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## Emerging Guidelines for Patient Engagement in Research



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### ABSTRACT

There is growing recognition that involving patients in the development of new patient-reported outcome measures helps ensure that the outcomes that matter most to people living with health conditions are captured. Here, we describe and discuss different experiences of integrating patients as full patient research partners (PRPs) in outcomes research from multiple perspectives (e.g., researcher, patient, and funder), drawing from three real-world examples. These diverse experiences highlight the strengths, challenges, and impact of partnering with patients to conceptualize, design, and conduct research and disseminate findings. On the basis of our experiences, we suggest basic guidelines for outcomes researchers on establishing research partnerships with patients, including: 1) establishing supportive organizational/institutional policies; 2) cultivating supportive attitudes of researchers and PRPs with recognition that partnerships evolve over time, are grounded in strong communication, and have shared goals; 3) adhering to principles of respect, trust, reciprocity, and co-learning; 4) addressing training needs of all team members to

ensure communications and that PRPs are conversant in and familiar with the language and process of research; 5) identifying the resources and advanced planning required for successful patient engagement; and 6) recognizing the value of partnerships across all stages of research. The three experiences presented explore different approaches to partnering; demonstrate how this can fundamentally change the way research work is conceptualized, conducted, and disseminated; and can serve as exemplars for other forms of patient-centered outcomes research. Further work is needed to identify the skills, qualities, and approaches that best support effective patient-researcher partnerships.

**Keywords:** patient-centered outcomes research, patient engagement, patient participation, patient-reported outcomes.

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### Introduction

Researchers and clinicians have long recognized that understanding patient perceptions of their health provides a fuller appreciation of the range of symptoms and life impact of chronic conditions. Yet, until recently, it was also believed that the responsibility for defining outcomes and creating measures rested largely with health professionals. Beginning in the late 1970s, select groups began to acknowledge that beyond serving solely as research subjects, patients had an important view to consider. Nevertheless, the idea that patients could offer valuable input as research partners gained traction only when people with HIV/AIDS began insisting that they had a right to help identify research priorities and outcomes [1]. By the millennium, several

scientific organizations (e.g., Outcome Measures in Rheumatology [OMERACT]) championed the necessity of always involving people living with health conditions as collaborative research partners.

Sixteen years later, much has been accomplished and several approaches have emerged as a growing number of researchers and organizations seek to improve research by directly engaging patients. In the International Society for Pharmacoeconomics and Outcomes Research (ISPOR), the Patient-Centered Special Interest Group (SIG) began in 2013 and the Patient Engagement in Research Work Group began in 2014. Similarly, in the International Society of Quality of Life Research (ISOQOL), a patient engagement SIG was formed in 2012. Despite growing interest, evidence for the impact of patient engagement on outcomes

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research, measurement development, and health care decision making is limited [2–6]. Furthermore, little guidance is available for approaches that work well, for whom, and in what context [7].

To further understand how to integrate patients into all aspects of outcomes research, including patient-reported outcome (PRO) development, we describe and discuss the experiences of three patient-centered outcomes research (PCOR) stakeholders: a clinical research leader, a patient research partner (PRP), and a representative of a PCOR funder. These real-world examples illustrate different approaches and levels of PRP integration and the added value PRPs contribute to outcomes research, and also highlight lessons learned to optimize engagement. Although each organization represented has created organization-specific principles and recommendations for engagement, a set of basic guidelines for optimizing success of research partnerships, generalizable to outcomes research, emerges across the groups.

## A Researcher's Experience

Professor John Kirwan (consultant rheumatologist in Bristol, UK), an experienced clinical researcher working to improve the lives of people with rheumatic diseases, has integrated patients into the international research organization OMERACT. He was responsible for guiding and implementing the present policy in OMERACT that states that outcome measures can be adopted only if patients have participated in their development [8,9].

OMERACT is an independent initiative of international health professionals that uses a data-driven, multistakeholder consensus process to identify and improve outcome measures in musculoskeletal conditions [10]. Since 1990, OMERACT has served a critical role in developing and validating rheumatology outcome measures. Evidence supporting existing PROs as primary outcomes or the need to develop new PROs is presented at biennial meetings. There is detailed small group discussion followed by plenary summaries. All participants, including the PRPs are involved in decision making through real-time electronic voting to determine whether proposed measures are endorsed by OMERACT.

At present, patients are integrated into all stages of the OMERACT process because the personal experiential knowledge of living with their condition adds to the theoretical and empirical knowledge of researchers and clinicians. Direct patient engagement, however, started only in 2000 at OMERACT 5; because deliberations were being held to gain consensus on clinically important change in existing measures in rheumatoid arthritis (RA), it was recognized that patients also might have a

view on this. This spurred discussion on how patients could potentially contribute more widely to the development and selection of outcomes in clinical trials, and OMERACT resolved to include patients at the 2002 meeting. From 2000 through 2012, Dr Kirwan was responsible for coordinating patients' input into the OMERACT process and meetings. By 2016, patients were fully incorporated into all activities (Fig. 1).

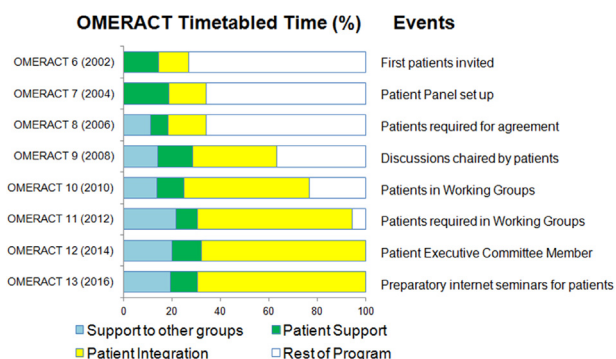
As experience with patient engagement accumulated, the benefits were more widely appreciated and valued, and patients were incorporated into all activities [8]. Today, all OMERACT working groups include PRPs because they undertake research between biennial meetings; groups presenting during plenaries must fund at least one PRP to attend. At meetings, patients have full voting rights and participate in all sessions. Attendance at several meetings has allowed some patients to become very familiar with the process, and they now occupy a “halfway house” between researchers and patients. Patients continue to provide their experience-based perspective, a perspective researchers do not have; PRPs involved over time are able to understand more, and are more comfortable with the language of, and constraints imposed by, the research process. Indeed, one PRP (Maarten de Wit) undertook doctoral studies and became a researcher in his own right.

These changes have had a large impact. Researchers already committed to doing the best for their patients recognize the benefits of including patients when conceiving, designing, and carrying out research and disseminating results [11]. Perhaps the most dramatic consequence has been the refocusing of the research community on fatigue in RA. Initially, fatigue was omitted from the 1992 core outcome set. PRPs highlighted how fatigue affects everyday life, stimulating research to quantify its impact and demonstrate how fatigue assessment adds to the understanding of trial outcomes. As a result, OMERACT now endorses fatigue as a necessary assessment in all RA trials [12–14].

By now, the involvement of PRPs (about 10% of conference participants) has been so pervasive that it is difficult to separate their contribution from those of researchers and other stakeholders. Nevertheless, achieving this required a sustained effort by organizers to ensure patient involvement across successive meetings. Important lessons have been learned. A commitment to funding PRP participation in working groups and conference attendance was an early step, as was increasing the educational support and training given to patients at conferences. For example, each day, organizers of the next day's sessions meet with PRPs to explain how they came to be on the program, what they hope to achieve, what patients should look for, and how they might best contribute to small group discussions. This is an example of the type of research training that can benefit partnerships by ensuring that patients understand the research agenda and goals and can feel comfortable in the discussions while recognizing the unique perspective they bring.

In OMERACT, PRPs organize training to prepare new PRPs and update experienced ones. At OMERACT 2016, experienced PRPs held an introductory webinar and half-day session for new participants immediately before the meeting. They provided a glossary explaining terms such as randomized controlled trial and validity. (The glossary has proven to be so popular that all attendees now receive a copy.) Lay summaries of each session are included in the program.

Over 16 years, PRPs and researchers have learned new skills and OMERACT has published recommendations for meaningfully engaging PRPs in all working groups [15]. The OMERACT experience highlights the importance of education and training to support successful partnerships, and how attitudes of researchers, PRPs, and organizations create a culture in which partnerships can thrive.



**Fig. 1 – Evolution of patient involvement in OMERACT activities and organization (planned as on March 23, 2016). OMERACT, Outcome Measures in Rheumatology.**

## APRP's Experience

Maarten de Wit lives with psoriatic arthritis (PsA) and is a PRP. He worked with the European League against Rheumatism (EULAR) to create recommendations for patient engagement in scientific projects [16] that helped guide the development of a new measure in PsA. Because there was no existing measure reflecting the patient perspective [17,18], EULAR facilitated the development and validation of the Psoriatic Arthritis Impact of Disease (PsAID) score [19]. PsAID developers now use this work as a case study of a successful patient-research partnership in developing a new outcome measure [20].

This project serves as a best practice exemplar because it demonstrates *multiple forms of PRP participation* throughout PRO development. Different PRPs were involved in subsequent phases, contributing in diverse ways, and at all levels. This example also demonstrates the role of research team attitudes in creating an environment that supports partnership. Here is a summary of the range of activities that the PRPs undertook.

## Steering Committee

Two PRPs were part of the steering group, participating in all discussions and decision making.

## Foundational qualitative work

Initially, PRPs from 11 European countries participated in a meeting (led by a nurse researcher and patient) to identify life impact domains in accordance with EULAR recommendations (Table 1) [16]. PRPs were recruited through the clinics of participating physician-researchers to identify those who could travel, had relevant skills, and were interested in collaborating on this project.

**Table 1 – European League against Rheumatism recommendations for the inclusion of patient representatives in scientific projects.**

1. Participation of patient research partners is strongly recommended for clinical research projects and for the development of recommendations and guidelines, and should be considered for all other research projects.
2. Participation of patient research partners should be considered in all phases of the project to provide experiential knowledge, with the aim of improving the relevance, quality, and validity of the research process.
3. A minimum of two patient research partners should be involved in each project.
4. Identification of potential patient research partners should be supported by a clear description of expected contributions.
5. The selection process of patient research partners should take into account communication skills, motivation, and constructive assertiveness in a team setting.
6. The principal investigator must facilitate and encourage the contribution of patient research partners and consider their specific needs.
7. The principal investigator must ensure that patient research partners receive information and training appropriate to their roles.
8. The contribution of patient research partners to projects should be appropriately recognized, including coauthorship when eligible.

\* Adapted with permission from de Wit et al. [16].

## Questionnaire development, refinement, and validation

A total of 139 patients prioritized 16 life impact domains, and 65 patients provided feedback on item wording and offered alternative terms when translating the questionnaire into different languages [21]. Initial validation included 499 new patients from 11 countries who completed questionnaires and underwent a clinical examination.

Although there was agreement on many things, there was also some discordance. For example, patients strongly favored including coping questions as this was viewed as an important indicator of poorly controlled disease. There was debate about three items that queried embarrassment/shame, social participation, and depression. Many of the professionals and some patients questioned the added value of asking all patients in a clinical trial about the psychosocial consequences of PsA; others argued that they were important for some, and should be part of patient-physician conversations. Given that the initial objective was to develop a tool appropriate for both clinical trials and practice, the team developed two versions: a 9-item PsAID focusing on measurement objectives to meet the needs of trialists, and a 12-item version for clinical practice because many patients want the psychological impact of living with PsA to be part of broader conversations. Most researchers agreed that involving patients was essential when developing PROs.

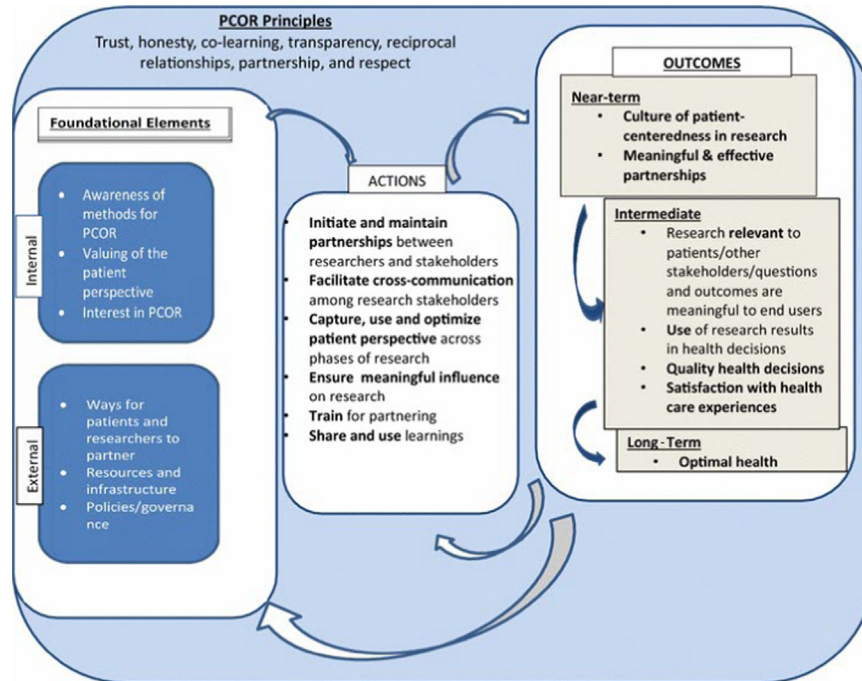
Evidence from EULAR and others suggests that the investigators play a key role in successfully integrating PRPs into projects and eliciting meaningful contributions [22–24]. As with OMERACT, EULAR PRPs received education and support to better understand the research process, fully participate in meetings, and confidently voice opinions, while still providing their unique experience-based perspective. PRP sessions were held before team meetings. A glossary helped them learn about research (e.g., the experimental method). Project-specific education included the following: 1) explaining the goals and process of PRO development and 2) providing basic information on how PROs are validated and why this is important. Newsletters kept all team members informed of progress. PRPs helped draft the manuscript as coauthors [25].

Thus, PsAID development demonstrates that PRPs and researchers can successfully collaborate to develop new patient-centered instruments for research and clinical settings. This example illustrates how training enabled patients to participate fully in meetings, how patient involvement strengthened the measures that emerged, and how attitudes of trust, respect, co-learning, and reciprocity facilitated the partnership.

## A Funder's Experience

The Patient-Centered Outcomes Research Institute (PCORI) is a nonprofit, nongovernmental organization that funds patient-centered clinical comparative effectiveness research. PCOR is defined as the “evaluation of questions and outcomes meaningful and important to patients and caregivers” [26]. PCORI requires stakeholder engagement in all its funded research, defining stakeholders as any end user of the research, including (but not limited to) patients, caregivers, clinicians, hospital administrators, health care policymakers, industry researchers, and drug and device manufacturers.

To meet PCORI research engagement requirements, awardees must demonstrate that patients or other relevant end users are included in the production of research evidence, beyond serving as subjects. Engagement can take many forms. Advisory panels, generally implemented as meetings between researchers and intended end users, are a common model of engagement among PCORI awardees. In practice, PRPs engage with researchers in diverse ways, from serving as consultants on select portions of



**Fig. 2 – Conceptual model of patient-centered outcomes research.** From Frank et al. [27]. PCOR, patient-centered outcomes research.

the project to co-investigators signifying influence on and responsibility for the work on par with researchers. PCORI encourages partnership across different stages of research (e.g., determining study questions, study design, implementation, and dissemination) as appropriate (see <http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>).

### Conceptual Model of PCOR

To guide applicants and researchers, PCORI and others created a conceptual model of PCOR, on the basis of relevant literature and consultation with the PCORI Patient Engagement Advisory Panel [27]. This conceptual model can serve as the basis for measurement models to test relationships between elements in the model (Fig. 2), along with a companion evaluative framework for research engagement [28].

The model identifies foundational elements for PCOR, including channels for communication, resources and infrastructure, and organizational policies, each supporting the research partnership. Action elements are the behaviors that researchers and partners engage in to permit successful PCOR. Communication is key, as is active solicitation of patient perspectives throughout the research process and sharing of results with end users. The ultimate goal of PCOR is optimized health outcomes.

### Learning about Engagement in Research from PCORI Awardees

To identify best practices in research engagement and to develop descriptive information from which elements of the conceptual model can be evaluated, PCORI has collected information from awardees focused on engagement with research partners or other end users. Early data identified time as a challenge for both researchers and partners [29]. Nevertheless, establishing and maintaining relationships between researchers and end users requires time. For many researchers, factoring in time to meet with research partners is a new practice but it is notable that many awardees see the value of restructuring team activities to

allow for time with research partners. Doing so has altered the research: questions and study designs have been changed, as have ways in which participants are recruited and information is shared with patient communities [29]. These findings are consistent with OMERACT and EULAR experiences, pointing to the resources required to establish and maintain research partnerships, including familiarizing PRPs with relevant terminology and research processes to optimize their contributions.

PCORI's goal is to help people make informed health care decisions through funding research guided by patients, caregivers, and the broader health care community. Guidelines about research partnerships for applicants, such as the PCORI Engagement Rubric and the Methodology Standards, echo elements from OMERACT and EULAR. Training of patients and researchers is recommended, with recognition of the different resource requirements needed to establish and maintain research partnerships. Principles of trust, co-learning, reciprocity in relationships, and respect emerge from awardees as important elements. Attitudes toward engagement, along with institutional policies, are important for establishing a foundation in which research engagement can proceed.

### Discussion

These examples from different stakeholders converge on several points, from which guidelines for engagement in outcomes research can be distilled. PRPs represent the voices and needs of patients and enhance all phases of research. Across different models presented, similar principles to guide integration of PRPs in research have emerged that include the following:

1. establishing supportive institutional policies;
2. fostering supportive attitudes, with understanding that optimal partnerships evolve over time and are grounded in strong communication and shared goals;
3. adhering to principles of respect, trust, reciprocity, and co-learning;

4. addressing training needs of all team members to ensure productive communication and that PRPs are familiar with the language and process of research;
5. identifying and providing the resources and advanced planning required for successful patient engagement; and
6. recognizing the value that research partnerships bring across all stages of research, from research conceptualization through dissemination of findings.

Although similarities appear across examples, each project is unique, necessitating clear communication about expectations of all members. More research is needed to identify the skills and qualities that contribute to successful research partnerships in terms of individual and collective needs, values, and required resources. Further work also is needed to develop insights and best practices for training of researchers and patients to work well together in designing new measures and implementing outcomes research. Consensus-driven guidelines for reporting patient engagement are available (e.g., GRIPP2 [guidance for reporting patient and public involvement]) [30], highlighting the importance of detailing the context (support, training, funding, and time); processes adopted (methods adopted, levels of engagement, and stages of the research during which patients were involved as research partners); and outcomes. Careful documentation of these aspects can contribute to the development of a knowledge base for engaged research.

### Challenges in Patient-Research Partnerships

PRPs should possess a set of core competencies that align with the project's objectives and process, but considerable uncertainty remains around identifying these. The reality of limited time must be faced because time spent identifying and developing productive relationships with PRPs too often represents "unfunded activities." OMERACT allocated funds and personnel to support patient engagement from the initiation of working groups. As a funder, PCORI recognizes that meaningful engagement of patients in research may add time and costs to research projects, and application reviewers are made aware of the different resources and needs that this type of research can produce, relative to nonengaged research models. The cultural impact of PRPs also warrants evaluation, including attention to positive and negative consequences for researchers and PRPs.

### Conclusions

We have described three ways in which outcomes research was improved by involving PRPs. Supporting patients in their role as full research partners enables them to contribute their experiential knowledge and helps ensure that results are relevant and address patient needs, preferences, and priorities.

Organizations such as the ISPOR, ISOQOL, OMERACT, EULAR, PCORI, and others recognize the benefits and mandate that patient partners are incorporated into their structure and function. In the ISPOR, the patient-centered SIG is poised to facilitate this (see [http://www.ispor.org/sigs/patientcentered/pc\\_engagementinresearch.aspx](http://www.ispor.org/sigs/patientcentered/pc_engagementinresearch.aspx)). As PCOR spreads to other organizations, it will be important to collect evidence on the impact of engaging PRPs in research and to identify ways to facilitate it across disciplines. Although views about the value of patient engagement are not based on controlled trials (e.g., comparing engagement vs. no engagement), recognizing the value of patient engagement can both reflect and drive the cultural shift among researchers.

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