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**Health  
Research BC**  
RESEARCH ETHICS BC

# REBC 2024 KNOWLEDGE EXCHANGE EVENT SUMMARY

Tuesday March 12, 2024

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As a provincial organization, we recognize that our work extends across many Indigenous lands and territories throughout British Columbia. We acknowledge with respect and humility that our Vancouver offices are located on the traditional and unceded territories of the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh (Squamish) and sə̌lwlətaʔt (Tsleil-Waututh) Nations.

# Introduction

On March 12, 2024, Michael Smith Health Research BC (Health Research BC) hosted the Research Ethics BC (REBC) Knowledge Exchange event. This virtual meeting brought together the research ethics community from across British Columbia, including research ethics board (REB) members, administrators and advisory council members. The event aimed to share progress on current provincial and national initiatives, exchange knowledge and expertise, and develop pan-provincial relationships.

REBC provided the framework for the day with guidance from the REBC advisory council and independent facilitator, Kira Tozer. We were honoured to have Elder Alec Dan from the Musqueam Indian Band and Coastal Wolf Pack welcome all attendees with his reflections on the impact of research on all communities.

## Goals and approach

The goals of the Knowledge Exchange event were to:

1. Share knowledge and expertise
2. Spark collaboration and identify opportunities for cross-provincial connection and sharing of best practices

The agenda was filled with presentations on ongoing work in health research ethics in the province. Following each talk, participants joined breakout groups to reflect on the work, with facilitators capturing all questions and ideas. The insights are summarized in this report's "[Overall themes from the day](#)" section. The themes reflect the diverse perspectives and priorities identified in the discussion, illustrating key areas of interest and potential avenues for collaboration in advancing ethical processes and considerations of research in BC.

## Presentations from the day

The presentations provided a snapshot of important work underway in BC. Each highlights the complexities we face and emphasizes the need for further collaboration to strengthen standards and processes. Links to the project sites are added and a copy of the presentation abstracts is attached below.

### **Rapid assessment of British Columbia's health research system**

**Danielle Lavallee, VP, Research Programs, Health Research BC**

This assessment aimed to understand the changes made since the 2014 directions for health research in BC. Findings indicated that opportunities and strengths were found in four areas - governance, financing, building capacity, and producing and using research.

The greatest strength and advancement in governance is centered around the work being done within the ethics community to ensure collaboration across institutions and harmonized ethics. The funding environment in BC is not increasing, so securing and allocating research funding equitably and with accountability is paramount. Attracting and retaining talent will help to grow and support research in the province by building capacity.

Finally, the work to further integrate First Nations, Métis and Inuit perspectives into ethics is a start to producing community-driven research that is by and for communities. This report is available on the Health Research BC website for further review.

## Developing a research ethics review process at First Nations Health Authority (FNHA) from the community up

**Ashley Simpson, Project Director, Indigenous Harm Reduction Research**  
**Taban Behin, Manager, Research and Ethics, FNHA**

This presentation highlighted ways to bring Indigenous perspectives into ethics through community engagement and reciprocal accountability. With the goal of empowering Indigenous communities engaging in research, the presenters emphasized the importance of creating research ethics frameworks that support data management to build capacity within Indigenous communities.

## Research Approvals Process Project (RAPP)

**Julia McFarlane, Director of Research, Ministry of Health**

The RAPP initiative was created to address the challenges researchers in BC face as they navigate research approval processes, particularly in cross-sectional research, which currently varies across health authorities. This initiative seeks to streamline the processes in the following areas: research ethics review, operational approvals, data and privacy, contracts and agreements, and information management. This is a large complex process with many layers and activities in motion. More updates on RAPP will be provided as the project moves forward.

## Indigenizing Health Research Ethics in British Columbia with Indigenous Communities, Collectives and Organizations (ICCOs)

**Dr. Krista Stelkia, Assistant Professor, Simon Fraser University (SFU) Faculty of Health Sciences (FHS) and Co-Director of the Centre for Collaborative Action on Indigenous Health Governance (CCAIHG)**

Recognizing that current frameworks are derived from western approaches, British Columbia Network Environment for Indigenous Health Research (BC NEIHR) conducted an environmental scan of current ethics processes for Indigenous health research in the province. The scan found that many ICCOs have developed their own nation-based guidelines that institutional board members either were not aware of or had little understanding. Dr. Stelkia spoke to the critical role that research ethics guidelines have in ensuring that health research with Indigenous people is conducted in a culturally safe, respectful, and collaborative manner.

## Harmonized Research Ethics Evaluation

**Hanna Jones-Eriksson, Manager, Research Ethics BC, Health Research BC**

This evaluation was completed in 2022 to assess the harmonized models of ethics reviews established in 2016. The goals were to understand how the models function to improve efficiency, consistency, and research integrity. 14 recommendations for improvement came out of the report, and REBC is currently working on two of those recommendations. The first (#6) is to work with REBs to align on what multi-jurisdictional studies require review from partner institutions. The second (#14) is for a clearly articulated long-term vision within the provincial and national landscape for research ethics in BC. Updates will be provided around project progress in the coming year.

## Provincial Vision for Clinical Trials in BC

**Alison Orth, Portfolio Director, Research Programs, Health Research BC**

In 2022, Clinical Trials BC helped lead the community in defining a [shared vision](#) where clinical trials are maximized for the benefit of all British Columbians. Building on this, a round table hosted by Clinical Trials BC and attended by provincial leaders and policymakers in November 2023, agreed on [three main priorities](#): create agile services to support clinical trials; fund and support sustainable clinical trial infrastructure; and enable streamlined and timely research ethics review.

## **Accelerating Clinical Trials (ACT) Consortium**

**Erika Basile, Director, Research Ethics & Compliance, Western University**

**Susan Marlin, President & CEO of Clinical Trials Ontario (CTO)**

The Accelerating Clinical Trials (ACT) Consortium has two main objectives to address the process of research ethics proposals. First, establish appropriate timeline goals for overall review and approval, and second, develop a group to oversee the single national minority review and approval process. They identified the complexities in creating a scalable, customizable and flexible review system that efficiently navigates the evolving review process while being operationally sustainable.

## **Overall themes from the day**

Four main themes emerged through the discussion:

### **1. Inclusivity**

This was the most prominent theme, highlighting the importance and challenges of ensuring that diverse community, patient, and Indigenous voices are appropriately and authentically involved in research endeavours.

- *“Research is a tool for community, community is not a tool for research”*
- Indigenous representation and expertise are needed on REBs
- Equity, diversity and inclusion should be at the forefront of new and ongoing projects
- Create strong foundations and set boundaries
- Unlearning: addressing and recognizing the colonial framework within research ethics
- Patient safety and voices: identifying what populations are not represented and why
- Establish reciprocity between institutions (establishing trust of shared knowledge, expertise, and guidance for best practices)

### **2. Human and system capacity building**

Strengthening the skills and competencies of the entire research community, resources, systems, and frameworks will set the foundation for creating effective and sustainable work going forward to advance health research in BC.

- Identify “who is in the room” and what strengths / weaknesses there are
- Ensure equal access and distribution of provincial resources (funding, expertise, staffing, etc.) for all research initiatives
- Prioritize adaptation strategies and change models to provide education for inclusiveness in research
- Support and encourage community-based knowledge and experience
- Increase operational support for implementation and maintenance
- Create transparency in research funding and resources allocation across the province

### **3. Relationship building**

Without collaboration and partnership, none of the work being done would be possible, therefore it is important to remain committed to collaboration and relationship building to avoid siloed work and duplicated efforts.

- Focus on mechanisms to build partnerships/collaborations (communities, patient partners, Research Ethics Board Administrators (REBAs), researchers)
- Establishing and respecting boundaries of Indigenous Communities, Collectives and Organizations (ICCOs) (i.e.: nation/region)
- Encourage and foster new collaborations and connections between patient partners, community, and researchers within BC
- Government support from Ministry of Health and health authorities are necessary for growth

#### 4. Harmonizing research practice

Navigating standardization and quality requires a careful balance of the desire for efficiency and streamlined approaches. As we move further towards research harmonization, symposium participants identified the need for thoughtful consideration of the following:

- What are best practices for timeline management of study applications, ethics reviews, etc. ?
- Is it possible to produce specific guidelines and scripts to ensure consistency around regulations such as adherence, expectations, risk, and impact?
- Quantity over quality - is quality impacted when standardization takes precedence?
- What can be done about fragmentation among health authorities?
- How can we include all voices in the larger scale projects (RAPP, ACT, harmonization)?
- What are best practices for data management and privacy?

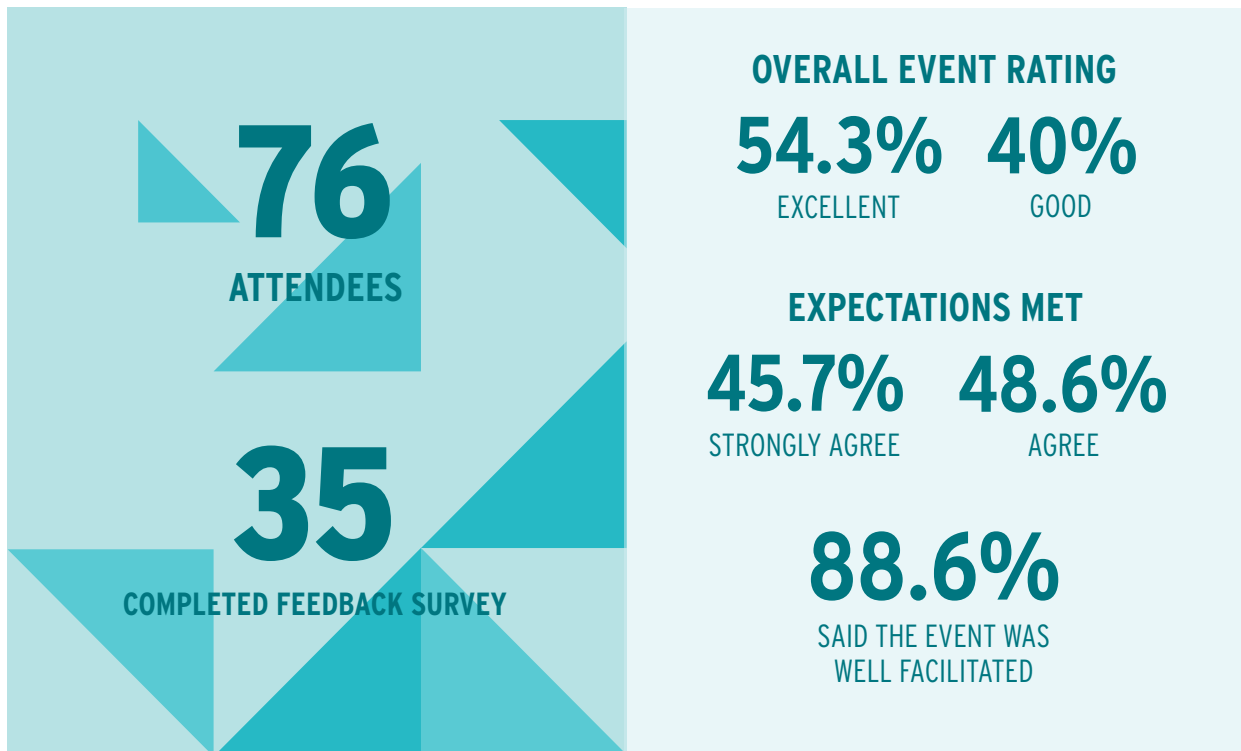
## Participant feedback

Feedback from participants at the Knowledge Exchange event was overwhelmingly positive. Attendees noted that the presentations were insightful and valuable to their work and provided “clarity on priorities and direction of ethics in both Canada and BC.” Many appreciated how well the event was organized and facilitated, allowing for fruitful conversations in the breakout rooms. There was a general preference for an in-person/hybrid event to provide more space for networking and engagement. Participants also requested regular updates on the initiatives presented.

Three main topics were identified as important for future discussions:

1. The role of artificial intelligence (AI) in research
2. Mechanisms to encourage resource sharing
3. Current or potential collaborations between groups

Overall, the event was well received and regarded for its educational value and collaborative nature.



## APPLICABLE CONTENT

**25.7%**

STRONGLY AGREE

**42.9%**

AGREE

### THREE MOST RELEVANT PRESENTATIONS BEING:

1. DEVELOPING A RESEARCH ETHICS REVIEW PROCESS AT FNHA FROM THE COMMUNITY UP
2. RESEARCH APPROVALS PROCESS PROJECT (RAPP)
3. HARMONIZED RESEARCH ETHICS EVALUATION (2022)

## Conclusion and next steps

The Knowledge Exchange event celebrated advancements and acknowledged complexities in the research ethics landscape. Attendees expressed enthusiasm for the numerous projects underway and appreciation for collaborative efforts to enhance this field. The event identified capacity and inclusivity as crucial drivers for catalyzing change. Ensuring researchers have full capacity to participate, fund, develop, conduct, and engage in their own research practices is key. Attendees emphasized the need to apply decolonizing and inclusive approaches to their work to ensure research is safe and accountable.

The provincial system focuses on strengthening health research and institutional accountability while recognizing the colonial framework that has historically influenced these systems. The presentations highlighted that provincial support is crucial, particularly in addressing gaps such as the exclusion of elderly populations, as well as Indigenous, rural, and Métis Nations communities. Due to technology barriers, Indigenous representation and cultural safety with nation-focused reviews and the establishment of foundational policies, is essential. There is a growing body of work guided by the Indigenous philosophical foundation of the four R's: respect, reciprocity, relevance, and responsibility (e.g. environmental scan by the BC SUPPORT Unit and resources available on the FNHA research website). It is exciting to see community-informed practices developed by and for Indigenous communities advancing research methodologies.

Harmonizing research ethics is a priority, and ensuring that there is a system that works for all institutions involved in research is crucial. As demonstrated by these projects, the current systems are evolving. The next steps include building on the strong foundations laid, integrating new learnings, and moving towards a research system that is reflective of the current landscape.

REBC would like to thank the presenters and attendees for creating connection and making the event a success. We look forward to meeting again in future to share knowledge and discuss the evolution of research ethics in British Columbia.

# Appendix

## Rapid Assessment of British Columbia's Health Research System

**Danielle Lavallee, VP, Research Programs, Health Research BC**

In June 2023, Michael Smith Health Research BC, in collaboration with the Health Research Council of BC, conducted a high-level assessment of the provincial health research system. The goal was to better understand current strengths, weaknesses and key areas of opportunity for improvement. Interviews were conducted with 55 people – from universities, patient groups, provincial government, Indigenous Nations and organizations, health authorities, and the life sciences sector – and findings were analyzed according to the World Health Organization (WHO) framework for health research systems and its four components: governance, financing, building capacity, and producing and using research.

Overall, findings from this rapid, high-level assessment suggest that British Columbia's health research system is characterized by world class institutions and people, substantial goodwill, and collective interest in collaborating to continue to build and sustain a strong health research system. A major finding from the assessment suggested that coordination and leadership within the BC health research system is a key area of opportunity, as were related actions around provincial vision, research priorities, standards and processes, and measuring and evaluating impact. The Ministry of Health's leadership on accessible data for research was appreciated, though ongoing access was identified as a challenge, as was the use of research evidence in practice and policy, which requires concerted efforts by both the broader research community to address. Inequities in health care and health outcomes are stark, especially for First Nations, Métis, and Inuit people. Applying a decolonizing and equity, diversity and inclusion lens to future work will be critical to strengthening our health research system.

## Developing a Research Ethics Review Process at First Nations Health Authority (FNHA) from the community up

**Ashley Simpson, Project Director, Indigenous Harm Reduction Research**

**Taban Behin, Manager, Research and Ethics, FNHA**

First Nations Health Authority (FNHA) is the first and only provincial entity of its kind in Canada. Its vision is to foster healthy, self-determining, and vibrant BC First Nations children, families, and communities. This presentation outlines the progress made in First Nations research ethics. It will also outline some preliminary thoughts related to FNHA's research ethics framework, which will include the development of a community-driven ethics review board that represents the voices of its 204 member Nations. Some background will also be offered on FNHA's governance structure and how it is able to continually ground its endeavours in the interests of First Nations across BC.

## Research Approvals Process Project (RAPP)

**Julia McFarlane, Director of Research, Ministry of Health**

The Research Approvals Processes Project (RAPP) is a Ministry of Health initiative, in partnership with British Columbia's Health Authorities, to streamline approval processes for research projects occurring across more than one Health Authority. These research approvals include ethics, privacy, data access and sharing, contracts and operational approvals.



## **Indigenizing Health Research Ethics in British Columbia with Indigenous Communities, Collectives and Organizations**

**Krista Stelkia, Assistant Professor, Simon Fraser University (SFU) Faculty of Health Sciences (FHS), and Co-Director of Centre for Collaborative Action on Indigenous Health Governance (CCAIHG)**

Ethical guidelines are critical in ensuring that health research with Indigenous peoples is conducted in a culturally safe way. While Chapter Nine of Tri-Council Policy Statement 2 guides the ethical conduct of research involving First Nations, Inuit, and Métis peoples of Canada, there is a need to develop ethical protocols that are distinction-based, recognizing the specific rights and interests of distinct groups.

This presentation provides an overview of a three-year CIHR-funded project to Indigenize health research ethics in BC. The project aims to improve BC's Indigenous health research ethics processes to be more culturally safe and aligned with Indigenous knowledge and distinctions-based guidelines. The project will:

1. Conduct a scoping review to identify wise practices and ethical guidelines used by Indigenous Communities, Collectives and Organizations and research ethics boards in Indigenous health research.
2. Explore the perspectives of research ethics partners on gaps, barriers, and experiences in Indigenous health research ethics.
3. Facilitate a convening space for ethics partners to co-create solutions and resources to improve Indigenous health research ethics.

Data collection includes interviews, sharing circles, and graphic recording. The findings will contribute to improving the health of Indigenous peoples by transforming health research ethics to be more culturally safe.

## **Harmonized Research Ethics Evaluation**

**Hanna Jones-Eriksson, Manager Research Ethics, Health Research BC**

Research Ethics BC (REBC) leads province-wide work to streamline and improve the review of research ethics applications in British Columbia. Introduced in 2019, the harmonized models of ethics reviews were intended to make the ethics review process timelier, and more effective through the models for minimal risk and above minimal risk as well as pilot a clinical trials model for non-industry sponsored clinical trials.

REBC continues to support the network of 27 research ethic boards in applying the models and the long-term goal of a provincially resourced Indigenous research ethics review process for Indigenous research. The 2022 Research Ethics BC Harmonized Research Ethics Evaluation Report aimed to formally evaluate the harmonized research ethics models for the first time. The report captures how the harmonized research ethics models function and whether they are achieving their objectives of improving efficiency, consistency, and research integrity.

The evaluation surfaced five main findings and 14 recommendations. REBC's presentation will share how the evaluation continues to inform improvements to the harmonized research ethics approach.

REBC will take action on two recommendations:

1. Recommendation 14 - Identify long-term vision for Research Ethics BC within the provincial and national ethics landscape
2. Recommendation 6 - Multi-jurisdictional review: REBC is poised to be the support organization to launch this initiative as many others do not have the capacity or resources to do so.

## **Provincial Vision for Clinical Trials in BC**

**Alison Orth, Portfolio Director, Research Programs, Health Research BC**

Clinical trials are essential for developing new treatments and supporting optimal care delivery in the healthcare system. The clinical trial landscape, nationally and internationally, is evolving rapidly, especially in terms of regulatory modernization. This evolution responds to advances in technology, new and innovative health products, and the development of more powerful and efficient clinical trial methodologies. British Columbia's comparative advantages position the province to house a unique and highly successful clinical trial ecosystem, delivering health and economic benefits.

In 2022, Clinical Trials BC, part of Michael Smith Health Research BC, consulted with more than 170 members of the clinical trial ecosystem in BC and Canada to develop a shared vision for clinical trials. Those consulted include investigators, trial participants, funders, life sciences companies, research ethics administrators, health system policymakers and more to create a vision for such an ecosystem. Consultation participants across all roles expressed deep frustration with the current state of clinical trials in BC, but they were hopeful this consultation and resulting vision would accelerate action towards understanding and resolving challenges.

The vision – bold, aspirational and achievable – reflects a future in which clinical trial investments are maximized for the benefit of all British Columbians:

*A robust, innovative, coordinated, and person-centred clinical trials ecosystem improving health and economic outcomes for British Columbians.*

This presentation reviews how the vision was created, where research ethics fits in and why a collaborative and multi-partner approach with engagement across BC's entire health research system is required to realize this vision.

## **Accelerating Clinical Trials (ACT) Consortium**

**Erika Basile, Director, Research Ethics & Compliance, Western University**

**Susan Marlin, President and CEO of Clinical Trials Ontario (CTO)**

In early 2023, the Canadian Institutes of Health Research committed \$39 million over three years to the newly created national consortium Accelerating Clinical Trials (ACT) / d'Accélérer les essais cliniques (AEC). The consortium aims to facilitate the conduct, implementation, and translation of high-quality, high impact randomized controlled trials (RCTs) to improve health in Canada and around the world.

This pan-Canadian consortium brings together hundreds of researchers from 28 networks, 11 trial units, patient partners, the biotechnology industry, the government, and experts in research ethics review processes, contracts, insurance, regulatory processes, patient engagement, clinical trials training, communications, and knowledge mobilization – from Nova Scotia to British Columbia and Nunavut.

Regarding research ethics review, the review process for starting and conducting multisite RCTs across Canada can be streamlined to reduce unnecessary burdens and barriers. ACT Canada has set a goal to design and guide the implementation of a single, pan-Canadian, distributive Research Ethics Board (REB) review and approval process with strict timelines for initiating and conducting randomized control trials across Canada. The presenters will discuss this national consortium subcommittee and may include recent updates as recent as the Vancouver REB planning meeting held February 28, 2024, in Vancouver.