

## Indigenous Health Research in Québec: Changing the Landscape Through Relationship Building

*Sherri L. Bisset, Leila Qashu, Sonia Périllat-Amédée & Treena Delormier,*

### Article Info

*Keywords*

NEIHR  
Indigenous health research  
Self-determination  
Decolonization  
Research institutions  
Community-based research  
Community-led research  
Implementation analysis

### Abstract

To better respond to the specific health research needs of Indigenous peoples in Canada, the Canadian Institute for Health Research (CIHR) created the Network Environments for Indigenous Health Research (NEIHR). This paper presents the Québec NEIHR to provide a reflexive account of the first 5 years. The Tahatikonhsontóntie' Québec Network Environment for Indigenous Health Research (QcNEIHR) is driven by, and grounded in, Indigenous communities in Québec. Using implementation analysis as a methodology, the QcNEIHR evaluator used documents, participant observations and interviews to compare the proposed QcNEIHR grant plan with what the QcNEIHR actualized. The co-authors, members of the Operations Circle (OC), provided additional information and interpretations as the manuscript was being written. The QcNEIHR governance circles were invited to approve the presentation of results. Through this analysis we found that QcNEIHR activities aligned with three of four objectives in the initial research proposal. The Operations Circle of the QcNEIHR successfully navigated through several competing interests, listed here: 1) finding a balance between consulting and taking concrete actions, 2) being inclusive while prioritizing a few targeted activities, 3) administering institutional research funds within an Indigenous community-based organization, 4) maintaining an efficient bilingual governance structure with diverse conceptualizations of health and research, 5) managing an organic Operations Circle for innovation and creativity while assuring accountability and timely deliverables. During the first five years of operation, the strategy of the QcNEIHR OC was based upon building relationships and mobilizing a diverse lively network. This strategy sets the foundation for community-shared ownership and leadership for the next iteration of the QcNEIHR, where community-driven Indigenous health research in Québec will continue to strengthen and grow with the support of provincial and national research institutions.

### Author Info

Sherri L. Bisset  
Québec Network Environment for Indigenous Health Research  
Email: [sherri.l.bisset@umontreal.ca](mailto:sherri.l.bisset@umontreal.ca)

## INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

Leila Qashu

Québec Network Environment for Indigenous Health Research

Sonia Périllat-Amédée

Québec Network Environment for Indigenous Health Research

Treéna Delormier

Québec Network Environment for Indigenous Health Research

10.32799/ijih.v20i1.42219

©2024 The Authors. This is an open access article under the CC BY-NC-ND 4.0 license.  
(<https://creativecommons.org/licenses/by-nc-nd/4.0/>).

## Introduction

Indigenous peoples have been producing and sharing knowledge to inform wellbeing practices for centuries (Cajete, 2000; Castellano, 2014). However, as colonial institutions decided on what knowledge was credible and had scientific validity, the value of this knowledge and processes used for its development were marginalized and dismissed as irrelevant. As a result, Indigenous peoples have been disenfranchised from their own knowledge bases and systems. In turn, access to health-generating structures that can maintain or improve wellbeing, such as health and education, has been impacted (Battiste et al., 2013; King et al., 2009).

Recent advances by research and academic institutions focus on Indigenous ways of knowing with the aim of respecting Indigenous peoples' inherent rights to determine their research agendas and contribute to knowledge development. As one out of nine operational grants awarded by the Canadian Institutes for Health Research (CIHR), the Tahatikonhsontóntie' Québec Network Environment for Indigenous Health Research (QcNEIHR) aims to contribute to this advancement. The QcNEIHR grant is a collaborative effort including 39 individuals, 19 of whom are Indigenous (49%), and 17 organizations/institutions, nine of whom are Indigenous (53%). Most NEIHRs are housed within academic institutions, however the QcNEIHR is community-based, hosted by the Kahnawà:ke Schools Diabetes Prevention Program (KSDPP). Situating the operation of the network in a community is important to creating environments that support Indigenous research. In so doing, Indigenous communities are leading research activities and resources are thus managed under the decisions of the community.

One of the earliest documented Indigenous participatory health research partnerships in Canada originated in Québec (Tremblay et al., 2018). Beginning in 1985, research has traced the development of the Indigenous academic community research partnership associated with KSDPP, created in 1994. The KSDPP Code of Research Ethics (Macaulay et al., 1998) became a cornerstone for research principles both within the community of Kahnawà:ke and across Canada (Tremblay et al., 2018). The Québec Native Friendship Center association (RCAAQ, 2021), the Assembly of First Nations of Québec and Labrador (APNQL, 2014), and the Québec Native Women's Association (FAQ, 2012) have joined other Canadian initiatives in the aim of ensuring that all research with Indigenous communities is grounded in Indigenous research principles (Bonneau & Bergeron, 2024). Indigenous organizations in Québec are increasingly participating in scientific activities that respond to their own needs, protocols, and epistemologies (CSSSPNQL, 2018, Rowe et al., 2020).

Although self-determination in Indigenous research is advancing, inequities are present in communities' research needs, as well as in their readiness to conduct research due to the history of colonization and its ongoing impacts (Fraser et al., 2018; FNQLHSSC, 2018; Macaulay et al., 1997). Challenges include limited resources allocated to building or enhancing community capacity, distrust by Indigenous communities of external researchers, colonial institutions privileging western-based knowledge, a low representation of Indigenous scholars in faculty positions and positions of power, and the overburdening of Indigenous scholars in these positions (ITK & NRI, 2007; Morton-Ninomiya & Pollock, 2017; Tuck & Yang, 2014). Thus, in the face of this progress, further advances are needed to build capacity for Indigenous peoples to participate in research in self-determining ways.

In response to the need to address the health research needs of Indigenous peoples in Canada, in December 2018, the CIHR announced a research grant for Indigenous health research centers across the country under its Network Environments for Indigenous Health Research (NEIHR) program. The NEIHR program is set to be funded from 2019 to 2034 (15 years). Each NEIHR provides supportive research environments for Indigenous health research driven by, and grounded in, Indigenous communities in Canada. The consortium of networks ensures continued growth, broad regional development, and national and international collaborations.

In its submission to the CIHR in 2019, the QcNEIHR grant proposal included four objectives, namely: 1) to build community research capacity through creating, sharing, and translating knowledge; 2) to push academia to value Indigenous knowledge and capacity; 3) to respond to specific Indigenous research capacity needs by supporting research training; and 4) to develop an Indigenous health research program.

## Objective

This manuscript aims to provide a reflexive account of the QcNEIHR and how it set out to improve Indigenous health research environments in the province of Québec between 2019 and 2023. More specifically, the authors describe what the QcNEIHR planned and what was accomplished in terms of operations and research outputs. It aims to deepen understanding of how the QcNEIHR objectives were put into action and to explain the evolution of network activities, including the factors that influenced adaptations.

## Methodology

This paper presents an implementation analysis (Champagne et al., 2011). Multiple qualitative data sources were used for this research, including documents, observations, and interviews. Data was collected and analyzed by the evaluator (Bisset, first author). A QcNEIHR committee selected the evaluator through a competitive process. The evaluator has been part of the Operations Circle since January 2022. One of the evaluator's roles is to act as a 'critical friend' by asking reflexive questions regarding the rationale for activities, their planning and anticipated effects. Responses to questions are recorded as observational notes.

Documents used for this research included the QcNEIHR's 2019 research proposal and three annual activity reports (2019-2021, 2021-2022, 2022-2023). Participant observations over 19 months (January 2022 to October 2023) included quarterly governance meetings, weekly operations meetings, recurrent events (e.g., Webinars, Discussion Circles, Kitchen Tables, Annual Retreats), one-time events (e.g., Cultural Safety Roundtable) and working group meetings to plan events. In the spring of 2022, a storytelling exercise captured the relationships between activities and outcomes (LaFrance & Nichols, 2009) and involved five group discussions. Eight individual interviews were completed

with members of the Operations Circle (OC), and three interviews with members of the QcNEIHR governance in 2022-2023. The interview guide included questions such as: 1) From your point of view, what has the QcNEIHR achieved? 2) To what extent does this correspond to what you expected? and 3) How has the QcNEIHR adapted and what has influenced adaptations in the QcNEIHR?

Data analysis included a systematic comparison of research protocol (i.e., what was intended) with what the QcNEIHR implemented (i.e., actions in reality). This analysis began with documents (CIHR proposal and activity reports). Notes from observations, group discussions and interviews were then analyzed to explain adaptations and identify the factors that contributed to these adaptations. The co-authors, all members of the Operations Circle (Delormier, Nominated Principal Applicant; Qashu, Executive Director; Périllat-Amédée, Research Coordinator), provided interpretations as the manuscript was being written. Discussions were designed to achieve consensus across co-authors. The QcNEIHR governance circles were provided with the manuscript to offer comments.

Ethical considerations for this manuscript are built into the governance structure of the QcNEIHR (Macaulay et al., 1998). All activities, knowledge products and processes were approved by the Network Advisory Circle and the Research Circle. All aspects of the evaluation, including questions, tools and products were discussed before implementation and all knowledge products shared. The evaluator, who is bilingual and non-Indigenous, aimed to maintain a culturally reflexive and responsive evaluation practice (Gautier, 2022) to build trust and increase the usefulness of the evaluation. The evaluator pursued ongoing professional learning to maintain cultural competency (McBride, 2011) and practiced reflexivity to maintain cultural humility (Tervalon & Murray-Garcia, 1998).

## Results

During the first four years, the QcNEIHR activities aligned with three of the four grant proposal objectives, namely: 1) to build community research, 2) to address needed academic transformation and, 3) to respond to specific Indigenous research capacity needs by supporting research training. Additionally, a new objective emerged, which was to ensure the relevance of the QcNEIHR through governance and networking. Consequently, activities aligned with one of the four objectives, namely, developing an Indigenous health research program, were reduced, and activities aiming to expand and strengthen the QcNEIHR network's relationship, were increased.

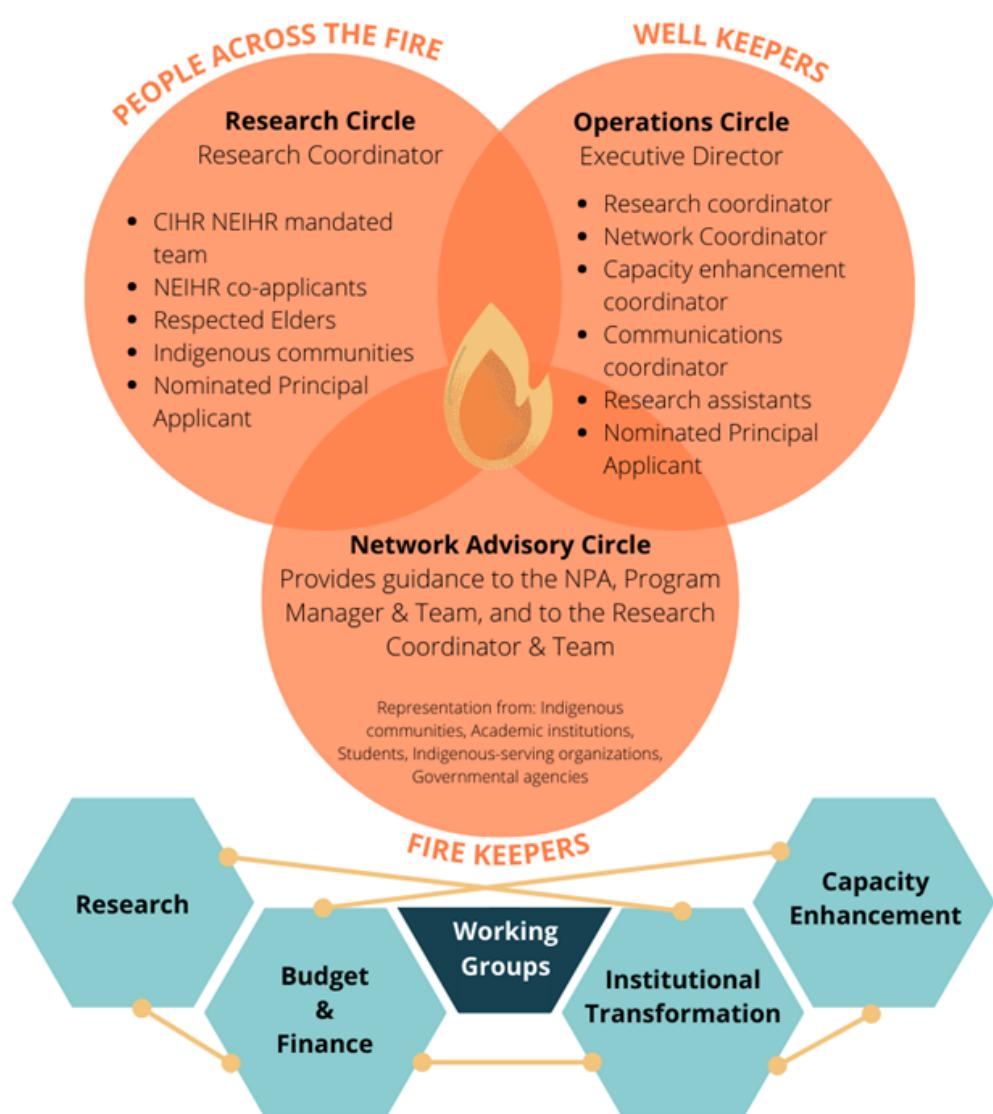
### **Ensuring the relevance of QcNEIHR objectives and activities through governance, networking and relationship building**

Although the QcNEIHR grant proposal identified the importance of developing respectful and equal partners, relationship building was not formally recognized as an objective and specific activities were not included in the grant proposal. Still, the OC implemented activities of this nature and grew a network of relationships by identifying new partners, initiating connections, and listening. Listening permitted the OC to, 1) deepen their understanding of the context, 2) identify opportunities to innovate, and 3) offer events for co-learning and the reinforcement of relationships. Listening took place when attending the events of partners, and during the QcNEIHR working group and governance meetings (Figure 1).

The COVID-19 measures limited some QcNEIHR activities, which could not occur as planned (e.g., community tours). This slower pace allowed the team to reflect on how QcNEIHR activities and governance might be operationalized. During this time, terms of reference and a governance structure inspired by Haudenosaunee decision-making (Figure 1) were completed. The Network Advisory

Circle (NAC) would represent communities and Indigenous serving organizations, the Research Circle (RC) would represent the research and academic community, and the elders, decision-makers and policy-makers would participate across both the NAC and RC. The OC would report and take direction from both the NAC and RC. Overall, this structure aimed to assure the QcNEIHR was accountable to Indigenous communities and contributed to the advancement of relevant Indigenous research.

**Figure 1**  
*Tahatikonhsontónie' (QcNEIHR) governance structure*



## INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

During the first annual retreat (2021), accomplishments were shared and validation was sought. Participants emphasized the importance of creating a lively network driven by a shared vision and values. The Operations Circle's role was to mobilize a diverse network of communities into action. Relationship building thus became the operating strategy during the first phase (2019-2024). Expanding relationships occurred through four types of activities: 1) raising awareness about the QcNEIHR's existence, 2) listening and learning about what was happening in Indigenous health research in Québec, 3) identifying current issues and needs and, 4) defining actions in collaboration with the QcNEIHR governance circles. Consequently, the QcNEIHR grew and diversified. Diversity included active involvement of 10 Nations and Inuit, students/Youth, Elders, individuals representing their community, and Indigenous organizations. With this level of diversity, health research can include a broad range of health determinants, including environment, education, language, arts/dance, spirituality, and ceremony.

### **Strengthening Indigenous communities' capacity, interest, and infrastructure for relevant health research**

#### ***QcNEIHR proposed actions***

To strengthen community-driven Indigenous health research, the QcNEIHR proposed to consult with regional and urban community organizations leading research programs in Québec. Through consultations, the QcNEIHR would share health research experiences by: 1) developing a profile of stories, 2) identifying promising practices, 3) including successes and challenges, and 4) identifying infrastructures in place to support self-determined research. By documenting and sharing successful models and principles with community and regional organizations, the QcNEIHR aimed to build co-learning relationships. In so doing, the QcNEIHR would respond to the need to develop understanding of research in diverse Indigenous communities and organizations.

To achieve these aims, the QcNEIHR proposed to implement five activities (Please see Table 1) including: 1) Annual network institute, 2) Virtual discussion circles, 3) Webinars, 4) Website and blog (text) or vlog (video), and 5) Social media presence.

#### ***QcNEIHR actions in reality***

The QcNEIHR OC implemented six activities aiming to strengthen Indigenous communities' capacity, interest, and infrastructure for relevant health research (Table 1) including: 1) consulting directly with communities, 2) collecting testimonials on Indigenous health research, 3) communicating through social media platforms, 4) sharing promising practices from KSDPP, 5) inviting new and existing QcNEIHR members to annual retreats, and 6) coordinating a cultural safety event.

The COVID-19 measures forced the OC to reconsider the proposed actions as many communities had safety measures in place. QcNEIHR's governance advised the OC to explore projects with academic partners. Once sanitary restrictions were lifted, the OC reached out to community health centres, friendship centres, and community researchers with the aim of planning in-person visits (i.e., community tours). Between the fall of 2021 and 2023, the QcNEIHR OC visited eight communities. Visits were most successful when, together with the community, the QcNEIHR prepared an agenda with specific ideas to discuss. Without sufficient preparation, communities were likely to misinterpret QcNEIHR's visits as being part of the development of a research project.

As evidenced by limited interest to maintain regular communication with the QcNEIHR, exploring and investing in health research was not a priority for many communities. Understanding community-driven research and its potential to strengthen community health is not obvious for

## INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

many. Building an understanding of the benefits of a health research network requires persistence and patience. Due to low interest in the aftermath of the COVID-19 pandemic, the sharing of stories to build understanding of Indigenous health research (as planned with the Annual Network Institute) did not occur. In response, the OC continued to consult with the NAC and RC to learn how to build interest for Indigenous health research.

The OC hosted “Kitchen Table Talks” as one way of explaining the mission of the QcNEIHR and to discuss how the QcNEIHR could serve Indigenous research. An elder noted the significance of sitting around the kitchen table to build relationships and learn from each other. These discussions confirmed that current understandings of ‘Indigenous health research’ could limit interest in the QcNEIHR. Consequently, the community tour activity shifted to creating video capsules called ‘Better understanding research’.

With communities working toward self-determined research, and academic partners seeking community partnerships and mechanisms to respectfully create these relationships, the need for research coordinator positions in Québec emerged from discussions with partners. Discussions took place to explore and consult on community research coordinator positions, resulting in a formal description of the position and one Nation agreeing to participate in a pilot project.

Finally, in 2023 the QcNEIHR coordinated a three-day Cultural Safety in Research Contexts Roundtable with three partner organizations. This event responded to the growing interest in cultural safety in Québec, due in part to the circumstances leading to the tragic death of Joyce Echaquan and the controversies surrounding the response from the provincial government. Racism and prejudice continue to be problematic in the Québec health system (Viens, 2019) and contributed to the death of Joyce on September 28, 2020. The Cultural Safety Roundtable, the first of its kind in Québec, provided an opportunity for the QcNEIHR to respond directly to the needs of researchers as well as Indigenous organizations, both French and English, to come together in person, build relationships, discuss research contexts and create synergies to advocate for culturally-safe Indigenous health research.

INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

**Table 1.** QcNEIHR planned and realized activities aiming to strengthen community research capacity

Planned 2019	2020-21	2021-22	2022-23	2023-24
<ul style="list-style-type: none"> <li>• Annual network institute</li> </ul>	<ul style="list-style-type: none"> <li>• Annual Retreat</li> </ul>	<ul style="list-style-type: none"> <li>• Annual Retreat</li> </ul>	<ul style="list-style-type: none"> <li>• Annual Retreat</li> <li>• Community research coordinator consultations</li> </ul>	<ul style="list-style-type: none"> <li>• Annual Retreat</li> <li>• Community research coordinator consultations</li> </ul>
<ul style="list-style-type: none"> <li>• Real-time virtual discussion circles</li> </ul>	<ul style="list-style-type: none"> <li>• Kitchen Table discussions</li> <li>• In-person community outreach</li> </ul>	<ul style="list-style-type: none"> <li>• Kitchen Table discussions</li> <li>• In-person community outreach</li> <li>• “Better Understanding Research” videos</li> <li>• Cultural Safety Roundtable planning</li> </ul>	<ul style="list-style-type: none"> <li>• In-person community outreach</li> <li>• “Better Understanding Research” videos</li> <li>• Cultural Safety Roundtable</li> </ul>	<ul style="list-style-type: none"> <li>• In-person community outreach</li> <li>• “Better Understanding Research” videos</li> <li>• Cultural Safety Roundtable</li> </ul>
<ul style="list-style-type: none"> <li>• Webinars</li> </ul>		<ul style="list-style-type: none"> <li>• Online event sharing KSDPP model with RCAAQ</li> </ul>		<ul style="list-style-type: none"> <li>• Webinar series: research led by and for Indigenous communities</li> </ul>
<ul style="list-style-type: none"> <li>• Development of the Website</li> </ul>		<ul style="list-style-type: none"> <li>• Quarterly Newsletter launch</li> </ul>		<ul style="list-style-type: none"> <li>• Website launch</li> <li>• Monthly Newsletter</li> </ul>
<ul style="list-style-type: none"> <li>• Social media</li> </ul>	<ul style="list-style-type: none"> <li>• Presence on four social media platforms</li> </ul>	<ul style="list-style-type: none"> <li>• Presence on four social media platforms</li> </ul>	<ul style="list-style-type: none"> <li>• Presence on four social media platforms</li> </ul>	

## Adapting institutional research capacity, interest, and infrastructure for relevant Indigenous health research

### *QcNEIHR proposed actions*

The QcNEIHR aimed to support research institutions to identify how their systems were valuing, supporting, and integrating Indigenous knowledge. The QcNEIHR would help research institutions self-identify the resources mobilized, regulations and conventions in place and the values being communicated. It was hypothesized that this process would mobilize the research community to implement changes. To mobilize change, this process would need to move beyond increasing the number of Indigenous people in an academic institution, towards a change in how Indigenous knowledge and health research are supported.

Concrete ‘transformative’ results could include examining current ethical guidelines and approval processes for research, developing, revising, or promoting guidelines, revisiting implementation, and building capacity to follow these guidelines. It was further hypothesized that the implementation of these measures would result in improving the quality of the relationships between academic and Indigenous communities.

To achieve these aims, the QcNEIHR proposed implementing two distinct but interconnected activities (Table 2): 1) appointing at least one Professor of Practice, and 2) studying McGill University’s Taskforce Report “Indigenous Studies and Indigenous Education” to develop a consensus on the actions needed to improve research relationships with Indigenous communities through a research ethics review. This institutional report was selected due to the nominated principal investigator’s affiliation with McGill and McGill’s collaborator role.

### *QcNEIHR actions in reality*

Between 2020 and 2023, the OC implemented six activities aiming to adapt institutional research capacity, interest, and infrastructure (Table 2), including: 1) hosting the Environmental Scan Workshop to disseminate results and discuss next steps, 2) coordinating a Webinar Series, 3) coordinating Inter-Institutional Discussion Circles, 4) writing an annotated bibliography on institutional best practices, 5) building institutional research partnerships, and 6) designing academic research facilitator positions.

To mobilize institutional change, the QcNEIHR began with an environmental scan of academic research institutions. Rather than identifying actions needed from the McGill Taskforce Report, the QcNEIHR profiled reconciliation and decolonization practices in universities. The scan also looked at how the QcNEIHR could support efforts to improve environments. Results were shared during an internal QcNEIHR feedback workshop with partners and members and an external ethics-approved workshop.

In response to the needs revealed from the scan and the workshop, the OC hosted a Webinar Series and coordinated four Inter-Institutional Discussion Circles (IIDC). Participants followed how institutional environments respond to reconciliation policies, shared strategies and successes, and learned from one another. By facilitating conversations in safe, sharing spaces, it was hypothesized that individual capacities could be strengthened, thus translating into structural change. The OC became aware that the sustainability of IIDCs depends upon leadership emerging from these groups.

Activities also developed to create an academic-based position that could liaise between academic institutions and communities. The Professor of Practice was based on positions that academic institutions (i.e., Queen’s, McGill) were trying to put in place. These entailed a knowledgeable Indigenous community member or knowledge keeper/elders in remunerated positions. Changing the university accreditation (merit-based) system requires faculty members to advocate and negotiate conditions

INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

and thus, the QcNEIHR's influence is limited. As a result of these limitations, the creation of academic-based positions became a low priority. Instead, the OC focused on designing a position within a research institution to serve as a liaison between academic institutions and Indigenous communities. These positions would be supported with funds from McGill University's Office of the Provost and Vice-Principal (Academic). The nominated principal investigator's academic affiliation with McGill University further provided an opportunity for the QcNEIHR to become a co-applicant for the Canada First Research Excellence Fund (CFREF). The proposed role of the QcNEIHR would be to advise health research and to ensure genomic research met community expectations of decolonizing research and guidelines for ethical research. This project, called "DNA to RNA: An inclusive Canadian approach to genomic-based RNA therapeutics (D2R)", was granted funding in 2023 and liaison positions are in the process of being created.

**Table 2.** QcNEIHR planned and realized activities aiming to adapt institutional research capacity, interest, and infrastructure to be relevant to Indigenous health research

Planned 2019	2020-21	2021-22	2022-23	2023-24
			<ul style="list-style-type: none"> <li>• Professor of Practice</li> </ul>	<ul style="list-style-type: none"> <li>• Research Facilitator/ university and community liaison positions proposed for DNA to RNA - Canada First Research Excellence Fund (CFREF)</li> <li>• Success of "DNA to RNA" funding (CFREF).</li> <li>• Pilot research facilitator positions</li> </ul>
<ul style="list-style-type: none"> <li>• Use McGill's Indigenous Actions for reconciliation plan to review research with Indigenous communities</li> </ul>	<ul style="list-style-type: none"> <li>• Questionnaire for environmental scan of all Québec Universités developed</li> </ul>	<ul style="list-style-type: none"> <li>• Questionnaires and discussions/ interviews with all Québec universités</li> </ul>	<ul style="list-style-type: none"> <li>• Environmental Scan presentation;</li> <li>• Workshop ethics application and feedback sessions with KSDPP and QcNEIHR partners</li> <li>• Annotated bibliography</li> <li>• June workshop</li> <li>• Discussion Circles and Webinars</li> </ul>	<ul style="list-style-type: none"> <li>• Annotated bibliography complete.</li> <li>• Discussion circles and webinars</li> </ul>

## Improving access and increasing interest among Indigenous students for Indigenous health research

### ***QcNEIHR proposed actions***

The QcNEIHR proposed to build Indigenous research capacity through two distinct training programs. The first program focused on three contexts: 1) university settings (a classic scholarship), 2) undergraduate or college settings, and 3) setting outside the institution. During the development of these scholarships, the QcNEIHR would coordinate with the Québec Indigenous Mentorship Network (QIMN) to ensure that activities were complementary. Over time, the QcNEIHR would carry on successful QIMN projects. The classic scholarship would support graduate students. The undergraduate or college scholarship would be coordinated with the QIMN and the QcNEIHR would learn from their successes. The “Experience-ships” bursaries would be located outside the institutional setting and provide funding to both a mentor (notably Indigenous Knowledge Keepers) and a mentee who would not be affiliated with an academic institution.

The second research training program would focus on Indigenous faculty, Institutional Review Boards (IRB), and graduate students. This training program would build understanding and know-how of research with Indigenous communities according to ethical principles. Together, these two research training programs would allow a reconceptualization in the definition of who an Indigenous health researcher is and to better encompass Indigenous knowledge systems and ways of knowing within and across institutional research training programs.

To achieve these aims the QcNEIHR proposed to implement 3 distinct activities (Please see Table 3), including: 1) “Experience-ships” mentoring program to fund a mentor/apprentice pair involved in research activities, 2) in-person, 1 to 3-day training institute based on co-learning circles and priority setting workshops, and 3) coordinating, aligning and continuing training activities with the QIMN.

### ***QcNEIHR actions in reality***

Rather than pursuing partnership with the QIMN, the OC completed community consultations. Consultations influenced the Graduate Scholarship application process by altering them to: 1) accept video, audio and written submissions in French or English, 2) allow unofficial transcripts, 3) allow letters of reference past the deadline, and 4) provide bilingual step-by-step videos on how to fill out the application. Also, applicants who were not selected received feedback to improve their application. This tailored approach caught the attention of research funding institutes in Québec, including the Fonds de recherche du Québec (FRQ) and Mitacs’ Indigenous Research Award (INDRA) Program. Consultations resulted in the QcNEIHR leveraging FRQ funds to support master’s students.

The “Experience-ships” mentoring program was launched following consultations in 2023. Experience-ships encourage transmission of traditional Indigenous knowledge by funding pairs of Indigenous individuals to learn, practice, and share information for the benefit of future generations. Recipients of Experience-ships are not affiliated with an academic institution. Both the mentor and the mentee receive equal compensation. The goal is for mentor/mentee pairs to disseminate knowledge via sharing events or an approach of their choosing.

Beginning in 2021, the NEIHR National Coordinating Centre (NCC) initiated a training institute through the annual National Gathering of Graduate Students (NGGS). The QcNEIHR supports students’ participation with the presence of Indigenous faculty, the NEIHR Knowledge Keeper and OC members.

INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

**Table 3.** QcNEIHR planned and realized activities aiming to respond to specific Indigenous research capacity needs

Planned 2019	2020-21	2021- 22	2022-23	2023-24
• QIMN aligns with QcNEIHR on activities				
• Experience-ships funding		• Consulting to determine the relevance and structure of an “Experience-ship” QcNEIHR funding program		• Launching the experience-ships program
• Training institute/co-learning circles/priority setting workshops		• National Gathering for Graduate Students (NGGS)		• National Gathering for Graduate Students (NGGS)
• Setting health research priorities for Indigenous communities	• Consultation of how the QcNEIHR could appropriately support student researchers.	• Québec NEIHR launched its Graduate Scholarships program	• Offering seven QcNEIHR Graduate Scholarships	

## Developing an Indigenous health research program and knowledge from the NEIHR

### *QcNEIHR proposed actions*

The final objective aimed to implement a research program. This program included three research questions each with distinct methodologies, moments of data collection, analysis, and reporting. The first two questions aimed to identify specific needs and thus refine the three QcNEIHR objectives. The two questions were: 1) How do we redefine and support community-academia partnerships for health research in Québec? and, 2) How do we enhance structural and individual support for Indigenous scholarships in Québec? The third question was an evaluation research question aiming to trace the extent to which the QcNEIHR implemented planned or revised activities and offer observations on the implications of these activities.

### *QcNEIHR actions in reality*

Both research questions remained relevant, however, apart from the environmental scan and the evaluation, data collection and analysis did not address research questions. Results were shared with the NCC and the CIHR for accountability, and specific evaluation activities and annual reports informed learning. The overall research plan of the QcNEIHR is participatory and has continued through research evaluation in the form of participation and analysis of meetings, events, reports, and feedback.

**Table 4.** QcNEIHR planned and realized activities aiming to develop an Indigenous health research program and knowledge from the NEIHR

Planned 2019	2020-21	2021-22	2022-23	2023-24
<ul style="list-style-type: none"> <li>• Research plan around specific questions (including interviews, ethnographic study, narrative inquiry)</li> </ul>	<ul style="list-style-type: none"> <li>• Building institutional research partnerships by supporting select research and participating in team research grants</li> </ul>	<ul style="list-style-type: none"> <li>• Reflexive learning through feedback cycles</li> </ul>	<ul style="list-style-type: none"> <li>• Building institutional research partnerships by supporting select research and participating in team research grants.</li> </ul>	

## Discussion

The discussion presents six main challenges the QcNEIHR faced during its first 5-year cycle. Challenges included: 1) Balancing the expansion with the strengthening of the network, 2) Developing community capacity to administer the QcNEIHR, 3) Maintaining interest in the QcNEIHR governance with clear roles and responsibilities, 4) Operating the QcNEIHR with high quality and

## INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

stable human resources, 5) Investing and planning for linguistic inclusivity for all Québec communities, and 6) Creating synergies across the nine Canadian NEIHRs.

### 1) Balancing the expansion with the strengthening of the network

During its first 5-year cycle, the QcNEIHR invested in building relationships, a vital component of engaging and collaborating in research related to Indigenous peoples. The expansion of the QcNEIHR facilitated a democratization of the QcNEIHR. Namely, as Zoom became the accepted means of communication due to COVID-19 regulations, it became possible for a wider audience to be consulted. This expansion allowed for the QcNEIHR to avoid duplicating actions and to identify potential synergies. However, as the size and diversity of the network grew, so too did the number of ideas for action. Thus, the OC was challenged to find an equilibrium between consulting to identify needs and opportunities and moving forward with collectively defined projects. Members of the OC wanted to move ahead, but found this difficult due to consultation and decision-making processes which could be lengthy. The OC also set broad goals with many priorities and found themselves involved in too many initiatives.

### 2) Developing community capacity to administer the QcNEIHR

As one of three community-based NEIHR, the QcNEIHR is based on the KSDPP's administrative structure. Implementing the QcNEIHR administrative structure has not been without challenges. This takes time and has required the OC to work with KSDPP to learn new tasks and to adopt procedures that align with university administration. Through our own experiences and listening to other Indigenous community organizations, we have many examples showing that if we want to see more Indigenous community-led research centers and academic partnerships in the future, administrative support is essential.

### 3) Maintaining interest for the QcNEIHR governance with clear roles and responsibilities

The distinction between the NAC and the RC became less clear over time. Overlapping discussions and time needed to maintain regular meetings for both groups, led the OC and QcNEIHR members to question the efficiency of this governance structure. In addition, the OC is reflecting on how partners benefit from giving their time to the QcNEIHR governance. Therefore, the next iteration of the QcNEIHR will clarify the roles and responsibilities for the governance as well as the reciprocity between the governance members and the QcNEIHR.

### 4) Operating the QcNEIHR with a high quality and stable team

Earlier iterations of the Indigenous mentorship research networks emphasized the importance of a dedicated staff as it was found that academic researchers are unable to devote sufficient time to the operation of the network while fulfill their research and academic obligations. Our experience reiterates this. Running a bilingual research network in Québec requires an investment in human resources but challenges remain. The QcNEIHR has integrated, and continues to integrate, unilingual Indigenous researchers into the Operations Circle, however, this poses challenges to fluid communications. Ideally, simultaneous translation would be offered across all meetings, however this is not possible due to budgetary limitations. Maintaining an OC with sufficient skill, patience, openness, and dedication requires taking time during the hiring process, and turnover made this process time consuming. Similarly, creating synergies based on complementary talents and competencies required the right approach to leadership. The next iteration of the QcNEIHR will benefit from the lessons learned by management experiences.

## INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

### 5) Investing and planning for linguistic inclusivity for all Québec communities

The financial and human resources required to run a bilingual network cannot be underestimated. By offering simultaneous interpretation or translation for all its events and communications, the QcNEIHR bridges two distinct colonial language groupings of Indigenous peoples in Québec (French and English), each language with its own unique socio-historic context and relationship with non-Indigenous institutions. This is without considering that many Indigenous peoples have their own first languages and dialects. The QcNEIHR hopes to support a wider audience of expression in the future with simultaneous interpretation and translation that includes Indigenous languages.

### 6) Creating synergies across the nine Canadian NEIHRs

Finally, both the OC and the evaluation component of the QcNEIHR appreciated connecting with the Canadian network of NEIHRs. NCC was found to be essential to take inspiration, share learning, build common visions and to co-create a collective performance framework. The opportunity to leverage the collective voice across the NEIHRs and advocate for institutional change is also recognized. The role the NCC plays in this respect is of key importance to the QcNEIHR.

## Conclusion

Consulting to develop innovative approaches to strengthen network environments for Indigenous health research in Québec was a key strategy for the QcNEIHR during this first phase of implementation. The OC of the QcNEIHR focused on achieving a balance between taking time to listen and understand the Indigenous health research environment in Québec and then implemented specific activities to achieve the objectives outlined in the research proposal. This balance was achieved by implementing activities that mobilized a diverse and lively network. By mobilizing institutional, organizational, and community-based actors, the OC built ownership and strengthened interest for shared leadership of the QcNEIHR.

## References

Appadurai, A. (2006). The right to research. *Globalization, Societies and Education*, 4(2):167–77.

Assemblée des Premières Nations du Québec et du Labrador (APNQL) (2014). *Protocole de recherche des Premières Nations au Québec et au Labrador*.

Battiste, M. (2013). *Decolonizing education: Nourishing the learning spirit*. University of British Columbia, Purich Publishing.

Bonneau, M. A. and Bergeron, O. (2024). *Indigenous Research Principles: Contributions to Public Health Collaborations: State of Knowledge*. INSPQ, Government of Quebec.

Cajete, G. (2000). *Native Science: Natural Laws of Interdependence*. Clear Light Publishers, Santa Fe, NM.

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2018). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

Cargo, M. and Mercer, S. L. (2008). The value and challenges of participatory research: strengthening its practice. *Annual Revue of Public Health*, 29:325–50.

Castellano, M. B. (2014). Ethics of aboriginal research. In Teays, W., Gordon, J.-S., and Renteln, A. D., editors, *Global Bioethics and Human Rights: Contemporary Issues*, page 273–288. Rowman & Littlefield.

Champagne, F., Brousseau, A., Hartz, Z., Contandriopoulos, A. P., and Denis, J. L. (2011). L'analyse d'implantation. In Brousseau, A., Champagne, F., Contandriopoulos, A. P., and Hartz, Z., editors, *L'évaluation : concepts et méthodes (2ième Édition)*. Les Presses de l'Université de Montréal.

CSSSPNQL (2018). *Priorités de recherche pour les Premières Nations au Québec*. CSSSPNQL.

Femmes Autochtones du Québec Inc (FAQ) (2012). Lignes directrices en matière de recherche avec les femmes autochtones.

First Nations Information Governance Centre (2014). *Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance*.

First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) (2018). *Toolbox of Research Principles in an Aboriginal Context*. Quebec.

Fraser, S., Vrakas, G., Laliberté, A., and Mickpegak, R. (2018). Everyday ethics of participation: a case study of a CBPR in Nunavik. *Global Health Promotion*, 25(1):82–90.

Gautier, L. (2022). Towards CR2 evaluation: Culturally – reflexive and -responsive evaluation in crises times and beyond. *International Journal of Health Planning and Management*, page 1–5.

Global Indigenous Data Alliance. *Care Principles for Indigenous Data Governance*.

Godmaire, H., Sauvé, L., and Boileau, J. (2003). Explorer, comprendre et agir ensemble: une recherche collaborative avec les Innus du Labrador. *Éducation relative à l'environnement*, 4:147–62.

Institut nordique du Québec (INQ) (2018). Report on the: Forum on the research needs of first peoples. *Québec: Institut nordique du Québec*, (3).

Inuit Tapiriit Kanatami (ITK) and Nunavut Research Institute (NRI) (2006). Negotiating Research Relationships with Inuit Communities: A Guide for Researchers. In Nickels, S., Shirley, J., and Laidler, G., editors, *Inuit Tapiriit Kanatami and Nunavut Research Institute: Ottawa and Iqaluit*.

Israel, B. A., Eng, E., Schulz, A. J., and Parker, E. A. (2005). *Methods in Community-Based Participatory Research for Health*. Jossey-Bass, San Francisco.

## INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH

Kahnawà:ke Schools Diabetes Prevention Program (2023). *Code of Research Ethics*. Kahnawà:ke, QC.

King, M., Smith, A., and Gracey, M. (2009). Indigenous health part 2: The underlying causes of the health gap. *The Lancet*, 374(9683):76–85.

Lachapelle, L. and dak Puana, S. (2012). Mamu minu-tutamutau (bien faire ensemble): L'éthique collaborative et la relation de recherche. *Éthique publique*, 14(1).

LaFrance, J. and Nichols, R. (2009). *Indigenous Evaluation Bundle*. Alexandria: American Indian Higher Education Consortium.

Macaulay, A. C., Cross, E. J., Delormier, T., Potvin, L., Paradis, G., and McComber, A. (1998). Developing a Code of Research Ethics for research with a Native community in Canada: a report from the Kahnawake Schools Diabetes Prevention Project. *International Journal of Circumpolar Health*, 57(Suppl 1):38–40.

Macaulay, A. C., Delormier, T., McComber, A., Cross, E., Potvin, L., and Paradis, G. (1997). Participatory research with native community of kahnawake creates innovative code of research ethics. *Canadian Journal of Public Health / Revue canadienne de santé publique*, 89(2):105–8.

McBride, D. F. (2011). Sociocultural theory: providing more structure to culturally responsive evaluation. *New Directions in Evaluation*, 131:7–13.

Montambault, P. (2018). *Research Priorities for Quebec First Nations. First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)*.

Morton-Ninomiya, M. E. and Pollock, N. J. (2017). Reconciling community-based indigenous research and academic practices: Knowing principles is not always enough. *Social Science & Medicine*, 172:28–36.

National Aboriginal Health Organization (2011). *Six Principles of Métis Health Research: Ethical Principles to Guide the Métis Centre in its Work*.

Nunavut Research Institute & Inuit Tapiriit Kanatami (2007). *Negotiating Research Relationships with Inuit Communities: A Guide for Researchers*. Inuit Tapiriit Kanatami and Nunavut Research Institute Ottawa and Iqualuit.

Regroupement des centres d'amitié autochtones du Québec (RCAAQ) (2021). *Cadre de référence en recherche par et pour les Autochtones en milieu urbain au Québec*. Available:

Row, R. K., Bull, J. R., and Walker, J. D. (2020). Indigenous self-determination and data governance in the canadian policy context. In Walter, M., Kukutai, T., Carroll, S. R., and Rodriguez-Lonebear, D., editors, *Indigenous Data Sovereignty and Policy*, page 81–98. Routledge.

Tervalon, M. and Murray-Garcia, J. (1998). Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for Poor Underserved*, 9(2):117–125.

Tremblay, M. C., Martin, D. H., McComber, A. M., McGregor, A., and Macaulay, A. C. (2018). *Understanding community-based participatory research through a social movement framework: a case study of the Kahnawake Schools Diabetes Prevention Project*. BMC Public Health, 18:487.

Truth and Reconciliation Commission of Canada (2015). *Honouring the Truth, Reconciling for the Future. Summary of the Final Report of the Truth and Reconciliation Commission of Canada*. Library and Archives Canada Cataloguing in Publication.

Tuck, E. and Yang, K. W. (2014). *R-Words: Refusing Research. Humanizing research : decolonizing qualitative inquiry with youth and communities*.

Viens, J. (2019). *Public Inquiry Commission on relations between Indigenous Peoples and certain public services in Québec: listening, reconciliation and progress*. Government of Quebec.