

Diffusion of Personal Health Information:
Self-determining and Empowering Practices for Manitoba Inuit

by

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Abstract

This paper describes Inuit cultural considerations when defining and communicating electronic health concepts and personal health information services to urban Inuit audiences. Applying a *two-eyed seeing* model to build on and describe contextual meanings for Western and Inuit versions of health information and information communication technologies is critical to sustained relevance of electronic health information. Overarching concerns include reclaiming Inuit ownership and vision; sustainability; and; authority and capacity. It is within an electronic health space that Inuit can attain self-determination for the management of their own personal health data and develop a set of culturally safe and empowering practices for communicating ownership and cultural relevancy of health and health information in an evolving health care system.

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Focus and Framing

Introduction

Personal health information services available through electronic health record systems can be difficult for any non-expert to comprehend. For Manitoba Inuit, accessing personal health information and related services at an individual level can be even more daunting because of cultural barriers. Efforts to protect Inuit health information have unintentionally resulted in a situation where regional Inuit organizations may have difficulty in obtaining health data and statistics about urban Inuit from aggregate health information for their own purposes (N. Batzel, personal communication, October 27, 2011). Improving the health of Aboriginal peoples requires community and government to engage in a collective manner with the objective of knowledge transfer and establishing linkages that foster collaboration (National Aboriginal Health Organization, 2002). This principle is integral to the conversation of developing leadership capacity around biomedical health information management within these communities.

The central research question that this study has aimed to answer is: “How can culturally safe practices for accessing personal health information services assist Manitoba Inuit with their right to self-determination?” My research draws from and contributes to health communication and health policy literature specific to Indigenous populations in order to explore how unintended consequences of bureaucracy have contributed to electronic health programming that does not well serve or reach Inuit populations in urban environments. I support this premise through the review of the relevant academic literature in the disciplines of health communication, cultural safety, health literacy, Indigenous health, knowledge translation and electronic health and my synthesis of the grey literature available from government agency reports and web sites. My review of the literature revealed key emergent themes including definitions of health

information systems, gaps in service delivery for Inuit, social determinants of health and health literacy and knowledge translation issues.

The overarching goal of this research is two-fold: to empower Inuit to attain self-determination for the management of their own personal health data; and, to develop a set of culturally safe and empowering practices that can be utilized by the Manitoba Urban Inuit Association (MUIA) in the realization of this objective. It is critical to understand Inuit self-determination in their dealings with government agencies and services and therefore comprehend the processes by which Inuit may practice self-determination. I hope to empower the MUIA through this research so the knowledge gained can be applied to other like projects. I intend to accomplish my goals and objectives by applying decolonizing principles to Inuit information gathering, with a specific focus on the principle of cultural co-learning.

To that end, this research is situated and guided by the critical pedagogy and theoretical perspective of Paulo Freire. Freire believed dialogue could develop a consciousness in people's social and political environment (Freire, 1974). Freire's theories are relevant to this research insofar as broad public participation in the design process of electronic health information is important in building community and public spaces that can be accessed and utilized by all members of the Inuit community.

The theory of diffusion of innovation also guides this study. Diffusion is the process by which an innovation is communicated through channels such as human interaction, media or instruction over time among members of a social system. An innovation can include an idea, technology, information, products and services as they are new and being introduced (Dearing and Meyer, 2006). Electronic health products and services require a combination of channels for their public adoption to be fully realized. Inuit concepts of health communication and approaches

to contributing to the discussion of communication tool development involve the recognition of Inuit sustainability, self-determination and language preservation because these ideas are fundamental to channelling a dialogue with trustees of electronic health information and the realization of an empowered, healthy urban Inuit community.

Opportunity

Electronic health continues to evolve, be it through telemedicine procedures, electronic health records, delivery of clinical information from source systems (laboratory results, diagnostic imaging, encounters, visit reasons, discharge summaries), mobile devices, e-learning tools, personal health information portals and the like. Each of these technologies can trigger a variety of issues as they are adopted by Inuit. Inuit society faces complex challenges in relation to electronic health: understanding complex technical systems, access to technologies, remoteness, and a general mistrust of government information systems. Methods for communication that allay Inuit citizens' fears and address accessibility will be important steps for diffusion of innovation strategies and realizing meaningful adoption of these technologies among Inuit populations. Currently, there is growing awareness that culture needs to be taken into consideration when determining the ways in which health programs are communicated, and electronic health needs to be an integral part of this conversation.

As stated in Health Canada's Blueprint on Aboriginal Health (2005), "no single approach to health will address or resolve the needs of all Aboriginal communities" because of differences in traditions, identity and location. Inuit in Manitoba make up only 0.3 percent of the total Aboriginal population in the province (Manitoba Aboriginal and Northern Affairs, 2012). Although provincial and federal services are available to Inuit under cross-cutting Aboriginal programs targeted at First Nations, Métis and Inuit groups, Inuit are often left out of

consultations for program development and have experienced difficulty in accessing services (N. Batzel, personal communication, October 27, 2011). For Manitoba Inuit, tools can be developed specifically for Inuit about electronic health information systems in the province, their relevance to how healthcare is delivered, and how their health data plays a role in that delivery. Levinia Brown, the past vice president of the MUIA, stated that “the more Inuit are empowered to have access to their personal health information and are involved in decisions that impact our health as a community, the stronger we will be” (L. Brown, personal communication, October 7, 2011).

There is very little published research available regarding the communication of health delivery services and, therefore, this fact begs for a greater understanding of the organizational aspects of communicating about public health (Parrott, 2004), particularly within an electronic health information context. Minore, Katt, and Hill (2009) argued that advancing Aboriginal health through health information systems is hindered by an absence of data that documents essential facts about Aboriginal peoples’ health status and services utilization. Without a means to collect such data, these knowledge deficiencies will persist, making the planning and provision of culturally appropriate services more difficult to achieve. This deficit can be avoided by having more public consultation with Aboriginal populations and seeking culturally appropriate communication tools to enlighten this group to incorporate modules specific to their related sociocultural and health needs. In addition to health information systems containing important data related to Aboriginal peoples’ health, more tools are needed to educate Aboriginal populations about electronic health systems in general and how to access tools that can assist them with the management of their care. Further, culturally safe tools are needed that allow Aboriginal peoples to supplement personal health information that is available through the

electronic health record with information that can be more commensurable with their worldview and essential to their perspectives on health.

With the emphasis on the continued formation and use of information communication technologies in the healthcare system, Manitoba Inuit can increase their health outcomes by improving their quality of life through their own management of their personal health information. Communication strategies around this subject that are deployed by the MUIA will inform and assist Inuit in Manitoba with the navigation of electronic health information systems and better manage electronic health activities. This includes increased public health campaigns around electronic health information programming and education about the right to access, maintain, and control their personal health information record.

Positionality

Born in Churchill, Manitoba, I am of Inuit and Scottish/Irish ancestry and an Inuk Beneficiary of the Nunavut Land Claim Agreement (Whale Cove). I am a Senior Program Analyst at Manitoba eHealth, where I am involved with key performance indicators and benefits evaluation of the provincial electronic health record system, and a member of the First Nations, Métis and Inuit Health Research Group of the Faculty of Medicine, University of Manitoba. While my purpose is to assist in the creation of communication tools that can be used at a community-based, organizational level, I also wish to put forward the idea of how to foster a critical discourse about information communication technologies within an Indigenous cultural context.

An element of my methodological position is to pay particular respect to my positionality in this research. In his seminal work, *Research as Ceremony*, Wilson (2008) stated that Indigenous epistemology, methodology, axiology and ontology occur in an emergent, circular

form, each entity blending into the next and being inseparable from one another within a single consciousness. An Indigenous axiology incorporates values and insights that are important to the design of Indigenous methodologies, especially in relation to ethics (Wilson, 2008). In my role as a researcher, I have accountability to the Manitoba Inuit community because of my family relations and the network of “northerners” who exist in the urban Inuit community of which I am a part. Wilson (2008) described the researcher as a part of the research and inseparable from his or her participant or site. Integral to my research design, I needed to consider the following questions: “Do my methods help me build a relationship with Manitoba Inuit and electronic health information systems?”; “Am I building a respectful relationship with the Manitoba Urban Inuit Association?”; “What is my role as researcher, and what are my responsibilities?”; “Am I contributing to the conversation of increasing Inuit cultural safety in electronic health information systems and will I continue this discussion after the research has been conducted?” These questions are not necessary or even desirable within many Western research paradigms, but they are essential to my stance as an Inuk researcher doing research about Inuit electronic health information.

Battiste (2000) stated that Aboriginal consciousness cannot be upheld and sustained without critiquing the suppositions of contemporary society and that restoration of language remains a challenge for Aboriginal peoples to undertake in their realization of decolonization and self-determination. These ideas were important for me to consider in the context of Inuit society and electronic health information because health is an underlying and fundamental component of Inuit culture. By incorporating Inuit culture into discourses around personal health information, Inuit can assume a more meaningful level of ownership of biomedical health data obtained through electronic health information services.

My unique standpoint on diffusion of Inuit electronic health information relates to a *two-eyed seeing* model that incorporates traditional cultural contexts for health with personal health data that are biomedical in nature. Iwama, Marshall, Marshall & Bartlett (2009) described two-eyed seeing as a guiding principle that draws on the strengths of Indigenous and Western knowledge bases because it integrates linguistic components of health, thereby creating a vision that consists of more than one perspective. I believe there is an opportunity to incorporate Inuit ways of knowing and Western biomedical data into forms that Inuit can better appreciate and use.

Literature Review

I have always been attracted to feminist discourses, perhaps because I originate from a marginalized segment of the population. Feminist theories taught me that my standpoint provided another way of seeing within a larger mainstream context, which in effect provides a two-eyed seeing perspective (Harding, 1991). It was therefore inevitable that the feminist organizing processes of cooperative enactment, integrated thinking and connectedness would resonate with my own experience and thinking process. In the Inuit community, we rely on traditional knowledge and oral histories to share information. These customs are part of how we live and treat one another and it is not uncommon for other colonized societies with long held traditions of ancient communication rituals to conduct themselves in a similar manner. I have often recognized that when community engagement took place in my community, people are deeply present in the activity of sharing knowledge. I believe these concepts are important to consider for the diffusion of Inuit electronic health information because many of the spaces where opportunities for communication exist are located within a colonized healthcare system. In Canada, colonization, as a historical or modern process, is seen as the cause of health disparities

and other social inequities experienced by First Nations, Métis and Inuit (Wilson & Yellow Bird, 2005). Colonization involved the creation of First Nations reserves (Mussell, 2008), Métis townships (Barron, 2000) or the relocation of Inuit to permanent settlements (Pauktuutit Inuit Women of Canada, 2002). Before the arrival of Europeans, Aboriginal groups in North America were largely independent and self-determining of their own philosophies and approaches on sociocultural and economic matters that impacted their health systems (Royal Commission on Aboriginal Peoples, 1996). Processes and practices of domination set up by the colonizers have allowed colonialism to continue to persist in these communities into today (Neu, 2000).

Stemming from feminist discourse, I have made decolonizing theory that supports an Indigenous paradigm for research a crucial component of this research. Indigenous peoples' interests, knowledge and experiences must be at the heart of research methodologies about Indigenous peoples (Rigney, 1999). A decolonizing theoretical paradigm includes critiques of research conducted by non-Indigenous researchers (Smith, 1999), epistemologies (Wilson, 2008) and culturally safe research (Anderson et al., 2003). Smith (1999) argued that Indigenous researchers are expected, by their communities and by the institutions that employ them, to have an informed sense of the historical and critical analysis of the role of research in the Indigenous world. It was critical for me to consider the worldview of Inuit and their perspectives on modern healthcare delivery for the purposes of doing this research.

Batiste (2000) argued that cognitive imperialism as a form of cognitive manipulation has been used to disclaim other knowledge bases and values outside the mainstream. In the healthcare system, this has been a result of institutionalized racism, which was established over time by a result of a series of policies that governed Aboriginal healthcare practices throughout Canadian history (C. Cook, personal communication, April 29, 2012). The disjuncture between

the dominant biomedical approach to health and the holistic understanding of approaches to health in many Aboriginal cultures is the root cause of the fact that Aboriginal peoples suffer ill-health at much higher rates compared to the rest of the population in Canada (Mundel & Chapman, 2010). A decolonizing approach is needed to address the disparities that exist between biomedical and Inuit worldview perspectives. This kind of research approach can then provide the basis for developing a set of culturally appropriate tools that Inuit can use while maintaining Western scientific models of health information in order to survive in a modern healthcare system.

Inuit are believed to be the first humans that arrived in North America around 30,000 BC and are the Indigenous peoples of the arctic and circumpolar regions of the earth (Minority Rights Group, 1994). There are approximately 50,480 Inuit who reside in Canada (Statistics Canada, 2006). Of this population, 78 percent live in the Inuit Nunangat, while the other 22 percent primarily reside outside of this region, and among this population segment, 76 percent are settled in urban areas (Inuit Tapiriit Kanatami, 2008). Inuit have the youngest population of the three Aboriginal groups in Canada, with a median age of twenty-two years (Clark, Whetung, Kinnon & Graham, 2010). Inuit children account for 40 percent of the total Inuit population (Gionet, 2008), and an urban population is rapidly increasing. This growing Inuit population may create an increased demand for services in the provinces such as healthcare. According to Statistics Canada (2006), there are 560 Inuit who live in Manitoba, which is approximately the same number of Inuit that live in a small community in the Inuit Nunangat.

Disease has led to colonization and loss of Inuit self-determination and a distinct Indigenous identity. By the 1900s, smallpox, tuberculosis and other communicable diseases had nearly decimated Inuit communities in Canada (Young, 1984). Since then, there has been a

variety of policies which have shaped the management of Inuit healthcare in Canada and has evolved into the formation of the First Nations and Inuit Health Branch (FNIHB) of Health Canada in 2000 (Health Canada, 2012). While Inuit who live outside of their traditional territories are supported by provincial health programs, FNIHB continues to provide non-insured health benefits for approved health services not covered by provincial health plans (Health Canada, 2012). Inuit are recognized as “Aboriginal Peoples” under Section 35 of the Constitution Act as a distinct group and are separate from the First Nations; however, there is no clear legislation that is comparable to the Indian Act that defines them as a distinct people. Clark, Whetung, Kinnon & Graham (2010) stated that an essential point to make when discussing Aboriginal peoples and health in Canada is that:

according to the *British North America Act* of 1867 (now the *Constitution Act* of 1982), the federal government was given responsibility for “Indians and lands reserved for Indians” (Section 91 [24]), while provincial/territorial governments were given the responsibility for both health and education delivered off-reserve. This division of jurisdictions has created gaps in accessing health services and inequities across systems (p. 44).

The federal government, however, assumes the responsibility for providing the same level of services to Inuit as if they were registered Indians (Waldrom, 2006). At the national level, Inuit currently receive health programs and services aimed at all of Canada's Aboriginal peoples, which does not always work because First Nations and Inuit are distinguished by geography, culture and different traditional healing methods (Manzer, 2000). This fact is no different in urban centres. For example, when dealing with large health organizations and institutions in urban settings in Newfoundland and Labrador, Inuit were intimidated by the layers of complexity

they faced in accessing healthcare services (Hanrahan, 2002). Health providers' inability to appropriately address cultural differences has contributed to high rates of Inuit aversion toward using mainstream health facilities even when service is needed, due to feelings of fear, disrespect and alienation (National Aboriginal Health Organization, 2003).

A study conducted by the Social Planning Council of Winnipeg (2008) revealed that most Inuit who relocated to Manitoba found that accessing information about urban services presented a varying degree of difficulty. The majority of respondents stated they needed to acclimatize to living outside of the Inuit Nunangat because there was insufficient support available specifically for or targeted at Inuit. Most of the Aboriginal services that are available are tailored toward First Nations or Métis, which can cause further exclusion of already marginalized, isolated Aboriginal group who are living away from their traditional homeland and potentially separated from other family members. Too often, when it comes to government programming, Inuit community needs and realities are subsumed with the First Nations and Métis populations.

A complexity that exists in urban environments is the fact that most of the health programs and services targeted at Aboriginal populations are based on pan-Aboriginal policies of federal and provincial governments and regional health authorities. This issue creates challenges because of the well documented fact that there is a significant disparity between the health of Inuit and that of Aboriginal peoples in general, compared to that of the general Canadian population (Smylie, 2001). To further exacerbate this fact, formal schooling has repeatedly failed to address particular cultural and community needs for Canada's Inuit population without providing the necessary tools to help them negotiate their identities as Inuit Canadians (Santo, 2004), inadvertently contributing to the social economic determinants of health impacting this group. If Manitoba Inuit are unaware of or misunderstand electronic health information concepts,

there is a risk that non-communication and suboptimal provider care could occur. The value of relationships with public service organizations and access to information on a wide variety of service-based initiatives cannot be underestimated and must be undertaken with Inuit-specific cultural sensitivity (Social Planning Council of Winnipeg, 2008).

Owning and controlling personal biomedical data that is culturally safe can be empowering to Inuit as their healing from past social injustices ensues. A culturally sensitive approach would focus on:

appropriate health education efforts that could change attitudes, beliefs and behaviours of cultural participants by tailoring messages to cultural characteristics of audience members, the culture-centered approach emphasizes at changing social structures surrounding health through dialogues with cultural members that create spaces for marginalized cultural voices (Dutta, 2007, p. 304-05).

Personal health information services from an electronic health record system can be difficult for any non-expert to apprehend. For Manitoba Inuit, accessing personal health information services can be even more daunting because of cultural barriers. The health system in Canada has created an environment that makes it difficult for Inuit to access services, which could be due to social economic determinants of health or other related issues. Health Canada offers specific programs for Inuit living in the Inuit Nunangat, however the responsibility shifts to the provinces for programs offered to urban Inuit. This obligation includes the services that are provided through electronic health. Electronic health is a wide and complex area of the healthcare system and includes a variety of interconnected parts. Synchronization of care for Aboriginal communities requires health information to be accessible to providers across jurisdictional governments, thus increasing data sharing issues of health communication systems (Williams, 2011).

To further add to this complexity, electronic health information systems have unique definitions that are jurisdictionally dependent. In Manitoba, clinical systems are defined as (a) an electronic medical record, which is used within primary healthcare and specialist clinics for the collection and management of patient information; (b) an electronic patient record, which is a facility-based record that contains patient health information that is typically related for point-of-service care within that facility; and; (c) an electronic health record, which is a secure and lifetime record of an individual's key health information that can be viewed electronically by authorized providers across the spectrum of care (Mackling & LaFléche, 2011). For the purposes of this research, I have focused on the electronic health record.

An electronic health record facilitates the sharing of timely and accurate health information among authorized healthcare professionals and promotes integrated care, improved patient safety and enhanced quality of care (Peister, 2005). These systems are designed so that the provider will spend less time tracking down patients' lab tests, medication histories, allergies, diagnostic imaging results, immunizations, diagnoses, discharge summaries and the like. Schneider (2010) stated that the electronic health record is one of the most prevailing methods for an individual to protect personal health information while maintaining levels of control and accuracy.

In Manitoba, a central component to the electronic health record system is known as *eChart Manitoba*, which was branded as such in order to create more sustained meaning with the public (S. Stokoloff, personal communication, April 11, 2012). First announced in April 2007, the 40-million dollar project is supported by the Province of Manitoba and Canada Health Infoway, a federal organization that invests in information communication technologies within the healthcare system (Sylvain, 2011). The purpose of the eChart system is to help providers

manage all aspects of patient care electronically, eliminating dependence on the availability of patient paper charts, and allowing providers to access records simultaneously and at multiple facility locations on an as required basis (Manitoba eHealth, 2012). Centralized electronic health records that disseminate accurate personal health information of patients can facilitate a more accurate and complete diagnosis, help avoid errors and adverse drug interactions, and improve health care treatments through improved patient education (Journal of the American Optometric Association, 2010). Components of patients' personal health information are often initially generated and maintained in several source information systems irrespective of the information domain. EChart Manitoba includes source information from various contributors to the overall system including: the Drug Programs Information Network; Manitoba Immunization Management System; Manitoba's Predominant Radiology Information System; diagnoses and encounters from St. Boniface Hospital's electronic patient record; as well as laboratory test results that are sent by participating laboratories' source systems respective of their integration dates (Manitoba eHealth, 2012). Further modules can be added on to an electronic health record depending on system maturity, provider demand and jurisdictional priorities. Since electronic health records are unique blueprints across Canadian jurisdictions, these systems are being built based on existing info-structures that can integrate source data. Fiscal and political decision making priorities are also factors in their ongoing development.

EChart Manitoba was publicly launched by the Manitoba Minister of Health in the spring of 2011 (Province of Manitoba, 2011). To educate and create awareness of eChart Manitoba, a provincial public awareness campaign was developed. As of the spring of 2012, two paid-media campaigns that consisted of print and electronic media have been deployed since the system implementation began. To supplement the paid-media campaigns, Manitoba eHealth

collaborated with regional health authorities to heighten exposure across the province and also partnered with Canada Health Infoway on two national public awareness campaigns that were regionally targeted. Additional coverage occurred in association newsletters, and health and trade magazines (S. Stokoloff, personal communication, April 11, 2012).

These early communication strategies were not specifically directed at Inuit; however, tactics that include provider-patient communication and grassroots social marketing campaigns orchestrated by the Inuit community could potentially be effective ways to reach this audience in the future. Given that eChart is still a relatively new innovation and not yet fully established in Aboriginal communities throughout the province, great opportunity exists for providers to use this solution with Aboriginal patients as it becomes available in their healthcare facility. A communication strategy should consider culturally safe discourses when communicating the personal health information that is available in eChart.

First developed by Maori nurses in the post-colonial climate of New Zealand, cultural safety is concerned with mitigating the unequal access levels to structured healthcare that is a common reality for Aboriginal populations (Anderson et al., 2003). The National Aboriginal Health Organization (2000) defines cultural safety as what is felt or experienced by a patient when a provider [or organization] communicates in a respectful and comprehensive way that empowers the patient in decision-making and builds a relationship where the patient and provider work together to optimize a maximum level of care. Cultural safety involves the building of trust with Aboriginal patients and recognizing the role of social economic determinants of health and requires communicating respect for a patient's beliefs, behaviours, and values (Brascoupé & Waters, 2009). Culture and ethnicity create a unique pattern of beliefs and perceptions as to what "health" or "illness" actually mean. In turn, this pattern of beliefs

plays a role in how symptoms are recognized and interpreted, which affects the frequency when health services are sought (Anderson et al., 2003).

Smylie, Williams & Cooper (2006) noted that Aboriginal approaches to literacy are inherently linked to and correspond with Aboriginal notions of and approaches to health because it deals with empowerment and community engagement on underlying social economic determinants of health. Inuit social economic determinants of health include several factors including acculturation; productivity; income distribution; housing; education; food security; health care services; social safety nets; quality of early life; addictions; and, the environment (Inuit Tapariit Kanatami, 2007). Chiarelli & Edwards (2006) argued that policies in health literacy need to address two perspectives: how basic literacy skills influence the health of individuals and populations; and, the degree to which individuals have the capacity to obtain and comprehend basic health information and services needed to make necessary health decisions.

The fields of health literacy, health promotion, and Indigenous knowledge translation must take into consideration the need for the understanding and applicability of local sociocultural realities because the field has tended to consider literacy as a common skill set, which is a disconnection from sociocultural realities of a specific Indigenous population (Smylie et al., 1996). Health literacy is defined as the degree to which an individual is able to read, understand, and use knowledge to make informed healthcare decisions (Rudd, Moeykens, & Colton, 1999). More distinction is needed in the creation of Inuit health communication tools that are specific to urban Inuit populations and environments (Smylie et al., 1996). Understanding the issues involved will make these processes more culturally commensurable. For example, it would be valuable for providers who have urban Inuit patients to gain contextual knowledge about an Inuit historical and cultural framework instead of consolidating this population group

within with an “Aboriginal” demographic. As stated earlier, Inuit culture is different than First Nations or Métis cultures; therefore, it would be valuable for clinicians to understand an Inuit world-view perspective in order to increase effective provider-patient communication.

Perspectivism suggests that persons can know no fact without thoughtful consideration or hold no claim of that reality independent of belief and that there are many ways to view a particular phenomenon (Folger, Poole & Stutman, 2005). Perspectives of Inuit should not be sub-standardized with other Aboriginal groups in Manitoba, because Inuit culture, particularly as it merges with southern Canada can take on multi-dimensional meaning because the community is widely dispersed over large geographic areas. We do not have the same sorts of systems that First Nations and Métis populations have since our traditional land base is far and wide from urban centres. Interpretation of health data and communication tools that uphold Inuit perspectivism would be valuable for the MUIA and its stakeholders in the healthcare field to consider when translating the value of the electronic health record to Manitoba Inuit. Chang (2007) argued that providers have an obligation to facilitate the transfer of knowledge that includes an assessment of cultural and literal needs because it can improve health outcomes for patients.

The Indigenous world-view is based on societal shared philosophies that have deep-rooted cultural meanings and are blueprints for interpreting customs, laws, rules and actions (Littlebear, 2009, cited in Battiste). Estey et al. (2010) argued that the inclusion of multiple perspectives that preface social and political issues facing Aboriginal communities would extend the evolving theories of knowledge translation in a health context. Manitoba Inuit have their own distinct perspectives on health and as such should develop proprietary tools that can help to educate their community members about electronic health in ways that are culturally

commensurable and can lead to self-sustaining models for healthcare and electronic health information management. It is through community collaboration that a solid understanding of electronic health information processes for Inuit will be achieved and subsequently guide health promotional efforts extended by providers and health organizations (McShane et al., 2006).

In the realm of Inuit health, little research that is concerned with cultural safety in Inuit populations has been conducted; however, some work has been conducted by Inuit Tuttarvingat, the Inuit health research centre of the National Aboriginal Health Organization. Given the level of regional focus that is being placed in First Nations and Inuit through the devolution of healthcare services from Health Canada on the provinces and territories (First Minister's Meeting, 2004), regional Inuit organizations will be required to assist in the level of health promotion and protection policies, patient care and patient safety measures. With the exception of some national, provincial and territorial campaigns and organizing efforts, almost all prevention, promotion and protection programs targeted at Aboriginal peoples are designed and delivered by grassroots movements (Kinnon, 2002).

There have been many studies regarding specific types of healthcare delivery to this group in northern areas, however, less is known about the Inuit living in urban areas and their ability to access health care services in these locations (McShane et al., 2006). Much of the work accomplished to date has been undertaken by Tungasuvvingat Inuit, an Ottawa-based organization that focuses on strengthening and enhancing the lives of Inuit living in Ontario (Tungasuvvingat Inuit, 2012). The Manitoba Urban Inuit Association (MUIA), the organization that supports and advances the quality of life for Inuit living in Manitoba, has an opportunity to develop communication tools that educate its members about electronic health information, its purpose, and the personal health information services these types of health programs offer. These

discourses can include tools that could be used to supplement the health data that is typically associated with an electronic health record with information that is more contextual with Inuit cultural perspectives. Systems of Inuit health information that were communicated orally prior to European contact were broken down by colonization processes (L. Brown, personal communication, October 7, 2011), and as such, there is an opportunity to develop a space for dialogue about personal health information within an Inuit health, sociocultural and biomedical context.

When members of the MUIA were consulted about the electronic health record program in Manitoba, most were unaware of eChart Manitoba, or the degree in which various electronic health information systems worked together within the context of healthcare delivery. To foster culturally-safe health protocols for their members, it would be valuable for the MUIA to establish practices related to public education efforts to do with electronic health information programming, privacy and culturally-specific tools that can supplement personal health information available from systems such as eChart Manitoba.

Diffusion is the process by which an innovation is communicated through channels such as human interaction, media or instruction over time among members of a social system. An innovation can include an idea, technology, information, products and services as they are new and being introduced (Dearing and Meyer, 2006). Electronic health information education requires a combination of these channels for their public adoption to be fully realized. Clinicians can provide effective and culturally-safe health information and services for urban Inuit by an increased understanding of their culture, community and adhere to communication strategies that foster collaboration in the development and diffusion of community-based health information programs.

In addition to provider-patient communication, tools and programs can be developed with cultural safety in mind from planning and development through to execution. Including Inuit in participatory forms of program planning and development can deliver promising results. There is mounting evidence that shows that at least half of patients cannot comprehend basic healthcare information and this low health literacy can contribute to an increased risk of medical error and negatively impact the health outcomes of patients (Rudd, Moeykens & Colton, 1999). The use of simple information and pictorials, avoiding medical jargons, and encouraging provider-patient engagement can contribute to improved electronic health literacy and health outcomes for Manitoba Inuit.

Method

The central research question that this study has aimed to answer is: “How can culturally safe communication practices for accessing personal health information services assist Manitoba Inuit with their right to self-determination?” Because this question seeks the answers of both Inuit community members in Manitoba and stakeholders involved with Aboriginal electronic health program delivery, it was necessary that I pursue a qualitative style of research. As Denzin & Lincoln (2003) described, qualitative research is an activity that situates the researcher’s point of view and consists of a set of interpretive, substantive practices that encourages an awareness through conversations and storytelling. I used this research style to collect data because it offered me a means to gather stories and ideas, in a collaborative way, and reflect on their meaning prior to deriving at conclusions and eventually putting together an interpretation (Marshall & Rossman, 1999).

Qualitative research is commensurable with an Indigenous methodological framework because it is a framework of interpretive actions and “prefers no single methodological practice

over another” (Denzin & Lincoln, 2003, p. 9). It is the broadest research strategy that can be best used as a way to interpret views of Manitoba Inuit and their perspectives on the electronic health record and personal health information services. A qualitative research strategy was the most meaningful way to incorporate the significance of Inuit culture on the topic I was researching and to make meaning of information that could be used to describe a set of practices that are based on Inuit cultural implication and meaning.

To prepare for the research process, I approached the MUIA to determine whether or not there was a fit for the research being proposed and secondly, I developed a process for accountability based on a set of guiding principles for this research (Appendix A). In addition to posing the research issue to the MUIA Board of Directors in October 2011, I met with the MUIA on two occasions to clarify the research process. The method used and the proposed research questions were agreed on by the association prior to the research commencing (Appendix E).

Data collection techniques employed included holding two focus groups with Inuit participants that were recommended and endorsed by the MUIA, and key informant interviews with electronic health program stakeholders in Manitoba who are responsible for the delivery of electronic health in First Nations and/or Aboriginal communities. My access to these subjects was facilitated by my partnership with the MUIA. Focus groups were conducted with support from the MUIA and included urban Inuit members residing in Winnipeg who are respective Inuk Beneficiaries of the Nunavut Land Claim Agreement. Key informant interviews were conducted after the focus groups took place in order for the data collected from these sessions to provide context to the interview discussions.

My knowledge of research ethics borrowed from my experience as Director of Communications at the National Aboriginal Health Organization provided additional insight into

research protocols when working with Aboriginal communities. Ethical guides provided by Royal Roads University and the Principles of Collaboration Agreement between myself and the MUIA were adhered to throughout the research process.

Research Approach

Prior to starting the research, a meeting of the MUIA took place in October 2011 to determine if this research idea was a subject matter that would be of value to the organization and its membership. Upon approval, it was determined that a collaboration agreement was not available to support an ethical review process because the organization had not yet established guiding principles and procedures for collaborative research projects of this nature. A template agreement from the Pilot Project between the Assembly of Manitoba Chiefs (AMC) and the Canadian Aboriginal AIDS Network was suggested by the Manager, Research and Social Development Initiatives at AMC. This document was revised and adapted for an Inuit research project to cover the goals of the project, expectations of the researcher, the role of the association, data storage, consent and publishing and distribution. The template was versioned and re-titled as “Principles of Collaboration Agreement” and is now an instrument that can be used for future research projects, customized for specific research by the MUIA and its research partners.

The MUIA and I agreed to acknowledge and respect Manitoba Inuit’s right to self-determination, including the authority to do this research. In doing so, the research process was built upon mutually respectful interactions and meaningful engagement between the parties involved. Furthermore, I agreed to respect the privacy, dignity, culture and rights of Manitoba Inuit. The MUIA and I also agreed that we would not sensationalize issues in Manitoba Inuit communities, but would present a balanced representation that focused on an equal aspects of the

more positive aspects of the issues discussed. As such, I understood that I would collaboratively prepare draft findings to the MUIA prior to submission for publication or presentation and require approval from the MUIA. The draft findings were reviewed in a timely manner and any questions regarding the research from the MUIA were responded to in a timely manner with due consideration for the timeframe within this project was undertaken.

It was essential that all research participants understood the ethical guidelines of the project. Costellano (2003) argued that Aboriginal communities have the right to participate as principals or partners in research that affects their culture, identity, and well-being even though their axiology may clash with prevalent norms in Western research. There were a number of documents used to help guide the ethics process as part of this project, including, Tri-Council Policy Statement (2010) and ultimately the agreed to Principles of Collaboration Research Agreement with the MUIA. The Agreement recognizes and emphasizes Manitoba Inuit cultural values and perspectives into the research process of this project. A resolution was passed by the MUIA Board of Directors on April 1, 2012 that the Agreement was acknowledged as an instrument for the conduct and provision of research throughout the project. It was my responsibility to follow the Agreement throughout the project as a service provider to the MUIA and to fully understand and comprehend the Royal Roads University Research Ethics Policy (2011).

After conducting the literature review, I deployed a strategy that included conducting one focus group with MUIA members and three key informant interviews with stakeholders involved in Aboriginal health information programming. For the focus group, I developed a set of questions that related to health, history with the health care system, privacy, and pointed questions that related to the clarity of the eChart Manitoba concept, personal health information,

information request forms, and slides that included selected screen shots of the eChart Manitoba system.

I found the focus group method of using a reflexive dyadic interview to be culturally appropriate to the task at hand. The focus group was an ideal method for working with the participants because it allowed conversation from elders and community members in a manner that each participant was able to gather information from one another while participating in a communal experience. The reflexive dyadic interview approach allowed me to interject additional comments about policy, technical, jurisdictional or system issues while maintaining a decolonizing research strategy keeping the discussion focussed on the perspective of the participants and their Indigenous worldview.

According to Ellis and Berger (2003), the reflexive dyadic interview is a continuous and symbiotic dialogue that evokes stories and perspective between a researcher and participant. Focus groups are a qualitative research method that allows a researcher, through a group dialogue, to focus discussion amongst a group of people on a focused topic (Morgan, 1996). Focus groups are guided by a facilitator that maintains a discussion that if focused on the research topic can stimulate a dialogue from participants involved (Morgan, 2001).

To keep the focus group dialogue on the topic, I developed an interview guide to assist with questions and facilitating conversation. This guide was merely a set of questions and a time allotment to keep the focus groups within the set timeframe. Careful attention to the questions, the order they were asked, and the timing, were important elements of the focus group process (Packer-Muti, 2010). Furthermore, the length of time of the focus group was an important consideration and executed within a two-hour timeframe to avoid fatigue among participants (Tang, Davis, Sullivan, & Fisher, 1995). For the focus group interview (Appendices C, and E) it

was important to me that I maintain the sense of an Inuit axiology through the questions I raised. This required that I respect the flow of the conversation and inserting my knowledge on an as needed basis to do with electronic health or my experience an Inuk who has used health services in Manitoba. The participants each offered individual points of view while maintaining an Inuit axiological perspective (Wilson, 2008).

At the first focus group, I had four participants present to participate, which was a lower than expected level of involvement. For that reason, a second focus group was held in an Inuk elder's home in Winnipeg with five Inuit in attendance. For each focus group, the research consent form was explained thoroughly before each participant signed the document. A follow up interview with one Inuk elder occurred after the focus group sessions took place in order to reconnect on Inuktitut meanings and other traditional knowledge that was discussed during the focus group sessions. The same questions posed at the focus groups were used. Inuit protocols for interviewing elders required that I follow rules when interacting with elders within this study. As stated in the Nunavut Arctic College Interviewing Inuit Elders Guide:

Respected elders are role models in Inuit communities who serve as mentors, teachers, philosophers and advisors. Elders play an important role in keeping the strength of close-knit families, which is being lost. As Inuit, we still respect our elders regardless of status and family lineage. All of our Inuit elders have stories related to their knowledge and experience and the hardships they went through (Nunavut Arctic College, 2008, p. 4).

Elder members of the family hold positions of high respect in community structure within Inuit society and are often sought for their advice on a particular issue (Pauktuutit Inuit Women of Canada, 2002). The elders involved in the study were able to provide extraordinary experiences

and points of view about historical issues, culture, language and a vision for the future which are invaluable to the research outcomes of this project.

The second research tool I utilized was the key informant interviews with electronic health stakeholders in Manitoba who are responsible for the delivery of electronic health in First Nations and/or Aboriginal communities (See Appendices B, D, and F). The theoretical basis for the interview method was influenced by ethno-methodology scholars and feminist scholars (Campbell, 2003). Holstein and Gubrium (1995) asserted that all interviews are active interviews: they are collaborative, interactive and are meaning-making. Holstein and Gubrium's (1995) primary concerns were with both the process of the interview and the content it generates, or what they termed as the "hows" and "whats". The researchers stated that the interview process (the how) is given more attention than the content (the what) and making meaning of the lived experiences of the participant. These interviews were meant to capture supplemental information to help inform the analysis and assist in the development of practice recommendations that are meaningful and achievable at a grassroots level.

The third research tool I utilized was a reflexive dyadic interview with an Inuk elder. This conversation provided me with information and knowledge that helped help shape my consciousness of the subject matter and make recommendations to the MUIA. The same interview guide used during the focus groups was used to guide this interview.

To summarize, the research participants included nine members of the Manitoba Inuit community, ages twenty-one to seventy, who are involved with MUIA governance or in healthcare delivery, health and social policy as well as three managers of electronic health information programs. These participants were selected based on their knowledge of Inuit culture and language, or their proximity to the health sector. A total of twelve participants were involved

in the research data collection process. By including a mixed method of data collection, I was able to maintain the two-eyed seeing principle of incorporating perspectives that were both Western and Indigenous in nature.

Data Analysis

Upon completion of the set of interviews conducted, it was necessary to understand the data that was captured. Creswell (2003) stated that data collection is a preparation for moving deeper into understanding a topic and making interpretation of its larger contextual meaning. I transcribed the digital recordings in solitude so that I could connect to the material on a philosophical and spiritual level. To summarize the data, I used spreadsheet software to help sort, code and filter responses. I developed a system of categories that helped me organize salient issues that came out of the data and sorted and coded these further in order to identify trends and comparisons which broadened and deepened my understanding of the data (Auerbach & Silverstein, 2003).

Coding was used to make sense of the streams of data from the respective interviews which uncovered the emergent and cultural themes that could be considered promising practices within a program delivery framework (Coffey & Atkinson, 1996). The final written analysis of the data was sent to all interview participants to provide them an opportunity change or remove information they did not want to make public (Jefa Dei & Singh Johal, 2005).

Study Findings, Considerations & Conclusion

The research findings and discussion are divided into three sections. The first section provides the study findings in organized themes. Themes emerged based on commonalities in the data collected from various participants. Inuit culture was used as a lens to analyze the data collected because it provided the contextual significance regarding the types of tools that can be developed

around electronic health information in order for it to have increased meaning for Manitoba Inuit. Section two describes tools to be considered by the MUIA for communicating electronic health information concepts to its membership. In the concluding section, I present my recommendations for next steps of the research project and its findings.

Study Findings

The common themes of the research were identified as (a) reclaiming ownership and vision; (b) sustainability; (c) authority and capacity.

Theme # 1: Reclaiming Ownership and Vision.

The study findings revealed a core theme of Inuit reclamation of ownership and vision of personal health information. Participants described this recovery as their right and need for self-determination in the control and ownership of health information and a long-term vision for how Inuit can manage their health data and in turn develop programs for an Inuit constituency-base in Manitoba:

Traditional knowledge collection projects that have relevance to health have occurred in the past but these are not easy for us to find, especially if live outside of our home communities. The data is often stored inside institutions. We need [this data] repatriated to us. Make these more accessible in order for us to retain this knowledge.

We lost a lot of our personal identification and traditional knowledge with the Christian missionaries who thought they had all the answers. Loss of control. There is now a deficit model where we do not have a balance without histories. We have learned new ideas of health but they are mostly physical, some mental but not at all holistic. We used to have spiritual health and understood more about our thinking patterns which may have related to our health.

The notion of ownership of health data is not a new concept in Indigenous self-determination and self-governance (Jeffrey et al., 2006). This study does not suggest the MUIA would claim stewardship for Inuit health records in any real way other than for research and policy making purposes; however, there was agreement among MUIA members that they would

like more information about electronic health information in general in order to build capacity among its membership base so that they can interact with a modern healthcare system. They stated a desire to have access to health statistics that could be made available from electronic health information systems in Manitoba in order to prioritize efforts the organization is making with government partnerships. Naasautit, an Inuit-based organization in Ottawa established in 2011, organizes and reports Inuit statistics to regional Inuit organizations and communities for use in meaningful ways (Naasautit, 2012).

Historically, when data was collected for medical or research purposes we were not told why [information] was not being gathered nor were we informed of the outcomes of that data collection. Now we have the right to know as individuals, so it is important we understand the tools that are available for personal health information services.

Prior the establishment of Naasautit, some of the first national statistics on Inuit health were derived from the comprehensive survey study that was conducted in the Inuvialuit Region, Nunavut and Nunatsiavut communities in 2007-08 (Health Council of Canada, 2009). Additional data continues to be available from Health Canada and Statistics Canada; however, there is a desire to have regional control over this information with Inuit leadership in Manitoba. While there remain bureaucratic and political issues related to ownership of data, Manitoba Inuit, as individuals, can succeed by taking control over their own personal health information and taking responsibility for their own personal health data. Info-structure issues extend beyond the technological capabilities of data sharing, as the issues are primarily based on the policies that are imposed by whoever is in charge (Atherley, 2012). A comprehensive, tri-lateral planning approach is needed that is built on a robust monitoring and evaluation system (Inuit Tapiriit Kanatami and Inuit Circumpolar Council Canada, 2007). These facts provide good reason for MUIA to support a Naasautit driven policy framework for Inuit in order for decision making to occur at a national and regional level.

Anderson and Smylie (2009) argued that Indigenous health system performance measurement infrastructures are underdeveloped in Canada, particularly at local levels, which undermines community or regional health planning in these communities. Discussion took place about the MUIA using its membership list to provide names with a stated intent to a partnering organizations such as Manitoba Health and research groups to pull out the health information for just those names, strip out personal health identification numbers, execute a data analysis process in order to study trends over segmented periods such as statistics for conditions, hospitalizations and the like. This exercise would avoid the need to include an Inuit identifier in the health record in the short term; however, the MUIA expressed a desire for provincial and regional health systems to include a unique Inuit identifier in their demographic information over the long term to assist with data aggregation and statistical purposes.

Theme # 2: Sustainability.

In Nunavut, language affects all levels of service delivery and Inuit have become remarkably skilled at adapting the language to accommodate foreign words, therefore language is a critical area that impacts public administration of policy and programs (Okalik, 2011). The outcome of cross-cultural studies can depreciate culture rather than legitimize it because the process is meant to validate and legitimize dominant epistemological forms (Duran & Duran, 2000).

Participants noted that great care should be considered when determining Inuktitut words for expressing health information terminologies such as lab test, immunization, medication, diagnoses or the like.

Barriers can be overcome when a space is created for Manitoba Inuit and healthcare agencies to work together on established electronic health priorities.

Designing communication tools targeted at First Nations, Inuit and Métis groups in Manitoba poses a degree of difficulty because of linguistic variances and being able to interpret these differences.

In fact, the feedback received from virtually all participants indicated the importance of incorporating elements of Inuit identity into health information promotion and knowledge translation activities related to electronic health information systems and processes.

Human communication and interaction takes place at the level of personal identity that reaches beyond understandings of physicality and, as such, multi-perspective conceptions of specific human contexts goes beyond the traditional understanding of interaction and communication (Botin, 2007). There is an opportunity, however, to use the health space to connect health conversations with Inuit identity. Inuktitut words for *health*, such as *satuimajuq* and *arniaqtuliriniq*, should be used and built upon. In the North West Territories, Inuit have coined the term *nunatsiarmi aannianirmut nalliukkungmat*, which stands for *territorial health plan*. Seeman (2009) argued that Inuktitut can help communicate important unifying concepts in healthcare that may be elusive in English, a notion echoed by participants:

Inuktitut should be an option for Inuit accessing communication tools because it shows respect for the culture and language of the Inuit community and it also helps avoid language barriers which may interfere with an Inuk patient's well-being.

It would be extremely beneficial to break language barriers for our community. Also, for those who are not familiar with eChart, having their personal health information and the option for interpretation tools to be presented in our language will decrease any difficulties understanding this type of information.

For some members of the Inuit community, language poses barriers for those who wish to access personal health information services, particularly elderly Inuit or Inuit who are new to the Manitoba health system. In the restoration of whole-health in Inuit communities, there is a need to recover cultural meaning and perspectives that contribute toward Indigenous thought and Inuit relationships with ancestry, traditional teachings and lands. How can Inuit become self-

determining by utilizing health information systems that were developed by and managed by non-Inuit people that are predisposed to ways of thinking that is different than theirs? One participant suggested that Inuit need to develop a task force that considers words for describing health information and technology names in Inuktitut:

We need to see our language more prevalent in our service resources in order to keep our language alive, especially in a health context.

It is within this nimble space of electronic health that cultural protection can occur and open-door perspectives within an Inuit world-view can promote a sustained relationship with an evolving healthcare system. The naming of *Inuit Tuttarvingat* of the National Aboriginal Health Organization was arrived at through input from the Inuit community because there was no word for *centre* in Inuktitut. *Tuttarvingat* was selected because it comes from the Inuktitut work *tarvik*, which best describes the idea of a centre. *Tuttaq* means where something such as a ptarmigan lands; a landing base where it may exist for a period of time (Inuit Tuttarvingat, 2008). Similar opportunities for language can be discussed and considered to give back to the Inuit community in Manitoba, and exchanged with family and friends in the Inuit Nunangat or other urban locations where Inuit reside.

Theme # 3: Authority and Capacity.

The third theme addresses the issue of authority and capacity when outside agencies are collaborating with Aboriginal organizations to do with electronic health information systems and consideration of the imbalances of power that exist between these entities. This is an important issue to consider because, in relation to government relationships, particularly at multiple levels and jurisdictions, Inuit can be left out of political priority decision making because of the vastness of the Inuit populous in Canada (Nunatsiaq Online, 2011). Aboriginal peoples need to be involved in the ownership and control of the data that is stored in the electronic health record

and its source systems and therefore should be included in the governance structures of that data (Atherley, 2012), a principle explicitly supported by some participants:

[MUIA] needs to work with the health information service providers to understand our cultural needs. In the past, there was more widespread fear of government information systems, but today we are becoming more aware of our rights. As our younger generations become more education in healthcare and information communication technologies, we can develop stronger relationships and rebuild trust.

Governments need to recognize there are cultural differences when communicating e-health to Aboriginal communities and that this should not be a cookie cutter approach. Agencies need to start with an open mind, listen, and learn opposed to older methodologies which were built as top down approaches. They need to ask first before they implement.

In recent years, interest in Aboriginal traditional knowledge has increased among Canadian social scientists (Social Sciences and Humanities Research Council, 2003) and government. Notable to this change is the Government of the Northwest Territories, which was the first Canadian jurisdiction to officially recognize the value and role of traditional knowledge and propose its application within a governing system through the implementation of the Traditional Knowledge Policy. “This policy represents an early attempt to define traditional knowledge and to promote its use by committing that the Government will incorporate traditional knowledge into government decisions and actions where appropriate” (Northern Voices, Northern Waters, 2010, p. 15). Government in Manitoba, at all levels, need to recognize Inuit as traditional peoples of the Arctic but also as a people who also had traditional territory in Northern Manitoba along the Hudson Bay shoreline. The MUIA needs to be capable and engaged to help move along the processes for communication to assure their voices are heard at consultations related to Aboriginal health. Government tends to work with Aboriginal groups (First Nations, Métis, and Inuit) and there needs to be room for the MUIA on these occasions to build these relationships. The issue is that there has not been an authoritative voice for Manitoba

Inuit, although the Manitoba Metis Federation states on their web site that they are the recognized authority for Manitoba Inuit in the province (Manitoba Metis Federation, 2012).

Hodges et al. (2010) argued that systems of care are bounded by confines of world-view, Western conceptual frameworks, and the professional subcultures within which these exist. In an Aboriginal context, part of this relates to an understanding of who the Manitoba Inuit are. From the focus groups with MUIA members, it was determined there are 4 types of Inuit who access the Manitoba health system inclusive of (a) Inuit residents of Manitoba, e.g. Inuit residing in Manitoba for a period longer than 1 year; (b) new Inuit residents; (c) Inuit students and migrant workers living temporarily in Manitoba; and; (d) Inuit who come to Manitoba to access health services. It is estimated that over 15,000 Inuit residents of Nunavut potentially seek health services in Manitoba either through the Winnipeg Regional Health Authority or healthcare services through facilities in Churchill (Manitoba Health, 2008). This indicates a need for more effective outreach to this diverse demographic:

We should have more communication tools available especially as our younger generation becomes more educated in the south so they understand the privacy laws and we can have a strong Inuit community that is informed of its rights.

This participant quote is an example of how this type of capacity building can have long term human capital and community investment and ownership possibilities. Ownership is a very important concept to understand because it minimizes the altruistic nature of outsiders wanting to “help”. The best way one can help others is to enable and encourage leadership in ways that are suited to the peoples’ unique social needs. Rethinking educational models to recognize communication is more about sharing knowledge than dictating it will be a critical point of consideration.

Discussion of Findings and Recommendations

Assuring that capacity development continues to occur for Inuit in healthcare and health information systems will be critical for the future. Governments need to be aware of who within the Inuit community can provide input to programming and evaluation of health information systems. There is also the need for the MUIA to have the in-house expertise that can understand and interact with the healthcare system, complex information communication technology systems, and issues related to electronic health information delivery and privacy law.

The MUIA must have an organizational relationship with the Government of Manitoba and the Winnipeg Regional Health Authority, both in order to provide input into communication tools and to be aware of an evolving electronic health information atmosphere in which to inform its membership. Participatory processes that combine technical expertise, rational decision making, and public values and preferences are needed for improving risk management in communication planning (Renn, 1998). These processes must, however, involve Inuit epistemologies in a participatory framework. Participatory communication models for Inuit need to include knowledge sharing opportunities that are incremental and in an open series of dialogue points that occur and assure a level of cultural fluidity of which embraces dialectics that seek out solutions to tensions that exist.

The following are three recommendations from the research undertaken:

1. MUIA consider a proactive approach to establish inquiries that could aid in the design of customized communication tools and processes for personal health information services tailored to their constituency-base.

Inuit society, like those of all Indigenous populations, is based on oral histories and story (Archibald, 2006). Audio-visual tools that can depict electronic health information systems and

training for Inuit in the use of this information can yield the highest returns in terms of educating and informing Inuit about Manitoba eHealth's complex system constructs and policies. Spalding (2007) argued that vignettes (stories that describe a typical patient's use of health information) have a practical value as representations that can improve action because they offer a tool for patient reflection. The design and use of culturally appropriate audio-visual aids that highlighted verbal and visual rather than written educational tools and channels was an effective strategy for communicating with story-based peoples around health issues (Kreuter et al., 2002).

2. MUIA design communication tools in plain language that use narrative forms to document and educate about health information systems and include Inuktitut language reference points and other Inuit visual representation where appropriate.

For health communication strategies to be effective, they must be in "synchronicity with the target audience culture at all message levels, the textual and the visual, the denotative and the connotative, and be explicitly symbolic" (Kar, Alcalay & Alex, 2001, p. 109). The feedback from the participants was unanimous in its support of the idea that Inuktitut should be incorporated into tools used to communicate about e-health and personal health information services. To further emphasize communication with this group, using visual symbolism that Inuit could identify with would further increase overall effectiveness. Working with national and regional Inuit organizations to determine standards for words used in health information systems to create a lexicon is outside the scope of this research, but it is highly recommended that this process be started by the MUIA.

3. MUIA create an environment where consultation and engagement with members occurs to measure and evaluate the effectiveness of their health information programming.

A method to help a building capacity model is knowledge transfer facilitation through “learning by doing” in engagement (Singhal & Dearing, 2006). Through the interaction with personal health information services processes, the MUIA can determine how these methods might be culturally incommensurable or how might they be improved in order to meet the needs of the community. Gibson, Lacey, and Dougherty (1993) discussed the idea of civic engagement by calling for a paradigm shift in public participation and civic culture from a system that is modeled on the expert/professional model to one that integrates citizens into every aspect of government. Communication models that will work for the MUIA must stray away from rigid, top-down approaches toward fluid dialectical frameworks for participation that embraces knowledge exchange that is equally balanced (Papa, Singhal & Papa, 2006). Communication planning must incorporate opportunities for dialogue that are respected within Inuit social systems and assures a process that is well documented in order for participants to evaluate its effectiveness at a later date.

Conclusion

A two-eyed seeing research model can lead to outcomes that find spaces for self-determination within existing electronic health information systems. The findings of this study drew from both Inuit and non-Inuit participants to reveal a high degree of commensurability around themes related to: (a) reclaiming ownership and vision in relation to ownership and control over personal health information; (b) building a sustainable framework for accessing personal health information services that includes Inuit cultural perspectives and language; and; (c) identifying an authoritative body to consult on electronic health information issues and building capacities in order for expertise of clinical, technical and legal matters within the electronic health information space are contained within the Manitoba Inuit community for an ongoing dialogue to continue.

An extensive literature search was conducted to identify published articles which address electronic health information delivery and health communication strategies to Inuit and other Indigenous people. Most of the available national and community level data on these subjects were interspersed among various Indigenous populations and little information was available that was specifically related to Inuit, particularly in urban settings. The need for more information regarding Inuit electronic health and health communication strategies has been identified.

I consider this study to be the first step to develop communication tools that educate urban Inuit on electronic health and personal health information services. It may be that a national study could supplement the work needed in developing Inuktitut specific vocabularies that could further advance the discourse that is necessary regarding electronic health information in Inuit communities throughout Canada. This will not come without its challenges because there are often no words to describe technological terminologies in Inuktitut; however, emphasis on existing definitions can provide a knowledge-base around health that could potentially add to the contextual nuances of information communication technologies in healthcare.

Another limiting factor of this research is the systemic racism that continues to pervade Canadian institutions that serve Aboriginal peoples. There needs to be more emphasis placed on opening the door to new ways of working with these communities in order for true and meaningful support to occur. The need to incorporate Inuit traditional knowledge and world-view perspectives in health record keeping is absolutely necessary for the restoration of whole health and the survival of these peoples.

In the short time I had to do this research, I discovered the value of incorporating Inuit knowledge into conversations which relate to electronic health information and personal health information services in a manner that can benefit the Inuit community and non-Inuit stakeholders

in this field. I believe the information I gathered will be helpful for building bridges in a modern healthcare system and it will be the role of communication specialists in this space who will guide these conversations further into practicality.

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Appendix A: Principles of Collaboration Agreement

Principles of Collaboration Agreement Between the Manitoba Urban Inuit Association and Wayne Clark for the Research Project “Diffusion of Inuit Personal Health Information Services”

Parties

This document constitutes an agreement of collaboration between the Manitoba Urban Inuit Association (“the MUIA”), as represented by Nichola Batzel, President and Wayne Clark, Royal Roads University Student (“the Researcher”).

Purpose

The purpose of this Agreement is to establish a set of principles that will guide the conduct of the research project entitled “Diffusion of Inuit Personal Health Information Services.” These principles recognize and emphasize Manitoba Inuit cultural values and perspectives into the research process.

Process

The researcher will coordinate all administrative matters related to the above named research project, with recognition of the collaboration partnership with the MUIA. The Researcher will be based at XXX XXX XXX.

Ethical Considerations

The research collaboration partners to this agreement collectively share the responsibility for ethical standards throughout the project. Ethical codes of conduct for Aboriginal communities have been articulated in the federal government’s Tri-Council Statement (2010), and the Canadian Institutes for Health Research Guidelines for Research with Aboriginal Peoples (2008). In addition, each party of the research project has responsibility for raising ethical concerns and/or issues. Ethical dilemmas are to be resolved on the basis of the research party striving for a significant degree of consensus.

Duration and Amendments

This Agreement on Research Collaboration will be in effect throughout the entire research process, from the moment efforts are made to implement the proposal, through the development of the research methodology and questions, data collection, and analysis phases into the dissemination of and publication of the findings. This agreement can be amended upon mutual consent by the MUIA and the Researcher.

The MUIA and the Researcher agree to follow these principals in the manner outlined below:

- Research Advisory Committee: The committee will consist of the Board of Directors of the MUIA and the Acting Executive Director of the MUIA.
- Reporting: The Researcher will report to the Research Advisory Committee during the course of the project.
- The Research Advisory Committee and the Researcher acknowledge and respect Manitoba Inuit right to self-determination, including the jurisdiction to decide about research and projects in their communities. In doing so, the research process shall be built upon meaningful engagement and mutually respectful interactions between the research team and Manitoba Inuit communities. In addition, in recognition of the obligatory role of the MUIA in serving Manitoba Inuit the research process shall be built upon meaningful engagement and mutually respectful interactions between the parties. Further, the Researcher agrees to respect the privacy, dignity, culture and rights of Manitoba Inuit.
- The Research Advisory Committee and the Researcher will strive to include meaningful and equal participation from Manitoba Inuit community members. Therefore, the parties will be jointly involved as partners from the development of the operational plan, methodologies and questions, data collection, and analysis phases into the dissemination of and publication of the findings. The MUIA agree that its operational office for the purposes of research is at: 823 Ellice Avenue, Winnipeg, MB R3G 0B9
- The Research Advisory Committee will strive to demonstrate leadership support by obtaining and attaching resolutions or letters from Manitoba Inuit leadership, when required. Primarily, the task of negotiating evidence of Inuit leadership supports and resides with the MUIA.
- The Research Advisory Committee and the Researcher fully respect the rights of individuals and the confidentiality of their health data, the rights of Manitoba Inuit to control their community information and traditional knowledge; and the rights of contributors to their intellectual property rights, which shall not supersede the rights of Manitoba Inuit.
- The Researcher will collectively make decisions on research questions, in data collection, interpreting results, in drafting report, and dissemination of findings.
- The research questions will seek to address the purposes of the research study and will work to ensure that the research project is relevant to Manitoba Inuit.

- In dissemination strategies to Manitoba Inuit communities, the Researcher agrees that language and manner of sharing will be appropriate to Manitoba Inuit. All material disseminated to Manitoba Inuit communities must be jointly developed by the Researcher and the MUIA.
- The Research Advisory Committee and the Researcher agrees they will not sensationalize problems in Manitoba Inuit communities, but will present a balanced portrait that also focuses on equal attention on the more positive aspects. As such, the Researcher understands that they will collaboratively prepare draft findings prior to submission for publication or presentation. Any draft findings prior to submission for publication or presentation must receive commentary from the MUIA, even if it is only a note that has been reviewed. The draft findings will be reviewed in a timely manner and any questions regarding the draft findings from team members posed to other committee members must be answered in a timely manner with due consideration for the time frame within this project is undertaken.
- Given that all members of the Research Advisory Committee will be provided the opportunity to review and comment on finding prior to publication or presentation, any one member of the research team may not, particularly once initial dissemination occurred, further analyze, publish or present findings resulting from the above mentioned research study unless the entire team reaches consensus.
- The Researcher is responsible for maintaining the integrity of all data collected, such as story participant consent forms, storing raw data, and identifying who will destroy the data. Determination of how the integrity of the data will be maintained will be made by consensus. If no consensus can be reached, then data must be maintained at a site identified or acceptable to the MUIA and the Researcher, upon recommendation by the Elder Members of the MUIA Board of Directors.
- Once the privacy and confidentiality of participants has been demonstrated, data sets in the form of appropriate computer files may be shared with all members of the research team. In cases of disagreement over transfer of data sets, the MUIA and the Researcher will strive to achieve a significant degree of consensus.
- The Research Advisory Committee and the Researcher agrees to provide meaningful and appropriate capacity-building, as indicated by the MUIA and Manitoba Inuit community.
- The Research Advisory Committee and the Researcher agrees that Manitoba Inuit communities have the right to follow cultural codes of conduct and community protocols. In situations where Manitoba Inuit community members are in disagreement, the

Research team will strive to resolve conflict towards achieving a significant degree of consensus.

- The Research Advisory Committee and the Researcher agree that it may be necessary to seek advice and support from Manitoba Inuit Elders and other leadership, including situations where difficulties arise in obtaining consensus. Recognition of who is considered an Elder is made by the MUIA, who is, or would be, informed by Manitoba Inuit communities and individuals.

Authorship

Criteria outlined by Huth (1986) will be used as guidelines for authorship of publication based upon the findings of the research. The criteria recommended that the author(s) must (1) make a substantial contribution to the conception, design, analysis, and/or interpretation of data; (2) be involved in writing and revising the manuscript for intellectual content; (3) approve the final draft. Those who have made other contributions to the work (e.g. data collection with interpretation, etc.), or only parts of the criteria should be credited in the acknowledgements, but not receive authorship.

- All members of the Research Advisory Committee will be provided with an opportunity to review and comment on findings prior to publication or presentation.
- The explicit permission of an individual or organization must be sought prior to acknowledging their contribution in a paper or presentation.
- A Research Advisory Committee may choose to include a disclaimer if they do not agree with the content or views presented in a publication or presentation. In the case of a presentation, the disclaimer must be incorporated into the presentations in a manner which gives it the possibility of noticeable attention by those attending the presentation. The manner which the disclaimer is to be included must be approved by those providing the disclaimer.

Signed this ____ day of _____, 2012 at Winnipeg, Manitoba.

Nichola Batzel
President, Manitoba Urban Inuit Association

Wayne Clark
Researcher, Royal Roads University Student

Witness

Appendix B: Invitation to participate (key informant interview)

<Date>

Dear _____:

My name is Wayne Clark, and I am a member of the Inuit community in Winnipeg, MB. This research project is part of the requirement for a Master of Arts in Professional Communication at Royal Roads University. My credentials with Royal Roads University can be established by telephoning Dr. Joshua Guilar (MAPC Program Head) at (250) XXX-XXXX.

The purpose of the research is to consider how culturally-safe practices for accessing personal health information services can assist Manitoba Inuit with their right to self-determination.

The overarching goal of this research is two-fold: to empower Inuit to attain self-determination for the management of their own personal health data; and, to develop a set of best practices that can be utilized by the Manitoba Urban Inuit Association (MUIA) for realizing this objective.

Research questions are based on ways government agencies can support Inuit communities to manage their personal health information in ways that is meaningful to their culture.

Addition information related to the research study, including protection for anonymity and confidentiality, opportunity to review the research findings and participants' right to voluntarily withdraw from the study is enclosed in the attached research consent form.

If you would like more information about the study, please feel free to contact me at (204) XXX-XXXX or by email at XXXX..

Thank you for your time and consideration.

Respectfully yours,

Wayne Clark

Appendix C: Interview consent form (focus group)

My name is Wayne Clark, and I am a member of the Inuit community in Winnipeg, MB. This research project is part of the requirement for a Master of Arts in Professional Communication at Royal Roads University. My credentials with Royal Roads University can be established by telephoning Dr. Joshua Guilar (MAPC Program Head) at (250) XXX-XXXX.

This document constitutes an agreement to participate in my research project, the objective of which is to understand how culturally-safe practices for accessing personal health information services can assist Manitoba Inuit with their right to self-determination.

The research will consist of interview questions and is foreseen to last 30 minutes. In addition to submitting my final report to Royal Roads University in partial fulfillment for a MAPC degree, I will also be sharing my research findings with the Manitoba Urban Inuit Association (MUIA). I may also co-publish the research findings with the MUIA in select health or cultural studies journals.

Information will be recorded with a digital voice recorder and, where appropriate, summarized, in anonymous format, in the body of the final report. At no time will any specific comments be attributed to any individual unless specific agreement has been obtained beforehand. All audio tapes of participants will be destroyed after the data analysis has been completed. If a participant wishes, he/she can respond to a questionnaire only. An opportunity to review the notes and analysis of the interview data will be made available to you prior to publication or presentation. All documentation will be kept strictly confidential.

A Collaboration Agreement between the MUIA and I has been executed to establish a set of principles that will guide the conduct of the research project under the guidance of a Research Advisory Committee appointed by the MUIA. The principles of the Collaboration Agreement recognize and emphasize incorporation of Manitoba Inuit cultural values and perspectives into the research process. If you would like more information about the Collaboration Agreement with the MUIA please contact Acting Executive Director, Lorraine Thomas at (204) XXX-XXXX.

I am responsible for maintaining the integrity of all data collected, such as participant consent forms, storing raw data, and identifying who will destroy the data. Determination of how the integrity of the data will be maintained will be made by consensus.

In addition, the MUIA will be provided the opportunity to review and comment on findings prior to publication or presentation. The MUIA and I have agreed that we may not, particularly once initial dissemination occurred, further analyze, publish or present findings resulting from the above mentioned research study unless the entire team reaches consensus.

You are not compelled to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

By signing this letter, you give free and informed consent to participate in this project.

Name: (Please Print): _____

Signed: _____

Date: _____

Appendix D: Interview consent form (key informant interview)

My name is Wayne Clark, and I am a member of the Inuit community in Winnipeg, MB. This research project is part of the requirement for a Master of Arts in Professional Communication at Royal Roads University. My credentials with Royal Roads University can be established by telephoning Dr. Joshua Guilar (MAPC Program Head) at (250) XXX-XXXX.

This document constitutes an agreement to participate in my research project, the objective of which is to understand how culturally safe practices for accessing personal health information services can assist Manitoba Inuit with their right to self-determination.

The research will consist of interview questions and is foreseen to last 30 minutes. In addition to submitting my final report to Royal Roads University in partial fulfillment for a MAPC degree, I will also be sharing my research findings with the Manitoba Urban Inuit Association (MUIA). I may also co-publish the research findings with the MUIA in select health or cultural studies journals.

Information will be recorded with a digital voice recorder and, where appropriate, summarized, in anonymous format, in the body of the final report. At no time will any specific comments be attributed to any individual unless specific agreement has been obtained beforehand. All audio tapes of participants will be destroyed after the data analysis has been completed. If a participant wishes, he/she can respond to a questionnaire only. An opportunity to review the notes and analysis of the interview data will be made available to you prior to publication or presentation. All documentation will be kept strictly confidential.

A Collaboration Agreement between the MUIA and I has been executed to establish a set of principles that will guide the conduct of the research project under the guidance of a Research Advisory Committee appointed by the MUIA. The principles of the Collaboration Agreement recognize and emphasize incorporation of Manitoba Inuit cultural values and perspectives into the research process. If you would like more information about the Collaboration Agreement with the MUIA please contact Acting Executive Director, Lorraine Thomas at (204) XXX-XXXX.

I am responsible for maintaining the integrity of all data collected, such as participant consent forms, storing raw data, and identifying who will destroy the data. Determination of how the integrity of the data will be maintained will be made by consensus.

In addition, the MUIA will be provided the opportunity to review and comment on findings prior to publication or presentation. The MUIA and I have agreed that we may not, particularly once initial dissemination occurred, further analyze, publish or present findings resulting from the above mentioned research study unless the entire team reaches consensus.

You are not compelled to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

By signing this letter, you give free and informed consent to participate in this project.

Name: (Please Print): _____

Signed: _____

Date: _____

Appendix E: Focus group questions

1. What is your relationship with the health care system? For example have you had good experiences navigating through it?
2. Based on the slides shown in the presentation would eChart Manitoba be easy to understand if you wanted to access personal health information?
3. Did the access to personal health information services forms (access to personal health record, receive a copy record of user activity; and add/remove a disclosure directive) look accessible and easy to understand?
4. How significant is the Inuktitut language for Manitoba Inuit for the creation of communication tools about eChart Manitoba?
5. How important is privacy of your personal health information?
6. Would it be helpful for MUIA to develop tools for assisting Manitoba Inuit become more aware of/understand eChart Manitoba?
7. Do you think the “N” Number should be included with your personal health record along with your Manitoba Health number?

Appendix F: Interview questions

1. Do you think there are barriers for Inuit that want to access their personal health information (E.g. access forms, language, bureaucracy or the like)?
2. From your experience in Aboriginal health, how critical would it for Inuit to feel empowered by managing their own personal health information?
3. Can you think of ways that government or health care agencies can support Manitoba Urban Inuit Association to assist members in managing their own personal health information?

Appendix G: Glossary of terms

Aboriginal Peoples	Aboriginal Peoples are all Indigenous people of Canada, including First Nations, Métis and Inuit people.
Arniaqtuliriniq	Inuktitut (Roman Orthography) term for health.
First Nations	A commonly used term to describe the Indigenous peoples of Canada who are not Métis or Inuit.
Métis	One of the Indigenous peoples of Canada who are of First Nations and European heritage.
Indigenous	Is a word used to describe people of the planet who are also considered as “First Peoples”.
Inuit	The Indigenous people of the arctic and circumpolar regions of the earth and stands for “the people” in the Inuktitut language.
Inuktitut	Inuktitut is the language of the Inuit.
Inuk	Is the singular noun of Inuit.
Inuit Tapariit Kanatami	The national organization representing Inuit who reside in the Inuit Nunangat regions of Canada.
Inuit Tuttarvingat	The Inuit Centre of the National Aboriginal Health Organization.
Inuvialuit	Is one of the four Inuit regions of the Inuit Nunangat which means “the real people” is the homeland of Inuit people who live in the Western Canadian Arctic region.
Naasautit	The national Inuit authority that organizes and provides readily available Inuit statistics in forms that is easy to understand and use.
Inuit Nunangat	Is the term used for the land base that covers land of the four Inuit territorial claims, including Inuvialuit, Nunavut, Nunivak, and Nunatsiavut.
Nunavik	Is one of the four Inuit regions of the Inuit Nunangat and comprises the northern third of the province of Quebec. It means “place to live”.
Nunatsiarmi Aannianirmut Nalliukkungmat	The Inuktitut language term for territorial health plan.
Nunavut	Is one of the four Inuit regions of the Inuit Nunangat which means "our land" in the Inuktitut language.
Nunatsiavut	Is one of the four Inuit regions of the Inuit Nunangat which means 'our beautiful land' and is the homeland of Labrador Inuit,
Satuimajuq	Inuktitut (Roman Orthography) term for recover health.
Tungasuvvingat Inuit	An Ottawa-based urban Inuit association that serves the interests of Inuit living in Ontario.