

Improving health research among Indigenous Peoples in Canada

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Historically, owing to a dominant Western science paradigm, Indigenous methods, methodologies, epistemologies, knowledge and perspectives have been dismissed as unsuitable for health research.¹ As such, Indigenous health research frequently remains poorly aligned with the goals and values of Indigenous Peoples.² Furthermore, research involving Indigenous people has been tainted by historical atrocities.³ The process of reconciliation in Canada should include the indigenization of health research, which will contribute to deconstruction of colonial control.⁴

Employing the core ethical principles of “respect for persons, concern for welfare, and justice” used in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*,^{5,6} we review the history of Indigenous health research in Canada and outline critical considerations for non-Indigenous researchers. Our aim is to promote a collaborative approach to Indigenous health research in Canada that prioritizes the goals, knowledge and strengths of Indigenous partners.

How has the history of Indigenous health research in Canada shaped current governance?

Many Indigenous people are highly involved in health research. However, many remain hesitant to participate, given the historical context of research involving Indigenous people in Canada.⁷ Examples of historical research atrocities committed by non-Indigenous researchers are nutritional experiments and BCG vaccine trials, which are outlined in Boxes 1 and 2. Although there may have been knowledge accrued from these studies, as with Nazi Holocaust experiments and the Tuskegee syphilis study, the motivations, rationale and methods involved were highly unethical and have bred a culture of mistrust of health research.

In response to this history of unethical research, the Royal Commission on Aboriginal Peoples outlined the first statement on Indigenous research ethics.⁹ This, and guidelines from the Canadian Institutes of Health Research, among others, outlined in Box 3, informed the current Tri-Council policy statement on Indigenous health research and ethical conduct of research in Canada.^{5,13} The Tri-Council policy statement describes the misappropriation

KEY POINTS

- Indigenous methods and methodologies are increasingly recognized as valuable tools to improve research practices and outcomes.
- Ethical guidelines, community-based and partnership approaches, and reflexive allyship are transforming how researchers approach Indigenous health research.
- When reporting on Indigenous health outcomes, it is crucial to provide context for Indigenous health challenges observed, and highlight strengths, to avoid contributing to stigmatization in wider society.
- It remains important to reflect critically on our attempts as researchers to act as allies, and to highlight the unique knowledge and skills possessed by Indigenous scholars and community leaders.

and abuse of Indigenous knowledge, property, culture and biological samples as well as “failure to share data and resulting benefits; and dissemination of information that misrepresented or stigmatized entire communities.”⁵ The chapter “Research involving the First Nations, Inuit and Métis Peoples of Canada” in the Tri-Council statement is self-described as “a step toward establishing an ethical space for dialogue on common interests and points of difference between researchers and Aboriginal communities engaged in research,” and it includes a requirement for community engagement, recognition of diverse interests within communities, and respect for customs and traditions — including research traditions.⁵ Indigenous communities and organizations may also have ethical guidelines for research of their own, which must be considered along with the tenets of the Tri-Council policy statement.⁵ These guidelines act as a starting point for researchers to understand the complex array of concepts important to conducting ethical Indigenous health research.

Although research that is obviously unethical is no longer conducted, problematic issues still arise. For example, a 2014 review found a considerable lack of community engagement in research on neurodevelopmental disorders among Indigenous children in Canada.² Of 52 included papers, only three used community-based participatory research methodologies, and one 1999 study, conducted without consent, was stopped at the request of the

Box 1: Nutrition experiments conducted in residential schools and Indigenous communities³

Nutritional experiments were conducted on children in residential schools and Indigenous communities between 1942 and 1952 in Canada and include the following:

- 1942 study in five northern Manitoba Cree communities
 - The study involved physical examinations, blood tests and radiographs.
 - Researchers commented on profound malnutrition and near starvation.
- 1947/48 James Bay Survey of Attawapiskat and Rupert's House Cree First Nations
 - The study involved physicians, a dentist, an x-ray technician, a photographer and three anthropologists.
 - The study aimed to examine nutritional status, and provide guidance regarding combatting of not only malnutrition but also the threat of Indigenous "dependency."
- Studies on malnourished Indigenous populations in northern Manitoba, 1942–1944
 - There is little evidence of informed consent.
 - The study was conducted on 300 malnourished Indigenous people: 125 were given vitamin supplements that were poorly understood in this era, and the remainder were controls.
- Residential school experiments, 1948–1952
 - Observations in 1944 had already established poor nutrition in residential schools.
 - Rather than immediately improving food, schools were treated as laboratories to study nutrient requirements in malnourished children.
 - At the Alberni residential school, observing riboflavin deficiency, researchers allowed continued insufficient milk consumption and riboflavin deficiency for two years to provide a "baseline," followed by providing increased milk.
 - At Shubenacadie residential school, children were found to be deficient in multiple vitamins and minerals, including ascorbic acid; researchers carried out a double-blind randomized trial in which children were given either ascorbic acid or placebo to examine the effect on gums.
 - At the Blood residential schools, children found to be deficient in thiamine endured a two-year baseline measurement, with a diet known to be inadequate, after which they were given supplemented flour.
 - At St. Mary's school, a high deficiency in riboflavin was found; children were given "Newfoundland Flour Mix," illegal to sell outside of Newfoundland owing to added thiamine, riboflavin, niacin and bone meal, and children became anemic.
 - At Cecilia Jeffrey residential school, children were given the option of eating whole wheat bread combined with an education program to examine the effect of education on food choices.
 - The St. Paul's residential school served as a control for the other schools in the study (Alberni, Shubenacadie, Blood, St. Mary's and Cecilia Jeffrey); no changes or interventions occurred despite well-established knowledge of existing malnutrition.
 - Researchers requested that dental services for the children at all the schools under investigation (Alberni, Shubenacadie, Blood, St. Mary's, Cecilia Jeffrey and St. Paul's) be withheld for the duration of their studies so as to not interfere with the results.

None of these experiments had any evident positive or lasting effect on the health of those under study. These experiments exploited rather than addressed the issue of malnourishment and any larger structural causes, reflecting how, at the time, "bureaucrats, doctors, and scientists recognized the problems of hunger and malnutrition, yet increasingly came to view Aboriginal bodies as 'experimental materials'" rather than human beings deserving of bodily autonomy and adequate food.

community.^{2,15} It is worth highlighting that 51 of the 52 Indigenous neurodevelopment studies focused solely on fetal alcohol spectrum disorder (FASD),² despite higher incidence of autism spectrum disorder, and similar incidence of cerebral palsy to FASD in North America. This skewed research in only one area of neurodevelopmental disorders can be highly stigmatizing.¹⁶ To date, no other systematic review examining community engagement in Indigenous health research has been identified, although we are

Box 2: Qu'Appelle vaccine trials⁸

The Department of Indian Affairs was concerned about the spread of disease from reserves to settlers. At the time, bacille Calmette–Guérin (BCG) vaccination was only for individuals at very high risk of tuberculosis or with low socioeconomic status. Despite doubts about the effectiveness and safety of the BCG vaccine, the Department of Indian Affairs supported experiments with BCG vaccination. In 1933/34, infants were given doses, and additional infants were selected as controls. Although the vaccine did successfully prevent tuberculosis in most infants assigned the BCG vaccine, almost one in five Indigenous children involved in the trial died of other poverty-related illnesses. Vaccine success does not erase the concerning motivations and methods of the trial and the implication that Indigenous lives were considered of lesser value than settler lives.

Box 3: Major ethical guidelines in Indigenous health research*

- *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (chapter 9)⁵
- OCAP (ownership, control, access and possession) framework^{10†}
- Royal Commission on Aboriginal Peoples statement on research ethics⁹
- Assembly of First Nations: *First Nations Ethics Guide on Research and Aboriginal Traditional Knowledge*¹¹
- *First Nations Regional Longitudinal Health Survey: Code of Research Ethics*¹²
- *CIHR Guidelines for Health Research Involving Aboriginal People (2007–2010)*¹³
- Inuit Tapiriit Kanatami: *National Inuit Strategy on Research*¹⁴

*This list is not exhaustive. Communities, regions and organizations may have their own guidelines. It is the researcher's responsibility to determine which guidelines are appropriate, in collaboration with stakeholders. †OCAP is a registered trademark of the First Nations Information Governance Centre (FNIGC; www.FNIGC.ca/OCAP).

currently undertaking an assessment of Indigenous participation in pediatric research in Canada. As Indigenous participation improves, researchers should continue to critically examine the risk of tokenism and consider whether the involvement is truly meaningful.¹⁷ Throughout this analysis, we delve more deeply into present-day issues of nonintentional harms, such as those to community values, autonomy and justice.

Why are Indigenous ways of knowing resisted?

Incorporation of Indigenous methodologies and methods into research is increasingly recognized as critical to generating

results that truly represent the perspectives of Indigenous participants.^{1,18} Their use recognizes Indigenous Peoples as having the tools to best address concerns of their own communities. Several qualitative studies have successfully used culturally appropriate methods of data collection, as we outline in Table 1.²⁹

However, Indigenous researchers continue to face pressure to prove these methodologies and methods rigorous and credible using Western standards.¹ Often Western funding bodies cite concerns about the validity of Indigenous methodologies, methods and epistemologies.³⁰ This imparts a pressure to assimilate.¹ Some non-Indigenous researchers may unconsciously feel Indigenous knowledge is threatening to Western knowledge, as differ-

Table 1: Examples of Indigenous or culturally appropriate methodologies and methods

Example	Description
Methodology: The theoretical lens or standpoint through which research is understood, designed and conducted¹⁹	
A tribal methodology with Nêhiyaw Kiskêiyhtamowin (Plains Cree knowledge) at the core	<ul style="list-style-type: none"> Built on qualities of Plains Cree tradition, including “holistic epistemology, story, purpose, the experiential, tribal ethics, tribal ways of gaining knowledge, and overall consideration of the colonial relationship”²⁰ Example: Kovach’s doctoral studies examining Indigenous perspectives of Indigenous methodologies²⁰
Two-eyed seeing	<ul style="list-style-type: none"> Belief that one can see from both an Indigenous and Western viewpoint simultaneously, recognizing these systems can exist side by side²¹ Example: In research by Marsh and colleagues, Indigenous strategies included working with Elders to include knowledge sharing, ceremony, and developing an approach depicted through the medicine wheel, and Western strategies included the approach to statistical analysis of survey responses²²
The petal flower	<ul style="list-style-type: none"> Framework envisions research as a flower. The flower includes roots as foundational elements, flower centre as self, who is central to the search; leaves as journey; stem as methodologic backbone and supports; petals as diverse ways of search for knowledge; and environment as academic context²³ Example: Absolon used this framework in research of Indigenous methodologies used by Indigenous graduate “searchers”²³
<i>nayri kati</i> (“good numbers”)	<ul style="list-style-type: none"> A quantitative methodology, defined as “good numbers” in the <i>palawa</i> Tasmanian Indigenous language, which explicitly states the Indigenous standpoint of the researcher along with the following key tenets: 1) privileges Indigenous voices, knowledges and understandings, 2) does not take Euro-Australian as the unacknowledged norm, 3) does not presume Indigenous deficit as a starting point¹⁹ Example: Walter and Andersen report on numerical scales to measure performance with an Indigenous worldview¹⁹
Methods: The tools or techniques to conduct research	
Symbol-based reflection	<ul style="list-style-type: none"> Anishinaabe arts-based method²⁴ Participants use symbols to reflect their perspectives²⁴ Respects belief that participants’ energy is put into their symbol(s) with spiritual importance²⁴ Example of use: Carter and colleagues used symbol-based reflection to “explore practices that support positive First Nations identity” and “provide suggestions for practicing culturally safe care”²⁵
Storytelling/conversational method	<ul style="list-style-type: none"> Honours oral tradition²⁶ Participants share their perspective through telling their story Relational process with protocol stemming from tribal knowledge²⁶ Example of use: Kovach used storytelling to examine “the challenges facing Indigenous doctoral researchers of engaging Indigenous knowledges in their research methodology”²⁶
Sharing circle	<ul style="list-style-type: none"> Comparable to focus groups²⁴ Participants, including facilitator, are all equal²⁴ Healing method grounded in historical practices²⁴ Example of use: Lavallée described using sharing circles to explore the “physical, mental, emotional, and spiritual impacts of a physical activity program: a martial arts (tae kwon do) program offered at the Native Canadian Centre of Toronto”²⁴
Photovoice	<ul style="list-style-type: none"> Participants take photographs representing their lived experience regarding the research question²⁷ Intention of photos is to elicit emotion from policy-makers viewing photographs, leading to tangible results²⁷ Example of use: Gabel and colleagues used photovoice for their work, which “sought to explore one southern Labrador Inuit community’s intergenerational relationships, with a focus on seniors’ perspectives and understandings of health and well-being”²⁸

ent interpretations of the same issue may arise from the two epistemologies.³⁰ However, the defensive response to “protect accepted paradigms” fundamentally contradicts what research is intended to do — discover new knowledge.³⁰

Which research methodologies have been used successfully in Indigenous health research?

One commonly used methodology is community-based participatory research. Motivated by the desires and interests of the communities being studied, community-based participatory research includes active involvement of those affected by the research, in every step of the project.⁵ Employing a partnership approach shifts the research toward priorities that are practically meaningful to the community, with increased social and contextual validity.³¹ Whereas a partnership approach may demand deeper reflection, accountability and effort, it results in research with a more substantial positive social influence.^{31,32}

When used with Indigenous communities, community-based participatory research is about restoring power and control, and indigenizing the research process. Indigenizing can be seen as an approach that not only draws upon existing structures, but privileges and validates Indigenous narratives and systems.⁷ When Indigenous health research involves non-Indigenous researchers and Western methodologies, there are inherent power relationships derived from colonization that must be acknowledged.³³ Where research decisions are taken without the meaningful participation of Indigenous researchers, organizations, traditional knowledge holders and communities, there is risk of harm through issues such as misrepresentation or conducting research in a disrespectful way.⁵ Furthermore, engagement must consider overburden of communities and research fatigue, which threatens effective involvement and inhibits community control.^{33,34}

The design and methods of a 2009 qualitative study investigating storytelling as a research method to understand the Inuit experience of living with diabetes offers an example of meaningful community engagement.³⁵ The research team held community brainstorming sessions and had a community steering committee that assisted with grant proposals, survey tool appraisal, logistic guidance, hiring local assistants, reviewing results, translation services and directing community knowledge translation efforts.³⁵ Working with appropriate leadership groups, this project incorporated methods more culturally appropriate for the Inuit community than traditional interviews.³⁵ The community was able to benefit not just from the results of a research project, but also from the research process itself. Data collection methods such as photovoice, symbol-based reflection, sharing circles and storytelling have also been used successfully in qualitative studies, as outlined in Table 1.²⁹

Indigenous methods have been used within Western methodologies, such as grounded theory, or within Indigenous methodologies, such as Kovach’s methodology based on Nêhiyaw Kiskêyîhtamowin (Plains Cree knowledge).^{20,29} Qualitative tradition has been particularly instrumental in integrating Indigenous and Western ways of knowing, because many qualitative methodologies embrace the existence of multiple truths and subjectivity of participant experi-

ence.²⁹ As Indigenous methods and methodologies become accepted in the qualitative tradition, we encourage researchers to look to their Indigenous colleagues for guidance regarding how these may be integrated in quantitative research. *Indigenous Statistics: A Quantitative Research Methodology* is the first book published on Indigenous quantitative methodologies and provides one of few leading examples.¹⁹ Described therein is an approach to inclusion of the Indigenous standpoint in quantitative methodologies and methods, including the example shown in Table 1.

What can be used to avoid “deficit discourses” when undertaking Indigenous health research?

A deficit discourse “describes a mode of thinking that frames and represents Aboriginal identity in a narrative of negativity, deficiency and disempowerment.”³⁶ There is a danger, especially in the field of health, of conflating the social problems Indigenous people face as a result of social, economic and political marginalization experienced since colonization, with cultural characteristics of Indigenous Peoples.³⁷ Non-Indigenous health practitioners may label social problems as “Indigenous problems” through failure to recognize the association between such problems and recent Indigenous history.⁷ Research that describes health deficits without providing historical context promotes a deficit discourse. Health researchers should be aware of this framing, how research may perpetuate it and how it leads to stereotyping of Indigenous Peoples in wider society.

Further than reframing deficit narratives in the context of colonization and westernization, researchers could take a strength-based approach that capitalizes on the capacities, abilities, knowledge and talents that already exist in Indigenous communities.³⁷ For example, a 2016 qualitative photovoice study framed the positive influence on health and well-being from strong intergenerational relationships, providing a strength-based discourse on their analysis of intergenerational influences on health.²⁸

How can non-Indigenous health researchers act as allies to Indigenous Peoples?

Allyship is an active role or process focused on eliminating social inequalities that allies benefit from, or extending these benefits to marginalized people.³⁸ A non-Indigenous person cannot be an expert on Indigenous issues, and cannot speak for Indigenous Peoples, but can strive to be an ally.³⁹ However, only Indigenous people can determine whom they consider an ally. Allyship requires a willingness to make mistakes and to be uncomfortable, as well as an ability to step aside and allow Indigenous people to lead.³⁹

In health research, Indigenous allyship includes working to eliminate barriers to Indigenous scholars. Examples of this include using positions of power to pressure prominent journals to accept Indigenous methodologies as valuable, or supporting Indigenous scholars to take leadership positions in research projects. Allies should also develop meaningful relationships with Indigenous people and communities, ensuring a sense of accountability on the part of the researcher to their participants and communities unto which the research reflects.^{38,40} Meaningful

relationships are based on trust, time, personal risks, interaction, reciprocity and open-minded listening.^{39,41} Despite the competitive nature of academia with regard to authorship positions, academic appointments and funding, allyship also often means taking a supportive rather than leading role in projects and publications.³⁸

Allyship can be thought of as a reflexive process.³⁸ In the qualitative tradition, reflexivity, defined as thoughtful self-awareness, is a tool that contributes to the trustworthiness and integrity of some methodologies.⁴² Being a reflexive non-Indigenous researcher may mean making a conscious effort to transcend one's worldview and accepting that there are truths different from one's own. Reflexivity requires a constant questioning of one's beliefs, assumptions and motivations, and consideration of how these affect the research.⁴² Allyship has been described as a process, "as allyship requires one to constantly cast a critical eye on themselves."³⁸

Table 2: Considerations for successful engagement in Indigenous health research

Area of consideration	Suggestions
Historical context	Develop relationships, read, and attend talks or conferences to learn about the history of Indigenous health research.
Present-day context	Meaningfully engage Indigenous scholars, organizations or communities in every stage of the project.
	Ensure research is respectful to, desired by and beneficial for the community involved from their perspective.
Ethical guidelines and protocols	Review ethical guidelines that could inform the research; appropriate guidelines will vary based on the community.
	Endeavour to learn more about the participants' comfort levels, priorities and cultural protocols.
Indigenous methods and methodologies	Evaluate, with Indigenous team members, what Indigenous methods, methodologies may be appropriate for the project if desired by Indigenous stakeholders.
Community-based research	Consider in what tangible ways the research project could restore power and control to Indigenous Peoples.
	Determine how the Indigenous voice will be represented, recognizing Indigenous people as experts on their own lives.
Deficit- versus strength-based research	Assess whether the research has the potential to stigmatize the community of interest and, if so, how this can be avoided.
	Look for ways to highlight or acknowledge strengths, talents and skills of the community of interest in the research.
Research allyship	Develop relationships with Indigenous people to which you are accountable.
	Consider who will be benefitting the most from the research.

A 2016 study informing Inuit community-based HIV and sexually transmitted infection prevention and sexual health promotion programming is one example of successful allyship in research.⁴³ Here, the author employed Indigenous methodologies and methods, drawing upon Inuit Qaujimajatuqangit (Inuit worldview), postcolonial theory, community-based participatory research principles, and a two-eyed seeing framework (Table 1).⁴² High rates of sexually transmitted infections are identified in the article but contextualized within colonization and westernization.⁴³ The investigator identified and positioned her role in the community, used an advisory committee, and received funding from the Kugluktuk Hamlet Council, ethics approval from a University Ethics Review Board and a Nunavut research licence — all indicating support from key actors.⁴³ An Indigenous storytelling method was employed for data collection, with the understanding that "Inuit women are experts in their own lives."⁴³

Conclusion

We've explored some concepts of particular importance when engaging in Indigenous health research, particularly from the position of a non-Indigenous health researcher, to help researchers understand the historical and present context of this field. Engaging Indigenous worldview and values, specific to the group(s) one hopes to collaborate with, is critical to producing research with meaningful findings from participant perspective. Research with Indigenous people and communities demands thorough and continuous reflection, as well as accountability to participants. Table 2 outlines suggestions for researchers hoping to participate in constructive Indigenous health research.

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