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Abstract

The 2010 edition of the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* introduced a new chapter, titled "Research Involving the First Nations, Inuit and Métis Peoples of Canada." The goal of our study was to explore how this chapter is being implemented in research involving Mi'kmaw communities in Nova Scotia. Qualitative data from four groups—health researchers, research ethics board representatives, financial services administrators, and Mi'kmaw community health directors—revealed that while the chapter is useful in navigating this ethical space, there is room for improvement. The challenges they encountered were not insurmountable; with political will from the academy and with guidance from Indigenous community health and research leaders solutions to these barriers can be achieved.

Keywords

Indigenous health, research ethics, TCPS2, decolonizing methodologies, community-based participatory research, Canada

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Implementing the *Tri-Council Policy on Ethical Research Involving Indigenous Peoples in Canada: So, How's That Going in Mi'kma'ki?*

In Canada and other similarly colonized states (e.g., the United States, Australia, and New Zealand), the framework for ethical academic research involving Indigenous¹ communities² now includes an overarching guiding principle that such research must advance the goals and priorities of Indigenous communities, encourage community participation, produce knowledge that is useful to them and their members, and support mutual capacity building (Ball & Janyst, 2008; Brunger & Wall, 2016; Bull, 2010). Ethical research in the context of Indigenous communities includes more than just respect for persons, concern for welfare and justice, or informing participants about their rights in the research process—rather, it is also about ensuring reciprocity in the research process (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences and Humanities Research Council of Canada [SSHRC], 2010). That is, Indigenous Peoples participating in research 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). This has not always been the case, but it has now become policy in Canada.

In line with this evolving ethical landscape, in 2010 the Canadian Institutes of Health Research (CIHR), together with the other two Canadian federal research agencies, the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC), revised its original (1998) joint policy, called the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) and introduced a new chapter, Chapter 9: “Research Involving the First Nations, Inuit and Métis Peoples of Canada.” However, policies often have unintended consequences (Chace, 2013; Ebenstein, 2010; Kot, Castleden, & Gagnon, 2011). Thus, the overarching goal of our study was to explore how health researchers, institutionally-based research ethics boards (REBs), and financial service administrators, as well as community-based health directors in one region of Mi'kma'ki (specifically, Nova Scotia), operationalized the Chapter 9 articles of the Tri-Council

¹ We use “Indigenous” when referring to First Peoples in Canada and beyond; in Canada, we mean this to include First Nations, Inuit, and Métis peoples, who are often referred to collectively using the “umbrella term” Aboriginal.

² We recognize the contested nature of “community” in academia; here, we use “communities” to denote “community(s)/organization(s)/group(s),” as Indigenous research can involve any or all of these designations.

Policy Statement (colloquially known as TCPS2)³ in health research involving Mi'kmaq communities on the east coast of Canada.⁴

Background

Historically, we know that research involving Indigenous Peoples in Canada and other Indigenous Peoples worldwide has often exploited, misrepresented, and pathologized them (Ball & Janyst, 2008; Castleden, Sloan Morgan, & Lamb, 2012). For example, the colonization of Indigenous Peoples was justified by research produced by Eurocentric scientific theories, which argued that because Indigenous people were “uncivilized,” colonizers had the right to “conquer them, dispossess them of their lands, language and traditions, and even to kill them outright” (Namaste & Jauffret, 2006, p. 65). Not only has academic research of the past been, at best, largely immaterial to Indigenous communities, it has also not reflected their respective systems of knowledge (Brant Castellano, 2004). The result of exploitative, culturally insensitive, and frequently one-sided research is that Indigenous communities tend to regard academic research with a certain degree of mistrust or apprehension (Bharadwaj, 2014; Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Cochran et al., 2008; Smith, 1999).

Indigenous-led research has been happening for hundreds of generations, but its legitimacy has been silenced by both the professionalization of Western science in the academy, and the double burden of colonialism and racism (Smith, 1999). To date, most academic research that has involved Indigenous Peoples and communities in Canada has been designed and implemented by non-Indigenous researchers and continues to be led mainly by non-Indigenous investigators (Ball & Janyst, 2008; Castleden et al., 2012; CIHR et al., 2010). In many cases, such research has done more to support the academic career advancement of the primary investigators than to support the needs of the Indigenous communities with whom the research was concerned. This has perpetuated Western society's view that it alone is the center of legitimate knowledge (Blodgett, Schinke, Smith, Peltier, & Pheasant, 2011; Castleden, Sylvestre, Martin, & McNally, 2015).

³ TCPS2 was updated in 2014 primarily to define terms and clarify specific points in the document. At the time of writing, this is the version in use. It is still referred to as TCPS2 since there were no substantive changes.

⁴ Carla Moore is Mi'kmaq from Unama'ki. She coordinates Indigenous-focused research through Dalhousie University. Her involvement in Indigenous health research follows from her work in health promotion involving Indigenous communities in Atlantic Canada. During the study period, Carla was the Director of the Atlantic Aboriginal Health Research Program (AAHRP); at the time of this publication, she is the Director of Health Services at Millbrook First Nation. Heather Castleden is a White settler scholar-ally who holds a Canada Research Chair in Reconciling Relations for Health, Environments, and Communities at Queen's University. She undertakes community-based participatory research projects in partnership with Indigenous Peoples in Canada and has a long-standing research trajectory regarding the ethical challenges of such research. Susan Tirone retired in 2016 after serving as the associate director of Dalhousie University's College of Sustainability and holding a faculty position in the School of Health and Human Performance for more than 15 years. Her academic endeavours included research with youth and families who identify with non-Eurocentric ethnic groups and people who live in rural and urban adjacent communities. Debbie Martin is an Inuk scholar and an associate professor of health promotion in the School of Health and Human Performance at Dalhousie University. Her research involves working with Indigenous communities to identify health research needs and priorities, and capacity building in the area of Indigenous health research, particularly in relation to the Indigenous determinants of health.

Academic research involving Indigenous Peoples has, however, changed in recent years. In response to the refrain “we’ve been researched to death,” Indigenous Peoples who recognize that the potential utility of research now often say that they need to be “researching ourselves back to life” (Brant Castellano & Reading, 2010). Indigenous communities are also becoming better informed about the risks and benefits of participating in academic research projects (CIHR et al., 2010); today, the willingness of many communities to participate in such projects is dependent on the extent to which their communities will directly benefit from them (Ball & Janyst, 2008). In this vein, philosophical and methodological approaches that are compatible with Indigenous ways of knowing— for example, community-based participatory research, whereby research participants are partners with academic researchers in all stages of the research process from concept to conclusion—are gaining traction (Castleden et al., 2012).

The original Tri-Council Policy Statement (CIHR et al., 1998) was viewed as inadequate by researchers and Indigenous Peoples (Taniguchi, Taulii, & Maddock, 2012) and made only brief mention of ethical considerations for research involving Indigenous Peoples. When Chapter 9 was introduced in 2010, it served as a broad framework for the ethical conduct of research involving Indigenous Peoples and communities. Its aim was to ensure that such research would always be premised on respectful relationships, collaboration, engagement, and reciprocity between researchers and participants (CIHR et al., 2010). Chapter 9 also replaced an established pan-Canadian ethics protocol for health research that was developed in 2007: the *CIHR Guidelines for Health Research Involving Aboriginal People* (CIHR, 2007). These guidelines were widely regarded for both their rigor and the collaborative approach taken in their development. At the time, health researchers were becoming increasingly aware that research collaborations were necessary to enhance the impact of research on public health (Colquhoun et al., 2013). There was also a growing awareness among some researchers of a need to be supportive of Indigenous communities’ desire to take control of research that was affecting them (Patterson, Jackson, & Edwards, 2006) and to respect the cultural norms and ethical obligations of knowledge sharing, such as gifts or honoraria for Elders or knowledge holders who participated in research (Brant Castellano, 2004; Castleden et al., 2012). While such ethical awareness was present amongst those who engaged in health-related (and other) research, this awareness is still a work in progress throughout the research community, and it has not always translated across jurisdictional borders within the academy and beyond.

To achieve our research goal, we collected qualitative data from Nova Scotia-based health researchers, REB representatives, financial service administrators, and health directors from Mi’kmaw communities in Nova Scotia to both explore how the policies contained in Chapter 9 were moving from theory to practice in their work and to identify any obstacles or challenges they faced when applying Chapter 9 to research involving Mi’kmaw communities. Ultimately, the guiding principle of our study was to propose recommendations that could be used by Mi’kmaw communities, university REBs, university administrators, and researchers to support the uptake of ethical research practices in Mi’kmaw communities. The importance and timeliness of this study in terms of its contribution to existing literature, which is emerging from other jurisdictions in this country (see for example Brunger & Russell, 2015), lies in its aim to convey the necessity of avoiding “one size fits all” approaches to research involving Indigenous Peoples and to caution against unintended consequences of policy implementation.

Methods

To collect institutional data, we targeted four universities in Nova Scotia with relatively high numbers⁵ of researchers who had received competitive funding to conduct Indigenous health research, as their high numbers of recipients indicated that the universities' REB representatives and financial services administrators would have experience with (a) reviewing ethical protocols and (b) research accounting oversight. Data were collected over four months (between June and September of 2014) using two methods: semi-structured interviews and a focus group.

We held semi-structured interviews with nine health researchers, four REB representatives, and three university-based financial services administrators. The semi-structured nature of the interviews provided participants with the opportunity to raise issues that they felt were relevant (see Agnew & Pyke, 2007). Our open-ended questions helped to ensure that all topics were covered so as to address the study's research objectives (Neuman & Robson, 2009). Data saturation became evident after six interviews with the health researchers, but we continued to interview those who had agreed to participate in case new themes or concepts emerged, although none did. While we attempted to reach data saturation with both the REB representatives and the financial service administrators, we were restricted to the four targeted institutions and experienced some difficulty recruiting sufficient numbers of participants; however, we were able to draw important insights from our dataset, which are shared here and could be explored further in future research.

In addition to the semi-structured interviews, we held a focus group with seven health directors working in Mi'kmaw communities, six of whom were Mi'kmaq. They were responsible for overseeing health research in their community. The focus group was used to explore the participants' views on Chapter 9; to develop an understanding of how the policy was being interpreted, applied, and experienced in research across several Mi'kmaw communities; and to create an opportunity for participants to interact with each other's perspectives on ethical research relationships.

Interviews and the focus group were audio recorded and transcribed verbatim. These data were manually coded and thematically analyzed (Creswell, 2009). From this analysis, three key themes emerged: relationships are critical to enacting Chapter 9 articles, community control and the challenge of capacity, and understanding each others' lived realities. To increase the validity of the analysis, these themes were reviewed and vetted by participants (Baxter & Eyles, 1997; Neuman & Robson, 2009). Each theme is discussed below and representative participant quotes are provided to enhance and contextualize these findings.

Findings

Theme 1: Relationships Support Researcher Compliance with Chapter 9 Articles

Our data revealed that health researchers who have established partnerships with Nova Scotia Mi'kmaw communities largely adhere to the principles laid out in Chapter 9 of the TCPS2. Health directors provided concrete examples of how those researchers with whom they have good relationships adhere to

⁵ We say "relatively" high numbers because this is still a field with limited institutional capacity in Canada (see Richmond, Martin, Dean, Castleden, & Marsden, 2013).

the Chapter 9 articles. The health researchers, when discussing their own research practices, also indicated that they believed they were generally in compliance with Chapter 9. The health directors noted that although some researchers continue to initiate contact with the communities about research ideas, they said that the communities agree to participate in the research only if the topic is relevant to them. As one health director said:

A researcher contacted me and . . . we chatted around research and so we began a research study around [the topic] because that was a big issue for our nurses. (HD#1)

The health directors elaborated that of those researchers with whom they have good working relationships, their relationships were developed over time, and the attitudes of the researchers were important. Once the relationships were developed, health directors tended to return to those same researchers with research ideas that were of importance to their communities. They said that the researchers they worked with:

- a. Supported Mi'kmaw community control of the research,
- b. Supported research partnerships without burdening the communities,
- c. Submitted their proposals to the local community research boards or Indigenous ethics committees,
- d. Supported community research capacity (via, for example, advisory committees),
- e. Supported the involvement of the community in developing proposals,
- f. Signed a research agreement if they were asked,
- g. Were respectful in their approaches,
- h. Were trustworthy,
- i. Shared their analyses with the communities to confirm their soundness (i.e., they sought the community's feedback), and
- j. Ensured that the community was given credit in published reports that resulted from the research (i.e., they provided co-authorship credit or acknowledgement where appropriate).

One health director summed up this part of the discussion by saying:

You have to have that relationship and build trust with the community and involve the community through the whole process. (HD#1)

Health researcher data revealed that they were well aware of the articles in Chapter 9 and most said that they followed them. That is, when describing their relationships with Mi'kmaw communities, they referred to them as collaborative partnerships and emphasized that relationship building was an important aspect of those partnerships. One researcher described these research relationships as:

Definitely partnerships, collaborative partnerships. So I wouldn't do research in a community unless I was invited into the community by the community, and all research is designed collaboratively and agreed upon collaboratively. And that's a continuous process. (HR#6)

When asked whether their Mi'kmaq community partners were involved with all stages of the research process, most researchers said that their partners were involved in developing research proposals, collecting and analyzing data, and disseminating the research results. They noted, too, that this level of community involvement would be difficult to achieve without partnerships. One researcher said:

The majority of the work is community initiated. So it's people coming to me saying, "[researcher name], I've got this idea. Could you help me with it?" That's how it generally works. (HR#2)

These participants also noted that cultivating and maintaining such relationships helped them to understand what it means to behave ethically in the community. In the context of their roles as researchers, being taught by community partners about community customs and protocols was something they identified as an important aspect of conducting ethical research. Discussing key ethical considerations, one researcher reflected:

It's knowing the protocols, knowing when to offer tobacco, knowing when to offer gifts, knowing to respect sacred knowledge that should not necessarily be exposed. (HR#3)

The health directors and researchers who participated in this study indicated that ethical research with Indigenous communities was supported by long-term, well-established partnerships, and both the directors and the researchers agreed that these partnerships adhered to the guidelines of Chapter 9 in particular and of ethical research in general.

Theme 2: Community Control and the Challenge of Capacity to Operationalize Chapter 9

The health directors and health researchers participating in this study noted that the Mi'kmaq of Nova Scotia wanted more control in research involving their communities, which continues to have implications for institutional REBs, financial services, and researchers. Participants noted that Mi'kmaq communities are taking a more active role in research, particularly in health-related research, mainly because they had more experience with research and more awareness of the value of data. As one health director put it:

We all have a better understanding . . . on how data can be useful and not so useful . . . and whether or not research can be useful. (HD#1)

The health directors also spoke about how equal control over and an equal say in the research process could be a way to prevent data from being manipulated by researchers, and that it was important that the expectations of both parties—researchers and community partners—were addressed in research agreements. One health director said:

You want to know what's going on, and so we've learned that. Previously it was like it was done, fine, go ahead. But now . . . let's say we value it more and we want to be part of it because we want to have the control. We don't want other parties to dictate what comes out of the data. We want to be there from the start so we can see and if they're doing something that's straying from what was agreed to, they can be called upon to set it right again. It's like we're not passive anymore. (HD#7)

Additionally, the health directors noted that community aspirations were important, and it was not acceptable for others, such as government departments, to prescribe what should be important for them. The same health director said:

We want to be in control. We want to be heard, not just seen, and we don't want to see, let's say, higher departments controlling what our needs are supposed to be, what we should have, what's needed in the community . . . You should be listening from the ground up, not from the top down. (HD#7)

Researchers, they explained, need to partner with their communities rather than conduct research *on* the communities, as had been done in the past. The health directors shared stories during the focus group of researchers contacting communities about prospective research projects without communities initiating the request.

I think that if there's a researcher that comes off as arrogant or whatever . . . or comes off as a know-it-all, then it already creates a barrier from day one, and communities will not participate in research. (HD#1)

Health directors and researchers noted that refusing to participate was one mechanism that communities and community members employed to maintain control over research that would have an impact them.

As much as community involvement in research is essential, health directors were quick to note that communities should not be overburdened by research engagement. They urged researchers to avoid overloading community professionals and leaders with the research process itself, as they were generally already working at or over capacity. One health director put it this way:

It was her [i.e., the researcher's] approach, I guess. She was very good with the women. She listened to the women. She passed everything by them. She wasn't bugging us all the time, which is important. (HD#5)

Health researchers shared similar perspectives. One researcher noted:

Service providers, health care professionals or teachers, who just completely are carrying caseloads that are far beyond what's actually manageable, what can you reasonably expect in terms of their involvement? So you make sure you're optimizing the knowledge they bring to the study, but your study doesn't become another burden in this person's life. (HR#6)

As much as health directors valued the notion of engagement and the importance of having meaningful collaborative partnerships (as per the TCPS articles), they often lacked the time to participate fully in the research process as such activities, including relationship building, are time consuming. One health director explained:

We don't have a lot of time. We have limited resources in a community. So we don't have a lot of time to devote to researchers. (HD#5)

The health directors were not just referring to their own time but also that of their staff members, indicating they, too, had limited resources to devote to research.

[Research is] a big commitment . . . you do need staff that can work on the ground whether it's coordinating a focus group or contacting people . . . so there is a big time commitment. (HD#1)

Health directors were concerned about the overall challenges associated with the capacities of their communities to participate in research. Some of the challenges that they noted included not understanding the value or benefit of a particular research project or not understanding why they were asked to participate in a particular study. Again, time was a factor in determining whether individual community members agreed to participate in research projects. As one health director put it:

Time is precious when you have five or six kids. Do you want to sit there for two hours with a researcher, or do you want to clean your house or take care of your kids or go to the beach? (HD#5)

In short, health directors identified a lack of both research capacity and understanding about how to use research data to their benefit, as well as time constraints, as key factors hampering the ability of Mi'kmaw communities to participate more fully in research projects. As such, these factors pose a significant impediment to communities' efforts at taking greater control over the research process.

Theme 3: Understanding Each Other's Lived Realities in the Application of TCPS2

Across the board, the data revealed a general unfamiliarity across jurisdictions, particularly between the workings of Mi'kmaw communities (and researchers in communities) and the workings of institutionally-based REBs and financial administrations with respect to the TCPS2 and the lived realities of both contexts. For example, while health directors noted that they had seen improvements in the ways in which researchers were approaching their communities to do research, they, along with financial service administrators, were not familiar with the specific contents of the TCPS2 in general or Chapter 9 in particular. When asked if they had heard of the TCPS2 and Chapter 9, one health director responded:

Well, I'm aware of it but I've never actually read it. (HD#1)

Another health director disclosed:

I just became aware of it when you sent the [inquiry and request for participation] email. (HD#4)

In response to the same question, a financial service administrator revealed:

That's not my area, ethics . . . I don't know the details of research involving human participants. (FSA#3)

Both groups said that they had not heard much about the TCPS2 before we contacted them about our proposed study. They also indicated that they knew very little about what constituted an ethical review at a university. One health director found the entire process confusing, and noted:

I still don't get a clue on that whole thing really . . . I'm not sure what [the universities] use, what Mi'kmaw Ethics Watch uses. Do they use the Tri-Council guidelines? I doubt it . . . So I don't know, I just think that . . . I don't know. (HD#1)

Similarly, interviews with financial service administrators and REB representatives revealed both a general lack of knowledge about the life circumstances of people in Mi'kmaw communities and a lack of understanding of what is typically involved in community-based participatory Indigenous research. At the same time, however, these participants acknowledged that they are called upon to make decisions about the ethical conduct of such research projects and the expenditures that enable the studies to be conducted. For example, an REB representative, when discussing ethics reviews of projects involving Mi'kmaw communities, considered the communities an example of “vulnerable” populations (i.e., a designation typically used with reference to children, seniors, prisoners, and individuals with diminished capacity), but factored neither culture nor language in her or his reviews. This representative stated:

You know, there are multiple groups who self-identify in a particular way or signal their desire to be treated as high-risk or highly vulnerable . . . I don't see the First Nation population as radically different from many other populations. (REB#1)

This perspective was not the view of all REB representative participants, however; others indicated that accommodations (e.g., including someone with Indigenous research experience on REBs) should be made when reviewing proposals for research involving Mi'kmaw participants.

Interviews with researchers revealed a general belief that REB representatives did not fully appreciate the tenets of community-based participatory Indigenous research. When discussing the tension around conducting ethical Indigenous research, one researcher said that the REB wanted a detailed timeframe of activities related to the research, without recognizing that a community-based participatory approach to the project should be organic, fluid, and respectful of the community's timeframes—not those of the researcher or the university. The researcher said who received this REB feedback noted:

The real tension . . . is the tension between being able to do an emergent process and just really being kind of frustrated with the exercise of having to spell out the minutiae for the . . . research ethics board, who in their line of questioning, I felt was really kind of undermining the power of the community to make decisions over the evolution of the project. It felt as though I was being left with a process where the community had a leash that was two inches long, and every decision that they wanted to make of any significance, [the university] had to okay before they could go ahead moving forward on the project. (HR#4)

Additionally, researchers expressed doubts that financial services administrators understood the socioeconomic conditions of some of the community research participants. As noted by one researcher:

There is some inflexibility and lack of recognition that not everybody has a [credit card], and the people that you hire to work in the communities don't have the resources to be able to do what other people do. And that's the expectation . . . "Book your travel, and we'll reimburse you." Well, it just doesn't work that way [in] the community. They may not have those kinds of resources. (HR#9)

Another researcher expressed frustration with financial services administrators not grasping the costs associated with doing community-based participatory research:

[They] need to be more aware that the process of doing [Indigenous] research is not cut and dry like a survey or a quick interview. It's much more engaging and it's much more involving the participants. (HR#3)

Finally, when discussing some of the problems they encountered with privacy, researchers spoke of the lack of understanding from financial services administrators about what constitutes ethical research. One researcher said:

[Financial services] wanted the names of participants . . . the name of who you gave the honorarium to, which breaches confidentiality. (HR#3)

On the other hand, however, was the fact that financial services administrators and their staff members were also bound to the same confidentiality requirements as researchers; thus, the above researcher's comments that financial services staff members had requested privileged information signaled a lack of understanding and communication about the responsibilities of different parties involved in research projects. In sum, what these findings point to are significant gaps between how differently situated groups within the research enterprise understand one another's lived realities. As a result, the misunderstandings that are likely to arise from these gaps create barriers to carrying out ethical research with Mi'kmaw communities.

Discussion

Our findings suggest that the principles of Chapter 9 of the TCPS2 are being borne out in positive ways for research involving Nova Scotia Mi'kmaw communities and that the policy itself has contributed to cultivating a relational approach to ethical research in these communities. Mi'kmaq in Nova Scotia are seeking more control over research that impacts their communities and the articles in Chapter 9 support such increased control. Additionally, established relationships between Mi'kmaw communities and health researchers support researchers' adherence to the articles in Chapter 9. At the same time, our findings also show that there are barriers to undertaking ethical research in Mi'kmaw communities. Despite a desire to participate fully, lack of community capacity, lack of resources, limited resources to establish community-researcher partnerships, and a lack of institutional understanding about how research is carried out in Mi'kmaw communities pose challenges.

Supporting Ethical Research in Mi'kmaw Communities Through Relationships

Mi'kmaw communities are seeking more control in research projects that impact them; this is consistent with the literature, which illustrates that other Indigenous communities in Canada and elsewhere are seeking more control in similarly impactful research projects (e.g., Ball & Janyst, 2008; Castleden et al., 2012; Schnarch, 2004; Smith, 1999; Weir & Wuttunee, 2004). The TCPS2 also acknowledges that Indigenous Peoples in Canada are more widely engaging in initiatives to assume leadership roles in research (CIHR et al., 2010). In our study, health directors spoke about how communities are taking more dynamic roles in research, ranging from deciding when to participate in a project (or opting out of a project) to leading or co-leading projects. This, they said, was due in part to a better understanding of, and more experience with, research, but it is also due to a clearer understanding of their collective community rights in the research process. They made clear that as health leaders for their communities, they were no longer passive participants in research; as such, these health directors were inclined to support only projects that were important to their communities.

Health directors and researchers in this study also revealed how important respectful partnerships were to their communities, and that researcher attitudes—particularly humility—were instrumental to the development of strong partnerships. The notion that well-established relationships between researchers and communities create the space for ethical research is well supported in existing literature (see for example Ball & Janyst, 2008; Brant Castellano, 2004; Bull, 2010). Without them, it would be difficult to move forward. However, building these relationships requires time, understanding of local ways, and skilled leadership.

Factoring time into developing respectful relationships is an important consideration for both funding agencies (e.g., the time between issuing a funding opportunity and the deadline to submit an application is often very short) and academic institutions (e.g., the time needed to undertake community-based Indigenous research is longer than most conventional research, but this is not well understood in either annual reviews or tenure and promotion contexts). By recognizing the need for this relational ethic, research collaborations that result from these relationships can help to support capacity building, generate new research questions, and broaden understanding and knowledge for all involved (Colquhoun et al., 2013). Moreover, well-established research partnerships can result in research that helps to eliminate health disparities that may exist in the communities, as partnerships can both facilitate the use of culturally relevant research designs and methodologies, and be more responsive to the concerns of the community (Cochran et al., 2008).

Health directors and researchers in this study cited limited financial resources as another obstacle to operationalizing the relationships they wanted. Meadows et al. (2003), writing about the challenges of conducting ethical research with Indigenous communities, have argued that it is important for researchers to budget adequate funds to allow this relational approach to emerge. Funding is needed, for example, to support engagement with the community, to hire community members to support data collection and analysis, to report findings to the communities, and to provide honoraria to participants and advisory committees. Brant Castellano and Reading (2010) have noted that, while the TCPS2 is not principally concerned with funding, it has been adopted by the Tri-Council and thus Canada's three research-funding agencies must ensure that their funding policies align with TCPS2's ethical requirements. Furthermore, they have argued that, while academic institutions receive "indirect"

funding to alleviate the administrative costs of research, Indigenous communities do not see even a portion of these resources. As such, Brant Castellano and Reading recommend that researchers (Indigenous and non-Indigenous), institutional leaders, and professional organizations push the Tri-Council to make available funding that would allow for ethical research that is in accordance with the TCPS2. From our findings, we would add that it is critical to ensure not only that funding policies fit the Tri-Council's ethical requirements, but also that those policies are operationalized and understood by REB members and financial services administrators in ways commensurate with ethical approaches to research involving Indigenous communities. Indeed, such understanding—between researchers, institutional leaders and employees, and the Indigenous communities with whom they work—is necessary to achieving ethical programs of research that include Indigenous control and participation.

Capacity as a Barrier to Ethical Research in Mi'kmaw Communities

Challenges accompany the positive aspects of these research collaborations. Limited capacity in Mi'kmaw communities to fully engage in research processes is problematic in the context of operationalizing the TCPS2. Our findings show that, although communities want more control of research, they are not always able to achieve an appropriate level of control. Health directors noted that either they did not have the specialized (i.e., Western) knowledge or skills necessary to be meaningfully involved, or they had too many other demands on their time to be fully engaged. Capacity building was a key concern for them, and they explained that ways to support such capacity building needed to be available (e.g., through community training in health professions and health research, hiring community members as research staff through researchers' funding awards, and integrative health knowledge translation). Indeed, research training for community health staff, for example, can build communities' capacities to undertake projects of their own in the future, but it can also ensure an ongoing awareness of ethical research practices and thereby create environments wherein communities are more likely to recognize and intervene in unethical research practices that they see occurring in their communities. While capacity building does not guarantee that research projects will achieve their stated goals (Bull, 2010), it does increase the likelihood that research will provide meaningful benefits for communities.

Although Mi'kmaw communities want to initiate research projects and have more control over them, our data from researchers and health directors revealed that much research continues to be conducted by non-Indigenous researchers working with communities. In Canada, initiatives such as the Aboriginal Capacity and Developmental Research Environments (ACADRE) and the Network Environments for Aboriginal Health Research (NEAHR) programs,⁶ both of which have now ended, were introduced in part to increase the number of Indigenous researchers in academia; yet in Nova Scotia (and Canada more broadly), there remains a shortage of university-trained Indigenous researchers who are available to participate in or co-lead research with communities (Richmond et al., 2013). A re-organized focus on supporting the capacity of Mi'kmaw and other Indigenous communities in research is needed so that communities can participate in and control research in their communities. In order to build that capacity at the regional and national levels, additional funding is needed (Richmond et al., 2013) and,

⁶ ACADRE centers were established across Canada in 2001 by the Institute of Aboriginal Peoples Health of CIHR to facilitate Aboriginal capacity in health research. The program ended in 2007, and the NEAHR program was launched in 2007 to sustain the momentum of the ACADRE program. Its funding was cut in 2014.

while CIHR is in the process of developing new Indigenous Mentorship Network Programs in Canada, it has less financial resources than its predecessors did.

Understanding Each Other's Lived Realities in the Context of TCPS2

In Canada, Bull (2010), Brunger and Russell (2015), Brunger and Wall (2016), Stiegman and Castleden (2015), and others have begun to explore the unintended consequences of operationalizing the TCPS2 in Indigenous research; collectively, their findings point to the risk of potentially perpetuating colonial relationships. As Brunger and Wall (2016) have stated, “community engagement—if done uncritically and in the service of ethical guidelines rather than in service to ethical research—can itself cause harm” (p. 1862). To counteract this, Indigenous communities and organizations have created their own policies to guide the ethical conduct of research in their communities or territories (e.g., the Mi'kmaw Ethics Watch, the NunatuKavut Community Council Research Advisory Committee, the Kahnawake Schools Diabetes Prevention Project's Code of Research Ethics, and the First Nations Information Governance Centre's OCAP® Principles⁷). However, even with these checks and balances, our findings indicate that understandings between communities and campuses, and within and across campus jurisdictions, are necessary to better understand the nuances of ethical Indigenous research and the disconnects between policy(ies) and practice(s).

The focus group with health directors revealed that they have a limited understanding of the university-based policies and procedures that inform academic research practice, and this limited understanding was mirrored by REB representatives and financial service administrators interviewees, who noted that they did not understand the realities of being a part of, or working with, Mi'kmaw communities. This was further evidenced by the interviews with researchers, wherein they shared the common perception that many REB members did not fully understand the tenets of community-based participatory Indigenous research and that financial services administrators had neither sufficient awareness of Mi'kmaw communities nor understanding what ethical research meant in the context of working with Indigenous communities. If financial services administrators who are responsible for ensuring appropriate spending on research grants at the universities do not understand what ethical research in Indigenous spaces entails, then they may be less likely to approve requests that support ethical research. For instance, the Tri-Council's financial policy indicates that “costs of entertainment, hospitality and gifts, other than those specified above such as regular interactions with colleagues from the institution and personnel meetings” are ineligible expenses (CIHR et al., 2016, Non-Eligible Expenses section, para. 2). Yet, Chapter 9 recognizes that there is a “need to respect a community's cultural traditions, customs and codes of practice [in] First Nations, Inuit and Métis communities” (CIHR et al., 2014, p. 110) and it “is not intended to override or replace ethical guidance offered by Aboriginal peoples themselves” (p. 109). Thus, a researcher purchasing tobacco for ceremonial purposes or providing door prizes at a community dinner would be acting in accordance with the latter policy, but not the former. Chapter 9 also states, “Development and participation costs incurred by the community and the researcher should be factored into proposals *to the extent possible within funding guidelines* [emphasis added]” (CIHR et al., 2014, p. 127). The practice of gift-giving, whether for ceremony or for community events, is

⁷ OCAP®, which stands for Ownership, Control, Access, and Possession, is a registered trademark of the First Nations Information Governance Centre (FNIGC) (for details see www.FNIGC.ca/OCAP).

common in Mi'kmaw and other Indigenous communities and explicit acknowledgement of such practices by funding guidelines, universities, and the policies that regulate how researchers' grant funds are spent would support ethical Indigenous research.

The financial services administrators who participated in this study indicated that one of the main reasons why they were inflexible regarding grant administration was that they were apprehensive about being audited by the Tri-Council and that being in "good standing" with the Tri-Council was very important to them. Therefore, there could be a problem with the institutional relationship between financial services administrators and researchers, insofar as both parties appear to misunderstand what the other does, what motivates them, and what their ethics protocols are.

In terms of the REB process, requiring detailed work plans before research begins (i.e., the REB review) could also dissuade Mi'kmaw participation because, if plans are pre-determined, then their ability to have more control over the research is immediately diminished. Moreover, they might regard their lack of involvement in decision-making as disrespectful and certainly not indicative of collaborative research (Stiegman & Castleden, 2015). Notwithstanding REB reviews or the Chapter 9 articles about community engagement, the degree of a community's involvement with a given research project should be decided by the participating community, and "forcing" community engagement can reduce the effectiveness of research, create an unethical space, and result in barriers to future research with the community.

Finally, and perhaps most importantly, not providing accommodations in ethics reviews—by, for example, including someone on the REB with lived Indigenous experience or with a good understanding of Indigenous issues and concerns and relevant methodologies—could jeopardize the ethical conduct of research in Mi'kmaw (and other Indigenous) communities. For instance, approving ethics applications without an understanding of the complexities of life in a particular Mi'kmaw community could result in harm to that community. Likewise, there could be political ramifications for those partnering in research in some of the communities. Chapter 9 recommends that when ethics applications regularly involve Indigenous communities, the REB membership should be modified to ensure that someone on the board has a strong understanding of Indigenous cultures and customs; our recommendations below suggest going beyond such token representation. In any case, this general lack of knowledge about the life circumstances of those living in Mi'kmaw communities and/or about community-based participatory Indigenous research could limit the participation of Mi'kmaw people in research projects. They may not agree to partner on a project because they do not want to or are unable to complete lengthy and complicated procedures that do not align with their cultural protocols.

Policy Recommendations

In light of our findings, we offer six modest recommendations to continue expanding on the gains that have been made in reconciling academic approaches to Indigenous research:

1. Additional time and financial resources should be written into Tri-Council and other funding opportunities and project timelines and budgets to account for relational approaches to ethical Indigenous research practice;

2. Institutions should receive training on Chapter 9 of the TCPS2 that targets REB members, financial service administrators, faculty, and students who have no lived experience in Indigenous communities but are interested in developing research programs in the area;
3. Creation of institutionally-based standing sub-committees of knowledge holders to advise REBs when proposals involving Indigenous communities are being reviewed;
4. Clarify text and provide substantive examples of how Chapter 9 articles could be applied in Indigenous research (beyond those provided in the TCPS2 Course on Research Ethics' Tutorial);
5. The Tri-Council should review their financial policies (e.g., allowable expenses) to ensure that they are compliant with Chapter 9; and
6. The Tri-Council should make funding available to support capacity building and mentorship so that Indigenous communities can participate in and control the research undertaken in their communities and throughout their traditional territories (see Kershaw, Castleden, & Laroque, 2014).

Concluding Comments

Chapter 9 of the TCPS2 has contributed to positive change in how academic research in Nova Scotia Mi'kmaw communities is undertaken. On the one hand, these communities and others like them are seeking more control over research that is relevant to and done in their communities, and the Chapter 9 articles support that increased control. On the other hand, however, the implementation of a relational approach to ethical research is dependent upon pre-existing relationships between researchers and these communities (whether the parties were intimately familiar with the TCPS2 or not). Our study revealed several institutional and community-based challenges related to Chapter 9 and noted some of the barriers that could impact ethical research in Mi'kmaw communities: limited community capacity, limited community resources, and limited awareness and clarity regarding the articles themselves among researchers and within universities.

Our findings contribute to the literature on the ethics of academic research involving Indigenous Peoples by highlighting the gains and unintended consequences of this national policy. For those researchers, health directors, and others working with Mi'kmaw communities, our findings provide new insights into what they must consider before engaging in research relationships. For those working in the area of Indigenous research ethics, our findings can be used in efforts to reform policy to ensure it works towards ethical practice—from Mi'kmaq and other Indigenous perspectives. Most importantly, collaborative research like community-based participatory research supports both the autonomy of Indigenous Peoples and their abilities to ask the right questions and find their own solutions to their communities' challenges. The barriers that were identified in our research are not insurmountable; with political will from the academy and with guidance from Indigenous community health and research leaders, solutions to these barriers can be achieved.

References

- Agnew, N. M., & Pyke, S. W. (2007). *The science game*. Don Mills, ON: Oxford University Press.
- Ball, J., & Janyst, P. (2008). Enacting research ethics in partnerships with Indigenous communities in Canada: "Do it in a good way." *Journal of Empirical Research on Human Research Ethics*, 3(2), 33-51. doi: <http://doi.org/10.1525/jer.2008.3.2.33>
- Baxter, J., & Eyles, J. (1997). Evaluating qualitative research in social geography: Establishing 'rigor' in interview analysis. *Transactions: Institute of British Geographers*, 22(4), 505-525. doi: <http://doi.org/10.1525/jer.2008.3.2.3310.1111/j.0020-2754.1997.00505.x>
- Bharadwaj, L. (2014). A framework for building research partnerships with First Nations communities. *Environmental Health Insights*, 8, 15-25. doi: <http://doi.org/10.4137/EHIS10869>
- Blodgett, A. T., Schinke, R. J., Smith, B., Peltier, D., & Pheasant, C. (2011). In Indigenous words: Exploring vignettes as a narrative strategy for presenting the research voices of Aboriginal community members. *Qualitative Inquiry*, 17(6), 522-533. doi: <http://doi.org/10.1177/1077800411409885>
- Brant Castellano, M. (2004). Ethics of Aboriginal research. *Journal of Aboriginal Health*, 1(2), 98-114.
- Brant Castellano, M., & Reading, J. (2010). Policy writing as dialogue: Drafting an Aboriginal chapter for Canada's Tri-council Policy Statement: Ethical Conduct for Research Involving Humans. *International Indigenous Policy Journal*, 1(2). doi: <http://doi.org/10.18584/iipj.2010.1.2.1>
- Brunger, F., & Russell, T. (2015). Risk and representation in research ethics: The NunatuKavut experience. *Journal of Empirical Research on Human Research Ethics*, 10(4), 368-379. doi: <http://doi.org/10.1177/1556264615599687>
- Brunger, F., & Wall, D. (2016). "What do they really mean by partnerships?" Questioning the unquestionable good in ethics guidelines promoting community engagement in Indigenous health research. *Qualitative Health Research*, 26(13), 1862-1877. doi: <http://doi.org/10.1177/1049732316649158>
- Bull, J. (2010). Research with Aboriginal Peoples: Authentic relationships as a precursor to ethical research. *Journal of Empirical Research on Human Research Ethics*, 5(4), 13-22. doi: <http://doi.org/10.1525/jer.2010.5.4.13>
- Canadian Institutes of Health Research (CIHR). (2007). *CIHR guidelines for health research involving Aboriginal People*. Retrieved from <http://www.cihr-irsc.gc.ca/e/29134.html>
- Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC). (1998). *Tri-Council policy statement: Ethical conduct for research involving humans* (TCPS). Retrieved from <http://www.pre.ethics.gc.ca/eng/archives/tcps-eptc/Default/>

- Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC). (2010). *Tri-Council policy statement: Ethical conduct for research involving humans* (TCPS2). Retrieved from <http://www.pre.ethics.gc.ca/eng/archives/tcps2-eptc2-2010/Default/>
- Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC). (2014). *Tri-Council policy statement: Ethical conduct for research involving humans* (TCPS2). Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf
- Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC). (2016). *2016 Tri-Agency financial administration guide*. Retrieved from http://www.nserc-crsng.gc.ca/Professors-Professeurs/FinancialAdminGuide-GuideAdminFinancier/index_eng.asp
- Castleden, H., Garvin, T., & Huu-ay-aht First Nation. (2008). Modifying photovoice for community-based participatory Indigenous research. *Social Science & Medicine*, 66(6), 1393-1405. doi: <http://doi.org/10.1016/j.socscimed.2007.11.030>
- Castleden, H., Sloan Morgan, V., & Lamb, C. (2012). "I spent the first year drinking tea": Exploring Canadian university researchers' perspectives on community-based participatory research involving Indigenous Peoples. *The Canadian Geographer*, 56(2), 160-179. doi: <http://doi.org/10.1111/j.1541-0064.2012.00432.x>
- Castleden, H., Sylvestre, P., Martin, D., & McNally, M. (2015). "I don't think that any peer review committee . . . would ever 'get' what I currently do": How institutional metrics for success and merit risk perpetuating the (re)production of colonial relationships in community-based participatory research involving Indigenous Peoples in Canada. *International Indigenous Policy Journal*, 6(4). doi: <http://doi.org/10.18584/iipj.2015.6.4.2>
- Chace, M. J. (2013). *Evaluating intended and unintended consequences of health policy and regulation in vulnerable populations* (Doctoral dissertation). Retrieved from <https://dash.harvard.edu/handle/1/10423843>
- Cochran, P. A. L., Marshall, C. A., Garcia-Downing, C., Kendall, E., Cook, D., McCubbin, L., & Gover, R. M. S. (2008). Indigenous ways of knowing: Implications for participatory research and community. *American Journal of Public Health*, 98(1), 22-27. doi: <http://doi.org/10.2105/AJPH.2006.093641>
- Colquhoun, S. M., Carapetis, J. R., Kado, J. H., Reeves, B. M., Remenyi, B., May, W., . . . & Steer, A. C. (2013). Pilot study of nurse-led rheumatic heart disease echocardiography screening in Fiji: A novel approach in a resource-poor setting. *Cardiology in the Young*, 23(4), 546-552. doi: <http://doi.org/10.1017/S1047951112001321>

- Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed-methods approaches*. Thousand Oaks, CA: Sage Publications, Inc.
- Ebenstein, A. (2010). The “missing girls” of China and the unintended consequences of the one child policy. *Journal of Human Resources*, 45(1), 87-115. doi: <http://doi.org/10.3368/jhr.45.1.87>
- First Nations Information Governance Centre (FNIGC). (2017). *The First Nations principles of OCAP®*. Retrieved from <http://fnigc.ca/ocap.html>
- Kershaw, G. G. L., Castleden, H., & Laroque, C. P. (2014). An argument for ethical physical geography research on Indigenous landscapes in Canada. *The Canadian Geographer*, 58(4), 393-399. doi: <http://doi.org/10.1111/cag.12092>
- Kot, M., Castleden, H., & Gagnon, G. A. (2011). Unintended consequences of regulating drinking water in rural Canadian communities: Examples from Atlantic Canada. *Health & Place*, 17(5), 1030-1037. doi: <http://doi.org/10.1016/j.healthplace.2011.06.012>
- Meadows, L. M., Lagendyk, L. E., Thurston, W. E., & Eisener, A. C. (2003). Balancing culture, ethics, and methods in qualitative health research with Aboriginal Peoples. *International Journal of Qualitative Methods*, 2(4), 1-14.
- Namaste, V., & Jauffret, P. (2006). Negotiating partnership and ownership in community-based research: Lessons from a needle exchange in Montréal. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*, 1, 65-74.
- Neuman, W. L., & Robson, K. (2009). *Basics of social research*. Toronto, ON: Pearson, Allyn and Bacon.
- Patterson, M., Jackson, R., & Edwards, N. (2006). Ethics in Aboriginal research: Comments on paradigms, process and two worlds. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*, 1, 47-61.
- Piquemal, N. (2000). Four principles to guide research with Aboriginals. *Policy Options*, 21(10), 49-51.
- Richmond, C., Martin, D., Dean, L., Castleden, H., & Marsden, N. (2013). *Transforming networks: How ACADRE/NEAHR support for graduate students has impacted Aboriginal health research in Canada*. Retrieved from <http://hdl.handle.net/1828/5419>
- Schnarch, B. (2004). Ownership, Control, Access, and Possession (OCAP®) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, 1(1). Retrieved from http://www.naho.ca/jah/english/jah01_01/journal_p80-95.pdf
- Smith, L. T. (1999). *Decolonizing methodologies: Research and Indigenous Peoples*. New York: Zed Books.

- Stiegman, M. L., & Castleden, H. (2015). Leashes and lies: Navigating the colonial tensions of institutional ethics of research involving Indigenous Peoples in Canada. *The International Indigenous Policy Journal*, 6(3). doi: <https://doi.org/10.18584/iipj.2015.6.3.2>
- Taniguchi, N. K., Taulii, M., & Maddock, J. (2012). A comparative analysis of Indigenous research guidelines to inform genomic research in Indigenous communities. *The International Indigenous Policy Journal*, 3(1), 1-23. doi: <https://doi.org/10.18584/iipj.2012.3.1.6>
- Weir, W. & Wuttunee, W. (2004). Respectful research in Aboriginal communities and institutions in Canada. In B. Fairburn & N. Russell (Eds.), *Cooperative membership and globalization* (pp. 207-236). Saskatoon: Centre for the Study of Co-operatives, University of Saskatchewan.