"IF I WASN’T THIS ROBUST”
PATIENTS’ EXPECTATIONS AND EXPERIENCES AT THE OUTCOME MEASURES IN RHEUMATOLOGY CONFERENCE 2010

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ABSTRACT

Background Patients are incidentally involved in scientific conferences as collaborating partners. Little is known about how they engage with researchers.

Objective The purpose of this study was to explore the expectations and experiences of new patients to better understand the specific features of collaborative research during conferences in its complexity.

Study design After a thematic literature review, we conducted fourteen interviews with eight delegates: Four men and four women with three rheumatic diseases and representing five countries. They participated for the first time in the bi-annual conference on Outcome Measures in Rheumatology (OMERACT) in 2010. Data were subjected to a thematic content analysis.

Results Before the conference, patient participants had felt privileged to be invited but insufficiently prepared and uncertain about what was expected from their participation. They had anticipated a learning experience and had hoped to be able to make a contribution. In fact most experienced the conference program as physically and mentally challenging, partially due to poor moderation or lack of individual support. They doubted their input had been beneficial. After the conference these patients also described their participation as having been a valuable, meaningful and learningful experience. Although they presumed that they had not been very productive, they expected their contribution would be more effective at future conferences.

Conclusions Patient delegates attending a scientific conference need clear information about their role prior to the event. Personalized support and a facilitative moderation style during sessions are advantageous for maximizing valuable contributions. Participation leads to personal learning curves and various benefits.
Introduction
Patient participation in the international conferences on Outcome Measures in Rheumatology (OMERACT) has had a significant influence on the research agenda. However, we know little about how patients experience the new role of ‘collaborating partner’ and how they establish effective relationships with researchers. Patients have to adjust to the use of medical jargon and scientific terminology, and they are not always familiar with the rules for clinical research. Additionally, an imbalance of professional status and power creates a barrier to building equal partnerships and there is concern about overburdening patients beyond their physical capacities. There may be a coercive nature to participation as patients might feel unable to decline an invitation to be involved to please their consultant or to prevent jeopardizing their care; alternatively there may be an effect of self-selection. This raises questions about the representativeness of the patients participating in the conference; are they a fair representation of the target group or only representing a particular group of society? Finally, patients’ experiential knowledge may not be accepted as a valid source for scientific research. These issues are encountered regularly by many organizers of and participants in symposia and scientific conferences.

OMERACT is a data driven, international bi-annual conference that aims to develop consensus on outcome measures for clinical trials in the field of rheumatology. Since 2002 58 patients with different rheumatic conditions have been invited to provide the patient perspective in all parts of the conference. OMERACT 10 took place over six days in May 2010 at a residential conference center. It focused on four rheumatic diseases and on the methodology of choosing domains of interest and instruments appropriate to measuring these domains. There was a special interest in the definitions of remission and flares from a patients’ point of view. As in previous meetings, the program consisted of a mixture of plenary sessions, intense small group discussions and, towards the end, formal presentations and proposals which are voted on to achieve international consensus. New patients were expected to contribute to the breakout sessions dedicated to their own disease, but were also encouraged to participate in sessions about other diseases if their condition allowed.

Of the 200 places, 20 were allocated to patients and recruitment was usually through the clinics of participating physicians. They considered their capacity to travel, to express themselves in English, personality, social competencies and health condition. The profile, role and tasks of the patient group have developed over time. At the first conference (2002), all patients had RA, no experience in scientific research, and carried out a limited number of tasks centred on one workshop. This role has grown and
developed so that at the conference in 2010, the group was heterogeneous, involved in many working groups and carried a variety of responsibilities similar to those of professional delegates. The role of patients was not passive: Patients actively debate with researchers in the breakout sessions, they give presentations, and they may co-moderate sessions and may be responsible for reporting back to plenary sessions. They participated as full conference delegates with equal rights.5

Patients represent a valuable source of knowledge that has previously been excluded in scientific research10 and as described above OMERACT has been exemplary in the inclusion of patients in their activities.5 This study took place in the context of a wider evaluation of a decade of patient participation in OMERACT and explores the expectations and experiences of people with a rheumatic condition who attended OMERACT 10 (Malaysia, 2010) for the first time. We report the results of a responsive evaluation including 14 semi-structured interviews with eight new patient participants before, during and after the conference. It explores how patients explained and experienced the event: why did they accept the invitation, what did they expect to contribute and how did they prepare for this? How did they experience their role and how did they perceive their contribution? We wanted to know whether they faced similar challenges as patients reported in other research contexts, and to consider how these challenges might be lessened.

Methods
A responsive evaluation is appropriate to describe the phenomenon of collaboration from a multiple ‘insiders’ perspective.16 17 We started with a thematic document analysis of OMERACT conference proceedings and grey literature followed by 14 semi-structured interviews with eight new patient participants and participant observation. The first author attended six patient meetings during the conference: The patient dinner before the start of the conference, the training session, three patient update sessions and the final evaluation meeting on the last day of the conference. At request of the patient group, written notes were taken instead of recording to guarantee an open and safe environment.

For the interviews broad interview guides (table 1) were developed 18 from the document analysis, two pilot interviews, and the first author’s personal experience of participating in three OMERACT conferences.
To gain insights into changing perceptions, three patients were interviewed three times: the day before the start; on the afternoon of the third day; and immediately after the end. For these epic interviews the selection was done by the first and last author through purposive sampling taking into account gender, coming from three different continents and having different rheumatic diseases. For these three epic interviews, additional topics included their motivation, expectations and experiences during the conference.

Because of the richness of the first interviews, as well as the motivation of not-selected participants to share their views and experiences with the first author, three additional interviews were held during the conference. To achieve saturation another two interviews took place within two weeks after the conference. Finally, the experiences of eight out of nine new patient participants were collected (table 2).

The interview transcripts were analyzed using thematic content analysis, which allowed us to derive code categories directly from the text data. The analysis of 12 interview transcripts and two reports by the first two authors resulted in a comprehensive
code tree. In accordance with the components of trustworthiness, scoring of all 14 interviews was done separately by the first author and an independent health researcher with extensive experience in qualitative research (MK) who had never worked with active patient involvement before. Codes were compared and discussed during three four-hour face-to-face meetings. The project group represented various backgrounds each contributing equally to the data analysis.

Table 2 Characteristic respondents

<table>
<thead>
<tr>
<th>Characteristic respondents</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Average age</strong></td>
<td>51 year (range: 28-68)</td>
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<tr>
<td><strong>Gender</strong></td>
<td>Male (n=4), Female (n=4)</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>Rheumatoid Arthritis (n=4), Ankylosing Spondylitis (n=2), Vasculitis: Wegener's Granulomatosis (n=2)</td>
</tr>
<tr>
<td><strong>Average disease duration</strong></td>
<td>19 year (range: 6-28)</td>
</tr>
<tr>
<td><strong>Countries</strong></td>
<td>Australia (n=2), France (n=1), Malaysia (n=2), Netherlands (n=2), United Kingdom (n=1)</td>
</tr>
<tr>
<td><strong>Professions</strong></td>
<td>Engineer, zoo-employee, psychotherapist, translator, former medical doctor, former business man, former cultural attaché, former teacher biology</td>
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</table>

All authors randomly cross-checked the coding and confirmed that there were no significant discordances. To incorporate the patient perspective in the phase of data interpretation and synthesis, a patient research partner (SC), representing the group of patients that attended OMERACT for the first time, joined the project group as a full member. Reported benefits of involving patients as co-researchers in the phase of analysis include: adjusting researchers’ misinterpretations; highlighting new themes; identifying findings the most pertinent to the patient community; challenging the interpretations of researchers and making adjustments to how findings are reported.21 During several extensive meetings the project group elaborated on the codes and potential categories. Finally, the group agreed on a set of nine main themes relevant to the expectations and experiences of new patient delegates (Table 3). All codes were allocated to one of the nine main themes in a code sorting exercise. Specific measures were taken to reduce the risk of observer bias and to prevent misinterpretations.22 23 Through member checks interviewees responded to the interpretations of the interview transcript by the researcher. The co-researcher also played an important role in checking
the interpretations of the researchers during regular meetings of the project group. The first author attended and made note of six patient meetings. Triangulation took place by synthesizing data derived from the document analysis, interviews and participants observation. Overall, the approach of three epic interviews with three new patient delegates, combined with the use of responder checks, participant observation, involvement of a patient research partner and triangulation of data, has enhanced the validity of our findings.

Results
All patients gave informed consent. An interview guide was used in 13 out of 14 interviews. One interview took place without an interview guide and, on request of the interviewee, without recording. One interview was done by e-mail and one by Skype. Twelve were audio-recorded, transcribed and sent to the interviewees for a responder check. Twelve were held in English (for seven this was not the native language) and two in Dutch. The average duration was almost 50 minutes. From the thematic analysis 116 codes were derived and were encompassed within 9 main themes (table 3). Three time frames emerged which provide a useful framework: 1) pre-conference preparation; 2) support patients received during the conference (process and context) and 3) acknowledgment of patient contributions and personal learning curves (contribution and benefits). Illustrative quotes are annotated by the patient identifier.

Table 3 Main themes from the data analysis

<table>
<thead>
<tr>
<th>PRE-CONFERENCE PREPARATION</th>
<th>THE ACTUAL CONFERENCE: PROCESS AND CONTEXT</th>
<th>AFTER THE CONFERENCE: OVERALL BENEFIT AND CONTRIBUTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Selection procedure</td>
<td>• Moderation</td>
<td>• Patient perceived contributions</td>
</tr>
<tr>
<td>• Motivation and expected</td>
<td>• Relationships</td>
<td>• Patient reported personal benefits</td>
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<tr>
<td>contribution</td>
<td>• On-site support</td>
<td></td>
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<tr>
<td>• Patient perceived</td>
<td></td>
<td></td>
</tr>
<tr>
<td>competencies</td>
<td></td>
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<tr>
<td>• Preparations</td>
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Pre-conference preparation
Participants started the conference with mixed feelings. They held positive expectations and felt privileged to be invited but were concerned by a lack of preparation caused by late invitation; These concerns included an overload of information; and uncertainties about their own role, contribution and competencies.
Selection procedure
Most patients had never heard of OMERACT before they were personally approached. Many learned from the internet that OMERACT is an inclusive and interactive conference but did not find any information about the role and contribution of patients. Most were invited very close to the time of the conference, and those who wanted to bring a relative or a friend had to find additional funding at short notice. None remembered any discussions about the reasons for their suitability for the role.

Motivation and expected contribution
All patients were excited about attending, but most had no concept of their role: “I came with a fairly open mind” (PE) or “I’ve no idea because I don’t know what will happen during these six days. I’m completely open” (PB1). Some expectations were adjusted during the conference: “We brought a lot of information with us on the history of my illness and that kind of thing, but looking at it now, I don’t know whether that is the sort of thing they are after ... the way I feel is more what they are looking for? How I feel within myself and different symptoms, I guess? The way I describe them?” (PC1). Even before the conference commenced, they were highly motivated, and dedicated to the objectives of the conference, often for altruistic reasons. In contrast, almost all also expressed feelings of uncertainty or doubts about their capacity to meet the expectations of the organization: “My main concern is: do I understand enough to really be able to contribute anything?” (PE).

Patient perceived competences
Most patients felt competent about their own communication skills and thought it had been an important factor in their selection: “be able to understand simple English and dare to speak up” (PB2). Terminology was not seen as a problem and interviewees expected to ask, consult the glossary or approach their physician if anything was not clear. Patients attributed their selection to an adequate experience of the illness but being well enough to travel. One supposed her economic independence and an amazing recovery were important criteria. Those for whom English was not their first language were concerned about their ability to express themselves and others worried they might not adequately recall their various experiences of illness or that their condition would reduce their stamina and limit participation.
**Preparation**
Patients received the same conference information as other participants and some felt overwhelmed by the volume of background literature, and not able to select the information relevant for their participation. About three weeks before the conference, patients received a patient delegate pack and were allocated a ‘buddy’, an experienced patient who had attended OMERACT before. This first contact with a fellow patient was experienced as helpful by most of the interviewees though some thought that the conference was “not really something you can prepare for” (PC1).

**Process and context**
The equality between patients and professionals hoped for by the conference organizers was not experienced by all new patient delegates, some of whom found the program extremely arduous and the moderation style sometimes reduced their sense of participation. Patients faced unanticipated intellectual and emotional challenges, and were never sure if their contributions were useful.

**Moderation**
Moderating styles in small group discussions were very variable and a good moderator was felt to be crucial for feeling useful, confident and respected. Patients felt frustrated when objectives were not clearly defined and background information was not provided. Clear differences were reported between good moderation: “...did thank everybody for coming, made us all feel welcome and stopped a couple of times through the session to say ‘what do the patients think?’” (PC2), and poor: “She just brushed me aside ... So I just say: ok, if all the lecturers are like this, why should I go in?” (PB2). Many suggestions were offered for good moderation (table 4).

**Relationships**
Many thought their strong, ‘robust’ personality contributed to their selection but during the conference felt seriously challenged. There were barriers caused by an existing clinical relationship. One patient who actively contributed in a breakout session was upset about the sudden negative response of her physician: “She had no idea of my sensitivity. I think she sees me as very strong. It's her disapproval I can’t handle and that’s a danger for the patient”. Regarding the subsequent misunderstanding about her input, the patient responded: “If I wasn’t this robust, I wouldn’t confront her, and it would really affect my relationship with her” (PE).
Table 4 Facilitative style of moderation according to patient participants

- Provide information, questionnaires or manuscripts that are crucial for understanding the objective and content of the session in advance and make sure that they are understandable for patients
- Send out invitation at least 6 weeks in advance of the event
- An open layout of the room (U-form or Square) stimulates interaction between participants
- Make patients feel welcome by introducing them and acknowledging their contribution
- Build bridges between patients and professionals by promoting a dialogue that respects the value of different kinds of knowledge
- Include patients in the discussion by giving them the opportunity to tell their story, by asking questions and providing explanation if something is not clear to the patient
- Be alert for similarities and differences between conditions of the patients
- Take care of presenting data that might be confronting for patients like risk factors, co-morbidities, mortality rates or adverse events
- Be aware of cultural and economic differences between patients, eg, inequities to health care arrangements or different perspectives on evidence-based medicine
- Prevent manipulation or intimidation by strong personalities who try to push their opinions, and make sure everybody gets the chance to speak up freely
- Experienced patients might be involved in different tasks like co-chairing or reporting back

The loyalty of another patient delegate was at stake when a contribution made by her physician was criticized. She expressed empathy with the arguments of her physician but later reported that she was concerned that this compromised her personal experiential knowledge as a patient: “Maybe I am not critical enough though because we have already gone a long road together” (PP). While some participants were satisfied about the collaboration with professionals others could not avoid placing themselves in an unequal position and explained that they looked up to these “very qualified, high educated professors” and “we keep quiet because we don’t know anything” (PF).

Participant observations identified a group of patients coming from one country who did not talk to each other due to economic, regional and cultural differences, and in the
interviews they discounted the competencies of their fellow participants. There were difficulties with language barriers and resentment based on different types of disease, and with more experienced patient participants who hardly mingled with the new patients. Some perceived experienced patients as competitors, others as less suitable representatives because they had become too professional and “they lose their role” (PB3).

Support
All interviewees appreciated the welcome dinner and introduction session immediately before the conference where they met all the other patients and their experienced ‘buddies’. On the first morning an information session for all patient delegates was helpful in setting the scene and understanding their role: it “made it pretty clear that they were looking for words from me, and not fully understanding the numbers” (PC2). Patients appreciated the short disease-specific update sessions provided during the conference in preparation for subsequent workshops. They also valued the OMERACT glossary, providing definitions in lay language.25

Despite this support, there were barriers that prevented patients from fully contributing (table 5). New participants felt a strong obligation to attend as many sessions as possible and often participated beyond their physical limitations. They sometimes felt mentally exhausted and emotionally challenged when physicians or researchers did not realize the impact of their passing comments. A patient in remission was suddenly confronted with new information: “I was surprised to see mortality as one of the four highest on the list... that I found a little bit scary!” (PC2). Even the whole process of participation in itself was a challenge: “I run from my illness, I try to keep ahead of it and not have to think about it too much. But this has really made me confront that. It’s been emotional; I’ve remembered some really painful things” (PE).

For some patients the buddy system worked well: “She was most helpful in the initial stages, happy to answer even ‘silly’ questions. She was also great at checking in with me throughout the week to ensure I was coping, supporting me and encouraging me to rest when I felt I was feeling overwhelmed” (PC3). For some it was “useful before the conference” (PE), but newcomers who had collaborated with researchers before reported no advantages of the buddy system on-site.
Table 5 Patient reported barriers for participation in OMERACT 10, and their suggestions for overcoming them.

<table>
<thead>
<tr>
<th>PATIENT REPORTED BARRIERS</th>
<th>PATIENT REPORTED SUGGESTIONS</th>
</tr>
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<tbody>
<tr>
<td>• Insufficient preparation</td>
<td>• They emphasized that the selection procedure should be optimized by an intake interview and most of them agreed that patients should have additional capacities regarding collaboration with professionals.</td>
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<tr>
<td>~ Late notice invitation</td>
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<tr>
<td>~ Pre-reading material comes too late, is too much and without clear guidance</td>
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<tr>
<td>~ Not being informed about the expected role and contribution</td>
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</tr>
<tr>
<td>• Lack of personal support</td>
<td>• They gave tips to improve the use of pre-reading materials by indicating which information would be relevant for separate workshops.</td>
</tr>
<tr>
<td>~ Feeling lonely, feeling lost</td>
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<tr>
<td>~ Being on your own in a session</td>
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<tr>
<td>• Feeling incompetent to contribute because of</td>
<td>• To make the program less burdensome patients should receive a personalized schedule of meetings recommending which they should attend.</td>
</tr>
<tr>
<td>~ Discouraging style of moderation: feeling disqualified, ignored or intimidated</td>
<td></td>
</tr>
<tr>
<td>~ Lack of knowledge about medicines, methodology, medical jargon, themes under discussion or questionnaires</td>
<td>• The buddy system could be improved by providing similar program schedules for new patients and their buddies, giving clear instructions to the buddy and mindful of nationality and language factors when matching newcomers and buddies.</td>
</tr>
<tr>
<td>~ The English language</td>
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<tr>
<td>~ Lack of knowledge about other conditions</td>
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<tr>
<td>~ Not feeling representative</td>
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<tr>
<td>• Participation is physically challenging</td>
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<tr>
<td>~ Demanding program causes fatigue and more pain</td>
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<tr>
<td>• Participation is mentally challenging</td>
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<tr>
<td>~ Having to face painful memories or shocking data</td>
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<tr>
<td>~ Transforming existing patient-doctor relationship into a partnership causes anxiety</td>
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</table>

Overall benefit and contribution

In spite of doubts about their ability to contribute something useful, by the end of the conference patients felt they had grown as individuals and were all ready to participate in a future conference. They not only identified barriers for their participation, but they also provided practical solutions for improving the support for patient delegates (table 5).

Patient perceived contribution

During the conference patients’ ambivalent expectations regarding the added value of their input changed: “Very quickly I realized that my own experience of the disease would be more than enough” (PE). Topics which are directly experienced by patients (pain, disease flares, remission) were thought more likely to benefit from patient participation.
than more distant topics (biomarkers, imaging, statistics). Most interviewees felt uncomfortable in sessions dedicated to other rheumatic conditions where differences between diseases limited potential contributions. Some were satisfied about their contribution: “I believe that I could provide some valuable input from my own disease experience in the gout session when we discussed the frequency of flares” (PP). After the conference, patients were less sure about the extent and benefit of their contribution: “I didn’t feel like I made very much of a contribution although I did feel 90% of the comments I made were relevant and necessary” (PC3). One reflected that while a lot of patient input was provided off-topic, outside the breakout sessions and often in the corridors, she still struggled with the question of whether combining scientific outcomes with the daily experiences and emotions of patients had been achieved during the conference.

**Personal benefits**
Despite some difficult encounters, all new patient participants were still highly motivated at the end of the conference. They experienced OMERACT 10 as a positive and rewarding event not only because they believed that their involvement will improve health care provision in the future, but also because of personal gains. They confirmed that they had started new friendships and learned a lot about outcome research. Patients appreciated meeting other people with a rheumatic condition, had learned about new diseases and had acquired new information about their own disease. Although feeling that they had not been fully productive: “Your first OMERACT you’re learning so much that you may miss contributing in a few things” (PE), they felt more knowledgeable and believed that they would contribute much more at a future conference, to which they were all eager to be invited.

**Conclusion**
In many areas patients collaborate as partners with professionals. To better understand the characteristics of the patient-researcher partnership from the patients’ perspective we explored the expectations and experiences of arthritis patients attending a scientific conference for the first time. From the results we found that three components are important when organizing patient involvement in a scientific conference like OMERACT: The pre-conference preparation phase, tailoring the support for patients during the conference to the specific context of the event, and acknowledging the value of personal learning curves.
Our findings showed that before the conference patient participants felt privileged to be
invited but inadequately prepared and uncertain what to expect from their participation.
They expected it to be a learning experience and hoped to be able to make a contribution.
During the conference active participation in the program reassured many, but was
physically and mentally challenging. Instances of poor moderation or lack of individual
support produced doubts that their contribution was helpful. After the conference some
thought their contribution could have been greater. Nevertheless all felt their
participation worthwhile and expected their contribution will be more effective at a
subsequent conference since they have learned about the OMERACT culture and its
procedures. Overall we see this as a process of relational empowerment: along the way
patients become more self-confident, gain a more positive self-experience, dare to
become more critical and out-spoken, and more creative and skilled in their interactions
with researchers.

Discussion
Until recently, active patient participation in outcome research has been limited. The
in-depth interviews with new OMERACT patient participants have provided insights in
the conditions for improvement of the collaboration between patients and researchers.
Whether the patterns in the way new patients responded to their participation can be
generalized to other conference settings is unclear because there were only 8 interviewees
and OMERACT conferences have a particular structure. Nevertheless, some issues
appear inherently relevant to many settings, others would clearly be relevant to future
OMERACT conferences and some would benefit from further research.

Being excited and having mixed feelings about personal competencies and meeting
the expectations of the organizers are common responses to something new. In becoming
a member of any group there is a ‘code of representation’ of which some rules are
unwritten and will not be explained. Emotional responses to poor moderation of a
session, inappropriate disclosure of personal information, or competition between new
and old members are also recognized aspects of group development. In the complex
international scientific environment of a medical conference patients also face difficulties
with the English language, medical jargon, inconveniences of intercontinental travel, and
a demanding program. These challenges can be lessened by techniques which include
improved use of pre-reading materials (information about their personal contribution and
asking about specific needs for information, access, assistance and support), personal
briefing by local researchers (to discuss mutual expectations) and prior involvement in
local research.
Patients face the challenge of the asymmetric relationship between them and senior professionals, hoping their feedback makes sense. They feel unsure whether professionals will listen to them as reported in other disease areas. Doubts are often related to the low status of experiential knowledge and narratives of patients, and fears concerning the preconceived power of researchers to ignore their perspective. The contributions of patients depend upon the phase and type of research, and change over time. They develop expert knowledge in the opposite direction to professionals. Patients transform their experiences (‘being familiar with’) into practical knowledge (‘knowing how’) and thence into expert knowledge (‘knowing that’) by meeting fellow patients and finally by collaboration with researchers. Organizers of the OMERACT conferences set out to make patients equal participants but some new patients did not always feel this and sometimes felt disempowered, as reported in other fields. Successful collaboration between patients and professionals requires initially different responsibilities. Researchers must accommodate the needs, anxieties and doubts of patients, and create an atmosphere in which all participants feel confident. Patients have to learn how their everyday experiences can be utilized in a specific research context (here the OMERACT process) including the procedures and concepts of knowledge production. Our results suggest the interactive nature of OMERACT provides a good platform to recognize that making patient participation work is the responsibility of all stakeholders and inherently acknowledges the patient as a credible partner.

More discussion and research is needed regarding the concept of ‘representation’. In our qualitative study, we found significant differences between the patient population and those acting in the conference in terms of professional, cultural and socio-economic background. Most people were Caucasian, middle age, well educated and had higher positions in society. However, for the first time three patients from Asia joined the patient group. In particular their participation made clear that searching for a more diverged representation requires recalibration of procedures for selection, communication and support. Unique for the OMERACT selection procedure are the participating physicians who identify eligible patient participants from their own clinics. It is assumed that they know what is required of patients to make a useful contribution and to deal with a six-day scientific conference. Although they will feel responsible for adequate support of ‘their’ patient, there are disadvantages. One might not only argue the representativeness of the patient group that is selected this way, our findings also confirm that some patients found it difficult to compartmentalize their role: a patient in the clinic and a collaborative partner at the conference.
Although OMERACT conferences appear to be unique in their selection procedure, their inclusive and interactive program design, and the intense involvement of patients in all activities, it is our expectation that many conference organizers and facilitators can learn from the patient reported challenges that have been presented in this chapter.

Acknowledgements
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