> <li>• Imperceptibility of contributions</li> <li>• Lack of continuity</li> </ul>	<ul style="list-style-type: none"> <li>INTENSITY OF THE PROGRAM</li> <li><b>SKEPTICISM</b></li> <li>COMPOSITION PATIENT GROUP</li> </ul>	BARRIERS

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