

# Conducting research in psoriatic arthritis: the emerging role of patient research partners

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## Abstract

Since 2003, patients have become increasingly involved in research endeavours related to psoriatic arthritis (PsA), progressing into a patient research partner (PRP) role. This paper reviews the general considerations related to PRP involvement in research endeavours and more specifically, the evolution of PRP contributions related to PsA research. The addition of the perspective from individuals with lived experience of PsA can bring unique insights to the research process, and increase the likelihood that the results of research are meaningful and relevant to PsA patients. There are also potential issues to address when incorporating PRPs, such as the need for additional time and effort to identify, train, and collaborate with PRPs as members of a research team. Overall, while there are challenges to overcome, and the opportunities to include PRPs are sometimes overlooked, efforts to include PRPs in PsA research should offer significant benefits to patients, researchers, and trials.

**Key words:** psoriatic arthritis, clinical trials and methods, patient attitude to health, attitude of health professionals, outcome measures

### Rheumatology key messages

- Patient research partners can enhance research outcomes when involved throughout a psoriatic arthritis research project.
- Challenges remain to ensure patient research partner involvement in psoriatic arthritis research initiatives.
- Inclusion of patient research partners in psoriatic arthritis research has evolved and increased over 15 years.

## Introduction

Historically, involving patients in reporting outcomes that are meaningful to them is a concept that has been present since the 1960s when Donabedian first proposed that patient satisfaction could be utilized to assess the quality of medical care [1]. The 1970s and 1980s saw increasing assessment of outcomes of value to and reported by patients in research [2–5]. Now, beyond measuring patient reported outcomes (PROs), involvement of patients in research initiatives as partners has become de rigeur, with increasing adoption evident in both public and private settings.

Traditionally, research experts designed studies and analysed and reported the data while patients were participants. In today's environment, researchers, government, funding agencies, health agencies, advocacy organizations,

patients, and caregivers are recognizing this paradigm is no longer appropriate. Partnering with patients in research, also known as participatory research, should increase the likelihood that the results of the research are more relevant to patients. It may also improve the conduct and value of the research since patients can provide unique insights based on their individual lived experience with the disease [6]. With government-supported initiatives, e.g. the UK National Institute for Health Research's INVOLVE programme in 1996, the European Commission's Patient Partner Programme in 2008, and the US Patient-Centered Outcomes Research Institute (PCORI) in 2010 [7], patients have been moving beyond being research subjects to contributing to the research agenda.

In rheumatology, OMERACT was arguably the first organization to have patient research partners (PRPs) involved in influencing research outcomes, starting in 2002 with a single patient focus group evolving to full participation in the biennial meeting and working groups [8]. The EULAR presented recommendations for the inclusion of PRPs in research projects in 2010 [9]. In PsA specifically, the Group for the Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) has been fostering collaborations with

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**TABLE 1** Evolution of PRPs in PsA research and education

2003	Individuals with PsA present at the GRAPPA Annual Meeting for the first time
2006	Four individuals with PsA present at OMERACT First PsA Core Domain Set developed without significant patient input endorsed
2012	Two PRPs with PsA invited by GRAPPA to OMERACT
2012	First PIOMPSA meeting PRPs involved in the EULAR recommendations for the pharmacological treatment of PsA
2013	Eight PRPs invited for the first time to the GRAPPA Annual Meeting
2014	PsAID questionnaire published, with PRPs involved throughout its development
2014	Fatigue voted to be added to the PsA Core Domain Set at OMERACT
2015	PRPs involved in development of GRAPPA Treatment Guidelines PRPs involved in the update of the EULAR recommendations for the pharmacological treatment of PsA
2016	Revised PsA Core Domain Set, reflecting physician and PRP input, endorsed at OMERACT A Patient's Guide to Treatments for Psoriatic Arthritis, a guide for patients, written by GRAPPA PRPs
2017	GRAPPA PRPs develop governance document
2018	PRPs involved in the 2018 ACR/NPF Guideline for the Treatment of PsA

GRAPPA: the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; NPF: National Psoriasis Foundation; PIOMPSA: Patient Involvement in Outcome Measures for PsA Special Interest Group; PRP: patient research partner; PsA: psoriatic arthritis; PsAID: PsA Impact of Disease.

individuals with psoriatic disease since 2003 [10] (Table 1). Subsequently, individuals with PsA were present at OMERACT 2006 [11], though not as full-fledged PRPs. At OMERACT 2012, three PRPs with PsA were present for the first time for the GRAPPA-OMERACT workshop [12]. A meeting of the Patient Involvement in Outcome Measures for PsA Special Interest Group (PIOMPSA), a GRAPPA initiative incorporating PRPs, was subsequently held later that year and again in early 2013. Individuals with PsA attended the GRAPPA annual meeting as PRPs for the first time in 2013 [13].

Subsequently, PRPs have been involved in various workstreams across GRAPPA, including the update of the Core Domain and Outcome Sets for PsA [14], development of the 2015 GRAPPA Treatment Recommendations for Psoriatic Arthritis [15], and the efforts of the GRAPPA Collaborative Research Network [16, 17]. Aside from GRAPPA, there has been evidence of the influence of PRPs on recent research in additional public/academic [18–24] and industry endeavours [25, 26] in PsA. However, there are also recent examples where PRPs are still not apparently involved in research relevant to them [27–31], demonstrating that opportunities for increasing the involvement of PRPs still exist in PsA. This article will review the emerging role of PRPs in PsA research.

### Patient research partners

To understand the evolution of PRPs in PsA research, one first has to understand the context regarding the inclusion of PRPs in any research endeavour and the inherent challenges that exist in doing so. Some of the questions that have arisen related to PRP involvement are presented and discussed below.

#### Who can be a PRP? How do we address diversity and representativeness?

Patients inherently can have different roles in research endeavours, e.g. research participant, lay member of an

institutional review board/ethics committee, but not all patients desire the role of being a PRP. One definition of a PRP is a patient who partners with medical researchers to help decide what research is done and how it is done [32]. Another definition indicates that PRPs are 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 [9]. Yet another is PRPs are members of the research team and involved in the planning, conduct and dissemination of the research [33]. Depending on the setting and the requirements of the research project, a PRP could therefore be an individual with the disease, a caregiver, a family member, or organizations representative of the population of interest [9, 32–37], with a caregiver or family member being especially instrumental if the individual with the disease, for example, is a child or incapacitated.

Regardless, a constant theme related to participatory research is that PRPs should have experiential knowledge of the disease and be willing to share their knowledge related to the disease openly [9, 38, 39]. Additional characteristics of PRPs include being able and willing to learn, ask questions and understand the goals of research. These often will entail the ability to understand and converse in English, especially for international projects, as this is the language in which most medical meetings and relevant literature are presented. PRPs should be willing to speak on behalf of all patients and not identify only the issues based on their personal experience with the disease. Confidence, assertiveness, and willingness to collaborate and share information are necessary attributes in order to ensure ideas can be communicated, respectfully challenged, and heard [9, 40].

Beyond these characteristics, the educational background of the PRP needs to be considered [8, 33, 40, 41]. Individuals with a scientific, including a medical, background may have the benefit of being able to cross the divide between lay person and researcher with more

facileness. The research team may appreciate having such people in their group as PRPs, since such PRPs may be able to better highlight the differences between researcher vs patient perceptions and contributions using common scientific terminology. Whereas OMERACT does not prevent such individuals from serving as PRPs [42], scientific PRPs may be barred from some research endeavours where a 'pure' lay person is desired or where the additional knowledge is seen as introducing a potential competing interest or causing bias. The possession of advanced scientific knowledge by a PRP may also create a perceived power imbalance with respect to other PRPs that may be on the research team, in that the non-scientific PRPs may feel less accepted or capable. Alternatively, such scientific PRPs could make the non-PRP researchers feel threatened by possessing both scientific knowledge and personal knowledge related to the disease. Note similar issues could also arise when being a PRP becomes an individual's profession or when the PRP acquires significant medical knowledge and research skills through their long-standing work as a PRP [9, 43]. The most significant concern in all of these settings is the PRP may lose or not have the ability to properly represent the patient perspective. It is incumbent upon all PRPs, regardless of background or tenure as a PRP, to be aware of their own potential for bias and to ensure they represent the patient perspective in their role. To ensure this, PCORI, while not barring PRPs with dual roles (e.g., researcher and PRP), indicates that at least one PRP on a research team should not have any other role [33].

A recent survey conducted in the USA found approximately one-third of patients surveyed overall were interested in participating as PRPs in research endeavours, though there was a low (15.3%) pre-existing awareness of participatory research opportunities and even lower rates of actual participation (2.7%) reported [32]. Respondents of higher socioeconomic status and with more positive attitudes regarding their health and healthcare were more likely to be interested in participatory research. Somewhat surprisingly, as the majority of OMERACT and GRAPPA PRPs are Caucasian [44, 45], non-native individuals and people of colour were more likely to be aware of participatory research [32]. This survey highlights that opportunities exist for increasing the awareness of the PRP role and incorporating PRPs in research, and that individuals that participate as PRPs are unlikely to reflect the entire population with the disease.

Therefore, even if a minimum of two PRPs are part of the research team as recommended by EULAR [9], the research team should not have the expectation that the PRPs represent the entire population with PsA with respect to, for example, gender, age, race, ethnicity, geography/culture, socioeconomic status, health literacy, and availability of a caregiver/support [42, 45, 46]. The role of the PRP on the team is to ensure that a broad patient perspective is incorporated during the research process and to support that issues related to diversity of the patient population to be studied are considered. The entire research team needs to address whether a representative

sample of patients have or have not been engaged in the study itself, and if not, to report the limitations of the study in the publication of results [47].

#### How do we identify and where do we involve PRPs?

Although various research endeavours mention how PRPs may be identified, no articles apparently address best practices for PRP identification [9, 35, 37, 40, 48]. Identifying PRPs may be facilitated by organizations representing individuals with the relevant disease or the researchers themselves. PCORI and EULAR have indicated that PRP identification should be supported by the expected contributions, such that the aims of the research can be fulfilled [9, 33].

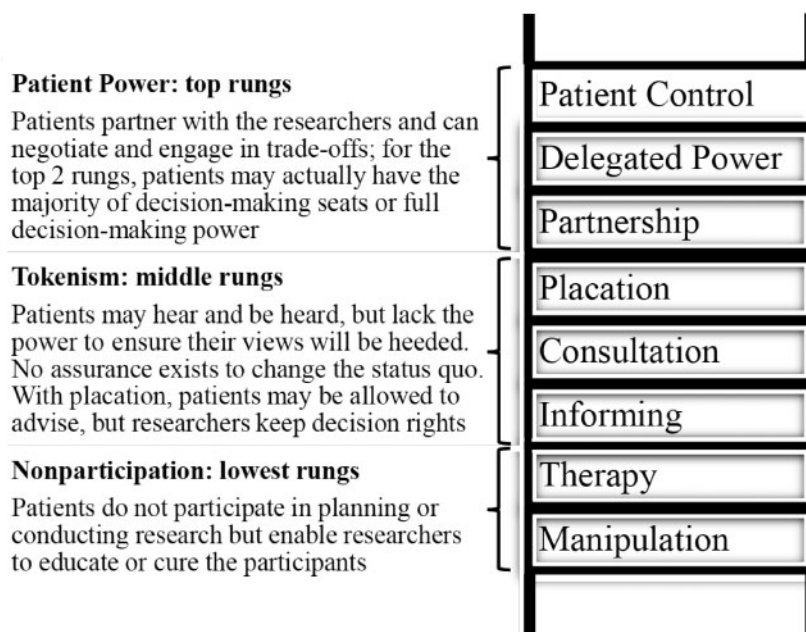
Arnstein's ladder of citizen participation has been utilized to understand different forms and degrees of patient and public involvement (Fig. 1) [49]. Many models adhere to the principles of engagement outlined by Arnstein, using the terms informing and consultation to address aspects of tokenism, and collaboration and user-controlled research to address patient power [35, 37, 40, 50, 51]. Patient and public participation increase in meaningfulness and magnitude as one moves to the top of the ladder. Full partnership or collaboration, though still uncommon, involves shared leadership where the PRPs make decisions with authority that is equal to that of the researchers, sharing responsibility for the planning, conduct, analysis, dissemination, and adoption of research findings [35–37].

With this in mind, numerous groups have addressed how PRPs may be involved throughout the research process [9, 35–37, 52–56]. Ideally, but ultimately dependent on the nature of the research, PRPs should be involved from the outset and throughout the project to have the most influence. This includes the preparatory (agenda setting and funding), execution (study design and recruitment, data collection and analysis), and translational (dissemination, implementation, evaluation) phases of a study [33, 34, 37, 40, 42, 43, 50, 54, 57].

#### What are the benefits and challenges of PRP involvement? How can outcomes related to PRP involvement be measured?

Patient engagement has been shown to empower patients, to increase study enrolment and retention rates, to improve the quality of and to expand the applicability of research, to increase dissemination of information, to educate researchers, and to aid them in obtaining funding, designing protocols, and choosing relevant outcomes [6, 8, 35, 37, 40, 41, 43, 55, 58]. Potential challenges reported include identification of appropriate PRPs; communication, e.g. establishing a common language; patient frustration related to the length of time required for training, transportation or attendance; the potential costs borne by patient participants; and extra time and funding required to complete research [6, 35, 37, 40, 41, 43, 57, 59]. Further concerns exist related to tokenism, i.e. the practice of making only a perfunctory or symbolic effort to include patients as research partners [35, 43, 60] in order to provide apparent legitimacy to, for example, grant applications or publications.

Fig. 1 Ladder of patient participation



Adapted from Arntein's Ladder of Citizen Participation [49], originally published by Taylor and Francis, Ltd. on <https://www.tandfonline.com/toc/rjpa20/current> and redrawn with permission.

While it is acknowledged that an increasing literature base exists related to participatory research and the potential outcomes, overall the information regarding the details of and effectiveness of PRP involvement is incomplete [6, 35, 37, 40, 43, 55, 58]. The results provided to date are often observational and empirical, and do not typically delineate the levels at which PRPs were involved [40, 54, 61]. Standardized reporting of details regarding PRP involvement and resultant outcomes are critical not only to understand the benefits and challenges but to effect best practices [54]. In one qualitative analysis, participants indicated support for assessing the impact of participatory research to improve its methodology, to convince sceptics of its value, to reduce tokenism, and to justify its cost and time; individual feedback to PRPs regarding their input was also seen as valuable to improve their contributions and motivation to remain involved [6]. Multiple frameworks have been or are being developed to detail PRP involvement and the resulting outcomes [34, 40, 42, 54, 56, 62]. Utilizing such frameworks should enhance the consistency and transparency of reporting participatory research and allow for improved synthesis of the evidence regarding the impact of PRP involvement [54].

#### What are the requirements and responsibilities of the researchers and research team?

In order to engage with PRPs optimally, researchers have various responsibilities and requirements as well. Critical to participatory research, regardless of the team

member's role, is to have effective, open and honest communication, listening skills, and a willingness to learn [37, 60]. Further, the institution(s) within which the research is conducted need to support the research endeavours and have policies that allow for PRP engagement [63]. PCORI outlines the principles of reciprocal relationships, co-learning, partnerships, transparency, honesty, and trust as essential to involvement of PRPs by research teams [33]. These echo similar principles outlined by OMERACT and EULAR [9, 42]. Developing rapport between research team members is enabled by mutual transparency, honesty, respect, trust, and effort put forth by the researchers and PRPs to promote equality between them in the face of a relationship traditionally characterized by an imbalance of power [50, 55]. Researchers should see PRPs as equal members of the team, rather than viewing their inclusion as a burden or requirement/obligation [40]. They should understand the roles of the various members of the team, how the roles differ, and the needs and capacities of each member, including accommodations for disability [33, 40]. Goals and expectations should be discussed in the early stages of the project [9, 63–65].

Co-learning occurs when researchers assist PRPs in learning about the research process, but in turn train themselves to better adhere to and have increased awareness of participatory research principles and opportunities [40]. Inherent in co-learning is that time and effort will need to be spent providing education and training of the PRPs

to ensure that understanding and productive dialogue are possible [9, 40]. Partnership reflects that PRP time and contributions are valued, and fair financial compensation is provided [33]. OMERACT and EULAR detail that the contribution of PRPs should be appropriately acknowledged by the research team, including co-authorship and/or co-chairing and co-presentation [9, 42].

Involving PRPs is an ongoing process, with evidence supporting that while challenges exist to incorporating PRPs within research endeavours, the benefit of making the research more relevant to individuals with PsA may improve overall outcomes.

## The evolution of PRPs in PsA research

The earliest apparent involvement of a patient in PsA research in a role other than study participant occurred when at least two individuals with PsA present at the GRAPPA Annual Meeting in August 2003 voted on recommended domains for the initial PsA core set along with rheumatologists and dermatologists [10] (personal communication, DD Gladman). Subsequently, four individuals with PsA were present at OMERACT 2006, with one sharing their perspective on the disease [66]. At that meeting, via voting by OMERACT members, which did not yet include PRPs, consensus was reached on the Core Domain Set for PsA trials based primarily on Delphi exercises with rheumatologists but no patients, the results of the 2003 GRAPPA meeting, and data mining from completed randomized controlled trials (RCTs).

Subsequently, patient participation evolved to being two PRPs with PsA who for the first time were invited to be present for the GRAPPA-OMERACT workshop at OMERACT 2012 [12]. At this meeting, one PRP presented her perspective as an individual with PsA. The PRPs voted on the evaluation of composite measures to assess PsA, and a commitment was made by the GRAPPA-OMERACT Working Group to continue to engage PsA PRPs to ensure that their views on disease activity and assessment were included in future work.

Consequently, PIOMPSA meetings were held in August 2012 and in February 2013 with both rheumatologists and PRPs each present in equal numbers at each meeting [13, 61]. As a result of these meetings, it was determined via a literature review that much of the work to date related to the PsA Core Domain Set and outcome assessments in PsA had been performed without substantial incorporation of the patient perspective. Then, eight individuals with PsA attended the GRAPPA Annual Meeting as PRPs for the first time in 2013 [13]. A plenary session chaired by a PRP and researcher was held to introduce the concept of patient participation in outcome research, and two researchers and two PRPs presented. During the meeting, the PRPs were also provided with the opportunity to weigh in on ongoing research projects related to the patient perspective. They also summarized their experience at the meeting in a published report.

Since then, PRPs with PsA have been invited to and present at each annual GRAPPA meeting [16, 17] and each biennial OMERACT meeting [14, 67–69]. Over that

time, PRPs have been meaningfully integrated into the work related to the Core Domain Set and Outcome Set for PsA [16, 68–70]. They have also had the opportunity to contribute to many educational and research activities such as the GRAPPA Treatment Guidelines, including the slide deck and PRP-generated patient guide; the Research Committee, including the Collaborative Research Network and grant review; and the development of their own governance document [15–17, 71]. This latter activity is especially important as it demonstrates the maturation of the PRP group within the GRAPPA organization.

Aside from the development of the GRAPPA Treatment Guidelines, PRPs have also been involved in the development of the EULAR recommendations for the management of PsA with pharmacological therapies published in 2011 and the subsequent update published in 2015 [72, 73]. More recently, individuals with PsA were members of the Expert Panel, Patient Panel, and Voting Panel supporting the development of the 2018 ACR and National Psoriasis Foundation Guideline for the Treatment of PsA [18, 74].

In parallel, individuals with PsA have been involved in the development and assessment of at least three PRO measures related to PsA. Patients were noted to have provided input for the development of the Psoriatic Arthritis Quality of Life (PsAQoL) questionnaire at each stage, but PRPs were not a part of the research team [75]. Almost 10 years later, the PsA Impact of Disease (PsAID) questionnaires and the VITACORA-19 were developed to better assess PsA based on patients' experience of the impact of the disease on their health. The VITACORA-19 utilized patients to generate and select items for the final questionnaire but similar to the PsAQoL, there were no PRPs on the research team [76]. In contrast, throughout the process of the PsAID questionnaires' development, up to 12 PRPs were involved as members of the research team, contributing to domain generation, scoring and item formulation. PRPs have also been involved in the ongoing work to develop a flare instrument [77].

Another initiative of importance is the development of the USA-based ARthritis Partnership with Comparative Effectiveness Researchers (AR-PoWER) Patient-Powered Research Network, also known as ArthritisPower®. ArthritisPower is notable in being the first patient-led, patient-centred research registry for arthritis conditions, including PsA. ArthritisPower is part of PCORnet, the National Patient-Centered Clinical Research Network, a large US network of patient groups, registries, and health systems conducting clinical outcomes research [78].

Industry has also partnered with individuals with PsA in research initiatives, although it is not always well known what the results of such efforts have been or the exact level of patient participation. Eli Lilly has a form soliciting potential members for a PsA Patient Advisory Board to express ideas and 'guide the development of resources for the psoriasis community' [26]. Pfizer has created the Global PsA Narrative Advisory Committee, comprising

people living with PsA as well as rheumatologists, dermatologists and patient organizations from eight countries [25]. One of the results of their efforts, via a global survey of individuals with PsA, was the PsA Narrative US Patient Survey Infographic. Celgene supported the conduct of the Multinational Assessment of Psoriasis and Psoriatic Arthritis Survey, a large population-based survey of psoriasis and/or PsA patients in North America and Europe; the survey was developed with input from patients, advocacy groups and physicians [79].

Despite these efforts, many opportunities for PRP involvement still exist. While some research efforts do involve PRPs [19, 22, 23, 80, 81], many other research efforts evaluating outcomes of importance to patients still do not appear to acknowledge PRP involvement in their publications [27–31]. As an example, one common subject of research is evaluating the discrepancies between the results of the patient and physician global assessments of disease activity in PsA [22, 28–31]. Most studies focused on pain, fatigue, and disability as some of the, if not the primary, contributors to discordance between the physician and patient global assessments. In contrast, the study that included at least one PRP on the research team, via use of the PsAID as an outcome measure, identified fatigue but also decreased coping and social participation as contributing to the discrepancies, and not pain or disability. While each research effort evaluated the discrepancies slightly differently, use of PROs (aside from the assessment of pain and function) and implementation of the patient perspective in research efforts may identify new opportunities for intervention that may improve disease outcomes.

### The illustrative example of fatigue

The addition of fatigue to the Core Domain Set for rheumatoid arthritis was endorsed at OMERACT 2006 [82], influenced by the patient perspective. In contrast, fatigue was not recommended for inclusion in the Core Domain Set for PsA until OMERACT 2014 [67]. The history of the inclusion of fatigue in the Core Domain Set for PsA follows.

At the GRAPPA 2003 Annual Meeting, fatigue was proposed to be added to the research agenda for the PsA Core Domain Set [10]. At OMERACT 2004, while different instruments had been used to assess fatigue in RCTs of PsA, fatigue only had a vote of 48% in favour of inclusion in a Core Domain Set for PsA [83]. Fatigue was maintained on the research agenda. Subsequently, at OMERACT 2006, though the Functional Assessment of Chronic Illness Therapy-Fatigue scale was emerging as a potential instrument to evaluate fatigue in PsA, the best instrument to measure fatigue still needed to be determined. Therefore, fatigue was included in the middle circle of the Core Domain Set, meaning it was recommended to be measured in RCTs but not mandatory [66]. At PIOMPSA in 2013, the PRPs present indicated that fatigue should be considered for inclusion in the Core Domain Set along with other domains [61], highlighting that it had received a vote of 70% at OMERACT 2006.

Subsequently, the PsAID study identified fatigue as the third most important domain related to disease impact from the patient perspective [24]. At OMERACT 2014, fatigue was finally endorsed with a vote of 72% to be included as a core domain in the Core Domain Set. This was reaffirmed via the work performed to revise the Core Domain Set for PsA, in which fatigue was included as a core domain based on the input of both PRPs and physicians [84].

### Conclusion

Overall, incorporation of the patient perspective in PsA research has made significant progress since the initial patients were first present at the GRAPPA 2003 Annual Meeting. Certainly, while the inclusion of fatigue as a core domain in the Core Domain Set may have occurred without PRPs highlighting its importance from the patient perspective, there is no doubt that the insistence of PRPs on its inclusion as well as evidence garnered from patients influenced the outcome. As the evolution of PRPs in PsA research continues, hopefully the opportunities to include PRPs in various research efforts related to PsA will continue to be increasingly realized with improved outcomes for individuals living with PsA.

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