Tackling Patient Centricity: A Report from the GRAPPA 2016 Annual Meeting

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ABSTRACT. In line with the global trend to have disease-related organizations be more patient-centric in their approach, the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) has made substantial progress incorporating patient research partners (PRP) into psoriatic arthritis and psoriasis research. Herein we summarize the involvement of PRP at the GRAPPA 2016 annual meeting. Plans for future PRP engagement were also discussed. (J Rheumatol 2017;44:703–5; doi:10.3899/jrheum.170152)

Key Indexing Terms:
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Over the last few years, the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) has made substantial progress to engage patients and incorporate their input into the group's work and to increase the group's patient centricity. Patient centricity is a broad term. Because patients are the source and would-be beneficiaries of research and healthcare delivery related to any disease state, their specific needs are important to consider. Three pillars of patient centricity have been proposed: (1) input and understanding: engaging patients in a meaningful way so that patients can inform the work being performed within an organization; (2) outcomes and solutions: taking the insights gained and using them to shape results to ensure they meet patients' needs; and (3) culture and community: consideration of the organization's approach and willingness to address patient needs[1].

At the GRAPPA 2016 annual meeting, the strides made in becoming a more patient-centric organization and general next steps for patient involvement were reviewed. These will be the focus of our paper.

Before the meeting, 2 patient research partners (PRP) participated in and provided input to the annual GRAPPA leadership retreat, which led to the creation of a 5-year strategic plan for the organization. This was followed by an inclusive PRP meeting to review ongoing projects and planned participation during the 2-day annual event. The review of ongoing projects included a detailed discussion related to Dr. Laura Coates's planned study to further build upon data from the tight control of inflammation in early psoriatic arthritis (PsA; TICOPA) study[2]. Also discussed was the completed work for the Outcome Measures in Rheumatology (OMERACT) core domain set and ongoing work to define the OMERACT core outcome measurement set[3]. Last, distribution and use of the PRP-produced *A Patient's Guide to Treatments for Psoriatic Arthritis* booklet and the pending PRP addendum to the Benchmarking Care in Psoriasis and Psoriatic Arthritis report were considered.

Eleven PRP with PsA, representing 4 continents and 6 countries, participated in the annual meeting. Six of the group were women. Four were first-time attendees. Since the original meeting to which a patient was invited (in 2010) and the subsequent involvement of 8 PRP formally at the 2013 GRAPPA annual meeting for the first time, 18 PRP overall have been involved with GRAPPA. Including attendance at

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the 2016 meeting, 14 PRP have attended 2 or more GRAPPA-related events, and 6 have been to 5 or more events.

GRAPPA activities in which PRP have been and are currently involved were highlighted during the meeting. This included the update of the OMERACT PsA core domain set in which PRP were included in all phases of the process. Endorsement of the updated set was obtained with a 90% vote at the OMERACT 2016 meeting. One important feature of the updated core domain set was the movement or inclusion of items to the inner and middle circles (fatigue, participation, emotional well-being) that were of particular importance to patients[3,4]. Additional items important to patients were also added to the research agenda (independence, sleep, treatment burden). PRP are involved in the planned update to the core outcome measurement set scheduled to be presented at OMERACT 2018.

Other activities in which PRP have been involved include the production of *A Patient's Guide to Treatments for Psoriatic Arthritis*, a lay interpretation of the GRAPPA treatment recommendations published earlier this year[5], the definition of musculoskeletal inflammation, the definition of flare[6], and the Benchmarking Care in Psoriasis and Psoriatic Arthritis report during the review phase. Activities in which PRP had not been involved at the outset but would be in the future include those related to treat-to-target and composite outcome measures, with a consensus meeting planned to incorporate both PRP and physician viewpoints, as well as research.

Challenges related to PRP engagement that have been highlighted previously[7] were reviewed, including those related to representativeness and the timing to implement PRP participation. Although it was noted that great strides have been made in PRP representativeness related to geographic location, it was acknowledged that none of the PRP had psoriasis only, and whereas 2 Asians and 1 Latino were now a part of the PRP group, the remaining members were all white[8].

The successful update of the PsA core domain set has emphasized the benefits of PRP engagement in all stages of a project, from beginning to end. This experience suggests that other projects could similarly benefit from comprehensive PRP involvement throughout.

These issues were further analyzed in a PRP breakout session, which was led by a PRP and attended by 1 rheumatologist/researcher, 1 medical student, and 1 industry member. The discussion focused on evaluating the current status of PRP membership in GRAPPA, and identifying opportunities for optimization. The outcomes of the discussions are reported below. Because of the limited number of attendees at the breakout session, especially other PRP, the ideas presented serve as a starting point and undoubtedly will need further exploration and development.

While it was agreed that the currently identified PRP served as a good-sized core group, additional PRP should be engaged periodically to allow for a continuous refreshing of perspectives. To facilitate education and participation of PRP, current means of communications by e-mail, teleconferences, and Skype would continue to be used. The frequency of these interactions could be expanded as needed to involve PRP identified at a regional or local level to facilitate researcher access for their initiatives.

Currently, some countries and regions are increasing incorporation of the patient voice into their processes guiding the conduct of research or the provision of healthcare; the United Kingdom is 1 such example with the National Health Service, the National Institute for Health and Care Excellence, and the James Lind Alliance[9,10], all exemplifying opportunities for patient involvement. The United States is another example, where the US Food and Drug Administration has developed multiple routes for patient engagement in the regulatory process to approve new therapeutics and devices, e.g., through the Patient Engagement Advisory Committee, the Patient-Focused Drug Development Program, the Patient Representative Program, and the Drug Development Patient Consultant Program[11,12]. These efforts provide guidance regarding the incorporation of patients to ensure the relevance to patients of the organization's work.

A concern was raised as to whether PRP should be involved in all activities related to GRAPPA. The researcher mentioned a continuing medical education program at which patients presented their experience in a combined clinic for PsA; overall, the feedback from attendees of the program had been positive regarding this educational approach. In another example, it was mentioned that some could consider it sufficient to conduct a patient survey through a patient community to obtain the information required to inform one's research. A counterargument to this approach would be that a PRP could help with the design and wording of the questionnaire to potentially improve the quality and usefulness of the information obtained.

One attendee relayed the experience of a patient representative being excluded from the safety committee of a local hospital board to avoid the perceived constraints imposed on other members by the patient's presence. The potential value of including a patient on the board may have been for other board members to learn what aspects of hospital safety are most important to better address patient needs. In turn, this could improve patient satisfaction with the delivery of care. While it was agreed that engaging patients poses a learning curve for many organizations, no clear scenario was presented in which patient involvement in the process would not positively augment the result.

The industry member indicated that his/her company, like others, is increasingly involving patients in every step of the drug development processes[13]. In doing so, the company carefully defines its interactions with patients to maintain professional boundaries, with research as the main focus.

Regarding potentially involving the PRP at GRAPPA, the industry member reported that he/she would appreciate it if defined variables could be arranged to have PRP, with their agreement, help with the review of informed consent and patient materials, as well as evaluating study designs regarding procedures and time commitments.

Last, it was discussed that as the PRP group within GRAPPA gains experience, they themselves may start to pose and lead the investigation of their own questions related to the disease process. The research agenda items, e.g., independence, from the update of the PsA core domain set would fall into this category. It was suggested that exploration of funding through the Patient-Centered Outcomes Research Institute might be of interest.

PRP have become a part of the fabric of the GRAPPA community. As their role matures within the organization, their voices will be increasingly incorporated into GRAPPA initiatives. Further, with appropriate support, we envision a time when PRP will identify and lead their own projects, thus adding to the growing movement of patient-centric research.

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