

# A New Era of Indigenous Research: Community-based Indigenous Research Ethics Protocols in Canada

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## Abstract

Indigenous communities across Canada have established principles to guide ethical research within their respective communities. Thorough cataloging and description of these would inform university research ethics boards, researchers, and scholars and facilitate meaningful research that respects Indigenous-defined ethical values. A scoping study was conducted of all relevant peer-reviewed literature and public-facing Indigenous research ethical guidelines from First Nations, Metis, and Inuit communities and organizations in Canada. A total of 20 different Indigenous research ethics boards, frameworks, and protocols were identified. Analysis resulted in three key themes: (1) balancing individual and collective rights; (2) upholding culturally-grounded ethical principles; and (3) ensuring community-driven/self-determined research. Findings demonstrate how employment of Indigenous ethical principles in research positively contributes to research outcomes.

## Keywords

indigenous populations, community-based research, research ethics, research ethics committee, self-determination, culture, collective rights

## Introduction

### *History of Research in Indigenous Contexts*

Following research that was widely deemed unethical and extractive, academic institutions moved to regulate and establish research protocols to ensure the protection of research participants (Champagne, 2015). University Research Ethics Boards (REBs) were established to review the ethical appropriateness of all research involving human participants conducted by their faculty, staff, and students (Government of Canada, 2018). However, contemporary ethical protocols and standards that have come to govern the conduct of research involving humans in academic and health service institutions have generally emerged from a Western worldview that reflects traditions of Western moral philosophy, cultural and methodological perspectives, and political and social theory (Carrese & Rhodes, 1995; Chattopadhyay & De Vries, 2008; Simonds & Christopher, 2013). Scholars have argued that university REBs are narrowly focused on protecting university/researcher reputations and legal matters rather than shielding participants from harm or ensuring that researchers and institutions are meeting their responsibility to participants and Indigenous communities (Dingwall, 2008, 2012, 2016; Hedgecoe, 2016; Schrag, 2010; Stark, 2012). Consequently, these ethical protocols and standards—along with the institutional REBs that enact

and enforce them—have been critiqued by Indigenous communities for not adequately addressing problems in research and for sanctioning research that has caused harm (First Nations Information Governance Centre [FNIGC], 2014).

Indigenous people have the right to self-determination in all aspects of their lives (United Nations Declaration on the Rights of Indigenous Peoples [UNDRIP] and Truth and Reconciliation Commission of Canada), which includes the establishment of research ethics protocols. This paper was undertaken in a larger context of a regional project under the Canadian Institutes of Health Research's (CIHR) Network Environments for Indigenous Health Research (NEIHR). In Manitoba, the NEIHR project is called *Kishaadigeh*, which translates from *Anishnawbemowin* (Ojibway language) to “she who guards the lodge.” The basis for this project is to resource Indigenous communities and organizations to equip themselves to develop the research structures they need to enhance self-determination,

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which can include identifying their research priorities and establishing mechanisms to apply for and fund their own research. A large part of this work is related directly to the development of Indigenous community-based research ethics protocols and frameworks. This paper will outline the various ways that Indigenous people have asserted self-determination over the research process. As noted by Chief Norman Bone of Keeseekoowenin First Nation “Indigenous People have always done research, always searched for understanding, ways of being and knowing the world around us in order to survive. We just didn’t call it ‘research’” (University of Manitoba, 2014).

Our NEIHR project recognizes that research on and with Indigenous people in Canada has a long and complicated history including serious atrocities, such as the nutritional experiments conducted on residential school children (Mosby, 2013). Research focused on Indigenous health has historically regarded Indigenous people as “subjects” and has been dominated by non-Indigenous researchers (Canadian Institutes of Health Research; Natural Sciences and Engineering Research Council of Canada; & Social Sciences and Humanities Research Council of Canada, 2014; Cram et al., 2013; Smith, 2012). This notion is commonly reflected in the language utilized in research contexts, where participants are often referred to as “subjects” (Canadian Institutes of Health Research, 2019; United States Department of Health & Human Services, 2016). In some cases, academic research has been condemned by Indigenous communities for a myriad of issues including, but not limited to, a history of perpetuating colonialism; neglect of local needs and priorities; power imbalances between community and researchers/institutions; failure to benefit communities while still advancing the careers of academics; stigmatization; and a disregard for Indigenous cultural understandings and approaches (Cram et al., 2013; Maar et al., 2007; Mair, 2011; Poudrier, 2007; Simonds & Christopher, 2013).

Mair (2011) points to how a focus on risks can be used to partition certain groups from the general population based on their risk behaviors or characteristics, resulting in the labeling of such groups as problematic. Indigenous peoples have also highlighted how research has reinforced negative stereotypes and pathologized and problematized communities while neglecting exploration of root causes of health disparities (Nelson & Wilson, 2017). Research has often utilized Western-based standards, measures, and tools which result in a focus on deficits by providing unfair comparisons (Reading & Wien, 2013). This type of research is not helpful or useful to Indigenous communities seeking to address health concerns and can serve to justify paternalistic interventions that are discriminatory and that reinforce the “marginalization of the already marginalized” (Poudrier, 2007, p. 256). Moreover, scholars have highlighted how research has failed to be accountable to Indigenous communities, who have commonly experienced disintegration of

engagement following project completion along with challenges in accessing project data and results (Castellano, 2004; Maar et al., 2007). Indigenous leaders and academics around the globe are openly challenging researchers and cautioning communities about these types of research practices, as well as those based on exploitation, racism, and power (Reading, & de Leeuw, 2014; Smith, 2012).

### *Efforts to Facilitate Ethical Research with Indigenous Peoples*

Various frameworks for ethical academic research involving Indigenous communities or people have consequently emerged with the increased involvement of Indigenous peoples. As Castellano (2004) has stated, “If we [Indigenous peoples] have been researched to death, maybe it’s time we started researching ourselves back to life” (p. 98). These emerging guidelines largely aim to establish meaningful and mutually beneficial relationships to guide reciprocal research that is community-driven, self-determined, action-oriented, and culturally responsive and that upholds Indigenous sovereignty of data and information. These emerging guidelines fall into two schools of thought: those that seek to change the research structure from within institutions and those that wish to create a new path forward outside of institutions. Simpson (2011, p. 32) states:

While theoretically, we have debated whether Audre Lourde’s [*sic*] “the master’s tools can dismantle the master’s house,” I am interested in a different question. I am not so concerned with how we dismantle the master’s house, that is, which sets of theories we use to critique colonialism; but I am very concerned with how we (re)build our own house, or our own houses. I have spent enough time taking down the master’s house and now I want most of my energy to go into visioning and building our new house. Our Elders and Knowledge Holders have always put a great emphasis into how things are done. This reinforces the idea that it is our own tools, strategies, values and processes and intellect that are going to build our new house.

Important research and academic institutions have increasingly taken up these guidelines. For example, in 2010 a new edition of the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS) was released and again updated in 2014 to the TCPS 2 (TCPS 2, 2018). It includes a chapter specifically on research involving Indigenous peoples that incorporates principles derived from key national research ethics documents developed out of collaborative processes led by Indigenous peoples (TCPS 2, 2018). The TCPS 2 governs research involving humans that is funded by Canada’s three federal research agencies—CIHR, the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council of Canada. CIHR states that “the intent is to promote health through

research that is in keeping with [Indigenous] values and traditions” (CIHR, 2013). In other words, this chapter is meant to assist the researchers and institutions in approving research that is culturally appropriate and ethical when it involves Indigenous people. When Indigenous people choose to participate in research, they are not to be “passive givers of knowledge that is somehow to be extracted by the researchers from their memories, but active partners in the research” (Piquemal, 2000, p. 51).

The University of Manitoba’s *Framework for Research Engagement with First Nations, Metis, and Inuit Peoples* was developed in partnership with First Nations, Metis, and Inuit communities in Manitoba (University of Manitoba, 2014). Although the consultations were hosted by the Faculty of Medicine, the framework developed was flexible and open ended to allow for it to be adapted to a variety of research projects from diverse disciplines. This is a major strength of the document, and the consultation process should not be a one-time event to reach consensus on a process, gather documentation, or provide step-by-step instructions for researchers. Rather this consultation process could be an example of maintaining respectful dialogue and ongoing conversations around research ethics and engagement frameworks as the document refines procedures.

Another important framework for ethical academic research involving Indigenous communities is the First Nations Principles of Ownership, Control, Access, and Possession (OCAP<sup>®</sup>) (FNIGC, 2014, 2020b). OCAP<sup>®</sup> was developed in 1998 and trademarked in 2015 by the First Nation Governance Centre to help guide the development of the First Nations Regional Health Survey (FNRHS) and to be used as a framework to negotiate research relationships where First Nations’ rights to their own data are protected. The FNRHS was the first national survey to be developed by First Nations to obtain the data they wanted and needed. OCAP<sup>®</sup> asserts that First Nations have control over data collection processed in their communities and that they own and control how this information will be used. First Nations require control over their data, as it is their inherent right to self-determination and is supported by UNDRIP, which Canada endorsed in 2016. The Metis and Inuit communities in Canada also have similar principles that promote self-determination in research.

Specifically, the four principles are defined as follows:

- *Ownership* refers to the collective right of First Nations to their cultural expertise, data, and information.
- *Control* affirms that First Nations, their communities, and representative bodies are involved in research projects from start to finish.
- *Access* refers to the fact that First Nations must have access to information and data about themselves and their communities regardless of where it is stored.
- *Possession* raises the point of physical control of data collected.

Other Indigenous groups such as Inuit Tapiriit Kanatami put forth the National Inuit Strategy on Research (NISR), which is a pivotal document launched in March 2018 in Ottawa, targeting governments and research institutions (Inuit Tapiriit Kanatami, 2018). The strategy identifies areas that can strengthen the Inuit Nunangat (geographical location) research for Inuit. The document lists five priorities, one being the enhancement of ethical research conduct. Echoing the OCAP<sup>®</sup> principles, this priority seeks to “ensure Inuit access, ownership, and control over data and information” and the development of “respectful and beneficial research that serves the needs and priorities of Inuit” (Inuit Tapiriit Kanatami, 2018, p. 5). Since the adoption of this document is still in its infancy, the impacts of it cannot yet be evaluated.

A partnership between ArcticNet, the Nasivvik Centre for Inuit Health and Changing Environments, and the Northern Contaminants Program supports a regional Inuit Research Advisor position in each of the four Inuit Land Claim regions of the Canadian Arctic, including Inuvialuit Settlement Region, Nunavik, Nunatsiavut, and Nunavut. These positions review proposals to confirm the alignment with community research priorities, respect traditional knowledge, support knowledge mobilization and result dissemination, and encourage youth capacity building for future Inuit-led projects (ArcticNet, 2020).

In addition to these broader Indigenous ethical principles and frameworks, many Nations—referring here to bodies of Indigenous peoples united by common culture, language, or political affiliation, such as individual bands/communities, tribes, or wider related cultural groups—have established their own policies or protocols regarding research that go beyond merely acquiring approval from community leadership (ArcticNet, 2020, Inuit Tapiriit Kanatami, 2018; Clayoquot Alliance for Research, Education and Training, 2005; First Nations of Quebec and Labrador Health and Social Services Commission [FNQLHSSC], 2014; Kahnawá:ke Schools Diabetes Prevention Project, 2007; Ktunaxa/Kinbasket Tribal Council, 1998; Manitoulin Anishinaabek Research Review Committee, 2003; Mi’kmaq Confederacy of PEI, 2019; Mi’kmaq Ethics Watch, 2016; Nuu-chah-nulth Tribal Council, 2008; Six Nations of the Grand River Territory, 2014; University of Manitoba, 2014). Having distinct ethical reviews of proposed research places control within the community to define what ethical research entails. Members of the ethics boards also consider the community’s priorities to confirm the proposed research will be meaningful and relevant within the community. To our knowledge, Indigenous research ethics boards across Canada, along with their unique protocols and standards, have not been thoroughly cataloged and described. A comprehensive exploration of these boards, protocols, and standards could be instrumental to informing university research ethics boards, researchers, and scholars and facilitate meaningful research that respects Indigenous ethical values in academic research.

Consequently, this article conducted a review to inventory the various Indigenous community research ethics boards, protocols, frameworks, and guidelines across Canada. Although Indigenous community ethics boards may appear in various forms, such as Elders Councils, Band Councils, within Indigenous languages, or other forms unidentifiable within this scope of academia, the primary aim nonetheless was to identify the various Indigenous community-based ethical processes, protocols, and principles using an outlined inclusion criterion.

In this paper, we explore the ways in which Indigenous communities are enacting their own processes for research ethical review. We identify common themes that emerge across different Indigenous ethical protocols from across Canada. We also examine how Indigenous worldviews, values, and ethical and moral principles are being integrated into the ethical protocols and standards upheld by institutional REBs. We follow this with a discussion on why Indigenous communities are implementing ethical protocols, principles, and standards and how research processes and outcomes have been subsequently shaped by these contributions from Indigenous communities.

## Methods

We utilized the scoping framework defined by the Canadian Institutes of Health Research (CIHR, n.d.), Arksey and O'Malley (2005), and Levac et al., (2010). Unlike systematic reviews, scoping studies address broader topics and topic areas, in which many different study designs might be applicable (Arksey & O'Malley, 2005). We modified this method to include an online search of grey literature.

Six stages were involved in collection, evaluation, and presentation of the literature: (1) identifying the research questions; (2) identifying relevant studies/literature; (3) study/literature selection; (4) charting the data; (5) collating, summarizing, and reporting the results; and (6) a consultation exercise (Arksey & O'Malley, 2005). This process was modified to search online grey literature in recognition that many Indigenous communities may have different understandings and approaches to ethical research review processes that are not always formalized in the academic literature or identified as REBs. First, we defined the research focus as well as specific inclusion and exclusion criteria for the literature search. The research questions were as follows:

1. What are the Indigenous community research ethics boards, frameworks, and protocols that exist in Canada?
2. How are Indigenous worldviews, values, and ethical and moral principles being integrated into community research ethics boards, frameworks, and protocols? and
3. How have research processes and outcomes been subsequently shaped by these contributions to ethical understandings from Indigenous communities?

Second, this study reviewed all relevant original studies and literature reviews from peer-reviewed journals, and scientific reports were identified along with all public-facing research ethics guidelines and community-based research ethics board reports from First Nations, Metis, and Inuit communities and organizations in Canada.

In the third step, literature and relevant documents were closely reviewed by the research team in a comparative- and consensus-orientated process. This involved examination of Indigenous ethical protocol to document similarities for the purpose of identifying common themes across protocols, while also detailing their distinctions and differences.

In the fourth step, the data was charted. Charting is “a technique for synthesising and interpreting qualitative data by sifting, charting and sorting material according to key issues and themes [...]” (Arksey & O'Malley, 2005, p. 15). Sifting thus involved extracting information about ethical protocols, principles, and standards outlined in each document and, if available, how they were established (i.e., through community-engagement processes or under guidance from leadership or knowledge keepers) along with how they have been employed in research programs. Charting involved documenting extracted information (in this case into a spreadsheet) so it could be easily sorted according to comparative ethical protocols, principles, and standards across documents, while also highlighting distinctions.

In the fifth step, the reviewed literature was collated, summarized, and reported. Overarching themes were identified and described by the research team from the data sifted, charted, and sorted in the fourth step. As noted above, extracted data included ethical protocols, principles, and standards which might involve instructions on how to conduct ethical research with the community, including how researchers should engage community/leadership in the research process, recommendations on the integration of culture into the research process, adherence to data and information sovereignty principles, and more. Also included where available were data on how processes, protocols, and standards were established and how they have been integrated into research programs.

Lastly, the sixth step involved consultation with an Indigenous community-based researcher who has been involved in research governance and ethics discussions within the First Nation context serving on the Health Information Research Governance Committee—a First Nations research ethics board mandated by the Assembly of Manitoba Chiefs—and the First Nation Information Governance Centre Board—a non-profit organization operating with a special mandate from the Assembly of First Nations' (AFN's) Chiefs-in-Assembly with the mission to assert data sovereignty and support the development of information governance and management at the community level (FNHSSM, n.d.; FNIGC, 2020a). As recommended in the consultation stage, we also

incorporated several project-specific ethical protocols to illustrate how Indigenous ethical principles are also being incorporated into community-driven research projects. This Indigenous resource, who is also a coauthor (Stephanie Sinclair) on this paper, met with the research team monthly to provide guidance on the charting process, the identification and description of emergent themes, and the synthesis of the outcomes for discussion within the broader literature on ethics in research with Indigenous peoples.

## Results

This section presents an overview on Indigenous-led research ethical protocols, principles, and standards being implemented across Canada. A total of 20 different boards, frameworks, and protocols were identified in this scoping study, which are summarized in Table 1 and further detailed in the Supplemental Appendix. The findings are presented through three main and intertwining thematic areas that emerged out of the analysis of Indigenous community research ethics boards, protocols, and standards.

**Table 1.** Summary of Indigenous Ethics Boards, Frameworks, and Protocols Identified in the Scoping Study.

Indigenous ethical protocol	Scope
Health Information Research Governance Committee (University of Manitoba, 2014)	Research that identifies Manitoba First Nations at a regional level
The First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC, 2014)	First Nations of Quebec and Labrador
Indigenous Health Research Advisory Committee (ACHH, 2017)	Research conducted within the Chronic Pain Network involving Indigenous populations
Six Nations Research Ethics Committee (Six Nations of the Grand River Territory, 2014)	Research being conducted on Six Nations of the Grand River Territory
Manitoba Metis Federation Research Ethics Board (University of Manitoba, 2014)	Manitoba Metis
The Labrador Aboriginal Health Research Committee (Brunger & Bull, 2011)	Indigenous communities of Labrador
Mi'kmaq Ethics Committee (Mi'kmaq Ethics Watch, 2016)	Mi'kmaq communities represented by the Sante' Mawio'mi (Grand Council)
Mi'kmaq Confederacy of PEI Ethics Review Committee (Mi'kmaq Confederacy of PEI, 2019)	Research involving communities represented by the Mi'kmaq Confederacy of PEI
UINR—Unama'ki Institute (UNIR, 2016a, 2016b)	Five Mi'kmaq communities of Unama'ki—Eskasoni, Membertou, Potlotek, Wagmatcook, and We'koqma'q
Inuit Research Advisors (ArcticNet, 2020)	Research conducted in the Inuit Land Claim regions of the Canadian Arctic
Inuit Tapirit Kanatami: The National Inuit Strategy on Research (Inuit Tapirit Kanatami, 2018)	Inuvialuit Settlement Region (Northwest Territories), Nunavut, Nunavik (Northern Québec), and Nunatsiavut (Northern Labrador)
Standard of Conduct for Research in Northern Barkley & Clayoquot Sound Communities (Clayoquot Alliance for Research, Education and Training, 2005)	Research involving communities of the Clayoquot Sound Biosphere region
Nuu-chah-nulth Tribal Council Research Ethics Committee (Nuu-chah-nulth Tribal Council, 2008)	Research that involves Nuu-chah-nulth communities
Ktunaxa Nation's Code of Ethics for Research (Ktunaxa/Kinbasket Tribal Council, 1998)	Research projects that relate to the Ktunaxa Nation
Manitoulin Anishinaabek Research Review Committee: Guidelines for Ethical Aboriginal Research (Aboriginal Health Research Review Committee, 2003)	Research in First Nations communities in the Manitoulin district
A Community Guide to Protecting Indigenous Knowledge (Brascoupé & Mann, 2001)	Indigenous communities across Canada
Manitoba First Nations Education Resource Centre, Inc.: Guidelines for Ethical Research in Manitoba First Nations (MFNERC, 2014)	Research with Manitoba First Nations
Assembly of First Nations—First Nations and Inuit Health Branch Engagement Protocol (Assembly of First Nations, 2015)	First Nations and Inuit Communities with programs delivered/funded by FNIHB
USAI Research Framework (OFIFC, 2016)	Research projects conducted by the Ontario Federation of Indigenous Friendship Centres (OFIFC) and urban Indigenous communities, in which the OFIFC is involved
Alberta First Nations Information Governance (AFNIGC, 2015)	First Nations Peoples of Treaty 6,7, and 8

These subsections focus on (1) balancing individual and collective rights; (2) upholding culturally grounded ethical principles; and (3) self-determined research processes, methods, and knowledge translation. We discuss the themes in the context of the literature and present components of Indigenous community research ethics boards and protocols that exemplify each theme.

### *Balancing Individual and Collective Rights*

Balancing collective rights with individual rights emerged as an important theme across identified Indigenous community research ethics boards, protocols, and standards. Generally, this theme touched on two issues as it pertains to individual versus collective rights. First, most identified ethical boards, protocols, and standards included reference to assessing a research project's process for obtaining free, prior informed consent on a collective basis in addition to an individual basis. For example, the Health Research Information Governance Committee—which oversees research that identifies Manitoba First Nations at a regional level—highlights obtaining free prior informed consent on a collective and individual basis as one of four criteria for assessing research applications (University of Manitoba, 2014). Collective consent must be obtained when you will be referring to a group of people or identifying the place of residence at any point in the research process.

Obtaining collective consent can take many forms, depending on the community's identified protocols. As noted, some communities have established research ethics boards that possess the authority to approve, guide, and oversee research, which often requires obtaining support and consent from the appropriate overseeing body. In some cases, this may comprise local research ethics boards/committees, Metis local board members, or elders councils who are identified by the community as the appropriate group to obtain support and consent. Conversely, other communities that do not have a research ethical review process may simply provide an indication of support and consent from appropriate leadership such as the elected Chief and Council, which can then be provided to university research ethics boards.

Of important note is that Indigenous ethical protocols and standards indicate that collective consent may not replace the consent of individuals involved in the research project and that researchers must protect confidentiality, anonymity, and privacy of individual research participants as well as the larger community where necessary (FNQLHSSC, 2014; FNIGC, 2014).

Next, several identified ethical boards, protocols, and standards included an emphasis on consideration of collective ownership of Indigenous knowledge versus individual intellectual property rights. For instance, the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)—established in 1994 to

provide “technical support for research,” which is supportive of the community priorities for population health among Quebec and Labrador First Nations—includes an assertion that Quebec and Labrador First Nations are the guardians, interpreters and collective owners of their cultures and past, present, and future knowledge systems (FNQLHSSC, 2014). The FNQLHSSC Research Protocol notes a need to consider the balance between collective and individual rights, particularly concerning the intellectual property versus the collective property of research products, which should be clarified between the research project partners and stakeholders (FNQLHSSC, 2014).

Moreover, the principles of OCAP<sup>®</sup> adopted by Indigenous community research ethics boards across the country assert collective ownership by Indigenous peoples over information about themselves and their members (Castellano, 2004; FNIGC, 2014). The principle of Ownership states that a community or group owns information collectively in the same way that an individual owns their personal information (FNIGC, 2014). The principle of Access outlines First Nations communities' and organizations' right to manage and make decisions regarding who can access their collective information (FNIGC, 2014).

### *Upholding Cultural Norms and Values*

The upholding and integration of cultural norms and values emerged as a prominent theme across identified Indigenous community research ethics boards, protocols, and standards. Indigenous ethical frameworks emphasized the incorporation of culture into how research methods are chosen, how methods are employed, and how the data is analyzed and interpreted. The ways in which Indigenous communities have developed and enacted culturally-grounded ethical principles include various points of intervention from nation-specific ethics watches and community-based research review committees, within academic institution alliances, or by creating project-specific structures such as advisory circles. For instance, the Labrador Aboriginal Health Research Committee (LAHRC), which consists of members belonging to Nunatsiavut, Innu, and NunatuKavut communities, assumes the role of community advisory team to researchers looking to conduct research with the aforementioned communities (Brunger & Bull, 2011). One of the LAHRC's primary goals is to ensure that research is “conducted in a manner that is appropriate to the spiritual, cultural, social and environmental context of the community” with which it is conducted (Brunger, 2013, p. 5).

This is also exemplified in the efforts of the Mi'kmaq Ethics Watch. The Mi'kmaq Ethics Watch is an appointed committee who oversees research conducted with communities in the Mi'kmaq Sante' Mawio'mi (Grand Council) in Nova Scotia. All research involving collective Mi'kmaq knowledge, culture, arts, spirituality, or traditions or having the potential to impact treaty or Aboriginal rights must be reviewed by Mi'kmaq Ethics Watch. It is a

committee established to study and develop a set of principles and protocols that will protect the integrity and cultural knowledge of the Mi'kmaw people (Mi'kmaw Ethics Watch, 2016). In particular, the Mi'kmaw Ethics Watch seeks to ensure that “data interpretation and conclusions drawn from...research will be subject to approval [from them] to ensure accuracy and cultural sensitivity” (Mi'kmaw Ethics Watch, 2016).

The integration of cultural norms and values into research is also exemplified by the Clayoquot Alliance for Research, Education, and Training, which is an ethical framework developed through a partnership between the University of Victoria and many First Nations communities (Clayoquot Alliance for Research, Education and Training, 2005). This document governs research by the University of Victoria specifically for the geographical location of the Clayoquot Sound Biosphere reserve region, an area that extends beyond the reserve lands to include Ucluelet and the northern portion of Barkley Sound and Clayoquot Sound. The foundation of this framework is “respect for the well-being and interconnectedness of individuals, communities, and ecosystems,” which is a concept consistent with the Nuu-chah-nulth principles of *Iisaak* (living respect) and *Hishuk ish ts 'awalk* (everything is one or everything is connected) (Clayoquot Alliance for Research, Education and Training, 2005). These cultural values inform the ethical standards and expectations for researchers, as well as the community research guidelines outlined in the framework (Clayoquot Alliance for Research, Education and Training, 2005).

The Manitoulin Anishinaabek Research Review Committee (MARRC) developed *Guidelines for Ethical Aboriginal Research* involving First Nations in the Manitoulin Area as an outcome of a community-based health research conference in 2001, where participants discussed their experiences with health research on Manitoulin Island (MARRC, 2003). The guidelines are based on the Anishinaabe (Ojibway) Seven Grandfather Teachings of respect, wisdom, love, honesty, humility, bravery, and truth. Each sacred teaching contains “practical examples of the actions and attitudes that are required for ethical research in local communities” (MARRC, 2003, p. 8). Researchers are asked to make every effort to work within the spirit of the Seven Grandfather Teachings in all stages of the research process.

Another well-known framework grounded in Indigenous methodologies is the four R's of Indigenous research originally described by Kirkness and Bernhardt (1991). These values are respect, relevance, responsibility, and reciprocity. Restoule (2008), Styres and Zinga (2013), Wilson (2008), and others have incorporated a fifth R of relationships. These values are interwoven with ethical considerations for conducting research with Indigenous communities and are embedded in formal guidelines such as the TCPS 2 (Restoule, 2008; Styres & Zinga, 2013). They are frequently

referenced in community and project-based codes of ethical research such as The Kahnawá:ke Schools Diabetes Prevention Project (Kahnawá:ke Schools Diabetes Prevention Project, 2007).

Several Indigenous community research ethics boards, protocols, and standards uphold the integration of Indigenous culture and worldviews into research methodologies. For example, The Indigenous Health Research Advisory Committee (IHRAC) is a working group of the Chronic Pain Network comprised of community members, elders, patients, clinicians, and health researchers from across Canada striving to facilitate authentic partnerships between Indigenous communities and researchers (Aboriginal Children's Hurt and Healing [ACHH] Initiative, 2017). Research conducted by members of the IHRAC found that the way Indigenous children's pain is assessed and treated by non-Indigenous health care providers can be ineffective, and have a range of far-reaching negative effects (ACHH, 2017). Moreover, Indigenous children and youth were notably underrepresented in pain treatment, despite research demonstrating that they may experience pain at higher rates than their non-Indigenous counterparts (Latimer et al., 2012, 2014). The committee was formed as a response to research findings that highlighted important cultural differences in pain expression by Indigenous children (Latimer et al., 2012, 2014). This research suggested that Western ways of investigating and interpreting pain had not adequately captured the complexities of this experience through Indigenous understandings, which likely contributed to the observed inequity in pain care for Indigenous children and youth (Latimer et al., 2014).

Consequently, IHRAC advocates for research investigating pain in Indigenous populations to utilize a “two-eyed seeing” approach. The “two-eyed seeing” framework, proposed by Mi'kmaw Elders Albert and Murdena Marshall, is a means to bridge Western science and Indigenous knowledge. This approach to research recognizes the benefits of seeing from one eye with the strengths of Indigenous ways of knowing and to see from the other eye with the strengths of Western ways of knowing and finally to use both of these ways of seeing simultaneously (Iwama et al., 2009). Applying a “two-eyed way of seeing” research approach enables Indigenous and Western “ways of knowing” to combine and work alongside one another with respect and balance. The committee puts forth that research considering both Western and Indigenous views offers a more balanced perspective and can lead to more meaningful pain assessment and treatment in Indigenous children and youth (ACHH, 2017; Latimer et al., 2014).

*Wijji 'idiwag Ikwewag* Restoring the Sacred Bond Initiative (formerly the Manitoba Indigenous Doula Initiative) integrates culturally grounded ethical principles in both program delivery of as well as in the research conducted within the initiative. The initiative is guided by the Seven Sacred Birth Teachings: love, respect, courage,

humility, honesty, wisdom, and truth and aims to reclaim and support cultural practices and sovereignty over bodies and birth experiences (Restoring the Sacred Bond Initiative, 2020). The principle of reclaiming sovereignty over birth experiences extends to research emerging from the initiative as well, where the community has sovereignty over the research process (Winnipeg Boldness Project, 2018). The inclusion criteria for participants in the initiative were community-driven and resulted in the participation of youth in care under 18 years old, as they were identified as being the most in need of support of a doula (S.Sinclair, personal communication, June 22, 2020). This notion connects with the subsequent section in which we discuss the theme in Indigenous ethical protocols concerning self-determination within the research process.

### *Self-determination in Research*

Self-determination in research was identified as a primary objective of Indigenous community ethical protocols in research. For instance, the First Nations Information Governance Centre (FNIGC) was created over 20 years ago to design a new national First Nations health survey and guide the development of the OCAP<sup>®</sup> principles (2014). The FNIGC board is made up of members from across Canada who are appointed by their region to promote First Nation data sovereignty in alignment with their respective distinct worldviews. The FNIGC works with First Nations to design and develop national surveys that meet the needs of First Nations. FNIGC works with each region to implement the research process based on their respective distinct worldviews.

The Alberta FNIGC (AFNIGC) works to promote, protect, and advance the First Nations' Ownership, Control, Access and Possession (OCAP<sup>®</sup>) principles, the inherent right to self-determination, and jurisdiction in research and information management (AFNIGC, 2015). The AFNIGC represents the culmination of a 20-year process to strengthen First Nations control and capacity in ethical and relevant processes for research and the collection, utilization, and storage of data. AFNIGC also developed Indigenous health indicators to measure health.

The FNQLHSSC also highlights "Collaborative Research" as one of the core tenets in their research ethical protocol "to stress the importance for First Nations to actively participate in and collaborate to [*sic*] all the steps of the research process in their environment" (FNQLHSSC, 2014).

The Health Information Governance Committee in Manitoba has four criteria for research with First Nations, which was endorsed by the Chiefs in Assembly. The four criteria used to promote self-determination of research include Free Prior Informed Consent (on a collective and individual basis); First Nations OCAP<sup>®</sup> principles; First Nations ethical standards; and benefits to First Nations.

This means that research must be beneficial to First Nations in terms of the outcomes, infrastructure, and resources and must be determined to be useful research.

The NISR contains protocols for community engagement that are designed to ensure self-determination in research taking place in *Inuit Nunangat*—the Inuit-preferred name of the geographic, political, and cultural region encompassing the Inuit homeland (Inuit Tapiriit Kanatami, 2018). The objective of Inuit self-determination in research is a dominant theme embedded in all five priority areas outlined in the strategy (Inuit Tapiriit Kanatami, 2018). The strategy requires research institutions to partner with appropriate Inuit representational organizations in order to implement engagement processes that respect Inuit in decision making for research involving Inuit people, wildlife, and environment (Inuit Tapiriit Kanatami, 2018).

Manitoulin Anishinaabek Research Review Committee *Guidelines for Ethical Aboriginal Research* highlights local First Nations' vision for research that is community-based, meaning it must emphasize a direct benefit to local community health; be guided by a local steering committee; address the protection of traditional knowledge; employ methodologies that are culturally acceptable at the community level; and incorporate traditional values into the research approach (MARRC, 2003).

The Ontario Federation of Indigenous Friendship Centres (OFIFC) was founded in 1971 and has been undertaking community-driven research for most of its history. Any OFIFC research projects are asked to formally pass the OFIFC's Research Ethics Committee (REC). The ethical review process starts with an application to the OFIFC REC to describe how their proposed project will be "community-driven and how the project will safely and respectfully work with Indigenous communities" (OFIFC, 2013, 2016). In 2012, OFIFC developed the first iteration of the utility, self-voicing, access, and inter-relationality (USAI) research framework. This framework was created to guide Indigenous research projects conducted by the OFIFC and other urban Indigenous community research that involves OFIFC. The utility is understanding that research must be based on the priorities of the community; self-voicing is acknowledging that communities are authors and are fully recognized as the knowledge creators and knowledge keepers; access regarding cultural knowledge and practice does not require interpretation, rather "it speaks everybody's language; it is situated in the present, supported by the past, and contemplates the future" (OFIFC, 2016); and inter-relationality is the belief that although research occurs in the present, it is never neutral and builds on the heritage of the community.

Generally, Indigenous ethical protocols and frameworks do not specify a particular research approach to ensure community engagement and self-determination in research but instead recommend that approaches be determined via collaborative decision making between researchers and



communities. As noted by the FNQLHSSC, the values of respect, equity, and reciprocity are more important than the type of approach (FNQLHSSC, 2014). This sentiment was echoed across many Indigenous community ethical protocols (ArcticNet, 2020; Clayoquot Alliance for Research, Education and Training, 2005; First Nations of Quebec and Labrador Health and Social Services Commission [FNQLHSSC], 2014; Inuit Tapiriit Kanatami, 2018; Kahnawá:ke Schools Diabetes Prevention Project, 2007; Ktunaxa/Kinbasket Tribal Council, 1998; Manitoulin Anishinaabek Research Review Committee, 2003; Mi'kmaq Confederacy of PEI, 2019; Mi'kmaw Ethics Watch, 2016; Nuu-chah-nulth Tribal Council, 2008; Six Nations of the Grand River Territory, 2014; University of Manitoba, 2014).

This scoping study is limited in two ways. Firstly, scoping studies provide a narrative or descriptive account of research and do not seek to appraise their quality or effectiveness (Arksey & O'Malley, 2005). Thus in the context of this paper, which seeks to describe Indigenous ethical protocols, we do not evaluate protocol content, approaches to establishing protocols, or their uptake by researchers and academic institutions. Secondly, this study is limited to the review of public-facing, written Indigenous ethical protocols only. Further exploration into informal, oral, and/or non-publicly facing Indigenous research ethical protocols and frameworks would be required to create a more comprehensive picture of how Indigenous peoples are defining ethical research.

## Discussion

In this section, we discuss why Indigenous communities are implementing ethical protocols, principles, and standards and how research processes and outcomes have been subsequently shaped by these contributions from Indigenous communities. With this, we aim to contextualize these frameworks within the history of research on Indigenous peoples, colonial ethical understandings, and oft overlooked and neglected Indigenous worldviews, ways of knowing, and ways of being.

As noted, the balancing of individual and collective rights is an important theme that arose out of analysis of Indigenous ethical protocols. The AFN produced a policy document in 2007 entitled *Ownership, Control, Access and Possession: First Nations Right to Govern First Nations Data*, which states that Indigenous cultural knowledge, data, and information is “owned collectively by the Nation as an individual owns their personal information” (2007, p. 2). The subject of collective rights for Indigenous peoples in Canada is complex. Indigenous peoples are more than an aggregate group of individuals; they are a collective of people who share a common heritage, history, culture, language, land base, traditions, and thus, a shared identity. Indigenous ontologies or ways of

being also typically emphasize relationality and a collective, interconnected worldview (Hart, 2010; Wilson, 2008). Indigenous peoples transmit traditional knowledge from generation to generation, and it belongs collectively to community members. Each community has customary law which dictates how knowledge is kept and transmitted across generations (FNQLHSSC, 2014; Morse et al., 2010; World Intellectual Property Organization, 2016). Traditional knowledge does not “belong” to individuals to whom it has been transmitted to by, for instance, elders. Individuals, however, are responsible for keeping it and using it for the benefit of their community.

While Indigenous rights and treaty rights are understood as collective rights, legislation such as the *Canadian Human Rights Act (1985)*, the *Charter of Rights and Freedoms (1982)*, personal health information legislation, privacy law, and intellectual property law, generally tend to support the upholding of individual rights. Accordingly, there is considerable discussion in the Canadian legal and legislative landscape around the balancing of individual and collective rights in Indigenous contexts (Morse et al., 2010). On an international level, the *United Nations Declaration on the Rights of Indigenous Peoples (2007)* outlines the collective aspect of traditional knowledge and its “intellectual property” considerations:

Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions. [...] They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge and traditional cultural expressions. (United Nations, 2007, p. 12)

Indigenous ethical protocols and standards such as OCAP<sup>®</sup> add a further layer of privacy protection for individuals as they ensure the protection of an individual’s personal identity from disclosure and associated harms, along with their group identity and status as a member of a community (FNIGC, 2014). Indigenous ethical protocols add another layer to standard policies guiding the ethical conduct of research involving humans in Canada, which tend to focus more generally on the protection of individuals (TCPS 2, 2018). Nevertheless, Chapter 9 of the Tri-Council Policy Statement 2 emphasizes consideration of collective rights, interests, and responsibilities with conducting research with Indigenous populations (TCPS 2, 2018). *Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada* gives guidance for balancing individual and collective interests in the domains of privacy and confidentiality and discusses the application of the principles of OCAP<sup>®</sup> and the importance of developing research agreements in partnership with a community that detail, from the outset, how intellectual property rights and the collection and of human biological materials will be dealt with (TCPS 2, 2018).

The balancing of individual and collective rights guided by Indigenous ethical protocols means that Indigenous communities collectively own research data and information and have control over how it is collected, accessed, used, and disclosed (FNIGC, 2014). This is essential to ensuring community self-determination in research and preventing the harms experienced by communities from past research. As noted in the report of the Royal Commission on Aboriginal Peoples, “the gathering of information and its subsequent use are inherently political” (Royal Commission on Aboriginal Peoples, 1996, p. 498). Knowledge production has played an important role in reproducing colonial relations (Espey, 2002). Governments, researchers, and academic institutions have gathered data on Indigenous communities without their knowledge or consent and used this information to inform harmful policies and theories and/or perpetuate racial prejudices (FNIGC, 2014; Kaufman & Ramarao, 2005). They have expropriated traditional knowledge and cultural property for museums or for profit (FNIGC, 2014). As noted by Juengst (2000) in the context of human genetic research, to the extent that research can “impose risks on all the members of a socially definable group, they have a collective interest in how the research proceeds” (Juengst, 2000, p. 52). The guidelines established by Indigenous ethical protocols thus aim to ensure that communities’ collective interests in research are safeguarded and risks to the collective are mitigated.

Many of the reviewed Indigenous community ethical protocols advocate for research methodologies grounded in Indigenous culture and worldviews to be taken up as an important component of ethical research programs with Indigenous communities. Research methodologies may carry subtle forms of epistemological imbalances that give precedence to academic or “Western” forms of knowledge over other worldviews or ways of knowing (Smith, 2012; Wilson, 2008). The intention of an Indigenous methodology is to decolonize the methods of collaboration and knowledge production between Indigenous and Western modes of research while requiring the research approach to “[flow] from an Indigenous belief system that has at its core a relational understanding and accountability to the world” (Kovach, 2010, p. 41). An Indigenous research methodology operates from an Indigenous worldview that recognizes the “interconnectedness of physical, mental, emotional, and spiritual aspects of individuals with all living things and with the earth, the star world, and the universe” (Lavallée, 2009, p. 23). The spiritual domain in particular is still frequently neglected in research (Hatala, 2008; Kildea & Kumar, 2018; Wilson, 2008). As Copenace et al. (2021) highlight, research needs to emphasize the importance of understanding the connections that exist between water, men, women, and children, as well as the spiritual and physical realms, the natural world, and the creation story.

Moreover, an Indigenous ontological and epistemological positioning contrasts with those that commonly inform

Western approaches. From an Indigenous worldview, value is placed on subjectivity—as opposed to objectivity—and the research process requires a focus not purely on realities, knowledges, or ideas generated, but on the relationship we share with them (Hart, 2010; Wilson, 2008). Indigenous methodologies create space for incorporating an Indigenous ontology that is relational, requiring researchers to answer to all their relations and reflect on how they are fulfilling their roles and obligations in the research process (Hart, 2010; Lavallée, 2009; Wilson, 2008). Employing Indigenous methodologies thus facilitates the upholding of culturally-grounded ethical principles that call for researcher relational accountability, reflexivity, and the balancing of power.

Research methodology and approach can be an important means of assuring Indigenous ethical protocols and standards are adhered to in the research process. As noted already, historically, academic research did not undergo ethical and moral engagements with Indigenous communities, and academic scholarship and research have been tainted with a clandestine history of colonialism and neocolonialism (Smith, 2012). These approaches—which continue to exist to some degree today—inform a top-down view of community engagement with minimal or no impetus for responsible and reciprocal forms of relationship building between researchers and community members. In an attempt to move away from these harmful research practices of the past, most Indigenous ethical protocols analyzed for this review advocate not only for the meaningful engagement of community at each stage of the research process but for self-determination in research overall.

As a result of the efforts of Indigenous community research ethics boards, protocols, and standards, research is increasingly integrating cultural notions, values, and understandings into the selection of methods, how methods are employed, and the interpretations of outcomes. Indigenous ethical protocols support research that manifests Indigenous values and beliefs that are meaningful to community. As a result, research is increasingly utilizing methods that are congruent with Indigenous cultural norms and values, including, but not limited to, conversational interviewing, storytelling, sharing circles, and arts-based methods (Hammond et al., 2018; Hatala & Bird-Naytowhow, 2020; Kovach, 2010; Ober, 2007; Lavallée, 2009). These approaches are more suited to incorporate decolonizing methods that break down the power hierarchy between researcher and participant/community, challenge dominant perspectives, create space for Indigenous beliefs and ideas, and contribute to the overall renewing and healing of the communities involved (Kovach, 2009, 2010; Smith, 2012; Wilson, 2008). Moreover, research is increasingly being honored as a ceremony, a process that should be approached with sacredness and reverence. This includes not only the sacredness of knowledge that emerges from research and the relationships formed throughout the process, but the

consideration of spirituality in research methods as well (Bird-Naytowhow et al., 2017; Copenance et al., 2020; Magnat, 2012; Wilson, 2008).

Researchers and community partners increasingly employ research approaches that aim to meet the objective of enhancing self-determination in the research process advocated by many of the Indigenous ethical protocols reviewed here. Participatory action research, community-engaged research, and community-based participatory research are methodological approaches that have become common and effective strategies for knowledge generation, mobilization, exchange, and translation that facilitate community-driven research and uphold Indigenous self-determination (Castleden et al., 2012; Kovach, 2009, 2010). These methodological approaches “directly [involve] the participants of the research in a practical and real way” and aim to equalize power differences, build trust, and create a sense of ownership in an effort to bring about social justice and change (Lavallée, 2009). Due to their focus on building community relationships, creating reciprocal and mutually beneficial relationships, equalizing power relationships, pursuing social justice, and creating transformative action out of research, these research approaches become a means by which systemic forms of power imbalance, racism, and epistemic oppression can be addressed within and throughout a research project. As such, outcomes from these approaches to research are more likely to align with the priorities and experiences of Indigenous communities, increasing the potential for positive impacts and fostering constructive relationships between Indigenous research collaborators, communities, and academic researchers.

Many of the Indigenous community ethical protocols analyzed in this review state that they are aiming to remedy the shortcomings and harms experienced in research in the past (Brunger & Bull, 2011; FNQLHSSC, 2014; Inuit Tapiriit Kanatami, 2018; MARRC, 2003; FNIGC, 2014; Six Nations of the Grand River Territory, 2014). They point to the lack of noticeable benefit despite being “researched to death” and note a history of exploitation, dehumanization, and racism (FNQLHSSC, 2014; Inuit Tapiriit Kanatami, 2018; MARRC, 2003). They also note the misuse and detrimental effects of research findings and how research has been a tool of colonialism and oppression (Brunger & Bull, 2011; Six Nations of the Grand River Territory, 2014). Indigenous ethical protocols aim to thwart these harms and champion community self-determination by ensuring meaningful community engagement as an integral component of the entire research process.

Challenges of implementing community ethics boards and protocols can occur when university research ethics boards are unfamiliar with their existence and mandate. If researchers bypass community ethical protocol by communicating directly with community members to present or decide on research, protections and considerations learned from the shortcomings and harms of past research may be absent. Many community

research ethics boards, Indigenous scholars, and community leaders are working to actively inform and educate university or institutional REBs of their existence, but with membership rotations and limitations in capacity and financial support, this work can be challenging. Another challenge involves adhering to Tri-Council guidelines that recognize diverse sources of community authority, while at the same time acknowledging that Indigenous communities have the right to self-determination of research activities that occur in their communities (Glass & Kaufert, 2007).

## Best Practices

Research involving Indigenous peoples must strive to follow the ethical guidelines, protocol, and processes established by the specific community involved. As L.Star notes (personal communication, April 10, 2019), the most important part of the TCPS 2 document is actually the preamble which states:

This chapter is designed to serve as a framework for the ethical conduct of research involving Indigenous peoples. It is offered in a spirit of respect. It is not intended to override or replace ethical guidance offered by Indigenous peoples themselves. (TCPS 2, 2018)

Overall, ethical research with Indigenous communities strives to protect the collective rights and interests of a community as an additional layer to individual-level protections. Researchers must ensure that research involving Indigenous peoples is premised on respecting the self-determination of communities and is carried out with collaboration and engagement between researchers and participants. While respecting self-determination, ethical research with Indigenous communities endeavors to integrate community cultural notions, values, and understandings into the selection of methods, how methods are employed, and the interpretations of outcomes.

Facilitating meaningful and mutually beneficial relationships between Indigenous communities and external institutions is an important role of Indigenous community ethical protocols in research. Reciprocal and meaningful relationships between Indigenous communities and external partners are an important mechanism to ensuring Indigenous ethical protocols and standards are upheld. Frameworks, committees, and boards analyzed for this paper aim to educate and connect researchers with appropriate governing bodies depending on the scope of projects. They also provide information on what research built on reciprocity and trust means and how to achieve ethical research by community standards. Several protocols and committees detail more formal processes for establishing relationships through means such as designing data sharing agreements and memorandums of understanding and suggested processes for integrating ceremony into the research process.

It is clear that ensuring relationships are established and carried out in a way that is meaningful to Indigenous peoples is a crucial component of what defines ethical research with Indigenous peoples. The Indigenous-developed frameworks demonstrate that for research to be transformative, meaningful, and reciprocal to community, it must endeavor to uphold Indigenous ethical principles and protocols. Research must acknowledge that Indigenous communities and people know what is best for their own communities.

## Educational Implications

Institutions that conduct research involving Indigenous peoples in Canada must incorporate means to improve competency in Indigenous ethical processes and principles. Institutions and their Indigenous partners must work collaboratively and creatively to develop approaches to addressing the needs for balanced, culturally-grounded, self-determining ethical research with Indigenous peoples. Such approaches, therefore, will likely vary significantly across different institutions and Indigenous territories. Overall, efforts must not only aim to inform researchers of formally established and institutionally recognized Indigenous ethical processes and principles, but also provide them with the tools needed to build relationships and meaningfully engage Indigenous peoples in order to understand, support, and adhere to local ethical guidance that may not yet be formalized in Western institutions and research approaches.

## Research Agenda

Further research is needed on the following topics:

- Exploration into informal, oral, and/or non-publicly facing Indigenous research ethical protocols and frameworks to create a more comprehensive picture of how Indigenous peoples are defining ethical research.
- Further examination of how efforts to promote and uphold Indigenous research ethical protocols and frameworks contribute to research, health, and social outcomes.
- Evaluation of how Western institutions and funding agencies are upholding Indigenous research ethical protocols and frameworks.

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## Author Contributions

Ashley Hayward conducted the literature review, charted the data, summarized the results, and contributed to the writing of the manuscript. Erynne Sjoblom's role in this work involved charting the data, summarizing the results, contributing to the writing of the manuscript, and assisting with the submission processes. Stephanie Sinclair contributed to the analysis of the results and in the consultation exercise—offering a perspective from her experience in Indigenous research governance and ethics. She also contributed to the editing of the manuscript. Jaime Cidro contributed to the analysis of the results to the writing and editing of the manuscript.



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## Supplemental Material

Supplemental material for this article is available online.

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