EDITORIAL

Why and How to Use Patient-Oriented Research to Promote Translational Research

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As we discussed in our first editorial in the December 2018 issue (Polaha & Sunderji, 2018), an emerging science of knowledge translation (also known as implementation and dissemination science) aims to bridge the disconnect between evidence and practice. Researchers are increasingly engaging with knowledge users and other stakeholders as a key strategy to promote uptake. This may include policymakers, payers, and—the focus of this editorial—patients. Patient-oriented research is featured in national research agendas around the world including in Canada (Canadian Institutes of Health Research, 2018) and the United States (Patient-Centered Outcomes Research Institute, see https://www.pcori.org/), in part as it may contribute one solution to the “bench to bedside” gap (Greenhalgh, Jackson, Shaw, & Jannahian, 2016; Jull, Giles, & Graham, 2017; McGavin, 2017). In this editorial, we provide a general introduction to patient-oriented research, its potential, and its realized value. We also suggest strategies for conducting patient-oriented research effectively, including a description of common barriers and how they can be dealt with. We hope this background will inspire you to get started with patient-oriented research and to learn more, as well as to share your patient-oriented research through Families, Systems, & Health.

Who Are Patients and What Is Patient-Oriented Research?

Patients may refer not only to individuals receiving health care but also to people and communities living with a health problem or health systems problem (Manafo, Petermann, Mason-Lai, & Vandall-Walker, 2018). Essential to the mission of this journal, families, loved ones, and caregivers are also included under this umbrella. In mental health and some other areas of health care where people do not feel comfortable with the label of patient, other terms are often used including clients, mental health service users, consumer-survivors, and people...
with lived experience, with each term having unique connotations, strengths, and limitations. For practical reasons, in this article, we will use the term patient while respecting that not all may identify with it. Patient-oriented research entails partnering with patients at some or all of the following stages of research: setting research priorities, carrying out and overseeing research, studying outcomes that matter to patients, and promoting uptake of research findings in practice (Canadian Institutes of Health Research, 2014).

Patient-oriented research has been described along a spectrum from sharing of information about research with patients (low engagement) to consultation or collaboration (moderate engagement) to true partnership with sharing of power and decision-making (high engagement) and even patient-led/controlled research, as shown in Figure 1 (Arnstein, 1969; “IAP2 Spectrum,” 2018; Maybee, Clark, McKinnon, & Nicholas Angl, 2016; Snow, Tweedie, Pederson, Shrestha, & Bachmann, 2013). Continuing in this vein, high-engagement research approaches may include community-based participatory research or participatory action research, wherein research priorities are defined by the affected community, power and decision-making are shared equitably throughout all stages of the research, and the research enterprise aims to further strengthen the community with an equity and social justice lens (Allen et al., 2017). However, “high” engagement is not necessarily better, as different levels of engagement may be appropriate in different settings or for different purposes. In a systematic review of patient-oriented research strategies and outcomes, Bombard and colleagues (2018) found that lower levels of engagement were more likely to lead to educational tools, policies, and other “discrete” products while higher levels of engagement were correlated with “structural outcomes” such as changes to service delivery and governance models.

**Why Should We Do Patient-Oriented Research?**

Numerous arguments have been mounted in support of patient-oriented research including moral and “consequential” arguments (Manafo et al., 2018; Wilson et al., 2015).

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**Figure 1.** Spectrum of engagement. Adapted from Patterson Kirk Wallace as cited by Health Canada (Corporate Consultation Secretariat, Health Policy and Communications Branch, 2000). This figure is an adapted copy of an official work that is published by the Government of Canada and the reproduction has not been produced in affiliation with, or with the endorsement of, the Government of Canada. See the online article for the color version of this figure.
Moral arguments include those based on democratic principles—it is the right of citizens or taxpayers to participate in publicly funded research, as well as ethical arguments—patients have a right to participate in any research or health care being done “to” them (Kendall et al., 2018; Wilson et al., 2015). In consideration of health as a human right, it has been proposed that patient participation in health research will make it more responsive to public needs and that inclusively engaging diverse patient partners can better address inequities, social determinants of health, and the quality of people’s lives (Beresford, 2007; Beresford & Branfield, 2006; Canadian Institutes of Health Research, 2014; Rifkin, 2014). Boivin, Lehoux, Lacombe, Burgers, and Grol (2014) tested the idea that patient engagement makes research more responsive to public needs in a randomized controlled trial in which Canadian communities set priorities for improving chronic disease management in primary care with or without patient participation in the priority-setting process. When patients were included, priorities better aligned with concepts in the chronic care model and patients’ medical home that support population health needs, for example, access to primary care, self-management support, shared decision-making, community partnerships, whereas without patients, health care providers were more apt to focus on technical measures of excellence in single disease management.

Engaging patients in research is consistent with the mission of dissemination and implementation science in helping develop interventions that have better potential for uptake and sustainability in real world settings (Allen et al., 2017). Patient engagement in research may also improve study enrollment and attrition rates, selection of outcomes meaningful to patients, and dissemination through project outputs relevant and accessible to affected communities (Domecq et al., 2014; Kendall et al., 2018). Patient-researchers’ direct experience and empathy can ensure research methods are responsive to, and effective in engaging, research participants, and their involvement can equalize relationships to facilitate a truly informed consent process (Beresford, 2007). They can support ongoing dialogue, increasing participants’ knowledge of research developments and feeding back ideas to researchers (Beresford, 2007), whereby researchers and patients/community members become colearners (Cawston & Barbour, 2003). Wright and colleagues (2016) described how a long-term action partnership between researchers and Aboriginal Community Controlled Health Services in New South Wales, Australia, trained and engaged its staff in the research process (including coauthoring articles) and thereby increased the tendency for study data to be owned, understood, and used locally.

While the impact of patient-oriented research on the research process is fairly well illustrated, its effects on health services, patient outcomes, and patient experiences are less studied and more poorly reported (Domecq et al., 2014; Manaf et al., 2018; Staniszewska et al., 2017). Inconsistency and uncertainty about terminology and definitions pose a major barrier to evaluation (Canadian Institutes of Health Research, 2016), as does a lack of agreement about what success in patient-oriented research looks like (Johannesen, 2017; Snape et al., 2014). Furthermore, it’s difficult to directly attribute outcomes to patient engagement activities given the complexity of these activities and their context-dependent nature; this, in turn, hinders cost–benefit analysis (Pizzo, Doyle, Matthews, & Barlow, 2015).

Rather than focusing on the impact of patient-oriented research on health outcomes, patient-oriented research may be better understood as a process to support implementation and sustainability of health interventions and programs (Rifkin, 2014). “Linkage and exchange” between academics (traditionally knowledge producers) and knowledge users (including but not limited to patients) “builds two-way bridges” (p. 409) that facilitate collaboration and potentially a greater social impact of research (Greenhalgh et al., 2016); see our December 2018 editorial (Polaha & Sunderji, 2018) for more on the bridge as a metaphor for translation of research into practice. Greenhalgh et al. (2016) hypothesized that because of its emphasis on civic engagement, intersectoral collaboration, power sharing, and ongoing conflict resolution, co-created research might have particularly strong and enduring impact on health and wider outcomes in the local or regional setting in which universities are located. (pp. 393–394)
What Are the Challenges in Doing Patient-Oriented Research?

Challenges in doing patient-oriented research stem from longstanding biases and narrow frames in which the patient role is cast. Historically, patients have often been involved in research as participants or advisors in a tokenistic way: without regard to whose voices are or aren’t heard, without being adequately resourced or compensated for their contributions, without being sufficiently oriented to the research to shape or respond to the questions being asked, and without seeing resulting changes after their perspectives have been taken.

Pragmatic barriers include the need for additional time, funding, and flexibility; engagement strategies to reach diverse and appropriate patients based on the research initiative; training for all research team members in patient-oriented research (not only for the patient members of the team); and inclusive mechanisms and processes for communication and decision-making that support power sharing throughout all phases of the work (Ocloo & Matthews, 2016). Scheduling meetings at times that are convenient for both patients and researchers can be challenging, especially if the researchers are also clinicians and if patients’ multiple competing demands are to be equally respected.

Attitudinal barriers include a reluctance to acknowledge power and privilege and redesign decision-making processes to be more egalitarian (Domecq et al., 2014; Gilbert, 2016; Greenhalgh et al., 2016; Ocloo & Matthews, 2016). Researchers may privilege their own scientific expertise, and clinicians and managers their pragmatic expertise, ahead of the experiential expertise of patients. Beresford (2005) noted, “[t]his problem is magnified for mental health service users . . . and they are frequently treated as though their knowledge is suspect because they are seen as irrational and lacking reliable perceptions and judgment” (p. 7). In addition, there is the more conceptual issue of how to reconcile tensions between experiential knowledge, empirical evidence and theoretical models. In a study involving the codesign of a cardiac health resource, Witteman and colleagues (2017) described the difficulties of agreeing on a final design that satisfied the sometimes-conflicting recommendations of clinicians, behavioral scientists, patients, and graphic designers.

In our experience, even with the best of intentions and adequate time and resources, there are also a number of structural hurdles to overcome. For example, research administration bodies such as research ethics boards (or institutional review boards) and human resources departments may have inflexible requirements that make it challenging for patients to become paid research team members. As well, grant applications require a concrete budget and timeline for engagement, whereas, by its very nature, effective engagement is flexible and responsive and may develop organically.

What Are Enablers of Good Patient-Oriented Research?

Greenhalgh and colleagues (2016) discussed cocreation of research by academics and other stakeholders emerging in a variety of fields including business, design, technology, and community development, and they identified common features of successful endeavors: (a) adoption of a complex adaptive system perspective (research is a nonlinear process and allows for emergence and unpredictable outcomes), (b) framing of “research as a creative enterprise with human experience at its core” (p. 412, research engages imagination to empathically design experiences for patients), and (c) heightened attention to process to reduce and mitigate power differentials (research is organized and carried out with attention to governance, relationships, inclusive leadership, and conflict management). Other principles espoused by the Canadian Institutes of Health Research’s (2014) Strategy for Patient-Oriented Research are inclusiveness, support, mutual respect, and co-building solutions (see Appendix A).

Beyond the adoption of these principles, there are many concrete enablers that can support research teams to conduct ethical and effective patient-oriented research. A preengagement reflection and planning process can help researchers achieve clarity on the aims of their engagement and the level of engagement they are prepared for (“Deliberative public engagement,” 2008). This reflection starts by articulating the problem the research will address and how involving patients will help: What are the goals of the engagement? Who, in particular,
will have insights into the questions being asked? Who are key stakeholders? Do not shy away from harder-to-reach populations or gatekeep against “unwanted” perspectives, but rather seek to engage and include disadvantaged groups whose exclusion would otherwise perpetuate health inequities (Beresford, 2007; Davis, Gaines, & Pandhi, 2017; Ocloo & Matthews, 2016). These may include, but are not limited to, people experiencing learning, language, or literacy challenges; poverty; mental illness or addictions; homelessness; or justice system involvement, as well as those who are single parents or part of diverse ethnic groups (Beresford, 2007).

Assess readiness for patient engagement in the research team and program in terms of attitudes, resources, and flexibility (Andreoli et al., n.d.; Oostendorp, Durand, Lloyd, & Elwyn, 2015; Patient Voices Network, n.d.); the latter facilitates clear communication at the time of engagement regarding any parameters limiting the outcome (in other words, what cannot be changed). These can be minimized by ensuring that the goal for engagement matches and is built into the stage of the existing program of research.

Engaging at least one experienced patient-researcher to help design and lead the process is invaluable, especially if they can commit the time to recruit harder-to-reach participants, help educate and orient participants to the research and to the information they will require to provide meaningful input, help create a welcoming environment, and act as a “neutral” party and a resource to help both patients and researchers navigate the challenging terrain of power differentials and decision making processes (Alberta SPOR Support Unit, 2018). A welcoming environment should consider the choice of location (not only accessibility but also the associations with given settings), provision of refreshments, number of participants (patients should not be greatly outnumbered), and elimination of financial and other barriers to participation (e.g., transportation, childcare) over and above pay for participation. Additional recommendations include using accessible language and starting meetings with icebreaker activities that can help to establish rapport and equal standing among team members.

Ideally, participants should have a range of choices about whether and in what capacity to participate. Consider that technology can act as a facilitator or barrier to engagement depending upon the people involved and how it is used (e.g., it may eliminate geographical barriers, or may introduce economic or literacy barriers or hinder formation of relationships; Forsythe et al., 2016).

Time is a crucial resource to find and orient participants, dialogue, and adjust the research—where necessary—in response to their feedback. Sustaining engagement work over time often fosters the ability for divergent and critical perspectives to be heard and responded to and for the purpose and nature of engagement activity to evolve, if desired.

Successful leaders are adept in recognizing and building upon participant strengths, flexible and open minded, active in their efforts to mitigate power differentials, and prepared to blur boundaries that reinforce power structures. Participation should increase patients’ capacity to engage in research (e.g., knowledge and skills, confidence, connection to a network) and may include orientation and training. Research findings should be fed back to participants in ways that are meaningful and understandable to them, enabling patients and communities to appreciate the value of their contributions and allowing researchers to better understand the implications and future directions of their work.

How Can You Get Started Doing Patient-Oriented Research?

In closing, we wish to offer some ideas for early patient engagement opportunities in your own research, as well as resources and further reading in Appendix B. Patient/community focus groups can be engaged to define priorities for future. Study advisory boards can include patients and help to shape protocols, recruitment strategies, and communications. Study outcome measures can include patient-reported outcome measures and patient-reported experience measures developed and selected with patients, using importance from patients’ perspectives as a key criterion (e.g. focused on quality of life and functioning, recovery, activation in own care, continuity of care, and so on; Ion, Sunderji, Jansz, & Ghavam-Rassoul, 2017; Nelson et al., 2015; Pincus, Scholle, Spaeth-Rublee, Hepner, & Brown, 2016; Sunderji, Ion, Lin, Ghavam-Rassoul, & Jansz, 2018; Tang, Ion, Stewart, & Sunderji, 2018; Wodchis, 2016). Projects underway or recently completed
could develop patient- or public-oriented outputs by or with—and for—patients who communicate study findings and implications for themselves and their communities.

In our first editorial (Polaha & Sunderji, 2018), we emphasized our vision for making a strong contribution to point-of-care delivery research. As a key knowledge translation strategy, an introduction to patient-oriented research seemed a natural follow-up, and with this in mind, we set out to write an informative, pragmatic, unbiased article. Easier said than done. For while advocacy has so far outpaced evidence, as researchers, clinicians, and patients who participate in patient-oriented research, we continuously observe the positive effects it has on our work and on us personally. This is our lived experience of patient-oriented research, and we encourage you to try patient-oriented research for yourself. Continue learning about it, approach it with a critical lens, measure as best you can the effects it has on our work and on us personally. This is our lived experience of patient-oriented research, and we encourage you to try patient-oriented research for yourself. Continue learning about it, approach it with a critical lens, measure as best you can the process and the outcomes, and . . . please share with us at Families, Systems, & Health your patient-oriented studies and insights.

References


WHY AND HOW TO USE PATIENT-ORIENTED RESEARCH


Appendix A

CIHR’s Principles of Patient-Oriented Research

Inclusiveness

Patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution—that is, patients are bringing their lives into this.

Support

Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial compensation for their involvement.

Mutual Respect

Researchers, practitioners and patients acknowledge and value each other’s expertise and experiential knowledge.

Cobuild

Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.

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(Appendices continue)
Appendix B

Useful Resources for Patient-Oriented Research

Key National Websites

- Involve (United Kingdom): https://www.involve.org.uk
- Patient-Centered Outcomes Research Institute (United States): https://www.pcori.org
- Strategy for Patient-Oriented Research (Canada): http://www.cihr-irsc.gc.ca/e/41204.html

Sites to Search for Specific Resources

- Patient Advisors Network: https://www.patientadvisors.ca/index.cfm?pagepath/H11005/Partnering_in_Healthcare/Resources/Health_Research_at_a_Glance&id=79500
- St. Michael’s Hospital: http://stmichaelshospitalresearch.ca/patient-engagement-resource

Training Resources and Courses

- Alberta Innovates: https://albertainnovates.ca/patient-oriented-research-training-program
- CHILD-BRIGHT: https://www.child-bright.ca/2018-summer-learning-series
- European Patient Ambassador Programme: www.EPAPonline.eu
- Ontario SPOR Support Unit: http://ossu.ca/training
- St. Michael’s Hospital Knowledge Translation Program “Partners in Research”: https://knowledgetranslation.net/education-training/partners-in-research

Guidelines and Toolkits for Patient Engagement

- University of Wisconsin Health Innovation Program HIPXChange’s Patient Engagement in Redesigning Care Toolkit: http://www.hipxchange.org/PatientEngagement

Tools for Evaluation and Dissemination