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How to Involve Patients in GRAPPA Research as Partners

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ABSTRACT. Patient research partners (PRPs) have been actively participating in the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) annual meetings, working groups, and research activities since 2013. As they have evolved, the PRPs operate as a cohesive group supported by their GRAPPA-approved handbook and policy documents. The number of involved PRPs has increased, allowing more opportunity for the incorporation of the patient voice and experience in GRAPPA activities. In the GRAPPA proceedings, PRPs regularly report on their involvement in the meetings and research projects. During a 30-minute plenary session at the GRAPPA 2023 annual meeting, attendees were informed about the evolving roles of PRPs in GRAPPA and beyond and were asked to provide feedback on their experience and opinions regarding PRP involvement in psoriatic disease research. Here we report the key messages of the session, including polling results, examples of PRP involvement, and ongoing challenges.

Key Indexing Terms: GRAPPA, patient participation, patient research partner, psoriasis, psoriatic arthritis

Introduction

To celebrate 10 years of patient research partner (PRP) involvement, the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) 2023 annual meeting in Dublin, Ireland, included a dedicated session on PRPs in psoriatic disease (PsD) research. There are many ways patients can be involved in research, including as representatives, consultants, partners, or leaders, each with increasing influence on decision making in the research process.[1] GRAPPA PRPs are persons with PsD who collaborate with a research team to share knowledge from their lived experience with their illness and to speak on behalf of other people with PsD. They contribute the patient perspective throughout the research process, from preconception and study design to study conduct, analysis, and dissemination.[2]

Since 2013, GRAPPA has increasingly involved PRPs in its research activities. The purpose of this article is to report on the PRP presentation during the annual meeting, which reflected on the current level of engagement of PRPs within the GRAPPA community. We also provide examples of PRP involvement in GRAPPA and consider ongoing challenges.

PRP session with polling questions

At the session start, the current PRP Network members were introduced to facilitate GRAPPA delegate interaction with the PRPs attending the meeting. We then polled GRAPPA delegates on 4 questions related to their experience involving PRPs in their work. Answers were electronically collected using an application downloaded by the attendees to their own electronic devices, with assistance from the technical team. The questions and answers are reported in Table 1. The number of respondents due to difficulties in downloading the required application for voting was relatively low.

The results of the polling regarding the involvement of patients as research team members were positive overall. Respondents reported feeling comfortable with the idea of PRP involvement (question 2) and reported few negative experiences working with PRPs (question 3). Nevertheless, the results raised concerns regarding the ongoing low level of experience working with PRPs (question 1). One-third of the respondents reported no experience with PRP involvement (question 3) and had never discussed the value of PRP engagement with other investigators (question 4).

Importance of PRP involvement

After the polling, Dr. Suzanne Grieb (PRP) opened the session and highlighted the growing importance of PRP involvement in research. In the last 2 decades, patients have been playing a much more active role in their care. Patient-centered care and shared decision making are now widely accepted and adopted in most healthcare systems.[3] Patients also have had an important role in advocating for health policy changes and in shaping clinical practice guidelines.[4] Patient involvement in research, however, has not rapidly progressed despite support from government initiatives; for example, in Europe (eg, the UK National Institute for Health Research's INVOLVE program) and the US (eg, Patient-Centered Outcomes Research Institute).[5-7] There have been increasing calls by numerous funding agencies for more

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Table 1. Results of 4 polling questions.

	Question	Response	No. of Responses
1	Do you work with patients as partners in your research studies? (n = 6)	Not at all	0
		Only once	0
		In some studies	5
		In all my studies	1
2	How comfortable are you with including patients as partners in your research studies? (n = 14)	Very comfortable	6
		Somewhat comfortable	8
		Somewhat uncomfortable	0
		Very uncomfortable	0
3	Have you personally ever had a negative experience working with patients as partners in a research study? (n = 22)	Never	10
		Only once	1
		A few times	3
		Often	0
		No previous experience with patients as partners	8
4	What have you heard from GRAPPA members or other researchers about the value of patients in a research team? (n = 27)	Mostly positive comments	17
		No added value	0
		Mostly negative comments	1
		I have not heard anybody talk about it previously	9

involvement of patients in the research process. PRP involvement in research increases the relevance of research, alignment with patient priorities, and focus on patient-centered care.[8,9]

Benefits of PRP involvement

There are numerous benefits to involving patients in the research process, but these benefits are partially dependent on how that involvement occurs (eg, to what extent patients are involved in influencing the research along the way).[10] PRP involvement can assist in obtaining funding for research, since this involvement prioritizes patient perspectives and adds credibility to the need for the research to take place. PRPs can assess the proposed research question and methods.[11] PRPs can also help improve study recruitment and retention and increase the likelihood that the research will truly impact patients.[12] Dissemination of research results to end-users, including patients, the broader community, and policymakers, may become more effective due to improvements in understandable reporting guided by PRPs.[13]

History of PRP involvement in GRAPPA

Dr. Maarten de Wit (PRP) presented the 10-year history of sustained PRP involvement in GRAPPA (Table 2). This involvement started in 2012 during a preliminary meeting of a GRAPPA special interest group for Patient Involvement in Outcome Measures for Psoriatic Arthritis (PIOMPSA).[14] Since 2013, PRPs have participated in each GRAPPA annual meeting. The roles of GRAPPA PRPs have expanded and have been more formalized over the past decade[15] to include membership on GRAPPA committees; review of GRAPPA publications, pilot grants, and annual meeting abstracts; attendance at every 5-year strategic retreat; presentations at the annual meeting and educational events; and contributions to the GRAPPA treatment recommendations, among other roles.[16]

Examples of PRP involvement

Subsequently, Dr. de Wit presented 2 examples of successful PRP involvement. The first example highlighted that Jeffrey Chau was the first PRP invited to speak at the GRAPPA symposium during the Asia Pacific League of Associations for Rheumatology (APLAR) congress in 2022. He presented a psoriatic arthritis (PsA) case study demonstrating not only the contributions but also the challenges of engaging PRPs in research studies, both for researchers and PRPs.[17] After the APLAR presentation, Chau joined the working group responsible for developing the APLAR guidelines for the treatment of PsA.

Another example is the involvement of PRPs in the Health Initiatives in Psoriasis and Psoriatic Arthritis Consortium European States (HIPPOCRATES).[18] Four PRPs (2 from GRAPPA, 2 from the European Alliance of Associations for Rheumatology [EULAR]) participated in the first in-person consortium meeting, during which the research proposal was developed. Involving PRPs as early as possible in writing the Innovative Medicines Initiative grant application, including the outline of a patient and public involvement strategy, was instrumental in the grant's subsequent funding. The engagement with PRPs was highly praised in the grant reviewers' summary statement: "A strength of this proposal is that patient representative organizations seem highly integrated in the proposal and will be important avenues for dissemination." After the grant had been awarded, a total of 12 PRPs were divided over all work streams, the management team, and the external advisory board.

Discussion

GRAPPA has shown that PRPs can be involved in PsD research in a variety of ways. The organization and its members should be proud to have implemented a successful and long-term partnership with PRPs that provides valuable input to many GRAPPA

Table 2. Milestones of patient involvement in GRAPPA research.

Year	Milestone
2012	• PIOMPSA special interest group as part of a GRAPPA initiative to address the historic lack of patient involvement in the development of PsA outcome measures[14]
2013	• Eight PRPs attend the annual GRAPPA meeting for the first time[22] • A 1-hour plenary session on PRP involvement in research[14]
2014	• PRP network is formalized and chooses chair and future chair[23]
2016	• Three PRPs write "A Patient's Guide to Treatments for Psoriatic Arthritis"[15] • Pivotal role of PRPs in updating the GRAPPA-OMERACT Core Outcome Set[24]
2017	• The GRAPPA PRP Network Member Handbook is developed, including governance document[25]
2019	• GRAPPA PRPs enter the HIPPOCRATES consortium at the grant writing stage[18]
2020	• Foundational manuscript on PRP involvement in PsA research by Niti Goel is published[15]
2021	• PRPs become coauthors of the GRAPPA treatment recommendations[3]
2022	• PRP invited as speaker at the APLAR congress GRAPPA symposium[17]

APLAR: Asia Pacific League of Associations for Rheumatology; GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; HIPPOCRATES: Health Initiatives in Psoriasis and Psoriatic Arthritis Consortium European States; OMERACT: Outcome Measures in Rheumatology; PIOMPSA: Patient Involvement in Outcome Measures for Psoriatic Arthritis; PRP: patient research partner; PsA: psoriatic arthritis.

projects and activities. This partnership is documented through numerous publications coauthored (sometimes as the lead author) by PRPs (examples in Table 2).

Despite a number of projects with successful PRP involvement, there are still challenges with full inclusion of PRPs on research teams. Many of these challenges have been highlighted previously.[15] Some researchers might have difficulties giving up control. PRPs may experience difficulties communicating with the researchers, as medical and research language is not easy to understand and PRPs require lay summaries and dedicated time for training as well as needing peer support. Achieving diversity and broad representation remains problematic,[19] as improving these requires time, energy, and funding resources. Addressing these challenges is a continued priority of the GRAPPA PRP Network leadership.[16] Finally, as evidenced by the polling results, a general lack of knowledge on building effective partnerships continues to exist for many researchers and PRPs. Recommendations from other research groups, such as EULAR and Outcome Measures in Rheumatology (OMERACT), emphasize the need for training and support as well as a designated PRP coordinator.[20,21]

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