

Patients as Partners in Research: It's the Right Thing to Do

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The health research landscape is changing, and it is time for the *Journal of Orthopaedic & Sports Physical Therapy* (JOSPT) community to “up our game” by fostering authentic opportunities for patient engagement in musculoskeletal research and practice.

In this editorial, we argue that successful patient engagement improves the quality of physical therapy research. Although authentic engagement has challenges, the benefits are well worth the investment of time and energy to overcome these challenges. We outline 3 steps JOSPT is taking to promote and support patient partnership in musculoskeletal research.

What Is Patient Partnership in Research?

Researchers have traditionally served as gatekeepers—researchers decide which questions to answer, which treatments to study, and how to measure treatment

success. After analyzing and interpreting their measurements, researchers disseminate their findings through academic channels such as peer-reviewed journals and presentations at conferences. Often, the articles reside behind paywalls, and conferences have their doors firmly closed to patient participation.

The “researcher-as-gatekeeper” paradigm has generated a wealth of knowledge and has contributed to improved treatment in many conditions. However, there are risks with such a paradigm, including (1) pursuing questions that do not capture key aspects of the patient

experience, (2) measuring outcomes of limited relevance to patients, and (3) inadequate knowledge translation that prevents patients and clinicians from effectively applying research findings in real-world settings. When researchers partner with patients (and clinicians) to do research, these risks are reduced. “Patient-oriented research” must meet at least 1 of the criteria in **TABLE 1**.

The Canadian Institutes of Health Research Strategy for Patient-Oriented Research: Patient Engagement Framework (<http://www.cihr-irsc.gc.ca/e/48413.html>) and the International Association for Public Participation spectrum of public participation framework (**FIGURE**) are two frameworks that can be used to foster partnerships among researchers, patients, and clinicians. JOSPT aims for the “collaborate” level of engagement.

TABLE 1

CRITERIA FOR PATIENT-ORIENTED RESEARCH⁶

Condition	Description
1	Patients (including relatives, family caregivers, and the public) are involved as research partners with multidisciplinary or transdisciplinary team members (including decision/policy makers, patients, and clinicians) along a continuum in addressing patient priorities or planning/conducting research (eg, formulation of the question; data collection/analysis; interpretation, diffusion, dissemination, and application of results), or both addressing patient priorities and planning/conducting research
2	Studies aim to (a) address outcomes deemed important by patients; (b) have a direct impact on at least 1 of the following targets: patient health and experiences, health professionals' practice, or health care services and policies; or (c) achieve both objectives a and b

for sports participation, which would not have been included as a core domain if not for guidance from patients. These are concrete examples of patients articulating what is important about their condition and partnering with researchers to ensure its inclusion in research.

Now Is the Right Time for Partnerships Between Researchers and Patients in Musculoskeletal Rehabilitation Research

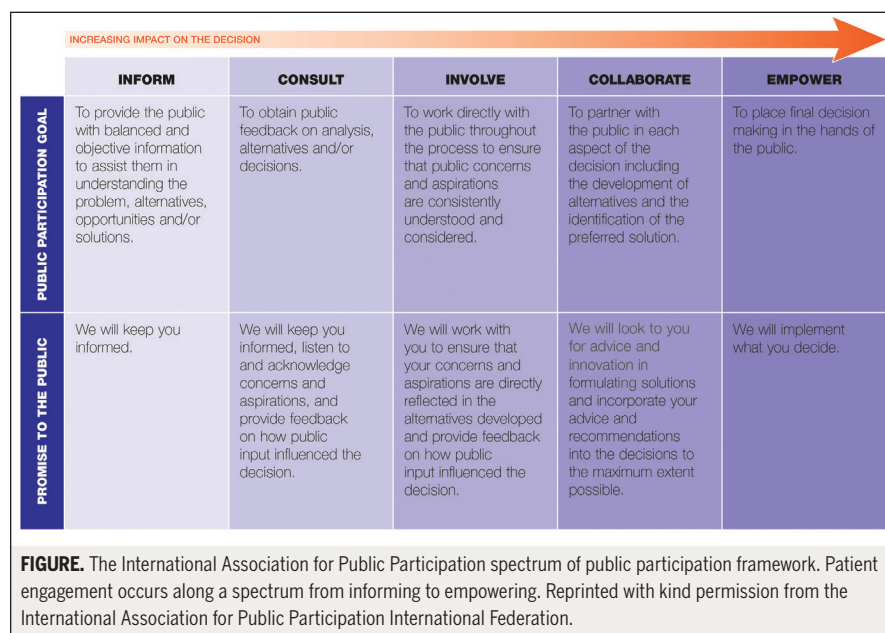
Many participants in studies published in JOSPT are people living with pain who sacrifice their time to help future patients. In addition to being participants in research, people with lived experience bring valuable knowledge—contributing to a broader understanding of the treatments researchers study, improved knowledge translation, and more successful outcomes.

Rather than researchers informing patients and clinicians about a condition and instructing patients how to behave, engaging in a way that promotes sharing and understanding of a patient's unique, lived experience can mean that patients, clinicians, and researchers answer key clinical questions together. Leading biomedical journals (eg, the *BMJ* and *CMAJ Open*) have policies and initiatives to promote patient-oriented research. It is time for JOSPT to enter this arena.

Challenges When Building Patient Partnerships for Research

Because patient partnership is a relatively new approach to doing research,³ there is limited experience in “how” to do this well. Typical challenges faced by research teams new to this type of research partnership include the following.

1. Partnering with patients requires an investment of time, and researchers want to be confident that the outcomes are worth this investment. Fortunately, there are promising trends in patient-partner research, including higher recruitment and retention rates and greater intervention adherence.⁴
2. There is no single recipe for how to do patient-partner engagement well.



How Patient Partnerships Can Benefit Research

It is challenging to measure the impact of patient partnerships on a research program, and research on patient partnerships is in early stages.⁹ There is a benefit to participant recruitment and retention—the bane of many studies.¹ There is also a growing list of conditions in which patients have alerted clinicians to core domains and to what should be considered (eg, fatigue associated with rheumatoid arthritis⁷).

During the Fifth International Scientific Tendinopathy Symposium, held in 2018 in Groningen, the Netherlands, health care practitioners (n = 28) and

patient partners (n = 32) collaborated to develop a consensus statement on persistent tendinopathy. After the first stage of the Delphi survey, only 36% of health care practitioners believed that psychological impact was an important domain of persistent tendinopathy. Seventy-seven percent of patients thought that psychological impact was important.

If the Delphi survey had not included patient partners, the psychological impact domain would have been dropped from consideration. After stage 2 (in-person discussion among health care practitioners and patient partners), the psychological impact domain achieved 88% consensus. The results were similar

TABLE 2

SUCCESSFUL PATIENT-ENGAGEMENT APPROACHES FOR HEALTH RESEARCH^{2,5}

1. Engage patients as early as possible and continue engagement
2. Clearly define the patient-engagement plan: be clear on roles, duties, and expectations between patients and researchers
3. Provide orientation and education about research and patient engagement
4. Provide ongoing support, encouragement, and recognition for patient contributions
5. Facilitate mutual respect and valuing of patients' expertise based on knowledge gained through experiences
6. Ensure a trusting and positive environment by providing structural support
7. Include a plan for evaluating engagement

TABLE 3

SHARED CHARACTERISTICS OF SUCCESSFUL PATIENT ENGAGEMENT IN HEALTH RESEARCH⁸

- Clear purpose, role, and structure for engaging patients
- Initiate and maintain partnerships between researchers and stakeholders
- Take the time required to foster relationship building as the most critical component in establishing trust
- Clear leadership from principal investigator and/or wider culture of involvement
- Promote the need for facilitation of cross-communication among all groups
- Capture and facilitate patient perspectives across all phases of research
- Ensure meaningful patient influence on research by validating the need for respect and support for patients
- Ensure adequate training for researchers and patients
- Share and promote research findings, including evaluation efforts

However, there are teams in Canada, the United Kingdom, and Australia researching preferred methods for how to recruit, orient, train, and work with patient partners, and subsequently to measure the effectiveness and outcomes of these partnerships. *JOSPT* authors can contribute to and help develop this field of research.

Overcoming these barriers will be best addressed by purposeful attention to and use of best practices in patient engagement in research (current best evidence and practice).

How *JOSPT* Plans to Support Authors

The *JOSPT* patient-partnership editorial series will (1) describe key frameworks

and approaches for developing patient partnerships in research (TABLE 2), (2) share tips and resources for researchers considering patient partnership (TABLE 3), and (3) outline *JOSPT*'s policy on patient partnership in research.

Call to Action: Next Steps for the *JOSPT* Community

JOSPT is taking concrete steps to promote and support patient partnership in musculoskeletal research.

1. Requiring all new manuscript submissions from January 1, 2020 to include a statement about how (if at all) patients were involved in the research
2. Welcoming Ms Joletta Belton as patient-partnership lead on the *Journal's* Editorial Board
3. Establishing a patient-partnership working group to connect with our community, ensuring we address the issues that matter to you

We invite readers and authors to contribute to the discussion on patient partnership in research. Connect via our social media channels (Twitter: @JOSPT; Facebook: @JOSPTOfficial) and share your ideas. We welcome your suggestions for future editorials in this series. How can this space best serve researchers, educators, and clinicians? How can it serve those who live with an injury/condition/disease/pain or other symptoms, and those who love or care for them? ●

"It is our lives that are at stake, after all. Shouldn't we have a say? It is we who have to live with these conditions and experiences for which we are seeking care. We seek care because we cannot figure it out on our own. We need your expertise, your knowledge of the research, your clinical expertise. We also need for you to bring your own humanity to the table. To see us as fellow humans who are trying to make sense of things and find a way forward. That we will not be in your care forever. That even while we are in your care, we are largely living with these experiences and conditions on our own. You are in the best position to help us find that way forward with us. It can only be discovered together."

—Joletta Belton

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