

IMPLEMENTING CHAPTER 9 OF THE TRI-COUNCIL POLICY STATEMENT ON
THE ETHICS OF RESEARCH INVOLVING ABORIGINAL PEOPLES IN CANADA:
HOW'S THAT GOING?

by

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ABSTRACT

The second edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans was introduced in 2010 along with Chapter 9, titled ‘Research Involving the First Nations, Inuit and Métis Peoples of Canada’. The goal of this study was to explore how Chapter 9 is implemented and adhered to in research involving Mi’kmaq communities in Nova Scotia. Interviews with health researchers, research ethics board representatives, financial services administrators and health directors working in Mi’kmaq communities revealed that researchers who worked with Mi’kmaq communities adhered to Chapter 9, Mi’kmaq communities wanted more control of research, Mi’kmaq communities lacked capacity to participate fully in research, health directors and financial services administrators had limited knowledge of Chapter 9, research ethics board representatives and financial services administrators lacked an understanding of research in Mi’kmaq communities, and research ethics board representatives and researchers found Chapter 9 vague. Recommendations to reduce barriers are included.

LIST OF ABBREVIATIONS USED

AAHRP	Atlantic Aboriginal Health Research Program
ACADRE	Aboriginal Capacity and Developmental Research Environments
CBPR	Community-Based Participatory Research
CIHR	Canadian Institutes of Health Research
CRT	Critical Race Theory
CV	Curricular Vitae
FSA	Financial Services Administrator
HD	Health Director
HR	Health Researcher
IAPH	Institute of Aboriginal Peoples Health
MEW	Mi'kmaw Ethics Watch
MHRG	Mi'kmaq Health Research Group
NAHO	National Aboriginal Health Organization
NEAHR	Network Environments for Aboriginal Health Research
NSERC	Natural Sciences and Engineering Research Council of Canada
OCAP™	Ownership, Control, Access, Possession
PAR	Participatory Action Research
REB	Research Ethics Board
SSHRC	Social Sciences and Humanities Research Council
TCPS	Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (1 st ed)
TCPS2	Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2 nd ed)
UNSI	Union of Nova Scotia Indians

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CHAPTER 1 INTRODUCTION

1.1 EXAMINING THE IMPACT OF THE TCPS2 ON MI'KMAQ COMMUNITIES IN NOVA SCOTIA

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 the joint policy on what constitutes ethical research involving humans in the second edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. It is often referred to as the TCPS2. The Tri-Council also introduced a new chapter dealing exclusively with research involving First Nations, Inuit and Métis peoples in Canada as the previous 1998 Tri-Council Policy Statement (TCPS) was viewed by many as inadequate (Taniguchi, Taulii, & Maddock, 2012). This Chapter 9 serves as a framework for the ethical conduct of research that involves Aboriginal¹ people and communities and aims to ensure that research involving Aboriginal people is premised on respectful relationships, collaboration and engagement between researchers and participants (CIHR, NSERC, & SSHRC, 2010). The newest edition of the TCPS2 (2014) has replaced the TCPS2 (2010), but no new changes were made to Chapter 9 (CIHR, NSERC, & SSHRC, 2014). The purpose of this Master's research is to examine the impact of Chapter 9 of the TCPS2 on research in Mi'kmaq² communities in Nova Scotia, and identify any barriers to its application that could jeopardize ethical research in these communities.

¹ I use the word 'Aboriginal' when referring to First Nations, Métis and Inuit of Canada.

² I use 'Mi'kmaq' as plural or a noun and 'Mi'kmaq' as the singular of 'Mi'kmaq' or as an adjective.

1.2 BACKGROUND OF THE PROBLEM

Principles of ethical research involving Indigenous³ communities⁴ include the overarching idea that 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). Ethical research is more than informing participants about their rights in the research process – it is about involving them in all aspects of the research process. That is, Indigenous participants 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).

Historically, research involving Aboriginal people in Canada as well as other Indigenous people worldwide has exploited, misrepresented and pathologized them (Ball & Janyst, 2008; Castleden, Sloan Morgan, & Lamb, 2012). The colonization of Indigenous people was justified by research through scientific theories that 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 research of the past been harmful to Indigenous communities, it has not reflected Indigenous world views (Brant Castellano, 2004). The result of exploitative, culturally insensitive, and frequently one-sided research

³ I used the word ‘Indigenous’ when referring to First Peoples inside or outside of Canada, sometimes interchangeably with Aboriginal.

⁴ I use ‘communities’ to denote ‘community (s)/organization (s)/group (s)’ as Aboriginal research can involve any one of these designations.

is that Aboriginal communities tend to regard academic research with a certain degree of mistrust or apprehension (CIHR, NSERC, & SSHRC, 2010; Cochran et al., 2008).

Most research that has involved Aboriginal people and communities in Canada has been designed and implemented by non-Aboriginal researchers and continues today to be led mainly by non-Aboriginal investigators (Ball & Janyst, 2008; Castleden, Sloan Morgan, & Lamb, 2012; CIHR, NSERC, & SSHRC, 2010). It has often done more to serve the needs of western-trained, non-Indigenous academics than the Indigenous communities, and has perpetuated the dominant culture's view that it is the centre of legitimate knowledge (Blodgett, Schinke, Smith, Peltier, & Pheasant, 2011). Research involving Indigenous peoples has also often failed to transfer skills and knowledge to them (Bharadwaj, 2014).

Research with Aboriginal peoples is, however, evolving over time. In response to the refrain that 'we have been researched to death', Aboriginal people who recognize that research can be useful are now saying that we need to 'research ourselves to life' (Brant Castellano, 2011). Indigenous communities are becoming better informed about the risks and benefits of research (CIHR, NSERC, & SSHRC, 2010). Gone are the days when Indigenous people participated in research as subjects to produce knowledge for the 'greater good', or for the benefit of the researchers doing the research – today their participation must directly benefit them in one way or another (Ball & Janyst, 2008).

Methodological research approaches that are compatible with Aboriginal ways of knowing, such as community-based participatory research (CBPR), where research participants are equally involved in defining the research question and in data collection,

analysis and dissemination, have become more widely adopted in research with Aboriginal people to help balance power among those involved (Castleden, Garvin, & Huu-ay-aht First Nation, 2008). International guidelines for ethical research involving Indigenous people recommend the use of research approaches like CBPR and participatory action research (PAR) because they involve power sharing and decision-making among collaborators, the research is more culturally sensitive, and Indigenous communities are encouraged to lead and implement the research process (Jack, Brooks, Furgal, & Dobbins, 2010). Not only do such approaches help to create more equitable research relationships, they also help to increase the validity and reliability of research findings, both of which improve the utility of the study's conclusions (Brant Castellano, 2004; Cochran et al., 2008). Culturally sensitive and community-driven research can help to ensure that it meets the needs of the community.

Researchers engaged in health research are also becoming increasingly aware that research collaborations are necessary to enhance the impact of that research on public health (Colquhoun, Geary, & Goodman, 2013). Ethical research collaborations with Aboriginal communities are essential to finding ways to reduce their health disparities. Research deemed unethical by Aboriginal communities, such as Dr. R. H. Ward's research with the Nuu-chah-nulth First Nation in B.C., as described in Taniguchi et al., (2012), jeopardizes the credibility of the research and thus its usefulness, as well as puts at risk future access to those communities (Piquemal, 2000). To advance ethical research with Aboriginal communities, researchers and their institutions have to be supportive of Aboriginal communities' desire to take control of research that affects them (Patterson, Jackson, & Edwards, 2006). Furthermore, they must respect the cultural norms and

ethical obligations of knowledge transfer such as gifts or honoraria for Elders or knowledge-holders participating in research (Brant Castellano, 2004; Castleden et al., 2012), and the rights of these communities to be active participants in the research process from its design to implementation of findings and publication of results.

Supporting the Aboriginal communities' aspirations for more control and involvement in research, however, can lead to challenges. For example, the time commitment on the part of community representatives, who are often already over-committed, is a challenge (Patterson et al., 2006). Additionally, some Aboriginal communities will insist on ownership of the research, including the results and right to publication (Patterson et al., 2006). This of course, challenges long-standing institutional policies that say that the university or researcher is the owner of intellectual property (Patterson et al., 2006). Researchers having to relinquish the role of principal investigator and take directions about priorities from the community so that meaningful collaboration can exist are also challenges (Cochran et al., 2008). Another challenge to respectful ethical research partnerships with Aboriginal communities is that funding agencies do not typically provide sufficient funds at the start of a project for partnership building (Bull, 2010). The participation of the Aboriginal community in decisions about the research plan may not be possible without the provision of funds for them to attend planning meetings because individuals may not have money to travel, or the partnering organization may not have funds in the budget for its representatives to travel. The money to travel is typically provided only after a research proposal has been funded (Ball & Janyst, 2008).

Other institutional barriers to partnership research include: institutional timeframes which may not be respectful of Aboriginal community timeframes where other competing priorities may delay them from responding to research activities in a timely manner, the hiring of research staff by institutions rather than by the Aboriginal community, the control of the research product by the researcher's institution to meet faculty publications, and the flow of research funds to the institution rather than to the Aboriginal community (Stoecker, 2009). Such current institutional practices are not conducive to respectful research collaboration with Aboriginal communities and need to be challenged.

1.3 STATEMENT OF THE PROBLEM

Challenging institutional and other barriers to ethical research with Aboriginal people is essential in order for ethical research to proceed. Furthermore, when such challenges remain unresolved, there is the danger that Aboriginal communities will again decline participation in research (Brant Castellano, 2004). Documenting these challenges and subsequent solutions is needed so that institutions, researchers, and Aboriginal communities have a better idea of what comprises ethical research with Aboriginal communities and what can be done to ensure that it is ethical. As there is a lack of information about how the various articles in Chapter 9 are applied in health research involving Mi'kmaq communities in Nova Scotia, it was important to hear from community health directors, researchers, research ethics board (REB) representatives and university administrators about how they understood and used the chapter to determine if ethical research was being conducted with these communities. By describing how Chapter 9 is applied in research with Mi'kmaq communities, and by identifying

subsequent obstacles, it is anticipated that researchers, research ethics boards, and those working with the communities will have a better understanding of what is needed to better support ethical research with these communities. Furthermore, documenting the benefits and challenges of applying the Chapter 9 articles of the TCPS2 in research with Aboriginal people/communities like the Mi'kmaq of Nova Scotia would provide information about how to do research 'in a good way' (Ball & Janyst, 2008). Doing research in a good way – that is, collaboratively, respectfully and ethically – could help to ensure that research is effective and therefore, better able to address health inequities in Aboriginal communities.

1.4 PURPOSE OF THE STUDY

The goal of this qualitative study was to explore, through qualitative methods (i.e. semi-structured in-depth interviews and a focus group), how health researchers, REB representatives, and university financial services administrators based at four universities in Nova Scotia, as well as health directors working in Mi'kmaq communities in Nova Scotia interpreted, applied and experienced the Chapter 9 articles of the TCPS2 and to identify obstacles in applying Chapter 9 in research involving these Mi'kmaq communities. The participants were selected through purposive and/or snowball sampling.

1.5 SIGNIFICANCE OF THE STUDY

This Master's research was important because discerning how Mi'kmaq community health directors, university-based researchers, REB representatives, and university financial services administrators interpreted and implemented Chapter 9 of the

TCPS2 provided information about what constituted ethical/unethical research practices in these Mi'kmaq communities. New knowledge about the application of the TCPS2 in research with Mi'kmaq communities is important as it can give researchers, the Mi'kmaq community participants, and others working in Mi'kmaq communities some of the information they need to better support ethical research.

Moreover, the application of Chapter 9 of the TCPS2 in research with Mi'kmaq communities was studied because identifying ethical research practices could better help Nova Scotia Mi'kmaq communities and health researchers collaborate in research that is useful to the communities. For example, by interviewing the community health directors about whether researchers include them in all aspects of the research process, from identifying the research questions/s to disseminating the results at the end, practices that support collaborative research can be revealed. Identifying ethical research practices, such as ways that support collaborative research, could lead to research that helps find relevant solutions (e.g. interventions) to health inequities that exist in these communities, as research shows that there is a “disproportionate burden of ill health and social suffering upon the Aboriginal populations of Canada” (Adelson, 2005, p. S45).

In Nova Scotia, for example, the Regional Health Survey⁵ data collected in 2002-2003 showed that 20 percent of adult men and women living on reserve in the province reported having diabetes, whereas just 6 percent of the general Nova Scotia population reported the same (Mi'kmaq Health Research Group (MHRG), 2007). The asthma rate for the on reserve Mi'kmaq children in the province at the time of this survey was 13

⁵ The First Nations Regional Health Survey, also known as the FNRHS or RHS, gathers health and wellness information about the on-reserve and northern First Nations communities in Canada.

percent, compared to less than 9 percent for Canadian children (MHRG, 2007). Mi'kmaq mothers who smoked during their pregnancy in the 2008/10 version of the regional health survey was 56.3% and for Canadian mothers in the general population at the same time, it was 10.5% (UNSI, 2012).

By revealing how Chapter 9 is interpreted and applied in research with the Mi'kmaq communities and identifying ethical research practices and barriers in research involving these communities, researchers, financial services administrators and REB members can be equipped with information that helps them to better support ethical research in these communities. Lastly, the findings associated with participant data could be used to improve Chapter 9 of the TCPS2 in future iterations to ensure that its contents support ethical research with Aboriginal people.

1.6 RESEARCH QUESTIONS

The overarching goal of this study was to explore how health researchers, REB representatives, and university financial services administrators based at four universities in Nova Scotia, and health directors working in Mi'kmaq communities in Nova Scotia interpreted, applied and experienced the Chapter 9 articles of the TCPS2 and to identify obstacles in applying Chapter 9 in research involving these Mi'kmaq communities. To achieve this goal, four key objectives were identified: 1. Examine how health researchers applied the Chapter 9 articles of the TCPS2 policy in their research with Mi'kmaq communities in Nova Scotia and how health directors viewed their research practices; 2. Explore whether the articles in Chapter 9 of the TCPS2 policy were adhered to when doing research with Mi'kmaq communities in Nova Scotia, by interviewing researchers about their research experiences, health directors about researchers' practices, REB

representatives about proposal reviews, and financial services administrators about their administration of research grants; 3. Identify challenges/barriers to the implementation of articles in Chapter 9 of the TCPS2 in research with Nova Scotia Mi'kmaq communities by interviewing health researchers, health directors, REB representatives and financial services administrators about issues that arose in research collaboration, proposal review, and grant administration; and 4. Propose recommendations that could be used by Mi'kmaq communities, university research ethics boards, financial services administrators, and researchers to support the improved uptake of ethical research practices in the Mi'kmaq communities. I anticipated that the objectives outlined above would help to illuminate how some of the Chapter 9 articles (i.e. those discussed by participants) were being used in research with Mi'kmaq communities in Nova Scotia, what barriers to ethical research in the communities existed, and ways in which Chapter 9 and the uptake of ethical research could be improved in Mi'kmaq communities.

1.7 RESEARCH DESIGN

The data for this exploratory study were collected using qualitative methods (i.e. semi-structured in-depth interviews and a focus group), as I felt that these were the best way to hear from health directors, health researchers, REB representatives and financial services administrators about their thoughts and experiences concerning Chapter 9 of the TCPS2 and about ethical/unethical research practices in Nova Scotia Mi'kmaq communities. The health directors were interviewed using a focus group and the remaining participants were interviewed using semi-structured interviews.

In an exploratory study, the researcher examines a new or emerging area to frame particular questions that can be used for future research (Neuman & Robson, 2009).

Qualitative interviews are conducted with a selection of people to gain an in-depth understanding of the topic of study; a focus group has a similar purpose to the qualitative interview except that it is done with a group of people at one time (Neuman & Robson, 2009).

Information gathered about Chapter 9 by those who were impacted by it and by those who interpreted and applied the information outlined in the chapter helped to identify ways that the policy worked and ways in which it could be improved. The findings and recommendations could help the Tri-Council improve the chapter, although they are specific to the participating Mi'kmaq communities. Research ethics boards, financial services administrators, researchers and Mi'kmaq communities/organizations here in Nova Scotia could use the information so that ethical research is better supported in Nova Scotia Mi'kmaq communities.

1.8 THEORETICAL FRAMEWORK

This study was inspired in part by critical race theory (CRT) that focuses attention on race and how racism is deeply embedded in society. Using CRT, the researcher foregrounds race and racism in all research processes, challenges traditional research paradigms, and recommends solutions to racial, class and gender subordination in societal and institutional structures (Creswell, 2007). While I did not use CRT in this study, the tenets underlying CRT, particularly the notion that traditional western research paradigms, texts and theories should be challenged in research with Aboriginal people, influenced my decision to study the impacts of the TCPS2 on research with Mi'kmaq people in Nova Scotia. It appears that Chapter 9 represents a challenge to the mainstream model of undertaking research and that raises questions about how it is being

implemented, whether it is making a difference in how research is conducted in Mi'kmaq communities, and what barriers are encountered.

I also view my research through the lens of decolonizing approaches and methodologies, which involves dismantling the barriers created through Western-centric Institutions and deconstructing Western scholarship by placing emphasis on how Indigenous people gather knowledge (Smith, 1999). Much like participatory action research, decolonizing methodologies such as Indigenous Methodologies provide an alternative to “dominant positivistic research paradigms”, and are meant to “give voice and prominence to communities previously marginalized in research practices” (Evans, Hole, Berg, Hutchinson, & Sookraj, 2009, p. 894). Indigenous methodologies involves research by and for Indigenous peoples using methods that are drawn from their own traditions (Evans et al., 2009) and aims to place research “under the control of indigenous peoples” (Braun, Browne, Ka'opua, Kim & Makuau, 2013, p. 123). Decolonizing research is not just about the struggle for methods that support Indigenous worldviews, but more about the spaces that make such research possible (Zavala, 2013). It also involves eliminating any barriers at the university and funding levels that could jeopardize the conduct of ethical research in Indigenous communities. That is, policies that promote Mi'kmaq control and self-determination in research are needed so research that is relevant to them can proceed in these communities. As Smith (1999) points out, “research can no longer be conducted with indigenous communities as if their views did not count” (p. 9).

My study contributes to the work of decolonizing the academy, in that the research questions that I explored in this study and my analysis serve to illuminate

institutional barriers that may jeopardize the ethical conduct of research involving Mi'kmaq communities.

Finally, my educational training in health promotion impacts my desire to find ways to improve research practices in Mi'kmaq communities, so that effective solutions to health inequities are found. That is, health promotion's holistic conceptualization of health, its preventative focus, and its support for changes to social and economic conditions as a means to improve health (Mundel and Chapman, 2010) underlie my philosophy about how best to work with Mi'kmaq communities to find solutions to their health concerns. It is the combination of CRT, decolonizing methodologies/research, and health promotion that impacts how I view my research.

1.9 MY POSITIONALITY AS RESEARCHER AND MEMBER OF THE MI'KMAQ NATION

I am personally and professionally connected to this thesis research and to the communities involved. I am the Program Director of the Atlantic Aboriginal Health Research Program (AAHRP)⁶, a member of one of the Nova Scotia Mi'kmaq communities, and I have a genuine concern for the health of people in general, and more specifically, for Aboriginal people in Canada. Through my work experience with AAHRP, as a health policy analyst for the Atlantic Aboriginal communities, as a nutritionist for the Mi'kmaq communities in Nova Scotia, and having grown up in a Mi'kmaq community, I saw how health inequities affected the health of Mi'kmaq in Nova Scotia. Also through my work with AAHRP, I have at times heard complaints from

⁶ AAHRP is one of the Aboriginal Capacity and Developmental Research Environments (ACADRE) centres that were established in 2001 by the Institute of Aboriginal Peoples Health of CIHR across Canada to facilitate Aboriginal capacity in health research. That program ended in 2007. The Network Environments for Aboriginal Health Research (NEAHR) program was launched in 2007 to sustain the momentum of the ACADRE program.

Aboriginal people about how research was conducted in their communities, and how university and funding body policies sometimes resulted in negative research experiences.

Taken together, I identified the need for ethical research practices in the communities that help to address health inequities, and I recognized that documenting what works best in those communities, and in particular, how Chapter 9 of the TCPS2 is working to ensure that ethical research takes place in their communities, is important. The knowledge generated from this thesis research would be useful to researchers and the institutions that govern their actions, as well as Mi'kmaq communities that are affected, either positively or negatively, by the research itself.

1.10 LIMITATIONS OF THIS STUDY

There are limitations in my research including the fact that I did not interview many REB representatives and financial services administrators as the scope of my study was four universities in Nova Scotia and I only wanted to interview those with the most experience from each group. By excluding other REB representatives and financial services administrators at other Nova Scotia universities, I may have omitted some important perspectives related to Chapter 9 and research involving Mi'kmaq communities. Furthermore, data saturation did not seem to happen in the case of the REB representatives or the financial services administrators, possibly because I was not able to recruit as many participants for each of these groups. I also did not interview all 13 health directors working in the Nova Scotia Mi'kmaq communities, as some did not respond to my invitation to participate in the study. Without the input of all health directors of the Nova Scotia Mi'kmaq communities, I may have overlooked perspectives that could have made the findings relevant to all Mi'kmaq communities in the province.

The fewer number of Mi'kmaw community representatives compared to university-based representatives may have created a particular bias in my sample as well.

My lack of experience with focus groups, and a somewhat rigid focus on the interview guide questions may also have resulted in some gaps in knowledge that could have been filled had my experience been greater. I also did not follow up with those I interviewed for clarification purposes due to limited time, although I did provide them with their transcripts so that they could make changes and I shared the preliminary themes with them. Another limitation is that the interviews were conducted by phone – due mainly to my lack of funds for travel and my personal time constraints (I work full-time), the result of which could have impacted the quality of the information shared. I also selected researchers who had more experience in Aboriginal research, but had I selected other researchers with less experience in Aboriginal research, I may have had different results. Finally, the findings are limited to Mi'kmaq communities in Nova Scotia.

1.11 SCOPE OF THIS STUDY

The scope of my study included 7 health directors⁷ working in Nova Scotia Mi'kmaq communities, 9 health researchers who have worked with Mi'kmaq communities in the past, and 3 financial services administrators and 4 REB representatives representing the 4 universities of interest. All participants, excluding one health researcher who had recently moved, were based in Nova Scotia.

⁷ Six of these participants were health directors working in the Mi'kmaq communities in Nova Scotia and one was a health coordinator working for one of the Mi'kmaq provincial territorial organizations in NS. From this point, I refer to all seven participants as 'health directors'.

1.12 SUMMARY OF THIS THESIS

The following thesis includes a literature review of relevant information related to ethics in research involving Aboriginal people (Chapter 2), a detailed explanation of the methods I used for the study (Chapter 3), the findings from the data collected (Chapter 4), a discussion of those findings (Chapter 5), and a discussion of the implications of my research in the conclusion chapter (Chapter 6), including a list of recommendations to improve Chapter 9 and support ethical research in Nova Scotia Mi'kmaq communities.

CHAPTER 2 LITERATURE REVIEW

2.1 UNETHICAL RESEARCH OF THE PAST

The word ‘research’ is “one of the dirtiest words in the indigenous world’s vocabulary” and when mentioned it “stirs up silence, it conjures up bad memories, [and] it raises a smile that is knowing and distrustful” (Smith, 1999, p. 1). Research involving Aboriginal people has often occurred in the context of researchers ‘parachuting’ into their communities, collecting data from them, and leaving without reporting research findings back to the communities, resulting in their resentment and scepticism of research (Castleden et al., 2008). More importantly, research in Aboriginal communities has often caused them harm (CIHR, 2007).

One particularly concerning case of unethical research involved a University of British Columbia researcher, Dr. R.H. Ward⁸, who in the 1980s took blood samples from *consenting* Nuu-chah-nulth participants for an arthritis study. After the study was completed, the same blood samples were moved to other research centres *without* the participants’ consent so that their DNA could be isolated for other studies not authorized in the original agreement (e.g. a genetic anthropology study) (CIHR, 2007; Taniguchi et al., 2012). Their DNA was treated as the researcher’s property and was the source of several other unrelated academic publications without the Nuu-chah-nulth’s consent or knowledge (Stevenson, et al., 2013). It took 20 years for the blood samples to be returned to the community. This unfortunate incident resulted, however, in a positive outcome -

⁸ One of Dr. Ward’s articles using the Nuu-chah-nulth’s DNA without their consent is: Ward et al., (1993). Genetic and linguistic differentiation in the Americas, *PNAS*, 90 (22), 10663-10667.

the development of a community committee to establish rules that future researchers would have to follow if they wanted to do research with the Nuu-chah-nulth (Taniguchi et al., 2012). Another example of unethical research involving Indigenous people occurred in the United States where Arizona State University researchers, in particular, Dr. Therese Markow⁹, took blood samples from *consenting* members of the Havasupai Tribe for a diabetes study and used the samples, *without* consent, to look at human migration patterns, inbreeding and mental illness (Cochran et al., 2008; Taniguchi et al., 2012). This breach of ethics led to a court case against Dr. Markow and the university, resulting in a large settlement to those affected. The many unethical examples of research involving Indigenous people like the Nuu-chah-nulth and the Havasupai have resulted in a high level of anxiety and mistrust among Indigenous people about all forms of research conducted by non-Indigenous academic researchers (Taniguchi et al., 2012).

In response to the unethical research of the past, Indigenous leaders and organizations have called for an end to research being “conducted ‘on’ Indigenous peoples for the benefit of non-Indigenous scholars and agencies without meaningful engagement of Indigenous peoples” (Ball & Janyst, 2008, p. 33). Moreover, researchers who want to work with Indigenous people/communities are now being challenged to recognize that in addition to the need for collaborative research, there are ethical dimensions to their choice of research topic, capacity building opportunities and research dissemination (Ball & Janyst, 2008).

⁹ One of Dr. Markow’s articles using the Havasupai’s DNA without their consent was: Markow, T., Hedrick, P.W., Zuerlein, K., Danilovs, J., Martin, J., Vyvial, T., & Armstrong, C. (1993). HLA polymorphism in the Havasupai: Evidence for balancing selection. *American Journal of Human Genetics*, 53 (4), pp. 943-952.

2.2 RESPONSES TO UNETHICAL RESEARCH OF THE PAST

In recognition that things needed to change with respect to the ways that research was being conducted with Aboriginal and other Indigenous communities, procedures and policies have been developed that put focus on the rights of Aboriginal communities/people in the research process and on what constitutes ethical research with them. Accordingly, several Aboriginal organizations, universities and funding bodies began to produce ethics guidelines, statements, policies and protocols (e.g. NAHO's OCAP™ principles, the Association of Canadian Universities for Northern Studies statements, Mi'kmaw Ethics Watch (MEW), and Kahnawake Schools Diabetes Prevention Project) to minimize harm to Aboriginal communities, while also encouraging a critical examination of unethical research practices (Castleden et al., 2012).

Aboriginal people have sought control of research that affects them through means such as the development of the OCAP™ principles (Schnarch, 2004). The OCAP™ principles refer to ownership, control, access and possession of Aboriginal-generated data. These principles were developed in response to “tenacious colonial approaches to research and information management” by universities, government and industry and offer “a way out of the muddle of contemporary Aboriginal research and the ethical dilemmas that characterize it” (Schnarch, 2004, p. 80). In the past, Aboriginal people were not consulted about what information would be gathered about them, who would gather and maintain that information, and who would have access to that information (Schnarch, 2004). The OCAP™ principles are intended to help prevent these unethical practices from happening yet again by providing information to communities about their rights in knowledge production through research. The OCAP™ principles

also benefit Aboriginal communities in their application through “the rebuilding of trust, improved research quality and relevance, decreased bias, meaningful capacity development, and community empowerment to make change” (Schnarch, 2004, p. 80).

The development of the Mi’kmaw Ethics Watch (MEW) is another example of how Aboriginal people took matters into their own hands in response to unethical research conducted in their communities. In 1999, the Grand Council of the Mi’kmaq¹⁰ mandated the development of an ethics review committee, composed of Mi’kmaq leaders, Mi’kmaq academic researchers, and Mi’kmaq community members, called the Mi’kmaw Ethics Watch, to help protect Mi’kmaq communities and their Indigenous knowledge from unethical researchers. The MEW developed its *Research Principles and Protocols* to “guide research and studies in a manner that will guarantee that the right of ownership rests with the various Mi’kmaq communities” and that “interpretations and conclusions drawn from the research will be subject to approval to ensure accuracy and cultural sensitivity” (MEW, 1999, p. 1).

In addition to these Aboriginal-led responses to unethical research, the Institute of Aboriginal Peoples’ Health of CIHR undertook extensive conversations with Aboriginal people, communities and organizations, and university-based researchers and produced the *CIHR Guidelines for Health Research Involving Aboriginal People* (CIHR, 2007). These guidelines outlined what should be done to conduct ethical research with Aboriginal communities (CIHR, 2007) and incorporated Aboriginal world views to address issues such as partnerships, consent, and benefit sharing (Brant Castellano &

¹⁰ The Grand Council or Sante’ Mawio’mi, is the traditional governing body of the Mi’kmaq Nation.

Reading, 2010). They were also a source of inspiration for Chapter 9 (Research Involving the First Nations, Inuit and Métis Peoples of Canada) of the TCPS2 (CIHR, NSERC, & SSHRC, 2010; Flicker & Worthington, 2012; Taniguchi et al., 2012), which replaced Section 6 of the first edition of the TCPS (1998). Section 6 (Research Involving Aboriginal Peoples) affirmed that Aboriginal people have rights and interests that need to be respected by the research community but it was deemed to be inadequate because the Tri-Council did not have discussions with Aboriginal people about its content (Taniguchi et al., 2012). The CIHR Guidelines were in effect from May 2007 to December 2010, when the TCPS2 replaced it.

Chapter 9 deals exclusively with research involving First Nations, Métis and Inuit of Canada and serves the goal of creating an ethical space where Aboriginal communities in Canada and researchers can collaboratively participate in research that is based on mutual respect and trust, both of which had been lacking in many instances in the past (Brant Castellano & Reading, 2010). Chapter 9 is discussed in more detail below.

2.3 SPECIFICS OF CHAPTER 9 OF THE TCPS2

As stated earlier, the TCPS2 is a joint policy of Canada's three federal research agencies (CIHR, NSERC, SSHRC). Because the TCPS2 is an overarching policy, it has to meet the needs of all three agencies, and is thus written to be broadly applicable to them (Brant Castellano & Reading, 2010). In order for institutions to be eligible for and receive funding from one of the three federal research agencies, they must adhere to the TCPS2. As such, researchers employed by these institutions must also adhere to this policy statement, and institutions must support their efforts to do so (CIHR, NSERC, & SSHRC, 2010). The institutions do so by creating Research Ethics Boards, which are

typically composed of voluntary academic faculty members providing ethical peer review of researchers' proposed research to ensure adherence of the TCPS2.

Chapter 9 of the TCPS2 acknowledges the unique status of Aboriginal peoples of Canada, as affirmed in the Constitution Act of 1982, by interpreting how the core principles of Respect for Persons, Concern for Welfare, and Justice apply to research involving Aboriginal people (CIHR, NSERC, & SSHRC, 2010). Chapter 9 does this specifically by providing guidance to researchers on the ethical conduct of research involving Aboriginal peoples. Moreover, it supports the notion that engagement with the community is integral to ethical research involving Aboriginal peoples (CIHR, NSERC, & SSHRC, 2010).

Chapter 9 includes twenty-two articles and is divided into three main sections: key concepts and definitions; interpreting the ethics framework in Aboriginal contexts; and, applying provisions of the policy in Aboriginal contexts. The specific articles are found in the section about applying provisions of the policy in Aboriginal contexts and are subdivided under different headings such as: requirement of community engagement in Aboriginal research; respect for First Nations, Inuit and Métis governing authorities including their own ethics committees; respect for community customs and codes of practice; research agreements; strengthening research capacity; recognition of the role of Elders and other knowledge holders; and interpretation and dissemination of research results (CIHR, NSERC, & SSHRC, 2010; Flicker & Worthington, 2012). Within the different sub-sections, the policy provides advice to researchers about how to apply each group of related articles in research involving Aboriginal people. For example, article 9.14 addresses the idea that research projects should support capacity building of

Aboriginal communities, and the advice about how to apply this article is that researchers “should foster education and training of community members to enhance their participation in research projects” through things such as employing Aboriginal community members as research assistants (CIHR, NSERC, & SSHRC, 2010, p. 129).

The table below is an abridged version of Chapter 9.

Table 1: Abridged Version of the 22 Articles in Chapter 9 of the TCPS2

<i>Article 1</i>	Where the research is likely to affect the welfare of an Aboriginal community, or communities, to which prospective participants belong, researchers shall seek engagement with the relevant community.
<i>Article 2</i>	The nature and extent of community engagement in a project shall be determined jointly by the researcher and relevant community.
<i>Article 3</i>	Where a proposed research project is to be conducted on lands under the jurisdiction of a First Nations, Inuit or Métis authority, researchers shall seek the engagement of formal leaders of the community.
<i>Article 4</i>	For the purposes of community engagement and collaboration in research, researchers and REBs shall recognize Aboriginal organizations and service organizations and communities of interest, as communities.
<i>Article 5</i>	Where alternatives to securing the agreement of formal leadership are proposed, researchers should engage community processes and document measures taken, to enable the REB to review the proposal with due consideration of the community authority structures.
<i>Article 6</i>	Researchers should ensure, to the extent possible, that they take into consideration the views of all relevant sectors.
<i>Article 7</i>	Research involving Aboriginal peoples that critically examines the conduct of public institutions, First Nations, Inuit and Métis governments, institutions, organizations or persons exercising authority over First Nations, Inuit or Métis individuals may be conducted ethically, notwithstanding the usual requirement of engaging community leaders.
<i>Article 8</i>	Researchers have an obligation to become informed about, and to respect, the relevant customs and codes of research practice that apply in the particular community or communities affected by their research.
<i>Article 9</i>	Research ethics review by community REBs or other responsible bodies at the research site will not be a substitute for research ethics review by institutional REBs.
<i>Article 10</i>	When proposing research expected to involve First Nations, Inuit or Métis participants, researchers shall advise their REB how they have engaged, or intend to engage, the relevant community.

<i>Article 11</i>	Where a community has formally engaged with a researcher or research team through a designated representative, the terms and undertakings of both the researcher and the community should be set out in a research agreement before the participants are recruited.
<i>Article 12</i>	As part of the community engagement process, researchers and communities should consider applying a collaborative and participatory approach as appropriate to the nature of the research, and the level of ongoing engagement desired by the community.
<i>Article 13</i>	Research should be relevant to community needs and priorities, and benefit the participating community.
<i>Article 14</i>	Research projects should support capacity building through enhancement of the skills of community personnel in research methods, project management, and ethical review and oversight.
<i>Article 15</i>	Researchers should engage the community in identifying Elders or other recognized knowledge holders to participate in the design and execution of research, and the interpretation of findings.
<i>Article 16</i>	Researchers and community partners shall address privacy and confidentiality for communities and individuals early on in the engagement process and addressed in a research agreement. Researchers shall not disclose personal information to community partners without the participant's consent.
<i>Article 17</i>	Researchers should afford community representatives engaged in collaborative research an opportunity to participate in the interpretation of the data and findings before the final report is completed and before finalizing any publications.
<i>Article 18</i>	Intellectual property rights should be discussed by researchers, communities and institutions and specified in a research agreement before the research is conducted.
<i>Article 19</i>	Researchers shall address and specify in the research agreement the rights and proprietary interests of individuals and communities in human biological materials and associated data to be collected, stored and used in the course of the research.
<i>Article 20</i>	Secondary use of data and human biological material identifiable as originating from an Aboriginal community or peoples is subject to REB review.
<i>Article 21</i>	Where research relies only on publicly available information, or on legally accessible information as defined in Article 2.2, community engagement is not required.
<i>Article 22</i>	REB review is required where the researcher seeks data linkage of two or more anonymous datasets or data associated with human biological materials and there is reasonable prospect that this could generate identifiable information.

2.4 ISSUES RAISED IN THE APPLICATION OF THE TCPS2 IN RESEARCH WITH ABORIGINAL COMMUNITIES

The application of ethical principles and practices for doing research with Aboriginal people has evolved over time as a response to criticisms from Aboriginal people about the ways in which research about them had been undertaken (Flicker & Worthington, 2012). That is, research of the past has often misrepresented Aboriginal people, it has been conducted without their informed consent, and it has led to stereotypes about them due to its focus on pathology and dysfunction within their communities (Castleden et al., 2012). Furthermore, critics of research in Indigenous communities have documented patterns of cultural insensitivity by researchers, the lack of community involvement and feedback during the research process, and the exploitation of the communities for academic and commercial gains (Stevenson et al., 2013).

New approaches to ethics and research with Aboriginal people have evolved over the years and are now reflected in Chapter 9 of the TCPS2. The focus of research involving Aboriginal communities now maintains the need to include Aboriginal peoples in all stages of the research process, from identifying the research question to carrying out and disseminating the results of the research. But, with these changes come challenges to the community/organization, researchers and institutions. Some of these challenges include: differences in cultural values and research goals of the researcher and Aboriginal community, Aboriginal community partners exercising more control in decision-making, which can impact the implementation of the study, the communication of research results, and the need to protect Indigenous knowledge (Flicker & Worthington, 2012). Some academic researchers, for example, may find it difficult to accept that they may not be

able to disseminate the results of a project without the community's approval to do so (Ball & Janyst, 2008). Such concerns can be addressed through open and honest discussions between researchers and the Aboriginal communities about their expectations of that research, before the research is initiated.

Also a challenge to this collaborative approach to research is the Tri-Council's financial policy that states that co-investigators cannot be paid from Tri-Council funded grants. This makes it difficult to conduct ethical research with Aboriginal people in that Aboriginal community partners who participate in or lead the direction of the research but are not being paid to do so by any community-based organization cannot receive compensation and serve as a co-investigator (whereas collaborators can do so but, according to the Tri-Council's own description of these roles, collaborators play a lesser role, not a leading role) (Castleden et al., 2012), which may prevent them from being able to participate in the research. If community-based researchers are to be included as co-investigators and since they are not paid to undertake research by their communities normally, it may be necessary to include financial compensation in the budget for them. The financial policy treating co-investigators the same makes it difficult to comply with the TCPS2, and such conflicting policies can be a challenge to ethical research with these communities.

Additional challenges include the practical and conceptual application of the TCPS2 in the communities themselves. Realistically speaking, "the current scope of Western research ethics is not always sufficient for engaging in research with culturally diverse, or non-Western populations" (Stevenson et al., 2013, p. 3). For example, ensuring community confidentiality when conducting research with remote First Nations

can be difficult to achieve (Stevenson et al., 2013). Not only is stigmatization a real concern in research with Aboriginal communities, as stated earlier, but breaches in confidentiality can also stereotype individuals and families, and may lead to discrimination from employers or insurance companies depending on the nature of the study (Stevenson et al., 2013). That is, because of the complex ties in Aboriginal communities between the individual, family and the community itself, community-wide confidentiality may be difficult to attain (Stevenson et al., 2013). Additionally, the ethical requirement of community anonymity may not be something that individual community members want to follow, given their desire for autonomy and self-determination, particularly “in the face of a history of subjugation within poor research practice” (Stevenson et al., 2013, p. 4).

Furthermore, while the intent of Chapter 9 of the TCPS2 is commendable, it is at times, confusing. For example, on the one hand it says that Chapter 9 is not meant to override Aboriginal community processes for ethical reviews but on the other hand, does little to explain what research ethics boards or researchers should do when the ethical guidance of Aboriginal peoples is contradicted by a university or institution-based REB (Stiegman & Castleden, 2015).

2.5 CONDUCTING ETHICAL RESEARCH IN ABORIGINAL COMMUNITIES

Researchers working with Aboriginal communities have begun to recognize the need to include Aboriginal communities in all stages of the research. Research focused on community engagement, such as CBPR and PAR, can help restore power to Aboriginal people in their interaction with academics and institutions, and support the rights of Aboriginal people to control the flow of information from them to researchers

and then to the public (Ball & Janyst, 2008). Participatory action research for example, whereby the research focuses on the process of knowledge generation and shared understanding to mobilize action for change (Kendall, Sunderland, Barnett, Nalder, & Matthews, 2011), is conducted within a respectful relationship between those involved, and is driven by those most affected by the topic. The researchers in PAR become facilitators rather than experts (Kendall, et al., 2011) and those most impacted by the issue decide where the research will go.

Ethical research in Aboriginal communities must include the viewpoints and knowledge of their stakeholders. Bartunek and Louis (1996) - as cited in Castleden and Kurszewski (2000) - discuss the notion of insider/outsider researchers and say that by linking the perspectives and products of both, a more robust picture of what is being studied can be produced. It is also important to note that without the insider's participation, the outsider researcher could represent the information differently than the way an insider would. That is, outsiders "will use different frameworks and perspectives from which to gather, interpret, and appreciate the knowledge. As a result, they will reach different conclusions and develop inappropriate solutions on the basis of the knowledge that was generated" (Kendall et al., 2011, p.4). By engaging in these more participatory forms of research practices, in addition to supporting Aboriginal control of research, collaboration between the insider (Aboriginal) researcher and the outsider (non-Aboriginal) researcher can yield better information (Castleden & Kurszewski, 2000).

But researchers must be aware of more than just the ethical guidelines that help support respectful research with Aboriginal communities. Researchers engaged in ethical practice with Aboriginal communities should learn about the history of trauma (e.g.

residential school attendance) that impacts Aboriginal people to improve their understanding of their community partners, and to reduce the chance of triggering traumatic memories in them when asking sensitive questions, or at least be able to respond accordingly should such memories come to the fore (Ball & Janyst, 2008). In addition to learning about the history of Aboriginal people, researchers must also maintain good working relationships with the community. This can be supported by hiring community research assistants and by regularly visiting the community, in order to receive feedback about how to ask questions and to ensure that data are collected in a respectful manner (Ball & Janyst, 2008). With improved research partnership comes the potential of minimizing harm to the community. That is, actively engaging in the research process can prevent the external stigmatization, for example, that can happen when the community participants are not involved in the development of the research design, the interpretation of the data, or the dissemination of the research results (Macaulay et al., 1999).

Prior to the growing body of literature by Indigenous scholars and organizations, as well as the development of frameworks for ethical research with Aboriginal people by the Tri-Council, researchers and their university's or institution's ethics review boards were unclear about how to address these issues (Ball & Janyst, 2008). They were unsure, for example, about how to negotiate recommended research agreements with Aboriginal people, or how to follow or interpret Aboriginal community cultural protocols, or how to address the Aboriginal community's concern about the research. With more debate and better tools and resources, more researchers are beginning to understand what they need to do to support ethical principles that are accepted by those involved (Ball & Janyst,

2008). Engagement with the Aboriginal community by researchers prior to data collection is necessary, as is taking the time to establish relationships that can help “promote mutual trust and communication, identify mutually beneficial research goals, define appropriate research collaborations or partnerships” (CIHR, NSERC, & SSHRC, 2010, p.114), and ensure that the conduct of researchers adheres to ethical principles laid out in the TCPS2. This can all be negotiated and laid out in a research agreement that describes the roles and responsibilities of the research collaborators and the expectations of both parties to the research. The CIHR Guidelines and Chapter 9 of the TCPS2 provide suggestions about what should be included in such an agreement.

2.6 THE IMPACT OF ETHICAL RESEARCH WITH ABORIGINAL COMMUNITIES ON COLLABORATING PARTNERS

The purpose of Chapter 9 of the TCPS2 is to ensure that ethical research proceeds in Aboriginal communities, but it can also add burden to both the community and researcher. Support for CBPR in Chapter 9 helps to ensure that ethical research is conducted, but it can require much from both the community and researcher. For example, the amount of time needed to develop successful CBPR may create frustration among community members who want to see immediate solutions to problems in their communities. Likewise, researchers need to devote a lot of time and effort to CBPR because the processes involved, such as adapting a project to the pace of the community, are typically slower and more drawn out than non-collaborative approaches (Tobias, Richmond, & Luginaah, 2013). Little acknowledgement from researchers’ institutions for that extra work can add to that burden. The academic environment, for example, has not accommodated CBPR well by recognizing and supporting the additional time and

effort required on the part of the university-based researcher (Kendall et al., 2011). According to Kendall and colleagues (2011), the tension that results from this lack of recognition and from all that is required of the researcher in CBPR can lead to researcher burnout, their withdrawal from the project, problems with the communities, and ultimately, withdrawal from Indigenous research. The community can also be impacted by all that is required of CBPR and may feel overburdened by “academic partners’ requests for input on formal products such as grant proposals or manuscripts, particularly if they have a limited number of paid staff members” (Anderson et al., 2012).

Additionally, the ethics review required by the TCPS2 can be complicated and take more time when Aboriginal communities are involved, leading to frustration by both the community and the researcher (Stiegman & Castleden, 2015). And, because Aboriginal communities tend to be described as vulnerable populations, when proposals include Aboriginal communities, they are often subject to full review, even if the focus of the research is rather benign. Documenting these challenges is necessary so that solutions to address them can be proposed.

CHAPTER 3 METHODOLOGY

3.1 RESEARCH DESIGN

The exploratory approach I took with respect to this research was qualitative methodology. Qualitative research is used to explore and understand the meaning that people and groups attribute to an identified problem. Data is collected in the participants' setting, analysis of data involves taking bits of information and creating themes, and the researcher interprets the meaning of that data (Creswell, 2009). This methodology was more appropriate for my study than quantitative methodology, which focuses on testing theories by examining the relationships among variables (Creswell, 2009), because I wanted to capture the understandings that participants had related to ethical research involving Mi'kmaq communities and how they applied and interpreted the articles in Chapter 9 of the TCPS2. In choosing this methodology, it flowed that there were particular techniques of data collection that were best suited to answer my research questions. These qualitative data collection techniques included semi-structured in-depth interviews and a focus group. The interviews and focus group were used to learn about the participants' perspectives around the thesis topic.

3.2 RECRUITMENT

Using a list of researchers whose research was funded by AAHRP¹¹ (I had access to the list because of my role as the Director of AAHRP), I focused on four Nova Scotia universities, including Cape Breton University, Saint Francis Xavier University, Mount

¹¹ AAHRP provided funding for pilot projects aimed at increasing research capacity in the Aboriginal communities in NS, NB, PEI and NF/LAB through partnerships with university researchers.

Saint Vincent University, and Dalhousie University, as these universities employed the researchers who were the main recipients in Nova Scotia of funding from the Atlantic Aboriginal Health Research Program. I thought that these four universities would, therefore, have more experience with research involving the Mi'kmaq communities, including related ethics reviews and the administration of relevant research grants, compared to the other universities in the province.

The REB representatives and financial services administrators at these four universities were selected for the in-depth interviews because they were the individuals at the universities who interpreted and implemented the Tri-Council policies. Health researchers were selected for the in-depth interviews because the TCPS2 is directed at the work they do. The health directors were selected for the focus group because they were the individuals who were responsible for overseeing health research in the community or they were approached by researchers who wanted to do research in the community and they are responsible for coordinating and supervising health-related programs and services in the community, particularly those funded by Health Canada.

The health directors, health researchers, REB representatives and financial services administrators were identified using either purposive or snowball sampling. Purposive sampling involves identifying particular types of cases for in-depth study, as these cases will be especially informative (Neuman & Robson, 2009). These particular cases or participants help the researcher understand the problem and the research question (Creswell, 2009). Snowball sampling involves finding a source who has the characteristics being sought, and who is then used to help contact others with similar

characteristics, “starting a process analogous to a snowball rolling down a hill” (Sadler, Lee, Lim, & Fullerton, 2010, p. 3).

In this study, I asked a financial services administrator at one of the universities to provide me with names and contact information of her counterparts (i.e. potential participants) at the other three universities (snowball sampling) as I thought that she would know them well enough to be able to do so. Using the list of AAHRP-funded researchers, three AAHRP principal investigators (PIs) helped me review the list of researchers to identify potential participants, including those whose research they knew well, and those whose research they did not know well. From that list of potential participants, I used *purposive sampling* to select those I thought would be informative in helping to answer my research questions; I decided to interview nine health researchers, including some of the researchers whose work the AAHRP PIs knew well, and some others whose work the AAHRP PIs did not know well, in order to capture the views of a broad range of researchers. The AAHRP PIs were not told who was included in the final list.

Also using purposive sampling, I contacted each one of the 13 health directors working in the 13 Mi'kmaq communities by email to invite them to take part in the focus group. Regarding the REB representatives, I went to the four university research or REB websites, and either called or emailed the contact listed on each website requesting help in identifying people I could interview for my study. I then emailed potential REB participants, as well as potential participants representing financial services administrators to invite them to participate in the interviews. With those emails, I included a short introductory letter that outlined who I was and the purpose of my research (see Appendix

A). Four REB representatives and 3 financial services administrators agreed to participate in the study.

Prior to the scheduling of interviews and after they had said that they were interested in participating, I sent each person the consent form (see Appendix B) that included information about the proposed research and risks and benefits of their participation, as well as how they could withdraw from the study. I also included a copy of Chapter 9 of the TCPS2. I offered to go over the consent form with them over the phone if they indicated that they wanted me to do so. Finally, they were asked to sign a signature page (see Appendix C) if they still wanted to participate in the study and email the consent form to me. After I received the signed consent form, I scheduled the interviews/focus group by email.

3.3 METHODS OF DATA COLLECTION

Data were collected using two methods - a focus group with 7 health directors working in Mi'kmaq communities and semi-structured in-depth interviews with 9 researchers, 4 REB representatives and 3 university-based financial services administrators, from June 2014 to September 2014, to address the four objectives of the proposed study outlined earlier.

The first method of data collection was a focus group of 7 health directors working in Mi'kmaq communities in Nova Scotia. Focus groups are “group discussions organised to explore a specific set of issues” (Kitzinger, 1994, p. 103). In focus groups, participants are encouraged to interact with each other by sharing their “thoughts, impressions and experiences on a topic of interest among the group” (Shrimpton, 2013, p.

1). Focus groups can be used to “reveal the reasons underpinning beliefs held by group members” (Shrimpton, 2013, p. 1) and to show how the participants react to each other’s comments (Shrimpton, 2013). Focus groups are not about achieving consensus, but rather about understanding an issue from the points of view of the group of people (Shrimpton, 2013).

I chose to have a focus group rather than interview the health directors individually because I wanted to get a sense of how they reacted to each other’s comments and whether or not there was consensus on the point of discussion; although consensus was not my goal, I anticipated that the focus group would be a good forum to study those interactions. The focus group was smaller than I had anticipated as I had hoped to recruit between 8 to 13 participants, but some of the health directors did not respond to my two requests to participate in the focus group. While focus groups generally last about 90 minutes (Neuman & Robson, 2009), this one lasted 73 minutes. However, all questions from the interview guide were asked and answered.

The focus group was used to capture the views of health directors about Chapter 9 of the TCPS2 policy to answer the objective about how the policy was being interpreted, applied, and experienced in research with Mi’kmaq communities. While it was not known whether the health directors were familiar with the specifics of the TCPS2, it was expected that they were familiar with the concepts upon which the articles in Chapter 9 of the TCPS2 were based (e.g. collaboration, community engagement, research capacity). Prior to the focus group, the health directors were sent an electronic copy of Chapter 9 of the TCPS2 for their information. I planned to hold the focus group before I interviewed the health researchers to help inform my interviews with the researchers, but scheduling

with the health directors was difficult and the interviews with the researchers had to be scheduled in order for me to complete my thesis in a timely manner. Although I interviewed three of the nine researchers before I held the focus group, the discussion in the focus group helped me to better understand the ethical issues in research with Mi'kmaq communities before I completed the remaining interviews with the health researchers.

With the focus group, I had hoped to gather different perspectives about what the health directors thought about Chapter 9 of the TCPS2 and research practices in general, rather than seek consensus on this research question. The concern of this method, however, was the possibility of 'group think', where to avoid conflict, a person leans "toward group consensus, even when the opinion of the group does not reflect his or her own opinions" (Neuman & Robson, 2009, p. 282). I do not feel that group think occurred, as most health directors shared their thoughts in response to my questions or in response to what others said during the discussion. One health director did, however, speak more than the other health directors, but her input was relevant to the questions asked and added to the flow of the conversation.

The second method of data collection was through semi-structured, in-depth interviews with 9 health researchers (all non-Aboriginal) who collaborated with Mi'kmaq communities in Nova Scotia, and with 4 REB representatives (non-Aboriginal) and 3 financial services administrators (non-Aboriginal) at four Nova Scotia universities to hear their perspectives about how Chapter 9 of the TCPS2 policy was applied in research with the communities. This method of data collection was used to help answer the research objectives/questions about how they interpreted and applied the TCPS2 articles in

Chapter 9 and whether any barriers to doing ethical research in the Mi'kmaq communities were apparent.

In-depth, semi-structured interviews in qualitative research involves “asking questions, listening, expressing interest, and recording what was said” (Neuman & Robson, 2009, p. 268) with the intent of learning about the participant’s perspectives and experience about the topic (Neuman & Robson, 2009). They also involve asking follow up and probing questions to obtain more details or descriptions about the topics discussed. With follow up questions, the interviewee is asked to expand on a particular point whereas with probing questions, the interviewee is asked to expand but without reference to a particular point (Neuman & Robson, 2009). The advantage of using in-depth semi-structured interviews is that information rich with descriptive detail will be gathered (Neuman & Robson, 2009).

The health researchers were interviewed before the REB representatives and financial services administrators because I anticipated that the information they provided could help to inform the interview protocols to be used with the REB representatives and financial services administrators. Prior to the in-depth interviews, the health researchers, REB representatives and financial services administrators were sent an electronic copy of Chapter 9 of the TCPS2 for their information. The financial services administrators represented two of the four universities, as those at the other two universities declined the interview or were unavailable. The REB representatives represented three of the four universities; the REB representative from the fourth university declined an interview due to illness.

In-depth, semi-structured interviews provided a depth of information that was essential to my overall understanding of the impacts of the TCPS2 on research in the Nova Scotia Mi'kmaq communities. The disadvantage of this method, however, was that people being interviewed could provide answers they thought the interviewer was looking for, and they could also answer questions in a way that made them look good (Northey & Tepperman, 2007). 'Interviewer effect', the notion that the interviewee responds differently to questions depending on the characteristics of the interviewer (Neuman & Robson, 2009), was also a possibility in this study, given the fact that I am Mi'kmaq, that I disclosed this to those who asked (i.e. two respondents asked if I was Mi'kmaq), and that others knew this to be the case. That is, my cultural identity might have affected the way respondents answered my questions. It is important to be mindful of these possibilities and take them into account when asking questions and analysing the data (Northey & Tepperman, 2007). I was aware of these possibilities and paid careful attention to them in this study, particularly when I interviewed them and later analysed the data. It would be difficult, however, to know whether or not participants were impacted by knowledge of my cultural identity without asking them specifically if that was the case, which I did not do. I had no sense that they were answering in a way that was different because I was Mi'kmaq.

The in-depth interviews were framed by a series of questions, but respondents were given the opportunity to raise other issues they felt were relevant as is standard practice in qualitative research (see Agnew & Pyke, 2007). This series of questions, or interview guide, helped to ensure that all topics were covered to address the research objectives (Neuman & Robson, 2009) mentioned earlier. The interview guide (see

Appendix D) was developed using information found in the literature, from questions used in another related study on ethics conducted by a team of researchers led by one of my supervisors (Dr. Heather Castleden) on the topic of the TCPS2 (I am a research associate on that project and signed an agreement of confidentiality to review the data), and through my experiences as a program manager of an Aboriginal health research funding program (Atlantic Aboriginal Health Research Program (AAHRP)) and other relevant research experience.

The interview guide was reviewed by my co-supervisors to determine if the questions fit the scope of my study. The in-depth interviews lasted anywhere between 26 and 68 minutes (average of 41 minutes). Data saturation became evident after a number of interviews with the health researchers were completed, but I continued to interview those who agreed to participate in case new themes or concepts emerged (Neuman & Robson, 2009). Data saturation did not seem to happen in the case of the REB representatives or the financial service administrators, possibly because I was not able to recruit as many participants for each of these categories.

In order to accomplish the task of data collection, it was important to do so with the help of digital recording equipment, particularly in the case of the focus group, as note taking during the process could have negatively impacted the flow of the discussion in the group. All interviews and the focus group were professionally transcribed and the professional transcriber signed a confidentiality agreement to protect the content of the interviews and focus group and identity of participants.

Below is a table that describes participants in general terms. It also distinguishes whether the participants were Aboriginal (A) or non-Aboriginal (NA).

Table 2: Participant Identifiers

Health Directors	Health Researchers	Research Ethics Board Representatives	Financial Services Administrators
HD#1 (A)	HR#1 (NA)	REB#1 (NA)	FSA#1 (NA)
HD#2 (A)	HR#2 (NA)	REB#2 (NA)	FSA#2 (NA)
HD#3 (A)	HR#3 (NA)	REB#3 (NA)	FSA#3 (NA)
HD#4 (A)	HR#4 (NA)	REB#4 (NA)	
HD#5 (NA)	HR#5 (NA)		
HD#6 (NA)	HR#6 (NA)		
HD#7 (A)	HR#7 (NA)		
	HR#8 (NA)		
	HR#9 (NA)		

3.4 ANALYSIS

The transcribed interviews were manually coded and thematically analysed using comparisons of the data. Coding is defined as “the process of organizing the material into chunks or segments of text before bringing meaning to information” (Creswell, 2009, p. 186) by taking text data, segmenting sentences into categories, and labelling the categories with a term based in the actual language of the participant (Creswell, 2009). To code the data, I reviewed all the transcripts three times, and identified the most commonly occurring categories. These categories were discussed with my supervisors, and then I proceeded to identify themes (Neuman & Robson, 2009). Six main themes emerged from the data. These themes (see Appendix E) were also reviewed with my supervisors and shared with those interviewed who indicated on their consent form that they wished to be contacted for that stage of the research. I asked them if the themes ‘rang true to them’, or in other words, resonated with them, and they did, so no further

analysis of the data was undertaken. The themes that emerged from the participants' interviews and focus groups were then brought together to form a full picture of their collective experience (Aronson, 1994).

To address reliability, which means “dependability or consistency” (Neuman and Robson, 2009, p. 112) or that consistent results are repeated, I maintained the meaning of my codes by writing memos about the codes and their definitions (Creswell, 2009) in the margins of the transcripts. Keeping memos about the codes and their definitions can help to prevent a “drift in the definition of codes” (Creswell, 2009, p. 190), or in other words, prevent “a shift in the meaning of codes during the process of coding” (Creswell, 2009, p. 190). By writing those memos, I was able to minimize distracting or interfering information (Neuman and Robson, 2009) that could have impacted the meaning or intent of my codes. I made sure that I reviewed the memos in the margins regularly while analysing the data so that a drift in meaning did not happen during analysis. I also used an interview guide with each interview and the focus group, keeping the discussion consistent among those interviewed. Finally, I listened to the audio recordings of my interviews to make sure that the transcripts did not contain mistakes made during transcription. I also made sure that the text attributed to participants of the focus group was correct as I knew the health directors and was able to accurately identify who said what during the recorded discussion. I also sent the transcripts to the participants who indicated on their consent form that they wanted to review them, to give them the opportunity to correct any errors or omissions. Two participants provided corrections and/or clarifications of the transcripts.

With respect to the validity of the research findings of this study, in qualitative research validity means that the researcher checks the accuracy of the findings by using certain procedures to determine if the findings are accurate from the viewpoint of the researcher, participant, or reader of the report (Creswell, 2009). Validity refers to the “match between a construct, or the way a researcher conceptualizes the idea in a conceptual definition, and a measure” (Neuman and Robson, 2009, p. 112) or in other words, how the social reality being studied matches with the constructs that the researcher uses to understand it (Neuman and Robson, 2009). When there is a poor fit between the constructs a researcher uses to describe or analyse a situation, and what actually happens, then there is an absence of validity (Neuman and Robson, 2009).

To ensure that my interpretations of the data were valid, I used ‘member checking’ to determine if those interpretations rang true to participants. Member checking is “one of the most important strategies for enhancing credibility since it involves checking the adequacy of analytic categories/constructs/hypotheses with members of the group (s) from which the data were obtained” (Baxter & Eyles, 1997, p. 515). With this member checking, rather than provide participants with the raw data I sent those who indicated on the consent forms that they wanted to see the analysis the themes that emerged from my analysis to determine if the participants felt that the themes were accurate. I also sent them quotes attributed to them to ensure that it was acceptable to include them in the report. All but one financial services administrator and four health directors responded to my request. Of those who provided feedback, all said that the information appeared accurate and all said that I could use their quotes in the final report.

Lastly, I am a Mi'kmaw woman, who grew up in a Mi'kmaq community in Nova Scotia. My interpretation of the data is shaped by this lived reality as well as my academic training and work experience in the area of health promotion and health research. While I did not distance myself from these facts during the interviews and analysis of the data, I did make sure to check my assumptions regularly as my interpretation of the findings will undoubtedly be shaped by my "gender, culture, history, and socioeconomic origin" (Creswell, 2009, p. 192).

3.5 ETHICAL CONSIDERATIONS

Prior to interviews, informed consent was sought whereby the study was explained, risks, benefits and the ability to opt in or out made clear, and my contact information and that of the university's REB and the Mi'kmaw Ethics Watch (MEW) were provided. The MEW, which gave ethics approval for my study, is an independent ethics review body (administratively based at Cape Breton University) that protects the integrity and cultural knowledge of the Mi'kmaq people. All interviews were recorded, and this was outlined in the consent form. Every effort was made to ensure the confidentiality of their information and their anonymity, with written or transcribed interviews stripped of identifying information. Anonymity and confidentiality could not be assured with the focus group, but participants' responses are codified (not attributed by name) in this thesis. The recordings and transcripts are kept in a locked cabinet in my locked office; computer and other digital data are password protected. As human participants were involved, the proposal was submitted to Dalhousie University's REB for review and was subsequently approved. Consent forms are stored apart from the interviews in a separate locked file cabinet in my office. Copies of data were shared with

my supervisory committee and are going to be stored in my office for five years.

CHAPTER 4 FINDINGS

Using a thematic analysis of data gathered from the focus group of health directors working in Nova Scotia Mi'kmaq communities and semi-structured in-depth interviews with REB representatives, financial services administrators, and researchers at four Nova Scotia universities, six main themes emerged from the data:

1. Mi'kmaq communities in Nova Scotia are seeking more control of the health research conducted in their territory.
2. Well-established relationships between researchers and Nova Scotia Mi'kmaq communities support the researchers' adherence to the articles included in Chapter 9 of the TCPS2.
3. There is a lack of capacity in Nova Scotia Mi'kmaq communities to be better engaged in research.
4. Research ethics board representatives and some researchers find the articles in Chapter 9 of the TCPS2 to be vague at times, leading to some confusion about their application.
5. Community-based health directors and institutionally-based financial services administrators have limited knowledge about the TCPS2 and Chapter 9.
6. University-based financial services administrators and REB representatives generally have a lack of understanding about the realities of conducting research in Nova Scotia Mi'kmaq communities.

Each theme is described and explained below, drawing on representative quotes from participants to elucidate my findings.

4.1 THEME 1: MI'KMAQ COMMUNITIES IN NOVA SCOTIA ARE SEEKING MORE CONTROL OF THE HEALTH RESEARCH CONDUCTED IN THEIR TERRITORY

The health directors and health researchers participating in this study noted that the Mi'kmaq communities in Nova Scotia wanted more control of research which has implications for research ethics boards, financial services, and researchers. The focus group discussion with health directors revealed that Mi'kmaq communities in Nova Scotia are taking steps in terms of seeking more control of health research. Participants were asked if they noticed any positive changes about how research is conducted now versus how it was conducted prior to the Tri-Council ethics guidelines. Although not directly attributing changes to research over time because of these guidelines, they said that First Nation communities are taking more active roles in research now, they are now leading research because they have more research experience, they have a better understanding of the difference between good and bad research, and they no longer passively participate in research. The health directors spoke of how their communities were taking more active roles in research, particularly in the area of health, mainly because they had more experience with research and more awareness of the value of data. One health director said,

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

The health directors also spoke about wanting control and equal say in research as a way to prevent data from being manipulated by researchers and that it was important

that expectations of both parties were addressed in research agreements. One health director said,

“It’s like any...you want to be in control. 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 we’re more...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)

The health directors also said that community aspirations are important and that 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)

They spoke about being left out of potential research projects in the past and that they accepted being excluded, but said that now, they feel empowered to decide what research should be done in their communities. For example, one health director said that when a round table of researchers was convened nationally about research in mental health, Aboriginal mental health was not even considered. In response to finding out about that, the participants representing Aboriginal communities stepped out of the

meeting room, held their own discussion about their research needs, and decided to initiate their own research.

“So now they all started chit-chatting in the hallway...and they said, “Let’s do our own”. So that’s what they did. They all came together, the groups that felt excluded from this big scientific doctors and whoever else was involved with this process, they came out of the meeting room, came together, and developed their own thing....” (HD#1)

When asked about their experiences with researchers in general, they said that researchers, for the most part, were no longer able to come into their communities uninvited. They said that they heard stories from other health directors about some researchers who successfully bypassed proper channels in the past to conduct research. That is, the researcher gained access to the community without Chief and Council and/or health director approval and carried out research in the community, but the health directors said that this is much less likely to happen now. In reference to this practice, one health director said,

“...sometimes they [researchers] could go in the backdoor. Like they bypassed you [health director].” (HD#7).

On the same topic, another health director said,

“...I’ve heard stories where researchers go in and the health director doesn’t even know about it [research project], or Chief or Council. They don’t even know about the Mi’kmaw Ethics Watch”. (HD#4)

Researchers, they said, now needed to ‘partner’ with their communities rather than ‘conduct research on’ the communities, as had been done in the past. Prior to the ethics guidelines, they said that researchers would contact the communities about research projects with no request to do so by the community. The health directors spoke about how important it now was for researchers to develop respectful relationships with the communities and that the researcher’s attitude towards them was critical to that relationship.

“I think what happens, it deals a lot with personality. I think that if there’s a researcher that comes off as arrogant or whatever...or comes off as know-it-alls, then it already creates a barrier from day one, and communities will not participate in research...if there’s no respectful personal kind of relationship. You have to have that relationship and build trust with the community and involve the community through the whole process....” (HD#1)

The health directors talked about the need for research questions to come from the communities¹² rather than from researchers and that those questions needed to be backed by data. They did acknowledge, however, that despite the fact that they believed that research should be initiated by the community, there continued to be times when researchers did contact them first about a research idea, but now, rather than passively agree to participate in the research, communities decide whether or not to partner with the researcher based on what is important to the community. One of the health directors said

¹² While the topic of my research did not come from the Mi’kmaq communities, I did talk to some of the same health directors interviewed for this study about my potential topic, and they said that it would be a good area to study. I chose the topic because of my own interest in it.

that an Elder in the community often reminded the health staff that if the research did not benefit the community, they should not participate in it. The health director said,

“She [the Elder] would always ask every researcher, what benefit is it to our community? What benefit is it to me? What benefit is it? If there’s no benefit, then there’s no reason for us to participate in this.” (HD#1)

The health directors agreed that the research idea, regardless of who brought the question forward, needed to benefit their communities.

The following passages largely include the perspectives of the health researchers about the theme discussed above. Interviews with researchers who collaborated with Mi’kmaq communities also confirmed that the communities were seeking more control of and participating more actively in research. Most researchers, when asked whether any non-academic Mi’kmaq community partners were involved in any of the four stages of the research process (i.e. research development, data collection, analysis and dissemination), said that their community partners were involved in most, if not all stages of the research. They said that they engaged directly with the communities as most of the research they collaborated on was community-initiated.

“The majority of the work is community initiated. So it’s people coming to me saying, “[X], I’ve got this idea. Could you help me with it?” That’s how it generally works. And so I always, always, always...it’s always very much direct, very much engaged, very much ‘community first’ work.” (HR#2)

While this was the response of most of the researchers, some did say that although Mi’kmaq communities expressed the need to be fully involved in the research, they made

sure that they did not overburden their community partners. This meant that the researcher would undertake the more time-consuming aspects of research, such as proposal and report writing.

“You know, I did quite a bit of the writing, and rather than burdening the community members who I was working with the writing process, I just ensured that they had multiple opportunities to review and edit and comment on the writing...” (HR#5)

Another researcher also noted that in order to do research in an ethical way, it was important to not overburden the community.

“It’s also, I think, trying to be aware of the tension between, quote, unquote, empowering people to participate in work and draining the resources in the community that are already dealing with a lot of other very pressing matters, not wanting to be a burden...” (HR#4)

Furthermore, one other researcher, in response to the same question about doing research in a good or ethical way, said,

“Reasonably what can be expected and what is the most optimal way of ensuring involvement and inclusion in the research project without bounding in and saying, “Oh, everybody’s going to be involved from start to finish”. And the reality is that sometimes people just don’t have...you know, if you’re just trying to keep a roof over your head, keep moving from day to day, or 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)

The health directors reiterated the notion that communities should not be overburdened by research. One health director, when discussing whether or not researchers had attempted to develop respectful relationships with the community said that a researcher's approach is important and that they shouldn't overburden the communities with too many details about the research. She said,

"It was her 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)

The perspectives of the health directors and health researchers both showed that Mi'kmaq communities were indeed seeking more control of research and actively participating in research, but they cautioned that it was important that the communities were not asked to take on more than they could manage.

4.2 THEME 2: WELL-ESTABLISHED RELATIONSHIPS BETWEEN RESEARCHERS AND NOVA SCOTIA MI'KMAQ COMMUNITIES SUPPORT THE ADHERENCE TO THE PRINCIPLES IN CHAPTER 9 OF THE TCPS2

The focus group of health directors and interviews with health researchers revealed that health researchers who have established partnerships with Nova Scotia Mi'kmaq communities are largely adhering to the principles laid out in Chapter 9 of the TCPS2. That is, the health directors provided examples of how those researchers with

whom they have good relationships adhere to the Chapter 9 principles of ethical research practices. The health researchers, when discussing their own research practices, revealed that they believed that they themselves generally adhered to the Chapter 9 articles.

The health directors said 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 of relevance to them. As one health director said,

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

The health directors spoke of health researchers with whom they have good working relationships¹³ and said that those relationships were developed over time and that the attitude of the researcher was important. Once those working relationships were developed, they tended to approach those same researchers when they had a research idea of importance to their community. They said that the researchers they worked with: supported Mi'kmaw community control of the research, supported a research partnership without burdening the community, submitted their proposals to the local community research boards or Aboriginal ethics committees, supported community research capacity (e.g. advisory committees), supported the involvement of the community in developing the proposal, signed a research agreement if asked, were respectful in their approach, were trustworthy, shared the analysis/report with the community for accuracy, and

¹³ Some of the researchers I interviewed were also the same ones mentioned by the health directors during the focus group.

ensured that the community was given credit in published reports coming from the research. One health director summed up 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)

Interviews with the health researchers revealed that they were well aware of the articles in Chapter 9 and most said that they followed the articles in their research collaborations with the Mi’kmaq communities. That is, in describing their relationships with the Mi’kmaq communities, they said that those relationships were collaborative partnerships and that relationship building was an important aspect of that partnership. One researcher, in response to a question asking her to describe her research relationship with Aboriginal people said,

“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 in all stages of the research, most said that their partners were involved in developing the proposal, in collecting and analysing the data, and in disseminating the research results and that this would be difficult to achieve without partnerships. One researcher said,

“I can’t even imagine doing research with First Nations people without having a partnership and collaboration and their involvement” and “...it was always driven actually by their interest.” (HR#3)

The researchers also discussed their thoughts about what ‘doing research in a good way’ meant to them, and many reiterated the principles underlying Chapter 9 of the TCPS2. They said that they believed that the needs of the community should come first, that research is something one does *with* people, not *on* people, that analysis of the data needs to be done with the community partners, and that the community partners should be involved in all aspects of the research process, from the design of the proposal at the start, to the dissemination of the product at the end. In discussing this question, one researcher spoke of the development of meaningful partnerships as an important piece of her doing research in a good way. She said,

“I think the most important thing with respect to doing research in a good way is that you’re constantly in meaningful relationships and communication with the community members and/or the Elders or students or whoever it is that are your primary research partners from the community’s perspectives so that you don’t get ahead of them or to the side of them.” (HR#1)

Being in well-established relationships also helps the researcher to understand what it means to behave ethically in the community. That is, being taught by community partners about community customs and protocols is an important aspect of ethical research. In discussing the most important ethical considerations when doing research with Aboriginal people, one researcher reflected on this point and said that,

“...I guess it’s understanding patterns or 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)

Lastly, researchers, in speaking about how Chapter 9 supports ethical research said that one of the most important principles to ethical research is the building of relationships. Without those established relationships, ethical research may be more difficult to achieve. One researcher said in reference to this point that,

“...sometimes people in research don’t recognize the need for...building relationships in order to do ethical research. (HR#2)

Ethical research with Aboriginal communities is supported by long-term, well-established partnerships and the health directors and health researchers both agreed that these partnerships were key to the adherence of Chapter 9 or to ethical research in general.

4.3 THEME 3: THERE IS A LACK OF CAPACITY IN NOVA SCOTIA MI’KMAQ COMMUNITIES TO BE BETTER ENGAGED IN RESEARCH

While there was a recognition that research had changed since the ethics guidelines were implemented, although not attributing the change to the guidelines, the health directors said that the ability for the communities to collaborate with researchers in meaningful ways is often hampered by a lack of capacity in communities. When asked to discuss their current or previous relationships with researchers, the health directors said that although it is important to have meaningful collaborative partnerships with the researchers, they lacked the time to participate fully in the research process as research activities and relationship building are time consuming. A health director said,

“...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)

They also said that they have few staff in the community to devote to research. They reiterated that it is important for the Mi'kmaq communities to participate fully in research but that this could only be achieved with more staff. One of the health directors said that the communities need dedicated staff to participate in research activities because other staff, much like themselves, do not have the time necessary for research when they have so many other roles and responsibilities in the communities.

“...it can get time-consuming. You need to have a lot of staff to be able to dedicate to it [research].” (HD#5)

Another health director said,

“[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)

The health directors also spoke specifically about the lack of capacity in the communities to participate in research. They said that some of their staff may not understand the importance of research or may not care about research but participate only because they have been asked to do so by the health directors. They said that this was not ideal, and that their staff could be overwhelmed as a result because they have to juggle two or three different things, as research is not their sole responsibility. One of the health directors said that in order to deal with this lack of knowledge, interest or time by some of their staff to participate in research activities, the communities need to hire people in the community who deal specifically with research. Another said that they would like to see

staff who could write their own reports based on data, rather than have to rely on others to write reports for them. This, she said, is about taking ownership of research.

They also spoke about the lack of capacity in the community to review research agreements to make sure that the community is protected. They said that even though they may have some lawyers in their communities, they lack the expertise to review agreements that deal with privacy concerns and data, as their focus may be on other areas of law.

Furthermore, the health directors said that some community members do not understand the importance of research or why they have been asked to participate in a study. They also said that time was a factor in whether or not individual community members agreed to participate in research. 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, a lack of research capacity and understanding about how to use data to their benefit, as well as time constraints were identified by health directors as being key factors in hampering the communities’ ability to participate more fully in research.

4.4 THEME 4: RESEARCH ETHICS BOARD REPRESENTATIVES AND SOME RESEARCHERS

FIND THE ARTICLES IN CHAPTER 9 OF THE TCPS2 TO BE VAGUE AT TIMES, LEADING TO SOME CONFUSION ABOUT THE WAY TO APPLY THE ARTICLES

Although there was general support for Chapter 9 of the TCPS2 among REB representatives and health researchers in the study, several of those interviewed said that the articles were vague which they felt led to confusion during ethics reviews and in the application of research ethics principles. When questioned about their thoughts on whether or not Chapter 9 captured the ethical considerations of doing research with Aboriginal people, some of the researchers said that the chapter was vague at times, had confusing wording or content (e.g. unclear about what constitutes community consent), and did not provide enough instruction about how to do ethical research with Aboriginal communities. One researcher said,

“I think it [Chapter 9 of TCPS2] needs more clarity. I think there’s a lot in there but I think it’s confusing for some folks. It’s a good thing to have but I think it also leaves questions, like consent from the community. Who is community?” (HR#3)

Another researcher said,

“That vagueness [in Chapter 9] is sometimes really apparent. But I don’t think it gives enough instructions to researchers as to how to act in their research very specifically, like what are some of the steps. I don’t think it goes far enough in doing that. And I think that it instructs researchers how to do things, but doesn’t quite go as far to get them to commit to some of those things.” (HR#5)

While there were criticisms of Chapter 9 because of the ambiguous wording in it, researchers were also supportive of the chapter and said that it was better than what had been available in the past and that they followed the chapter despite its vagueness. One researcher said,

“I think it’s [Chapter 9] ground breaking in a lot of ways in terms of bringing attention to really how research in the social sciences needs to shift quite profoundly. And I don’t think it’s limited to social sciences actually...I mean professional research institutions like universities [and even hospitals] need to seriously rethink very well entrenched and embedded approaches to research.” (HR#6)

Interviews with REB representatives also revealed criticisms of Chapter 9. They said that the contents of Chapter 9 were vague, which they felt led to confusion during ethics reviews (e.g. the requirement of community engagement or dissemination of the findings are unclear). The vagueness, they said, forced them to interpret the content as best they could. They also said that they felt that the vagueness led researchers to misinterpret the principles underlying Chapter 9, as was evident in their proposals to the research ethics boards. For example, because of the chapter’s ambiguity, a REB representative alleged that some researchers thought that they had to give back to the community much more than was ethically necessary. The REB representative said,

“The requirement to give back to the community in terms of the research findings, I think that hasn’t been a misunderstanding only on the side of the research board but also on the side of the researchers. Some have believed that you have to give the

community everything, including people's raw data, who your participants were, without really understanding that that's not what the mandate's about." (REB#3)

It is important to note here for clarification that Chapter 9 (Article 9.8) does state that researchers have an obligation to respect the codes of research practice that apply to that particular community, including the adoption of the OCAP™ principles, and that researchers should ensure that OCAP™ is consistent with their institutional policies and when that is not the case, this needs to be resolved prior to the start of the research (CIHR, NSERC, & SSHRC, 2010).

The researchers and REB representatives said that Chapter 9 needed to be enhanced and that real life examples should be provided. One REB representative said,

"...it's kind of an overview right now, but I think they could actually provide more guidance...like how to apply certain sections of Chapter 9..." (REB#2)

In addition to the inclusion of real life examples, the REB representatives recommended that more details or explanations supporting the chapter's articles should be provided to diminish uncertainty. For example, one REB representative said that they found it confusing about why adult community members couldn't consent on their own to be involved in a study without their community first having to consent. Another REB representative wondered what ownership of the data really meant within the Mi'kmaq community context.

While the REB representatives placed much of the blame on the vagueness of Chapter 9 for their own confusion, they did acknowledge that part of their confusion was also the result of the fact that they and other board members did not know much about

Aboriginal research. When they lacked this understanding, they deferred to the researchers to explain things to them, which they said resulted in more burden on the researcher.

“Sometimes when we weren’t clear about something, we would put it back on the researcher. “This doesn’t work, so think of something that might work. This violates this guideline, so can you think of something different that would not?” So we would put the task back to the researcher to figure out a solution if we couldn’t agree on a solution or if we couldn’t agree on...or if we couldn’t come up with suggestions for them.” (REB#3)

Another REB representative said,

“...they [Tri-Council] don’t seem to have any problem with the idea that a single sentence in the TCPS2 can add a huge burden to the researchers.” (REB#4)

Finally, with respect to the chapter’s ambiguity and the need for enhancement, a REB representative said that any enhancements to the chapter needed to be done with input from the Aboriginal communities and the research ethics boards. She said,

“...I think that they could do some more consulting with the communities and with REBs, as well, to see what can be done to improve it. I mean, we want to do it right, and Chapter 9 is better, but it can be improved.” (REB#2)

In addition to their general confusion about the articles in chapter 9, the REB representatives, much like the health directors, expressed their uncertainty about the role of Aboriginal community ethics boards or committees such as the Mi’kmaw Ethics Watch (MEW) and said that this was not clearly explained in Chapter 9. They spoke about not

knowing how a body such as the MEW fits into the ethics review process. They wondered, for example, if the MEW had to review the application before the university or vice versa. While there was general support for Aboriginal ethics review bodies such as the MEW, one REB representative expressed concern that the extra review by bodies such as the MEW would lead to less research being done with Aboriginal populations due to the time constraints of the researcher. She said that if she could change something about the ethical considerations when doing research with Aboriginal peoples, it would be to eliminate the additional review.

“I think that that [extra review process] has a long-term effect on the amount or duration of research with First Nations groups. Given all the constraints I named above, if you don’t have enough time or enough money and whatever, you’re going to find a different population to study.” (REB#1)

In addition to the confusion that sometimes arose during ethics reviews because of the ambiguity of Chapter 9, the REB representatives said that the vagueness of the chapter led to their overprotection of the Mi’kmaq community, which they felt was paternalistic. One REB representative said,

“It’s kind of a tension that’s constant about are we under-protecting or over-protecting? And the over-protecting coming in that the TCPS isn’t very clear on what counts as Aboriginal community. They aren’t clear in what counts as community at all, but because it’s required that you show evidence of collaboration, then the question about what counts as community becomes really challenging.” (REB#4)

In the end, however, the REB representatives agreed that even though Chapter 9 was not perfect, it was better to have it than to not have it. One REB representative said,

“...the guidelines now are not perfect, but they probably have...are probably better than no guidelines. But there’s also room for tweaking....” (REB#3)

Furthermore, another REB representative said that Chapter 9 allows the board to ‘call out’ researchers about unethical research with Aboriginal communities. The REB representative said,

“...because of the TCPS Chapter 9, we are now able to say basically, “Sorry, you can’t go ahead”. And if there’s nothing else wrong methodologically with the study, it’s harder to do that, but the TCPS Chapter 9 gives us a whole other set of grounds to say, “This is not ethical.” And I think that’s a really important one.” (REB#4)

Finally, in addition to the health researchers’ and REB representatives’ support of Chapter 9, financial services administrators expressed support of the TCPS2 – Chapter 9 in principle, but since ethics was not their area of expertise, they had little to offer about its merits or challenges.

4.5 THEME 5: COMMUNITY-BASED HEALTH DIRECTORS AND INSTITUTIONALLY-BASED FINANCIAL SERVICES ADMINISTRATORS HAVE LIMITED KNOWLEDGE ABOUT THE TCPS2 AND CHAPTER 9

While the health directors had seen improvements in terms of the ways in which researchers were approaching their communities to do research, there appeared to be a general lack of knowledge about the contents of the TCPS2 and its Chapter 9 by health

directors working in some of the Nova Scotia Mi'kmaq communities. Perhaps not surprisingly, the same could be said about the university-based financial services administrators participating in this study. Most of the health directors and financial services administrators (FSA) said that they knew very little about the TCPS2. When asked if they had heard of the TCPS2 and Chapter 9, one health director responded:

“Well, I’m aware of it [TCPS2 – Ch. 9] but I’ve never actually read it.” (HD#1)

Another health director said,

“I just became aware of it when you sent the email.” (HD#4)

In response to the same question, an FSA said,

“Well, that’s not my area, ethics...I don’t know the details of the research involving human participants.” (FSA#3)

Both groups said that they had not heard much about the TCPS2 prior to my contact with them about the proposed study. They also indicated that they knew very little about what constitutes an ethics review at a university or research institution. The financial services administrators said that they had limited knowledge about the TCPS2 because ethics was not their area of expertise. The financial services administrators did state though that while they did not know much about the TCPS2 or of ethics in general, they would be interested to learn more about the TCPS2, because knowing more about the guidelines would help them and their staff to better understand the intricacies of research. One FSA said,

“...it would be definitely good to have a read of that [the TCPS2], and I think about my staff too and just having a little bit more of an understanding. Because I have [several] people under me and they know that they don’t understand the whys of things, so I think it would be really interesting to look at that a little deeper.” (FSA#2)

Although the financial services administrators acknowledged that they had little knowledge of the TCPS2, they did seem to have some understanding of the challenges faced by researchers in terms of conducting ethical research in Aboriginal communities while also having to follow sometimes inflexible institutional requirements. That is, when discussing their experiences with researchers who collaborated with Aboriginal communities, one FSA said that they tried to support the research/researcher by accommodating the norms of the Mi’kmaq community (e.g. gifts to Elders), even though it was outside their normal practice. The FSA said,

“So we give somebody a cash advance and then they dished out the money. Well, we wouldn’t normally do that, but we took into respect the Elders and previous history, and we worked together and this is what we did for the situation. We just documented it all.”(FSA#2)

The same FSA also said that the university could try to be more lenient and give Elders more options of payment (e.g. pay in cash), as long as the university was compliant with the requirements of the Canada Revenue Agency.

The financial services administrators spoke of their apprehension about being audited by Tri-Council, so to veer slightly from those guidelines was not something they were comfortable doing even if it meant being more responsive to the needs of Aboriginal

research partners. One FSA said that this accountability to funders can sometimes cause friction between Financial Services and the researchers. For example, when asked about their experiences with university researchers who partner with Aboriginal communities, one FSA said,

“They’re occasionally challenging because the researcher is looking at it from their perspective only and doesn’t necessarily understand that we have an accountability to the funding agency, the university auditors, the general public, our internal auditors...”(FSA#3)

The health directors also spoke about their lack of knowledge about the TCPS2 and ethics reviews in general. In discussing ethical research and ethics reviews, one of the health directors said that she found the entire process confusing. She said,

“I still don’t get a clue on that whole thing really...I’m not sure what they use, what Mi’kmaq Ethics uses. Do they use the Tri-Council guidelines? I doubt it. And then but you would think that universities would use the Tri-Council guidelines, right? So I don’t know, I just think that...I don’t know. I’m lost now.” (HD#1)

The health directors did not elaborate on why they were not knowledgeable about the TCPS2 or ethics reviews in general, but their reasons may be similar to those of the financial services administrators in that ethics may not be their area of expertise.

Although the health directors reported that they knew little about the TCPS2 (Chapter 9) or ethics reviews, their discussion indicated that they did know more than they thought they did about the guidelines. As noted earlier under Theme 1, the health directors spoke of how the Mi’kmaq are seeking more control of research and are insisting on community

engagement, collaboration, research capacity building, reviews of draft reports for accuracy, and research agreements, for example. The articles in Chapter 9 recommend many of the things the health directors discussed in the focus group.

The health directors had a lengthy discussion about Aboriginal community-based ethics review groups such as the Mi'kmaw Ethics Watch (MEW). They said that they did not know what ethics guidelines the MEW followed during reviews of projects that involved the Mi'kmaq communities nor did they know what projects were approved or rejected by the MEW that could impact their communities. They also said that they were unaware of who the MEW was accountable to and who to complain to if there was an ethics issue related to an approved research project. As one health director put it,

“They [MEW] have no accountability to anybody”. (HD#1)

However, despite these concerns about community-based ethics review processes such as the MEW, the health directors did agree that it was good that these community-based ethics groups were established. A health director said,

“So it's like we have to ask them [MEW] but then I questioned what other things are they doing that we don't know about and that's the problem that I have with...I'm glad they're in place, but I wish there was more communication to people...” (HD#7)

Not only did the interviews reveal that health directors and financial services administrators lacked knowledge about Chapter 9, the same may be said about some REB members. The interviews with researchers who collaborated with Mi'kmaq communities revealed their doubts about how adequately REB members were versed in, or how well they interpreted, Chapter 9 of the TCPS2.

As one researcher put it,

“I’m not entirely convinced that members of ethics review boards are always aware even of the chapter’s existence, let alone its contents. And, I don’t think the ethics review structures at a lot of our universities are designed in such a way to...so as to accommodate the contents of the chapter.” (HR#6)

While most interviews with the REB representatives showed that they were indeed aware of and versed in Chapter 9, one interview supported the researchers’ assertion that this was not the case. When asked if they found Chapter 9 helpful in navigating ethical issues associated with research involving Aboriginal peoples, the REB representative said that Chapter 9 was not especially helpful, and when probed further said that she was,

“...vaguely familiar with it” [Chapter 9] and didn’t have “...a good working knowledge [of it].” (REB#1)

The REB representative, though, did say that her REB did not review many research proposals involving Aboriginal communities, so her lack of knowledge is not entirely surprising.

Finally, interviews with the REB representatives indicated that they perceived that some health researchers, even those who do much of their research with Aboriginal communities, may not be well-versed in Chapter 9 of the TCPS2. In response to a question about the challenges they dealt with in ethics reviews for projects involving Aboriginal people, the REB representative said,

“....some researchers have not read Chapter 9, and some surprisingly who do all their research with Aboriginal communities haven’t read Chapter 9.” (REB #3)

The same REB representative did say as well that quite a few university researchers (not specifically those working with Aboriginal communities) either did not know they had to follow the TCPS2 or they were unaware of what was included in the TCPS2 or how to apply the TCPS2. In discussing issues that came up with respect to researchers and the TCPS2, the REB representative said,

“Well quite a few don’t know that it [TCPS2] exists and it’s pretty clear several [researchers] haven’t read it. They couldn’t tell the difference between anonymous participation versus confidential participation...if you say the word “TCPS” they’ll give you a blank stare.” (REB#3)

The health directors had little to say about whether or not they felt the health researchers or other university-based staff knew about the TCPS2 or Chapter 9.

4.6 THEME 6: UNIVERSITY-BASED FINANCIAL SERVICES ADMINISTRATORS AND REB REPRESENTATIVES GENERALLY HAVE A LACK OF UNDERSTANDING ABOUT THE REALITIES OF CONDUCTING RESEARCH IN NOVA SCOTIA MI’KMAQ COMMUNITIES

My interviews with financial services administrators and REB representatives revealed their general lack of knowledge or understanding about the life circumstances of people living in the Mi’kmaq communities as well as their lack of knowledge or understanding of what is involved in CBPR. However, they know they are called upon to make decisions about the ethical conduct of these studies and the expenditures that allow

the studies to be conducted. An REB representative, for example, when discussing ethics reviews of projects involving Mi'kmaq communities said that these communities are no different than other vulnerable populations and that as such, required no additional accommodations during reviews. The REB representative said,

“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)

For clarification, while vulnerability of Aboriginal populations is not mentioned specifically in the TCPS2, aside from the vulnerability of certain groups within the Aboriginal population (see Chapter 9), there is a section in Chapter 1 that cautions that when groups have been treated unfairly and inequitably in research in the past, or have been excluded from research opportunities, they are vulnerable, therefore special attention may need to be given to them so that they are treated justly in research (CIHR, NSERC, & SSHRC, 2010). It is not unreasonable to conclude that this could be the case for Aboriginal populations, and accommodations may need to be considered. The view that the Mi'kmaq population is no different than any other vulnerable group and therefore, requires no added attention, however, was not the view of all REB representatives, in that others said that accommodations (e.g. including someone on the REB with Aboriginal research experience) should be included in the review of proposals involving Mi'kmaq participants.

Interviews with the researchers revealed their views that REB members did not fully appreciate the tenets of CBPR. When discussing the tension around conducting

ethical research with Aboriginal communities and research ethics board feedback she received for one of her research projects, a researcher said that the research ethics board wanted a detailed timeframe of activities for the research, without recognition that CBPR should be more emergent and respectful of the community's timeframes. The researcher said,

“...I think 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 [x university] 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, [x university] had to okay before they could go ahead moving forward on the project... ” (HR#4)

Another researcher, in response to the same question about the tensions that exist when doing Aboriginal health research in an ethical manner said that university ethics boards tended to be inflexible when it came to alternative or less main-stream research methods and tended not to see beyond what they deemed to be ethical research. Conflict arose, she said, when the research ethics board wanted her to comply with their ethics requirements over the requirements of the local Aboriginal ethics board. The researcher said,

“...they're [REB] so set in their ways and so structured that they really don't accommodate other viewpoints and other ideas, and that has to change because it's like,

Well, I'm in their territory. I'm with their people. I have to comply with what their wishes are. It has nothing to do with [x] University...”(HR#7)

Additionally, the researchers expressed their doubts that financial services administrators understood the socioeconomic conditions of some of the community research participants. For example, in response to a question about their experiences with their institution around their research with the Mi'kmaq communities, a researcher suggested that financial services administrators were unaware of the financial circumstances of some people in the community. The researcher said,

“So there is some inflexibility and lack of recognition that not everybody has a Visa, 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 when you have to hire the community. They may not have those kinds of resources.” (HR#9)

Another researcher said that financial services administrators lack an understanding of what is involved in research with Aboriginal people. The researcher said that FSAs,

“...need to be more aware that the process of doing Aboriginal 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, the researchers, when discussing some of the problems they observed in the reimbursement of expenses to Mi'kmaq community research participants, spoke of the lack of understanding by financial services administrators about what constitutes ethical research. One researcher said,

“They [FSA] wanted the names of participants...they wanted the name of who you gave the honorarium to, which breaches confidentiality.” (HR#3)

For clarification, the financial services administrators are also bound to the same confidentiality requirements as researchers according to the Tri-Council policies but this may not be common knowledge among researchers.

CHAPTER 5 DISCUSSION

Some of the key findings that emerged from the data suggest that Chapter 9 of the TCPS2 has had a positive impact on research in Nova Scotia Mi'kmaq communities. That is, Mi'kmaq communities in Nova Scotia are seeking more control of research and the articles in the chapter support that control. Also, long-term, well-established relationships between researchers and Nova Scotia Mi'kmaq communities resonate with the principles laid out in Chapter 9.

Other key findings, however, revealed issues of concern related to Chapter 9 and barriers that could potentially impact ethical research in Mi'kmaq communities. For example, a lack of time and capacity for research can be barriers to ethical research, in that the communities may not be fully engaged in research and may not be aware that some ethical practices have been breached. A lack of engagement could also lead to research that does not have the intended impact, making its outcomes less effective. Additionally, from the perspective of REB representatives, many researchers new to doing Aboriginal research as well as REB members themselves find the articles in Chapter 9 to be somewhat vague. This vagueness has led to confusion in both their application and in ethical reviews of research proposals involving Mi'kmaq communities. Furthermore, health directors working in the Mi'kmaq communities and university-based financial services administrators have limited knowledge of what is included in Chapter 9 and in the TCPS2, and what is involved in ethics reviews. Also of concern is that financial services administrators and REB representatives sometimes lack an understanding about the realities of conducting research in Mi'kmaq communities. The

latter four issues can reduce the effectiveness of the TCPS2 to protect Mi'kmaq communities from unethical research.

Below is a discussion about how ethical research is supported in Mi'kmaq communities in Nova Scotia by Chapter 9 through its encouragement of community control of research and respectful research relationships, and how a lack of capacity to participate in research along with a lack of clarity or understanding about Chapter 9 and/or ethical research in general by Mi'kmaq communities, financial services administrators, and REB representatives can diminish the protection that the chapter was created to do. The supports to ethical research focus on two of my findings and are discussed in section 5.1, and the barriers to ethical research focus on my remaining findings and are discussed in section 5.2.

5.1 SUPPORTS TO ETHICAL RESEARCH IN MI'KMAQ COMMUNITIES

My first research finding revealed that Mi'kmaq communities in Nova Scotia are seeking more control of the health research conducted in their territory. The health directors spoke about how the communities have taken more active roles in research, from deciding when to participate in a project to sometimes leading projects. This they said, was due in part to a better understanding of ethical and unethical research and more experience with research, but also because of their understanding of the communities' rights in the research process. The health directors said that they no longer passively participate in research and are inclined to only become involved in projects that are important to their communities. The articles in Chapter 9 support Mi'kmaq communities' aspirations to have more control of the research in that they encourage and/or require the need for: community engagement and full participation in the research, ethics reviews by

Aboriginal ethics review bodies, respect for community customs and codes of conduct (e.g. OCAP™), flexibility when institutional policies and community practices differ, and strengthening community capacity for research.

Although the health directors were clear about how research in Aboriginal communities is best served when it is initiated by the communities, they did acknowledge that they still became involved in research not initiated by them. One of the main reasons for not initiating the research themselves is that they have so many other priorities and research sometimes takes a back seat to those priorities. This is consistent with other Aboriginal communities in Canada who are continuing to participate in research not initiated by them, due in part because they are busy as well (Castleden et al., 2012). However, the difference now as compared to before Chapter 9 and other similarly focused ethics guidelines (e.g. CIHR Guidelines for Health Research Involving Aboriginal Peoples, OCAP™ Principles) were created is that the Mi'kmaq communities only participate in research that they believe will benefit the community. An example of where Chapter 9 supports this condition is Article 9.3 which states that research should be relevant to the community needs and priorities and should benefit the community.

Academic institutions and researchers in Nova Scotia should be aware that Mi'kmaq in the province want to have oversight over the research and in many instances play an active role in the co-production of new knowledge through research that takes place in their communities. Ways to support this shift should be encouraged at the academic (e.g. explicit policies supporting Aboriginal control of knowledge production) and administrative levels (e.g. financial policies that make it easier for the communities to participate in and control aspects of research) and discussions between the research

institutions and Mi'kmaq communities should take place to ensure that both groups benefit from the research. Research ethics boards should be better informed about this change and define, for example, what significant engagement looks like so that their reviews of ethics applications ensure that the communities are as involved as possible – or to the extent they want to be - in research that impacts them. With respect to financial services personnel, they could find ways to support payment to community-based research assistants in a timely manner rather than have them wait for remuneration weeks after starting work on a project. This extended period without pay could discourage community members from agreeing to work as research assistants on projects.

The interviews with the health directors revealed how important respectful partnerships were to the communities' goal of having more control of the research, and that individual researcher attitudes were instrumental to the development of that autonomy through partnerships. Article 9.12 in Chapter 9 supports the building of these partnerships and states that collaborative approaches with the communities are a way to create mutually respectful and productive relationships. The building of these relationships requires time, understanding of local ways, and skilled leadership for partnership development. Time as a factor in developing partnerships is an important implication for both funders and academic institutions, in that the length of time to complete community-based research projects with Mi'kmaq and other Aboriginal communities can be long, given the actions needed to develop partnerships. Additional time and financial resources should be built into project timelines and budgets to account for relationship building that often involves travel between communities and campuses, face-to-face meetings over meals, and recognizing the contribution of participating Elders

through honoraria and other culturally appropriate protocols (e.g. small gifts of appreciation). Likewise, administrators (i.e. Department Heads/Directors and Deans) at academic institutions could support researchers who participate in research with these communities by allowing them more time to complete their research. For example, universities could reduce teaching schedules and administrative duties for researchers doing Aboriginal research in order to give them more time to participate in CBPR. They could also revise their Tenure and Promotion guidelines to instruct their Tenure and Promotion committees to take into account the time needed to undertake research with Aboriginal communities. The Tenure and Promotion committees could also be educated about how long it takes researchers to do CBPR with Aboriginal communities.

The interviews revealed that both the health directors and the researchers thought that it was important for the researchers to support the communities to be as engaged as possible in the research, but that the communities should not be overburdened by the research. The health directors expressed their appreciation of researchers who involved them with important aspects of the research such as the review of transcripts and analysis, but said that they and their staff (tasked to be part of research advisory committees, for example) would often prefer not to be provided with all the details that go into the research because they do not have the time to be extensively involved. Staff, they said, did not have a lot of time to devote to research as they have other jobs and responsibilities that do not allow them enough time to participate fully in the research. Articles 9.2 and 9.10 remind researchers that it is up to the community to decide how much they want to be engaged in the research activities but that researchers should do what they can to support their involvement.

The second finding shows that long-term, well-established relationships between researchers and Nova Scotia Mi'kmaq communities resonate with the principles laid out in Chapter 9 of the TCPS2. The health directors spoke about researchers who have long-term relationships with the communities and their discussion revealed that these researchers participate in ethical research with the communities and follow the TCPS2. That is, the health directors said that the researchers they regularly work with support the communities' aspirations to have more control of the research, support research capacity building activities in their communities, use a research agreement when both parties agree that it is needed, submit research proposals to local Aboriginal ethics review committees in addition to the universities, ask the community partners to review any analyses or draft reports for comments/verification, give credit to the community in final reports, are respectful in their approach with the community, and they are trustworthy. Many of these actions and behaviours are described in the Chapter 9 articles.

The health researchers also reflected on the Chapter 9 articles when they spoke of their experiences working with the Mi'kmaq communities and said that relationships with the communities were key to being able to partner with them. Building trusting relationships was crucial to the long-term research partnerships the researchers spoke about and to their adherence of Chapter 9 whether they were intimately familiar with the text or not. The interviews with researchers confirmed that they were, indeed, adhering to Chapter 9. For instance, they said that they would not consider doing research in the Mi'kmaq communities without a collaborative partnership and without involving the communities in all stages of the research, from developing the proposal to disseminating the results.

In short, interviews with participating health directors and researchers revealed how important those relationships were to ethical research. In order to nurture those relationships, universities need to support researchers who work with these communities by giving them extra time to do the research in order build these critical partnerships. Financial services could release the funds necessary to support activities to help build these relationships. For example, funding would need to be given to support multiple meetings with the communities and to support community members' participation in those meetings and in other research activities. University financial policies would need to be flexible to encourage and support community participation in research.

The preceding section highlights how the Chapter 9 articles of the TCPS2 support ethical research in Mi'kmaq communities in Nova Scotia and how important respectful, long-term relationships between the communities and researchers are to ethical research. The remaining discussion focuses on the barriers to ethical research in these communities and ways to reduce those barriers.

5.2 BARRIERS TO ETHICAL RESEARCH IN MI'KMAQ COMMUNITIES

There are barriers to ethical research in Mi'kmaq communities including my third finding which shows that there is a general lack of capacity in Nova Scotia Mi'kmaq communities to participate fully in research. Although communities want more control of research, they are sometimes unable to do so because they either do not have the capacity to be more meaningfully involved in research or they do not have the time to be fully engaged in the research process. Capacity building was a key concern for the health directors and they said that ways to support that capacity needed to be available. They also said that community members should be educated on the importance of data and how

it could be used to improve their lives. Articles 9.13 and 9.14 support Aboriginal community research capacity and state, for example, that researchers should enhance that capacity by training and educating community personnel in research methods, project management and ethics reviews (CIHR, NSERC & SSHRC, 2010). These training responsibilities will undoubtedly require additional time and resources and these need to be built into research project timelines and research budgets.

As mentioned earlier, any activity directed at increasing or supporting research capacity in the communities requires financial support. The financial support is needed to train community members in research methods and to help them travel to research meetings because without this training and financial support, they may not be as fully engaged in the research as is necessary. Supporting engagement with Aboriginal communities can help to prevent unethical research from taking place in their communities and it can help make the research relevant to their needs. Financial support is an important implication in research projects and researchers should be aware of this and support activities aimed at increasing engagement in order for research to have the intended impact in the community.

Capacity building does not guarantee that research will have the desired effect (Bull, 2010), but it does make it more likely to be the case. Researchers and funding agencies like CIHR need to be aware that without the community's full participation in research, the research is less likely to be helpful. Sufficient funds that meet the needs of Aboriginal people who may not have access to banks and ATMs or vehicles to get to meetings are crucial to supporting community engagement. Likewise, funds to provide community members who volunteer on research advisory committees with training about

research methods helps ensure that they are better informed about research and more likely to recognize unethical research practices in their communities. Researchers need to make sure that the funds are available in their budgets for community partners to be as engaged as they want to be in research and funding agencies need to provide enough funds to make full engagement possible.

It is worth noting here that although Mi'kmaq communities want to initiate and have more control of research, my interviews with the researchers and health directors revealed that much of the research continues to be conducted by non-Aboriginal researchers working with the communities. Initiatives such as the ACADRE and NEAHR programs (see footnote #6), both of which have ended, were introduced in part to increase the number of Aboriginal researchers, yet in Nova Scotia and nation-wide, there remains a shortage of university-trained Aboriginal researchers available to participate in or co-lead research with the communities. A re-organized focus on supporting the capacity of Mi'kmaq and other Aboriginal communities in research is needed so that communities can participate in and control research in their communities. Additional funding to build that capacity continues to be needed at the regional and national level, through programs similar to the ACADRE and NEAHR that were aimed at increasing research capacity in Aboriginal communities and which both successfully supported that capacity in the past (Richmond, Martin, Dean, Castleden & Marsden, 2013).

The fourth finding shows that REB representatives and some researchers find the articles in Chapter 9 to be vague at times, leading to some confusion about their application. Both groups had criticisms of the articles in the chapter, not so much in

terms of intent, as both were supportive of the chapter, but rather in terms of the ambiguity of some of the content/wording. Suggestions to improve the chapter included providing more detailed descriptions or recommendations for each of the articles (e.g. clarify what constitutes a community (Articles 9.2 and 9.4) or engagement with the community (Articles 9.2 and 9.10)), with real life examples added. Both groups said that they did not feel that the examples given with the articles were sufficient and that they did not provide enough instruction about how to conduct research that was ethical.

This lack of comfort with the chapter could however, be related to how long researchers have worked with Mi'kmaq communities, how long REB representatives have been involved in ethics reviews, and whether or not they knew much about Aboriginal research, as experience would inevitably have impacted both group's understanding of ethical research with the communities. Experience partnering with Mi'kmaq communities in research or being part of an REB that regularly reviews Aboriginal research proposals does not always safeguard one from making unethical decisions in research, but it could make it less likely to occur.

Research ethics board representatives were more critical of the chapter than researchers because they were uneasy with having to interpret information both in the chapter and in ethics applications. The REB representatives said that the impact of poorly worded or insufficient information in the chapter led researchers to misinterpret the articles which resulted in additional revisions of ethics applications. There may also be instances where REB representatives misinterpreted the articles. In one of the interviews, an REB representative was critical of a researcher who stated in their ethics application that they would give the community's raw data back to them. The REB representative

said that this was unethical, but according to the OCAP™ principles, this is an ethical practice when Aboriginal communities are involved. The OCAP™ principles were developed by the Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey (Schnarch, 2004), now referred to as the Regional Health Survey, to guide activities around the implementation of the survey developed by this committee. In this case, there was no question about who owned the data. But, there are other initiatives where ownership of data is not so clear cut. For instance, in joint research initiatives, it is up to the partners to decide together who owns the data and who has access to it. Such decisions are typically laid out in a research agreement. For those communities and organizations that have adopted the OCAP™ principles, it can be ethical for them to be provided with the raw data, particularly if that was agreed to in discussions prior to the commencement of the research and this is outlined in Chapter 9 in Article 9.8. Issues surrounding OCAP™ are complex and where university policies and the OCAP™ principles are at odds with each other, such as the storage of raw data, Chapter 9 recommends that this should be resolved prior to the start of the research. Research ethics boards need to be aware that scenarios involving OCAP™ are varied and should not be reduced to a rule that applies to all situations.

Research ethics board members need to be aware that there are other codes of conduct (e.g. OCAP™) that need to be respected when conducting research with Aboriginal communities and that certain accommodations should be made. One way of doing that is to create a sub-committee of REB reviewers with expertise in this area. York University is an institution that has established such a protocol. In 2011, in recognition of the complexities of research involving Aboriginal people, the university

established a consulting advisory committee composed of Aboriginal researchers, students and scholars representing many communities that was tasked to provide advice to the REB on ethics protocols, policies and procedures as they relate to research involving Aboriginal people (York University Secretariat Policies, 2013). By creating similar committees at other universities, confusion surrounding the review of proposals involving Aboriginal people/communities can be reduced and ethical research practices supported.

One of the implications of vague wording in Chapter 9 is that often additional time is needed to proceed through an ethics review because of multiple revisions. That is, one REB representative said that when they are unclear about things like ‘community’ in research involving Aboriginal people, they defer to the researchers to work through the issues which requires revisions to their applications. The added work for the researcher and their Aboriginal community partners can be a burden to both. Additionally, the need to make revisions can be frustrating for both the researcher and Aboriginal community partners, and could ultimately risk the research not proceeding. Clear wording and better examples are needed in the Chapter 9 articles to eliminate the additional burden placed on those involved in Aboriginal research. Although it is important to be clear in the Chapter 9 articles, it is advisable that they are not too prescriptive as Mi’kmaq communities in Nova Scotia and other Aboriginal communities elsewhere are diverse and some flexibility is required to meet the varied needs of these communities.

Another issue identified by the REB representatives was the lack of clarity about the role of Aboriginal ethics review boards and committees (Articles 9.3 and 9.9), such as the Mi’kmaw Ethics Watch. Even though there was general support for such bodies, the

process to engage and include them in the ethics reviews was not clearly laid out in Chapter 9, according to participants. More prescriptive instructions about how to include Aboriginal ethics review bodies in the reviews are needed. They also felt that the extra ethics review process would add an additional burden on the researcher and could jeopardize Aboriginal research, in that academics would avoid this type of research because of the extra time and work needed to be granted ethics approval. Simplifying both ethics reviews could support those who want to advance Aboriginal research.

Finally, the vagueness of the articles in Chapter 9 could lead to paternalism by the REB toward applications involving Mi'kmaq communities, as uncertainty in the meaning or intent of the articles could lead to over-protection of the communities by the REBs. The REB representatives spoke of this possibility but said that the practice to over-protect could be reduced if Chapter 9 was more articulate in its wording and enhanced examples were provided.

The fifth finding shows that Mi'kmaq community-based health directors and institutionally-based financial services administrators have limited knowledge about the TCPS2, Chapter 9, and ethics reviews. The implication of this finding is that unethical research could be taking place in communities if the health directors do not understand the nuances of what academic perspectives on ethical research entail. Additionally, when financial services administrators, who are responsible for ensuring appropriate spending on research grants at the universities, do not understand what ethical research is in Indigenous spaces, they may be less likely to approve requests that support ethical research in the communities. For instance, providing gifts such as tobacco and honoraria to Elders is a form of reciprocity that recognizes their valuable input in the research. This

practice is common in Mi'kmaq and other Aboriginal communities and acknowledgement of that practice by universities and the policies that regulate how their grant funds are spent, supports ethical research in the community.

The underlying core principle of the TCPS2 is that all humans are worthwhile. Underlying this respect for human dignity is the notion that people have to be treated fairly and equitably in research so that they are not harmed by research and that they benefit from research. In the case of Aboriginal people who have not been treated fairly or equitably in research in the past, special consideration must be given to them so that they are treated justly in research (CIHR, NSERC, and SSHRC, 2010). Thus, while Mi'kmaq communities want more research control, it is worth noting here that health directors in some of these communities in Nova Scotia have limited knowledge about Chapter 9 and about ethics reviews which should remind the REBs that thorough reviews are needed to ensure that ethical research is being supported in these communities so that they are not harmed by research and that they benefit from it. Feedback to researchers about potentially unethical issues related to research with Mi'kmaq communities is essential and the REBs have an important role to play here. It is necessary, therefore, that REB members are familiar with CBPR, Indigenous research methodologies¹⁴, and Chapter 9 of the TCPS2 so that they can pinpoint areas of concern in applications they review. At the same time, without the lived experience of actually doing this research (the rhetoric versus the reality tension noted in Castleden et al., 2012), it can be difficult

¹⁴ Indigenous research methodologies are described by Margaret Kovach in her book, *Indigenous Methodologies* (2009) as the theory and method of conducting research that flows from an Indigenous epistemology. Epistemology is a system of knowledge that “references within it the social relations of knowledge production” (Kovach, 2009).

to do so. Meanwhile, the health directors expressed a lack of understanding about the role of Aboriginal ethics boards, such as the MEW, in the review of research proposals in their communities. Periodic discussions between the communities and the MEW could improve the understanding of the role of the MEW in protecting the Mi'kmaq communities. Likewise, such meetings could result in both the communities' and Aboriginal ethics boards' improved understanding of what is ethical research in the communities.

Lastly, the sixth finding shows that some university-based financial services administrators and REB representatives have a lack of understanding about the realities of conducting research in Nova Scotia Mi'kmaq communities. Interviews with researchers who spoke of their interactions with financial services and REBs held the perception that some REB members do not fully understand the tenets of CBPR, and that some financial services administrators do not have a good understanding of the financial position of those living in the Mi'kmaq communities, nor do they understand what ethical research means in the context of Indigenous communities. That is, researchers criticized the REBs that requested detailed research plans before the research was initiated, articulating that CBPR is emergent or evolves over time and that having strictly laid out plans at the outset of the research is counterproductive to this form of research.

Furthermore, the researchers spoke of the requirement for lengthy or complicated consent processes for participants by some REBs. Outside of the focus on REBs and financial reporting, researchers expressed concerns about CIHR's requirement for community partners to complete the Common CV. Both of these processes, they claimed, can be complicated and some community members may not be comfortable with the

wording of lengthy consent forms or in completing the Common CV, both of which can make a person feel incompetent or inferior. Not only is the Common CV complicated, it does not allow for spaces to showcase Indigenous knowledge but rather focuses largely on demonstrating Western academic accomplishments. Anecdotally, there may be some confusion about whether or not community partners are required to complete the Common CV or instead show their accomplishments/abilities/contributions in proposals in other less onerous ways, such as providing a resume with a cover letter. The application requirements of community partners should be clearly articulated by CIHR and should be similar across all initiatives involving these partners.

Criticisms directed at some of the financial services administrators by the researchers included the assertion that these administrators have an inadequate understanding that some Mi'kmaq research participants do not have enough money to cover their research expenses, or that some may not have a credit card to book a hotel room and await compensation, for example. One of the researchers claimed that it was unethical for financial services administrators to ask for the names of research participants for financial accountability, concluding that this was a breach of confidentiality. The individual did not, however, seem to know that financial services administrators are also bound to the same confidentiality requirements of the Tri-Council policies that researchers must adhere to. The financial services administrators also revealed in interviews that one of the main reasons why they were inflexible in grant administration was that they were apprehensive about being audited by Tri-Council and that being in 'good standing' with the Tri-Council is an essential aspect of their positions. There could, therefore, be a problem with the institutional relationship between financial

services and researchers for example, in that there appears to be a misunderstanding about what each other does, and their motivations.

This general lack of knowledge about the life circumstances of those living in the Mi'kmaq communities and/or about CBPR could negatively impact the participation of some Mi'kmaq people in research as they may not proceed beyond the consent phase or they may not agree to partner on a project because they do not want to, or are unable to complete lengthy and complicated procedures, such as the Common CV. Requiring detailed work plans ahead of the initiation of the research could dissuade Mi'kmaq participation because if plans are already laid out in advance, their ability to have more control of the research is diminished and their lack of involvement in decision-making, in what should be collaborative research, can be regarded as disrespectful. Nominal involvement may be preferable for some, as the degree of involvement should be decided by the community, but it can reduce the effectiveness of the research and can result in unethical or meaningless research in the community.

Ignoring the financial circumstances some face in the Mi'kmaq communities could also deter participation, as requiring those who cannot afford to pay for research expenses out of pocket for activities such as travel to a research meeting with reimbursement later is not realistic. Finally, and perhaps most importantly, by not providing accommodations in ethics reviews, such as including someone on the REB with a good understanding of Aboriginal issues/concerns and relevant methodologies, this could jeopardize the ethical conduct of research in Mi'kmaq communities. For instance, approving ethics applications without an understanding of the complexities of life in the Mi'kmaq community could result in harm to the community. Likewise, there could be

political ramifications for those partnering in research in some of the communities.

Article 9.9 in Chapter 9 recommends that when ethics applications regularly involve Aboriginal communities, the REB membership should be modified to ensure that someone on the board has a good understanding of Aboriginal cultures and customs.

Research ethics board members and financial services administrators should be educated about Mi'kmaq communities (e.g. social and political aspects) to reduce the risks associated with a lack of pertinent knowledge. Research ethics boards can initiate that education by inviting researchers and others with a good knowledge of the Mi'kmaq communities to meet with them to better inform them about Mi'kmaq communities and about CBPR or Indigenous methodologies, and by also committing to ensuring that at least one REB member has a good understanding of Mi'kmaq communities. Financial services can also become better informed about life in the communities through similar types of meetings and by committing to finding more ways to be flexible in supporting ethical research in the communities while also being accountable to funding agencies.

5.3 LIMITATIONS OF THIS RESEARCH

There are limitations in my research including the fact that I did not interview many REB representatives and financial services administrators as the scope of my study was four universities in Nova Scotia and I only wanted to interview those with the most experience from each group. By excluding other REB representatives and financial services administrators, I may have omitted some important perspectives related to Chapter 9 and research involving Mi'kmaq communities. Also, as data saturation did not seem to happen in the case of the REB representatives or the financial service administrators, possibly because I was not able to recruit as many participants for each of

these groups, important viewpoints could also have been overlooked. I also selected researchers who had more experience in Aboriginal research, but had I selected other researchers with less experience with Aboriginal research, I may have had different results. Without the input of all health directors of the Nova Scotia Mi'kmaq communities, I may have missed some findings that could have made the information relevant to all Mi'kmaq communities in the province. Lastly, my findings are limited to the Mi'kmaq communities in Nova Scotia and should not be assumed to be representative of other Aboriginal peoples/communities in Canada. This, however, is not meant to imply that my findings are not transferable to other Aboriginal communities in Canada, as my findings can have application in research involving them. Despite these limitations, the nature of my exploratory qualitative study was to look at how the TCPS2 was being used in Mi'kmaq communities and to document any challenges related to the ethical conduct of research in these communities, and as I accomplished this task, the data I gathered is still meaningful and can be useful for future research.

5.4 IMPLICATIONS OF THIS RESEARCH

The implications of my findings identify the need for revisions to Chapter 9 of the TCPS2 to eliminate the ambiguities identified by the researchers and REB representatives interviewed for this study. Additional work should be done to make the articles less vague by providing better real-life examples of how the articles could be applied in research involving Mi'kmaq and other Aboriginal communities. But, given the diversity of Mi'kmaq communities in Nova Scotia and other Aboriginal communities in Canada, caution should be taken to ensure that the TCPS2 articles do not become too prescriptive, as a one-size-fits-all set of guidelines can jeopardize research partnerships. Discussions

with the communities, health researchers, REB members and financial services administrators could help the Tri-Council to improve not only Chapter 9 of the TCPS2, which is a vital component of the ethical conduct of research in these communities, but also the other Tri-Council policies that exist and work (unintentionally) to counteract the goals of the TCPS2, in this case, specifically the “allowable expenses” as laid out in the Tri-Council financial policies.

Finding ways to support Mi’kmaq community capacity for research (e.g. through training opportunities and funding), researchers’ ability to participate in that research (e.g. through ‘teaching release’), and improvement of the well-intentioned Chapter 9 of the TCPS2 (e.g. by clarifying the articles and providing real-life examples) could help ensure that ethical research takes place in Mi’kmaq communities in Nova Scotia and in other Aboriginal communities elsewhere. Finally, reducing the barriers to CBPR that exist at both the REB and financial services levels is needed. For instance, preventing the feelings of inadequacy that can arise when community members are asked to complete complicated academic consent forms and the Common CV is essential to successful partnerships. One way to do this is for REBs to encourage and support the use of simplified, one page consent forms when language and education are concerns. This accommodation has been supported at the University of Calgary which has acknowledged that standard clauses in the university’s consent forms are long and awkward and that one page versions of informed consent could be used (Meadows, Lagendyk, Thurston, & Eisener, 2003).

Adding more than one person with Aboriginal research experience or knowledge of the communities to the REB would help to identify issues of concern, because by not

having enough people on the REB with that experience or knowledge, applications involving Aboriginal communities tend to be targeted for full-board review, even when they do not need that type of review. Also, allowing more time for the application stage of funding initiatives can increase the number of collaborations, as short time frames discourage participation by Mi'kmaq communities as was pointed out by one of the health directors during the focus group. Accommodations such as revising the articles in Chapter 9 to make them less ambiguous, finding ways to support the capacity for Mi'kmaq participation in research, simplifying research processes that encourage community participation, and adding people with knowledge and experience of Aboriginal communities to REBs are essential to supporting ethical research in these communities. Ways to address these considerations are areas that can be studied in future research related to research with Aboriginal communities.

In this study, I looked at how Chapter 9 was being used in Mi'kmaq communities in Nova Scotia by interviewing health directors working in those communities and researchers, REB representatives and financial services administrators at universities in the province. I identified ways that Chapter 9 needed to be improved, and I identified barriers and challenges to ethical research in these communities. In the following concluding chapter, I provide comments about how the findings relate to the literature and I summarize the impacts of my research. I also identify future research directions and provide recommendations to promote and support ethical research in the Mi'kmaq communities in Nova Scotia.

CHAPTER 6 CONCLUSION

6.1 INTRODUCTION

The goals of this study were to explore how Chapter 9 of the TCPS2 is implemented and adhered to in health research involving Mi'kmaq communities in Nova Scotia, to identify obstacles in applying Chapter 9 in research involving these communities, and to recommend solutions to reduce those barriers. To meet these goals, qualitative data derived from in-depth interviews with researchers, REB representatives and financial services administrators employed at Nova Scotia universities and a focus group of health directors working in the Nova Scotia Mi'kmaq communities were analysed. This chapter provides a summary of my key findings and I discuss how the findings relate to the literature. I also summarize the impact of my study on Mi'kmaq communities, policy and academia, including directions for future research. Lastly, I provide recommendations aimed at supporting the ethical conduct of research in Mi'kmaq communities in Nova Scotia and end the chapter with closing comments.

6.2 KEY FINDINGS

Using a thematic analysis of data gathered from the focus group of health directors working in Nova Scotia Mi'kmaq communities and semi-structured interviews with university-based REB representatives, financial services administrators, and researchers at four Nova Scotia universities, six main themes emerged from the data including: 1. Mi'kmaq communities in Nova Scotia are seeking more control of the health research conducted in their territory and Chapter 9 supports their aspiration; 2. Well-established relationships between researchers and Nova Scotia Mi'kmaq communities

support the researchers' adherence to the Chapter 9 articles of the TCPS2; 3. There is a lack of capacity in Nova Scotia Mi'kmaq communities to be better engaged in research; 4. Research ethics board representatives and some researchers find the articles in Chapter 9 to be vague at times, leading to some confusion in their application; 5. Community-based health directors and institutionally-based financial services administrators have limited knowledge about the TCPS2 and Chapter 9; and 6. University-based financial services administrators and REB representatives sometimes have a general lack of understanding about the realities of conducting research in Nova Scotia Mi'kmaq communities.

Overall, the study showed that Chapter 9 of the TCPS2 has had a positive impact on research in Nova Scotia Mi'kmaq communities and it has contributed to the emergence of ethical research in these communities. Mi'kmaq communities in Nova Scotia are seeking more control of research and the articles in Chapter 9 support that control. Additionally, established relationships between Mi'kmaq communities and health researchers working with the communities support researchers' adherence to the articles in Chapter 9. The findings also showed, however, that there are barriers to ethical research in Mi'kmaq communities because there is a lack of capacity in the Mi'kmaq communities to fully participate in research, the information in Chapter 9 is somewhat vague, the health directors and financial services administrators have limited knowledge about Chapter 9 and the TCPS2, and the financial services administrators and REB representatives have a lack of understanding about how research is carried out in the Mi'kmaq communities.

The first finding that Mi'kmaq communities are seeking more control of research is consistent with the literature which shows that other Aboriginal communities in Canada and elsewhere are also seeking more control of research (Schnarch, 2004; Weir & Wuttunee, 2004) and the TCPS2 acknowledges that First Nations, Inuit and Métis communities in Canada are engaging in initiatives to assume decisive roles in research (CIHR, NSERC, & SSHRC, 2010).

The second finding that well-established relationships between the researcher and community help ensure ethical research is also discussed in the literature (e.g. Bull, 2010). Without these established relationships, it would be difficult to make the case that research can benefit the communities. In order to facilitate these research collaborations, relationships built through trust and reciprocity are essential. 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). Furthermore, well-established research partnerships can result in research that helps to eliminate health disparities that may exist in the communities, as partnerships can facilitate the use of culturally-sensitive research designs and methodologies and be more responsive to the concerns of the community (Cochran et al., 2008).

Along with the positive aspects of these research collaborations come challenges. One obstacle to these collaborations is the third finding showing that there is a lack of capacity in the Mi'kmaq communities to be better engaged in research. Despite aspirations to have more control of the research process, a lack of research capacity can sometimes make this difficult for the Mi'kmaq to achieve. That is, asking health directors

and others in the community to contribute to the development of the research design and analysis when they have limited research capacity is unrealistic. This lack of research capacity has also been seen in other Aboriginal communities (Cochran et al., 2008). A lack of research capacity could be addressed through capacity building activities involving training in research methods and the hiring of community members as research assistants. Programs similar to the ACADRE and NEAHR programs can also support research capacity by funding those who want to learn how to do research through academic programs or at the community level by providing small pilot project grants that allow community members to learn about research methods, for example.

Another obstacle to these collaborations is that there are limited resources available for the development of relationships that support these research collaborations. Meadows et al., (2003) write about the challenges of ethical research with Aboriginal communities and say that it is important that researchers include in research budgets adequate funds to allow ethical research to proceed. For instance, funds are needed to support engagement with the community, reporting findings back to the communities, and for the provision of honoraria. Brant Castellano (2011) discusses this topic as well and says that while the TCPS2 is not a funding document, it has been adopted by the Tri-Council so the three agencies need to ensure that their funding policies fit with their ethical requirements. She says that researchers argue, for example, that they cannot engage with communities without funding to do so and there is no line item in funding applications for that work. She recommends that universities and professional organizations push the Tri-Council to ensure that funding provisions are available in order to conduct ethical research in accordance with the TCPS2. It is also important to note

that in addition to ensuring that funding policies fit the Tri-Council's ethical requirements, how those policies are operationalized and understood by peer-review committees and financial services employees is critical to achieving those ethical requirements.

Finally, while collaborative research like CBPR provides a way to overcome the legacy of unethical research of the past, the unanticipated ethical issues that may emerge in such research, such as offering substantial honoraria that may encourage economically disadvantaged people to participate in research or the dissemination of unflattering findings should be acknowledged ahead of time to eliminate any possibility of harm to individuals and the community (Flicker, Travers, Guta, McDonald, & Meagher, 2007). Bull (2010) writes about the importance of authentic relationships in ethical research with Aboriginal communities, but cautions readers that authenticity is not always synonymous with ethical research because "the ideologies and theories of how to conduct ethical research, and the practice of conducting ethical research" may differ among researchers and Aboriginal research partners (p. 19). Research ethics board members should be aware of the possible ethical issues that could arise with these collaborations and should plan accordingly by developing clear policies about how to address such concerns should they arise in proposal reviews or after they have found problems with the way research is being conducted in the community. For instance, REBs could have a policy that outlines what a dissemination plan should include to reduce potential repercussions of negative findings. Non-Aboriginal researchers need to also be aware of these issues by learning as much as they can about the community and Aboriginal values, culture and ethics before collaborative research is initiated. By doing these things, researchers, REBs and financial

services administrators can do their part to support ethical research in Mi'kmaq communities in Nova Scotia.

The fourth finding that REB representatives and some researchers find the Chapter 9 articles vague is discussed briefly in the literature. My interviews showed that the researchers and REB representatives are looking for direction from the Tri-Council about ethical research involving Aboriginal communities, given the ambiguousness of the Chapter 9 articles. The limited literature I could find about the TCPS2 and Chapter 9 does provide a brief overview of the challenges in writing the document. Brant Castellano (2011) describes the experiences of those who wrote Chapter 9 and said that the document had to take into account the diversity of the Aboriginal peoples of Canada (First Nation, Inuit and Métis), their locations (urban, rural), and the variations in culture (traditional, acculturated). There are also other constituents involved including researchers, institutions, policy makers and funding agencies. Inevitably, it was important that the writers found a balance that respected the needs of all the stakeholders (Brant Castellano, 2011). Furthermore, as the TCPS2 is an overarching policy for the three federal research agencies in Canada, it had to be broad enough so that it met the needs of all the research traditions that fall within the purview of the three agencies (Brant Castellano & Reading, 2010).

While the challenges that arose from the need for generalizability were discussed in the literature, the explanation for the vagueness of the articles in Chapter 9 is not clearly explained in its introduction in the TCPS2. There is acknowledgment that the chapter is a living document that will have to be revised as more information about its implementation becomes available. What is of particular interest in the introduction is the

statement that the document provides guidance for research involving humans, and that *other* guidelines exist that are more specific to particular programs, research disciplines and communities, so researchers and REBs are advised to consult those documents when the need arises (CIHR, NSERC, & SSHRC, 2010). It is clear from this statement that Chapter 9 is somewhat general and should not be used solely in the preparation of research proposals or in the reviews of such proposals by ethics review boards. The *CIHR Guidelines for Research Involving Aboriginal People* provides more specific information related to ethical *health* research in Aboriginal communities. These particular guidelines were in effect from 2007 to 2010 and are now archived on the CIHR website, but are easily found; it was evident from the outset that Chapter 9 was a ‘replacement’ for the CIHR guidelines. SSHRC has also developed *Guidelines for the Merit Review of Aboriginal Research* to complement TCPS2 and Chapter 9 (SSHRC, 2015).

Although the TCPS2’s Chapter 9 was written broadly to be inclusive of all three research agencies, the resulting vagueness requires that the chapter be revised to reduce the varying interpretations that invariably occur. How that can be achieved is unclear, given that the articles have to meet the needs of a number of stakeholders and must take into account that Mi’kmaq and other Aboriginal communities are diverse. But, based on the discussions with the REB representatives and researchers, better examples of how the articles can be applied in Aboriginal settings are needed, while also ensuring that they are not overly prescriptive. Though the chapter’s scope meets the needs of the three federal research agencies, it does not entirely meet the needs of universities tasked to implement the guidelines, nor does it fully meet the needs of researchers tasked to do ethical research

with Aboriginal communities or the needs of the communities themselves. Furthermore, the introduction to Chapter 9 should urge readers to use additional resources which describe the issues more thoroughly (e.g. *CIHR Guidelines for Health Research Involving Aboriginal People*). Research ethics boards and researchers need to undertake greater efforts to understand the nuances of the articles in Chapter 9, by better educating themselves through the use of complementary resources such as the CIHR Guidelines, but also by hearing from others who have plenty of research experience working with Aboriginal communities and from Aboriginal people with knowledge about the communities, including community Elders.

Finally, there are inconsistencies in the chapter that could lead to confusion among researchers and REB members. For example, at one point in the chapter, it says that the communities' aspirations to control research should be supported but in another section it says that academic freedom is necessary. In Article 9.17, it specifically states that if the community and researcher disagree over the interpretation of the data, that the community should be given the opportunity to contextualize the findings, but not necessarily the ability to block the publication of findings. These competing ideas can sometimes be difficult to reconcile. When such tensions emerge, it is important that a compromise is reached among research partners. The TCPS2 could provide additional recommendations about what to do when tensions such as these arise.

The fifth finding that Mi'kmaq community-based health directors have limited knowledge about the TCPS2, Chapter 9 and ethics in general is rather specific and is not discussed in the literature. Bull (2010) discusses the TCPS2 in Aboriginal research but focuses specifically on the Inuit, Innu, and Inuit-Métis populations in Labrador and

concludes that research capacity to improve knowledge is essential to ensure that ethical best practices are implemented. While the health directors working in the Mi'kmaq communities may have had limited knowledge of the TCPS2, and ethics reviews in general, other Aboriginal groups have a good understanding of ethics and have prepared documents to guide the ethical conduct of research in their communities or territories (e.g. Kahnawake Schools Diabetes Prevention Project's *Code of Research Ethics* and the National Aboriginal Health Organization's *OCAP™ Principles*).

Despite the health directors' limited knowledge of the specifics of Chapter 9, the TCPS2 and about what takes place in ethics reviews, they undoubtedly understand the differences between ethical and unethical research, as they were critical of unethical research that had been conducted in their communities in the past and emphasized the need for better research collaborations to protect their communities from harmful or unnecessary research in the future. Funds to support education sessions on ethical research and guiding principles would help to improve the health directors' knowledge of ethics reviews and of the TCPS2. Not surprising, I could find no peer-reviewed literature on whether institutionally-based financial services administrators had knowledge of the TCPS2 and ethics in general, or more specifically, what their knowledge is of Chapter 9 of the TCPS2 given this was generally perceived by my financial services participants as being outside the scope of their work. But what emerged from my research is that better institutional supports for financial services administrators who do 'quality control' on how researchers spend their grant funds are needed so that they can learn about what constitutes ethical research in the context of Indigenous communities. Without a good understanding of ethical research practices involving Aboriginal communities, they may

unwittingly create barriers to those ethical practices. However, given that they are following the policies of the Tri-Council on “allowable expenses”, the level of leeway that they have in supporting ethical research may be limited. What needs consideration is that the Tri-Council policies on “allowable expenses” should be revised to ensure that the policy supports ethical research with Aboriginal communities. For instance, revising the policy to permit community-based co-investigators to be paid from the grant could better support collaborative research with Aboriginal communities. Upstream changes such as at the financial policies level of the Tri-Council need to be considered in order to support ethical research with Aboriginal communities.

The final finding that some university-based financial services administrators and REB representatives have a lack of understanding about the realities of conducting research in Nova Scotia Mi’kmaq communities is not surprising given the narrow focus of responsibilities that financial services administrators have at universities and the diversity of disciplinary backgrounds of REB members. With the diversity of disciplinary backgrounds, it is conceivable that some REB members would have little knowledge of Indigenous research methodologies for instance, particularly if the REB does not have as a member someone with a background in Indigenous methodologies or knowledge of Aboriginal communities, although having knowledge of the communities does not necessarily guarantee that they will really grasp Indigenous methodologies. Some REB members may not have a good understanding of CBPR as well, because not all REB members are researchers, nor can they be expected to be knowledgeable about the various types of research methods and approaches. In a review of the perspectives of REB members about Aboriginal research, Flicker and Worthington (2012) noted that

most of their participants said that their REBs rarely reviewed community-based participatory projects, except in the case of Aboriginal research. Without much experience, it is likely that REB members would lack an understanding of Aboriginal research, and if Aboriginal research is limited at their institution, it is plausible that financial services administrators would also be unfamiliar about the realities of life in the Mi'kmaq communities.

Difficulties can occur when REBs defer to researchers to fill their gaps in knowledge as it creates an added burden on researchers. Moreover, the extra work and unclear articles in Chapter 9 could jeopardize Aboriginal research, as onerous reviews and uncertainty created by ambiguous information may discourage research in this area. But, by not encouraging research teams to consider the issues and find ways to resolve them, the REBs may be “unwittingly predisposing CBPR teams to not consider the full range of potential ethical issues” (Flicker et al., 2007, p. 486). Where gaps in knowledge exist, REBs need to provide accommodations such as the inclusion of people on the boards with that knowledge, so that fair and ethical reviews can take place. Financial services administrators could commit to becoming better educated about ethical research and about the socioeconomic conditions that some Mi'kmaq community members face to reduce the possibility of breaching ethics in the administration of Aboriginal research grants.

6.3 RESEARCH CONTRIBUTIONS

6.3.1 For Mi'kmaq communities

This study could benefit Mi'kmaq communities in Nova Scotia in that their opinions about ethical research will be heard. Hearing from them has the potential to influence the kinds of research practices that are used in their communities. How the academy views ethical research is often heard and written about in the literature, but it is as important that the voices of those who participate in research are heard in this debate as well.

This study will further benefit Nova Scotia Mi'kmaq communities in that participating in and hearing about the results of this research could improve their knowledge about ethical research, helping them to be better informed about the benefits and potential harms of research, thus making them more informed participants in the research process. It is conceivable, however, that there may be little perceived benefit to those who directly participated in the study, and that the primary benefit would be to the advancement of knowledge in this area.

6.3.2 For Policy

The results of this study could be used to help improve future iterations of Chapter 9 of the TCPS2 in that the identification of barriers to the application of the chapter's articles could help the Tri-Council address those barriers. For example, several participants noted that the wording in the chapter could be improved to further the understanding of the ethical issues that occur in research with Aboriginal peoples.

To ensure that more effective and ethical research is done in the communities, the Tri-Council could improve funding policies that better support the kinds of research methods

and approaches the Nova Scotia Mi'kmaq communities want. Helping university administrators (i.e. Department Heads/Deans) to understand which methodological approaches to research better support ethical research in these communities could also support those who work with these communities. For example, partnering with Mi'kmaq communities in CBPR could be a time-consuming process, but it could help to effectively address health disparities. Research approaches that focus on the needs of the Mi'kmaq communities can help to reduce the potential for research to be ineffective or unethical. If university administrators and decision-makers better understood this, researchers based at universities could be better supported by their employers in their decision to conduct collaborative, respectful and ethical Aboriginal health research.

Lastly, health promotion calls for the active participation of individuals and communities in the development of programs and services that impact their health. The results of this study showed that Chapter 9 of the TCPS2 promotes more active Mi'kmaq involvement in health research. Policies, such as the TCPS2 (Chapter 9), that support Mi'kmaq control of research as well as their active participation in it can help to promote ethical research that is more meaningful to the communities, and therefore, more likely to have the intended impact of promoting and improving better health in the communities.

6.3.3 For the Academy

The findings from this study will contribute to the body of knowledge about ethical health research involving Aboriginal communities in Canada. Effective strategies to address their health inequities (e.g. intervention research) are important and supporting effective research collaborations are needed. Recommendations about how to improve Chapter 9 of the TCPS2 could also help clarify questions researchers and REB members

could have about research with Aboriginal people which could lead to better research outcomes for both the researcher and Aboriginal community.

Challenging traditional research paradigms, texts and theories, which is emblematic of critical race theory was one of the reasons I wanted to study the impacts of Chapter 9 on research in Mi'kmaq communities in Nova Scotia. That is, I wanted to find out if these national ethics guidelines could support research that matters to Mi'kmaq communities. This study has shown that Chapter 9 encourages researchers to allow for Mi'kmaq control of research and ways of knowing that have meaning for the community. For instance, Article 9.8 calls for researchers to be informed about and respect community codes of research practice so that sacred knowledge is protected. Article 9.15 encourages researchers to engage with Elders and other knowledge holders in the community to help design the study and interpret the results in ways that are consistent with their traditional knowledge and cultural norms. Chapter 9 supports the use of Indigenous methodologies, and with its encouragement of Aboriginal community control of research, supports the notion that Mi'kmaq communities should choose research methods that work for them, and not just accept those prescribed by western-trained academic researchers.

6.4 DIRECTIONS FOR FUTURE RESEARCH

My findings showed that Chapter 9 of the TCPS2 should be revised, based on outreach to and direction from Aboriginal communities to eliminate the ambiguities identified by the researchers and REB representatives interviewed for this study. Research can be undertaken on how best to make the articles unambiguous while also meeting the needs of multiple constituents and stakeholders. Identifying better real-life examples of how the articles could be applied in research involving Aboriginal

communities is needed and the Tri-Council could do this collaboratively with the communities, health researchers, REB members and financial services administrators. Research focused on building capacity in the communities and supporting researchers who would like to do Aboriginal research could be studied. Using the experiences of the ACADRE and NEAHR centres is one way to accomplish this task. Finding ways to improve the understandings of REB members and financial services administrators about the realities of conducting research in Aboriginal communities are needed to ensure that ethical research is supported in these communities. Finally, conducting policy analyses on the Tri-Council documents should be done to tease out the inconsistencies across them, such as a review of their financial policies to ensure that they support the articles in Chapter 9.

6.5 RECOMMENDATIONS

From the analysis of my interview data, I have compiled a list of recommendations that could be the focus of additional research and/or be used to promote ethical research in the Mi'kmaq communities in Nova Scotia. Although the recommendations are specific to the Mi'kmaq communities in Nova Scotia, they can also be useful to others who are seeking to enhance ethical research with other Aboriginal communities in Canada.

1. REB members should be trained about CBPR and Indigenous research methodologies.
2. Financial services administrators should be trained about ethics, the TCPS2, and CBPR.

3. Additional support and training should be made available for faculty and students who want to do CBPR with Mi'kmaq communities (e.g. time release from teaching courses and the requirement that they read the TCPS2 and Chapter 9).
4. Chapter 9 of TCPS2 should be revised, making the text and examples clearer and more substantive, including more real-life examples of how the articles could be applied in Aboriginal research. Aboriginal people/communities/organizations, health researchers, REB members and financial services administrators should be involved in talks to revise the chapter.
5. When a researcher and community differ in their interpretation of ethical research, they need to be encouraged by the REB to come to a compromise so that both parties are satisfied.
6. Aboriginal ethics review bodies, such as the Mi'kmaw Ethics Watch, should periodically communicate with their participating communities and with university-based REBs (and vice versa), so that both are informed about research in their communities.
7. The Tri-Council Agencies should provide the funds and resources necessary to provide support to Mi'kmaq communities in Nova Scotia that want to learn more about ethical research and about the TCPS2 and Chapter 9.
8. People with Mi'kmaq research experience (e.g. Mi'kmaq researchers) or a good understanding of the communities (e.g. Elders) should be included on REBs at a minimum, or a standing sub-committee of knowledge holders who could advise an REB when proposals involving Mi'kmaq communities are being reviewed should be created.

9. Funds should be made available in both Tri-Council funding initiatives and in research budgets (e.g. to hire community-based staff to coordinate research activities) to support research capacity in Mi'kmaq communities. Programs similar to the ACADRE and NEAHR initiatives of the CIHR Institute of Aboriginal Peoples Health should be funded to further support Mi'kmaq research capacity. The ACADRE and NEAHR programs provided graduate student scholarships and grants for community-based research projects, both of which were successful and some form of the same should continue to be provided to support better engagement in research by Mi'kmaq communities.
10. The Tri-Council should undertake a review of their financial policies to ensure that they are compatible with Chapter 9 of the TCPS2, as well as ensure that these policies do not create barriers to implementing Chapter 9 in Mi'kmaq and other Aboriginal communities in Canada.

6.6 CONCLUDING COMMENTS

While this study has shown that the Chapter 9 articles of the TCPS2 are being adhered to by most researchers doing research with Mi'kmaq communities in Nova Scotia, and that researchers and REB representatives find the articles useful in helping them to safeguard Mi'kmaq communities in research, the articles in Chapter 9 can be improved. My research has revealed that Chapter 9 supports the aspirations of Mi'kmaq communities in Nova Scotia to have more control of research. It has also shown how vital long-term, well-established relationships between the communities and researchers are to the researchers' adherence to the articles in Chapter 9 (whether they were

intimately familiar with them or not). These two findings illuminated some of the conditions needed to support ethical research.

At the same time, my study also revealed that there were challenges surrounding the adherence of Chapter 9, including a lack of capacity at the Mi'kmaq communities level to participate more actively in research, and a lack of understanding of Chapter 9, the TCPS2, and ethics reviews by health directors working in the Mi'kmaq communities and by financial services administrators at some universities in Nova Scotia. Other challenges included the vagueness of some of the articles in Chapter 9 and that some REB representatives and financial services administrators had a lack of understanding about the realities of conducting research in the Mi'kmaq communities. These findings can jeopardize ethical research in the communities; solutions to those barriers are therefore needed.

My research is an important contribution to the body of literature on ethics in Aboriginal research because discerning how Mi'kmaq community health directors, university-based researchers, REB representatives and university financial services administrators interpreted and implemented Chapter 9 of the TCPS2 provided new knowledge about the supports and barriers to ethical research in Mi'kmaq communities. New knowledge about the application of the TCPS2 in research with these Mi'kmaq communities is important as it can give researchers, health directors, and others working in the Mi'kmaq communities some of the information they need to decide which research approach/practice could work best in the participating community prior to the start of the project.

Finally, the comments provided by the participants may now be used to improve Chapter 9 of the TCPS2 to further guarantee that its contents support ethical research with Mi'kmaq and other Aboriginal communities. More importantly, collaborative research, like CBPR, supports the community's ability to find solutions to health and social problems, as it is the community that ultimately knows what works best for them. Collaborative, ethical research is essential to helping Mi'kmaq and other Aboriginal communities resolve their health concerns. This study has revealed that there are challenges to ethical research in these communities and that the vagueness of Chapter 9 may contribute to those challenges. However, it has also shown that these challenges are not insurmountable and that with Tri-Council and university will, as well as direction from Mi'kmaq community health and research leaders, solutions to these barriers can be achieved.

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APPENDIX A Introductory Email Letter

Dear,

My name is Carla Moore. I am a Master of Arts Health Promotion (MAHP) student at Dalhousie University. I am conducting a thesis study about the ethical tensions and institutional challenges associated with doing Aboriginal health research.

Your voluntary participation would involve an approximately 45-minute phone interview. I have attached the consent form for your information as it contains more information about the study. If you agree to participate, I will send you the signature page.

My thesis study, titled "Is this good research?: Considering the ethical and methodological implications of health research with Mi'kmaq communities in Nova Scotia following the implementation of the 2nd edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)" has been reviewed and approval granted by the Dalhousie University of Research Ethics Board and by the Mi'kmaw Ethics Watch.

I know that you are likely very busy with your own work but I hope that you see the value in participating in this interview, as the goal of this study is to explore how ethical tensions arise and by identifying existing barriers, generate strategies on how to minimize them so that new scholars and Aboriginal peoples/communities are not discouraged from undertaking a program of research in this field.

I am looking forward to hearing from you at your earliest convenience.

Sincere Regards,
Carla Moore, MAHP Candidate
Dalhousie University

APPENDIX B Consent Form

Consent Form (For Health Researchers, REB Representatives and Financial Services Administrators)

Research Project: Is this good research?: Considering the ethical and methodological implications of health research with Mi'kmaq communities in Nova Scotia following the implementation of the 2nd edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)

Principal Investigator: Carla Moore, MAHP Candidate, Dalhousie University

PURPOSE: The second edition of Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2010) has drawn attention to the need for researchers' to confront unethical conduct in research with Aboriginal peoples, communities, and organizations (specifically TCPS2, Chapter 9). However, Chapter 9 does not take into consideration the ethical tensions and institutional barriers that pose challenges to doing Aboriginal health research 'in a good way'. This study is investigating Nova Scotia Mi'kmaq communities' health directors', health researchers', REB Chairs', and Research Financial Services Administrators' responses to these new guidelines, and/or the ethical challenges and institutional barriers they face in implementing them in their research. By exploring how these tensions arise and by identifying the existing barriers, we can better strategize to minimize them. At the conclusion of this study, a report will be shared with the 13 Mi'kmaq communities in NS, the Aboriginal Health Research Network Secretariat and The Canadian Association of Research Ethics Boards (CAREB) as well as public dissemination through peer-reviewed scholarly publications, Mi'kmaq Maliseet Nation News, and conference/meeting presentations.

YOUR PARTICIPATION: Your voluntary participation involves a one-on-one phone interview for approximately 45 minutes at a time of mutual convenience. During this interview there are no right or wrong answers – I am interested in your viewpoint and experiences. This interview has four key themes: (I) General background about your experience with research ethics given your current role; (II) Your experience reviewing ethics proposals for research with Aboriginal peoples; (III) Your experience and opinions about working within the TCPS2 guidelines; and (IV) Institutional policies and practices. Your interview will be digitally recorded. I understand that you may have an issue with audio recording and you are free to decline participation as a result. Furthermore, all recorded comments will be used in the study, and as result, your comments may be used as part of Carla Moore's thesis research and in public dissemination but your name (or institution) would not be attached to those comments. Again, if you do not agree with this, you are free to decline participation. Careful measures will be taken to keep your information confidential and your identity will not be revealed. In addition, your participation or refusal to participate in the study would have no impact on your employment, and data would not be shared with your employer. Any descriptions in the final report would be minimal so as to prevent you from being inadvertently identified by someone who knows you. Lastly, you could be contacted by me after preliminary analysis

of the data has been done so that you have an opportunity to check the information for accuracy.

HOW THIS RESEARCH WILL BE USED: Direct quotes of what you say may be used in any dissemination but they will remain anonymous. Participants will only be identified as university administrators, ethics board members, or health researchers. Any oral or written presentations of the research findings will not have your name (or institution) attached to your quotes.

BENEFITS OF THIS STUDY: The information obtained from this research is being used to further our understanding of the ethical tensions and institutional barriers associated with Aboriginal health research. These tensions and challenges may discourage new scholars from engaging in Aboriginal health research ‘in a good way’ that is, collaboratively, respectfully and ethically. A shortage of competent and willing Aboriginal health researchers will ultimately put the goal of positive Aboriginal health outcomes in further jeopardy. In addition, these tensions and challenges may discourage Aboriginal peoples/communities from collaborating in health research. These issues are the impetus for and ultimate benefit of the proposed study.

RISKS: There is minimal to no risk in participating in this study. But people are sometimes uncomfortable about being interviewed. Your comfort is my priority. At your request, I will strike comments that you have made during your interview. I will also strike comments made during your interview from the transcripts within two weeks following your interview if you are uncomfortable with them after your review of your transcript. Confidentiality and anonymity will be maintained, as I will not identify you or your institution in the final report or in any subsequent article.

WITHDRAWAL FROM THE STUDY: You may refuse to participate or to later withdraw from the study (includes withdrawal of your interview transcript) within two weeks following your interview with me without penalty by simply telling me (my contact details are below). You also have the right to leave unanswered any questions you prefer not to answer. You have the option of reviewing a preliminary analysis of your interview.

CONFIDENTIALITY: Because this research is being conducted with a targeted group of Aboriginal health researchers in Nova Scotia, and REB representatives and financial services administrators at 4 NS universities – a relatively small group of individuals, it may not be possible to keep your participation and responses completely anonymous. However, your name (and institution) will not be used and a pseudonym will be employed to ensure anonymity and confidentiality in the dissemination of this research. Furthermore, participants will only be identified as university administrators, ethics board members, or health researchers. All information shared during the one-on-one interview will be kept confidential and your identity will not be revealed. All data will remain with my supervisor (Dr. Susan Tirone) in a secure location on campus (password-protected computer and locked files in her office) and will be destroyed within five years of the study’s completion. The digital recording will only be available to me and my co-

supervisors, Dr. Susan Tirone and Dr. Heather Castleden, and a transcriptionist who has signed a confidentiality agreement.

CONSENT: I will go through this consent form with you over the phone if you prefer, answer any questions you might have about the research and your involvement in it, give you an opportunity to read the consent form, and then you can decide if you want to sign it, thereby agreeing to participate in the study. If you agree to participate in the study, please sign the attached signature page, and email the signature page in a PDF document to me at Carla.Moore@dal.ca. Signature pages will be kept in my office in a locked cabinet.

If you have any complaints or concerns about this research that you feel you cannot discuss with me, you can contact Catherine Connors, Director of Dalhousie University's Human Research Ethics Office at (1) Phone: (902) 494-3423; or (2) Email: ethics@dal.ca. This study has been reviewed by the Dalhousie University Research Ethics Board and by the Mi'kmaq Ethics Watch.

Consent Form (For Nova Scotia Mi'kmaq communities Health Directors)

Research Project: Is this good research?: Considering the ethical and methodological implications of health research with Mi'kmaq communities in Nova Scotia following the implementation of the 2nd edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)

Principal Investigator: Carla Moore, MAHP Candidate, Dalhousie University

PURPOSE: The second edition of Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2010) has drawn attention to the need for researchers' to confront unethical conduct in research with Aboriginal peoples, communities, and organizations (specifically TCPS2, Chapter 9). However, Chapter 9 does not take into consideration the ethical tensions and institutional barriers that pose challenges to doing Aboriginal health research 'in a good way'. This study is investigating Nova Scotia Mi'kmaq communities' health directors', health researchers', REB Chairs', and Research Financial Services Administrators' responses to these new guidelines, and/or the ethical challenges and institutional barriers they face in implementing them in their research. By exploring how these tensions arise and by identifying the existing barriers, we can better strategize to minimize them. At the conclusion of this study, a report will be shared with the 13 Mi'kmaq communities in NS, the Aboriginal Health Research Network Secretariat and The Canadian Association of Research Ethics Boards (CAREB) as well as public dissemination through peer-reviewed scholarly publications, Mi'kmaq Maliseet Nation News, and conference/meeting presentations.

YOUR PARTICIPATION: Your voluntary participation involves a 60 to 90 minute focus group at an Atlantic health directors meeting. During this focus group, there are no right or wrong answers – I am interested in your viewpoint and experiences. This focus

group has three key themes: (I) General background about your experience with research ethics/research in general, given your current role; (II) Your experience and opinions about ethics/ethics guidelines in research such as the TCPS2 guidelines; and (III) Institutional policies and practices that impact research in your community. The focus group will be digitally recorded as it would be difficult for me to facilitate the group discussion and take notes at the same time. I understand that you may have an issue with audio recording and you are free to decline participation as a result. Furthermore, all recorded comments will be used in the study, and if you do not agree with this, you are free to decline participation as well. Your comments may be used as part of Carla Moore's thesis research and in public dissemination, but your name (or community) would not be attached to those comments. Careful measures will be taken to keep your information confidential and your identity will not be revealed. In addition, your participation or refusal to participate in the study would have no impact on your employment, and data would not be shared with your employer. Any descriptions in the final report would be minimal so as to prevent you from being inadvertently identified by someone who knows you. Lastly, you would be contacted by me (if you indicate that you would like this option) after preliminary analysis of the data has been done so that you have an opportunity to check the information for accuracy.

HOW THIS RESEARCH WILL BE USED: Direct quotes of what you say may be used in any dissemination, but they will remain anonymous. Any oral or written presentations of the research findings will not have your name (or community) attached to your quotes.

BENEFITS OF THIS STUDY: The information obtained from this research is being used to further the understanding of the ethical tensions and institutional barriers associated with Aboriginal health research. These tensions and challenges may discourage new scholars from engaging in Aboriginal health research 'in a good way' that is, collaboratively, respectfully and ethically. A shortage of competent and willing Aboriginal health researchers will ultimately put the goal of positive Aboriginal health outcomes in further jeopardy. In addition, these tensions and challenges may discourage Aboriginal peoples/communities from collaborating in health research. These issues are the impetus for and ultimate benefit of the proposed study.

RISKS: There is minimal to no risk in participating in this study. But people are sometimes uncomfortable about being in a focus group. Your comfort is my priority. Confidentiality and anonymity will be maintained, as I will not identify you or your community in the final report or in any subsequent article. Focus group participants will be reminded of the need for and importance of maintaining confidentiality about what was discussed in the focus group.

WITHDRAWAL FROM THE STUDY: You may refuse to participate or withdraw from the study before the focus group has taken place without penalty by simply telling me (my contact details are below). You also have the right to leave unanswered any questions you prefer not to answer. You have the option of reviewing a preliminary analysis of the focus group.

CONFIDENTIALITY: Because this research is being conducted with a targeted group of health directors in the 13 Mi'kmaq communities – a relatively small group of individuals, it may not be possible to keep your participation and responses completely anonymous. However, your name (and community) will not be used and a pseudonym will be employed to ensure anonymity and confidentiality in the dissemination of this research. All information shared during the focus group will be kept confidential and your identity (or community) will not be revealed. All data will remain with my supervisor (Dr. Susan Tirone) in a secure location on campus (password-protected computer and locked files in her office) and will be destroyed within five years of the study's completion. The digital recording will only be available to me and my co-supervisors, Dr. Susan Tirone and Dr. Heather Castleden, and a transcriptionist who has signed a confidentiality agreement.

CONSENT: I will go through this consent form with you, either over the phone, or in-person, answer any questions you might have about the research and your involvement in it, give you an opportunity to read consent form, and then you can decide if you want to sign it, thereby agreeing to participate in the study. If you agree to participate in the study, please sign the attached signature sheet, and email the signature page in a Pdf document to me at Carla.Moore@dal.ca. Signature pages will be kept in my office in a locked cabinet.

If you have any complaints or concerns about this research that you feel you cannot discuss with me, you can contact Catherine Connors, Director of Dalhousie University's Human Research Ethics Office at (1) Phone: (902) 494-3423; or (2) Email: ethics@dal.ca. This study has been reviewed by the Dalhousie University Research Ethics Board and the Mi'kmaw Ethics Watch.

APPENDIX C Signature Pages

Signature Page for consent form (For Nova Scotia Mi'kmaq communities Health Directors)

Research Project: Is this good research?: Considering the ethical and methodological implications of health research with Mi'kmaq communities in Nova Scotia following the implementation of the 2nd edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)

Principal Investigator: Carla Moore, MAHP Candidate, Dalhousie University
Thesis Research Project

1. Do you understand that you have been asked to take part in a research study? _____
2. Have you read and received a copy of the attached Consent Form? _____
3. Do you understand the benefits and risks involved in taking part in this research? _____
4. Have you had an opportunity to ask questions about this study with Carla Moore? _____
5. Do you understand that you may refuse to participate or withdraw from the study before the focus group has taken place? _____

*You do not have to say why you have decided to withdraw.

6. Do you understand that your name (or community) will not be attached to the information, comments, quotes, or ideas that you provide while participating? _____
7. Do you understand who will have access to your focus group data? _____
8. I have agreed to be audio-recorded within the focus group interview. _____
9. Do you wish to review a copy of the focus group transcript to check for accuracy?
Yes
No
10. Would you like to be contacted once the data has undergone preliminary analysis to check for accuracy?
Yes
No

11. Would you like to see how quotes from the focus group are used before the report(s) are finalized?

Yes

No

12. Would you like an electronic copy of the final report?

Yes

No

I agree to participate in this research project.

Signature

Printed Name

Date

Signature Page for consent form (For financial services administrators)

Research Project: Is this good research?: Considering the ethical and methodological implications of health research with Mi'kmaq communities in Nova Scotia following the implementation of the 2nd edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)

Principal Investigator: Carla Moore, MAHP Candidate, Dalhousie University

Thesis Research Project

1. Do you understand that you have been asked to take part in a research study? _____
2. Have you read and received a copy of the attached Consent Form? _____
3. Do you understand the benefits and risks involved in taking part in this research? _____
4. Have you had an opportunity to ask questions about this study with Carla Moore? _____
5. Do you understand that you may refuse to participate in this study, or withdraw from this study within two weeks following your interview with me? _____

*You do not have to say why you have decided to withdraw.

6. Do you understand that your name (or institution) will not be attached to the information, comments, quotes, or ideas that you provide while participating? _____

7. Do you understand who will have access to your interview data? _____

8. I have agreed to be audio-recorded during the interview. _____

9. Do you wish to review a copy of your interview transcript to check for accuracy?

Yes

No

10. Would you like to be contacted once the data has undergone preliminary analysis to check for accuracy?

Yes

No

11. Would you like to see how quotes from your interview are used before the report(s) are finalized?

Yes

No

12. Would you like an electronic copy of the final report?

Yes

No

I agree to participate in this research project.

Signature

Printed Name

Date

Signature Page for consent form (For health researchers)

Research Project: Is this good research?: Considering the ethical and methodological implications of health research with Mi'kmaq communities in Nova Scotia following the implementation of the 2nd edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)

Principal Investigator: Carla Moore, MAHP Candidate, Dalhousie University
Thesis Research Project

1. Do you understand that you have been asked to take part in a research study? _____
 2. Have you read and received a copy of the attached Consent Form? _____
 3. Do you understand the benefits and risks involved in taking part in this research? _____
 4. Have you had an opportunity to ask questions about this study with Carla Moore? _____
 5. Do you understand that you may refuse to participate in this study, or withdraw from this study within two weeks following your interview with me? _____
- *You do not have to say why you have decided to withdraw.
6. Do you understand that your name (or institution) will not be attached to the information, comments, quotes, or ideas that you provide while participating? _____
 7. Do you understand who will have access to your interview data? _____
 8. I have agreed to be audio-recorded during the interview. _____
9. Do you wish to review a copy of your interview transcript to check for accuracy?
Yes
No
10. Would you like to be contacted once the data has undergone preliminary analysis to check for accuracy?
Yes
No
11. Would you like to see how quotes from your interview are used before the report(s) are finalized?
Yes
No

12. Would you like an electronic copy of the final report?

Yes

No

I agree to participate in this research project.

Signature

Printed Name

Date

Signature Page for consent form (For REB Representatives)

Research Project: Is this good research?: Considering the ethical and methodological implications of health research with Mi'kmaq communities in Nova Scotia following the implementation of the 2nd edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)

Principal Investigator: Carla Moore, MAHP Candidate, Dalhousie University
Thesis Research Project

1. Do you understand that you have been asked to take part in a research study? _____
2. Have you read and received a copy of the attached Consent Form? _____
3. Do you understand the benefits and risks involved in taking part in this research? _____
4. Have you had an opportunity to ask questions about this study with Carla Moore? _____
5. Do you understand that you may refuse to participate in this study, or withdraw from this study within two weeks following your interview with me? _____

*You do not have to say why you have decided to withdraw.

6. Do you understand that your name (or institution) will not be attached to the information, comments, quotes, or ideas that you provide while participating? _____
7. Do you understand who will have access to your interview data? _____
8. I have agreed to be audio-recorded during the interview. _____

9. Do you wish to review a copy of your interview transcript to check for accuracy?

Yes

No

10. Would you like to be contacted once the data has undergone preliminary analysis to check for accuracy?

Yes

No

11. Would you like to see how quotes from your interview are used before the report(s) are finalized?

Yes

No

12. Would you like an electronic copy of the final report?

Yes

No

I agree to participate in this research project.

Signature

Printed Name

Date

APPENDIX D Interview Guides

Interview Guide for Focus Group with Health Directors

Preamble

*Thank you for taking the time to speak with me in this focus group. As the **consent form** described, our conversation today will take approximately 60 to 90 minutes. If at any point you don't want to answer a question, we can skip it. You also have the right to withdraw from the study **up to the start of this focus group interview**. Do you have any questions before we get started? Ok, let's begin [turn on audio recorder] ...*

The focus group questions will involve discussions around the following three theme areas:

(I) General background about your experience with research ethics/research in general, given your current role; (II) Your experience and opinions about ethics/ethics guidelines in research such as the TCPS2 guidelines; and (III) Institutional policies and practices that impact research in your community.

1. Could you talk a bit about the extent to which you are personally familiar with the Tri-Council policy statement guidelines on ethical research, particularly the chapter dealing with research with Aboriginal people? What do you think of the guidelines?
2. Could you tell me about researchers and topics of research you have collaborated with since the guidelines came into effect in 2010?
3. Thinking about those researchers or others you know of, how familiar do you think they are with the CIHR guidelines? Did they try to develop a respectful research relationship with you or your community? If so, how? If not, how?
4. Could you tell me what issues arose with the researchers insofar as research ethics are concerned, and specifically, with the kind of participatory, community based research that the guidelines set out. For example, did the researcher come to you with a topic already identified? How were these issues resolved?
5. Are you aware of any issues that arose with the researcher's university about the research they collaborated with you on? For example, I'm asking about issues that the researcher might have mentioned to you relating to research ethics or to financial services.
6. Have you noticed any positive change in how research is conducted now in comparison to how it was conducted before the CIHR guidelines or in the past? Do you have any stories about research, either positive or negative, from this earlier period?
7. Do you have any other thoughts about the CIHR ethics guidelines or about ethical research in general?

Interview Guide for Health Researchers

Preamble

*Thank you for taking the time to speak with me. As the **consent form** described, our conversation today will take approximately 45 minutes. If at any point you don't want to answer a question, we can skip it. You also have the right to withdraw from the study, including your data, **within two weeks following your interview with me today**. Do you have any questions before we get started? Ok, let's begin [turn on audio recorder] ...*

Interview questions:

1. Could you tell me about your program of research, specifically with respect to Aboriginal health research?
2. How would you describe your research relationship with Aboriginal people, communities/organizations? Do you engage directly or indirectly with Aboriginal people, communities or organization in that research relationship?
3. Were non-academic Aboriginal people, communities/organizations involved in any stage of the research in: 1. Research development, 2. Data collection, 3. Data analysis, 4. Dissemination of the findings? How or in what way?
4. Have you ever used a formal research agreement (or memorandum of understanding) with your Aboriginal partner? Can you describe what was included in that agreement?
5. In thinking of your own work, what does doing research in a “good way” mean to you in the context of Aboriginal health research? What would you say are the most important ethical considerations for doing Aboriginal health research in a good way?
6. What would you say are the most significant tensions for doing Aboriginal health research in a good way?
7. Are you familiar with the 2nd edition of the Tri-council policy statement (specifically Chapter 9 – the one on research with Aboriginal people)? Have you read Chapter 9 of the TCPS2?
8. What are your thoughts on Chapter 9 of the TCPS2? Would you say that Chapter 9 is adequate or is it too much (overkill) in terms of capturing the ethical considerations for research involving Aboriginal people?
9. Have you ever served on a university-based research ethics board?
10. Could you describe your experiences with your university's REB process for your own research with Aboriginal people/communities/organizations? Were there any barriers or helpful aspects to that process?
11. Could you describe your experiences with your university's financial services for your own research with Aboriginal people/communities/organizations? Were there any barriers or helpful aspects to that process?
12. How do you deal with payment to community members for data collection; advisory committee honoraria; participant honoraria; travel expenses for Aboriginal partners to meetings or conferences? Are there any university policies that keep coming up with respect to those things?
13. Have you ever served on a tenure and promotion committee?

14. With respect to your own Aboriginal health research, are there any accomplishments, activities, or contributions that are not acknowledged by your tenure and promotion committee?
15. What advice would you give new researchers who want to do Aboriginal health research, particularly in a good way? What advice would you give to your university's REB and financial services that would help to support Aboriginal health research that is done in a good way?

This concludes my questions but is there anything you would like to add to our conversation today?

Interview Guide for REB Representatives

Preamble

*Thank you for taking the time to speak with me. As the **consent form** described, our conversation today will take approximately 45-50 minutes. If at any point you don't want to answer a question, we can skip it. You also have the right to withdraw from the study, including your data, **within one week after you have been sent your interview transcript (if requested)**. Do you have any questions before we get started? Ok, let's begin [turn on audio recorder] ...*

Interview questions:

1. Tell me a bit about yourself and your professional role at the university (how long have you been in this role, what do you do, etc.).
2. What are some of the biggest challenges you face as the REB representative with respect to implementing the TCPS2
 - a. Have you had any particular issues in dealing with university researchers with respect to the TCPS2?
 - b. Has this new Tri-Council Policy Statement, especially Chapter 9 – the chapter about research involving Aboriginal people - changed the way you deal with ethical matters, or require researchers to address the ethical issues for research involving Aboriginal peoples? (*have you read Chapter 9?*)
3. What, if any, specific challenges have you had to deal with regarding research ethics applications that involve Aboriginal peoples as participants or research team advisors?

Probe with questions regarding their familiarity with CBPR and any challenges associated with this sort of approach to scholarship.

- a. How would you describe your experience working with researchers who engage in this form of research (work with Aboriginal peoples)?
 - b. Given your experience, do you feel your research ethics board has sufficient capacity to adequately assess proposals that deal with Aboriginal research?
 - c. Do you think research involving Aboriginal participants should have different protocols when it comes to ethics than research that does not (why/why not, examples)?
 - d. Have you found Chapter 9 of the TCPS2 to be helpful in navigating ethical issues associated with research involving Aboriginal peoples?
 - e. Is there anything about working within the context of Chapter 9 of the TCPS2 that you have found to be particularly challenging?
4. How would you describe the current process (barriers/bridges) of obtaining ethical approval for research involving Aboriginal peoples at your institution?
- a. How do you envision successfully navigating any barriers?
5. If you could change something about the ethical considerations needed when it comes to research involving Aboriginal peoples, what would it be?
6. If you could change something about how researchers working with Aboriginal partners deal with the REB what would it be? Is there any advice you might like to give to researchers who do Aboriginal health research in terms of ethical considerations for research involving Aboriginal people/communities?
7. Universities are required to put in place processes that involve adherence to and implementation of the TCPS guidelines.
- a. What is the nature of the relationship you have with the funding agencies about these requirements?
 - b. Is there pressure on you either directly or indirectly from the funding agencies regarding adherence to and implementation of the guidelines,
 - c. What have been the consequences to universities for failure to follow the guidelines set by the TCPS? Are there examples where the funding agencies have stepped in and taken “disciplinary” action? Please describe.
 - d. Is there anything specific with respect to chapter 9 (for example, do you have any dialogue with agencies with respect to chapter 9)?

This concludes my questions but is there anything you would like to add to our conversation today?

Interview Guide for Research and Special Purposes Financial Administrators

Preamble

*Thank you for taking the time to speak with me. As the **consent form** described, our conversation today will take approximately 45 minutes. If at any point you don't want to answer a question, we can skip it. You also have the right to withdraw from the study, including your data, **within one week after you have been sent your interview transcript (if requested)**. Do you have any questions before we get started? Ok, let's begin [turn on audio recorder] ...*

Interview questions:

1. Tell me a bit about yourself and your professional role at the university (how long have you been in this role, what do you do, how many staff do you manage, etc.).
2. Can you give me a “day in the life of your job”?
3. What are some the biggest challenges you face in terms of the financial services aspect of your job with respect to the administration of Tri-Council research funds (any particular issues in dealing with university researchers in terms of how they report how they use research funds)?
4. What, if any, specific experiences have you had to deal with regarding (health) research that involves Aboriginal peoples as research participants or project team advisors?
 - a. How would you describe your experience working with university researchers who do Aboriginal (health) research (have you had positive or negative encounters)?
 - b. Do you think research involving Aboriginal participants should have different protocols when it comes to financial issues than research that does not (why/why not, examples)?

Probe with questions regarding their familiarity with CBPR and any challenges associated with this sort of approach to scholarship.

5. Are you familiar with the latest version of the Tri-Council Policy Statement on Research Ethics involving Human Participants (2010), especially Chapter 9 for research involving Aboriginal peoples? (If yes, proceed; if no, move to next question).
 - a. Has this new Tri-Council Policy Statement, especially Chapter 9, changed the way you deal with financial matters or require researchers to report on their use of funds for research involving Aboriginal peoples
6. If you could change something about your reporting requirements when it comes to audits, what would it be?

7. If you could change something about how researchers deal with financial services what would it be? What advice would you like to give to researchers in terms of financial services? Any special advice in particular for researchers who do Aboriginal (health) research?
8. Universities are required to put in place processes that involve adherence to guidelines with respect to financial accountability for research funds that are granted to university faculty.
- a. What is the nature of the relationship you have with the funding agencies about these requirements?
 - b. Are the funding agencies quite specific about the accountability measures they require (please explain).
 - c. Is there pressure on you either directly or indirectly from the funding agencies regarding adherence to and implementation of these guidelines?
 - d. What have been the consequences to universities for failure to follow the guidelines set by the TCPS and the financial accountability requirements? Are there examples where the funding agencies have stepped in and taken “disciplinary” action? Please describe.
 - e. Are there situations where there are inconsistencies with respect to the financial rules you are expected to follow, and the requirements faculty have to follow to do research in a way that is ethically responsible?
 - f. Specifically with respect to TCPS2 Chapter 9, have any inconsistencies of this kind arisen with faculty who are doing community based research with Aboriginal populations?"

This concludes my questions but is there anything you would like to add to our conversation today?

APPENDIX E Summary of Themes for Participants

Thematically analysing data gathered from the focus group of health directors working in Nova Scotia Mi'kmaq communities and semi-structured interviews with university-based research ethics board members, financial services administrators, and researchers at four Nova Scotia universities, **six** main themes emerged from the data. They include:

1. Mi'kmaq communities in Nova Scotia are seeking more control of the health research conducted in their territory.
2. Community-based Health Directors and institutionally-based Financial Services Administrators have limited knowledge about the TCPS 2 and Chapter 9.
3. There is a lack of capacity in Nova Scotia Mi'kmaq communities to be better engaged in research.
4. Research Ethics Board members and some researchers find the articles in Chapter 9 of the TCPS 2 to be generally vague, leading to some confusion about their application.
5. Those who are not doing research involving Indigenous peoples generally have a lack of understanding about the realities of conducting research in Nova Scotia Mi'kmaq communities.
6. Researchers who have established partnerships with Nova Scotia Mi'kmaq communities largely adhere to the principles put forth in Chapter 9 of the TCPS 2.

Theme 1 - Mi'kmaq communities in Nova Scotia are seeking more control of the health research conducted in their territory.

The Mi'kmaq communities are taking more active roles in research, are leading research because they have more research experience, have a better understanding of the difference between good and bad research, and no longer passively participate in research. They are involved in many aspects of the research from developing the research question to presenting the findings. Community resources and the capacity to participate in research were limitations, however.

Theme 2 - Community-based Health Directors and institutionally-based Financial Services Administrators have limited knowledge about the TCPS 2 and Chapter 9.

There is a general lack of knowledge about the contents of the TCPS 2 and its Chapter 9 by health directors and by university-based financial services administrators. Most of the health directors and financial services administrators said that they knew very little about the TCPS 2. Although the health directors reported that they knew little about Chapter 9, their discussion showed that they knew more than they thought about the guidelines. That is, they spoke of community engagement, collaboration, research capacity building, reviews of draft reports for accuracy, and research agreements, all of which are discussed in Chapter 9.

Theme 3 - There is a lack of capacity in Nova Scotia Mi'kmaq communities to be better engaged in research.

Although communities want more control of research, they are sometimes unable to do so because they either do not have the capacity to be more meaningfully involved in research or they do not have the time to be fully engaged in the research process. Capacity building was a key concern for the health directors and they said that ways to support that capacity needed to be available. They also said that community members should be educated on the importance of data and how it could be used to improve their lives.

Theme 4 - Research Ethics Board members and some researchers find the articles in Chapter 9 of the TCPS 2 to be generally vague, leading to some confusion about their application.

Research ethics board members and health researchers said that the articles in Chapter 9 were vague which lead to confusion during ethics reviews and in the application of research ethics principles. Chapter 9 had confusing wording or content (e.g. unclear about what constitutes community consent), and did not provide enough instruction about how to do ethical research with Indigenous communities. Both groups said that Chapter 9 needed to be enhanced with real life examples and more details or explanations supporting the chapter's articles should be included. Both groups were supportive, however, of the chapter and said that it was better than what had been available in the past.

Theme 5 - Those who are not doing research involving Indigenous peoples generally have a lack of understanding about the realities of conducting research in Nova Scotia Mi'kmaq communities.

Interviews with research ethics board members and financial services administrators at four universities in Nova Scotia revealed their general lack of knowledge or understanding about the life circumstances of people living in the Mi'kmaq communities as well as their lack of knowledge or understanding of what is involved in community-based participatory research with Mi'kmaq communities.

Theme 6 - Researchers who have established partnerships with Nova Scotia Mi'kmaq communities largely adhere to the principles put forth in Chapter 9 of the TCPS 2.

These researchers are largely adhering to the principles laid out in Chapter 9 of the TCPS 2. They supported Mi'kmaq community control of the research, supported a research partnership without burdening the community, submitted their proposals to local community research boards or Indigenous ethics committees, supported research capacity, supported the involvement of the community in developing the proposal, signed a research agreement if asked, were respectful in their approach, shared the analysis/report with the community for accuracy, and ensured that the community was given credit in published reports coming from the research.

APPENDIX F Mi'kmaw Ethics Watch Approval



April 23, 2014

Ms. Carla Moore

Dear Ms. Moore,

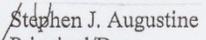
I wish to inform you that the Mi'kmaw Ethics Watch committee has reviewed and approved *"Is this Good Research?: Considering the Ethical and Methodological Implications of Health Research with Mi'kmaq Communities in Nova Scotia following the Implementation of the 2nd Edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans"*.

As your project moves forward with the approval of the Mi'kmaw Ethics Watch, I must note that individual communities have their own perspective on research projects and it is your responsibility to consult them to ensure that you meet any further ethical requirements. Governments, universities, granting agencies, and the like also have ethical processes to which you might have to conform.

When your project is completed, the Mi'kmaq Resource Centre at Unama'ki College would be pleased to accept the results in a form that could be made available to students and other researchers (if it is appropriate to disseminate them). Our common goal is to foster a better understanding of the Indigenous knowledges.

If you have any questions concerning the Mi'kmaw Ethics Watch review of your project please do not hesitate to contact me and I will forward them to the committee members.

Sincerely,


Stephen J. Augustine
Principal/Dean
Unama'ki College
Cape Breton University

CAPE BRETON UNIVERSITY | UNAMA'KI COLLEGE

Tel: (902) 563-1871 | P.O. Box 5300, 1250 Grand Lake Road, Sydney, NS B1P 6L2 CANADA | WWW.CBU.CA/UNAMA'KI

APPENDIX G Dalhousie University Research Ethics Letter of Approval



Social Sciences & Humanities Research Ethics Board Letter of Approval

June 06, 2014

Ms Carla Moore
Health Professions\Health & Human Performance

Dear Carla,

REB #: 2014-3246
Project Title: Is This Good Research?: Considering the Ethical and Methodological Implications of Health Research With Mi'Kmaq Communities in Nova Scotia Following the Implementation of the 2nd Edition of the TCPS

Effective Date: June 06, 2014
Expiry Date: June 06, 2015

The Social Sciences & Humanities Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*. This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Dr. Sophie Jacques, Chair

**Social Sciences & Humanities Research Ethics Board
Annual Renewal - Letter of Approval**

May 08, 2015

Ms Carla Moore
Health Professions\Health & Human Performance

Dear Carla,

REB #: 2014-3246

Project Title: Is This Good Research?: Considering the Ethical and Methodological Implications of Health Research With Mi'Kmaq Communities in Nova Scotia Following the Implementation of the 2nd Edition of the TCPS

Expiry Date: June 06, 2016

The Social Sciences & Humanities Research Ethics Board has reviewed your annual report and has approved continuing approval of this project up to the expiry date (above).

REB approval is only effective for up to 12 months (as per TCPS article 6.14) after which the research requires additional review and approval for a subsequent period of up to 12 months. Prior to the expiry of this approval, you are responsible for submitting an annual report to further renew REB approval. Forms are available on the Research Ethics website.

I am also including a reminder (below) of your other on-going research ethics responsibilities with respect to this research.

Sincerely,

Dr. Valerie Trifts, Chair