# Engaging Patient Stakeholders in Planning, Implementing, and Disseminating Occupational Therapy Research

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Patients[1] are experts on their own lives and the ways in which an illness, injury, or disability affects their health, activity, and quality of life. With its longstanding foundations in participatory action research, patient engagement has been gaining momentum across health care and related research. This momentum is supported by investments from several key research and federal policy–related organizations, including the Patient-Centered Outcomes Research Institute, National Institutes of Health, and Agency for Healthcare Research and Quality. Occupational therapy practitioners are uniquely positioned to champion patient collaborations. In this article, we discuss ways in which patient perspectives can be embraced in occupational therapy research, and we share insights from a research planning collaborative with adolescents and young adults that was led by occupational therapy researchers.

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Valuing the expertise of those with lived experience is a central assumption of participatory action research, which focuses on social action and generates research with direction from patients or consumers (Taylor et al., 2004). Until recently, however, collaborating with patients has not been widely adopted across research and health care delivery. Building on the premise of patient expertise, health care systems, researchers, and policymakers are increasingly recognizing the importance of engaging patients in the processes of scientific discovery and knowledge translation (Sheridan et al., 2017).

In 2010, Congress put further emphasis on patient experience and participation when it authorized the creation of the Patient-Centered Outcomes Research Institute (PCORI) through the Patient Protection and Affordable Care Act (ACA; Pub. L. 111-148; 2010). As one of several new entities established by the ACA to advance research and innovation in a changing health care system, PCORI was designed to be an independent, nonprofit organization (PCORI, 2017a). The institute aims to increase the amount of high-quality evidence available to all members of the health care community, thereby improving the process of health-related decision making (PCORI, 2013). Funding for PCORI comes largely from federal resources (PCORI, 2017b), and it primarily funds comparative effectiveness research that can be used by patients, providers, and other stakeholders to make informed decisions in health care. To maximize impact, funded projects must involve patient stakeholders from inception to dissemination (PCORI, 2018). By requiring collaboration across stakeholder groups in all stages of research planning and implementation, PCORI's approach has disrupted traditional research designs and stimulated widespread conversation on the values of patient engagement. Similarly, other key organizations are encouraging the inclusion of patients as active partners to improve the health and well-being of individuals and society (e.g., Agency for Healthcare Research and Quality, 2017; National Institutes of Health, 2018).

Although researchers and health professionals have important perspectives on science and practice, patients contribute unique expertise as individuals with lived experiences of a condition or disease and as consumers of the

[1]Although consumers of occupational therapy services are typically referred to as *clients,* we use *patient* to describe this population in order to correspond with literature on patient-engagement and patient-centered care.

health care system. Emerging evidence from studies that engage patients in research has demonstrated positive effects of such collaborations (e.g., Brett et al., 2014; Domecq et al., 2014; Williamson et al., 2010). Patient stakeholders have the potential to increase the relevance of research aims to real-world needs, improve recruitment and retention, and enhance dissemination (Boote et al., 2010; Brett et al., 2014; Carman & Workman, 2017; Domecq et al., 2014; Duffett, 2017). The desirability of these positive results is a driving force for expanding patient engagement in research.

With this momentum for patient engagement in the research and policy environment, our purpose in this article is to discuss the ways in which patient perspectives may be embraced in occupational therapy research. We explore how occupational therapy practitioners and researchers are uniquely suited to collaborate with patients and other stakeholders. Moreover, we share insights from a research planning collaborative, supported in part by PCORI and led by occupational therapy researchers, that involved adolescents and young adults (AYAs) with chronic conditions as partners in the process.

## Translating Patient Centeredness Into Research Collaboration

Terminology and conceptualization surrounding patient engagement is constantly evolving as it is put into practice. Numerous models have emerged for substantive ways to involve patients in research (e.g., Carman & Workman, 2017; Concannon et al., 2014; Duffett, 2017; Ruco & Nichol, 2016; Sheridan et al., 2017). For example, patients may act as consultants and provide knowledge on specific topics. On a more involved level, patients may be part of research leadership and actively inform and provide direction for studies from inception to dissemination.

Patient centeredness is a cornerstone of occupational therapy practice. The *Occupational Therapy Practice Framework: Domain and Process* (3rd ed.; American Occupational Therapy Association [AOTA], 2014) delineates the distinct expertise of patients in evaluation and treatment. By practicing therapeutic use of self, "occupational therapy practitioners shift the power of the relationship to allow [patients] more control in decision making and problem solving, which is essential to effective intervention" (AOTA, 2014, p. S12). Likewise, occupational therapy practitioners have challenged themselves to be introspective about the values, goals, and processes of clinical practice throughout the profession's history, and leaders in the field have discussed ways to foreground patient priorities (e.g., Hammell, 2013; Maitra & Erway, 2006; Rebeiro, 2000; Sumsion & Smyth, 2000). Often, fundamental differences exist between practitioners' and patients' beliefs and priorities, and institutional barriers affect truly collaborative relationships. Therefore, practitioners must be intentional to address real-world contexts and minimize these barriers to patient engagement in research and practice.

Because patient engagement inherently aligns with patient-centered values of occupational therapy, occupational therapy practitioners are well positioned to lead efforts to collaborate with patients in research. Advocating for improved occupational therapy practices, Franits (2005) cited the title of Charlton's (2000) book, *Nothing About Us, Without Us,* which espouses the sentiment of many patients and especially people with disabilities, who demand inclusion in health care decision making and policies that directly affect their lives. Franits called for therapists to hone their abilities to collect patient narratives as part of the therapeutic process and outlined ways in which they can be more open to patients' experiences in order to reduce gaps in power between patients and practitioners. Similarly, Mroz et al. (2015) highlighted occupational therapy practitioners' established skills to collaborate with patients and emphasized their responsibility to exercise these skills on multidisciplinary research teams.

Although it is not yet common practice, many occupational therapy researchers have advocated for patient engagement in research. In one example, Clark et al. (1993) called for more significant involvement of patients in the data collection phase of evaluation research, citing evidence that involving patients in survey development broadened the overall scope of surveys, whereas training patients to be interviewers allowed for research participants to share insights more freely. More recent examples demonstrate how occupational therapy researchers have partnered with patient

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communities to create meaningful change, with collaborations ranging from idea generation to community-based participatory action models (e.g., Kramer et al., 2011; Minkler et al., 2008; Poole et al., 2016; Taylor et al., 2004).

## Patient Engagement in Research: A Case Study

Although efforts to engage patients in research and clinical practice are increasing, transparency about the methods for doing so has been limited. In this section, we provide an in-depth case example of a research planning initiative to discuss ways in which patients and other stakeholders can have meaningful impact during research. We review the planning phases of the "Developing Meaningful Research for Adolescents and Young Adults With Chronic Conditions" project[2], which involved significant outreach to patients and provided many lessons for collaborating in research. The project team was focused on unique developmental goals and challenges for AYAs with chronic health conditions. This population has historically been underrepresented in research affecting their health care. In response, we forged a collaboration among this patient population, researchers, and health care providers to consider priorities for health care and research and to discuss effective strategies for patient engagement among AYAs and related stakeholders. This work was carried out in three stages, or tiers.

In Tier I, the project lead (Haywood) initiated partnerships with a cohort of AYAs in Los Angeles County who had a spinal cord injury (SCI) and their caregivers. During individual and group meetings at rehabilitation sites and in patients' homes, participants were asked to discuss their experiences and chief concerns related to disability and health care. Simultaneously, the project lead spoke with health care providers and researchers working with this population. From these conversations, barriers to engaging AYAs as research stakeholders were identified by patients, providers, and researchers, especially for people who have been historically marginalized because of race or ethnicity, socio-economic status, or geographic region. Barriers to engagement included limited knowledge of research processes and patient protections in research, lack of opportunities to be involved, and insufficient resources (e.g., financial, transportation, social) to support participation.

Information that emerged in Tier I highlighted several similarities among AYAs with an SCI and same-age peers with other types of chronic conditions (e.g., diabetes, rheumatic conditions). Primarily, young people with significant health care needs report a paucity of services to manage their health while navigating developmental challenges, such as increased independence from parents or caregivers, intensified emphasis on peer relationships, and pursuit of academic and career goals. A review of existing literature further revealed ways in which developmental processes present unique challenges for AYAs and their health care providers (e.g., Blakemore & Choudhury, 2006; Greydanus et al., 2010; Neinstein, 2013). Thus, we chose to expand beyond SCI to learn from—and share resources across—diagnoses. In Tier II, a team of experts working with AYAs with chronic conditions were recruited, along with a new patient cohort of AYAs with chronic disabilities or health conditions, which included SCI, diabetes, and rheumatic conditions.

The goal in Tier II was to identify gaps in existing literature relating to young adults' research priorities and to develop research questions that aligned with their concerns and had a potential for future funding. Efforts began with a hierarchical team structure in which the leadership team, consisting of researchers and occupational therapists, developed project goals and a corresponding work plan before recruiting patients. Over time, and with patient engagement, collaborations branched out from the leadership team to be more inclusive of patients, who shared perspectives and ideas as partners in the research. Members of the leadership team connected individually with the patient partners at least monthly by phone, by email, or through virtual or in-person meetings. Topics discussed included personal experiences and prominent concerns regarding their personal health care and the health care system. These encounters also revealed strengths and opportunities for engagement, intervention, and collaboration.

[2]"Developing Meaningful Research for Adolescents and Young Adults With Chronic Conditions" was funded by PCORI between 2015-2018 through a series of Pipeline-to-Proposal Awards (Tiers I-III). These awards supported collaborative efforts among patients, researchers, health care providers, and other stakeholders in order to generate patient-centered research.

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As the leadership team was listening and learning, so too were the patient partners; together, we spent meeting times discussing project goals and relevant literature, reviewing research processes, and introducing patient partners to the research community. Discussions also included brief training components on research design and implementation to fully include patient partners in decision making.

Finally, in Tier III, patient partners from Tier II continued on, and a member of the leadership team (Carandang), who identifies as both a researcher and a patient, became the project co-lead to ensure robust patient representation. We held monthly team meetings to narrow our scope of research priorities and to further discuss stakeholder engagement and related issues. Some patient partners assumed additional responsibilities for specific projects, including dissemination of project aims and lessons learned to the community. For example, four patient partners were involved in developing and presenting content on stakeholder engagement at the 2018 AOTA Annual Conference & Expo (Carandang et al., 2018).

## Lessons Learned Through the Research Planning Initiative

Over the course of the project, we routinely reflected on process and impact and learned critical lessons for patient engagement. In this section, we discuss the challenges faced and corresponding successes in our research collaboration efforts with patients, practitioners, and researchers.

### *Cohesion and Representation.*

Given the patient partners' limited knowledge of research, significant resources were dedicated to supporting their participation. We originally planned to collaborate across various stakeholder groups, including health care providers, community leaders, and payer groups, but in time, we pivoted to concentrate on advancing methods of communication with patient partners to generate and nurture these fundamental relationships. For example, one-on-one and small group meetings facilitated trust and allowed for tailored education relating to research and health care models. This targeted approach cultivated strong partnerships and open communication whereby patients were able to share personal stories and questions.

In addition, moving from SCI-specific aims to working across diagnoses generated opportunities to more broadly discuss inclusion and identity among the patient partners. Although from a researcher perspective it appeared that AYAs with various diagnoses experienced similar developmental needs within health care, being part of a diverse community of young adults with various chronic conditions was a shift in identity for some patients. One of the patient partners (Martinez), who has an SCI, reflected on it this way:

> Initially, I wasn't sure how we were defining "chronic conditions," and I wasn't sure I wanted to be affiliated with that term. I was never told that I have a chronic condition. In this project, I felt a bit out of my comfort zone. We all had lifelong challenges, but not everybody was in a wheelchair or had visible challenges like me. When I opened up to the group about this, I was surprised to find out how much we grew from this conversation. My perception expanded when I thought about a range of illnesses and conditions, and I realized that I actually had more in common with the other patient partners than I thought.

Such conversations elevated cohesion among the patient partners and helped us to better consider representation and knowledge gaps as the research was planned.

Finally, it was important to consider what types of stakeholders were part of the team, whose voices were missing, and why. For example, Tier I involved patients and their caregivers, but caregivers were asked to play only a minimal role in Tiers II and III. The exclusion of caregivers was a direct result of feedback from patient partners in Tier II, who wanted to represent themselves without the oversight or influence of others, who could potentially detract from their own voices. In addition, the patients who participated in this project were all individuals with some exposure to research (as participants), and they had the resources and interest to engage in research planning; we speculate that our team did

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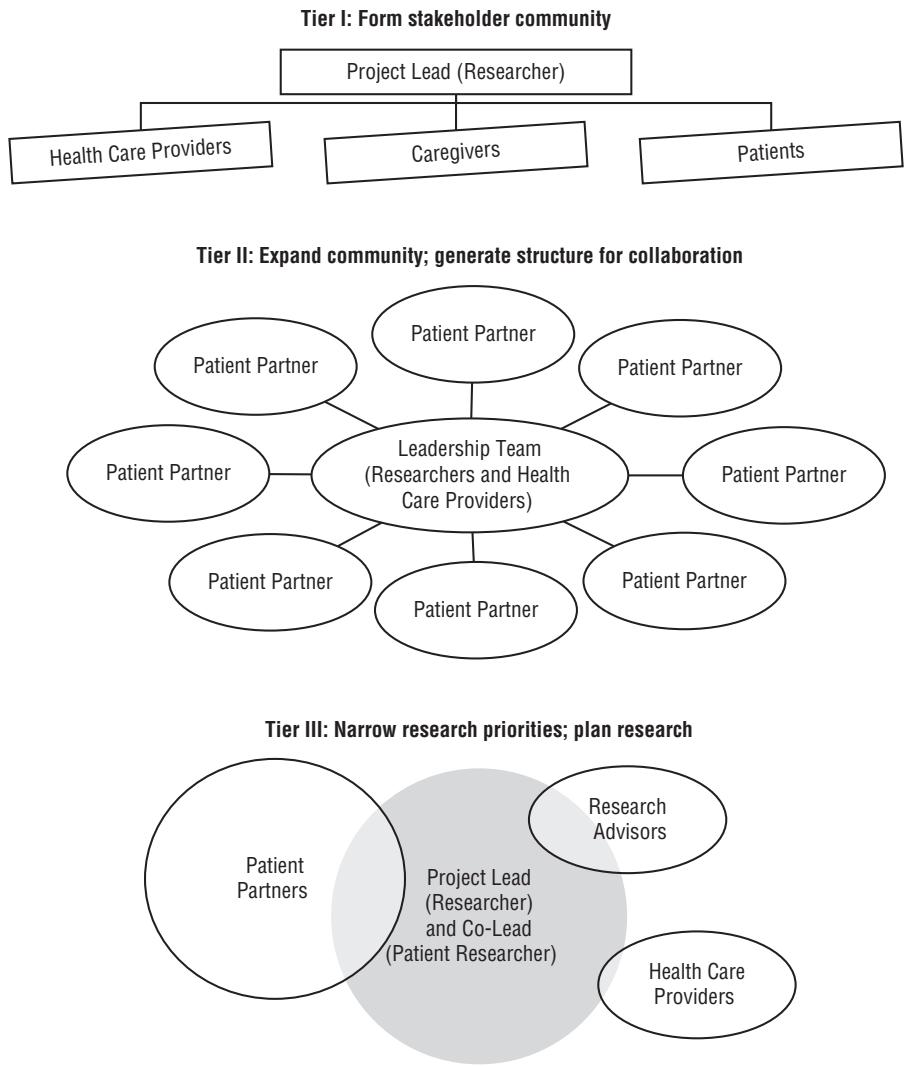
not include the perspectives of patients who lacked these resources and interests, perhaps as a result of structural or socioeconomic barriers to participation.

*Governance and Leadership.*

A primary outcome of the research planning initiative has been the development of guiding principles for future work, among these being ideas about governance (i.e., individual roles on the team and how decisions were made) and leadership. The project began with a top-down approach, acting from a researcher's idea and design. However, by the midpoint of Tier II, collaboration evolved toward a more distributed work model with a larger team of researchers and health care providers, along with increased integration of patients in planning and decision making. By Tier III, communication strategies shifted from individual to group meetings held monthly. See Figure 1 for a visual representation of team structure.

To support the participation of patient partners, who have a range of personal commitments, preferences, and needs, we offered in-person and online meeting formats for attendance. Individual follow-up was maintained to engage partners who were not able to attend the all-team meetings or who preferred speaking in a more private setting. In

**Figure 1. Evolving team structure as project aims shifted through tiers of funding mechanism.**

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addition, patient partners were provided a monthly stipend commensurate with their time and efforts on the project, and resources for communication (e.g., mobile technology and data plans, transportation) were distributed as necessary. By providing fair compensation for patient partners' expertise and addressing transportation barriers, most major decisions for research development could be made with input from all stakeholders, typically by majority vote after team discussion. Yet, in some cases, primarily with respect to administrative tasks or when expertise on grant funding processes were required, the project leads still made decisions and informed patient partners as quickly and thoroughly as possible.

### *Generating Deliverables.*

The primary aims of what PCORI (2017c) defined as a "pipeline to proposal," or P2P, project were to generate a fundable research proposal and establish a framework for ongoing engagement with the focal population. As stated previously, research and patient engagement strategies were developed through bidirectional communication: Patient partners presented ideas based on their experiences, and researchers generated ideas based on existing research literature (as exemplified by research priorities listed in Table 1). Given the organic nature of this process, not all patient priorities aligned well with existing funding opportunities. In these cases, patient partners' ideas outside the scope of possible funding were addressed through other activities in the PCORI grant to ensure that patient partners continued to gain desirable results from the research partnership. Therefore, in addition to outlining a research proposal with patient input, we accomplished several goals, described next.

### *Dissemination.*

To further engage patients as experts on their own experiences, we aimed to connect patient partners with a broad audience interested in health care research. Team members were invited to attend and present at local and national academic meetings and conferences (Carandang, Bashar, et al., 2016; Carandang, Haywood, et al., 2016; Carandang et al., 2017, 2018; Haywood & Carandang, 2016). In addition, team members advocated for patient engagement through professional networks and through social media, and they explored the use of digital storytelling as an effective medium for dissemination of personal narratives.

### *Patient Partner Resources.*

Over the course of the project, patient partners gravitated toward diverse aspects of patient engagement, including cultivating a safe space for themselves and their peers. They discussed ways in which the project team became a type of support; they expanded their social groups and facilitated connections with individuals who could relate to everyday challenges of being an AYA with a chronic condition. Friendships formed, and some partners even began to connect outside of meetings.

**Table 1. Sample of Research Priorities Generated in Tier II**

| General Topic | Source of Idea |
|---|---|
| Provider behaviors: impact on patients' engagement in health care and disease management | Team |
| Transportation: impact of accessibility on patient participation in health care and community | Team |
| Mental health: accessibility of, and AYAs' receptivity to, mental health services; effects of acute or long-term mental health services on coping | Patient |
| Complementary medicine and alternative therapies: availability of, and barriers to, complementary medicine | Patient |
| Knowledge dissemination: strategies for effectively sharing information across all stakeholder groups | Team |
| Public perception of health condition: influence of public perception on mental health, health status, and behaviors | Team |
| Role of peer mentors: accessibility to same-aged peers with similar experiences | Team |
| Developmentally tailored services: understanding age-specific needs of AYAs, including timing of diagnosis or injury | Researcher |
| Financial support: facilitators for, and barriers to, reliable medical coverage | Team |
| Target outcomes: differences between target outcomes between various stakeholders | Team |

*Note.* AYAs = adolescents and young adults.

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Patient partners were also interested in advocacy and personal and professional growth. To support this, we made a toolkit of resources relating to professional development, advocacy, patient organizations, and research. Throughout the project, patient partners gained experience in public speaking, professional networking, and writing. They gained new skills that were added to professional résumés and contributed to career goals.

### *Changed Perspectives.*

Although less tangible, researchers, health care providers, and patients involved in the project reflected on ways the research planning experience changed how they thought about research, representation, and practice. Patient partners learned more about research development, funding, dissemination, and strategies to use their voice for impact. Researchers explored ways to cultivate patient partnerships and learned about complex challenges that can emerge in daily life for young people with chronic conditions.

## Conclusion

Patient engagement in research directly aligns with values that support and inform patient-centered care. Patients have expertise on their own lives and on how an illness or disability affects health, activity, and quality of life. Moreover, patients provide insider perspectives on ways to reach their communities to communicate ideas and effect positive change. Given occupational therapy's longstanding commitment to empowering patients, involving patients as partners in research development and implementation is a natural next step in advancing the impact of occupational therapy and the wider health care field. There are many accompanying challenges, such as identifying common objectives, defining individual roles, and navigating dynamics of power and representation. However, these issues can be resolved with open communication and thoughtful collaboration. At a time when patient engagement is being recognized as a critical component of research, occupational therapy should be leading the way.

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