

Patient Participation in Psoriasis and Psoriatic Arthritis Outcome Research: A Report from the GRAPPA 2013 Annual Meeting

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ABSTRACT. For the first time, 8 patients with psoriatic arthritis (PsA) participated as full delegates at the 2013 Annual Meeting of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA). Patients were invited to provide their perspective for different sessions of the conference program. Before the conference, the patient delegates had a separate meeting to familiarize themselves with the conference program and to gain a better understanding of the vision and objectives of GRAPPA. During the conference, the patient group discussed options for increased involvement in research projects. Herein we summarize the presentations on patient participation in research, the experiences of the patient group, and plans to enhance the patient perspective in psoriasis and PsA research. (J Rheumatol 2014;41:1206–11; doi:10.3899/jrheum.140171)

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OUTCOME RESEARCH PSORIATIC ARTHRITIS PATIENT RESEARCH PARTNER
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Until recently, patients have rarely been seen as collaborative partners in health research. Despite being the individuals affected most directly by a disease, patients

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traditionally have had minimal direct influence on research agendas, study design, study conduct, or data interpretation related to their disease state. Since the 1990s, recognition has been increasing among researchers, regulatory agencies, and patient groups that patients should play a more active role in health research¹. For example, in December 2009, the US Food and Drug Administration (FDA) released its “Guidance for Industry Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims.” In it, the FDA clearly indicates the importance and requirement of patient involvement in the development of patient-reported outcome (PRO) measures to be used in therapeutic clinical trials².

Becoming a patient research partner (PRP) is not an instantaneous process, nor is it a role that every patient wishes to assume. It involves attaining a deeper understanding of the disease as well as knowledge of the aims and conduct of medical research. Patients need to have resources and support to develop their skills as PRP. The Outcome Measures in Rheumatology (OMERACT) group, which is focused on the development and validation of rheumatologic outcome measures, has been a leader in integrating patients in research. The OMERACT glossary³ and guiding principles⁴ highlight the evolution of patients into PRP since 2002. Rheumatology health research as a whole has benefited, for example, by the PRP contribution to recognition of fatigue as an important outcome measure in rheumatology. Per the OMERACT Website: “...patient input along with clinical trialist insight, epidemiologist assessment, and industry perspective, has led OMERACT to

be a unique decision-making group in developing outcome measures for all types of clinical trials and observational research.”⁵

At OMERACT 2012, where 3 patients with psoriatic arthritis (PsA) participated, it was highlighted that patients with PsA had no significant involvement in the development of the composite measures for assessment of PsA being proposed by the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA). GRAPPA subsequently incorporated patients into its research agenda, and 8 patients, all with PsA, came to its 2013 annual meeting (see Table 1 for a summary of the patients’ experiences).

Prior to the meeting’s start, GRAPPA members Philip Helliwell and Philip Mease provided the patient group with the history behind their presence at the meeting and helped orient them to the meeting content. Dr. Helliwell outlined patient involvement in research, delineating the differences between patient representatives, who negotiate on behalf of patients within the system, versus PRP, who contribute to research agendas. He indicated that at the government level in the UK, both the public and patients were being involved

Table 1. The patients’ voice. A summary of patients’ experiences at the 2013 GRAPPA annual meeting.

Summary
<p>Sitting in a plenary session of a medical conference for the first time can be insightful to patient attendees (i.e., learning about the issues, available therapies, new drugs being developed); however, for some patient attendees, the material presented can be somewhat beyond their initial comprehension. At GRAPPA, we all came from diverse backgrounds and with varying levels of knowledge of medical terminology. Consequently, patients only minimally participated in the general discussion after presentations. However, at the very least, our visible, physical presence in the audience served to remind researchers that they should consider what questions they need to ask us.</p> <p>Patients became more satisfyingly involved in the breakout groups. With smaller numbers, the situation automatically became more personable and interactive, discussion questions more specific and directed. Thankfully, moderators gave explanations as needed; thus, reliance on previously acquired medical knowledge was not so necessary. We felt valued when asked about our perspective. We could appreciate that the team needed to analyze the problem from all angles: not just from a researcher’s point of view, but from ours and society’s as well. If feasible, starting the meeting with a breakout group for patients might help patient participants achieve a level of comfort earlier.</p> <p>Amazingly, research physicians now communicated with us as people, as opposed to recognizing us only as objects of research. We do indeed have a large stake in the quality and direction of the ongoing research and we can fill in knowledge gaps, particularly if we are asked directly.</p> <p>For all of us at GRAPPA 2013, we found attending this conference to be rewarding and worthwhile. Since almost everyone around us was friendly and inclusive, we felt very welcome. Overall, patient attendees were very happy with the group’s initial contributions.</p>

GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis.

in an initiative to improve research agendas and the speed with which findings were incorporated into clinical practice⁶. He delineated the initial small steps required to introduce patient involvement to GRAPPA and facilitate their contributions. Dr. Mease then discussed the concepts behind a module of the meeting that focused on developing simple clinical criteria to help clinicians identify inflammatory arthritis, enthesitis, dactylitis, and spondylitis as distinct from degenerative, traumatic, or mechanical forms of these conditions. Because this module would include a nominal group exercise, the PRP input was important in the breakout and plenary sessions, providing a good example of the critical value of the patient perspective in the proceedings. Both GRAPPA members encouraged the patients to participate and ask questions throughout the conference and thanked them for their willingness to contribute.

Patient Involvement in Outcome Research

Four oral presentations were given during a 1-h plenary session chaired by Niti Goel and Oliver FitzGerald to introduce the concept of patient participation in outcome research. Neil McHugh summarized preliminary work undertaken by the Patient Involvement in Outcome Measures for Psoriatic Arthritis (PIOMPSA) group. He emphasized the need to incorporate patient input into PsA research and further explained recently developed composite outcome measures identified at the OMERACT 2012 meeting. PIOMPSA, first convened by Dr. FitzGerald in August 2012 and including 3 rheumatologists, a nurse researcher, and 3 patients with PsA, was charged with providing a roadmap to address these needs. The main conclusions, based on findings from the ongoing Psoriatic Arthritis Impact of Disease (PsAID) study⁷, were that some of the items identified by patients as being most important in terms of disease effect are not measured directly in the newer composite measures. PIOMPSA members also agreed to undertake a systematic literature review to definitively confirm levels of patient involvement in previous domain identification and outcome measure development. Finally, the group recommended that PsA patient perspectives should be incorporated in the planned PsA workshop at OMERACT 2014.

A further meeting of the PIOMPSA group was convened by Dr. McHugh in February 2013 and attended by 5 rheumatologists and 5 patients. William Tillett presented results of a systematic literature review, which confirmed minimal and no patient input, respectively, into current PsA outcome measures and the original Delphi process for definition of the OMERACT core domains for PsA⁸. A key meeting conclusion was that the OMERACT PsA core set may need revision, with fatigue and dactylitis considered for inclusion. Support existed conceptually for a minimal core set composite index, and possibly an expanded index to encompass broader domains. These would be incorporated

into recently developed instruments such as the Composite Disease Activity Index⁹ and the Arithmetic Mean of the Disability Function¹⁰.

Maarten de Wit, one of the patient participants, presented the results of a responsive evaluation of 10 years of patient participation in OMERACT. Since 2002, through physician participants, OMERACT has invited patient delegates to provide their perspective on the proceedings of the entire conference. Patients subsequently have had a significant influence on the research agenda demonstrated by the case of “fatigue.” Because patients brought this domain to the forefront as an important outcome in rheumatoid arthritis, fatigue assessment has received much attention¹¹. Researchers have explored the effect of fatigue and the language patients use to describe it, and have developed and validated instruments for measuring it in clinical research and practice. Making patient participation an integral part of the OMERACT vision, strategy, and procedures is attributable to the commitment, persistence, and financial support of the OMERACT leadership¹².

The encouragement and guidance of small-group moderators at conferences such as OMERACT and GRAPPA is crucial to ensuring opportunities for patient participants to contribute. The moderator should create a safe environment that enables genuine dialogue between patients and researchers to enhance mutual understanding, and continuous reflection is required by all to guarantee that obstacles are removed and doubts expressed. Some researchers are still skeptical regarding patient participation, arguing the benefits do not outweigh the investment in time, energy, and money. Other researchers sometimes question the added value in the areas of imaging, biomarkers, and health economics. OMERACT has addressed these concerns in guidelines on patient participation⁴.

Jana James gave a personal view of her PsA experience and of her motivation to contribute to research. Since the onset of her symptoms, she recalled the delayed diagnosis, many referrals to different health professionals, and multiple surgeries. Presenting at GRAPPA with a fused wrist, a metal elbow, and screws holding her neck together, she acknowledged that she wanted to do everything possible to prevent anyone else having a similar experience. She expressed interest in evidence-based medicine and her belief that everyone should have access to the best treatment available for their condition. She also opined that everyone should be protected from the “snake oil” salesmen who target vulnerable patients. Ms. James emphasized that knowledge is power: the more people understand about their condition, the better able they are to make informed choices.

She articulated positive experiences about her first PIOMPSA meeting where the patients’ opinions and input were valued as highly as those of the medical professionals. She was relieved when she realized that patients had not been invited only to “tick a box.” Although a skilled profes-

sional in her own field, working full-time as an engineer designing railway signaling systems, she was concerned that the “medical speak” would leave her behind. However, she was surprised by her own level of understanding and felt gratified that when patients sought clarification, they were not made to feel inferior.

As a patient participant, Ms. James wanted to ensure that researchers recognize that some aspects of arthritis that they rank as important may lead to developing treatments that only partially affect the features that arthritis patients consider important. Patients can provide a complementary perspective on all areas of treatment for both psoriasis and PsA.

Finally, Dr. FitzGerald highlighted examples where patient involvement might prevent a potential mismatch between the preferences, expectations, and experiences of patients and of professionals. One study demonstrated that although a good correlation exists for PsA disease activity assessments between patients and physicians, the latter usually evaluate the disease as less active than do patients¹³. This study also showed that patients with PsA attribute 50% of global disease burden to rheumatic symptoms, 25% to skin symptoms, and 25% to additional symptoms such as fatigue¹³. These findings were confirmed by the aforementioned PsAID study⁷. At least 3 of the 4 most important domains (pain, skin problems, fatigue, and work/leisure capacity) are not directly measured in each of the newer composite scores (Figure 1), although pain, skin problems, and fatigue are likely indirectly measured in the Patient Global visual analog scale. The differences in patients’ and physicians’ perspectives emphasize the importance of incorporating PRO in future PsA research.

To achieve this end, an important development in recent years is the involvement of PRP, persons with “a relevant disease who operate as active research team members on an equal basis with professional researchers, adding the benefit of their experiential knowledge to any phase of the project.” The European League Against Rheumatism (EULAR) has published recommendations that provide practical guidance for research partner involvement, capturing the (1) role of PRP, (2) phase of involvement, (3) recommended number, (4) recruitment, (5) selection, (6) support, (7) training, and (8) acknowledgment¹⁴. With these guiding principles in mind, patients’ input was sought at the GRAPPA meeting, especially at the breakout sessions on treatment recommendations and on the definition of musculoskeletal inflammation. Dr. FitzGerald ended by emphasizing that time was needed to get to know each other, develop an appreciation of the value of patient participation, and develop a research agenda to involve patients.

Discussion after the plenary session focused on whether PRP are representative of the general population of patients with PsA and on experiences of patient involvement in community-based participatory research.

Index	Patient VAS Global	Physician VAS Global	Joints	Skin	Enthesitis	Dactylitis	Spine	HRQoL	Function	Pain	CRP
PsAJAI ³¹	X	X	X						X	X	X
DAPSA ³²	X		X							X	X
CPDAI ⁹			X	X	X	X	X	X	X		
PASDAS ¹⁰	X	X	X		X	X		X			X
AMDF ¹⁰	X		X	X				X	X		

Figure 1. Domains captured in the various composite measures of disease activity in psoriatic arthritis (PsA). AMDF: arithmetic mean of desirability functions; CPDAI: Composite Psoriatic Disease Activity Index; CRP: C-reactive protein; DAPSA: Disease Activity in Psoriatic Arthritis; HRQoL: health-related quality of life; PASDAS: Psoriatic Arthritis Disease Activity Score; PsAJAI: Psoriatic Arthritis Joint Activity Index; VAS: visual analog scale.

Systematic Literature Review

During this GRAPPA conference, Dr. Tillett presented the findings of the systematic literature review initially presented at the PIOMPSA meeting in February 2013 that sought to determine the level of patient participation in the development of PsA outcome measures and OMERACT disease domains. Sixty-three articles relating to 26 outcome measures were identified. Only 1 outcome measure, the Psoriatic Arthritis Quality of Life (PsAQoL) questionnaire, described any patient involvement in the development process¹⁵. PsAQoL content was developed from initial qualitative interviews with patients with PsA and revised for clarity using feedback from PRP. Three articles relating to the development of PsA disease domains were identified, 2 of which reported GRAPPA exercises determining the original identification of disease domains, and during which there was no patient involvement^{4,16,17}. The other reflected a final consensus on domains achieved at OMERACT 8 (2006) where 4 patients with PsA participated as full delegates, with 1 presenting a personal story of living with PsA prior to the final voting exercise¹⁸. The review demonstrated that much of the PsA disease domain and outcome measure development was conducted without substantial patient involvement.

Patient Participation in Future PRO Research

In a separate session, several researchers requested particular input on their research from the PRP. Dr. Tillett presented preliminary data from the Long Term Outcomes in Psoriatic Arthritis II (LOPAS II) study, a prospective observational evaluation of work disability (WD) in 400

patients with PsA recruited from 23 hospitals across the UK. There is increasing recognition that WD is an important patient-centered QoL outcome that needs further investigation^{2,19,20}. A review of patients with PsA suggests that levels of WD are high (16–39%) and are associated with a range of clinical and social factors²¹. Interpretation of the existing data is hampered by the small number of reports, heterogeneity of data collected, and posthoc analyses²¹. LOPAS II is investigating the burden, associations, and the effect of treatment on WD. The patient group reviewed the study findings, made suggestions for future research, and agreed to review subsequent research proposals.

Ana-Maria Orbai introduced the Patient-Reported Outcomes Measurement Information System (PROMIS) initiated by the US National Institutes of Health. In a pilot study at the Johns Hopkins Arthritis Center, patients with PsA using a tablet completed 10 PROMIS computer adaptive test instruments in 10 min on average. The instruments assessed physical health (pain, physical function, fatigue, sleep quality), emotional health (depression, anger, anxiety), and social health (participation, satisfaction with roles), domains all identified as important to patients with PsA in a prior study²². Preliminary data suggested that impairments in physical function and levels of pain and fatigue may be significantly higher in patients with PsA than in the general population. A subsequent planned mixed methods study, i.e., qualitative research followed by quantitative data collection, was presented and the PRP agreed to review the initial draft proposal and to continue to contribute to the development of the study after the meeting.

Penélope Palominos highlighted that although 75% of

recent PsA articles in PubMed (2006–2010) reported use of at least 1 PRO²³, little knowledge exists regarding patients' beliefs about PsA and its treatment. In other rheumatic diseases, evidence indicates that patients' beliefs influence their adherence to therapy^{24,25,26}, coping patterns^{27,28}, disease effect²⁹, and side effects from therapy³⁰. A systematic literature review about beliefs and perceptions of patients with PsA and other inflammatory arthropathies is ongoing, and a qualitative study is to be conducted in Brazil and France to gain knowledge on patients' beliefs about PsA. The patient delegates were invited to collaborate in the latter effort by providing their opinions about the project and potential questions for inclusion in the semistructured interviews.

Finally, the patient group members gathered to evaluate their experiences during the conference. They formulated recommendations for GRAPPA to optimize the involvement of patients at future conferences (Table 2).

The official presence of patients for the first time at the GRAPPA Annual Meeting was an important first step in incorporating their voice into GRAPPA's research agenda. Moving forward, PsA PRP will be involved in future research initiatives with GRAPPA such as PIOMPSA, the development and validation of composite measures, the definition of musculoskeletal inflammation, and the development of updated treatment guidelines, as well as the PsA workshop at OMERACT 12 held in May 2014.

Table 2. Recommendations from the GRAPPA 2013 patient participants.

Recommendations
Meeting logistics
Provide premeeting time for patients to orient them to the meeting (potentially by phone)
Provide access to background information before the meeting
Provide reimbursement for accommodation, meals, airfare, and airport transportation
Appoint a patient group supporter from among the researchers
Breakout sessions
Identify sessions where patient input is needed or desired and adjust session layout
Offer patients the opportunity to participate and ask questions
Consider instruction or training for facilitators to ensure patient participation
Provide flipcharts for discussion points
Presenters
Provide handouts or e-mail information to patients in advance, to identify the patient input required at the meeting, and to involve patients in postmeeting activities
Patient research partners
Research partners should be supportive of one another within the patient group
GRAPPA
Consider appointing 1 or 2 patients to the GRAPPA Steering Committee
Consider involving patient participants with psoriasis, suggested by dermatologists

GRAPPA: Annual Meeting of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis.

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