

Empowering Patient Voices: Policy Change for More Inclusive Health Care Research

A Science & Policy Exchange Public Forum



An SPE Public Forum | *Un forum public DSP*

Empowering Patient Voices: Policy Change for More Inclusive Health Care Research

Moderated by | *Modérée par:*

 <p>Dr. Heather Shearer, PhD Senior Research Associate, Cerebral Palsy Resource Chargé de recherche principal, Cerebral Palsy Resource</p>	 <p>Annie-Danielle Grenier Advocate and patient partner Sensibilisation et partenariat patient</p>	 <p>Claudio Del Grande Research Officer, CRCHUM Agent de recherche, CRCHUM</p>	 <p>Marcel Saulnier Health Policy Associate, Santis Health Associé en politique de la santé, Santis Health</p>	 <p>Dr. Keith Misquitta Research Administration Coordinator, Ontario Brain Institute Coordinateur de l'administration de la recherche, Ontario Brain Institute</p>	 <p>My An Nyugen Complaints Delegate, CIUSSS Déléguée aux plaintes, CIUSSS</p>
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June 21, 2023 | Le 21 juin 2023
5:30 - 7:00 PM (EST) | 17h30 - 19h00 (HNE)
Interpretation in French and English | *Traduction simultanée en français et en anglais*

REPORT



DATE: June 21st, 2023

TIME: 5:30 to 7:00 PM EDT

TITLE: SPE Public Forum - Empowering Patient Voices: Policy Change for More Inclusive Health Care Research

Organized by: Science & Policy Exchange (SPE)

A [video recording of this forum](#) can be found on the Science & Policy Exchange YouTube channel.

Panelists:

- *Annie-Danielle Grenier* - Rare Disease Advocate and Patient Partner
- *Claudio Del Grande* - Research Officer at CRCHUM and PhD candidate at the School of Public Health of Université de Montréal
- *Marcel Saulnier* - Health consultant and strategist, Member of the CIHR Strategy on Patient-Oriented Research National Steering Committee
- *Heather Shearer* - Senior Research Associate, Institute for Disability and Rehabilitation Research, Ontario Tech University, Cerebral Palsy Resource

Co-moderators:

- *Keith Misquitta* - Public Forum Lead, SPE; Coordinator of Research Administration, Ontario Brain Institute
- *My An Nguyen* - VP External Relations Francophonie, SPE; Delegate to the Complaints Commissioner, CIUSSS West-Central Montreal

Context:

In 2011, the Canadian Institutes for Health Research (CIHR) launched the Strategy for Patient-Oriented Research (SPOR), a national strategy designed to improve the translation of new therapeutics and diagnostics into clinical care. A central tenet of the SPOR initiative is to improve the engagement of patients as partners in patient-oriented research. Patient partners (those with lived experience and their caregivers) are subject experts and possess unique experiences and knowledge valuable for all levels of the research study pipeline, including the definition of research priorities, study design, and implementation of new practices in healthcare settings. Despite improvements in practices for patient engagement throughout research networks in Canada, a number of barriers and challenges still exist to the effective inclusion of patient partners in research. On this panel, experts on the subject of patient inclusion from the patient, researcher, and policy perspectives discuss the best practices and ongoing challenges for the inclusion of patient partners in Canadian health research.



Patient partner perspective

- Patient partners [should be members of the research team](#). Including patients in all stages of research allows them to lend their expertise at every step such as data collection, data analysis and dissemination of research results/findings.
- Researchers need to foster an [environment of inclusion for patient partners](#), which includes inviting partners to decision-making meetings, including them in email chains, and focusing on accessibility (e.g. literacy, hybrid/virtual meetings, using lay language). It is important to consider patients' physical and mental limitations when including them in research (e.g. avoid having long interviews for patients with chronic pain).

Researcher perspective

- Patient partners have experience in the healthcare system, but also through their work or academic careers. Taking into account their expertise can help orient the directionality of the research.
- Structural barriers that impede the involvement of patients from marginalized populations in research should be considered (e.g. language, limited access to technology) to improve patient-research partnerships. [Here](#) is a guide on how to include patients and caregivers from marginalized groups.
- Researchers should be engaging in formal training around patient inclusion in research (e.g. university courses). To improve the quality of the Quebec healthcare system, the *Unité de soutien au système de santé apprenant (SSA)* has designed an online [toolbox](#) with specific training for researchers: what are patient partnerships, what is a learning health system, how to involve low-literacy patients in research, etc.
- Financial support should be offered to patient partners, even if they are willing to contribute their time and expertise voluntarily. If patient partners are on social assistance or solidarity programs, compensation can be offered in a way that does not prohibit the partners from receiving money from these programs (e.g. grocery package, clothes).

Healthcare policies

- Through the [CIHR-instituted Strategy for Patient-Oriented Research](#), there have been ongoing improvements in practices for inclusion of patients in research throughout Canada, but there are limited resources going directly to increasing patient engagement.
- Specific and universal training on the inclusion of patients in research is needed, akin to the [Tri-council ethics training certificate](#), to ensure researchers are able to engage patients effectively, communicate appropriately, and treat patients as equal partners in research.
- Patient partnership must be included in major public health system agreements to ensure uptake throughout the healthcare system and to centralize useful knowledge and practices.
- [Healthcare Excellence Canada](#) is an independent, not-for-profit charity funded primarily by Health Canada. They collaborate with patients and caregivers to improve healthcare in Canada. Recently, they collaborated with the [Patient Advisors Network \(PAN\)](#), a national group of patients and caregivers that can provide research teams with patient partners.

Science & Policy Exchange is a Montreal-based early-career researcher-led charity aimed at bridging the gap between science and society by highlighting the impact of science policy. For more information, visit: sp-exchange.ca

Citation

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¹Organization of the event

²Promotion of the event

³Event moderator and supporting volunteer

⁴Report writing

⁵Report translation

Acknowledgements

Science & Policy Exchange (SPE) is based in Tiohtiá:ke/Montreal, the traditional and unceded territory of the Kanien'keha:ka (Mohawk) - a place which has long served as a site of meeting and exchange amongst many First Nations including the Kanien'kehá:ka of the Haudenosaunee Confederacy (also referred to as the Iroquois or Six Nations Confederacy), Huron/Wendat, Abenaki, and Anishinaabeg. At SPE, we strive to support indigenous students and researchers by actively reaching out to and working with the Indigenous community to collaboratively advocate for their inclusion in evidence-informed decision-making.

We are further grateful to SPE's executive committee for their contributions in their respective roles to the proper development of this project.

Finally, we would like to thank the forum's panelists, moderators, and attendees for their contributions to the thoughtful discussions that form the foundation of this report.