Patient-Oriented Research: Enhancing Partnership-Engaged Knowledge Mobilization for Impact

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Abstract

Patient-engaged research requires strong patient and applied partnerships to realize innovative knowledge mobilization. Demonstrating impact and sustainability, advancing health equity, evaluating engagement and incorporating flexibility are key ingredients to advance engagement science.

Demonstrating Impact and Sustainability

Over the span of a decade, Canada's Strategy for Patient-Oriented Research (SPOR) has provided the impetus for core developments in patient-engaged research in the country (CIHR 2011). SPOR SUPPORT Units across the provinces and territories have built key infrastructure and capacity for patient-oriented research (POR), thereby strengthening the science and practice of POR. Ontario's SPOR SUPPORT Unit (OSSU), specifically, has been a major catalyst for patient-engaged research within the province. Since the launch of OSSU in 2015, the field of patient engagement and involvement in Ontario has shifted from foundational levels of involvement to increasingly advanced engagement (Hamilton et al. 2021). Core to advanced engagement is equal partnership and shared decision making, and the reciprocity of shared decision making and balanced partnerships illustrates the necessity of impact for sustainability. Perhaps the epitome of this evolution is that of meaningful partnership and integrated knowledge translation.

In 2017, OSSU initiated the Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach (EMPOWER) Awards to mobilize knowledge and enhance patient-partnered relationships arising from research seeking to integrate patient and community voices. Awardees addressed core criteria of partnership and demonstration of impacts for patients, policy and practice. Across the compendium of the 15 EMPOWER projects are valuable lessons learned, which can inform future directions to advance POR for improved health outcomes.

Of note, the supplement outlines the impacts achieved through patient partnership. Perhaps, a key descriptive – and foundational – word is "collective"; without collective efforts, the translational gains achieved would certainly be more modest. EMPOWER Award recipients emphasized project co-creation and co-design from inception to impact and partnerships often outlasting end-of-project funding. Common to all projects are strong and diverse engagement strategies that help involve end-users in knowledge mobilization. Some strategies are familiar, such as involving patients and caregivers on Advisory Councils, and patient participation in research team meetings. Other strategies have sought to "push the boundaries" of innovation (e.g., Syan et al.'s [2022] youth-led grant application preparation) and address engagement in virtual technology (e.g., Birnie et al.'s [2022] engagement with youth and families to develop best practices for virtual care). The

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projects also aptly illustrate that engaged partnership can begin anew or that enhanced partnerships can emerge from existing relationships. At the core are values of trust, humility, respect and shared vision, with an emphasis on communication, community, shared leadership, active and meaningful engagement and shared decision making (Haywood et al. 2017).

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Advancing Health Equity

A predominant and cross-cutting theme is the increasing recognition of and emphasis on health equity across projects. Health equity involves fairness in the distribution of resources needed for health, access to available opportunities and supports and health outcomes (CIHR 2019). Rigorous and diffuse integration of equity considerations is essential for meaningful research impact (Browne et al. 2012), and EMPOWER awardees appreciated the importance of equity, diversity and inclusion (EDI) in this manner. Some projects included diverse populations or communities reflective of end-users, with the goal of addressing priorities or translating best practices that would meaningfully meet the needs of stakeholders. Many authors embodied equity in shared design and decision making since project inception via patient- and community-driven projects; some projects specifically emphasized the inclusion of marginalized voices (e.g., Black, Indigenous and People of Colour communities) to address stigma, discrimination and bias; others had patients/caregivers directly affected by health issues as project leads in dissemination efforts. One project that highlighted advanced engagement was Mulder and colleagues' (2022) First Nations–led study on aging, which describes ongoing work with First Nations people, makes unique contributions by integrating traditional First Nations' knowledge and methodologies with health services data and calls attention to the need for action based on knowledge gained through research.

As we move forward in a learning health system that prioritizes EDI and Indigenous sovereignty, health and wellness, OSSU's Fairness is Excellence EDI Framework (Ontario SPOR SUPPORT Unit 2022) can serve as an exemplar for POR researchers, trainees and health system decision makers. In particular, the framework outlines concrete and specific steps that individuals can take to address health equity, from selecting a research topic, recruiting and retaining staff and students to analysis and knowledge mobilization.

Incorporating Flexibility to Address New Challenges

While these EMPOWER Awards outline a number of success stories of partnering with patients to conduct research and knowledge dissemination – much as with research in general – unanticipated challenges emerge. The most notable challenge was the emergence of the COVID-19 pandemic and the unanticipated health system impacts due to both direct and indirect impacts of the pandemic. The shift to virtual platforms and remote care as the default has forced teams to think and adapt. For projects that were already underway, teams had to rapidly pivot to incorporate virtual models. For example, the Transplant Ambassador Program (TAP), which traditionally situated TAP ambassadors in dialysis units and in hospitals, had to shift to virtual platforms. Yet by doing so, TAP ambassadors expanded their geographical reach to engage patients from across Ontario. Virtual tools have suddenly increased the scale of projects by removing previous geographical limitations and yet introducing challenges in terms of scope and feasibility.

Widespread use of virtual technology has also amplified concerns around digital equity: digital and virtual care may compound existing barriers if these options are inaccessible to some groups or for those who are vulnerable because of existing health inequities (Asmundson et al. 2020). Birnie al.'s (2022) project sought to address this challenge by specifically engaging a diverse sample of youth to ensure that recommendations for best practices for virtual care are inclusive and equitable. Furthermore, the perspectives of patients in Tingley et al.'s (2022) project shed light on another potential challenge: that of data sharing and privacy concerns. This team engaged patients as partners to better understand how core outcome sets can be implemented in research.

A recurring challenge that continues to emerge is sustainability: How do we continue to recruit and retain patient partners? Certain projects are particularly susceptible to this challenge, particularly those working with certain populations or diseases. For example, Syan et al. (2022) working with the Youth Wellness Quest resource, a youth-led resource for mental health, encountered multiple challenges with turnover, given the multi-year duration of the project combined with high mobility of youth. The landscape of patient partner researchers, while growing, remains small. Therefore, it can also be difficult to identify individuals to take on leadership roles in projects that require substantial time commitments for various reasons, including family commitments, employment or interest.

Strengthening Evaluation of Patient Engagement

There is growing recognition of the need to evaluate patient engagement, including its impact not only on patient outcomes but also on patient and researcher experiences and outcomes and research quality. There is also a need for transparency around potential biases/limitations that may occur, such as implicit biases surrounding diversity of experiences or capabilities for engagement. Impact evaluation remains an emerging field, with no established standard for measurement; however, it is vital to engage patient partners in the planning and conduct of any evaluation. Several of the EMPOWER awardees discuss tools or instruments used to evaluate engagement. Vanderhout et al. (2022) required members of the Parent and Clinician Team to complete the Patient Engagement in Research Scale (PEIRS), a 37-question instrument developed by Clayon Hamilton and Arthritis Research Canada (Hamilton et al. 2018). Other projects used the Patient and Public Engagement and Evaluation Tool (PPEET), which was developed by Julia Abelson and the PPEET Research-Practice Collaborative at McMaster University (Abelson et al. 2016). Both tools were developed in partnership with patient partners, adding relevant lived experience content expertise to the tool development process. Few projects evaluated the impact of engagement on health or health system outcomes.

There are other important questions to ask about evaluating patient engagement that require further research. Beyond the psychometric or performance properties of evaluation tools, what about the evaluation of co-design in patient partnership? The effectiveness of research co-design has seldom been evaluated, despite its widespread use and descriptions of the benefits and challenges of the design-led process (Slattery et al. 2020). Nor do we know what engagement methods work for whom and in what context. Furthermore, what about the impact on patient care and outcomes? Certainly, applying tools to evaluate patient engagement that have been co-designed with partners should be the minimum expectation to measure and yield critical input regarding how patients are involved in research, including adherence to the values of respect, collaboration and teamwork. But as outlined in Rahimi and colleagues' (2019) study, tools that predict the results of research that engages patients are also required, as well as how those results may vary by level of engagement or change over time. We further suggest evaluation of the impact of patient partnership on the research team and quality of research and movement beyond patient-specific measurement to assessment that includes multiple stakeholders. Moreover, study teams should outline how they have responded to patient engagement evaluation findings – evaluation and tools are only useful if they stimulate action.

Ingredients for Impactful Research

Grounded in values and shared decision making, EMPOWER recipients are clear on successful ingredients for impactful research: first and foremost is the central role of patients and communities. If POR is intended to yield impactful change, matching patient/community priorities and engagement approaches is essential for success in dissemination, uptake and wider impacts. Awardees emphasized the need to create engagement-capable environments and the strategies they used to achieve them: mechanisms to promote genuine inclusion, joint decision making about the research, intended impacts and mechanisms to achieve these impacts. Together teams co-created alternate methods of engagement, taking a multi-faceted approach – for example, including multiple patient partner perspectives, involving clinicians and policy makers, patient and researcher role-sharing, centralizing lived experience, providing resources and supports to increase awareness of roles, sharing collaboration along a pathway forward and active engagement in research priority setting.

Positive impacts exemplify the value-add of the projects: increased engagement and motivation to effect change on the part of both patients and researchers, mutual learning, strengthening team cohesiveness and mobilizing findings into policy recommendations. That all of the articles are either led or co-authored by patient partners speaks to the prioritization of patient and community perspectives and experiences.

The continuation of SPOR signals the ongoing importance of POR in Canada and a shift toward a rapid learning health systems approach. Learning health systems approaches leverage advancements in data science, experience and best practices for health system improvement (Menear et al. 2019). These systems are characterized by engaged patients, relevant and timely generation of data-driven evidence, appropriate decision-making supports and flexibility in governance, finances and service delivery to support rapid learning and performance improvement that fosters collaboration, continuous learning, adaptation and overall system improvement (Lavis et al. 2018). Patient and community engagement, experience and partnership are core to health system transformation at a time when building comprehensive and performance-effective systems are key to the best possible health outcomes. Moving forward in this context, it behooves us to consider how to embed patient engagement infrastructure and policies within our health institutions and organizations for meaningful impact.

Embedding POR within learning health systems will ensure that patient perspectives and experiences are centralized in health systems and infused throughout rapid-cycle learning and performance improvement efforts. How can we maintain or advance timely, meaningful research–practice–policy partnerships with patients and communities and avoid losing POR gains in the context of rapid-cycle health system improvements? Instead, how do we apply what we have learned in POR to maximize patient engagement in health system design and delivery? How do we shift the narrative such that involvement becomes part of everyday conversations? How do we support organizations and health systems to incorporate patient engagement within their governance and policies and evaluate their engagement strategies to foster rapid-cycle learning in this realm? And importantly, how do we create spaces to equitably include patient and community perspectives, avoid further marginalization and address intersectionality?

As patient partners expressed at the recent OSSU Training and Capacity Building Event, we need to "meet people at the intersections" to best understand how to address the determinants of health and achieve health equity for all. The messages assert a call to action to mobilize the knowledge we have gained as we continue to advance the science and practice of patient and community engagement. It is about enhancing *partnership*-engaged knowledge mobilization for impact. HQ

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