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# Incorporating the patient's perspective in outcomes research

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## Abstract

**Purpose of review—**Incorporation of the patients' perspective in clinical research is critical to ensure that outcomes measured reflect those, which matter most to patients. This review summarizes recent efforts to include the patients' perspective in the development of outcome measures and the importance of encouraging patient participation in decision-making and self-management.

**Recent findings—**Since the inclusion of fatigue as a patient-endorsed core outcome measure in rheumatoid arthritis (RA) trials, OMERACT has been instrumental in advocating for patient involvement in the development of core domains and instruments; current endeavors include cultivating an understanding of remission through the eyes of patients and gaining a sense of how to measure features of pain and 'stiffness' deemed as important to patients. The concept of remission was further explored in RA patients, highlighting a common goal of returning to normality; additionally, various tools have been developed to assess for unmet needs in rheumatology patients. Advances have also been made in the development and revision of patient-centered core measures in rheumatologic diagnoses outside of RA.

**Summary—**Incorporating the patients' perspective is now considered an essential feature in outcomes research. Future research should focus on how best to involve patients in specific research activities.

### Keywords

attitude; opinion; patient; perspective; preference; rheumatology

## INTRODUCTION

In order to ensure that clinical research studies generate information needed by patients to make decisions, greater emphasis is now being placed on incorporating patients' perspectives into outcomes research. Discrepancies between physicians' and patients' assessments of their disease activity [1–3], treatment preferences [4,5], factors utilized in decision-making [6–8], and thresholds to change treatment plans [9], underscore the importance of including the patients' perspective in outcomes research.

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**Conflicts of interest**

There are no conflicts of interest.

We begin this review with an evolutionary description of OMERACT (Outcome Measures in Rheumatoid Arthritis Clinical Trials), one of the leading initiatives to improve outcome measures in rheumatology, which emphasizes incorporation of the patients' perspective into outcome measurement. We then summarize recent papers, which addressed the patients' perspective in the development of outcome measures. Papers were chosen from the list of articles, published between 1 January 2015 and 31 July 2016, generated from three Medline searches of the following text words: first, 'OMERACT'; second, 'patient rheumatology' and 'attitude' or 'opinion' or 'perspective' or 'preference'; and third, 'rheumatology' and 'belief' or 'concordance' or 'congruence' or 'disagree' or 'discordance' or 'expectation' or 'outcome and perspective'. We focus specifically on papers including patients as active participants charged with representing the patients' perspective. Patient reported outcome measures (PROMs) are reviewed in a separate paper.

## EVOLUTION OF OMERACT

In 1992, OMERACT was founded as an initiative to develop research-driven recommendations for core sets of measures for rheumatoid arthritis (RA) and other rheumatologic conditions. Although prior outcome assessments in RA were based primarily on physician input, OMERACT has included patient research partners (PRPs) as full delegates with equal voting rights since 2002 [10,11]. In order to incorporate the perspective of those with firsthand experience of living with RA, patients were invited to participate in a series of focus groups to evaluate outcomes for RA at OMERACT-6, eventually leading to the recognition that sense of well being, fatigue, and disturbed sleep, should be considered as additional domains in the RA core set [12,13]. Further research demonstrated the responsiveness of fatigue in clinical trials and OMERACT-8 delegates voted in favor of measuring fatigue in future RA studies [14–16]. PRPs have evolved from the initial group of RA patients to a diverse group of patients carrying various rheumatic diagnoses. Patients are called to participate in OMERACT with different levels of involvement based on the type of research (e.g., limited involvement may be practical for more technical research such as imaging or laboratory research). Driven by the principle that patient participation strengthens outcomes research, a comprehensive conceptual framework to develop core outcome measures for rheumatologic conditions emphasizing patient involvement was established at OMERACT-11 in 2012 [17,18].

## RECENT OMERACT PUBLICATIONS

Incorporating the patients' perspective is especially important when characterizing the concept of remission [19]. At OMERACT-12, RA patient rankings of different aspects of remission were presented to a working group, which included 60–80 participants and at least six PRPs. Although pain received the highest ranking, the working group recommended including patients' global assessment of disease impact in its place, as it addresses additional aspects of disease including pain, fatigue, and physical functioning. The working group is charged with continuing this line of research to determine an optimal patient-centered measure of remission in RA [20■].

Incorporation of the patients' perspective is also important when characterizing RA flares, especially when flares warrant a change in treatment. At OMERACT-11, participants approved an RA flare core domain set that includes ACR (American College of Rheumatology) disease activity as well as fatigue, participation, stiffness, and self-management. The RA Flare Workshop at OMERACT-12 called for additional research to identify measures to better capture how patients experience stiffness [21]. Patients' ratings of pain, fatigue, stiffness, function, and participation were shown to have strong evidence of content and consequential validity. Additional research will be directed at developing a scoring system to grade the severity of flares [22■, 23■].

At OMERACT-12, the Vasculitis working group took further steps to develop a core set of outcome measures for Behçet's syndrome. Clinical experts and patients agreed on the need to develop a composite measure to assess disease activity. A weighting scheme was suggested as a way to address discrepancies between impairment of quality of life (QOL) and the severity of organ damage, for example, oral ulcers which significantly impact QOL but do not inflict organ damage vs. aneurysms, which are often asymptomatic but can be fatal. The working group expressed plans to conduct a Delphi exercise with physicians and patients to explore items for a composite measure and develop a core set of domains and instruments [24].

The Myositis working group at OMERACT-12 aimed to evaluate patients' experience of living with myositis in order to define core domains and further validate the MAP (Myositis Activities Profile) through cognitive debriefing. The working group is developing a revised MAP that will be the first PROM to include limitations of daily activity and participation in society from the patients' perspective [25].

The OMERACT Polymyalgia Rheumatica (PMR) special interest group was established to identify a set of core outcome measures for PMR. A Delphi survey including 60 clinicians and 55 patients (in the first round) was conducted to identify important domains and to add missing domains. Patients requested that 'stiffness' be considered rather than 'morning stiffness'; both patients and clinicians suggested adding certain adverse effects of glucocorticoids. Further research will be aimed at validating measurement instruments for each domain [26].

At OMERACT-11, vasculitis workshop participants discussed the need to develop a disease-specific PROM for patients with antineutrophil cytoplasmic antibody (ANCA)-associated vasculitis. Patients were interviewed and relevant themes were highlighted and recast as candidate items that were further reviewed and amended by PRPs. At OMERACT-12, a breakout group cohosted by a PRP and researcher voted that access to healthcare and information was important and should be measured. The group agreed that treatment effects should also be considered [27].

The OMERACT Vasculitis working group also conducted focus groups in Turkey and individual patient interviews in the United States with patients with temporal arteritis. The preliminary results were discussed at OMERACT-12 with patients reporting fatigue, other constitutional symptoms, extremity pain, limits to their physical activity, willingness to attend social events, and concerns about the long-term effects of their illness and therapy as important domains to consider. The working group agreed to include fatigue in any preliminary core set for large vessel vasculitis (LVV) as well as to initiate further research to understand its impact with the ultimate goal of establishing a core set of outcome measures for use in LVV clinical trials [28].

At OMERACT-12, the OMERACT Hand Osteoarthritis working group agreed that the preliminary core set should include the following domains: pain, physical function, patient global assessment, joint activity, and hand strength. A Delphi exercise involving experts in hand osteoarthritis, PRPs, and OMERACT participants, was performed to identify important contextual factors that should be mandatory in osteoarthritis studies. Data from the Delphi exercise were felt to be more ‘informative than decisive’ and the group called for additional research [29].

At OMERACT-12, a working group including PRPs, physicians, and researchers, was formed to determine the core set of domains for measuring shared decision-making (SDM) in trials with osteoarthritis. The participants reviewed SDM conceptual models and found that patients were involved in the development of only two of the 15 models. Participants drafted a core of domains to measure SDM: identifying the decision, exchanging information, clarifying views, deliberating, making the decision, putting the decision into practice, and assessing the effect of the decision. Further research will be directed toward the formation of subdomains and assessment of instruments to develop a core outcome measurement set [30■].

The Total Joint Replacement (TJR) working group at OMERACT-12 proposed that a preliminary core domain set for TJR include pain, function, patient satisfaction, revision, adverse events, and death. Additional efforts will include measuring function following TJR and finalizing the core domain set [31].

Prior to OMERACT-12, a pain workshop was established to discuss how to conceptualize and measure pain in clinical trials of musculoskeletal conditions [32■]. Participants discussed whether chronic pain should be considered a disease rather than a symptom or domain [33]. Additional domains including pain intensity and pain interference were recommended. Future research will be directed at confirming consensus on the domains with an emphasis on patient involvement [34■].

The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) has been a strong proponent for research in psoriasis and psoriatic arthritis (PsA) since its inception in 2003; starting in 2015, PRPs were incorporated to highlight the patients’ perspective. The GRAPPA-OMERACT PsA working group, which included PRPs, recently updated the existing PsA core domain set for clinical trials. The revised PsA core domain set was endorsed earlier this year at OMERACT-13 and includes musculoskeletal and skin disease activity, pain, patient global assessment, physical function, health-related QOL, fatigue, and systemic inflammation. Revisions from the 2006 core domain set include recommending measures of fatigue and systemic inflammation; measures of structural damage, participation, and emotional well being were strongly recommended but not classified as being required for all clinical trials. Stiffness, independence, treatment burden, and sleep were added to the research agenda for evaluation as possible domains [35–37]. Further research will be aimed at developing patient-centered therapeutic pathways that target both skin and joint manifestations [38].

## ADDITIONAL RECENT PUBLICATIONS INCORPORATING THE PATIENT PERSPECTIVE

Optimal care for chronic diseases requires that patients are able to effectively communicate their concerns to their physicians. A comprehensive tool to identify patients' unmet needs may improve patient–physician communication. Ahmed *et al.* [39] developed a Patient Concerns Inventory (PCI), using input from the published literature, expert opinion, and three patient focus group discussions. In a pre-post test study, patients in the post-PCI group asked significantly more questions and discussed a greater number of concerns compared with the pre-PCI group in the 'physical and functional well being', 'social care and well being' domains.

Research has shown that psychological interventions enhance medical therapy; however, there may be a disparity between the demand and the provision of psychological support. Dures *et al.* [40] described the results of a survey for patients with inflammatory arthritis developed by researchers, patient partners, and clinicians. Of 1210 patients surveyed, only 23% of patients reported being routinely asked about social and emotional issues by rheumatology professionals and 46% of patients stated they would like the opportunity to discuss the psychological impact of their disease. Patients reported preference for greater psychological support to manage the impact of pain and fatigue (82%), their emotions (57%), work and leisure (52%), relationships (37%), and depression (34%).

Another important measure from the patients' perspective is at-work productivity. Leggett *et al.* [41] evaluated 70 employed patients with a diagnosis of inflammatory arthritis or osteoarthritis to examine their understanding and interpretation of five global measures of presenteeism. Patients were randomly selected to be cognitively debriefed on three of the five following global measures: Work Productivity Scale—Rheumatoid Arthritis, Work Productivity and Activity Impairment Questionnaire (WPAI), Work Ability Index, Quality and Quantity questionnaire, and World Health Organization (WHO) Health and Work Performance Questionnaire, with the exception of the WPAI which was debriefed in all patients. Seventy percentage of patients considered a 7-day recall, as measured by the WPAI, to best represent how their disease affects work productivity.

Outcomes may also improve with satisfactory self-management. Dures *et al.* [42] conducted interviews with 19 patients with inflammatory arthritis to examine mechanisms for facilitating self-management. Patients' views regarding how rheumatologists could best facilitate self-management were summarized across three themes: first, patients and clinicians should view care as a shared endeavor in which the patient plays an active role rather than simply receive medical advice; second, clinicians must understand the challenges faced by patients and focus on patients' priorities; and third, clinicians should use an open communication style to cultivate a sense of shared responsibility. These three themes collectively encourage active patient involvement, which fosters the self-efficacy and coping skills required to deal with the impact of inflammatory arthritis.

As remission is becoming a realistic treatment goal for many RA patients, it is paramount to determine if current definitions of remission adequately reflect their perceptions. van Tuyl *et al.* [43■] conducted nine focus groups and found that patients' perspectives clustered into three themes: absence or marked reduction in symptoms; decreased impact of RA as evidenced by improved physical and emotional functional status; and a return to normality with ability to resume roles within the family and at work.

In a qualitative study evaluating early RA patients' preferred health and treatment outcomes, van der Elst *et al.* [44] confirmed the importance of attaining 'normality'. Patients interviewed twice over 1 year after initiating treatment emphasized the importance of returning to normal in terms of disease control, improved pain and physical function, mental well being, and participation at work, home, and leisure. Patients' perceptions on normalcy were noted to evolve with expectations shifting over time to a new definition of normality (e.g., acceptance of medication being essential).

Understanding how patients conceptualize remission is especially important when a decision regarding medication intensification must be made. Hendrikx *et al.* [45■] evaluated the influence of patients' perceptions of disease on actual medication intensification. Patients completed surveys prior to their visits that examined perceived health change, satisfaction with current health, willingness to change therapy, and expected health change up until the next visit. Treatment was intensified in 82 of the 453 patients surveyed. Willingness to escalate therapy was strongly associated with patients' satisfaction with their health state, perceived change (of arthritis from the last visit), and expected change after escalation. This study underscores the important impact of patients' perceptions and preferences on successful implementation of treat to target strategies.

The LupusQoL has been used to evaluate the impact of treatments for systemic lupus erythematosus. Meacock *et al.* [46] mapped the disease-specific LupusQoL to the SF-6D, a generic preference-based measure of health-related QOL. The authors developed an algorithm for those seeking to use existing data sets to estimate health state utility values from patient responses to the LupusQoL.

Mittoo *et al.* [47] conducted a mixed methods study to evaluate the impact of interstitial lung disease (ILD) in patients with connective tissue diseases (CTDs). Forty-five patients with CTD-ILD reported that cough and dyspnea have significant impacts on patients' ability to complete activities of daily living. Patients also identified the impact of psychosocial factors including living with uncertainty regarding the diagnosis (e.g., disease course, prognosis, management), struggle over self-identity (e.g., health status, disability, life expectancy), and self-efficacy. This is reported as the first study to evaluate CTD-ILD from the patients' perspective, providing a preliminary framework for use in patient care and to help identify a core set of domains and instruments for implementation in future trials.

## CONCLUSION

As discrepancies between patients and physicians play a substantial role in the management of rheumatic diseases, incorporation of the patients' perspective is crucial in outcomes research. This review summarizes recent efforts to include the patients' perspective in the development of outcome measures and the importance of encouraging patient participation in decision-making and self-management.

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## KEY POINTS

- Incorporation of the patients’ perspective is an essential feature of outcomes research.
- OMERACT has been a leader in advocating for patient-endorsed core measures.
- This review summarizes recent efforts to include the patients’ perspective in the development of outcome measures.
- Future research should focus on how best to involve patients in specific research activities.