

Research and Knowledge Translation Newsletter

‘WE’RE REAL PEOPLE WITH REAL LIVES’: PATIENT PARTNER IN NORTHERN BC SHARES THE POWER OF TELLING YOUR OWN STORY.

By: Kristine Ho, BC SUPPORT Unit Communications Team



Christina LaBerge cares deeply about creating safer spaces for patients, especially in Northern BC. “The North has some really

unique health needs,” she says. “Because people are spread out, it’s much harder to access things like housing, transportation and

“For me and my loved ones, we’ve had some very difficult experiences in our health care journeys. I wanted to bring to light that patients are not just statistics or numbers,” she says. “We’re real people with real lives.”

specialized care. All these things affect our health and our ability to live healthy lives.”

Christina is no stranger to BC’s health care system. In her professional life, she works in the field of mental health. As a patient partner, she’s been involved in many patient engagement and quality improvement projects over the years.

Her desire to support patient experiences in the North led her to volunteer on the Northern BC Research and Quality Conference planning team. The conference is held every two years and attracts health care staff, researchers, clinicians, patients and the public.

Christina joined a group of patient and family partners for the 2021 and 2023 conferences. She helped ensure that patient priorities were reflected in the conference’s vision, topics, invited speakers, and event accessibility and delivery.



At the 2023 event, Christina was invited to share parts of her own story and the importance of listening to lived experience.

After her talk, both health care providers and patients thanked Christina for sharing her perspective. Some of them had never heard a patient's story before.

The 2023 event saw over 200 registrants and over 100 presenters. It was well-received, with many agreeing that the event helped them build new skills in research, quality improvement or policy.

The conference is co-hosted by Northern Health and the University of Northern British Columbia. The BC SUPPORT Unit, Northern Centre provided support for patient partner involvement and staff support.

“Patient partners open up a whole new world of perspectives and opportunities you wouldn't have thought of,” says Marcelo Bravo. He is the co-lead of the Northern Centre, BC SUPPORT Unit, and Lead, Patient-oriented

“That presentation was right after an incredibly challenging time in my family's life. I shared some very personal things — I talked about my grandmother, my child, myself,” says Christina. “And while that was hard, I felt like it would bring value in that moment. It's very hard to look at someone as just a data point when they're standing right in front of you, telling their story.”



research and KT capacity building at Northern Health. “Christina and the other patient partners got us to consider what we might be missing when we look at research on its own — like what matters to patients,

plain language, or reaching out to the public. It's exciting to create this kind of legacy together.”

[The BC SUPPORT Unit](#), part of [Health Research BC](#), is a provincial initiative that moves evidence developed with patients and communities into practice. The BC SUPPORT Unit, Northern Centre connects care providers and decision-makers at Northern Health with the region's academic, patient and community partners.

Christina hopes that sharing her perspective will bring providers and patients closer together and make space for other patients to share their own stories.

“To change our system, we need diverse people — researchers, educators, advocates, doctors and patients,” says Christina. “There doesn't have to be a sole knowledge holder or a single person who has to get things right. When everyone shares the work, we get to breathe and lighten that load a little. I think that's the only way we can build up a better health care system as a whole.”

Source: [‘We're real people with real lives’: Patient partner in northern BC shares the power of telling your own story – Health Research BC](#)



TAKEAWAYS FROM THE VIRTUAL EVENT: CLINICAL RESEARCH ETHICS SYMPOSIUM 2024



By: Ramandeep Kaur, Coordinator, Research Ethics & Research Operational Approval

The Clinical Research Ethics Symposium took place virtually in collaboration with Research Ethics BC and Clinical Trials BC on Dec 3 – 4, 2024, via Zoom webinar. This symposium served as a vital platform for research ethics professionals and the broader research community to engage in meaningful discussions on clinical research ethics and clinical trials. It provided an opportunity to explore and address ethical topics of interest, fostering collaboration and knowledge-sharing both within British Columbia and beyond. The summary of each session, speaker details and key points are detailed below:

Session 1: The impact of climate change on study implementation



Date and Time: December 3 and 4, 2024 | 9 am – 11:30 am

Overview: This session explored how unexpected climate-related

events and other external factors can affect the ability to carry out research studies as planned. It delved into the ethical considerations of adapting studies to these unforeseen circumstances, with experts sharing insights and strategies for navigating these situations.

Speakers:

- **Aaron Orkin:** Associate Professor, Department of Family and Community Medicine, and Dalla Lana School of Public Health, University of Toronto
- **Carolyn Szostak:** Associate Professor, Psychology, University of British Columbia Okanagan
- **Corinne Hohl:** Professor and Head, Department of Emergency Medicine, UBC and Academic Director, Emergency Care BC, PHSA

Key points:

- **Impact of climate events:** The session highlighted how events like heat waves, wildfires, and pandemics can influence and disrupt research. Dr. Aaron Orkin emphasized the inevitability of unexpected events, stating, “The unexpected happens. We are all realizing that major events that we don’t expect are just part of our landscape. Expect it.”

- **Ethical considerations:** Conducting research in areas affected by wildfires and other climate events poses unique ethical challenges.

Special considerations are needed when participants are mental health service providers themselves.

The importance of participant contribution and adaptability throughout a research study was stressed.

- **Case study – BC’s 2021 heat dome:** Lessons from this event demonstrated how robust existing research networks and quick adaptations to protocols allow research teams to investigate emergencies and capture critical data.

These adaptations help inform future responses and ensure ethical reviews are thorough for projects impacted by or responding to climate emergencies.

The session provided valuable insights into the ethical complexities of conducting research in a changing climate and underscored the need for flexibility and preparedness in research methodologies.



Session 2a: The regulatory environment: Ethical influences and impact



Date and Time:

Tuesday, December 3, 2024 |
12:30 pm – 2:30 pm

Speaker: Jean Smart, Clinical Trials BC's Regulatory Affairs and Quality Officer

Overview: This session provided an in-depth look at the latest updates in governance and key regulatory documents that shape the ethical landscape of clinical research. Dr. Jean Smart emphasized the importance of staying informed to ensure ethical research practices.

Key points:

- **Historical context:** Dr. Smart shared the history of ethical standards from the Nuremberg Code to present-day regulations.
- **Good Clinical Practice (GCP):** Highlighted the importance of GCP and adapting to international benchmarks.

- **Role of ethics boards:** Emphasized the vital role of well-trained and knowledgeable research ethics boards in ensuring ethical oversight as the research landscape evolves.

Session 2b: Consent and ethical considerations in stroke research



Date and Time:

Tuesday, December 3, 2024 |
12:30 pm – 2:30 pm

Speaker: Michel Shamy, Associate Professor, Department of Medicine, University of Ottawa; Attending Neurologist, The Ottawa Hospital; Scientist, Ottawa Hospital Research Institute; Scientific Director, Ottawa Stroke Program; and Lead, Medical Ethics & Humanities, Faculty of Medicine, University of Ottawa.

Overview: Dr. Michel Shamy discussed the complexities of obtaining informed consent in acute stroke trials, particularly when participants are unable to consent due to unconsciousness or incapacitation, and substitute decision makers are unavailable.

Key points:

- **Challenges in critical care:** Explored the difficulties of navigating consent in high-pressure situations where immediate treatment is necessary.
- **Deferral of consent:** Explained how deferral of consent allows life-saving treatments to begin immediately, with formal consent sought later.
- **Advanced consent:** Introduced the concept of advanced consent, enabling patients at risk of stroke to document their wishes ahead of time.
- **Patient surveys:** Showed strong support for proactive consent approaches through patient surveys, emphasizing the need for clear communication and respect for autonomy.

This session highlighted the importance of adapting consent processes to ensure ethical standards are maintained, even in challenging circumstances.

Session 3: Behind the curtain of clinical trials



Date & Time:

Wednesday, December 4, 2024 |
10:30 am – 12:30 pm

Overview: This session provided a unique look into the experiences and challenges faced by clinical trials coordinators.

Speakers:

- **Ali Hosseini:** Clinical Research Coordinator, Fraser Health
- **Deborah Parfett:** Clinical Research Manager, Island Health
- **Dustin Mackay:** Clinical Trials Nurse Coordinator, BC Cancer Prince George – Centre for the North
- **Gayle Carney:** Clinical Nurse Educator, Island Health

Key points:

- **Real-world ethical issues:** The session highlighted ethical considerations

that arise during the implementation of approved protocols, which are often not discussed in research ethics board meetings.

- **Communication challenges:** Emphasized the importance of clear communication, especially in studies involving participants with dementia, where understanding is crucial.
- **Accessibility concerns:** Addressed the difficulties faced by patients in rural or remote areas in accessing clinical trials, underscoring the need for improved accessibility.
- **Inclusivity in trials:** Stressed the importance of accommodating cultural and language differences to ensure that clinical trials are truly representative of all participants.

This session illuminated the critical, often unseen work involved in managing clinical trials, caring for participants, and maintaining ethical standards to ensure meaningful research outcomes.

Overall, the 2024 Clinical Research Ethics Symposium covered important topics from climate resilience to innovative consent methods, ignited new ideas, and fostered collaboration within the research community. The event featured the ongoing need for partnership and proactive change in clinical research ethics.

Recordings of this symposium can be viewed [here](#).

Note: Images in this article were generated using Microsoft Copilot.



FROM INTENTION TO IMPACT: CANADIAN INSTITUTES OF HEALTH RESEARCH ANTI-ABLEISM ACTION PLAN



By: Editorial team

Understanding what ableism is and how it might be present in cultures and organizations is a necessary step to move towards a safer place for persons with disabilities. Ableism occurs through thoughts, beliefs, actions, and practices that discriminate against persons with disabilities, based on the assumption that they are less worthy of respect and consideration, less able to contribute and participate, or of less inherent value than others. Ableism may be conscious or unconscious, and may be embedded in institutions, policies, systems, or the broader culture of a society. It can limit the opportunities of persons with disabilities and reduce their inclusion in the life of their communities. ([CIHR – Glossary of Terms, 2024](#))

The Canadian Institutes of Health Research (CIHR) is committed to address barriers to accessibility and remove ableism in the funding system. This is why CIHR worked with the [External Advisory Committee on Accessibility and Systemic Ableism](#) to co-develop “From Intention to Impact: CIHR Anti-Ableism Action Plan”.

The External Advisory Committee on Accessibility and Systemic Ableism co-developed this action plan using the principles of respect, power-sharing, and collaboration. It also used information from an [environmental scan](#), [virtual](#)

[discussion sessions](#), [surveys](#), and a [review of our policies and practices](#).

The goal of this action plan is for CIHR and the health research community to be safer and create more welcoming places for persons with disabilities. This plan commits CIHR to actions that address barriers experienced by persons with disabilities who interact with CIHR. The actions are divided into four sections:

1. Who CIHR funds

The aim of these actions is to make participation in CIHR funding opportunities equitable for persons with disabilities. This section also focuses on strengthening communications, investing in training, and removing barriers when applying to CIHR programs.

2. What CIHR funds

The aim of these actions is to increase disability-focused research and anti-ableist

approaches to research funded by CIHR. It also focuses on increasing the capacity of health researchers to conduct disability-focused research.

3. How CIHR funds

The aim of these actions is to use anti-ableist approaches across all CIHR funding programs. It will be update CIHR’s policies and processes to eliminate barriers and ableism.

4. Organizational culture

The aim of these actions is to improve knowledge and awareness of disability and ableism at CIHR and beyond. Actions also focus on training, knowledge sharing, and using practical tools in day-to-day business and in decision-making.

To access the Action Plan, including next steps and provide feedback, visit CIHR’s dedicated page [here](#).



STUDIES APPROVED AT NH (NOVEMBER - DECEMBER 2024)



#	Principal Investigator	Institution	NH Affiliated Team Member	Study Title	HDSA/ Area	Facilitiesw
1	Kathryn V. Isaac	University of British Columbia	N/A	A provincial assessment of breast reconstructive care: A mixed methods study	Northern Interior	University Hospital of Northern British Columbia
2	Adeera Levin	University of British Columbia	Anurag Singh Celia Belamour	Studies of heart & kidney protection with BI 690517 in combination with empagliflozin: A multicenter international randomized double-blind placebo controlled clinical trial of the aldosterone synthase inhibitor	Northern Interior	University Hospital of Northern British Columbia
3	Christopher Buse	Simon Fraser University	Mary Charters	Enhancing mental health promotion for the rural and remote health emergency management workforce in British Columbia, Canada	Northern Interior	University Hospital of Northern British Columbia
4	Pat Camp	University of British Columbia	Jessica McGregor	Understanding barriers and solutions to spirometry access in remote and rural communities in British Columbia	All	Pulmonary Function Labs and primary care settings within NHA
5	Kaylee A Byers	Simon Fraser University	Esther Alonso Prieto Raina Fumerton Lisa Ronald	From knowledge to action: Developing a 'One Health' communications platform for regional mobilization	All	NA
6	Niels Agger Gupta	Royal Roads University	Karoline Patterson	A focus on physicians: A commitment to psychological safety and working towards a state of thriving at UHNBC	Northern Interior	University Hospital of Northern British Columbia



7	Anurag Singh	University of British Columbia	Pam Mulroy	Building capacity for a sustainable and equitable health care workforce in rural, remote, and Indigenous communities by implementing innovative team-based hybrid care	Northeast	Tumbler Ridge
8	Caroline Sanders	University of Northern British Columbia	Vanessa Salmons Jennifer Boon	Providing newborn care in eat sleep console: A qualitative exploration of nurses experiences	All	University Hospital of Northern British Columbia Terrace – Mills Memorial Hospital Fort St. John Hospital
9	Charles Au	University of Northern British Columbia	Robert Pammett	Quality improvement toolkit for PCN pharmacists – a project to assess toolkit uptake and utility	All	NI: Prince George NE: North Peace/ South Peace Bulkley Valley/ Witset



NH RESEARCH AND KNOWLEDGE TRANSLATION NEWSLETTER IS INTERESTED TO HEAR FROM YOU



We are inviting our readers to complete a survey about their use and to provide feedback on the Newsletter. This information will help us identify what is working well with the Newsletter, what can be changed or improved. This survey will be open until March 7, 2025. Access to this survey [here](#) or scan the QR code.



NH LIBRARY CORNER

The library has added 16 new books to its eBook [Nursing Collection](#). There are over 800 books in this collection, and they can be read online via a

web browser or downloaded on the [EBSCO Mobile](#) app for easy access while you're on the go. New titles include [Defining excellence in simulation programs](#), [Critical care nursing in resource limited environments](#), and [Essential law and ethics in nursing: patients, rights and decision-making](#). To register for a library account for NH staff, email library@northernhealth.ca.

EVENTS AND OPPORTUNITIES

NH Research Seminar Series

NH Research Seminar Series presents: Improving Long Term Care through a data-driven model, presented by Matthew Fagan, PhD.

Date: January 30, 2025
Time: 12:30 pm – 2 pm
Format: Online.

For this and past seminar recordings, visit the [NH Research](#) page.

N2 Annual Conference: The next chapter in clinical research: Tomorrow starts today

This event on February 11–12, 2025, is an opportunity to learn, connect, and grow in the field of clinical research. Don't miss this unique opportunity to engage with cutting-edge insights and maintain your edge in the ever-evolving clinical research landscape!

Date: February 11 – 12, 2025
Time: 12.00 p.m.– 5.00 p.m. EST
Format: Online. Registration and information on the [N2 website](#).

Indigenous Speakers Series

Organized by the Faculty of Medicine, University of British Columbia, the Indigenous Speakers Series is an original and important platform to begin, continue and advance the conversation about telling



the truth and reconciling for the future. Everyone is welcome to join in a spirit of integrity and understanding in this original new series.

Date: February 12, March 26, and April 23, 2025

Time: 12.00 p.m. – 1.30 p.m.

Format: Online. More information and programming on the [Indigenous Speakers Series webpage](#).

Quality Forum 2025

The Quality Forum is our annual conference that brings together British Columbia's health care community to share and discuss how to improve quality across the continuum of care.

Date: March 11 – 13, 2025

Time: All day

Format: In person (Vancouver Convention Centre) More information on the [Quality Forum website](#).

Five Days in May 2025

BC's health research month (May) is designed to educate, inform, inspire, stimulate, and transform. FDIM brings together researchers and students, patients and health care providers, decision-makers and members of the public to learn, share ideas and spark innovation. Events are open to everyone. The 2025 edition will host virtual and in-person events, stay tuned! More information on the [FDIM webpage](#).

Northern BC Research and Quality Conference 2025.

**Save the date:
October 23, 2025**

This upcoming conference is a forum enhanced with resources and skill development workshops to share health and health services research, evaluation, evidence-based practice and quality improvement initiatives in the North. It has been designed to profile Northern BC research, evaluation, and quality initiatives and will provide formal learning as well as informal opportunities

for participants to learn from each other. The conference is organized in partnership between Northern Health and UNBC. Upcoming information on the [Health Research Institute website](#).

Date: October 23, 2025

Time: All day

Format: Hybrid (In person in Prince George and selected content online)

WHO launches new clinical trials guidance – What do I need to know?

Recording available

Join WHO and The Global Health Network for an in-depth look at the groundbreaking WHO guidance on clinical trials aimed at sustained capacities, integrating research into health systems, and fostering diverse, active research networks worldwide. This session offered valuable insights directly from WHO leaders on how the new framework can enable patient-centric, ethical research. [Watch the recording](#).

OPPORTUNITIES

Patient Oriented Research (POR)-Mitacs Fellowship

The POR-Mitacs Fellowship Program was established to provide a mechanism to support projects that embed the fundamentals of POR and provide training opportunities that foster the development of research and professional skills that are applicable across diverse career trajectories.



Eligibility: Undergraduate and graduate students, as well as postdoctoral fellows across Canada.

Status: Applications are open until February 7, 2025. Learn more on [the webpage](#).

KT Canada Summer Institute 2025

The Knowledge Translation (KT) Canada Summer Institute will be held in Vancouver, British Columbia, from June 17-19, 2025. The theme for this Summer Institute will be “KT and Learning Health Systems”.

With the theme of KT and LHS, the summer institute will feature specialized training, networking opportunities, and a career panel that includes KT/implementation scientists working in LHS environments. They will share how their KT training has shaped their work.

The Summer Institute provides participants with the opportunity to increase their understanding of knowledge translation research as well as opportunities and challenges in this field. Costs and registration [here](#).

Call for applications: Advancing the Use of Evidence in Seniors' Home and Community Care Program

Applications are now open for a new funding opportunity that brings together health authorities and researchers to improve seniors' home and community care.

The Advancing the Use of Evidence in Seniors' Home and Community Care Program will fund teams of researchers and research users within BC's health system and academia to implement and evaluate the outcomes of evidence-based interventions.

The program will provide evidence to help decision-makers across BC to support programs that help seniors to live longer, healthier lives more independently in their communities.

The applicant LOI deadline is March 24, 2025. More information on the [Health Research BC website](#).



WOULD YOU LIKE TO WRITE AND PUBLISH A SHORT HEALTH RESEARCH ARTICLE?



The Research & Knowledge Translation Newsletter is accepting articles for future editions. We are open to all areas of health research and knowledge translation as well as evaluation, data analytics, quality improvement or innovation projects.

If interested to include an article or to share information about an upcoming event, email: research@northernhealth.ca