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Laying the Groundwork: A Practical Guide for Ethical Research with Indigenous Communities

Abstract
Although there are numerous ethical guidelines for research with Indigenous communities, not all research is conducted in an ethical, culturally respectful, and effective way. To address this gap, we review four ethical frameworks for research with Indigenous Peoples in Canada. Drawing upon our experiences conducting a transformative social justice research project in five Indigenous communities, we discuss the ethical tensions we have encountered and how we have attempted to address these challenges. Finally, drawing on these experiences, we make recommendations to support those planning to conduct research with Indigenous Peoples in Canada. We discuss the importance of training to highlight the intricacies and nuances of bringing the ethical guidelines to life through co-created research with Indigenous communities.

Keywords
research ethics, Indigenous communities, community-based research

Acknowledgments
We are deeply grateful to our partner communities who have walked beside us on our research journey.

Laying the Groundwork: A Practical Guide for Ethical Research with Indigenous Communities

In this article, we use the term Indigenous with reference to the original inhabitants of the territory now known as Canada and other places around the world that share similar experiences of colonization. In Canada, the term Indigenous includes First Nations, Inuit, and Métis Peoples. The goal of this article is to provide an overview of practical ethical considerations for conducting research with Indigenous communities. We describe a number of ethical principles, derived from diverse policies, and some of the challenges that we have faced when applying these principles to a multi-site Indigenous community-based research project. We begin by locating ourselves and then describe the research project that provided us with the opportunity to address and engage these ethical principles and their attendant challenges.

Self-Location

All of the authors of this article are involved in a research project called Walking the Prevention Circle: Re-Searching Community Capacity Building. Before exploring what we have learned about practical ethical considerations for conducting respectful research with Indigenous communities, we believe that it is important to first locate ourselves and describe the project. We are a group of five researchers who have all received graduate education. Julia Riddell is a young, Euro-Canadian woman currently in the third year of her doctorate. Due to her rural upbringing, she developed a deep connection with the land that has inspired her to work in solidarity with Indigenous communities. Angela Salamanca is a mixed-race, immigrant woman from Colombia who identifies as an uninvited guest and settler on Indigenous territory. Debra Pepler is a mother and grandmother who has focused her teaching and research on child and youth development in family and peer relationships. Her European ancestors came to Canada as visitors over a century ago. She has been on a learning journey to understand the strengths and challenges of Indigenous children and youth, particularly in the context of families and communities. Muskwas Nitanees, the Daughter of Little Bear, also known as Shelley Cardinal, is Cree and Mennonite. She was raised with stories of both cultural strength and the harm that Indigenous Peoples have endured. From a young age, she knew her life's work would contribute to addressing such harm. Today, she contributes to this vision through her violence prevention work with the Canadian Red Cross. Onowa McIvor is Cree and Euro-Canadian. Her ancestors come from the land surrounding what is now known as the Hudson's Bay and southern Saskatchewan. Onowa developed a love for research early in her academic life as a master's student in the early 2000s. Her love for her people and her belief in the potential for healing led her to a life devoted to Indigenous education and language revitalization, which she engages through teaching and shared research projects with Indigenous communities.

Project Description

Walking the Prevention Circle: Re-Searching Community Capacity Building (the WTPC research project) is a transformative social justice research project, which arose from a partnership between the Canadian Red Cross Respect Education programs and the Promoting Relationships and Eliminating Violence Network (PREVNet). Shelley Cardinal has been working in the area of violence prevention with the Canadian Red Cross since the 1980s and co-created the WTPC program in partnership with Indigenous communities. This program aims to address the historical and contemporary challenges of

Indigenous communities by promoting a systemic understanding of the impacts of colonization and supporting culturally-appropriate services and programs which promote healing and wellness (Fairholm, Fearn, & Ross, 2010). As an Indigenous-specific program, the WTPC is embedded within a larger community mobilization process that has been developed by the Canadian Red Cross, called Ten Steps to Creating Safe Environments. The Ten Steps program supports the creation of safe environments for children and youth, promotes community capacity, and provides resources for healing and preventing violence. Per this program, community leaders identify up to 20 key community members across diverse systems (e.g., health, education, police, social services, Elders). These members then work through the ten steps to develop an action plan and to mobilize other community members to implement the plan. The WTPC research project focuses on working with communities to study the change that occurs through both the Ten Steps process and the implementation of communities' action plans.

To initiate the research, we partnered with a number of Indigenous governing bodies (e.g., Chiefs of Ontario, Prince Albert Grand Council) that represent numerous smaller communities—such as First Nations or hamlets—which helped us identify communities that might be interested in participating in the project. Shelley Cardinal then connected with the leadership in four different communities and one urban Indigenous organization. If the community or organization was interested in the Ten Steps program and the associated research, then a memorandum of understanding (MOU) outlining the research partnership was developed collaboratively. The community leaders identified research advisors, who then suggested potential community members who could be hired as community-based researchers. These Indigenous community-based researchers collaborated with university-based researchers to create a Starting Point Story—aided by a blueprint developed by Indigenous scholars Kathy Absolon and Susan Dion—as a baseline for each community before the implementation of the Ten Steps. During and after the program, the community-based researchers gathered data to describe the process of change and community mobilization with ongoing support from the university-based researchers.

In the first section of this article, we discuss four ethical guidelines for conducting research with Indigenous Peoples that have been developed by either government funding agencies or Indigenous governance organizations within the area now known as Canada. We highlight the similarities and differences between the key principles that form the foundation of these four guidelines. In the second section, we review the literature on both the ethical ways of doing research with Indigenous communities as well as the literature on the challenges of applying the principles of ethical research. In the next section, we draw upon our experiences to discuss some of the ethical tensions that we have encountered when applying foundational principles of conducting ethical research with Indigenous communities. Specifically, we discuss how we have attempted to address these challenges. Finally, drawing on these experiences, we make recommendations about how to support those planning to conduct research with Indigenous Peoples.

Principles to Guide Ethical Research with Indigenous Communities

When conducting our research project with Indigenous communities in Canada, we have deeply considered the ethical principles governing such research. The distinction between research conducted by Euro-Western, non-Indigenous researchers *on* Indigenous communities, for the benefit of non-Indigenous scholars and agencies, as opposed to research that is conducted *with* Indigenous communities for *their* benefit, has been a matter of ongoing concern (Ball & Janyst, 2008). Santos (2008) has described Euro-Western research as extractive, insofar as universities and governments "send their 'experts' to a community, extract information from 'subjects,' and take away the data to write their papers, reports and theses with no reciprocity or feedback to the community" (p. 321). To ensure that such unethical research is not repeated, several Indigenous researchers, organizations, and funding agencies have articulated principles of ethical engagement for research with Indigenous communities. To this end, Canada's three research councils (referred to as the Tri-Council)—the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC)—have included specific chapters in their established guidelines for conducting ethical research that are specific to Aboriginal Peoples (CIHR, NSERC, & SSHRC, 2010, 2014). Indigenous governing bodies and organizations have also authored numerous research guidelines. However, in this article, we focus on the guidelines that are relevant to or have been adopted by the Indigenous communities with whom we partner on research, which we describe in the next section. Based on these guidelines, we have identified 13 key principles for conducting research with different groups of Indigenous Peoples in a Canadian context, which are summarized in Table 1.

Tri-Council Principles

One of the earliest documents created to address and prevent issues of unethical research with Indigenous communities in Canada was the Tri-Council's 1998 policy statement *Ethical Conduct for Research Involving Humans* (CIHR et al., 1998). However, concerns were raised about these guidelines due to the lack of formal consultation with Indigenous communities during their development (Israel & Hay, 2006; Stiegman & Castleden, 2015; Weijer, Goldsand, & Emanuel, 1999). In response to these critiques, CIHR engaged in consultations with Indigenous Peoples, communities, and organizations, as well as university-based researchers, concerning ethical research with Indigenous communities. CIHR (2007) produced a policy document in 2007, which was updated in 2010 in collaboration with the other two national research councils (CIHR et al., 2010). The document was further revised in 2014 (CIHR et al., 2014). The 2010 and 2014 versions of the document, the *Statement on Ethical Conduct for Research Involving Humans* (TCPS 2) (CIHR et al., 2010, 2014), contain a chapter outlining a policy for conducting research with Indigenous Peoples. The chapter "Research Involving the First Nations, Inuit and Métis Peoples of Canada" (Chapter 9) provides a framework that university-based researchers and research ethics boards (REBs) can use to evaluate research protocols, thereby ensuring that they meet the three guiding principles of the Tri-Council guidelines—respect, concern for welfare, and justice—in the context of research with Indigenous communities (CIHR, 2014; Stiegman & Castleden, 2015). The Tri-Council guidelines also highlight the importance of respectful relationships, collaboration, engagement, and co-creation between researchers and Indigenous communities and their members. When working with community leaders, community-based research advisors, community-based researchers, and key community members involved in the Ten Steps program, we have collaborated during every stage of the research process with as many community members as possible. For example, in developing each community's Starting Point Story, the community research advisor and community-based researchers identified those who held knowledge that was essential to the project.

Chapter 9 of the Tri-Council guidelines begins by explaining how the three general ethical principles that apply to all research (respect for persons, concern for welfare, and justice) are interpreted in the context of doing research with Indigenous communities. The first general principle, respect for persons, holds that consent to participate in research is to be free, informed, and ongoing. As opposed to considering only the individual participants involved in a study, this principle requires researchers to consider how the knowledge gained from their research will impact both the social and physical environment, as well as future generations. The second general principle, concern for welfare, involves considering the physical, emotional, social, cultural, and spiritual wellbeing of individual research participants, as well as the wellbeing of the broader community. This principle suggests that research should enhance the capacity of Indigenous communities to maintain their cultures, languages, and identities. The third general principle, justice, acknowledges the harm that has been done to Indigenous communities by researchers, both intentionally and unintentionally, which requires researchers to take time to develop trusting relationships with communities and collaborate with them at every stage of the research process (CIHR et al., 2014).

Chapter 9 also lists 22 specific articles that explain how to apply the provisions of the Tri-Council policy when working with Indigenous communities. These requirements specify that the nature and extent of community engagement be negotiated between researchers and communities, as well as between researchers and all relevant Indigenous organizations. As such, the nature of community engagement must be described in all applications to university REBs. Furthermore, researchers are required to have learned about community authority structures and respect local Indigenous governing bodies, such as formal leadership as well as traditional knowledge keepers (e.g., Elders, confederacy councils, hamlet councils, etc.). Before recruiting participants, a formal research agreement must be signed that clarifies:

- The nature and extent of community engagement,
- The process for individual consent,
- Privacy and confidentiality,
- Responsibilities regarding data collection and management,
- Intellectual property rights, and
- Plans for the dissemination of results.

Researchers are expected to recognize the diverse interests and perspectives within communities and conduct themselves in ways that respect community customs and codes of practice. Finally, the guidelines express an expectation that the research process will be collaborative, participatory, of benefit to communities, and strengthen communities' capacity for research.

Ownership, Control, Access, and Possession (OCAP®) Principles

The Ownership, Control, Access, and Possession (OCAP®) principles were developed to address the history of disrespectful, exploitive, and oppressive research carried out in Indigenous communities without members' informed consent or benefit. This response to the history of such research was the result of two converging factors: "1) An increase in First Nations' research capacity and involvement and 2) a widely-shared core value of self-determination" (First Nations Centre, 2007, p. 8). The OCAP® principles offer an Indigenous approach to all aspects of research, including consultation, decision making, research methods, data storage, and knowledge mobilization. Furthermore, the principles support Indigenous self-determination by offering a framework through which Indigenous communities can determine whether research will be of benefit to them.

The development of the OCAP® principles resulted from a meeting held in 1998 by the National Steering Committee—later the First Nations Information Governance Centre (FNIGC)—of the First Nations and Inuit Regional Longitudinal Health Survey (First Nations Centre, 2007). During this meeting, the first three principles of the guidelines were articulated: Ownership, Control, and Access. The principle of Possession was added later to recognize the importance of First Nations' ownership and physical possession of data (First Nations Centre, 2007). In our project, we specified in the consent forms that while the university-based researchers would only possess the data for 7 years, the community would possess it indefinitely. Therefore, participants were given a choice to provide consent for the ongoing use of their data by their communities and knew that the communities had control, ownership, and access to their stories and any other information that they shared.

Utility, Self-Voicing, Access, and Inter-Relationality Research Framework (USAI)

The Utility, Self-Voicing, Access, and Inter-Relationality (USAI) framework was developed by the Ontario Federation of Indian Friendship Centres to guide research processes and decisions within urban Indigenous communities and organizations. The principle of Utility refers to research being relevant and of direct benefit to communities. The principle of Self-Voicing affirms that communities must be fully recognized as authors and knowledge holders. The principle of Access recognizes that "all forms of knowledge including local knowledge, lived experience, community narratives, personal stories, and spiritual expressions are reliable and valid forms of authored research" (Ontario Federation of Indian Friendship Centres, 2012, p. 10). In the context of the WTPC research, these types of knowledge are what comprised the Starting Point Story, which was developed as the baseline data for each community. Access also means ensuring that research findings are presented in accessible language. Finally, the principle of Inter-Relationality refers to the understanding that research always occurs within historical and relational contexts. With this project, we have supported communities in understanding this context through the development of their Starting Point Stories. More broadly, the Ten Steps program focuses on the historical and relational context within Canada and within the community itself.

Although Participatory Action Research (PAR) emphasizes the importance of collaborative relations in research and the use of multiple sources of knowledge, it does not "go far enough to recognize local systems of knowledge and practice as fully authoritative and competent to design, conduct, and evaluate their own research" (Ontario Federation of Indian Friendship Centres, 2012, p. 7). In contrast, the Utility, Self-Voicing, Access, and Inter-Relationality framework provides principles for engaging in research and forming research partnerships in ways that recognize Indigenous partners as holders and authors of knowledge, not simply as "trusted informants, confidants, and advisors" (Ontario Federation of Indian Friendship Centres, 2012, p. 8). The National Association of Friendship Centres (NAFC) and the Urban Aboriginal Knowledge Network (UAKN) include both the USAI framework and the

OCAP® principles in their *Guiding Ethical Principles* (UAKN, 2015), a policy document that they have created to guide urban Indigenous organizations and their research partners. The ethical principles in the *Guiding Ethical Principles* document complement the Tri-Council principles and include an emphasis on community-driven research that addresses community priorities and protects the wellbeing of communities, organizations, and individuals. The document also emphasizes the importance of ongoing negotiations of consent, as well as ensuring fairness, respect, and honesty at every stage of the research process (UAKN, 2015). Moreover, it stresses that researchers must respect communities' or organizations' ownership of and intellectual property rights to data resulting from a research process, and it states that any profit stemming from a research project driven by the community should be given to the partner community (UAKN, 2015).

Inuit Ethical Principles

The Inuit Nipingit (National Inuit Committee on Ethics and Research) was formed as an advisory group in 2008 to develop and recommend guidelines regarding how to improve the processes and practices of research conducted with communities in the Arctic. Two organizations, the Inuit Tuttarvingat and the Inuit Tapiriit Kanatami, supported the Inuit Nipingit's mandate and operations (Inuit Tuttarvingat, 2010). The Inuit Tuttarvingat (2010) outlined four key principles of importance for researchers seeking to conduct work with Inuit:

1. Respect of intangible cultural property in the form of language and traditional knowledge.
2. Empowerment of the community and positive outcomes for regions and communities involved.
3. Mutually beneficial research through knowledge sharing with individuals, regions, and government.
4. Respecting animals through the research process and methods.

For example, we are studying the Ten Steps program, which is designed to increase capacity in communities and mobilize them toward increasing safety for children and youth. Inuit communities have identified this area as a priority due to the high rate of youth suicide in their communities.

Another source of guiding principles for conducting ethical research with Inuit communities is the Inuit Tapiriit Kanatami and the Nunavut Research Institute's (2007) *Negotiating Research Relationships with Inuit Communities: A Guide for Researchers*. Intended largely for non-Indigenous researchers, the guide has highlighted the considerations integral to negotiating respectful and mutually beneficial research partnerships with Inuit. In addition, the guide outlines the application process researchers must complete in order to secure a license to conduct research in the Arctic (Inuit Tapiriit Kanatami & Nunavut Research Institute, 2007). The Inuit Tapiriit Kanatami and Government of Nunavut (2002) have also put together a guide for communities: *Negotiating Research Relationships: A Guide for Communities*. This guide describes how communities can engage with research projects in ways that honor their rights and autonomy, while ensuring that the research is beneficial and relevant to them (Inuit Tapiriit Kanatami & Nunavut Research Institute, 2002).

Table 1. Key Principles for Conducting Research with Different Groups of Indigenous Peoples in Canada

Principle	TCPS 2 (Chapter 9)	USAI	Inuit-Specific Perspectives	OCAP®
Research benefits and supports community research efforts and builds local capacity.	X	X	X	X
Access by members of the community to knowledge collected about them.	X	X		X
Community ownership over process, data, and results.	X	X		X
Community control over research: "clear understanding and agreement on the control of data and research results, their storage and release" (ITK & NRI, 2007, p. 9; see also ITK, 2010).			X	
Research is relevant to community needs and priorities and increases positive outcomes.	X	X	X	X
Opportunities for co-creation: sharing of decision making, data management, and sharing of knowledge (community engagement).	X	X	X	X
Honoring traditional knowledge and knowledge holders and engaging existing knowledge and knowledge keepers.	X		X	
Opportunities for self-voicing: "research, knowledge and practice [that] are authored by communities, which are fully recognized as knowledge holders and knowledge creators" (OFIFC, 2012, p. 9).		X		
Respectful relationships (respect for cultural norms, knowledge systems, and the sharing of knowledge).	X	X	X	
Culturally appropriate research methods.	X	X		
Power balance (collective decision making as a complement to individual consent); respect for Indigenous governing authorities.	X		X	X
Inter-relationality: research must be "historically-situated, geo-politically positioned, relational, and explicit about the perspective from which knowledge is generated" (OFIFC, 2012, p. 10).		X		
Ethical treatment of animals in the research process.	X		X	

Note. ITK is the Inuit Tapiriit Kanatami. NRI is the Nunavut Research Institute. OFIFC is the Ontario Federation of Indian Friendship Centres.

Ethical Guidelines Articulated by Individual Scholars

In addition to the documents discussed above, a number of Indigenous and non-Indigenous researchers have proposed their own sets of ethical principles and guidelines for conducting research with Indigenous Peoples. Kirkness and Barnhardt (1991), for example, have articulated "the four Rs" of Indigenous research: respect, reciprocity, relevance, and responsibility (p. 6). Tobias, Richmond, and Luginaah (2013) have identified that the foundations of ethical research partnerships with Indigenous communities are "relational accountability" and "mindful reciprocity" (p. 130). Relational accountability acknowledges the importance of relationships, as they exist through all aspects of the research, thereby requiring that researchers pay extra attention to these relationships throughout the entire process (see Kovach, 2009; Tobias et al., 2013; Wilson, 2008). Mindful reciprocity challenges researchers to participate in thoughtful and compassionate relationships with community collaborators (see Pearson & Paige, 2012; Tobias et al., 2013). Similarly, Marsh and colleagues have proposed six core principles of ethical health research with Indigenous communities (Marsh, Cote-Meek, Toulouse, Najavits, & Young, 2015), which include open and honest communication, inclusion, community connectedness, and the involvement of Elders, the Aboriginal advisory group, and the research committee. Marsh et al. (2015) have explained that these principles seek to enhance respect and encourage equality in relationships, which is essential for doing ethical work in Indigenous communities.

Anishinaabe scholar Kathy Absolon (2011) has asserted that an integral part of carrying out ethical research involves the self-location of the investigators within the research relationship. She affirmed, "in Indigenous contexts location does matter. People want to know who you are, what you are doing and why" (p. 73). Self-location also identifies the power differentials between researchers and participants and "prompts awareness of the extractive tendencies of research" (Kovach, 2009, p. 112). The strongest theme in the literature on Indigenous research ethics is that every stage of research relies on relational processes—from the researchers' own intentions in seeking particular knowledge, through the design and implementation of methodologies and gathering of consent, to the analysis and dissemination of knowledge (Absolon, 2011; Kovach, 2009; Michell, 2012; Smith, 2012; Wilson, 2008). This relational approach to conducting research also highlights the importance of reciprocity, insofar as participating communities and individuals should benefit from research throughout the process, not just at the knowledge-sharing stage. For example, researchers are often encouraged to hire researchers locally and to assist with capacity building and skill development by offering lectures and workshops in the community (Inuit Tapiriit Kanatami & Nunavut Research Institute, 2007).

Challenges Associated with the Application of Ethical Principles

Researchers wishing to engage in research relationships with Indigenous people must follow both the Tri-Council principles and the relevant ethical guidelines created by Indigenous organizations and governments with whom they wish to work. Although such guidelines provide a strong foundation, conducting ethical, culturally respectful, and effective research with Indigenous communities remains challenging (Bull, 2010; Green & Mercer, 2001; Laird, 2002; Piquemal, 2000). There appear to be two main reasons for challenges associated with conducting ethical research with Indigenous communities.

First, there are few examples of ethical guidelines in practice within research projects; therefore, Indigenous communities continue to be negatively impacted by some contemporary and current research projects (Taniguchi, Taualii, & Maddock, 2012; Tobias et al., 2013). To address this problem, researchers have called for more guidance regarding specific aspects of the research process, such as explicitly addressing how informed consent can be effectively and appropriately obtained in Indigenous communities in accordance with both research ethics guidelines and community customs and practices (Sherman et al., 2012). Respecting individual confidentiality in small, connected communities and protecting research sources, sacred places, and traditional knowledge continues to be a challenging issue (Tobias, 2015). Regarding this challenge, Tobias (2015) has suggested that researchers ensure that participants and communities are given an opportunity to review the research findings (which must be presented in an accessible way) and to consent to the use of their knowledge as it has been presented.

Second, individual members of university-based REBs do not consistently interpret and apply the guidelines discussed above when they are reviewing researchers' project proposals (Castleden, Morgan, & Lamb, 2012; Flicker & Worthington, 2012; Guta, Nixon, & Wilson, 2013; Guta et al., 2010). This inconsistency has resulted in REBs acting as a barrier, rather than a support, to researchers conducting ethical community-based research with Indigenous communities (Stiegman & Castleden, 2015). For example, for her dissertation, Moore (2015) worked with Mi'kmaw communities in Nova Scotia, as well as health directors, financial services administrators (who are responsible for funding decisions), and REB representatives, to examine each group's perceptions of the ethical guidelines governing research with Indigenous communities. Moore found that health directors and financial services administrators had limited knowledge of the Tri-Council's guidelines for research involving the First Nations, Inuit, and Métis Peoples of Canada. She also discovered that REB representatives and financial services administrators lacked an understanding of ethical principles of research in Mi'kmaw communities. The researchers she interviewed reported that the Tri-Council guidelines were vague, had confusing wording and/or content (e.g., they were unclear about what constituted community consent), and did not provide enough instruction about how to ethically conduct research with Indigenous communities. The researchers and REB representatives conceded that the Tri-Council guidelines needed to be further developed with real examples of how researchers engaged the various guidelines (Moore, 2015). In this article, we aim to address this knowledge gap by providing examples of ethical issues that we have faced in our research, as well as how we have used available guidelines to inform our responses to ethical dilemmas. As such, we bring together multiple sets of ethical principles to "think through" how they together inform the research practices of investigators engaging with Indigenous communities and individuals.

Ethical Principles in Action—Considerations from the Walking the Prevention Circle Project

Concurrent with our analyses of the diverse ethical policies governing research with Indigenous communities, we have been working with communities to bring ethical principles to life through the WTPC research. In the following section, we describe the challenges that we have faced engaging with communities and how we worked to ensure that we upheld the multiple principles relevant to our diverse partner communities. We also provide a description of how we overcame these challenges, with the hope that such a description of real contexts might be useful for other researchers facing similar challenges.

1. Applying Multiple Sets of Ethical Principles

The Ownership, Control, Access, and Possession (OCAP®) principles were created by First Nations leaders, and thus they are central to conducting ethical research with these communities. These principles, however, are inappropriate for conducting research with Inuit communities. The framing of co-creation and data-sharing agreements as ownership and control is problematic when working with Inuit communities, which value the practice of sharing within the community (Pauktuutit Inuit Women of Canada, 2006). As such, we adjusted the language of our project's agreement for each community to reflect their ethical principles and values. The value of non-interference means that most Inuit "place a high regard on the right of individuals to lead their lives free from interference from others" (Pauktuutit Inuit Women of Canada, 2006, p. 40). This value can lead to discomfort when an Inuk is put in a position of power or authority. In our project, we tried to ensure that the community-based Inuit researchers were comfortable in their roles, and we worked to help them find ways to have power *with* others in the community as opposed to power *over* them. In this respect, it is essential that researchers understand not only the ethical principles of research, but also the cultural norms and values held by the community with whom they partner. Moreover, it is essential that researchers adapt ethical principles for different communities.

In addition, it is important to understand how cultural protocols may impact the nature of relationships. For example, in many traditional Inuit communities, a young person would never speak after an Elder or mentor has spoken, even if the young person disagrees with him or her or has something to add. Understanding this norm is essential to every stage of the research process, from discussing the research agreement to collecting data. In our project, for example, we had been training community-based researchers how to ask follow-up questions during interviews and after listening to the stories of community members so that they could gather the information needed for the Starting Point Story. When one of the university-based researchers was discussing how to ask follow-up questions with two of the community-based researchers, they explained that this practice would be disrespectful. As such, the research team worked together to develop an interview guide that asked different questions and did not use follow-up questions as a method of data collection.

To support researchers' learning about the ethical principles and cultural norms of the communities within which they work, it would be valuable for federal funding agencies to employ informed Indigenous scholars who can suggest resources for researchers to educate themselves and become culturally competent. Another means of support could be workshops where researchers can learn about both ethical principles of conducting research and the norms of the communities in which they hope to work. Ideally, communities and Indigenous leadership organizations would create these workshops with financial and technical support from an institution committed to promoting ethical research (such as the Tri-Council).

2. Building Trusting Relationships and Addressing Harm

It is important for researchers, boards, and review panels to be cognizant of the exploitative and violent history of research with Indigenous communities (Cochran et al., 2008; Mosby, 2013). Beginning by discussing this topic fosters an understanding of the resultant legacy of distrust and the general reticence of Indigenous Peoples to engage in research projects. Approaching a research project with the acknowledgement of the shameful history of colonization and the harm experienced by communities because of research can form the foundation for relationships that are based on open and honest communication, inclusion, and community involvement (Marsh et al., 2015).

During our project, we began a meeting with members of a partner community by acknowledging this history and talking about the research team's foundational values: respect, working together in a decolonizing way, open communication, ensuring learning in all places, responsibility, and accountability. By discussing these values, we hoped to express our desires to engage in an ethical relationship with our community partner—with specific, quantifiable parameters for trusting, collaborative work. The research team's emphasis on the necessity of responsibility and accountability comprised a critical aspect of this conversation with the partner community's members. Moreover, these values clarified the role of ethical guidelines and principles as designed to serve the community's interests; the community understood they could hold us accountable as researchers.

3. The Time and Funding Required to Co-Create the Research with Indigenous Communities

In 2011, a group of researchers, including Debra Pepler and Shelley Cardinal, submitted a proposal for WTPC, which was not granted. The letter of intent for the project's current grant was submitted the same year and the WTPC project received funding in 2012. Unlike some granting mechanisms, the funding for this project was released prior to the project obtaining ethics approval. This was essential in allowing us to develop strong and respectful research relationships with Indigenous governing bodies and the communities. Further, this funding was sufficient to support the iterative and collaborative nature of this project.

We anticipated that the process of engaging governing bodies and then individual communities would take approximately six months, as this was the timeline that the Canadian Red Cross followed to secure the agreements to deliver the Ten Steps program to Indigenous communities. However, with the research part of the program, this process took 2 to 3 years. Shelley Cardinal of the Canadian Red Cross visited each community once the community leadership had agreed in principle to participate in the Ten Steps program and its associated research. This visit was followed by numerous phone calls aiming to develop a partnership and research agreement and in some cases an additional visit to the community was required. These visits—to one urban and four remote communities—were funded from the research budget. In addition to the amount of time necessary to initiate research partnerships, delays in the project may have been related to some communities' deep distrust of research and researchers. There were also delays caused by unexpected crises in the community. Due to these significant delays, the funding organization withdrew one fifth of our funding, which had been allocated to knowledge mobilization during the last year of the project.

4. Challenges with the Ethics Review Process

At the beginning of an Indigenous community-based research project, difficulties can arise from the order of operations, developing consent forms with clear language, and indicating how contributions from community members will be used. To protect research participants, some funding agencies require ethics review prior to transferring funds and beginning to work with communities. For the initial application to a university REB, we needed to submit specific details of our planned engagement with communities, our methods, and the consent forms for the project. The initial consent form was a template and was submitted simply to satisfy the requirements of the application. Since the communities with which we worked were full research partners, we subsequently co-constructed the consent forms with input from the communities' leadership, research advisors, and community-based researchers. As the project unfolded, we continued to adapt the consent forms to reflect our ongoing learning about the community's language, literacy, and cultural norms. Consequently, we have submitted numerous amendments to the university REB, which required significant amounts of time and labour.

Furthermore, when creating our initial consent forms, it was challenging to balance two conflicting requirements. On the one hand, we were given requirements from our university that specified the information and wording that was required to receive REB approval. On the other hand, we had a responsibility to provide accessible, plain language explanations in the invitation to community members to participate in the research. Part of that responsibility necessitated that our invitations were not excessively complex or legalistic. In particular, we wanted to ensure that our consent forms helped participants understand the nature of the research, how their contributions would be used, and the relative risks and benefits of their participation. We also wanted to ensure that participants understood all other aspects of free and informed consent without having to parse a lengthy or confusing, jargon-filled consent form. Finally, we considered it essential to have resources available to translate the consent forms and other materials into each community's traditional language.

With the first community partnership, 10 researchers and research advisors helped shape the various iterations of the consent form. These individuals highlighted the shortcomings of the university-based descriptions of how the data would be used. Rather than being concerned about the security of data storage (which was included in our original consent form), community members wanted to know how the knowledge they shared would be used. Therefore, it was important for us to articulate how the knowledge would be both interpreted and shared by researchers.

We explained this to potential participants in the following way:

> **What will happen to the knowledge shared?** The knowledge you share is going to be put together with other people's knowledge. The research team will work together to find common themes from everyone's answers. We will then return to your community to tell you about what we have found and ask for your help making meaning from these themes. The overall knowledge gathered in this project will be shared with many people who work with Indigenous communities across Canada. Resources will be created to help with the Canadian Red Cross and other community program development, the education of professionals, and to support respectful research and work within communities.

Researchers working with Indigenous communities often require multiple amendments to standard institutional ethics applications to reflect the process of co-creation with communities, which must be factored into consideration for research timelines. To support researchers during this process, we recommend that, in collaboration with Indigenous communities, institutions, such as the Tri-Council, develop a standard initial consent form for research within Indigenous communities with the expectation that it will be adapted once engagement with the community begins. In addition, we recommend that federal funding agencies employ informed Indigenous scholars who can provide guidance throughout this important and complex ethical process. The arm's length perspective that externally employed Indigenous scholars might bring to the discussion, alongside the multiple lenses that researchers and community members bring, could greatly assist the ethical considerations within the project.

5. Balancing Community and Individual Interests and Rights

At the beginning of our research process, initial conversations with each community included discussions about rights and responsibilities around data stewardship and use. While researchers and communities both share responsibility for data produced by a research project, all parties need to consider participants' rights to confidentiality. Thus, the consent form is an agreement that the community and researchers must follow with respect to the storage and sharing of confidential information. Both research partners are accountable to participants for the terms of consent that are accepted either in writing or verbally. In our consent forms, we outlined the following rights and responsibilities of participants, communities, and researchers:

- Participants who consent have the right to choose to remain anonymous or to be credited for their perspectives and knowledge.
- Participants must have the option to choose whether to grant their community permission to use their data only for the specific project or for future research projects as well.
- The consent form should indicate the researchers' responsibility to destroy the original data in a specified number of years.
- With participants' consent, the community may keep the original data indefinitely.
- Figure 1 provides an example of the form detailing the levels of participant consent.

Based on each participant's choices on the consent form, the research team created a corresponding dataset for partner communities. That is, the community is given a copy of the data without identifying information for participants who want to remain anonymous and with clear identification of those who consent for their data to be used in future projects. In our consent form, we specified that the data will be kept for 7 years by the research team; however, each community can decide how long to keep their copies of the data (with participants' agreement).

Would you like to participate in the project? ☐ Gave approval ☐ Declined invitation

Audio-recording
I agree to be audio-recorded Yes ☐ No ☐
I agree for my audio-recordings (which can identify me) to be included in what is shared with my community Yes ☐ No ☐

Confidentiality (please choose one statement)
☐ I agree to be identified by name/be credited in writings and/or presentations OR
☐ I prefer not to be identified by name, please use____________________________ OR
☐ I prefer to be identified as "community member" and a code chosen by the team.

Future use of what you share today:
I consent to the use of the knowledge I shared today in future research: Yes ☐ No ☐
I consent to be contacted again if the knowledge I shared today is requested for use in future research: Yes ☐ No ☐

Figure 1. **Example of participant consent questions.**

Conclusion

The numerous ethical guidelines for conducting research with Indigenous Peoples highlight the complexities of such research processes and the critical role of communities in shaping every aspect of Indigenous community-based research. The four main guidelines we used (Tri-Council, OCAP®, USAI, and Inuit-specific) emphasize that all research needs to benefit and support communities and that communities co-own all data collected through research. One challenge of ethically conducting research with Indigenous communities is that there is scant literature available to inform the process of making ethical principles directly actionable. As such, we have written this article with aim to begin a conversation with other researchers, community members, REBs, and granting agencies. In addition, we offer recommendations to support co-created research with communities, to address their questions, and to address their concerns. Based on the challenges we faced conducting this project, we have four main recommendations for how to support those conducting research in partnership with Indigenous communities.

First, we recommend that funding agencies employ Indigenous advisors at the federal, provincial, and/or territorial levels to guide researchers in their efforts to acquire cultural competence. These advisors may provide arm's length perspectives on the multiple outlooks that researchers and community members bring to the ethical considerations within projects.

Second, we recommend that a federal agency—such as the Tri-Council—in collaboration with Indigenous communities, develop a standard initial consent form for research within Indigenous communities. This initial consent form should then be adapted once researchers begin to engage with communities.

Third, we recommend that there be active and consistent participation of Indigenous community members and researchers on REBs and grant review committees. Members of Indigenous ethics boards and review committees could assist with any necessary overhauls and/or rewritings of institutional ethics applications and review processes so as to better serve Indigenous communities. For situations in which it is not possible to have the constant presence of community members or Indigenous researchers on boards or review committees, we recommend including an Indigenous ombudsperson, advocate, or consultant who can advise on decisions related to research with Indigenous communities. In addition, we believe that institutions, such as universities, must respect any decisions made by Indigenous governing organizations to ensure protection and self-determination.

Fourth, we believe that it would be helpful for a federal granting agency—such as the Tri-Council—to collaborate with Indigenous leaders and develop workshops for individuals conducting joint university-Indigenous community projects. Given that the Tri-Council already has an online ethics tutorial, the agency could create additional online workshops specific to co-creating research with Indigenous communities. We suggest that researchers, university REB members, grant review panelists, and Indigenous community members could participate in these workshops to further develop their abilities to navigate ethical guidelines for co-creating research. These workshops could form the foundation of our understanding of ethical research relationships by including case studies or examples of how the Tri-Council principles and the relevant guidelines created by Indigenous organizations and governing bodies can be applied.

To this end, we have created a list of seven topics that might be included in these workshops. This list has been informed by our experiences applying relevant ethical principles and engaging with partner communities during the research process. Organized in order of the research process, these topics include guidelines for researchers to educate themselves on:

a. The traditions, protocols, and norms of potential partner communities,

b. The exploitive and violent history of research with Indigenous communities and how to discuss research values at the beginning of a project,

c. How to form initial agreements for the collaborative research project,

d. The nature of co-creation or collaborative research relationships and how to engage in this process,

e. How to co-create consent forms,

f. How to make meaning of research findings based on the community's interpretation of the findings, and

g. How to establish agreements about how to best share research findings.

Writing this article has given us the opportunity to analyze the points of intersection between diverse ethical frameworks. Our intentions in writing this article were to support other researchers and decision makers in their efforts to apply ethical principles to their everyday decisions in research processes with

Indigenous communities. We see this work as an incremental step toward improving ethical research practices for working with Indigenous communities. We look forward to the contributions of other researchers to this discussion regarding how to make such ethical principles actionable, common, and widely adopted. We are deeply grateful to our partner communities for showing us both the gaps in our understandings and what we needed to consider in order to do our work in a better way.

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