

Indigenous communities, collectives and organizations advancing decolonizing methodologies: perspectives from British Columbia Network Environment for Indigenous Health Research in Canada

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Abstract

Purpose – The British Columbia Network Environment for Indigenous Health Research (BC NEIHR) aims to support and advance research leadership among Indigenous communities, collectives and organizations (ICCOs) within British Columbia, Canada. The BC NEIHR provides support and funding to ICCOs for research development and knowledge sharing. This funding model supports ICCOs' self-determined health research by providing funds that are fully controlled by ICCOs, without the requirement of a non-Indigenous host organization.

Design/methodology/approach – We conducted a critical analysis of 35 ICCO research development and knowledge-sharing grant applications to identify how ICCOs are decolonizing research and methodologies.

Findings – Six themes were identified from ICCO decolonizing methodologies: (1) identified, driven, and led by Indigenous Peoples and community; (2) guidance from advisors, ethical guidelines, and local protocols; (3) follow

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This paper forms part of a special section “Honouring 25 Years of Linda Tuhiwai Smith's Decolonizing Methodologies: Research and Indigenous Peoples”, guest edited by Dr Jennifer Markides, Dr Stephanie Bartlett, Dr Lucy Delgado, Dr Laura Forsythe, Dr Sarah Green, Dr Jennifer MacDonald, Dr Robin Minthorn, Dr Julie Morin, Dr Meagan Ody, Dr Hangsel Sanguino, Dr Darlene St. Georges, Dr Mila Mary Rose Tucker and Dr Angie Tucker.

We acknowledge and respect all Indigenous Peoples, communities and ICCOs on whose traditional territories the ICCO-led projects were held on. We acknowledge and respect the *ləkʷəjən* peoples, on whose traditional territory the university and BC NEIHR offices stands, and the Songhees, Esquimalt and WSÁNEĆ peoples whose historical relationships with the land continue to this day.

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traditional and cultural practices; (4) determine what is knowledge and ways to share knowledge; (5) celebrating the sharing and returning of knowledge and (6) advancing relationality: building and strengthening relationships.

Originality/value – This paper highlights the impact of how the BC NEIHR and ICCOs are advancing decolonizing methodologies to support self-determined Indigenous health research led by, and grounded in, Indigenous communities. It reflects on the work of Maori scholar Linda Tuhiwai Smith's Decolonizing Methodologies: Research and Indigenous Peoples and contributes to the literature of decolonizing methodologies.

Keywords Decolonizing methodologies, Indigenous community, Indigenous collective, Indigenous organization, Indigenous health, Indigenous health research, Indigenous self-determination, Community-based research

Paper type Research paper

British Columbia Network Environment for Indigenous Health Research in Canada

The British Columbia Network Environment for Indigenous Health Research (BC NEIHR), one of nine NEIHRs across Canada, supports research leadership among Indigenous communities, collectives and organizations (ICCOs), Indigenous and non-Indigenous researchers and Indigenous trainees ([Canadian Institutes of Health Research \[CIHR\], 2018](#)). The BC NEIHR aims to support Indigenous-led health research within BC through: (1) developing infrastructure to support ICCO-led health research; (2) supporting Indigenous Peoples to lead health research reflective of their values, priorities and approaches; (3) providing funding to support ICCOs in research development and knowledge sharing and mobilization; (4) facilitating ethical and culturally safe research partnerships and (5) engaging with policy and organizational partners at local, regional, provincial, national and international levels to advance these objectives and ensure sustainability of the BC NEIHR.

The BC NEIHR includes a fast-growing interdisciplinary, inter-sectoral membership of individuals and organizations engaged in culturally grounded Indigenous health research. As of March 2024, there were 381 members, inclusive of ICCOs (76), Indigenous trainees (145), Indigenous academics and professionals (80) and allied academics and professionals (79). Most (72.4%) were studying or employed in Indigenous health research. Membership is geographically and culturally diverse, representative across all regions of BC.

Guiding principles and governance

The BC NEIHR follows Indigenous and non-Indigenous (Western) ethical guidelines including First Nations Principles of Ownership, Control, Access and Possession (OCAP[®]) ([First Nations Information Governance Centre, 2023](#)), Inuit Qaujimajatuqangit Principles [1], Principles of Ethical Métis Research ([Métis Centre of the National Aboriginal Health Organization, 2010](#)) and Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2), Chapter 9: *Research Involving the First Nations, Inuit, and Métis Peoples of Canada* ([Canadian Institutes of Health Research et al., 2022](#)).

The BC NEIHR is led by an Indigenous governing council, which upholds the guiding values, practices and principles and advises on BC NEIHR research priorities and strategic policies. The governing council includes a gender balanced representation of First Nations, Métis and, when possible, Inuit, including community, organizational, academic and geographical representation. Members include Elders and Knowledge Keepers (guiding members), community members, Indigenous graduate students and representatives from key partners.

Advancing decolonized methodologies

Across BC, ICCOs include 199 First Nations [2], 39 Métis Chartered Communities [3], 25 Friendship Centres [4] and other Indigenous-led collectives and organizations. ICCOs within BC are culturally diverse and often separated geographically by large distances. To advance

Indigenous health research driven by, and grounded in, Indigenous communities, the BC NEIHR provides annual funding for ICCOs for Indigenous health research development and knowledge sharing and/or mobilization. ICCO funding is fully controlled (held and distributed) by ICCOs, opposing mainstream funding practices where eligible institutions include research institutions.

Relationality and relationship building with ICCOs is prioritized to overcome the continued fear and mistrust of health research. To support ICCOs in leading their own research, the BC NEIHR provides ongoing comprehensive support for ICCOs to prepare for and/or undertake health research including an accessible and iterative funding application process, resources and support from Indigenous Health Research Facilitators (IHRFs) (Erb and Stelkia, 2023). Up to five IHRFs, one from each health region of BC, support the diversity of ICCOs. IHRFs are “on-the-ground” people who establish and strengthen relationships (Erb and Stelkia, 2023). IHRFs create a supportive environment for ICCOs and follow guiding values and principles of Indigenous self-determination, ethics, Indigenous and decolonizing methodologies, cultural safety and equity.

Cultural and professional humility as a facilitator have been fundamental in creating a supportive environment for ICCOs who come from diverse backgrounds - by honoring everyone’s knowledge we build trust and respect. It is our priority to learn how to bridge academic research language and concepts to non-academic Indigenous science. When we use simplified (i.e. avoid jargon), land based and metaphoric language we build a common ground of understanding that allows ICCOs to walk into the process of health research with security, confidence, and inspiration. Encouraging and respecting community leaders’ vision, mission, and self-determination on how to make things happen is key for ICCOs who are studying colonialism and its health impacts and systemic barriers. It is important to acknowledge that the relationship we build today can be a long-lasting connection. Is not only a research matter, but we also share songs, prayers, and healing for all our relations.

The BC NEIHR aims to decolonize research and research methodologies through advancing Indigenous-led research at the levels of community and health research institutions and systems. This resonates with advancing the Indigenous research agenda, conceptualized by Smith (2021), describing two pathways of community-led projects and Indigenous-led research centres and programs within institutions. In this paper, we present how ICCOs, funded by the BC NEIHR, and the BC NEIHR uphold and contribute to advancing decolonizing methodologies in Indigenous health research.

Background

Research that is “decolonized” represents an ongoing anti-colonial struggle that centers the needs and priorities of Indigenous Peoples and communities within Indigenous worldviews and ways of knowing and doing (Denzin *et al.*, 2008; Smith, 2021). Decolonized research places as much or more importance on Indigenous Peoples, communities and their voices (within collective spaces) compared to research methods used (Zavala, 2013). In Linda Tuhiwai Smith’s work, decolonizing methodologies enable the “existence, protection, ownership, and right to development of Indigenous entities” (Smith, 2021, p. 277). Indigenous community-led research is decolonial because it is initiated, driven and led by Indigenous Peoples, communities and their priorities within their worldviews.

The work of Smith (2021) has created space for Indigenous ways of knowing within Western settings, including research and education (Chu-Fuluifaga, 2023; Lee and Evans, 2021; Livstrom *et al.*, 2018; Louie *et al.*, 2017; Suaalii-Sauni and Fulu-Aiolupotea, 2014). Indigenous research in Western spaces requires the critical context of acknowledging and understanding the history of research within its roots of European imperialism and colonialism (Smith, 2021) and its historic and ongoing impacts for Indigenous Peoples and communities. Smith underlines how European ideology, exploration and knowledge-

seeking perpetuated a system of power and oppression over Indigenous Peoples, where Indigenous ways of knowing were assumed as inferior and frequently dismissed.

The Indigenous research agenda, described by Smith (2021), is a conceptual framework that centers self-determination, “the right of Indigenous Peoples to freely choose political, economic, social and cultural development” (United Nations General Assembly, 2007). To advance the goal of self-determination and decolonize the narrative of Western research, Smith names and describes 45 Indigenous research projects. All projects intersect with both the Indigenous research agenda and with one another and show how Indigenous research can advance the “acts of reclaiming, reformulating and reconstituting Indigenous cultures and languages” (Smith, 2021, p. 163). The work of Smith has decolonized the narrative of Western research while also inspiring decolonized narratives in other fields. Louie *et al.* (2017) envisioned the Indigenous research projects as principles to reimagine post-secondary teaching and pedagogy. Ways in which university–community partnerships engaged with decolonizing practices or whether colonial paradigms were upheld were examined using Smith’s work as a framework (Livstrom *et al.*, 2018).

Decolonizing research and research methodologies provides a platform for Indigenous Peoples and communities to prioritize their needs at local, national and international levels. This creates spaces within Western-dominant environments to transform systems that value knowledge over others, uphold lived experiences and initiate change through reciprocal, respectful relationship building in research and beyond.

Methodology

ICCO funding

The BC NEIHR provides annual funding for ICCOs, defined by the BC NEIHR, as any First Nation, Métis community, Aboriginal Friendship Centre or independent First Nation, Métis or Inuit organization or collective. Indigenous organizations or collectives (unincorporated associations) include at least 70% Indigenous membership. ICCOs in partnership with non-Indigenous institutions (e.g. university or health authority) are eligible if they are not hosted and/or funded by non-Indigenous institutions.

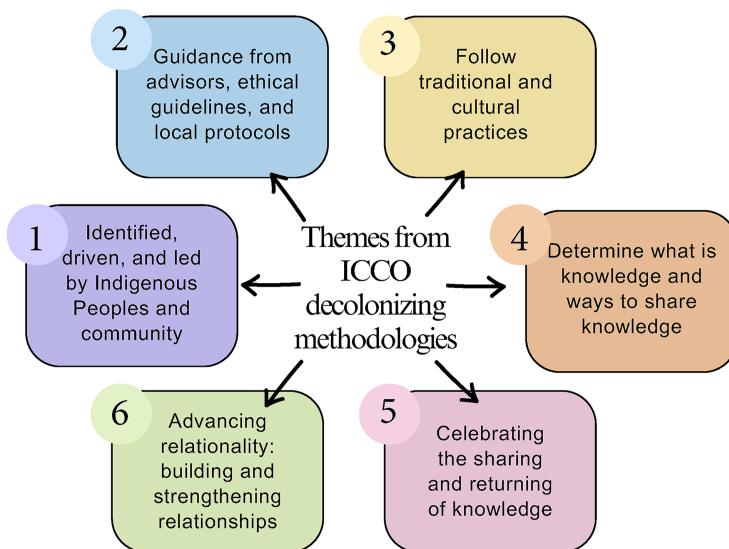
ICCO funding includes knowledge-sharing and mobilization grants and research development grants. Research funds are provided directly to ICCOs, who have full control (hold and distribute) of their research funds. Knowledge-sharing and mobilization grants support ICCO-led and decolonized projects focused on sharing ICCO-relevant research findings through culturally relevant and accessible venues and/or formats. Research development grants support ICCO-led and decolonized projects that engage in community outreach, priority setting and relationship or partner building. ICCOs are invited to share their work and experiences at an annual BC NEIHR-hosted gathering for Indigenous health research (for co-learning and sharing).

Learning from ICCO funding applications (analysis)

An analysis of ICCO funding applications identified ICCO-led decolonizing methodologies from knowledge sharing and research development projects. In total, 35 applications were analyzed including 16 knowledge-sharing and mobilization grants ($n = 8$: 2021–2022; $n = 8$: 2022–2023) and 17 research development grants ($n = 9$: 2021–2022; $n = 8$: 2022–2023). Applications were reviewed, and relevant information was extracted. Thematic analysis (Braun and Clarke, 2021) followed a reflexive and inductive approach facilitating open and organic coding to identify themes. Coding reliability and limiting potential bias were ensured through a structured approach (Braun and Clarke, 2021; Naeem *et al.*, 2023), multiple author independent review of applications (Barry and Erb) and consensus (Barry, Erb and Stelkia) of findings and final themes.

Knowledge from ICCO funding applications (findings)

Six themes related to decolonizing methodologies were identified from ICCO funding applications: (1) identified, driven, and led by Indigenous Peoples and community; (2) guidance from advisors, ethical guidelines, and local protocols; (3) follow traditional and cultural practices; (4) determine what is knowledge and ways to share knowledge; (5) celebrating the sharing and returning of knowledge and (6) advancing relationality: building and strengthening relationships. Although themes are presented separately, they are not mutually exclusive but interconnected. [Figure 1](#) provides a summary of identified themes.



Source(s): Authors' own work

Figure 1.
Summary of themes
identified from ICCO-
led funding
applications

Theme 1: identified, driven, and led by Indigenous Peoples and community

The first theme identified was that projects were focused on local and place-based specific research priorities identified by Indigenous Peoples and communities. ICCO projects were started by Indigenous community members, who identified the need for safe spaces to come together to practice culture, build relations and support health and well-being of Indigenous Peoples and communities. Moving forward, ICCOs held community engagement sessions with local Indigenous community members to further identify, determine and develop research priorities. To ensure research priorities were local and context-specific, some sessions were open to all community members, whereas other sessions were tailored and held for specific community members, including Elders and Knowledge Keepers, youth, 2SLGBTQ + youth, women and community members experiencing homelessness.

Indigenous Peoples and community members (co)led the projects. ICCO teams encompassed diverse knowledge and expertise, consisting of Indigenous community members including Elders, Knowledge Keepers, traditional healers, graduate students, language speakers, cultural leaders and advisors, matriarchs, youth, artists and community members. The development and facilitation of ceremony, protocols and cultural activities were led by Elders, Knowledge Keepers and advisors. Local Indigenous community members were hired or contracted to provide knowledge or services. Language speakers

provided language services (resources, transcription and translation), artists created and designed art and media and Indigenous community members provided services as cultural support workers, event facilitators, keynote speakers, traffic controllers and caterers.

Youth were empowered as the next generation of leaders through leadership, mentorship and youth-centered projects. Youth were included in ICCO teams and held roles as youth advocates, graduate students, assistants, paid interns and artists. Mentorship opportunities for youth included learning from Elders, Knowledge Keepers, Indigenous graduate students and leaders and healthcare professionals and accessing career and educational counseling. Through ongoing engagement, youth shared their knowledge, lived experiences and recommendations to contribute to research development, knowledge sharing and strategies to support youth leadership. Projects provided a safe space for youth to (re)connect with their Indigenous identity and learn about culture, language, rites of passage and create connections to land and community. Activities and resources centering youth included sharing circles, land-based camps and retreats and knowledge-sharing resources. Youth-centered knowledge-sharing resources included a youth rights comic, a youth wellness leader logo, custom hoodies and cultural story books and/or guides.

Theme 2: guidance from advisors, ethical guidelines, and local protocols

The second theme identified was that projects were guided by community advisors and advisory teams. Advisors and advisory teams – committees, councils and circles – included members of the community such as Elders, Knowledge Keepers, traditional healers and cultural and community leaders. Advisors were representative of the local community diversity, including First Nations, Inuit, Métis, on-reserve, off-reserve and community clans. Advisors provided regular and ongoing guidance for cultural and traditional teachings, values, and protocols and ensured local customs and cultural protocols were upheld. Advisors attended and facilitated activities, shared traditional knowledge, supported the inclusion of language, attended ICCO team meetings and were involved in and provided consultation and guidance for research development and knowledge sharing, including review and approval of project findings and resources.

Ethical guidelines, determined by community, ensured the protection of individual, collective and traditional knowledge. Individual and community rights were protected by legally reviewed community consultant contracts, privacy policies for community members' personal information, agreements for research partnerships, formal agreements with Elders to share their stories and community copyright of Elder-shared stories. Collective and traditional knowledge were protected by having advisors or advisory teams, and through online knowledge-sharing platforms maintained and hosted by the local community, ICCO or chosen steward, where some online platforms were accessible to local community members only. Ethical approval by a national governing council was given for one project, with a few projects following broader ethical guidelines including OCAP®.

Projects were held within community and followed local protocols. In respect of the land and its Peoples, project activities and gatherings were held in the local community or territory. This supported the local community as ICCOs purchased supplies (drum kits, smudge kits, etc.) and food locally, contracted local Indigenous Peoples and services (catering services, keynote speakers, local drum or dance group) and rented local meeting spaces. Elders and Knowledge Keepers offered guidance and shared knowledge prior to and during activities and provided ceremony including opening and/or closing, prayer, smudge, singing and drumming. In a few projects, invitation for community members to take part included providing gifts to community members or their Elders and Chiefs. Gifting protocols were followed to acknowledge team members, advisors and community. Advisors, advisory team members and Elders and Knowledge Keepers were gifted for attending activities and

gatherings, sharing knowledge and providing support for language, traditional practices, protocols and ceremony. Community members were provided honoraria, gifts or could take part in giveaways (door prizes and draws). Gifts included honoraria (cash and gift cards), traditional art, traditional medicines including sage and tobacco, blankets, custom hoodies and t-shirts and grocery cards.

Theme 3: follow traditional and cultural practices

The third theme identified was that the foundation of projects was Indigenous traditional and cultural practices, centering specific practice(s) or incorporating practices throughout. Specific practices that were centered included cedar weaving, language, drumming, storytelling and traditional food systems. For example, one project centered on cedar weaving focused on teachings, traditional uses and harvesting protocols of cedar while emphasizing the importance of language, local history and intergenerational transmission of knowledge. Another project centered the traditional pitcook and included teachings of traditional food practices and on-the-land harvesting. Other projects focused on combining traditional and Western knowledge, including using traditional knowledge, practices and language for creating educational resources for Indigenous students in a Western hospital setting, developing a culturally relevant yoga program and designing diabetes wellness retreats. For projects based within Western healthcare environments, community members informed recommendations for existing programs with embedded traditional practices and supported the development of traditional and land-based healing programs and youth-centered camps.

Traditional practices were place-based and community-specific, with language and land centered within projects. Language was incorporated through language sessions, sharing and teaching by local language speakers at activities and gatherings and was integrated into educational resources, curriculums, recordings and films. A connection to land was fostered through holding activities and gatherings on the land in community, within local traditional territories or homelands. Several projects were developing or adapting programs to include land-based activities and/or be held on the land. Projects held activities, gatherings, feasts and walks on the land, provided time to go on the land and held land-based camps. One project focused on protection and stewardship of the land and waters, conducting territorial surveys to inform future land-based projects. Traditional practices used within projects included harvesting, hunting, weaving, carving, traditional medicines, singing, drumming, ceremony, teachings and traditional foods, food practices and food knowledge systems.

Theme 4: determine what is knowledge and ways to share knowledge

The fourth theme identified was that knowledge within projects was inclusive of individual and collective knowledge, traditional and historic knowledge and descriptive knowledge. Individual and community collective knowledge encompassed stories, testimonies, journeys, lived experiences, reflections and other forms of (co)-created knowledge including art, photos and published works. Traditional and historical knowledge included teachings, language, songs, healing, ceremony, medicines, art, photos, historical and cultural records and territorial surveys. Descriptive knowledge consisted of quantitative self-identification information and reviews and scans of community resources. Knowledge was shared by Elders, Knowledge Keepers, knowledge creators and gatherers, youth and community members.

Knowledge was shared by the community and gathered in various ways (methods). Common ways of sharing knowledge were sharing and talking circles, focus groups, one-on-one discussions and community gatherings. Other ways of knowledge sharing included knowledge gifting ceremonies or sharing sessions, arts-based reflections and exhibits, panel

discussions, question and answer sessions and reviews. Knowledge gifting ceremonies and sharing sessions invited Indigenous Peoples to gift their knowledge to be shared in cultural resource centres and brought together Elders to share their stories. Knowledge sharing also occurred through arts-based reflections, which were curated into exhibits and other knowledge-sharing resources. Knowledge was also gathered by environmental scans, and review of archival documents, community resources and other relevant sources.

Storytelling was an important way (method) for sharing knowledge. Storytelling was often facilitated by Elders and Knowledge Keepers, who shared through both oral and visual storytelling, including stories, teachings, movement and art. Storytelling was used to build advocacy and raise awareness of gaps within Indigenous health, where community-shared or Elder-shared stories were shared with the public and organizations. Educational resources integrated storytelling into a story guide for a film of community-shared stories intended for post-secondary education and training and a storybook intended for youth attending a community high school. Elder residential school stories were shared orally and through videos to raise awareness and advocate for residential school survivor literacy and education. Storytelling also facilitated intergenerational transmission of knowledge. Stories and teachings were passed down by Elders and Knowledge Keepers during project activities and gatherings, as well as documented, recorded and held in digital and physical cultural resource centres, intended to pass on knowledge to youth, families, community and future generations.

Theme 5: celebrating the sharing and returning of knowledge

The fifth theme identified was that community gathered through celebration to share a meal, thank the people involved and share and return knowledge to community. Indigenous Peoples and communities gathered collectively at the beginning, throughout and at the end of projects. From the onset, projects started with community engagement, where community members shared knowledge and identified local priorities. Gatherings for ongoing engagement were held throughout and/or at the end of projects to share and celebrate the work completed. Gatherings included ICCO team meetings, community gathering discussions, traditional feasts, meals, potlucks, knowledge-sharing sessions and ceremonies, open houses, workshops, retreats and circles.

Knowledge was gifted back (returned) to community. Gifting knowledge occurred during community gatherings, where knowledge was presented through diverse ways including oral and visual methods, and through digital and physical formats, including community reports, audio and video recordings, films and webinars, art, and educational and learning resources. One project focused on gifting knowledge through ceremony, where academic works by Indigenous authors including theses, research papers, books and novels were gifted back to community and validated through Indigenous ways. Once returned to community, knowledge and resources were held by community in various forms including hardcopy and digital versions and within physical and online community directories, management systems and cultural resource centres hosted by local communities, ICCOs or chosen stewards. As decided by community, knowledge was accessible by the local community only, shared with other Indigenous Peoples and communities or shared more widely with the public and organizations.

Theme 6: advancing relationality: building and strengthening relationships

The final theme identified was that projects prioritized relationship building within ICCOs and communities, across communities and with non-Indigenous allies. Within ICCO teams, relationship building was ongoing and occurred through regular team meetings and during activities specific for team relationship building. Community built relationships during

community gatherings, meals and feasts, land-based camps, drum circles, sharing and talking circles and other traditional activities. Community activities created a sense of belonging and connection to oneself, community, culture and the land. ICCOs engaged in relationship building with Indigenous leaders, traditional healers, Elders, Knowledge Keepers and Indigenous community members from different communities across Indigenous communities, territories and nations to build community bridges for increased collaboration and partnership. In addition, ICCOs engaged in relationship building to increase partnership with non-Indigenous allies, supporters and organizations, including schools, universities, health systems and healthcare organizations. Relationship-building activities with allied partners included inviting non-Indigenous supporters to gatherings, increasing collaboration with Indigenous traditional healers and youth with Western healthcare professionals and sharing stories, community-identified recommendations and educational resources to support advocacy and support networks.

Discussion

An Indigenous research agenda, as conceptualized by [Smith \(2021\)](#), is advanced through two pathways, including community-led projects and institution-based Indigenous-led research centres and programs. The BC NEIHR is actively engaged in advancing both pathways to support decolonizing Indigenous health research at community and institutional levels. These six themes share an interwoven story of ICCO-led decolonizing methodologies that advance Indigenous self-determination and Indigenous ways of knowing, being and doing and relationality.

Community engagement, centered in ICCO projects, ensured that priorities were identified by Indigenous Peoples and communities. Community engagement creates space for the community to decide, define and develop research priorities and methods from Indigenous perspectives for Indigenous purposes ([Smith, 2021](#)), prior to starting research ([Canada Research Coordinating Committee, 2019](#); [Newhouse *et al.*, 2023](#)). The BC NEIHR upholds that ICCOs are the experts within their communities and hold the knowledge and lived experiences required to inform Indigenous-led health research.

Led by Indigenous Peoples and community members, ICCO projects privilege the concerns, practices and participation of Indigenous Peoples and communities as both the researchers and the researched ([Smith, 2021](#)). ICCO projects were created in response to the need for safe and inclusive spaces to come together to collectively identify priorities for community health and well-being. Throughout all stages of ICCO projects, Indigenous community members were engaged. Youth were engaged in leadership and mentorship opportunities, fulfilling community responsibility to nurture gifts and talents of youth, which strengthens community capacity and creates the next generation of leaders for community transformation ([Smith, 2021](#)). ICCO self-determination is actively supported by the BC NEIHR which provides funding that is fully controlled (research and research funds) by ICCOs and does not support projects or teams hosted and/or funded by non-Indigenous institutions.

ICCO projects were guided by advisors or advisory teams. Advisors and advisory teams included Indigenous community members who were responsible for decision-making, providing knowledge and guidance for local protocols and ensuring research remains relevant, respectful, responsible and reciprocal ([Kurtz *et al.*, 2024](#); [Morley, 2015](#); [Tremblay *et al.*, 2018](#)). Advisors include Elders and Knowledge Keepers to guide the research and researchers ([Datta, 2018](#); [Kurtz *et al.*, 2024](#); [Smith, 2021](#)) and play an influential role within community change and development of culturally appropriate programs ([Health Canada, 2011](#); [Stiegelbauer, 1996](#); [Viscogliosi *et al.*, 2020](#)). The importance of Elders and Knowledge Keepers as advisors within ICCO projects and the BC NEIHR align with Indigenous

worldviews, where Elders and Knowledge Keepers are respected teachers and guardians of values, protocols, tradition, history and culture.

Indigenous ethical guidelines go beyond Western ethics of the individual to uphold and protect the rights of the individual and collective (Hayward *et al.*, 2021; Smith, 2021). Most ICCOs did not explicitly state the use of Indigenous research principles (i.e. OCAP[®]) or ICCO-established ethical guidelines; however, ICCO projects enacted principles of ownership, control, access and possession in how knowledge was shared, gathered, used, stored and gifted back to community. Many ICCOs across BC have guidelines for ethical research and formal governing bodies to approve research. To support Indigenous and ICCO-led research and ethics, the BC NEIHR continues to investigate previously identified gaps in Indigenous research ethics processes (Erb and Littlechild, 2022) and has created an interactive map of 44 ICCO-established ethics and/or research frameworks. The BC NEIHR strongly adheres to Indigenous-established ethical guidelines, which further assert the right of Indigenous Peoples to self-determination in research.

Local protocols of providing gifts and honoraria were followed. Traditionally, Elders are offered tobacco as a request to share knowledge, and traditional healers are given a gift for healing services (Maar and Shawande, 2010; Stiegelbauer, 1996). Gifting protocols continue to be followed within Indigenous communities. Honoraria, often provided as cash, is not considered payment but an offering for knowledge, ceremony, participation and other services provided by Elders and Knowledge Keepers. Gifts of gratitude may be given on their own or in addition to honoraria. To respect ICCO self-determination, BC NEIHR funds can be used to provide honoraria to Elders, Knowledge Keepers and community members, as well as for culturally relevant gifts, in methods determined by the individual or community.

Traditional and cultural practices were foundational to ICCO projects to advance Indigenous self-determination by “reclaiming, reformulating and reconstituting Indigenous cultures and languages” (Smith, 2021, p. 163). ICCO projects, like the Indigenous research projects described by Smith, were diverse but intersecting. All ICCO projects included language and land, which are interconnected with land shaping language and language embedding land. Land and language (re)connect with Indigenous ways of knowing, being and doing and build and strengthen relationships to the land, oneself and community. Centering Indigenous ways of knowing and doing, ICCO and Indigenous-led research (Allen *et al.*, 2020; Health Canada, 2011; Morley, 2015) create space to (re)connect, (re)claim, (re)formulate and (re)constitute culture and language. In directing control of research and funds to ICCOs, the BC NEIHR entrenches culturally appropriate Indigenous ways of knowing, being and doing. ICCOs, funded by the BC NEIHR, now view Indigenous health research as a mechanism to actively resist Western knowledge and reawaken their own knowledge for their health and well-being.

Knowledge in ICCO projects was diverse and representative of community-specific individual, collective and traditional knowledge. Research within the dominant Western system defines and evaluates knowledge as legitimate or valid, which is problematic as it assumes superiority of one knowledge system over the other (Allen *et al.*, 2020; Smith, 2021). Western knowledge, reflected as measurements and statistics, is often presented within a deficits-based approach and functions to characterize, categorize, condense and standardize (Smith, 2021; Stelkia *et al.*, 2023). This colonial approach marginalizes and reinforces negative stereotypes by emphasizing difference while failing to address wider social and structural issues (Smith, 2021). Indigenous knowledge extends beyond measurements and statistics, holding “values and principles about human behaviour and ethics, about relationships, about wellness” (Smith, 2021, p. 182) and should be considered equal to, parallel or co-existing with Western knowledge (Datta, 2018; Snively and Corsiglia, 2016). The BC NEIHR aims to catalyze a shift in the present research environments, systems and institutions through support of ICCO self-determined research that determines what is

considered legitimate and/or valid knowledge, who can contribute knowledge and how knowledge can be contextualized as strengths-based (Chu-Fuluifaga, 2023; Smith, 2021).

Knowledge was shared through relational ways and storytelling. As Indigenous-determined methodology and the research process are as important or more important than the outcome or knowledge created (Kovach, 2005; Peltier *et al.*, 2020; Smith, 2021; Wilson, 2008), it is important for Indigenous beliefs and values to guide the research methodology and process. Indigenous and decolonizing methods are relational and follow Indigenous values to provide deeper understanding of the experiences of people and their collective contexts (Chu-Fuluifaga, 2023). Within these relational methods, storytelling plays an integral role to share knowledge and histories, connect people to each other and the land and create reciprocal relationships between the storyteller, the story and the listener (Kovach, 2010; Smith, 2021; Wilson, 2008). ICCO-led research decolonizes research methodologies and process by “reclaiming, reconnecting and reordering those ways of knowing which were submerged, hidden or driven underground” (Smith, 2021, p. 79). By providing funding that is supportive of Indigenous-led and decolonizing methodologies, the BC NEIHR supports space for ICCO-determined decolonizing methodologies, such as storytelling, to be embraced and nurtured.

ICCOs and communities gathered to (re)unite in the spirit of reciprocity to return knowledge to community as the primary beneficiaries of research. Returning or gifting knowledge (research findings and knowledge-sharing resources) is fundamental for Indigenous self-determination and reaffirms Indigenous principles of ownership, control, access and possession. The return of knowledge to community acknowledges Elders, Knowledge Keepers and community as owners, who hold the rights and responsibilities to determine what happens with the research findings (Datta, 2018; Newhouse *et al.*, 2023; Peltier *et al.*, 2020; Smith, 2021). The return of knowledge occurs during collective gatherings and ceremony, which further center Indigenous Peoples and communities. This concept of collective ownership opposes Western discourse where knowledge about Indigenous Peoples were first presented to the West and then, through the eyes of the West, to the colonized (Smith, 2021). ICCOs are asked to provide a summary of project processes and outcomes and are invited to share their work with other ICCOs at a BC NEIHR-hosted collective annual gathering. In respect of ICCO self-determination, the BC NEIHR does not require any information that violates Indigenous research principles.

Relationship building within the ICCO and community, across communities and with allied partners was an ongoing process. Respectful and reciprocal relationships, foundation to Indigenous health research, engage a 4Rs approach (Kirkness and Barnhardt, 1991; Kurtz *et al.*, 2024) of *respect*: for diverse Indigenous knowledge and practices; *relevance*: of community-identified priorities and culturally relevant and ethical protocols; *reciprocity*: for mutual benefit and respect for all and *responsibility*: for accountability through engagement, collaboration and decision-making. Gathering and engaging community, prior to starting research, follows Indigenous values of kinship to create strong relationships (Kurtz *et al.*, 2024; Sylliboy *et al.*, 2021). Relationship building that is ongoing creates space and time required to build, renew and nurture reciprocal and trusting relationships. Within this space, sharing a feast fosters Indigenous practices of finding connections, getting to know one another (Ball and Janyst, 2008) and connecting people to the land, language, history and culture. The BC NEIHR builds meaningful relationships with ICCOs through supporting, honoring and respecting ICCO self-determination, diversity and knowledge. Relationship building, viewed by the BC NEIHR, is an ongoing decolonial process that privileges Indigenous ways of knowing and doing, while nurturing long-term commitments that support self-determined research led by, and grounded in, Indigenous communities.

ICCO research development and knowledge sharing, supported by BC NEIHR funding, are critical to support Indigenous health research, capacity bridging and community well-being. ICCO-led decolonizing methodologies provide a shared and interconnected story that

informed five recommendations for ways Indigenous health research can be supported and advanced at the institutional level.

ICCOs have the right to determine whether research is undertaken with or without partner institutions, and in all research undertaken, ICCOs have the right to:

- (1) Full control over and equitable access to research funding. Funding agencies must consider ICCOs as eligible institutions authorized to administer grants and awards.
- (2) Set their own research priorities and develop, lead and evaluate health research that benefits their community and is guided by local and culturally relevant Indigenous ways of knowing, being and doing.
- (3) Ownership, control, access and protection of the research process, methodology, findings and outcomes.
- (4) Establish ethical guidelines for research. Research institutions and research ethics boards must require non-Indigenous and Indigenous researchers to prioritize ICCO-established ethical guidelines for research.
- (5) Establish community advisors, advisory teams or research governing bodies to guide the research and researchers.

Conclusion

The six interwoven themes share a story of advancing Indigenous self-determination, Indigenous ways of knowing, being and doing and relationality. Within the current landscape of decolonizing methodologies and Indigenous health research, ICCOs recognize the importance of working together to (re)assert Indigenous self-determination for health and well-being of Indigenous Peoples and communities. Indigenous self-determination is realized when research is led by, and grounded in, Indigenous ways of knowing, being and doing where knowledge and knowledge creation is returned to community. The BC NEIHR is an example of a promising relational approach toward supporting the self-determination of ICCOs in leading health research while overcoming systems-level barriers to accessing mainstream health funding.

Notes

1. "Inuit Qaujimagatuqangit", Nunavut Impact Review Board, Cambridge Bay, NU, available at <https://www.nirb.ca/inuit-qaujimagatuqangit>
2. "First Nations in BC", British Columbia Assembly of First Nations, available at: <https://www.bcafn.ca/first-nations-bc/interactive-map>
3. "Chartered Communities", Métis Nation British Columbia, Surrey, BC, available at: <https://www.mnbc.ca/citizens-culture/chartered-communities>
4. "Our Friendship Centres", British Columbia Association of Aboriginal Friendship Centres, available at: <https://bcaafc.com/>

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