Empowering and Accelerating Impacts of Patient-Oriented Research

Peter J. Gill, Diana Urajnik and Rebecca Ganann

Abstract

Patient partnerships require adequate planning, support and funding to mobilize knowledge and accelerate impact. We outline the themes and foreground ways in which the Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach teams have advanced patient-oriented research in Ontario.

Introduction

At its core, the aim of health research is to improve patient care and outcomes. Yet, for decades, patients have not been active members of the research enterprise. How can we ensure that healthcare research is relevant and applicable to the ultimate end-users without involving them from the outset? The growing recognition of the need to partner with patients has led to large-scale initiatives to put patients at the centre by engaging them in research teams and decisions. Canada has been a global leader with the launch of the Strategy for Patient-Oriented Research (SPOR) in 2015 (CIHR 2019). Patients should be involved in all stages of research, including the development of the research question, applying for and securing funding, conducting the study, interpreting the results, co-authoring knowledge products and disseminating information (Gill and Cartwright 2021). As we seek to address a key priority of the *CIHR Strategic Plan 2021–2031* to "Pursue Health Equity through Research" (CIHR 2021: 4), researchers need to pursue equity through patient-oriented research (POR) aims and through the composition of teams and engagement of patient partners throughout the research enterprise.

Parallel to the greater awareness and emphasis of patient involvement and health equity in research is the increased recognition of effective knowledge translation approaches. Simply conducting research and assuming that new information will naturally infuse into clinical practice is naive and wasteful. Knowledge translation refers to activities that help raise awareness of research findings (e.g., presentations, lay summaries, etc.) (CIHR 2016). In contrast, integrated knowledge translation (IKT) involves knowledge users, including patients and decision makers, as research team members from the outset. IKT is collaborative, with a commitment to co-production that increases the applicability and relevance of final products (Banner et al. 2019). Previous research has shown that projects incorporating an IKT approach, including integrating patients as partners, leads to optimized health system performance and improvements in health outcomes (CIHR 2015).

Patient partnership and IKT require adequate planning, support and funding. Recognizing the importance of knowledge mobilization, the Ontario SPOR SUPPORT Unit launched the Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach (EMPOWER) Awards in 2019 (OSSU 2021). These awards aimed to provide additional end-of-grant funding to POR projects to empower wider research impacts in Ontario.

EMPOWER Goals and Outcomes

Canada's Strategy for Patient-Oriented Research (SPOR) was created by the Canadian Institutes for Health Research to engage patients, researchers, clinicians, policy makers, industry representatives and other health system professionals. It is a national collaboration of federal, provincial and territorial partners dedicated to enhancing the integration of research into care. The goal of SPOR is to integrate funding, research and expertise with users' perspectives and experience to foster evidence-informed healthcare to ensure greater quality, accountability and accessibility and inform policy and practice.

The Ontario SPOR SUPPORT Unit (OSSU) is a collaboration of leading health research centres, research initiatives and a coordinating centre dedicated to supporting patient-oriented research (POR) in Ontario. The coordinating centre facilitates, connects and integrates activities across the network, including the facilitation, implementation and mobilization of SPOR in Ontario.

The Engaging Multi-stakeholders for Patient Oriented-research Wider Effects and Reach (EMPOWER) Awards launched by OSSU in 2019 aim to provide additional end-of-grant funding to recently completed POR projects to enhance and broaden the uptake and impact of research evidence. In particular, the goal is to promote and enable patient-partnered research teams to build relationships with patient partners and push evidence to those who can use it to inform their healthcare policy and decision making.

The articles in this special issue outline the experiences of the 15 EMPOWER Grant Award winners from 2019 to 2021. The special issue is divided into main themes based on the patient-partnering methods and tools used by the EMPOWER teams: (1) priority setting and best practices; (2) equity in patient partnerships; (3) co-designing interventions and tools; (4) tools for patient engagement; and (5) patient- or community-driven projects. This article will introduce these themes and foreground the ways in which the EMPOWER teams have advanced POR in Ontario. Each article is led or co-authored by patient partners, and the authors collectively describe how engagement was initiated and sustained, the insights gained through engagement and the impacts achieved.

Priority Setting and Best Practices

When conceptualizing research, an important question often arises: what topics or priorities should be researched? Identifying priorities provides a set of specific, concrete tasks to achieve over time. They are also strategic to focus limited time and energy. There are numerous ways that research networks, organizations, funding agencies and foundations can identify priorities. It can be done informally, such as based on strategic skills, or formally, such as based on burden of illness, cost and variation in care, or formally by using consensus methods (e.g., Delphi surveys) (Manafò et al. 2018). In alignment with POR principles, patients should be actively involved in identifying research priorities; James Lind Alliance Priority Setting Partnerships are a commonly used approach to engage patients, caregivers and clinicians in identifying and prioritizing unanswered research questions that are of shared importance (Nygaard et al. 2019).

After identifying the top 10 patient-oriented priorities in pediatric chronic pain (Birnie et al. 2019), Birnie et al. (2022b), in their 2020 EMPOWER project, partnered with youth and parents to maximize the impact of the priorities in research, care and policy. Building on the strong patient involvement strategies used to set the priorities, the team partnered with the pediatric chronic pain community to generate awareness, facilitate collaborative dialogue and innovation to address the priorities and engage the broader pediatric pain community to integrate and adopt the priorities into clinical practice, policy and advocacy.

Another example of patient-oriented priority setting was led by Ristevski et al. (2022b). These authors identified the top 10 research priorities in Canada for retinoblastoma (Flegg et al. 2020), a serious and rare cancer of the eye. Recognizing the challenges of mobilizing action on the priorities, they developed a number of knowledge dissemination tools and processes. One strategy entailed the unique approach of hiring a "parent in research" to lead the development and dissemination of the priorities. The Birnie et al. (2022b) and Ristevski et al. (2022b) projects illustrate that identifying priorities alone is insufficient – a multi-pronged approach is needed to ensure that these priorities result in further research and actual system change.

Equity in Patient Partnerships

The integration of equity and diversity considerations in patient partnership is essential for ensuring maximal impact of health research. Patient partnership, however, has been challenged as a result of the COVID-19 pandemic, along with exacerbation of social inequities in health (Sayani et al. 2021). While equity is a recurring theme in this special issue, the Birnie et al. (2022a) and Vanderhout et al. (2022) projects emphasize inclusivity and equity for patient engagement and research impacts in response to the pandemic.

One of the major impacts of COVID-19 restrictions in healthcare was the transition from in-person visits to virtual care. Recognizing that certain marginalized communities (e.g., People of Colour, Indigenous Peoples) were excluded from pain services and research, combined with the potential of virtual care to exacerbate health inequities, Birnie et al. (2022a) engaged with a diverse group of youths living with chronic pain and their families to develop best practice recommendations for virtual care. While the project identified opportunities for virtual care to reduce stigma, bias and discrimination, it also described key gaps, including lack of reliable Internet access and challenges associated with virtual delivery environments (e.g., access to private settings for visits). Key messages for patient-oriented care included the need for joint decisions with families about whether appointments should be virtual or in person.

The pandemic also had direct impacts on children and their families. The COVID-19 Study of Children and Families sought to better understand these impacts, building on the well-established TARGet Kids! Primary care research network. Vanderhout et al. (2022) describe the parent engagement in the development of the study, including co-developing documents and attending meetings as grant co-applicants. While parent engagement was described as successful overall, key shortcomings included difficulties recruiting fathers and parents who represent the ethnic and sociodemographic diversity of the target population.

Identifying priorities provides a set of specific, concrete tasks to achieve over time.

Co-Designing Interventions and Tools

With an emphasis on mobilizing knowledge from their existing patient-oriented studies, several projects engaged patient partners in co-designing interventions and tools to advance patient-oriented care. Collectively, these teams sought to promote POR in intervention studies, advance equity and demonstrate important returns achieved through investments in patient partnerships.

Parry et al. (2022), in partnership with Clinical Trials Ontario, aimed to widen the effects and reach of digital POR decision aids for patient partners and researchers. These capacity-building tools were created to support learning about POR, set priorities, expand understanding and evaluation of patient engagement in clinical trials, assess readiness and make decisions. The team engaged wide stakeholder audiences to mobilize these tools to end-users across Ontario. Parry et al. (2022) demonstrate the application of relevant frameworks to POR, patient-partner leadership roles in multi-faceted dissemination strategies and advocacy and offer insights into benefits and challenges associated with partner engagement in longer-term projects.

Similarly, Kuluski et al. (2022) built on their early engagement work to co-design an intervention to address delayed care transitions and improve care quality. The team co-designed a communication guide to engage and support patients and caregivers in transitional care communication, decisions and plans. Through meaningful partnerships, this team amplified patient and caregiver voices and advanced advocacy roles, by engaging their patient and caregiver council in creative knowledge mobilization that centralized lived experience perspectives.

The *MyDiabetesPlan* by Pan et al. (2022) aimed to evaluate the implementation and impacts of patient engagement in a large-scale innovative digital health trial. Impacts were explored from diverse stakeholder perspectives qualitatively. Their engagement evaluation showcases meaningful engagement and the mechanisms to achieve this. Notably, the team details the impacts of engaging with the *MyDiabetesPlan* tool and ensuring alignment with the specific needs of the target population. Pan et al. (2022) also offer critical insights into contextual factors that enabled and hindered engagement impacts.

Tools for Patient Engagement

Beyond co-designing interventions, the next theme focuses on patient-led projects that developed tools for patient engagement. Naylor et al. (2022) sought to increase access to kidney transplantation and living kidney donation; together, they developed the Transplant Ambassador Program (TAP), a volunteer patient-led program where patients with kidney disease are connected with someone who received a kidney transplant or who donated a kidney. Unlike busy healthcare professionals, these volunteers can dedicate more time, offer personal insights and provide inspiration to patients with kidney disease. TAP is part of a larger research network and trial, providing an example of patients informing important research questions and initiatives.

Identifying priorities and launching studies is by itself insufficient if research participants are not diverse or reflective of the population impacted. To address these concerns and building on the top 10 priorities in retinoblastoma research, Ristevski et al. (2022a) sought to catalyze patient involvement in research by developing a *Retinoblastoma Research and You!* booklet. The project, led by patients, used a human-centred design methodology to co-create a patient engagement booklet with healthcare professionals and researchers. The booklet helps explain what is involved and the benefits of partnering with research and has accelerated peer-to-peer recruitment efforts, particularly during the pandemic.

Patient engagement can be particularly fraught when it relates to marginalized communities; one such population is people with intellectual and developmental disabilities (IDD). Jiwa et al. (2022) illustrate the value of tools that can introduce patients to their providers and help patients prepare and document what happens during a visit. But more importantly, the project illustrated the importance of including patients with IDD, not just their family or workers, despite challenges such as those in comprehending verbal and written communication. For example, one patient advisor interacted with 60 physicians at a conference, sharing his experience and perspective with each individual, which ultimately challenged stereotypes.

As the science of patient engagement advances in Canada, researchers are challenged to push boundaries to integrate patients into innovative study designs and stages of research that have less frequently engaged patient partners in their design and implementation. Fox et al. (2022) offer one such example as they describe the powerful roles of patient partners in the development of selected tools to support early-phase clinical trials. The article highlights an innovative visual consent tool and non-technical summary, as well as an online peer-support model for trial participants. Through patient partnerships, the team gained critical insight into considerations that would not otherwise have been identified.

Patient- or Community-Driven Projects

Moving along the spectrum of patient participation to empowerment, the future of research is one in which research-based decision making is in the hands of patients and patient- or community-led projects. Four of the EMPOWER team articles showcase projects that were community- or patient-driven from the outset.

Tingley et al. (2022) – building on work that led to the recent development of core outcome sets for two rare inherited metabolic diseases (phenylketonuria and medium-chain acyl-CoA dehydrogenase deficiency) (Pugliese et al. 2021) – recognized the importance of identifying barriers and facilitators to implementing these outcome sets in future research. Two patient/family partners led the patient engagement strategy, which identified novel insights to guide future research (e.g., the importance of consent and privacy). Similarly, Syan et al. (2022) describe youth-led development and dissemination of the Youth Wellness Quest resource, which helps youth navigate mental health services. The youth-led team recognized the importance of developing an online version of the Youth Wellness Quest and led the grant application and subsequent implementation to develop a resource that is freely accessible (https://moodle8.camhx.ca/moodle/course/view.php?id=20).

Mulder et al. (2022) describe ongoing work related to the First Nations Aging Study funded by the Canadian Institutes of Health Research, which identified important health differences between First Nations people and non-First Nations people in Ontario. The authors set out to raise awareness about the key findings of the study, with key individuals working with First Nations people to better understand the impact of prior knowledge translation initiatives. They describe the importance of adding the principle of action to the traditional set of core principles of First Nations ownership, control, access and possession (OCAP®).

Finally, Sayani et al. (2022) outline the participatory co-design that led to the development of EMPaCT (Equity-Mobilizing Partnerships in Community), a community-designed patient partnership that aims to identify key areas for action in health equity for maximal impact. They provide unique insights about co-designing a scalable and sustainable model of equitable patient partnership. This team engaged in participatory co-design using an equity-oriented intersectional lens and trauma-informed approaches to engagement. This paper makes a unique contribution to POR by highlighting advancements in equitable patient partnerships, in particular, as they relate to sustainable and scalable models of patient engagement.

Conclusion

The diversity and range of projects supported by the EMPOWER Award illustrate the value of involving patients. They include examples of new partnerships formed to improve outcomes or innovative projects building off existing patient partnerships. The COVID-19 pandemic accentuated the critical inequities in our healthcare system and the communities disproportionately impacted by both SARS-COV-2 directly and the indirect impacts of lockdowns. Several EMPOWER Grant Award winners explicitly aimed to address health inequities in Ontario using a range of approaches, including stakeholder engagement with impacted communities.

While the style and structure of the articles vary, each project team outlines how the project started and how they sustained meaningful engagement and shares the experiences of both the research team and patients. Furthermore, they describe the overall value added through patient involvement and describe the evaluation of impacts, in particular, on patient partners, research, researchers and other key stakeholders. Teams also reflect upon real-world implementation challenges and how these challenges were mitigated.

What these projects have in common is the shared sense of purpose, where patients are placed at the centre. Ultimately, this special issue underscores that the key to making an impact in healthcare is valuable input from and uptake by end-users. These exemplary projects help to illustrate the "how to" for decision makers and other stakeholders so that they can catalyze research into impact and support the shift to meaningful engagement and involvement. HQ

References

Banner, D., M. Bains, S. Carroll, D.K. Kandola, D.E. Rolfe, C. Wong et al. 2019. Patient and Public Engagement in Integrated Knowledge Translation Research: Are We There Yet? *Research Involvement and Engagement* 5: 8. doi:10.1186/s40900-019-0139-1.

Birnie, K.A., K. Dib, C. Ouellette, M.A. Dib, K. Nelson, D. Pahtayken et al. 2019. Partnering for Pain: A Priority Setting Partnership to Identify Patient-Oriented Research Priorities for Pediatric Chronic Pain in Canada. *CMAJ Open* 7(4): E654–64. doi:10.9778/cmajo.20190060.

Birnie, K.A., T. Killackey, G. Backlin, F. Gavin, C. Harris, I. Jordan et al. 2022a. Ensuring Equity and Inclusion in Virtual Care Best Practices for Diverse Populations of Youth with Chronic Pain. *Healthcare Quarterly* 24(Special Issue): 25–30. doi:10.12927/hcq.2022.26778.

Birnie, K.A., C. Ouellette, J. Marianayagam, F. Campbell, C. Lamontagne, P. Forgeron et al. 2022b. Partnering with Youth and Parents for the Greatest Impact of Top Patient-Oriented Priorities in Pediatric Chronic Pain Research, Care and Policy. *Healthcare Quarterly* 24(Special Issue): 18–23. doi:10.12927/hcq.2022.26779.

Canadian Institutes of Health Research (CIHR). 2015, March. Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. Retrieved October 30, 2021. <https://cihr-irsc.gc.ca/e/45321.html#f1>.

Canadian Institutes of Health Research (CIHR). 2016, July. About Us – Knowledge Translation. Retrieved November 30, 2021. <https://cihr-irsc.gc.ca/e/29418.html>.

Canadian Institutes of Health Research (CIHR). 2019, May. Strategy for Patient-Oriented Research – Patient Engagement Framework. Retrieved August 20, 2021. <https://cihr-irsc.gc.ca/e/48413.html>.

Canadian Institutes of Health Research (CIHR). 2021, February. *CIHR Strategic Plan 2021–2031*. Retrieved November 30, 2021. <https://cihr-irsc.gc.ca/e/documents/cihr-strategic-plan-2021-2031-en.pdf>.

Flegg, K., M.J. Gelkopf, S.A. Johnson, H. Dimaras; for the Canadian Retinoblastoma Research Advisory Board Priority Setting Steering Committee. 2020. The Top 10 Retinoblastoma Research Priorities in Canada as Determined by Patients, Clinicians and Researchers: A Patient-Oriented Priority-Setting Partnership. *CMAJ Open* 8(2): E420–28. doi:10.9778/cmajo.20190221.

Fox, G., D.A. Fergusson, M. Foster, T. Hawrysh, S. Dupont, D.J. Walling et al. 2022. Building a Platform for Meaningful Patient Partnership to Accelerate "Bench-to-Bedside" Translation of Promising New Therapies. *Healthcare Quarterly* 24(Special Issue): 74–79. doi:10.12927/hcq.2022.26770.

Gill, P.J. and E. Cartwright. 2021. Partnering with Patients in the Production of Evidence. *BMJ Evidence Based Medicine* 26(3): 73–76. doi:10.1136/bmjebm-2020-111339.

Jiwa, M.I., J. Durbin, V. Pereira, E. Streisslberger, L. Steel and Y. Lunsky. 2022. "This Is about My Health": Partnering with Patients and Families to Share Knowledge and Tools about Health Care Communication for Adults with Intellectual and Developmental Disabilities. *Healthcare Quarterly* 24(Special Issue): 98–104. doi:10.12927/hcq.2022.26766.

Kuluski, K., I. McLaughlin, L. Bennett, G. MacGregor, L. Bilotta, B. Farrell et al. 2022. In Pursuit of Better Care Transitions: Lessons Learned from a Co-Designed Project. *Healthcare Quarterly* 24(Special Issue): 49–54. doi:10.12927/hcq.2022.26774.

Manafò, E., L. Petermann, V. Vandall-Walker and P. Mason-Lai. 2018. Patient and Public Engagement in Priority Setting: A Systematic Rapid Review of the Literature. *PLoS ONE* 13(3): e0193579. doi:10.1371/journal.pone.0193579.

Mulder, C., D. Debassige, M. Gustafson, M. Slater, E. Eshkawkogan and J.D. Walker. 2022. Research, Sovereignty and Action: Lessons from a First Nations–Led Study on Aging in Ontario. *Healthcare Quarterly* 24(Special Issue): 93–97. doi:10.12927/hcq.2022.26767.

Naylor, K.L., S.Q. McKenzie, A.X. Garg, S. Yohanna and J.M. Sontrop. 2022. Partnering with Patients to Enhance Access to Kidney Transplantation and Living Kidney Donation. *Healthcare Quarterly* 24(Special Issue): 69–73. doi:10.12927/hcq.2022.26771.

Nygaard, A., L. Halvorsrud, S. Linnerud, E.K. Grov and A. Bergland. 2019. The James Lind Alliance Process Approach: Scoping Review. *BMJ Open* 9(8): e027473. doi:10.1136/bmjopen-2018-027473.

Ontario SPOR SUPPORT Unit (OSSU). 2021. OSSU EMPOWER Awards. Retrieved November 30, 2021. <https://ossu.ca/for-researchers/work-we-support/ossu-empower-awards/>.

Pan, R.Y., K. Zhang, A. Sivakumar, D. Choi, A.H. Wang, P. Wijeyesekera et al. 2022. Evaluation of Experiences and Impact of Patient Engagement on e-Health Research: A Qualitative Study. *Healthcare Quarterly* 24(X): 44–48. doi:10.12927/hcq.2022.26775.

Parry, M., D.P. Richards, D. Wells, A. Najam, S. Hemani and S. Marlin. 2022. Building Capacity for Patient-Oriented Research: Utilizing Decision Aids to Translate Evidence into Practice, Policy and Outcomes. *Healthcare Quarterly* 24(Special Issue): 37–43. doi:10.12927/hcq.2022.26776.

Pugliese, M., K. Tingley, A. Chow, N. Pallone, M. Smith, P. Chakraborty et al. 2021. Core Outcome Sets for Medium-Chain Acyl-CoA Dehydrogenase Deficiency and Phenylketonuria. *Pediatrics* 148(2): e2020037747. doi:10.1542/peds.2020-037747.

Ristevski, I., J. Kiew, M. Hendry, M. Prunier, R. Noronha, M. Al-Hammadi et al. 2022a. The Retinoblastoma Research Booklet: A Catalyst for Patient Involvement in Retinoblastoma Research. *Healthcare Quarterly* 24(Special Issue): 61–68. doi:10.12927/hcq.2022.26772.

Ristevski, I., J. Robert, R. Baddeliyanage, R. Noronha, M. Gelkopf, K. Flegg et al. 2022b. EMPOWER Retinoblastoma: Engaging Patient Partners in Solving the Top 10 Priorities for Eye Cancer Research in Canada. *Healthcare Quarterly* 24(Special Issue): 11–17. doi:10.12927/hcq.2022.26780.

Sayani, A., A. Maybee, J. Manthorne, E. Nicholson, G. Bloch, J.A. Parsons et al. 2021. Building Equitable Patient Partnerships during the COVID-19 Pandemic: Challenges and Key Considerations for Research and Policy. *Healthcare Policy* 17(1): 17–24. doi:10.12927/hcpol.2021.26582.

Sayani, A., A. Maybee, J. Manthorne, E. Nicholson, G. Bloch, J.A. Parsons et al. 2022. Equity-Mobilizing Partnerships in Community (EMPaCT): Co-Designing Patient Engagement to Promote Health Equity. *Healthcare Quarterly* 24(Special Issue): 86–92. doi:10.12927/hcq.2022.26768.

Syan, A., J.Y. Lam, L.D. Hawke, K. Darnay and J. Henderson. 2022. The Youth Wellness Quest: A Comprehensive Online Mental Health Literacy and Self-Advocacy Resource Developed by Youth for Youth. *Healthcare Quarterly* 24(Special Issue): 55–59. doi:10.12927/hcq.2022.26773.

Tingley, K., M. Smith, N. Pallone, P. Chakraborty and B.K. Potter. 2022. Patient Engagement in a Multi-Stakeholder Workshop to Plan the Collection of Patient-Oriented Outcomes for Children with Inherited Metabolic Diseases. *Healthcare Quarterly* 24(Special Issue): 81–85. doi:10.12927/hcq.2022.26769.

Vanderhout, S.M., C.S. Birken, P.D. Wong, S. Weir, J. Batten and J.L. Maguire. 2022. Parent Engagement in a COVID-19 Cohort Study of Children and Families: Successes, Challenges and Next Steps. *Healthcare Quarterly* 24(Special Issue): 31–34. doi:10.12927/hcq.2022.26777.

About the authors

Peter J. Gill, MD, DPhil, MSc, FRCPC, is a staff physician and an associate scientist at the Hospital for Sick Children and assistant professor in the Department of Paediatrics and Institute of Health Policy, Management and Evaluation at the University of Toronto in Toronto, ON. He can be contacted by e-mail at peter.gill@sickkids.ca.

Diana Urajnik, BA, BSc, MA, PhD, is the director of the Centre for Rural and Northern Health Research at Laurentian University and an assistant professor in the Human Sciences Division at the Northern Ontario School of Medicine in Sudbury, ON.

Rebecca Ganann, RN, BScN, MSc, PhD, is an assistant professor in the School of Nursing at McMaster University in Hamilton, ON, and co-scientific director of the Aging, Community and Health Research Unit.