

Let's Talk about Inclusion: A Report on Patient Research Partner Involvement in the GRAPPA 2015 Annual Meeting

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ABSTRACT. Members of the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) have worked since 2012 to include the patient perspective in their psoriatic arthritis (PsA) research as well as in their annual meetings. Herein, patient research partners (PRP) report the progress made in their experience at these GRAPPA meetings and discuss their perception of the challenges that remain in ensuring that patients have a voice in PsA outcome research. (J Rheumatol 2016;43:970–3: doi:10.3899/jrheum.160117)

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PSORIATIC ARTHRITIS

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After the 2012 meeting of the Outcome Measures in Rheumatology (OMERACT) group, patients became actively involved in the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) scientific meetings and research projects. Patient participation has resulted in a series of publications that report the steady progress made in bringing the patients' voices into psoriasis and psoriatic arthritis (PsA) outcome research^{1,2,3,4}. GRAPPA members believe that patient participation is

necessary when, for example, developing therapeutic guidelines. Therefore, designated members have actively assisted patients to qualify as PRP and continue to work toward improved communications between patients and physicians in the GRAPPA organization. In this article, our objectives are (1) to report the patient experience at the 2015 GRAPPA meeting; (2) to elaborate on the process of ensuring continued involvement of patient research partners (PRP) in PsA outcome research; and (3) to reflect on the barriers and challenges that still exist.

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PRP Involvement in GRAPPA Activities

After GRAPPA's 2014 annual meeting in New York, one challenge was to include the patient perspective in ongoing research activities between annual meetings⁵. Some, but not all, of the "treatment recommendations" work streams made serious efforts to include PRP in their research endeavors, e.g., teleconferences to discuss overarching principles. All PRP, with various degrees of understanding of the treatment recommendations, were invited to participate in voting to approve the guidelines. One PRP was recused because of a conflict of interest. The PsA flare working group had a special PRP teleconference before the 2015 GRAPPA meeting to present research findings and to discuss the program and patient input for the flare module. Finally, several PRP contributed on different levels to the research activities of the GRAPPA-OMERACT working group.

PRP Involvement at the 2015 GRAPPA Annual Meeting

Twelve PRP were invited to attend the 2015 GRAPPA meeting in Stockholm. Nine participated: 4 men and 5 women, from 5 different countries and 2 continents, and each with their own unique patient experience and way of thinking

with regard to research challenges. All PRP had attended at least 1 previous GRAPPA meeting, which was a great advantage because all PRP started with a general level of knowledge about the disease states as well as expectations regarding meeting conduct.

Although the 2015 scientific meeting program was less patient-driven compared to the previous years, it included more designated patient-only sessions. The patient group had 2 new initiatives this year: a summaries booklet for non-physicians about ongoing GRAPPA research projects, and biographies of PRP. The summaries were written by 9 working group leaders who were making presentations during the meeting. These booklets helped the PRP understand and prepare for the program sessions. Finally, 2 physicians (William Tillett, Ana-Maria Orbai) were appointed to act as PRP supporters before and during the meeting, and 2 physicians (Dafna D. Gladman, Laura C. Coates) volunteered their time for further explanations prior to the start of the annual meeting.

On the first day of the meeting, PRP gathered in a pre-conference session to meet each other and to evaluate 2 years of PRP involvement in GRAPPA. Two physicians introduced the research around this year's main theme of "flares" and discussed with the group opportunities to contribute to the breakout sessions. The PRP also received an overview of the diversity of GRAPPA research activities and explored their interest to participate in working groups that would benefit from their involvement.

Plenary reporting sessions during the first day did not provide opportunities for significant PRP input, for instance in breakout groups. The second day, however, offered opportunities for PRP to provide their perspective during discussions at the plenary sessions as well as during 2 rounds of breakout sessions. Presentations by OMERACT-GRAPPA PsA working group members highlighted PRP contributions to the update of the OMERACT PsA core set⁶. An important moment occurred during the plenary flare session when one of the PRP objected to the suggestion that PsA fatigue is associated with fibromyalgia. The PRP stated firmly that fatigue was part of this illness and that it should not be "blown off" as another disease⁷. In the afternoon, the PRP participated actively in 2 breakout sessions, one dealing with the measurement of flares and another discussing the future of GRAPPA.

Let's Talk about Inclusion

A 45-min plenary session, "Let's Talk about Inclusion," focused on the PRP role in GRAPPA research activities. Tillett began by providing a brief history of patient participation in GRAPPA. Next, Willemina Campbell, a PRP from Canada, co-chair of the PRP panel, and member of the GRAPPA Steering Committee, presented a personal perspective on her 3 years of involvement in outcomes research. Campbell mentioned her rather confusing experi-

ence as a PsA representative for GRAPPA at the 2012 OMERACT conference. Since then her participation as a PRP has progressively evolved to become much more diverse and more satisfying. Yet she still faces some challenges as a PRP (Table 1), some of which are also reported by physician members. As a member of the working group for updating the OMERACT-GRAPPA PsA core set, she has participated in international teleconferences for planning as well as whole-day, face-to-face educational meetings to examine the existing domains and corresponding instruments. She took part in another OMERACT conference for clarification of plans for the PRP group's participation and since then has worked on the proposal for the PsA workshop at OMERACT 2016 and suggested questions to be asked in patient focus groups about the effect of PsA on daily life. The goal of the project is to achieve a greater understanding of what patients themselves consider important domains. Campbell has also helped to update the systematic literature review of domains and expects to help with the selection and formulation of Delphi survey questions. In 2016 she will participate in a consensus meeting with other GRAPPA PRP and physicians to agree on the draft updated core domain set and measurement instruments for PsA. In addition to other PRP work for a number of local research studies at Toronto Western Hospital, and her GRAPPA Flare study work, 2 other Global Health-OMERACT special interest groups keep Campbell interested and involved. The interactive approach of the Equity group and the Shared Decision-Making group, and their prompt and organized dissemination of reading materials, minutes, action items, and meeting announcements, helped her to manage expectations regarding her participation.

The session ended with 3 voting questions for the GRAPPA attendees. Results showed that half of the participants (51%, n = 40) engage PRP in their research activities and 29% (n = 23) do not but are considering doing so. Almost

Table 1. Challenges reported by one of the GRAPPA PRP.

- Lack of stability and consistency in working group membership: Am I or am I not a member? Have the groups now changed? Just where do I belong?
- Lack of ongoing involvement: Long periods of radio silence or blackout periods; not knowing the intentions, the whole process or when something would occur; resulting in lack of appeal or any commitment to the group.
- Not seeing any results or knowing what happened. "Hello. I am still waiting..."
- Indirect exclusion: Not having adequate information ahead of time so I can contribute wisely.
- Dropped off e-mail chains: Disappearing off working group membership entirely or just missing necessary information or telephone call notifications. I strongly recommended that leaders establish "group e-mail addresses" right at the start to avoid this inadvertent error.

GRAPPA: Group for Research and Assessment of Psoriasis and Psoriatic Arthritis; PRP: patient research partners.

70% (n = 51) indicated they experienced benefits or believe there would be benefits from the involvement of PRP in their research while 14% (n = 10) did not.

Summary of PRP Experiences

Overall, and more so than at previous meetings, most PRP expressed more confidence in contributing comments in a room full of physicians during plenary sessions. One PRP reported: “We really made progress this year: there is value in our participation.” Another PRP confirmed “Everything I have said is taken seriously.” Only a few PRP expressed more ambivalent feelings: “Are we just an ‘on-demand sporadic workforce’ or are we truly ‘equal partners?’” More quotes of PRP are presented in Table 2.

The group concluded that several of the challenges identified in 2014 still exist⁸. In many cases PRP are still not equal partners, equal meaning continuously involved, not only at the annual meeting, but also in ongoing working groups. Some members did not feel sufficiently prepared and thus did not understand some of the items being discussed at the meeting. The group believed some physician-researchers were reluctant to engage patients in their research activities or to listen to patients; it appeared difficult for them to change their mindset regarding patients as partners⁸.

PRP group members hope researchers will realize that as PRP learn the processes in an ongoing way, they become motivated to invest more time and effort in developing their understanding and contributions. PRP involvement will also enhance the feeling of “we” instead of “us versus them.” To achieve this, GRAPPA should continue to endorse and possibly develop incentives for researchers to liaise with PRP,

Table 2. Overview of quotes from 9 PRP before, during, and after the GRAPPA 2015 annual meeting.

Before:

- “It is important to show that we have a perspective to share, that we’re not just grease for their research grant.”
- “Do we know what the physicians want from us? Why they brought us in as a group?”

During:

- “Moderators in the breakout sessions were great. They really created opportunities for patients to speak up.”
- “The attitude of the researchers was so much different compared to two years ago.”
- “I was surprised that some of the researchers still remembered me from last year.”

After:

- “I was able to meet many more individuals in the various fields that do have something to say and are trying to ascertain the cures of illness people face in their everyday life.”
- “There was an increase in patient interaction by the doctors and researchers with a view to better understand what patients say and why.”

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perhaps by designating a physician in each working group as a contact person who could answer questions when PRP are preparing for meetings or asking about a project.

The group also noted an inadequate PRP representation at meetings that occur adjacent to congresses such as that of the American College of Rheumatology and the European League Against Rheumatism. To ensure that the patient voice is represented in ongoing GRAPPA activities, researchers should be encouraged to facilitate PRP representation at these meetings.

PRP reported great variability in the level and frequency of involvement among individuals. They wondered why some PRP were not involved in any working group while others seem to be involved in many. PRP also discussed considerations for enlarging the group to attract new patients with more diverse symptoms and perspectives and to provide appropriate education and support to newcomers. When recruiting new PRP, special attention should be given to racial, cultural, and geographical diversity.

GRAPPA needs ongoing support to achieve PRP goals. This may be possible with continued integration of PRP into GRAPPA working groups as fully participating members in all activities instead of being limited to the annual meeting. Ultimately, as a challenge identified in years past, patient participation requires a budget. PRP continued to report that meeting attendance is costly both in terms of potential income lost as well as the actual travel, and that they can incur substantial expenses that are not reimbursed (i.e., travel to and from airports, luggage fees, food expenses). GRAPPA is invested in providing support for PRP who cannot afford the expenses of attending the meetings.

Having 2 PRP as members of the Steering Committee shows GRAPPA’s commitment to encouraging PRP representation in working groups. However, the PRP group wondered whether a network liaison person would be of benefit, to enhance the inclusion of PRP in working groups that meet the expectations of GRAPPA members. Recruitment, education, and continuous support of patients are time-consuming but mandatory to ensure PRP feel confident to contribute and working group leaders feel facilitated to engage PRP in their projects. In particular, further education is desirable to make sure PRP understand the subjects under discussion, including the perspective of physicians.

GRAPPA has made progress since PRP participated in the 2013 annual meeting. PRP attendance has since become an accepted feature at the annual meeting and PRP feel more engaged. The improved comfort of PRP to participate in ongoing discussions reflects the time needed for physicians, researchers, and PRP to get acquainted with the partnership. Challenges have been identified that still need attention.

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