

Engaging with patients on research to inform better care

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Patients have always played a role in research, but this role has been traditionally passive, largely limited to providing data. The active involvement of patients in research activities is more recent, and research funders in Canada, the United States, the United Kingdom and elsewhere have urged the greater participation of patients, underlining the important stake that patients have in the outcomes of research and confirming that patients' lived experiences of health care offer unique and valuable perspectives. The Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) aims to engage patients in research in a variety of roles, including identifying research questions, designing studies, and contributing to decisions on recruitment, data collection and the analysis of findings.¹ This involvement is predicated on the belief that patients "must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians."¹

The commentaries in this supplement reflect on the experiences of 17 OSSU (Ontario SPOR SUPPORT [Support for People and Patient-Oriented Research and Trials] Unit) demonstration project teams that have involved patients in their research projects. In this introduction, we will discuss how the teams engaged with patients and service users, the challenges faced in this engagement and the learning that has emerged from these experiences.

Forms of engagement

Patients' engagement in their own care, in organizational activities aimed at improving care and services, and in broader policy decisions can be placed along a continuum that reflects how much information flows from providers and organizations to patients, and how involved patients are in decisions on their own care or in team and organizational decisions. Carman and colleagues describe this continuum as ranging from consultation to involvement to partnership and shared leadership.² When patients are consulted, they are given information but have limited impact on decisions; when patients partner, they share power and are active participants in defining agendas and

making decisions. Higher levels of engagement empower patients, but they may not necessarily be more effective or always desired by patients.²

This engagement continuum allows us to analyze how involved patients were in these research projects. Clearly patients in these projects were involved in many research activities. They participated in the design of the trials, selected outcome measures, aided in developing recruitment strategies, improved documentation for patients, participated in the design of knowledge-translation products and performed other tasks. The patients' roles in these efforts often went beyond simple consultation, and there are examples where patient insights influenced important decisions. For example, Ward and his team used existing hospital-based renal patient and family advisory councils to gain patient views on trial outcomes and alternative methods of patient consent in their MyTEMP study on hemodialysis (www.cmaj.ca/lookup/doi/10.1503/cmaj.180403). McGillion and colleagues describe how patient partners sought to have measures of the patient experience added to other trial outcomes, and together they developed a workshop that engaged patients in reviewing and selecting these measures (www.cmaj.ca/lookup/doi/10.1503/cmaj.180447). Measures of patient experience were also included in Reed and colleagues' study of guidelines for pediatric-concussion treatment, and these measures proved useful in guiding recommendations, for example, in suggesting different-sized elastic belts to use with accelerometers (www.cmaj.ca/lookup/doi/10.1503/cmaj.180450).

All the SPOR SUPPORT teams incorporated patient involvement in their research, and some altered their broader research strategies based on what they learned from patients. For example, Henderson and her team focused on improving access to services for youth with lived experiences of mental health and addictions. Although this research team initially was focused on understanding related symptoms, the youth participating in the project argued for a broader focus on functioning, and the outcome measures were altered to reflect this focus (www.cmaj.ca/lookup/doi/10.1503/cmaj.180328). Similarly, Christian Vaillancourt and colleagues note that prior studies of the Canadian C-Spine Rule focused on the extent to which the rule

identified relevant patients and guided their assessment, but with patient partners engaged, the authors undertook to assess a broader set of patient-relevant outcomes, including patient pain and discomfort, time spent in the emergency department before discharge or admission, radiation exposure and possible skin-pressure injuries resulting from prolonged immobilization (www.cmaj.ca/lookup/doi/10.1503/cmaj.180352). Researchers in several projects working with Indigenous communities discussed the critical role of partnerships with these communities and the need to collaborate from the development of their proposals. Walker and colleagues, in their First Nations Diabetes Project, identified the need for First Nations' ownership, control, access and possession of First Nations data and mutual capacity building of all the partners (www.cmaj.ca/lookup/doi/10.1503/cmaj.180479). That team also developed an integrated knowledge broker role that links the team to the Chiefs of Ontario, the Patient Advisory Group and other key leadership bodies whose support is essential for project success.

Challenges and opportunities

Several reviews have synthesized the literature to identify the challenges of engaging patients in research. Among key challenges are patients' frustrations with the timing and logistics of research, researchers' need to secure the funding required to recruit and sometimes compensate patients for their contributions and their travel, and the extra time that effective patient partnerships often requires.^{3,4}

These concerns are reflected in these commentaries. Time, resources and maintaining engagement are frequently mentioned challenges. Several projects found that recruitment, onboarding and support for patients were difficult, especially in contexts where the patient experience was limited in duration, such as emergency departments. In retrospect, several teams realized that they had not communicated their expectations clearly to the patients they recruited or fully communicated the time commitments they hoped patients could make. Some projects working with vulnerable populations realized that they had to be mindful of the burdens they were placing on the patients they asked to participate in the research, and that in some cases, the decline in patients' health status limited their participation over time and their ability to contribute as these projects advanced.

Several teams realized that they needed greater flexibility in their engagement strategies and recognized that patients could play various roles that broadened their contributions. For example, Lee and colleagues identified several roles for patients in their research: as patient advisors whose lived experiences with heart failure care informed the design of the intervention, as participants whose experiences would be assessed in the trial, and, later, as members of a stakeholder dialogue that will link a review of research evidence with the results of the discussions between citizens, patients, clinicians, researchers, administrators and policy-makers (www.cmaj.ca/lookup/doi/10.1503/cmaj.180462).

In several projects, the investigators learned that patients were not prepared to contribute to the tasks that investigators

had planned. For example, patients who were asked to evaluate quality indicators for primary care did not have sufficient background to assess the indicators on the traditional criteria used in research.

Recent reviews note that few projects include patients across all research activities, which limits their impact.^{4,5} Moreover, when they do participate, patient partners are often not representative of the broader populations of patients receiving care.⁶ Some teams in these commentaries deliberately focused on diverse engagement. For example, in research by Persaud and colleagues on access to medications for clients with limited incomes, the team recognized the possibility that they might exclude or underrepresent the views of vulnerable or disadvantaged individuals. To reduce selection bias, the team developed varying approaches to recruit participants, including working through community groups and handing out recruitment materials on the streets (www.cmaj.ca/lookup/doi/10.1503/cmaj.180415).

External factors also posed constraints in several projects, including the requirement that research teams receive approval from ethics review boards before engaging patients, a stipulation that creates a barrier to involving patients in the design of these projects.

Contributions from patient engagement

Many teams were creative in responding to these challenges. When Ivers and colleagues recognized that patients were struggling with the task of assessing quality indicators, they reframed the task to understanding what was important to patients in assessing quality of care and identified "unexpected and valuable insights" that are likely to inform future assessments (www.cmaj.ca/lookup/doi/10.1503/cmaj.180334).

Not surprisingly, engaging patients in identifying important outcomes of care led several teams to broaden the measures they developed, adding measures of patient experience and other patient-relevant metrics. Measures of patient and caregiver outcomes and experiences were identified in a study of care transitions for older adults. Researchers studying care for medically complex children are working with the caregivers of these children to identify trial outcomes that are meaningful for patients, including measures that reflect better care coordination. These measures, selected by parents and clinicians, will augment current research measures.

Researchers designing pragmatic trials need to understand how implementation strategies should vary depending on contexts. The lived experiences of patients who have received care in these settings is valuable input for trial design as researchers in several projects discovered.

More fundamentally, the experiences of these OSSU projects join in the beginnings of an important shift in relationships between researchers and patients. Growing appreciation of the world views of patients and users broadens the perspective of researchers, even for those working in clinical roles that focus on these populations. The shift is perhaps clearest in projects in which researchers are engaging communities, not just groups of patients with similar clinical experiences. For example, in their

efforts to design interventions for youth with lived experiences of mental health problems and addictions, researchers partnered with youth in the governance group, in a community advisory group and on the project working groups. Multiple interactions offer varying avenues for input into the design of youth-friendly initiatives. Several other projects focus on Indigenous health issues. Researchers in these projects underline the importance of community engagement aimed at understanding both the specific needs and the broader environment in which these needs exist and where interventions will be developed.

Patient engagement has important tactical challenges that require accommodation: creating and sustaining relationships over time; showing flexibility in the modes and means of interaction; and allowing patient partners to contribute in ways that hold meaning for them. Beyond tactics, successful collaborations need to address the values and meanings identified by those with lived experience. As Walker and Young note in reflecting on their research projects with First Nations, successful collaborations must build on an understanding of the values and principles critical to these communities and their experiences (www.cmaj.ca/lookup/doi/10.1503/cmaj.180479 and www.cmaj.ca/lookup/doi/10.1503/cmaj.180381).

Conclusion

Patient engagement in research has developed considerably over the last 20 years. The support of funding bodies such as the CIHR in Canada, National Institute for Health Research in the UK and Patient-Centered Outcomes Research Institute in the US has heightened interest in patient-oriented research. Journals have begun to ask researchers to declare how patients were engaged in the research. Researchers are beginning to realize that their views of important outcomes often reflect an unstated bias toward clinical and system outcomes rather than patient experiences, and that giving voice to patients can help to balance these perspectives.

The experience of researchers with patient engagement is still in early stages. There is yet limited evidence of the impact of patient engagement on research,^{4,6} and guidance on engaging patients is emerging, but not fully tested.⁷ Researchers and patients will continue to learn how to negotiate effective partnerships, identify shared interests, discuss and agree on

expectations and collaborate effectively. These competencies, coupled with evidence of the benefits of patient-oriented research, are likely to reinforce commitments to the patient-oriented research agenda.

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