

# Incorporating the Patient Perspective into Outcome Assessment in Rheumatoid Arthritis — Progress at OMERACT 7

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**ABSTRACT.** The Patient Perspective Workshop at OMERACT 7 addressed the question of assessing the outcomes of intervention in rheumatoid arthritis (RA) from the perspective of those who experience the disease. A particular emphasis at this workshop was placed on fatigue, but other areas included well-being, real-time assessment, patient priorities, and needs in early and late disease. Through a series of overview presentations, discussion groups, and plenary sessions, workshop participants (who included 19 patients) clarified what is known and what are the outstanding issues for future research. The importance of further work on clarifying the validity of fatigue measurements in RA has been confirmed, and with at least one suitable instrument available there will be strong pressure to include fatigue in a redefined core set of outcome measures in RA. In the other 4 areas covered there are important issues that can be addressed by enquiry and experiment and that together provide a challenging research agenda. At the final plenary session the OMERACT conference endorsed, by a large majority, the proposal that fatigue may warrant consideration for inclusion in the OMERACT core set for RA. (*J Rheumatol* 2005;32:2250–6)

*Key Indexing Terms:*

FATIGUE      WELL-BEING      REAL-TIME ASSESSMENT      PATIENT PRIORITIES

## Introduction

The Patient Perspective Workshop at OMERACT 7 addressed the question of assessing the outcomes of intervention in rheumatoid arthritis (RA) from the perspective of those who experience the disease. It was convened to review

progress<sup>1</sup> on the issues raised since the last workshop<sup>2</sup> in 2002 and to identify the work necessary to further the aim of including patient perspective outcome assessments in the internationally agreed “core set” for RA<sup>3</sup>. Financial and organizational commitments from the OMERACT Executive Committee ensured a wider representation of patients (and also included patients in several other sections of the OMERACT meeting). Participants in the workshop included 19 patients from 10 countries, 5 organizing group members, and about 155 other participants from those attending the OMERACT 7 meeting. The workshop (Table 1) consisted of 3 formal sessions each of 2 hours and working group meetings between and after the formal sessions.

A major issue emerging from OMERACT 6 was fatigue in RA and how it should be measured. Thus there was emphasis on reviewing progress in this area, all participants heard an overview presentation, and all discussion groups considered some aspect of fatigue. Four other topics were discussed, each by one-quarter of the discussion groups, who listened to an introductory presentation on their allotted topic. These were well-being, real-time assessment of symptoms, incorporating patient outcome priorities, and differences in outcome in early and late disease (Table 2).

This report has been prepared by the organizing group and the reporters from the discussion groups in the workshop. It briefly describes the outcome of the various sessions, and sets out the issues and research agenda identified

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Table 1. Structure of the Patient Perspective Workshop at OMERACT 7.

Session	Activities	Participants
Preamble meeting	<ul style="list-style-type: none"> <li>• Orient patient participants</li> <li>• Provide feedback on progress since OMERACT 6</li> <li><sup>a</sup> Identify key questions for the workshop</li> </ul>	Patient participants, organizing group, and active researchers in this area
Workshop	<ul style="list-style-type: none"> <li>• Consider issues in plenary presentation, introductory presentations to discussion groups, breakout discussion groups, reports back to plenary session and general discussion</li> </ul>	Patient participants, organizing group, and OMERACT participants who registered for the workshop
Post-workshop meeting	<ul style="list-style-type: none"> <li>• Assess feedback in detail and formulate research agenda</li> </ul>	Discussion group reporters, patient participants, organizing group, and active researchers in this area
OMERACT plenary session	<ul style="list-style-type: none"> <li>• Present and seek endorsement of final conclusions</li> </ul>	All OMERACT participants

Table 2. The contents of the Patient Perspective Workshop.

Plenary	<ul style="list-style-type: none"> <li>• Workshop aims and objectives</li> <li>• The nature of fatigue in RA</li> </ul>
Breakout fatigue questions	<ul style="list-style-type: none"> <li>• What is a useful improvement in fatigue?</li> <li>• Can/should we try to measure quantity and quality of fatigue separately?</li> <li>• Is fatigue part of or a consequence of RA?</li> </ul>
Breakout presentations and subsequent discussion questions	<ul style="list-style-type: none"> <li>• Is loss of well-being disease-specific?</li> <li>• The potential for “continuous” assessment of symptoms</li> <li>• Identifying patients’ priorities for improvement in health and incorporating them into measures</li> <li>• Are there differences in outcomes in early and late disease?</li> </ul>
Plenary	<ul style="list-style-type: none"> <li>• Is loss of well-being part of RA or a consequence of any disease?</li> <li>• Is loss of well-being in RA more than the result of all the other symptoms?</li> <li>• Would change in the pattern of symptoms be an important outcome measure?</li> <li>• Why would “continuous” measurement be better than weekly or monthly measurement?</li> <li>• Is pain the overriding consideration?</li> <li>• Does incorporating patient impact make outcome assessment better?</li> <li>• Does the value for some specific outcomes change as the disease progresses?</li> <li>• Are we talking about early and late disease, or moderate and severe disease?</li> <li>• Reports back from discussion groups</li> <li>• Summary and overview</li> </ul>

and the decisions endorsed by the final OMERACT plenary session.

### Topic 1: Fatigue

*Presentation, Sarah E. Hewlett:* Fatigue in RA

An opening presentation on fatigue in RA reminded participants that the OMERACT 6 meeting had identified fatigue, sleep, and well-being as symptoms important to patients. Subsequent patient focus groups undertaken in the UK to identify outcomes important to RA patients support these views<sup>4</sup>. A current, parallel study by OMERACT researchers in Sweden also seems to reflect these values (M. Ahlmén, personal communication and as reported<sup>1</sup>). Further, when the outcomes raised by the UK focus groups were sent to 323 patients in 3 UK centers, fatigue and well-being were ranked as the most important issues after pain and independence, and as more important than joint symptoms<sup>5</sup>.

To clarify the nature of fatigue, a qualitative study has explored RA patients’ descriptions of the nature of fatigue, and its cause, consequences, and management. The recently completed systematic analysis reveals 3 overarching themes: fatigue is overwhelming and different from normal tiredness; it permeates every sphere of life; and self-management is variable, but professional support is rare. Vivid descriptions tell how daily life can be halted by the sudden

but unpredictable onset of fatigue (“Wipeout”), which has both physical components (“Heaviness”) and cognitive elements (“Enthusiasm’s gone”). Patients believe fatigue is linked to RA inflammatory activity, poor sleep, and strain from working disrupted joints and muscles harder. Consequences are widespread (“It dumbs down everything”) and affect not only physical activities but also normal social roles. Self-management involves pacing and planning (“You’ve got to work to what you know you can do”), but has variable success; therefore many carry on regardless. The belief is that “Nothing can be done” and most patients did not discuss fatigue with clinicians. Those who did felt it was ignored (“He just sort of pooh-poohed it”).

### Discussion Groups

Clearly, fatigue is an important and intrusive issue for patients, so the workshop discussion groups considered 3 questions, and their conclusions are summarized below. There was unanimous agreement on the urgent need to clarify measures of fatigue, ensure they are valid for use in RA, and introduce them more widely.

*Can or should we try to measure quantity and quality of fatigue separately?* The suggestion was raised that quantity may be duration or amount of fatigue, whereas quality may relate to depth or intensity. These issues needed clarifying.

Perhaps measuring the consequence of fatigue (e.g., too tired to go to work) may be a surrogate for measuring severity of fatigue. While there seems to be good reason to suppose fatigue has several dimensions, it was felt that many multidimensional questionnaires are eventually summed into a single score. However, some participants recognized a background fatigue as being different from sudden overwhelming and short-lived episodes of fatigue, and it might be necessary to differentiate between them. If a visual analog scale (VAS) is recommended for measuring fatigue, then a standardized, validated phrase should be incorporated to ensure consistency of measurement. It is likely that cultural differences will influence the way fatigue is expressed and instruments may need to be validated in the culture in which they are being used.

*What is a useful improvement in fatigue?* It was recognized that what may be useful and measurable in an individual may be different from that in a group in a clinical trial. It was suggested that it might be easier to measure the manifestation or impact of fatigue rather than the sensation itself, or perhaps measure both aspects. A “useful” improvement might be defined as: getting back to normal; a reduction in severity, number, and duration of episodes of fatigue; a decrease in symptoms associated with fatigue; what the patient perceives to be an amelioration of this state.

*Is fatigue part of or a consequence of RA?* Fatigue states vary with time and with circumstance. There may be variation day to day, hour by hour, associated with differences in disease activity, during times of stress and disease flares, and sometimes due to the emergence of other factors such as the development of the menopause. Fatigue in some people is a stable and predictable symptom, while in others it occurs for short periods at either predictable or unpredictable times. In some people at some times fatigue may occur without any impairment of mental function (physical fatigue), while in others fatigue is associated with complete “shutdown of physical and mental functioning” (mental fatigue). Fatigue may be caused or aggravated by other conditions such as depression, sleep disorder/disturbance, or the menopause. This may complicate the interpretation and measurement of fatigue related to a specific disease. There was a feeling that fatigue may not be a linear phenomenon and may be an on/off occurrence. Patient experience in this group suggested the on/off as the predominant mode of occurrence. Overall, there was a feeling that fatigue is related to RA, but this is difficult to discern clearly.

## Topic 2. Loss of Well-Being

*Presentation, Stanton Newman:* Is Loss of Well-Being Disease-Specific?

Loss of “well-being” was interpreted for the purposes of the presentation to be reflected in 2 main areas of research: studies that examined psychiatric morbidity and studies that considered depression or depressed mood.

Psychiatric morbidity in arthritis was examined in a large random study of the population where individuals with no physical illness were compared to those with a single, self-reported physical illnesses (Newman, *et al*, submitted). A third group were those with 2 or more other physical illnesses. On a standardized psychiatric interview about 12% of those reporting arthritis were found to be classified as having a psychiatric problem compared to 6% of those with no physical illness. A number of other conditions (e.g., asthma and migraine) were found to have higher levels of psychiatric morbidity, while those with other physical conditions were found to have lower levels (e.g., diabetes). Individuals with arthritis and another chronic condition were found to have significantly increased levels of psychiatric morbidity compared to those with arthritis alone, suggesting that each physical condition imposes a psychological burden on the individual.

The prevalence of depression in RA has been found to range between 13% and 20%. The figures are dependent upon the sociodemographic characteristics of the sample, the disease characteristics of the sample, and the manner in which depression is assessed. Depression has been found to be associated with pain and disability. It is, however, important that many individuals with RA are not found to have depression, despite having pain and disability. Studies have also compared levels of depression in different rheumatological conditions<sup>6</sup>. A recent metaanalysis suggests that the highest levels of depression are recorded in those with a diagnosis of fibromyalgia<sup>7</sup>.

Overall, the research on psychological problems demonstrates that raised levels of psychiatric morbidity and depression tend to be found in subjects with all physical illnesses compared to those without any physical condition. Some differences have been found between individuals with different physical conditions and different rheumatological conditions. With these studies, which use standardized instruments, the question of whether the “loss of well-being is specific” cannot be clearly answered.

## Discussion Groups

*Is loss of well-being part of RA or a consequence of any disease? Is it more than the result of all the other symptoms?* The term “well-being” was considered to be frustratingly vague. The groups considered loss of well-being was not necessarily a part of RA as a disease process, but is in any case a consequence of having RA. It was felt that feelings of well-being may differ at various stages of the disease, may be influenced by how well the person adapts to the disease, and may be influenced by how the individual responds to illness in general. In this context, a patient in the group commented that she had a great sense of well-being, perhaps more so than some of her friends who do not have RA. The universal feeling was that the fatigue associated with RA is

more than the simple combined effects of the other symptoms of the disease, but that it encapsulated something related to the underlying disease process.

### Topic 3: “Continuous” Assessment of Symptoms

*Presentation, Tore Kvien:* The Potential for Continuous Assessment of Symptoms

Patients traditionally report their health status by completing questionnaires. During OMERACT 6, the patient representatives emphasized the variation in their health status from time to time and from day to day — highlighting that once a week or once a month completion of these questionnaires did not capture this variation. Many patients complete diaries, but access to and analyses of such data may be difficult. Collection of data via the Internet or via mobile telephone could be an alternative. We have examined the performance of health status measures on a personal digital assistant (PDA). After responding to the questions, the data are automatically transferred via the mobile telephone network to the data server in the hospital.

In a study with test-retest design, 30 patients with RA completed self-reported health status measures [Rheumatoid Arthritis Disease Activity Index; Modified Health Assessment Questionnaire (MHAQ); Medical Outcome Survey Short Form-36; VAS pain, fatigue and global] in a conventional paper-based questionnaire version or on a PDA (Hewlett-Packard iPAQ, model h5450). The completion of the questionnaires was repeated after 5–6 days. The performance of paper-based versions and electronic PDA versions was similar for feasibility, validity, and reproducibility. Thus it is an acceptable measurement technique. We are now comparing the use of paper and PDA as patient diaries in a project with a cross-over design, where patients are completing the questionnaires daily on a PDA and paper format over several weeks. In this project we are also testing some new questionnaires to assess variation in pain and fatigue during the day.

#### Discussion Groups

*Would change in pattern of symptoms be an important outcome measure?* Change in the pattern of symptoms might refer to changes over time (such as variations in intensity, diurnal variations, or activity-related variations) or change in site or region of the symptom source. (The only specific symptom referred to by the group was joint pain.) A patient who was present in the group had less difficulty relating to the overall concept than the other members of the group, who perceived a conceptual difficulty with the feasibility of measurement of change in pattern, and what tools might be appropriately employed to enhance discrimination. Despite this, there was an agreement that the concept was important and merited debate.

*Why would “continuous” measurement be better than weekly or monthly measurement?* What is meant is measurement

over short time intervals, e.g., once or several times a day. Using electronic diaries would avoid the problem of patients seeing their previous responses, as might be the case with paper diaries. Compliance with data recording might be improved because patients are prompted to answer questions at the right moment and the electronic diary registers the time and date that questions are answered. Real-time measurements will probably provide more reliable results than weekly or monthly measurements because there is less recall bias. There was concern that the use of PDA for assessments in clinical trials and other studies might bias the results, because patients with severe or worsening hand problems will not be able to use the small stylus to enter data in a PDA. This might cause selective dropout from the study of patients with worsening hand function. However, experiences with the use of PDA in Norway have shown that almost all patients can use PDA. A special stylus has been developed with a thicker grip that performs very well. It is not clear if we need continuous measurements for all outcomes. It is probably useful for fatigue because patients experience much variation, but not for outcomes that show less variations during the day. Research is needed to establish for which outcomes continuous measurements are needed. Probably a lot can be learned from other research fields that have more experience with continuous measurements. More information (from studies of the available literature or empirical research) is needed to establish which outcomes, in what situations, should be measured continuously.

### Topic 4: Identifying and Incorporating Patients’ Priorities for Improvement in Health

*Presentation, Turid Heiberg:* Identifying Value Differences and Incorporating Them into Measures

OMERACT patients have emphasized the value of focusing on their priorities for improvement. Few instruments are available for measuring importance and priorities perceived by patients. In the Arthritis Impact Measurement Scale 2 (question 60) patients are asked to choose 3 out of 12 areas of health where they would most like to see improvement<sup>8</sup>. The PET (problem elicitation technique) measures real changes in areas of difficulty and the importance to the patient through 2 interviews<sup>9</sup>. The MACTAR (McMaster Toronto Arthritis Patient Preference Questionnaire) focuses on activities that are limited by arthritis and which of these activities the patient would most like to do without discomfort<sup>10</sup>. This instrument identifies change in ability, detecting clinically important changes. It is designed for interviews but can be self-administered. The Canadian Occupational Performance Measure measures perception and satisfaction with activity performance, additionally rating importance of activities, all in a stepwise procedure with interview and scoring<sup>11</sup>. VAS can be used but tend to give a ceiling effect measuring priority for improvement. Ranking or weighting seems to be an important measuring priority, as well as



including items that are representative of the burden of the disease.

#### Discussion Groups

*Is pain the overriding consideration?* All participants thought the answer to this question was “No,” and that many other symptoms are important to many patients. The patients described how pain might go away but fatigue will continue. However, it was not clear how fatigue, pain, anxiety, and depression relate to each other in RA. It was also considered possible that priorities for different outcomes may not only differ between patients, but individual patients may have different priorities in different circumstances.

*Does incorporating patient priorities make outcome assessment better?* Although it was felt that this would be advantageous overall, it was recognized that the benefits would need to be clearly demonstrated. For example, elicitation of real priorities may be difficult due to bias associated with disclosure. “Truthful” priorities may be obscured by answers associated with guilt, gratefulness, dedication to helping in clinical trials, or second-guessing for desired answers. Further, priorities may be unstable with time and disease duration; for example, during a flare of inflammation, pain reduction may displace functional improvement as an immediate priority. (This may even provide a way to track disease state, functional status, mental state, or coping success.) Better care and more successful treatments might change expectations and result in greater functional ambition and a difference in priorities. Thus consideration of priorities is likely to enhance outcome measurement by making overall assessment of disease state and response to treatment more relevant to the patient, but in dealing with complex concepts such as priority there may be methodological difficulties.

#### **Topic 5: Are There Differences in Outcomes in Early and Late Disease?**

*Presentation, John R. Kirwan: Are There Differences in Outcomes in Early and Late Disease?*

There may be theoretical reasons for supposing that disease duration will affect priorities for outcome improvement, based on the recognition that joint destruction plays an increasing role in disability as the disease progresses. However, while an initial theoretical model suggested this might be the case<sup>12</sup>, subsequent application to real clinical data<sup>13</sup> showed that the major determinant of disability throughout the course of RA is recurrent episodes of inflammatory disease activity. However, there may be psychological and physical adaptations to arthritis as time passes and people get older, and experience of the disease might change expectations. There are few data on which to judge the issue. In one study<sup>14</sup>, older patients seem to have a different distribution of priorities for outcome, but closer scrutiny shows this to be related principally to the work role, which is clear-

ly of less importance after the age of retirement. Further, in 25 patients with RA who were asked to rate the importance of the HAQ (20 items) and MHAQ (8 domains), importance was not related to disease duration<sup>15</sup>. Thus there is no compelling argument to support the notion that disease duration might affect patient priorities for outcome improvement.

#### Discussion Groups

*Does the value for some specific outcomes change as the disease progresses? Are we talking about early and late disease, or moderate and severe disease?* (The discussions covered much the same ground and are reported here together.) There was an inherent feeling that, in spite of lack of hard evidence, there are changing priorities for patients and outcome measures over time and with progression from early RA to late disease. Adaptation to disease, expectations about symptoms and function, and expectations of the nature of life as people age were all considered likely influences on priorities. Disease duration and the development of comorbidities may also be relevant to outcome measures and their priorities. Early in the disease process, symptoms may be unrecognized, disability at work (and in other roles) may be highly relevant, and fear and anxiety are more likely to be evident. Late in the disease process there are additional requirements for consideration, such as the need for surgery and other major interventions, comorbidities, nonarticular organ involvement, and medication toxicities.

#### **The Emerging Research Agenda**

The brief reports of presentations and feedback from the discussion groups given above and the emerging research agenda (Table 3) can be better appreciated in the context of the progress made in some of these areas since OMERACT 6, reported elsewhere<sup>1</sup>. The importance of further work on clarifying the validity of fatigue measurements in RA has been confirmed, and with at least one suitable instrument available there will be strong pressure to include fatigue in a redefined core set of outcome measures in RA<sup>3</sup>. In the other 4 areas covered there are important issues, which can be addressed by enquiry and experiment.

The Patient Perspective Workshop took 5 questions to the final plenary session at OMERACT 7, where all participants in the conference have the opportunity to hear the main points emerging from individual workshops and modules and to pass a collective opinion about them (Table 4). For fatigue it was argued that: the majority of patients have fatigue for the majority of the time; we do not yet have the evidence that measurement tools have been validated in RA; there are some treatments that seem to alter fatigue when it is measured; and omitting fatigue reduces the face validity of the core set of outcome measures in RA. The conference delegates voted substantial support to the fatigue research proposals. For real-time assessment of outcome using information technology, evidence suggests that information tech-

Table 3. OMERACT 7 Patient Perspective Workshop research proposals.

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Fatigue

- Are current instruments valid in RA?
- Is RA fatigue different than in other diseases?
- Is it related to disease mechanisms?
- Is it responsive to RA treatment?
- Are unidimensional scales as good as multidimensional?
- What is an appropriate standard wording for VAS?
- What are the relationships between fatigue, pain, and depression?
- Press for frequent measurement, and possibly inclusion in core set, if suitable instrument identified

Well-being

- Evaluate in relation to ICF and direct link to RA as a disease process
- Define and distinguish from euphoria
- Explore relationship with “relative glucocorticoid deficiency”
- Research into positive effects of arthritis on well-being
- Does well-being relate to patient global in the core set?

Incorporating patient priorities

- Do priorities differ over time or between circumstances within individual patients?
- Further evaluate if incorporating priorities in measures provides greater sensitivity to interventions
- Consider changes in priorities as indicators of important but small changes in disease status
- Check how priorities might relate to personality

Real-time assessment of symptoms

- Can patterns of symptom change be quantified?
- Will information technology enable real-time symptom recording?
- Is IT-based symptom collection valid?
- Does AUC have greater utility than infrequent timepoint recording?
- Will patients benefit from being in control of their symptom records?

Outcomes in early and late disease

- Do priorities for disease symptoms and interventions change with age and disease duration?
- Does adaptation to disease change priorities?
- Are intervention outcomes different for patients with different disease durations?

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ICF: International Classification of Functioning, Disability and Health<sup>16</sup>. IT: information technology, AUC: area under the curve.

Table 4. Voting at the OMERACT 7 plenary session on proposals from the Patient Perspective Workshop.

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Questions	Proportion in favor, %
<b>Fatigue</b>	
Fatigue is an important symptom in RA	95
Measures of fatigue should be validated in RA	100
After further work fatigue may warrant consideration for inclusion in the OMERACT core set for RA	86
<b>Information technology</b>	
IT data collection techniques for outcome assessment should be adequately validated	100
<b>Priorities and well-being</b>	
Stability of patient outcome priorities and well-being are areas that may influence outcome assessments and are worthy of further study	92

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nology may offer new opportunities to collect real-time measurements of relevant outcomes, but the methodology could easily be introduced with enthusiasm before adequate validity testing. The plenary session fully endorsed the requirement that such technologies be positively shown to be valid methods before widespread introduction. For priorities and well-being it was pointed out that patient priorities for outcome assessment differ from those of health professionals; that priorities for outcomes also differ between patients; that well-being is frequently cited as an outcome priority, but how to measure it in RA is unclear; and that

there are strong impressions that a patient’s priorities for outcomes may change during the course of RA, but the small amount of evidence available is equivocal. In response to this, the plenary session strongly supported the idea that further work in this area is warranted.

For those interested in incorporating the patient perspective into trial outcome measures, the research agenda generated in the Patient Perspective Workshop should provide an important guide to where efforts would be most appreciated and perhaps most fruitful. The clear support of the OMERACT 7 plenary session will encourage all of us to take these issues forward.

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