Building Bridges between Researchers and Patient Research Partners: A Report from the GRAPPA 2014 Annual Meeting

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ABSTRACT. Concurring with a worldwide trend to include the patient perspective in outcomes research, the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) recently engaged patients as collaborative partners in psoriatic arthritis (PsA) research. We summarize Building Bridges, a session held at the GRAPPA 2014 annual meeting, where interactive dialogue was encouraged between all participants regarding GRAPPA's vision for patient research partner (PRP) involvement, including the mutual understanding of the roles and responsibilities of PRP and researchers in GRAPPA's working groups, meetings, and governance arrangements. We conclude that involving PRP in GRAPPA projects is pivotal to optimizing incorporation of the patient perspective in psoriasis and PsA research. (J Rheumatol 2015;42:1021–6; doi:10.3899/jrheum.150123)

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There is a trend worldwide to include the patient perspective in outcomes research[1,2,3]. The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) has made substantial progress since engaging patients as collaborative partners in psoriasis (PsO) and psoriatic arthritis (PsA) research in 2012. As a result the Patient Involvement in Outcome Measures for Psoriatic Arthritis (PIOMPSA) initiative was started to enhance the dialogue between patients and researchers. Ongoing research has been presented, including findings of a systematic literature review determining the level of patient involvement in development of existing PsA measures[4], which was reported at the GRAPPA 2013 annual meeting[5]. Subsequently, the PIOMPSA group met in Leeds, UK, to further the review of ongoing research projects and to prepare for the PsA workshop at the 2014 OMERACT (Outcome Measures in Rheumatology) meeting. This workshop presented "work completed over the last 2 years to incorporate the patient perspective in PsA outcomes research, review the OMERACT PsA core set on the basis of the patient perspective as well as new research findings, and to further develop PsA responder indices."[6]

Patients participated actively in the GRAPPA annual meetings in 2013 (Toronto) and 2014 (New York), and their representation has been formalized within the GRAPPA governance. One patient research partner (PRP) participated in deliberations of the Executive Committee, the deci-

sion-making body of GRAPPA, and 2 PRP joined the Steering Committee, its advisory board.

Eight PRP with PsA, representing 2 continents and 4 countries, participated at the GRAPPA 2014 annual meeting. Five were female and 3 were new participants. Speakers at different plenary sessions elaborated on the roles of patients in outcome measurement. The International Dermatology Outcomes Measures (IDEOM) group reported on the initiative to seek input from patients with PsO in the development of a core set for PsO[7]. The GRAPPA working group for OMERACT discussed updating the PsA core set and increased involvement of PRP in PsA outcomes research[8]. In 2 other GRAPPA sessions to define musculoskeletal inflammation in PsO and to discuss PsA treatment recommendations, the input of PRP was solicited in breakout sessions[9,10]. Finally, for the first time, a PRP-led session entitled Building Bridges explored the benefits and challenges of furthering relationships between PRP and researchers in GRAPPA's working groups, annual meetings, and governance arrangements. The preparations for this session began in March 2014, were finalized at a preconference meeting with the 8 PRP and a few physicians, and are reported here.

Building Bridges

Before the annual meeting, the patient group gathered for 1 day to finalize a 135-min session aimed at stimulating direct dialogue between all participants regarding GRAPPA's vision and objectives for patient involvement and to advance mutual understanding of the role, interests, and responsibilities of PRP and researchers. During the plenary introduction of Building Bridges, the recommendations of the European League Against Rheumatism (EULAR) for the inclusion of patient representatives in scientific research[11] were presented, as well as the recommendations of OMERACT for involvement of PRP in working groups[12]. The importance of clearly distinguishing the different roles of patients in the context of scientific research was stressed.

Patient roles are determined by the nature and level of involvement and can take many forms: as study subject, survey respondent, participant in an interview or focus group, advisor, PRP, or member of a steering group or committee. The research contribution is different for each patient role. In Building Bridges we specifically focused on the role of patients as collaborative partners in GRAPPA. We followed the EULAR definition of PRP as "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 a research project."[11] Thus, PRP are full members of the research team: they have equal opportunities to participate in the research process, receive the same information, and have full voting rights.

Of about 180 GRAPPA members who attended the 2014 annual meeting, 85 attended the 6 breakout sessions of Building Bridges, including 9 PRP (including a representative from the US National Psoriasis Foundation), 38 rheumatologists, 17 dermatologists, 17 industry partners, and 4 other professionals. Following nominal group technique, participants were asked to focus on ways to maximize patient involvement in 4 research areas: (1) revision of the core-domain set for PsA (2 groups); (2) development of a core-domain set for PsO (1 group); (3) design and conduct of clinical research (2 groups); (4) development of treatment recommendations (1 group). Most groups were moderated by PRP, assisted by physicians from the PIOMPSA initiative as reporters. The patient group distributed a breakout group guide to all moderators and reporters before the session and structured the discussions around the following key questions:

1. What are the potential benefits of structural patient participation?
2. What are the respective tasks and responsibilities of PRP and researchers?
3. What are the respective competencies required of PRP and researchers to maximize patient involvement?
4. What are the structural barriers for successful patient participation and how can these be overcome?

Because responses to the questions were similar regardless of the breakout session, the key results are summarized on the basis of the questions rather than the breakout session topics.

Potential Benefits of Structural Patient Participation

Several benefits of structural engagement with patients were discussed (Table 1). Participants stated that patient participation may resolve the established disconnect between the patients' and physicians' perspectives and may lead to more clinically relevant research. Characterizing the patient perspective in outcome research by collaborating with patients helps researchers understand the diverse effects of the illness on patients' daily lives and identify their priorities for treatment options and outcomes. Focusing on real-life experiences of patients encourages healthcare services to better serve the patient community, which in turn might drive improved adherence to treatment regimens and ultimately better health outcomes. Participants also expected that patient participation would lead to more efficient use of health services, although it was recognized that more research is required here. In addition, beyond the immediate goal of promoting health research that is more relevant to meeting patients' needs, collaborative research may improve healthcare by building increased trust between the research and patient communities and enhancing communication between patients and health professionals during consultations.

Tasks and Responsibilities of PRP and Researchers

Discussions between participants revealed the need to distinguish the role of PRP from other patient roles such as study subject, survey respondent, and interview or focus group

Table 1. Potential benefits of structural patient involvement, according to breakout group participants.

- More meaningful research and engagement with patients
- More success in recruiting patients
- Development and use of instruments that measure the *real* disease (face validity)
- Improvement of future standards of care and goals of therapy
- More complete understanding of treatment response
- Meeting the requirements and expectations of regulatory agencies, governments, payers, patient service organizations, healthcare providers, and patient families and caregivers
- Enhanced dissemination of research findings
- Enablement of patients to feel useful and contributory
- Increased awareness of the disease and better compliance
- Increased credibility of research among patients and the public
- Increased applications of individualized medicine to select and change therapy

participant. In the course of discussions on PRP tasks and responsibilities, it became clear that PRP could provide the patient perspective for different aspects of a study, e.g., they could advocate for study funding, refine research questions, participate in development of study protocols, review informed consent forms, advise on recruitment methods, contribute to the collection, analysis, and interpretation of data, and support dissemination of research findings.

Further, PRP contributions in team meetings could help physicians understand the effects of the disease on daily life and the respective needs and preferences of patients. With regard to core-set development, PRP could identify relevant domains from a patient perspective and make suggestions regarding development of appropriate measurement instruments to ensure their face validity (truth) and feasibility. In some cases, more experienced PRP could suggest specific instruments to be included in clinical trials or observational studies.

The responsibility of researchers was also discussed. Although PRP need to be involved at an early stage of a project to create a feeling of ownership and equal involvement in the project, participants realized that PRP inclusion is still a process largely dependent on physician initiative.

Physician researchers were also expected to support, facilitate, and motivate PRP, e.g., have an open mind when listening to patient stories, use plain language when explaining difficult terms or concepts, and spend time with the PRP. Physicians should contribute to PRP education by providing information and offering mentorship. In team meetings, they should actively solicit the patient perspective.

Finally, breakout group participants suggested a helpful list of competencies for both researchers and PRP (Table 2). These competencies should not be mandatory because they vary from study to study; however, they help define PRP and physician profiles for specific tasks or projects.

Table 2. Preferred competencies of PRP and researchers when collaborating in scientific research according to breakout group participants.

Preferred Competencies	
Patient Research Partners	Researchers
Have the disease	Have a sincere interest in engaging with PRP and establishing meaningful partnerships
Be knowledgeable about patients' needs and preferences, to represent the peer group	Have good listening and communication skills
Have the ability to learn	Be able to hear the patients' voice and include it in the research process
Be willing to learn the vocabulary	Be able to reflect on patient participation and be explicit about the role of patients in scientific publications
Have leadership skills	Educate PRP and explain the research process in lay language
Have the confidence to feel oneself an equal partner in the research effort	Have flexibility and patience
Have the ability to communicate and withstand intimidation	Be sensitive to the practicalities of patients regarding time, place, need of information, need of rest, and timely reimbursement of expenses (e.g., transportation, parking, printing costs)
Have an open mind and lack of fear of asking "stupid" questions	Act transparently and ethically
Be able to obtain or have an understanding of achievable study goals	
Commit time and be motivated	
Have presentation skills	
Understand context of treatment and treatment goals	
Understand and protect patient rights (e.g., privacy)	

PRP: patient research partner.

Challenges of Successful Patient Participation

Two challenges highlighted in the breakout groups were the recruitment of competent PRP and their representativeness of other patients with their conditions. The term "competent" referred sometimes to the ability to transcend the individual experience and to speak on behalf of the patient group. This concept is a challenging task because patient perspectives are highly individual as a result of diverse disease manifestations, variable disease duration, different levels of severity, and therapeutic responses to a wide array of agents. Also, characteristics such as sex, age, and cultural and socioeconomic background are important determinants of the patient perspective. Competence in this context means acknowledgment of one's own limitations: 1 or 2 PRP could never represent the entire spectrum of disease effect, nor should this be their role. Instead, they should ensure the patient perspective is considered in every phase of the research process. The PRP should also ensure the project's focus remains broader than their own disease experience. The challenge to identify the entire patient perspective is a respon-

sibility incumbent upon the entire research team and should be reflected in the overall study design. Depending on the objective of the study, the research team may need to broaden the input from PRP or add surveys, interviews, focus group meetings, or Delphi exercises to fill gaps — or to acknowledge the limitations of studies when gaps cannot be filled[13].

In the context of international initiatives, competence relates to the ability to speak English, to travel to meetings, and to participate in teleconferences. Participants suggested potential limitations regarding knowledge of biomedical research and the ability to contribute to research initiatives. The jargon of professionals and the use of complex statistics may hamper PRP understanding and their ability to contribute fully to discussions. The question was raised whether a scientific background or medical knowledge is advantageous for the collaborative role of patients. For some participants a minimum educational level is mandatory to contribute effectively. Others pointed out the risk of the medicalization of PRP, and advocated a rotating system to avoid patients becoming too professional, acquiring medical knowledge and aligning easily with the arguments of researchers instead of preserving a critical patient voice. One solution suggested was to strive for multiple ways to engage patients in research initiatives, e.g., to combine involvement of more experienced patients as PRP with a driving and informing role, with less experienced patients in the role of focus group participants or survey respondents.

Several participants reported the risk of tokenism, where PRP are involved primarily for extrinsic reasons, e.g., to meet funding requirements or because it is politically correct. In particular, PRP confirmed that patients are still often invited as partners but then not supported and facilitated as contributors. Unfortunately, they are sometimes involved incidentally, which is not in accordance with the concept and definition of a PRP. For this reason it is important to strive for continuous and structural involvement of PRP. When researchers are not intrinsically motivated to incorporate true PRP participation, patients do not feel valued as equal partners nor can they truly contribute. This scenario might also occur even when researchers are properly motivated to involve PRP but are too busy to fully accommodate PRP needs, e.g., when researchers have competing priorities such as reaching a deadline for publication or a grant application. The issue of researchers' lack of time was raised in several breakout groups; it is clear that involving PRP in research requires an investment of time, energy, and resources.

Finally, several structural barriers were identified: ethical regulations that hinder PRP participation; medical training that has been eminence-based versus evidence-based; and a lack of best practices for PRP involvement. Participants discussed ways to overcome these barriers: researchers should increase awareness of the need for PRP involvement in research, disseminate research findings influenced by PRP involvement, invest effort to involve PRP, make PRP feel valued as equal members of the research team, and make personnel available to coordinate PRP efforts and activities (Table 3).

DISCUSSION

In a relatively short time period, GRAPPA has encouraged active and meaningful involvement of PRP in its activities, e.g., the patient-initiated session Building Bridges, and has increased awareness and mutual understanding of PRP roles and the benefits of their participation in research endeavors.

Working groups are encouraged to consider PRP involvement in all phases of their projects and to explore patients' needs, preferences, and priorities. During the breakout groups of Building Bridges it became clear that engaging PRP in research projects confronts researchers with tasks for which they often are not prepared. Patient involvement in different areas of research must be defined, and the different roles of patients in research, e.g., focus group participant versus PRP, must be explored. Having a clear definition of the potential contributions of a PRP is useful to formulate selection criteria: a project-specific profile of a PRP makes it easier to exchange mutual expectations and to agree on the desirable form of partnership[14].

Representativeness was identified as a challenge. From the literature we know that the perspectives of patients and physicians are not the same[15,16] and that involvement of patients in research initiatives may enrich the research agenda[1,17]. However, the current GRAPPA PRP group tends to have limited representativeness for the entire PsO and PsA population, including total number, regional and educational backgrounds, and race. Similar to the OMERACT PRP panel, GRAPPA seems to attract "educated, white, middle class, and

Table 3. Ways to overcome barriers.

- Promote the importance of PRP involvement, not only among researchers but also among patient organizations and research funders
- Have an administrator who works directly with PRP to address logistics such as providing information and literature, maintenance of a database of the GRAPPA PRP members, and answering questions
- Stimulate sponsors to provide funds for PRP involvement
- Promote different types of involvement of patients to guarantee the representativeness of the study
- Establish a repository of best practices and other patient relevant documents on the GRAPPA Website
- Provide support and education (including medical and scientific terminology)
- Develop a publication supporting mandatory patient participation for outcomes research and to clarify the position of PRP regarding anonymity (privacy), financial issues (reimbursement of expenses, compensation) and legal issues (compliance with regulations)
- Create an environment in which PRP feel themselves to be equal partners with other GRAPPA members

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

socially skilled people."[18] Nonwhite patients are underrepresented in most clinical research settings for many reasons[19]. It is suggested that PRP could help research become more inclusive and consequently more representative. Although PRP cannot guarantee representativeness, they can advise on inclusion criteria, recruitment strategies, outcome measures, and additional methods of data collection that reflect inclusiveness. Further efforts should be made to ensure that race, sex, cultural, and regional backgrounds are properly considered by the GRAPPA project teams in every research initiative. Additionally, a preferred number of PRP in a working group or at the annual meeting should be discussed by everyone involved, including GRAPPA sponsors. A minimum representation of 2 PRP in working groups, per EULAR recommendations[11], could be considered. Per OMERACT recommendations[20], GRAPPA could aspire for a proportional representation of PRP at the annual GRAPPA meeting, although it takes time to arrange sufficient funding and overcome practical and strategic barriers. To guarantee the establishment of sustainable relationships between PRP and researchers and to avoid opportunistic involvement only at meetings, the involvement of PRP should continue throughout the research project.

Involving PRP in research has financial consequences for the GRAPPA budget and for PRP. Whereas physician researchers have an incentive to attend GRAPPA meetings to advance their professional roles and responsibilities, PRP may have limited financial means, especially if they must take vacation time to attend such meetings or arrange for care of dependents. Therefore, PRP who are invited to contribute to GRAPPA meetings should be encouraged to attend and provided with financial support, ideally including reimbursement of travel and accommodation expenses. Patient participation in research requires an investment of time, energy, and resources. Lack of funding to properly engage PRP seriously limits their participation and biases attendance toward a higher percentage of affluent participants, thereby decreasing the representativeness of PRP for the entire patient spectrum. Participatory research should be perceived as a worthwhile investment in sustainable relationships with the patient community that may ultimately result in increased credibility of research efforts and more funding, less distrust in the pharmaceutical industry, higher inclusion rates in clinical trials, and better dissemination and implementation of results.

Another challenge includes identifying and inviting PRP at an early stage in the planning of meetings. Because PRP typically lack medical knowledge, they need access to peer reviewed literature, information on writing style, tips on appraisal of scientific papers, and additional time to prepare and become familiar with ongoing research activities. PRP will be more strongly positioned to achieve partnership status with the researchers when they are involved in premeeting working group activities, which might also increase ownership of the research outcomes.

Involving PRP in GRAPPA projects is pivotal to optimizing incorporation of the patient perspective in PsA research. At the GRAPPA annual meeting, members discussed the benefits and challenges of involving PRP in research projects and defined the tasks, responsibilities, and competencies for collaboration between researchers and PRP. In future GRAPPA meetings and research initiatives, participants should address these challenges by collecting best practices and reporting the benefits, challenges, and lessons learned. Specific attention should be given to early involvement of PRP, appropriate support of PRP, and the issue of representativeness.

REFERENCES

1. Abma TA, Pittens CA, Visse M, Elberse JE, Broerse JE. Patient involvement in research programming and implementation: A responsive evaluation of the dialogue model for research agenda setting. Health Expect 2014; May 30 (E-pub ahead of print).
2. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. BMC Health Serv Res 2014;14:89.
3. Staniszewska S, Haywood KL, Brett J, Tutton L. Patient and public involvement in patient-reported outcome measures: evolution not revolution. Patient 2012;5:79-87.
4. Tillett W, Adebajo A, Brooke M, Campbell W, Coates LC, FitzGerald O, et al. Patient involvement in outcome measures for psoriatic arthritis. Curr Rheumatol Rep 2014;16:418.
5. de Wit M, Campbell W, FitzGerald O, Gladman DD, Helliwell PS, James J, et al. Patient participation in psoriasis and psoriatic arthritis outcome research: a report from the GRAPPA 2013 annual meeting. J Rheumatol 2014;41:1206-11.
6. Tillett W, Eder L, Goel N, De Wit M, Gladman DD, Fitzgerald O, et al. Enhanced patient involvement and the need to revise the core set — report from the Psoriatic Arthritis working group at OMERACT 2014. J Rheumatol 2015;42: in press.
7. Levin AA, Gottlieb AB. The International Dermatology Outcome Measures Group: Update from the GRAPPA 2014 annual meeting. J Rheumatol 2015;42:1027-8.
8. Tillett W, Eder L, Goel N, de Wit M, Ogdie A, Orbai AM, et al. Review of the psoriatic arthritis working group at OMERACT 12: a report from the GRAPPA 2014 annual meeting. J Rheumatol 2015;42:1048-51.
9. Mease PJ, Park J, Garg A, Gladman DD, Helliwell P. Development of simple clinical criteria for the definition of inflammatory arthritis, enthesitis, dactylitis, and spondylitis: a report from the GRAPPA 2014 annual meeting. J Rheumatol 2015;42:1041-3.
10. Coates LC, Kavanaugh A, Mease PJ, Ritchlin CR. GRAPPA treatment recommendations: an update from the GRAPPA 2014 annual meeting. J Rheumatol 2015;42:1052-5.
11. de Wit MP, Berlo SE, Aanerud GJ, Aletaha D, Bijlsma JW, Croucher L, et al. European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects. Ann Rheum Dis 2011;70:722-6.
12. Cheung PP, de Wit M, Bingham 3rd CO, Kirwan JR, Leong A, March L, et al. Recommendations for the involvement of patient research partners in OMERACT working groups. A report from the OMERACT 2014 working group on patient research partners. J Rheumatol 2015;42: in press.
13. Staniszewska S, Brett J, Mockford C, Barber R. The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. Int J Technol Assess Health Care 2011;27:391-9.

14. Abma TA, Nierse CJ, Widdershoven GA. Patients as partners in responsive research: methodological notions for collaborations in mixed research teams. Qual Health Res 2009;19:401-15.
15. van der Goes MC, Jacobs JW, Boers M, Andrews T, Blom-Bakkers MA, Buttgereit F, et al. Patient and rheumatologist perspectives on glucocorticoids: an exercise to improve the implementation of the European League Against Rheumatism (EULAR) recommendations on the management of systemic glucocorticoid therapy in rheumatic diseases. Ann Rheum Dis 2010;69:1015-21.
16. Hewlett SA. Patients and clinicians have different perspectives on outcomes in arthritis. J Rheumatol 2003;30:877-9.
17. De Wit M, Abma T, Koelewijn-van Loon M, Collins S, Kirwan J. Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences. BMJ Open 2013;3 pii:e002241.
18. De Wit M, Abma T, Koelewijn-van Loon M, Collins S, Kirwan J. Facilitating and inhibiting factors for long-term involvement of patients at outcome conferences—lessons learnt from a decade of collaboration in OMERACT: a qualitative study. BMJ Open 2013;3:e003311.
19. Hawk ET, Habermann EB, Ford JG, Wenzel JA, Brahmer JR, Chen MS Jr, et al. Five National Cancer Institute-designated cancer centers' data collection on racial/ethnic minority participation in therapeutic trials: a current view and opportunities for improvement. Cancer 2014;120 Suppl 7:1113-21.
20. Boers M, Kirwan JR, Tugwell P, Beaton D, Bingham CO, 3rd, Conaghan PG, et al. The OMERACT handbook. [Internet. Accessed February 24, 2015.] Available from: www.omeract.org/pdf/OMERACT_Handbook.pdf