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A Case Study of Telehealth Usage in Three First Nation Communities:  
Understanding the Role of Technology Users in Health Care Practice

by

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## **Abstract**

In Canada, decision makers and First Nation communities often relied on telehealth to address the need for health care services. However, telehealth implementation has been marked by a series of structural constraints such as health care policies, resources, and technology. In the literature, researchers have focused on the efficiency and effectiveness of telehealth in facilitating health care services in rural and remote First Nation communities without addressing user needs. This thesis research is a case study using mix methods to understand telehealth in three northern Alberta First Nation communities. Using a theoretical framework based on the social construction of technology (SCOT) and Giddens' structuration theory, the objective of the thesis is to understand the role that telehealth plays in First Nation communities' health care services – if any. As well, the thesis seeks to understand who or what shapes telehealth usage and its implication on health care practice.

**Methods:** The data in this study was collected using observations and interviews with 63 health care providers, administrators, staff, and patients over a period of approximately 1.5 years in the Athabasca Tribal Council Region. There are several key findings: first, telehealth does play a role in First Nation communities. However, this role is structured by institutional actors whose rules and resources constrain how telehealth is enacted in each First Nation communities. Second, while some users had positive perspectives of telehealth, their overall experience of telehealth revealed that negative human factors, space, and technology disrupted the development of relationships and negatively impacted users' desire to utilize telehealth. Despite these constraints, some users innovatively circumvented these challenges, managed their telehealth relationships, enhanced health care services, and changed how knowledge was shared in their communities.

**Conclusions:** The analysis confirms some of the findings on the structural constraints of telehealth use in First Nation communities. It also reveals that First Nation communities and individuals actively use telehealth when it enabled them to address specific health needs rather than general health needs. First Nation communities must be consulted to develop telehealth programs and technology designs that reflect their specific needs.

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## **List of Abbreviations**

- AFHCAN ... Alaska Federal Health care Access Network  
AFN ... Assembly of First Nations  
AFNTP ... Alberta's First Nations Telehealth Program  
ANT ... Actor-Network Theory  
ATC ... Athabasca Tribal Council  
BRAND ... Broadband for Rural and Northern Development  
CANARIE ... Canada's Advanced Research and Innovation Network  
CARNA ... College& Association of Registered Nurses  
CBC ... Canadian Broadcasting Corporation  
CHR... Community Health Representative  
CST ... Canadian Society of Telehealth  
FNIHB ..... First Nation Inuit Health Branch  
Fort Chip ... Fort Chipewyan  
KOTH ... Keewaytinook Okimakanak Telehealth  
HTU ... Health Telematics Unit (at the University of Calgary)  
IHAC ... Information Highway Advisory Council  
INAC ... Indian Northern Affairs Canada  
ISDN ... Integrated Services Digital Network  
Mbps ... mega bits per second  
NASA .... National Aeronautical Space Administration  
NP .... Nurse Practitioner  
NNADAP ... National Native Alcohol and Drug Abuse Program  
NNAPP... National Native Addictions Prevention Program  
PAR ... Participatory Action Research  
RNAO ... Registered Nurses Association of Ontario  
RN ... Registered Nurse  
STARPAHC .... Space Technology Applied Rural Papago Advanced Health care  
SCOT ... Social Construction of Technology  
SST ... Strong Structuration Theory  
TETRA ... Tele-health and Educational Technology Resource Agency

# Chapter 1: Introduction

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*“The Indians will perish in the same isolated conditions in which they have lived ...”*  
Alexis de Tocqueville (*Democracy in America*, 2004).

## Background to the Study

Much has changed since the days of Alexis de Tocqueville's observation of Indigenous communities in America: First Nation<sup>1</sup> self-governance, greater control of over resources, more technology and roads into communities. However, looking at Statistics Canada's 2001 Profile of First Nation communities would seem to suggest that Tocqueville's comments are still true: poor housing, sewage systems, and the lack of clean water, not to mention the high rates of chronic diseases, seem to suggest not much has changed in over 200 years (Health Canada, 2003b). Against this statistical portrait, many policy makers, decision makers and researchers regard telehealth as potentially bridging the geographic distance to provide necessary health care services in First Nation communities (Assembly of First Nations, 2005c; Health Canada, 2002a, 2005a; Romanow Commission, 2002).

People in the Northwest Territories face serious health issues including high rates of certain illnesses combined with a number of social factors that affect health. These challenges are exacerbated by the fact that health care services are stretched thin and access is seriously limited by the interplay of geographical expanse and limited health human resources and health care facilities. ... Because of ***the potential for telehealth to improve access to health care***, the Rural and Remote Access Fund should be used to expand telehealth applications (Romanow Commission, 2002: p.167).

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<sup>1</sup> Here First Nation communities refer to the Indigenous or the original peoples. In Canada, the word “Aboriginal” refers to the First Nations, Inuit, and Métis people (Dickason, 1992). However, the word “Indian” is still used by departments such as the Department of Indian and Northern Affairs Development (DIANAD). Health Canada is responsible for First Nations and Inuit health care because of treaty rights; the provincial governments are responsible for Métis health care. This discussion primarily addresses First Nations health care. While the Canadian population may perceive First Nations as one people, First Nations are comprised of many cultures (different languages and customs). In this thesis, the terms “First Nations”, “First Nation peoples” and “First Nation communities” are used interchangeable to denote more than one people groups. However, where the singular “First Nation” is used, it refers to a single community.

**Telehealth must also be considered as a valuable tool** to improve access of these communities to professional services and education, health education, remote family visitation etc. (Assembly of First Nations, 2005b: p.8).

It would seem that, since the impetus for telehealth diffusion in Canada is the need for improved access to health services, ***First Nations and Inuit communities are a natural environment for telehealth implementation*** (Health Canada, 2002b: p. iii).

The interest in implementing telehealth into First Nation communities can also be understood as an attempt to address the rising cost of health care services and the lack of human resources while trying to improve health care effectiveness and efficiency. These ideals of affordable universal health care services are not only at the heart of the Canadian public health care system (Romanow, 2002), but they are also a part of First Nation's claim to health care access as a treaty right (Fumoleau, 2004; Hildebrant, First Rider, & Carter, 1996). Telehealth has been presented as having the potential to fulfill both the visions of policy makers and to address the future of health care service needs in First Nation communities, perhaps even enabling First Nation communities to gain greater control of their health services.

While telehealth's potential and obstacles are foundational questions for comprehending telehealth operation and sustainability in First Nation communities, questions surrounding the changes in health care practice and relationships have not been considered. Using a theoretical frame based on the social construction of technology (SCOT) and Giddens' structuration theory, this thesis makes two arguments: first, users play a significant role in shaping telehealth use; second, the structure of health care services and health care practice shape telehealth use. In examining these two arguments, the larger dilemma for some First Nations is whether the act of using telehealth also restricts their health care autonomy within the larger provincial and federal structure of health care services. As well, there are jurisdictional implications for relying on the provincial health care system to deliver health services to communities under federal jurisdiction.

The purpose of this chapter is to provide the reader with an overview of this thesis research on telehealth in First Nation communities. The discussion below briefly recaps the research focus and the rationale for the research, followed by an overview of the selection of First Nation communities for the case studies, and finally concluding with the methodology of the research.

## **Research Focus and Rationale**

In Canada, telehealth<sup>2</sup> is defined as the “use of communications and information technology to deliver health and health care services and information over large and small distances” (Health Canada, 2002b: p. 3). In Canadian policy discourse, telehealth is positioned within a much larger system of e-health solutions to delivering healthcare services using information technologies (including electronic health records,<sup>3</sup> virtual teams<sup>4</sup> and other hand held devices<sup>5</sup>). Similarly the literature on telehealth, uses the term to encompass medical service (diagnostics such as radiology, psychiatry and ophthalmology) and health care services (such as peer-to-peer practitioner consultations and health education for patients and practitioners) (Rous, 2004). Through telehealth technology, users can use and transmit audio, video, and text (depending on the software and hardware installed) for a multitude of applications (examined in the literature review) to enable users the possibility of access to health information, clinical diagnosis and assessment, and, in the case of robotic surgery, surgical work on the human body. The term telehealth will be used to refer to the broader scope of distance applications using information communication technology, including the applications discussed in this thesis: patient to physician consultation and tele-learning (using telehealth technology to access educational sessions on health).

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<sup>2</sup> The term “telemedicine” may also be commonly used, but its usage is associated with clinical care (Demiris & Toa, 2005). According to Craig and Patterson (2005), telehealth refers to public health care services while telemedicine refers to the delivery of health care and health knowledge at a distance (p. 4). However, in Canada the most common term is telehealth, which is an umbrella term for the delivery of health care services at a distance; the various applications of telehealth are called tele-learning, tele-radiology etc. In the history of care at a distance, telemedicine was associated with the treatment of diseases and illness, but some telemedicine websites in Canada will use the term to include consultations, education, and meetings (House & Roberts, 1977; Ontario Telemedicine Network, 2010). See Chapter 3 for the development of telehealth in Canada.

<sup>3</sup> In Canada, electronic medical health records are computer systems that enable physicians to record and share patient health information with each other and patients. They have been slowly implemented to replace the traditional paper charts that physicians use.

<sup>4</sup> The development of virtual on-line forums and environments is being used to enable inter-professional collaboration and medical education (Wiecha, Heyden, Sternthal, & Merialdi, 2010).

<sup>5</sup> Portable hand held and portable devices are used to diagnose and monitor medical conditions such as high risk pregnancy, mental health, congestive heart failure, asthma, and diabetes (Bensink, Hailey, & Wootton, 2006). Some of these devices such as heart rate monitors and glucose meters can store and forward information to healthcare providers to enable care at home, nursing homes, and other non-hospital settings (Hebert, Korabek, & Scott, 2006; Rosenberg, 2007).

The studies on telehealth involve discussions on topics such as technology, organization readiness, and cost-effectiveness – in essence a focus on solving the problem of making telehealth and telemedicine operational and usable in clinical settings (Maheu, Whitten, & Allen, 2001). These studies arise from the perspective on health technology assessments (HTA) which employ methodologies that seek to evaluate the technology's efficiency and effectiveness. While this type of approach is important and necessary for understanding the operationalization and sustainability of telehealth in health care settings, without a focus on the users, it becomes a circular verification of organizational and systems' needs. The lack of focus on the users and their relations and interactions with telehealth technology means that changes in health care practice and the users' needs are missed. Instead including a focus on understanding telehealth users and First Nation communities may create more relevant, nimble and scalable telehealth programs that reflect the health needs of First Nation communities. This thesis focuses on the users in Alberta First Nation communities.

At the time of the research, the need to consider the role of users in shaping telehealth use in Alberta First Nation communities was pressing for several reasons: the telehealth technology infrastructure, funding and First Nation health policy was changing. In Alberta, 43 First Nation communities received telehealth access via the Alberta SuperNet.<sup>6</sup> At the time, First Nation Inuit Health Branch (FNIHB) paid for telehealth connectivity and managed the telehealth schedule of services while telehealth was in transition from an older system using telephone lines to a system operating on the SuperNet. The complexity of telehealth funding and jurisdictional challenges became muddier in 2007 when Canada Health Infoway announced they would fund telehealth services in First Nation communities, but telehealth programs in Alberta continued to be developed and provided by FNIHB. The structural changes to technology, funding, and the jurisdictional quagmire made the question of telehealth operation and use more challenging.

In the past, technology implementation from a top-down perspective resembling Rogers' *Diffusion of Innovations* in the late 1960s often ended in failure and sometimes

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<sup>6</sup> The network was constructed by the Government of Alberta, built by Bell and managed by Axia, ensuring all provincial funded organizations in Alberta's 429 communities receive connection.

with disastrous social and ecological consequences (Melkote & Steeves, 2001). Rather than repeat previous research based on organizational, top-down, or health technology assessment perspectives, the thesis will employ the social construction of technology (SCOT) and Giddens' structuration theory to provide a fresh perspective on telehealth use in First Nation communities: a focus on telehealth users (patients, administrators, nurses, physicians etc.) to understand telehealth appropriation in health care practice. This research endeavors to answer three pressing concerns:

**1) What is the role of telehealth in First Nations' health care service**

**delivery?** Often technology is implemented to achieve a particular function or purpose and the general assumption is that it serves the intended goals.

However, implementing telehealth in First Nation communities may or may not enhance health care services. This query enables a broad examination of telehealth – particularly, tele-learning and tele-consultation – in the day to day health care routine of the First Nation health care setting.

**2) What or who shapes the use of telehealth in health care settings?** In the social construction of technology (SCOT) literature, the word “shape” and “appropriation” has been used to denote the users’ and policies’ role in actively incorporating technology within a particular lifestyle, organization, or system.<sup>7</sup> In previous telehealth research on users, studies often focused on user satisfaction: a yes or no question that may function to verify the health care organizations’ need. The SCOT approach, however, compels us to consider: the larger social context of technology use; why users make the choices they do; and the mutual shaping of technology (technology shaping health care practice and health practice shaping technology use). This lens will enable us to consider the complexity of telehealth usage in First Nation communities struggling with limited human resources, jurisdictional

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<sup>7</sup> Sorensen and Williams (2002) indicate the social shaping of technology focuses on analyzing the influence of political, economic and cultural interests and values. Winner (1986) is one such author whose work demonstrates how existing political interests shape technology. The social construction of technology (SCOT) focuses on how technology achieves closure through interpretive flexibility (read chapter 2). However, Sorensen and William indicate that distinction between social shaping of technologies and SCOT is no longer as pertinent, since both approaches to technology acknowledge each other's contribution.

quagmires, overwhelming chronic health challenges and social and economic limitations.

- 3) What are the implications of telehealth on work practice and health care relationships?** Many studies and government reports have looked at the impact of telehealth on health care delivery, but they have not considered changes in relationships and work practices arising from telehealth usage. Without an adequate understanding of the complexity and changes in human relations in health care service delivery that affect patient privacy, quality of care, and trust, it is very difficult to provide universal health care services and the ethical delivery of care. In First Nation communities, the sensitivity to care is heightened due to the history of colonization and the existing power differential between the colonizers and the colonized. Giddens' structuration theory provides a lens to understand the structure (routines and practices) of telehealth practice amongst patients and health care providers in First Nation communities. At the deeper level, it also enables an understanding of the tension between First Nation's autonomy and the existing federal system of medical care services.

These questions provide a frame for considering telehealth use in three First Nations communities in Alberta as a means of understanding how to enhance the usage of telehealth in health care practices.

## **Methodology**

This thesis research uses a collaborative approach with First Nation communities to establish the course of research. It is a case study of three First Nation communities using ethnography as means of understanding telehealth use. The data was gathered by conducting 63 interviews with health care providers, administrators, staff and patients from three First Nation communities from January to April 2007 and again in the spring of 2008 for a second round of interviews in Fort McKay.<sup>8</sup> As well, observations were made about the everyday activities of the health care centres and recorded in a journal.

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<sup>8</sup> Chapter 4 provides an in depth discussion of ethnography and case study.

The data was organized using the open source software called Weft QDA and subsequently analyzed through an inducted and deducted approach.

## **Community Choice Selection**

The community selection process was based on Health Canada's (2001) pilot projects in five First Nation communities in Canada.<sup>9</sup> I have adapted the criteria in this project to include others. The criteria used in this study are:

- Remote, isolated or semi-isolated First Nation community;
- State of telehealth use or implementation;
- Community residing within the tribal council;
- Research supported by First Nation community Chief;
- Research supported by Athabasca Tribal Council;
- Research supported by Health Directors.

I have chosen the first criteria on remoteness or isolation, since the assumption is that remote or isolated communities would benefit from telehealth implementation. Secondly, the state of telehealth use or implementation was important because the duration of time may play a role in enabling users to use telehealth in First Nation communities. Lastly, the support of Chief, tribal council, and health directors were necessary to gain access to First Nation communities.

The three First Nation communities selected for this dissertation research had the support of the CEO of Athabasca Tribal Council (ATC), his associate, the Health care Director of ATC, the Chiefs and the health care directors within each community. The chart below summarizes the differences between the three First Nation community contexts: population size; distance from an urban center; date of telehealth implementation; Internet connectivity status; and the number of available nursing staff at the time of the research.

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<sup>9</sup> The pilot project's aim was to study the effectiveness of telehealth in First Nation communities.

**Table 1.1: Summary Table of Community Characteristics**

<b>Community Name</b>	<b>Population</b>	<b>Distance from Urban Centre (Fort McMurray)</b>	<b>Duration and Mode of Travel from Fort McMurray</b>	<b>Date of Telehealth Implementation</b>	<b>Internet Connectivity Status</b>	<b>Nursing Staff</b>
Fort Chipewyan (Mikisew Cree and Athabasca Chipewyan First Nation)	* 728 Aboriginal Peoples	291Km Or 188Km to Fort Smith NWT	~9.5hrs drive via winter road or fly in	1998	Yes (ISDN)	5
Fort McKay	**521	66.5Km	~1.5hrs drive	2004	Yes (Broadband)	2
Chipewyan Prairie (Janvier)	**271	123Km	~2hrs drive	2007	No <sup>10</sup>	1

\* Aboriginal Canada Portal (2008a)<sup>11</sup>

\*\* Statistics Canada (Tedlock, 2000: p. 455)

Of the three First Nation communities in the study, Fort Chipewyan (Fort Chip) is located the furthest away: 291Kms from the closest urban center (Fort McMurray), which requires 9.5hrs drive over a winter road of ice, frozen river, sand, and muskeg or a fly-in trip of about 45 minutes. Alternatively, many residents of Fort Chip have driven to Fort Smith (population of about 2,800Kms) in the Northwest Territories for weekend grocery shopping or other diversions. The second community, Chipewyan Prairie First Nation (Janvier), is 123Kms away from Fort McMurray and while there is a concrete road, it is narrow and slippery in the winter. Fort McKay is the closest to Fort McMurray (about 67Kms), but this road passes by many oil and gas plants with large tankers and lumber vehicles congesting a narrow road, making commuting in and out of the community treacherous and time consuming. These three communities provide an excellent opportunity to consider telehealth usage in its various stages: Fort Chip having telehealth for the longest time, Fort McKay First Nation with several years of telehealth experience,

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<sup>10</sup> At the time of the research, Janvier had received the telehealth equipment, but Health Canada had not connected the technology.

<sup>11</sup> The 2006 Census did not have population figures for Athabasca Chipewyan First Nation or the community called Fort Chipewyan, but it did have a population number for Mikisew Cree First Nation. Indian and Northern Affairs has a census figure of 463 people for Athabasca Chipewyan First Nation, but this only accounts for the Aboriginal peoples, not all inhabitants in Fort Chipewyan (a mixture of Aboriginal and non-Aboriginal peoples). The former Health Director of Nunee Health mentioned to me that there were about 1,200 people in 2007. I have chosen to use the Aboriginal Canada Portal figure, a middle number between the 2006 Census and the number given by the former Health Director.

and Chipewyan Prairie First Nation at the initial stages of telehealth implementation and use.

## **Overview of the Thesis Chapters**

Throughout most of Canada telehealth has been implemented as a tool to enhance health care service delivery, but much of our understanding of telehealth has been based on an organizational perspective that often ignores the role patients and health care providers play in shaping telehealth use in health care practice. This thesis research examines the use of telehealth in three First Nation communities from the users' perspective at a poignant time of changes in technology infrastructure, funding, and the transfer of health resources to First Nation community control. It contributes to the existing literature on telehealth by highlighting the users' agency in telehealth appropriation and fuels the theoretical debate on agency and structure, particularly since the deeper question for First Nation communities is whether telehealth enables them greater autonomy over health care services.

In the next chapter, I use a theoretical frame comprised of the social construction of technology and Giddens' structuration theory to recuperate the role of the user in telehealth usage in First Nation communities. While SCOT highlights the users' socio-economic and gender background as a context for technology use, it does not provide an adequate lens to understand the connection between technology use and structural formation or change. Giddens' structuration theory highlights the structures framing technology use – particularly, the rules and routines that shape technology usage.

In chapter three, I review the literature on telehealth in First Nation communities. It situates the research in an international context: the historical development of telehealth; the usage of telehealth in Alaska, Australia and Canada; and I include a discussion on the current forms of telehealth usage to offer the reader a background understanding of telehealth development.

Chapter four outlines the methodology and methods for undertaking the thesis research. This research involves a collaborative community based research approach to initiate the research process in First Nation community health leadership. The thesis is a

case study using ethnography to understand telehealth in First Nation communities. The methods deployed for data collection are interviews with telehealth users and participant observations over several months.

Chapter five provides the reader a background on First Nation health care policy as a means of situating telehealth usage in the complexity of jurisdictional responsibilities and the challenges of health care service delivery in First Nation communities. As First Nation communities increasingly seek to manage their own health care resources, the negotiation between various governmental agencies creates opportunities and barriers for telehealth use -- muddying an already unclear system of health care service delivery. This chapter illuminates some of the structures that frame health care service delivery, and conversely, telehealth use.

Chapter six contains the detailed descriptions of the three case studies written as individual community reports. Each of the cases is an in-depth account based on the interviews and the observations of health care service delivery and telehealth use in each community. The cases offer a reference point from which chapter seven draws from for an analysis of telehealth usage in the three First Nation communities. Chapter eight concludes with recommendations for future research and policy suggestions for telehealth usage in First Nation communities.

# Chapter 2 – Theoretical Framework

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## Introduction

Often decision makers and policy makers suggest that telehealth will bridge the health care service disparity between First Nation communities and urban centers (Assembly of First Nations, 2005c; Health Canada, 2002a, 2005a; Romanow Commission, 2002). This belief was often followed by a recommended course of action to implement telehealth technology into the First Nation communities, but researchers discovered a host of challenges (policy, economic sustainability, skills, usability, technical difficulties and many others) in the implementation process. However, very little research has been completed on how telehealth users<sup>12</sup> shape or incorporate telehealth into health care services. As well, there has been insufficient research examining how telehealth shapes<sup>13</sup> health care practices in First Nation communities. This thesis takes the view that technologies and users are mutually shaping each other (Hugh Mackay, Carne, Davies-Beynon, & Tudhope, 2000). The mutual shaping perspective enables us to evaluate and reconsider the notion that telehealth is simply a tool implemented into First Nation communities to enhance health care services. The argument is situated within an understanding of the agent and the structure of health care practice using the social construction of technologies (SCOT) and Giddens' structuration theory.

This theoretical discussion is a means of orienting the reader to the conceptual framework which guided the field research and the analysis of the data. It serves both to provide a terminology which addresses the gaps in the literature and an alternative lens to

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<sup>12</sup> In the literature on telehealth, authors often include health care providers and administrators as telehealth users, but I will expand term to include patients as well.

<sup>13</sup> The word “shape” has significantly different theoretical roots than the word “impact”; the former refers to individual or community agency in developing or incorporating a technology into a particular system and the later refers to the determined effects of technology, a linear progression of technological influence. While there are technological impacts, this research is concerned with the user’s role in including telehealth in health care practice.

conceptualize telehealth use in First Nation communities<sup>14</sup> in relation to: first, the role that technology users play in shaping the use of telehealth in health care practice; and second, in relation to how telehealth may shape health care practices. As such, two bodies of literature are examined to provide the framework for the thesis research: the social construction of technologies (SCOT) and Giddens' structuration theory. This dissertation proposes to follow a SCOT and structuration theory framework in considering the post-implementation stage of technology in a social system.

## **Background on Technology Approaches to Modernization**

In the 1950s and 1960s many new technologies were implemented into communities and organizations with the belief that technology would be the impetus for change and modernization. This technological deterministic perspective was embraced by many nongovernmental organizations that invested significantly in technological development and implementation to modernize third world countries (Melkote & Steeves, 2001). Deterministic perspectives, such as Rogers' *Diffusion of Innovations* in the 1960s, often focused on how decision makers influenced the implementation of technology, highlighted the success of technology, and identified technology as a linear progression from innovation to implementation with little regard for the social context of technological development and use. However, many of these technology projects ended in failure. Conversely, some believed that technology was not neutral, not simply a tool that propelled society forward, but rather ideological, inscribed with a specific rationality that foreshadowed a bleak human future, where technology dominated humanity (Marcuse, 1964). Such a perspective led some to suggest that individuals lacked any real agency in society except to be consumers of products manufactured by capitalist organizations (Horkheimer & Adorno, 1995). Both determinist and dystopic perspectives of technology disempowered the individuals' role in a technological society.

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<sup>14</sup> In chapter 3, the literature review, we see that telehealth is conceived as a tool to enhance health care services.

## **Recuperating Agency in Technology Theory**

### ***a. The Social Construction of Technology***

The Social Construction of technology (SCOT)<sup>15</sup> approach first initiated research focused on the user as an agent, capable of altering, influencing, or shaping technology innovation and use. SCOT countered the claims that technology determined social outcomes (Bijker, 1993; Pinch & Bijker, 1987). Unlike technological determinism, SCOT tried to embrace the notion that technology was a construction of the sociotechnical world, containing an ensemble of social practices and technical knowledge that reflect each unique group's interaction with their environments.<sup>16</sup> The intricate fusion of technical knowledge and social practices means that when we closely examine or look into the black box of technology, we can see the strands of the social world (Latour, 1992; Winner, 1993). However, from a SCOT perspective, the successes as well as the failures initiate questions into the intricate details of how the social dimension affects the selection of technologies for use (Kline, 2005; Wyatt, 2005), revealing the political dynamics involved in a technology's institutionalization. This section attempts to consider who the technology user is. While the discussion below on the user is by far not as complete as Oudshoorn and Pinch's (2005) review of the various different approaches to understanding the user, the discussion will elucidate some of the core concepts for undertaking the dissertation.

In this thesis, the approach to telehealth in First Nation communities follows SCOT's perspective of the user: a dynamic agent capable of altering, influencing, or shaping technology for a particular purpose to accomplish a particular goal. The key

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<sup>15</sup> SCOT is comprised of two arms: first, the strong program's focus on the sociology of knowledge and science studies as the basis for understanding users' involvement in technology development (Pinch & Bijker, 1987), which often emphasizes studies on the social world. The second arm focuses on systems or actor-network theory (ANT as it is commonly and debatably referred as) also a constructivist perspective with emphasis on the sociotechnical realm of study rather than the social world. The study of medical technology has used these two branches of SCOT as its theoretical source to graft the sociology of medicine (which includes discussion of medicine as a practice and the human body in relation to technology) (M. Berg, 1999; Brown & Webster, 2004).

<sup>16</sup> Much of the critique of Pinch and Bijker's (1987) work, however, pointed out that SCOT leaned heavily on examining the social world rather than the sociotechnical realm, which made SCOT the opposite of technological determinists, social essentialists.

concept in the SCOT approach that I will discuss below is Pinch and Bijker's concept of the relevant and irrelevant groups. The concept includes multiple technology user groups, but it also provides a means of explaining how particular groups may be marginalized or ignored in the technology design process. As well, the concept also enables us to understand that different user groups may assign different meanings to the same technology. This is particularly poignant given much of telehealth research has focused on health care providers and administrators without considering patients and their families as relevant users. Secondly, I will discuss participatory design. Contrary to the top-down design of technologies, participatory design involves the users in the design process, offering an alternative approach to technology design for First Nation communities.

### ***b. Pinch and Bijker: Users as relevant / irrelevant groups***

Pinch and Bijker's (1987) discussion of the bicycle provided the initial impetus for considering the social world in technology development; in particular, the users' relation to technology designs. Pinch and Bijker's study showed that the developers of the early bicycle responded to the users' needs, roles, and opinions. Various models of the bicycle were developed to respond to several relevant groups: for example, women saw it as a source of transportation and young men valued the bicycle for speed and athletics (Pinch & Bijker, 1987: p. 34). According to Pinch and Bijker, the most successful bicycle designs reflected relevant groups' purpose and social context. Up until the bicycle design stabilized, engineers openly sought solutions to solve the safety needs in a process of interpretative flexibility. According to this logic, in the interpretative flexibility process of solving safety concerns, designers were attempting to appeal to the users' needs and users were granted the greatest amount of power to influence the bicycle designs.

In the case of consumer technologies, relevant groups may enjoy a certain degree of power to negotiate the design of technologies.<sup>17</sup> According to Pinch and Bijker's

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<sup>17</sup> Many feminist researchers have argued that those not considered as relevant groups by designers still use technology and therefore are worthy of investigation (A.-J. Berg & Lie, 1995; Wajcman, 1991).

(1987) definition of relevant groups, those individuals outside the designers' scope are not considered relevant users for economic, social or political reasons, leading to technologies that either favored or spurned particular groups. For those using the technology, access is not merely a matter of technological use or action, but all the other associated social, political and knowledge networks that gird the technology's operation; the user becomes more than a simple consumer, but a participant enrolled in the societal structure that sustains a technology's usage; she participates in sustaining, creating, and supporting her and others' social, political, or economic position in which the technology functions (Star, 1991: p. 40; Winner, 1993: p. 369). For some technologies, a simple consumer choice to select an alternative technology shifts the consumer from one set of networks to another (perhaps from bicycles to rollerblades). Such choices are not problematic because other technological choices are available, but segregation or rejection from pervasive standardized technologies such as the computer or the Internet, can further perpetuate social and economic disadvantage for marginalized groups, since the stakes of non-participation may include exclusion from educational and economic opportunities.

In summary, SCOT offers several insights for this dissertation: first, relevant groups, whom the technology is designed for, may use technologies to retain or sustain existing social, economic, or political positions in society. Similarly, non-users that abstain or are socio-economically rejected from the technology category may face the impending results of not using the technology that relevant groups use. Second, the users' capacity to alter some of the intended rules governing technology usage or create new uses for the technology to meet the users' own needs is limited by the technology's design. Third, the web of relations and interactions around the technology shape how technologies are appropriated<sup>18</sup> within a particular environment. Lastly, technologies and the social context mutually shape the act of using the technology for a particular purpose.

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<sup>18</sup> The word "appropriate" or the appropriation of technology is more commonly used in feminist studies of technology where un-intended users, such as women, integrate technologies into their everyday life (Lie & Sorensen, 1996).

### ***b. Feminist Approaches to Science and Technology Studies***

Oudshoorn and Pinch (2005) indicates feminist approaches to science and technology studies (STS) have contributed to the literature by asking three questions: first, who is the user? The relevance of recognizing the user's gender is important, since designers of technologies often assume users are men (Berg & Lie, 1995) and others have contended that users experience technology as gendered, class and race (Kennedy, 2005). Technology design is not neutral, but gendered and often a reflection of their societies (Bray, 1997; Hess, 1995; Winner, 1999). The feminist approach further elaborates that technology is not black boxed, but rather users (women) appropriate technology to meet their own needs and purposes (Berg, 1995; Lie & Sørensen, 1996; Mackay & Gillespie, 1992). While there are some limitations to the appropriation of technology such as the obduracy of technology's shape and size, users shape technology and technology shape users' everyday practices, changing the meaning of work and everyday life.

Second, feminist scholars have also asked who are the "end users", "lay end users", and "implicated actors" (Oudshoorn & Pinch, 2005)? The distinction between each of these terms reflects not only who the technology is designed for, but who is affected by the technology's use (Saetnam, Oudshoorn, & Kirejczyk, 2000). Third, what are users' network relations and what are the associated choices in the technology's use? Cowan's (1987) landmark study was the first to demonstrate that the users' choice of technologies do not necessarily always lie within the design of the technology but rather in the product's associated networks of choices (the required products needed to operationalize the technology). The broader social and economic context in which technologies are developed and used challenges us to consider the systems operating outside the immediate relationship between the users and their technologies. When we consider the user as the beginning of technology design, we begin to understand that technologies are integrated into the larger socio-economic systems that gird technology use. Feminist approaches to STS opened questions on the need to understand the users themselves.

### **c. Participatory and Work Situated Approaches to Technology Studies**

While Pinch and Bijker's approach provides a historical understanding of how bicycle designs became popular among some groups, participatory design approaches to technology development actively recruited workers to participate in the design process to understand how users utilize technology in their workplace (Cherry & Macredie, 1999; Greenbaum & Kyng, 1991; Markussen, 1996). In many ways, participatory design's inclusive approach means that designers are no longer separate from users, but require users' specialty knowledge to create technologies that reflect the users' pattern of behavior or knowledge within an organization (Hammel, 2000). Participatory design approaches attempt to shift control and power from the sole realm of designers to include participants. However, as designers increasingly design technologies that reflect a greater degree of human skill and knowledge, some fear that the intended or unintended consequences of new innovations may replace workers (Clegg & Wilson, 1991; Tenner, 1997) or redistribute work to others (Oudshoorn, 2008). This concern is particularly poignant for First Nation communities using telehealth to enhance health care services, since off-loading work to over-worked staff in the communities may decrease the efficiency of existing health programs. Will telehealth shift some job tasks onto paraprofessionals such as community health representatives or nurses? Will telehealth technology replace job tasks once undertaken by health care providers? How will patients and their families feel about these types of changes? The challenging question that arises even when technologies are created with the user in mind is: to what degree do users' have agency in the use of technologies? Do users simply become a part of technologies designed to reflect their needs in organizational work?

In the 1990s, coinciding with the euphoria of information technology possibilities, a number of researchers attempted to understand the implications, challenges, and possibilities of information technologies in the workplace from sociological and organizational perspectives (Button, 1992; Clark & Fujimura, 1992; Luff, Hindmarsh, & Heath, 2000; Orlikowski, 1992; Suchman, 1995, 2000). From these types of research endeavors, we learned much about the changes in the organizations, the interactions between users using ICTs, different theoretical models for approaching future design and

research technology projects (DeSanctis & Poole, 1994; Orlikowski, Yates, Okamura, & Fujimoto, 1995). However, the study of technologies in the workplace while offsetting some of the flaws in the SCOT's strong program by examining the social structures that shaped the use of technologies and embracing the notion of dual structures (in organizations and in technologies) (Orlikowski, 1992) did not tackle the relationship between technology as an artifact and as a social structure (Hanseth, Aanestad, & Berg, 2004; Orlikowski, 2000). The challenge for current technology studies is to understand the tension between the user's agency and the pervasive social structures in technology use (including technology as an artifact within a particular structure and system), focusing on users engaging with technology.

#### ***d. Limitations to User Agency and the SCOT Perspective***

While Pinch and Bijker's (1987) approach recuperates the agency of technology users, the scope is limited to the users' context and does not provide an adequate lens to understand the structural (policy, professional practice, and resources) constraints or interaction with technology. The problem with focusing on the social context of technology use is that user agency and social structures cannot be disentangled. In many ways, the approach brackets the research lens to consider what the user is doing with technology without considering two very important realms of the social: the meaning of technology use or the social system in which use occurs. Firstly, the meaning of technology use involves knowledge relations within communities of practice that operate within a social system. This means that technology users interact with their peers, but they also interact with other types of technology users and non-users. Pinch and Bijker (1987) does not consider how the interactions between users and non-users within a social system change technology use. Secondly, social systems are not isolated in technology use relations. Hughes (1983) and Cowan's (1987) work on technological systems, both from the SCOT approach, reveals that technology is integrated not only into social systems involving many actors, but also technology systems, and the economic and political sphere. These integrated relations change our understanding of the complexity of users' relation to technologies. The user is neither completely

autonomous in shaping technologies to their social world in use relations nor are users the only agent in change. In Hughes' (1983) study of electrical systems, the interoperability and compatibility of technologies shaped the function and productivity of other technologies within its operation. Hughes' (1983) study revealed that technologies embody the social world and the principles of nature that shape how other technologies are developed and used. As well, when we consider other systems, we see that users' choice of technologies does not necessarily lie within the technology itself rather consumers are surrounded by a network of choices embedded in the economic sphere that shapes the purchase and use of the technology. Cowan's (1987) landmark discussion on the consumption junction of cast iron stoves reveals that the networks of choices associated with the stoves influenced the consumer's selection of a particular design of stoves that defies its cultural expectations. The broader social context in which technologies are developed and used challenges us to consider the systems operating outside the immediate relationship between the users and their technologies.

Does this mean that by considering the systems in which technologies operate, we obscure our understanding of the technology user? We must consider that the user is not separate from the system in which technology is designed and implemented. The question is: how do we study the users' relation to technology within the social system. A SCOT approach based on Pinch and Bijker's work only allows us to see that relevant groups are using, failing to use, or even negotiating its use within a particular context, but not necessarily what is required of the user (knowledge and skills) nor how interactions between different actors may change technology use. In some cases, a particular knowledge or skill set is required and in other cases, existing knowledge is enhanced or displaced; still in other cases, personal and work relations and interactions are shaped by technology within the social system. In each scenario, it is not simply the user that shapes technology, but technology shapes the users' practices<sup>19</sup> or actions.

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<sup>19</sup> The common understanding of practice is: the everyday activities and routines that individuals engage in (Barnes, 2001; Becker, 2005; Bourdieu, 2003; Giddens, 1984; Schatzki, 2001).

## **Giddens' Structuration Theory**

The social construction of technology offered researchers an invaluable understanding of the users' social context and the role users' play in facilitating technology usage. While this perspective seemingly gives users unlimited potential to shape technology, it does not examine the possibility of social structures shaping users' actions. The finer question of whether users are limited by their roles in organizations to act or use technology offers an opportunity to consider users' agency in practice, particularly in their work routines within a social system. The discussion below examines key aspects of Giddens' Structuration Theory that contribute terminology for this thesis to examine technology use within a social system.

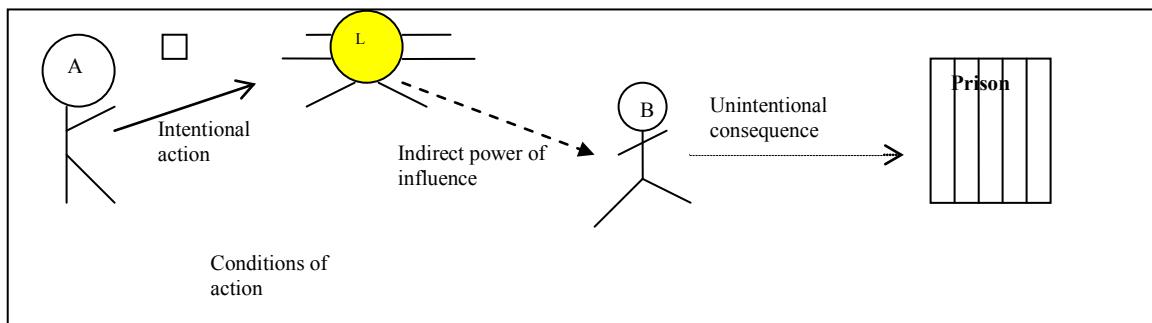
### ***a. Giddens' Concept of Agency***

Agency is not the most easily understood concept: how do we know when a person has agency? How can we measure or ascertain its existence? Giddens (1984) indicates that "agency refers to doing" (p. 8-10). Actors often not only monitor their own behavior but they also monitor the social and physical contexts in which they move (p.5). While some are motivated to act, motivation does not define agency, since it is not action (p.5-6). Giddens distinguishes agency according to intentional and unintentional action; an action occurs due to an individual's intervention, either directly or indirectly. He uses the example of a person turning on the lights in the house: her intention was to illuminate a dark room, but she unintentionally frightens a burglar, who flees the premises and is later arrested by the police. The home owner's intended action was to illuminate a room, the startled burglar and his escape from the house was not and neither was his arrest (p. 10-11). Giddens' primary concern is with the intended action of turning on the lights. The outcomes of the action, however, refer to the degrees of influence the person has. The diagram below illustrates that the closer the outcome is to the action, the more power the actor has of influencing or refraining from the action that affects the outcome; action is related to the power of influence (p. 14). The home owner had greater influence on startling the burglar than on his arrest, which may have occurred due to a series of

unrelated events (p.11). In Giddens' conception of agency, individuals self monitor their intended action.

The diagram below illustrates the greatest degree of power and influence resides in the immediacy of "A" turning on the lights and "B" fleeing the house.

**Figure 2.1: Unintentional Consequences of Action**



The arrows reflect the strength of influence resides strongest in "A" turning on the light and her influence of secondary outcomes dissipates as we move from left to right of the diagram.

It is easy to see agency when the individual intentionally desires a particular outcome and proceeds to act, but what of conditions that seemingly indicate that individuals have "no choice", but to "react"? Giddens indicates this lack of free choice does not dissolve action as is the case when an eye rapidly blinks due to sudden movement (p.15). To act is agency, since the individual has power to influence or transform desired outcomes (p.15). According to Giddens, individuals are not simply "docile bodies" that social institutions grind out (p.16).

In sum, agency can be seen to have three possible forms of analysis in this thesis. First, the direct action to use telehealth may produce unintended consequences. This is reflected in deeply institutionalized practices, particularly around jurisdictional obligations, professional codes of practice, and ethics, around health service delivery which may produce a series of unintended consequences when telehealth is used to provide or enhance health care in First Nation communities. Second, Giddens' notion of agency enables this thesis to consider the series of choices that an individual makes to use telehealth as an aggregate of intentional action in health care services. He indicates that the series of actions reflect agency of the most direct kind (p.13). Third, according to Giddens, the unintended consequence of action (using telehealth) reproduces the

conditions for action (telehealth use) is also a form of agency (p.14). Giddens' notion of agency as reflected in the individual's actions, consequences arising from telehealth use, and even some of the obscure consequences can be observed in the health care setting of First Nation communities.

### ***b. Giddens' Concept of Structure***

Giddens (1984) defines structure<sup>20</sup> as the rules and resources that shape or enable the actors' everyday activities and routines, across time and space (p.17). Actors engaging in social practices, in many ways, reproduce structural properties. This enables the reproduction of the social system – that is – the structural properties are both the means and the product of the practices they organize (this is the duality of structure) (p. 25). In his view, structures are produced and reproduced through the individuals' actions;<sup>21</sup> this repetitive cyclical process enables the stabilization of a social system, but it also affords opportunities for social change (Poole & DeSanctis, 2004).<sup>22</sup>

The chart below illustrates the distinction between structure(s), system(s), and structuration.

**Table 2.1: Distinction between Structure, System, and Structuration**

Structure(s)	System(s)	Structuration
Rules and resources, or sets of transformation relations, organized as properties of social systems	Reproduced relations between actors or collectivities, organized as regular social practices	Conditions governing the continuity or transmutation of structures, and therefore the reproduction of social systems

**Source:** Giddens (1984), p. 25

The agent draws upon her knowledge of the system and reproduces or changes the social system. Giddens' conception of structuration is that the production and reproduction of a social system is enacted through an actor's actions (Poole, 2007). However, the conditions governing the continuity of structures in the reproduction of the social systems

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<sup>20</sup> Culture is also a form of structure that encompasses language, symbolic meaning, and social practice (Reckwitz, 2002). Giddens (1984) does not specifically address culture as structure in this discussion, but Bourdieu's work does. In this thesis research, culture, as a category of analysis, is not specifically used and it is one of the limitations of the research.

<sup>21</sup> Below, I elaborate and discuss the different aspects of structuration theory that are relevant for this theoretical framework on telehealth in First Nation communities.

<sup>22</sup> Stones (2005) indicates that Giddens' concept of structure lacks analytical clarity: can structures be both memory traces and resources? Others like Bourdieu (2003) use the notion of habitus to distinguish the individual's disposition from resources as material artifacts.

means that under different conditions there may be different social systems and structures; it is not always necessarily the same. Conditions themselves may change, which means structures may be different.

Giddens' definition of structure not only provides a perspective of how actors in First Nation communities may engage with the social system, but also how the social system may change. In particular, his understanding of social systems prompts some pertinent questions: what type of knowledge or knowledge systems do actors in First Nation communities draw upon to use telehealth? What other social practices do First Nations people draw upon to make sense of telehealth? Does the health care system in First Nation communities change as individuals use telehealth? In what way does the system remain the same or change? Telehealth use in First Nation communities is not a neutral activity; rather actors have the capacity to change or sustain the way health care is delivered and organized. The actors' choice to use telehealth may also lead to unintended consequences not initially conceived when telehealth was implemented in the communities.

### **c. Structure: Rules**

According to Giddens, structure is comprised of rules and resources<sup>23</sup>. Within his definition of each, structural change is immutably intertwined with human actors' involvement and interaction. He defines rules as:

- **Routine**<sup>24</sup>: the simplest rule, based on habitual actions grounded in regular day-to-day activity.
- **Constitutive rules** (the essence or definition of) and **regulative** (command particular actions or follow an instructive order such as if “x” then “y”).

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<sup>23</sup> In his conception, rules and resources are intertwined. He further elaborates what he means by rules and resources. He indicates that resources are an important element of structure, but as an analytical category it is not being tackled in this dissertation. In brief, according to Giddens (1984) resources are private property, money, capital, labour contract, and profit (see p.186-192). These resources can be mobilized in the actors' daily life, which influences the degree of power they may have. However, the degree in which they are intangible, as rules are intangible, is contested since property is clearly a physical asset that limits a conception of instantaneous manifestation in their enactment (Sewell, 1992: p. 10-11).

<sup>24</sup> Much of Giddens' discussion on routines is heavily influence by Goffman's writings on routines. As result, the same criticism that applies to Goffman's work can also be applied to Giddens' notion of the body in relation to routines (Seymour, 1998).

***Regulative and constitute rules*** often exist together: one defines and the other sanctions its existence.

- ***Procedural or formulaic rules*** (generalizable to any conditions / contexts / occasions) form the basis for praxis. These types of rules are the generalizable techniques or procedures applied in the enactment of social practices such as language (p. 19-22).

Each type of rule plays a role in creating structure within the social system at different levels of actor engagement; at times, they may feed into each others' development. For example, when an actor follows a rule to arrive at work at 8:30AM, she may be following a personal work routine. However, starting work may be established by constitutive rules and regulated by unions, organizations or government that stipulates a 40 hour work week.

In Giddens' model, the trivial everyday procedures have a much more profound influence on social conduct, since they reflect deeply embedded structural properties of institutionalized practices (p.22). These daily routines, what we may deem the mundane or the ordinary, reflect our own creative involvement in developing procedures and rules that normalize our life. He proposes that the structuring qualities of rules can be studied in the forming, sustaining, termination, and reforming of encounters between agents (p.23). However, these encounters also draw from the wider social system (s) (diverse and heterogeneous collectives) and the rules governing the immediate situated practices (p.24). This means that practices in structure and the social system may transform when agents draw from different sources in their interactions with each other. Change is then linked to the actors' connectivity to potentially other social systems (organizations, communities) and other sources of knowledge.

While all three of Giddens' rules are relevant, this dissertation will examine routine closely as the framework for understanding the use of telehealth in First Nations' health care services.

#### ***d. Routines***

According to Giddens there are two important dimensions of routines: first, routines are a medium for individuals to exercise their autonomy in everyday life in the

social system. Second, routines are a context for self experience, activity, and connection to other actors in daily encounters. Thus, routines are seen here as establishing a pattern of daily life that enables the individual's sense of self to be moved along daily activities in the institutions of society, while reproducing society's structures (p. 60). The importance of the seemingly repetitive and mundane activities of daily life is illustrated in critical situations, such as the life of Jews in concentration camps at Dachau and Buchenwald, events that drastically shatter or alter a person's accustomed life. Critical conditions reveal that individuals need an orientation of their daily life to enable their own autonomy over encounters and routines. The ability of individuals' reflexive monitoring of their actions, their willful, planned, and sometimes highly reflective acts, is based on the existence of a stable social system that ensures the actors' security is maintained in her encounters. In many ways, individuals are able to reproduce a sense of security in her routines without being directly motivated to maintain and sustain conditions of trust because she tactfully integrates habitual practices across time and space (p. 64). Encounters are the basis of social interactions, since they follow in succession, typically as routine, throughout an individual's day and they may appear brief, trivial, and/or be substantive (p. 72).<sup>25</sup>

Daily routines also provide individuals with situated contexts for encountering others and for experiencing the self through action. According to Giddens, the body is the site of "spatial situation": the physical world comes into contact and is moved by the actor into action, but it is also the site in which the body experiences and comes to know itself by its ability to undertake tasks and activities (p. 65-66). In the body's flow of activities (action, talk, conversation, associations and etc) lies the capacity to be involved in garnering and building trust in the continuity of the social world in daily life both as activity and connection to others (p.66). Giddens uses the notion of co-presence to describe social connections and relations to others: the body's physicality occupies a similar space as others enabling the face and body to reveal intricacies of feelings and intentions within a field of action (p.67). Full presence is found in the individuals' ability to sense she is being perceived and can she can perceive other actors. In mediated

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<sup>25</sup> According to Giddens (1984) this does not mean the individual does not have choice, but choices are contextualized according to the person's position, frame of action (discussed below) and the individual's self identity project (Giddens, 1991).

communication such as using the telephone, co-presence is limited to the individual's ability to convey her feelings without physical visibility (p. 68). Giddens' concept of presence is tied to space and time: interactions are situated in a particular course of routines across a particular time and space. The situatedness of encounters<sup>26</sup> means institutional forms are implicated in daily life (p. 69). Encounters<sup>27</sup> are the basis of social interactions; they follow in succession, routine in manner, meaning they may be brief, trivial, or substantive in the iterative path of daily life; they reveal the fixity of institutions (p.72) that must be continuously worked on (p.86).

Giddens (1984) questions of why individuals are motivated to follow their routines and monitor their expressions in their encounters with others. Routines ensure a sense of stability, but self monitoring arises from the individuals' attempt to repair strains in the social fabric to ensure trust is maintained. Trust enables the individual to bracket out particular events in order for the individual to engage in daily activities without having to seriously contemplate every risk, which would normally produce paralysis, a sort a leap of faith is necessary (Giddens, 1991: p. 3).<sup>28</sup> This, of course, does not still account for incidents when individuals deliberately seek to tear the social fabric as is the case of critical conditions (social movements, revolutions, and wars), since the primary motive is distrust of the existing systems. As well, those individuals outside the perceived Western norm (non-Christian, visible ethnic minority and individuals with disabilities), are contending with prevailing social constructs in their encounters to seek trust and security, but the existing routines and those in institutions may continually fail to repair trust because it does not recognize these individuals or groups (Francis, 1995; Karim, 1993; Knowles, 1996; Taylor, 1994; Vorst, et al., 1991). Indeed the interactions may leave many feeling isolated, rejected, and unheard in daily life (Seymour, 1998).

Giddens' (1984) explanation for the obvious power differentials between actors is based on his discussion on positions. He indicates that actors are ascribed social

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<sup>26</sup> According to Giddens there are several types of connections that individuals make in their everyday life: gatherings (formal and informal), unfocused interactions, focused interactions, and encounters.

<sup>27</sup> Giddens goes on to explain that encounters are comprised of two principle characteristics: turn-taking and opening and closing that mark the boundaries between what is deemed appropriate and inappropriate given the context of the encounter such distinguishing the difference between nudity in art and medicine compared to a sexual encounter (p. 74).

<sup>28</sup> Giddens (1991) indicates that this bracketing out is a means of reducing our need to assess all the risks, the uncertainties associated with action, but this does not reduce the actual risks in our actions (p. 3-4).

positions or identities, constituted within the structure, with a range of responsibilities and obligations that signify and legitimize their role and power within the institution, but also in other areas of social life such as the home, neighborhood, city, and the large social system (p. 83-85). Positioning forms a part of the individual's identity. In our interactions, the individual's normative responsibilities and obligations in her position are exercised and formulated within a specific time and space (p. 86). These interactions are interpreted within frames, clusters of rules that define and regulate activities, where situated encounters are given meaning to enable actors to comprehend our initial desire to make sense of 'what is going on' (p. 87). This means that when we encounter others, our position is made obvious in the types of rules that become evident in our interaction within a particular frame.<sup>29</sup> Rules are implicated in encounters between individuals, contextualized within frames that enable us to interpret the meaning of our interactions.

In sum, according to Giddens, the connection between agency and structure lies in the actor engaging in social practices that reproduce structure. Giddens' actor is a rational actor, though engaged in routines and desiring stability to live her daily life, recognizes her position, her other knowledge systems, and the institutional context in which her actions are performed and which rules are applied or changed, so she can make decisions at particular instances. The actor is both an agent of potential change and influence within her institutional environment, but her environment also produces the context for her actions (both constraints and enablers). In this study, the connection between agency and structure lies in examining how actors perform, terminate, or change their routines in health care settings. In this way, we come to understand user agency and the structures surrounding and embedded in telehealth use.

## **The Application of Giddens' Structuration Theory to Technology Studies**

A number of studies on information technologies have adapted Giddens' structuration theory to examine the interaction between humans and machines. Most of

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<sup>29</sup> Giddens (1984) also accounts for the role appearance plays in facilitating or hindering an individual's encounters with others. The normative expectations of dress and conduct in any particular setting and encounter means the individual must consistently monitor her actions to be considered a capable agent within day-to-day life (p.79-80). Those deemed incapable (the mentally ill) often deviate from the normative opening and closings of conversations and talk in encounters between individuals.

these approaches conceive technology as embodying structure (rules and resources embedded into the technology) and appropriated by users (Orlikowski, 2000). The chart below briefly outlines four variations in the application of Giddens' structuration theory.

**Table 2.2 Application of Structuration Theory to Technology Usage**

Science and Technology After Giddens	Name	Application to technology Usage
Barley (1986)	Technology as an occasion for structuring	<ul style="list-style-type: none"> <li>Technology as an occasion for structuring (altering organizational and occupational work)</li> <li>Technology is a social object and structure is conceived as a process</li> </ul>
Orlikowski (2000)	Technology in practice <sup>30</sup>	<ul style="list-style-type: none"> <li>Technology is open to interpretative flexibility in usage</li> <li>Technology is not a structure, but only as it is instantiated in human action</li> </ul>
Poole & DeSanctis (2004)	Adaptive structuration theory	<ul style="list-style-type: none"> <li>Structures are built into technology</li> <li>Rules and resources of technology become the premise for structuration when “actors are moved to use them” (p.211)</li> </ul>
Greenhalgh and Stones (2010)	Strong structuration theory	<ul style="list-style-type: none"> <li>Structures are inscribed in technology</li> <li>Actors’ behaviors are shaped while engaged with technology (interpretative flexibility)</li> </ul>

All of the authors in the above chart have attempted to apply Giddens' structuration theory to study technologies within organizations and in doing so, revealed the limitations and strengths of his theory. Most of these types of studies indicate that Giddens' structuration theory is unable to tackle the empirical study of technologies in a tangible manner (Greenhalgh & Stones, 2010; Jones & Karsten, 2008; Poole & DeSanctis, 2004).

Barley (1986) indicates that technology usage become occasions or triggers for organizational change (rather than the cause of organizational change). Orlikowski (2000), Poole & DeSanctis' (2004), and Greenhalgh and Stones (2010) have all added to Barley's (1986) earlier work on the role technology plays in structuring organizational and occupational work.

Orlikowski (2000) attempts to examine the structures that shape the individuals' interactions with technology as they use technology (the cyclic perspective of existing structures, individual action and interaction with technology, and the emerging structures

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<sup>30</sup> Orlikowski's (1992) earlier work was on the duality of technology.

created in use) offers the possibility of understanding the dynamics of structural change.<sup>31</sup> Her perspective avoids the notion that technologies become stabilized and represent particular social and political structures after development; instead she follows Pinch and Bijker's (1987) notion of interpretative flexibility that the meaning, properties, and applications of technologies evolve through usage (Orlikowski, 2000: p.406).<sup>32</sup> Greenhalgh and Stones (2010) indicate that Orlikowski (2000) and Barley's (1986) work did not consider the evolution of technology as it was being used in organizations.

Poole and DeSantis (2004), on the other hand, indicate that structures (rules and resources) are inscribed into the technology. Their perspective embrace the idea that users use technology differently to create new structures (an appropriation of technology approach) – technology and users evolve as users interact with technology (p. 211). They interpret Giddens' notion of structuration as “the process of putting structures into action” (p. 210). However, they conceptually separate structure, action, and actor -- whereas Giddens' does not -- as a means of empirically studying information systems. They indicate their outline for structuration research in information systems would enable them to bracket each of their seven components into manageable units to comprehend the entire process of structuration (p.213-215).<sup>33</sup> While these seven requirements for information system research clarify some key areas for research (and indeed this thesis research may cover some of these areas), the very division may also prevent researchers from understanding and seeking other connections or actors not directly identified in the scheme. Furthermore, the approach is relevant for an organization, but community concerns such as privacy, confidentiality, and the ethical use of information may largely be ignored.

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<sup>31</sup> Orlikowski's (1992) earlier work followed the same theoretical proposition but she indicated that technology after being used became structures within the organization, contrary to Giddens' (1984) perspective that structures are similar to “memory traces” (p. 17).

<sup>32</sup> In subsequent research, Orlikowski and Iacono (Orlikowski & Iacono, 2001) indicate that much of technology studies has focused on understanding the technology context rather technology as an artifact (they identified five views of technology: 1) tool view; 2) proxy view; 3) ensemble view; 4) computational view; 5) nominal view).

<sup>33</sup> Poole and DeSantis' (2004) seven components of information system research are: 1) identification of structures; 2) relationship of structures and their contradictions; 3) analysis of the system, including effects of content; 4) identification of structuring moves: production and reproduction of structures; 5) effects of process on content; 6) analysis of actors and their roles; and 7) analysis of power dynamics and social ideologies.

Lastly, the chart above briefly summarizes, Greenhalgh and Stones' (2010) attempts to align structuration theory with actor-network theory (ANT) to map out the study of large health information systems. They propose that strong structuration theory (SST) has four particular components: connecting the agent (both the internal and external dynamic of action – thought proceeding action)<sup>34</sup> to organization and the evident outcomes of the actors. They also adopt two important elements from ANT for understanding technology within SST: a) use ANT's notion that social structures and material properties can be inscribed into technology; and b) take the notion of social shaping of human behavior in the social technical network while actors engage in interpretative flexibility (1289-1290). Strong structuration theory seemingly strengthens an empirical approach to studying technologies as they are used in practice. However, Jones and Karsten (2008) also caution that by changing one aspect of Giddens' structuration theory and including other aspects of ANT,<sup>35</sup> researchers will often fail to provide a coherent theory that is “philosophically, methodologically, and conceptually” integrated (p.148).

Each of the above approaches have attempted to retain core elements of Giddens' structuration theory while including other technology theories, particularly the social construction of technology and actor-network theory, to offset some of its perceived weaknesses. The notion that technology is inscribed with structure that shape and is shaped by human action seems to be a common adaptation of Giddens' structuration theory. This may seem contrary to Giddens' perspective that structure is similar to

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<sup>34</sup> Greenhalgh and Stones (2010) indicate that their concept of internal structure is reflective of Bourdieu's notion of habitus: “socio-cultural schemas, discourses, and world-views, moral and practical principles, attitudes, ambitions, technical and other embodied skills, and personal value commitments and orientations” (p.1288). However, they do not articulate how this smorgasbord of personal dispositions becomes refined and selected in the exercise of practice. Is there a competition between the individual's stocks of knowledge and the ability of the individual to apply it within a given encounter? What tension arises between culture (what may be unexpressed) and pragmatic knowledge / skills (i.e. between what we have become accustomed to and what our education trains us to exercise)? It is far too easy to create a list of the personal domain (they suggest it also overlaps Habermas' lifeworld) and indicate the individual simply draws from this source. Giddens' (1984) notion of signification, domination, and legitimization needs to be explained.

<sup>35</sup> Actor Network Theory (ANT) would consider technology an actor connected to other actors in a network. However, ANT has a tendency to flatten relations and grant actors with unlimited or limited power, which some find the indeterminacy of the actor its core strength (Callon, 2005). ANT, in particular Latour's (1992), question in opening up the black box of technology: how did technologies come to be? This is a different type of question than the question of, how is technology being used (Orlikowski & Iacono, 2001p. 6)? For more discussion on ANT see Latour (1987), Callon (1986) and Law (1992).

“memory traces”, produced and reproduced through the actors’ actions (p.17). However, one can imagine that a particular set of actors created the technology (telehealth) to embody the structures of a large social system (provincial health care system) so that actors in First Nation communities may utilize the technology within their health centers (a social system). If structures are enacted as human actors utilize the technology, the technology becomes a part of the structuration process – the human agent utilizes the technology and she has the opportunity to change the social system in which she exists in.

### **Concluding Comments: Theoretical Direction of Thesis Research**

Given the limitations that many discovered applying Giddens’ structuration theory to technology studies and the need to include ANT and SCOT to facilitate an understanding of technology relations to the user, this thesis application of Giddens’ theoretical concepts and SCOT will likely have some limitations as well.<sup>36</sup> This thesis is focused on a particular aspect of technology usage within the health care system: the role technology users play in shaping telehealth in First Nation communities. This means the thesis will consider technology usage in First Nation communities from the perspective of human actors as they engage in their day to day routines of doing health care work and seeking health care with the insight that telehealth technology may also shape the actions of users. The thesis acknowledges that telehealth is created for rural and remote communities (relevant group), but whether this group includes First Nations users is another question that needs to be answered. As well, telehealth usage exists within a complex system, perhaps a layering of multiple systems (federal and provincial governmental organizations integrated with First Nation community governance) and technology systems.

In sum, SCOT enables a theoretical frame that allows this thesis to consider the users’ relation to telehealth and the social context in which technology is used. Giddens’ (1984) work enables this research to tackle the relationship between users and structure from examining the routines of users.

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<sup>36</sup> The limitations of this theoretical approach will be examined after the data from the research has been analyzed.

# Chapter 3 - Review of the Literature on Telehealth

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## Introduction

There are several contributing factors that challenge the delivery of health care services to First Nation communities in Canada. First, the vast disparity between health care services in urban communities and many First Nation communities in Canada can be attributed to the concentration of medical services in large urban centers (Report of the Royal Commission on Aboriginal Peoples, 1996; Savin, Garry, Zuccaro, & Novins, 2006). Second, Canada's vast geography hinders the delivery of timely medical services from urban centers to rural and remote communities. In Canada, approximately 30% of the Canadian population, or nine million people, live in rural communities. Of this total, more than half of the First Nation population live in rural community, which occupy 95% of Canada's geography (Health Canada, 2007e). These barriers challenge the delivery of medical services to rural and remote First Nation communities and contribute to the decline of First Nation health.

The overall health of First Nation communities has always been statistically shocking. In the 1990s Statistics Canada released *A Statistical Profile on First Nations in Canada* that revealed First Nation peoples had higher infant mortality rates and higher death rates due to suicide, accidents, and chronic diseases than the national average (Health Canada, 2003: p. 21). There are some cases where disease and infection in First Nation and Inuit communities verge on epidemic levels compared to the national average: tuberculosis is six and seventeen times higher respectively, obesity rates are twice as high, and genital Chlamydia and HIV is much higher than the national average (Health Council of Canada, 2005p. 6). Meanwhile, the First Nation population is growing twice as fast compared to the national average: First Nation girls between the ages of 10 to 14 years old are having children nine times higher than children in the rest of the Canadian population; this rate is also comparable to First Nation teenagers between 15 to 19 years old at five times the rate compared to the national average (Health Canada, 2003b, p. 13).

To add to the complexity of health care challenges, the number of health care providers in rural communities, the closest neighbors of First Nation communities that provide hospital services, is on the decline. According to the Ministerial Advisory Council on Rural Health (2002), 17% of family physicians, 18% of registered nurses, and 4% of specialists work in rural communities (p. 1-2).

The number of health issues and challenges in First Nation communities compared to the rest of Canada is so vast that it may seem like an impossible hurdle to overcome and any solution may merely be seen as an arm extending over a chasm. Into this situation, many policy makers, First Nation governments, and researchers suggest that telehealth technologies may play a significant role in enhancing health care services by bridging geographic distances (Assembly of First Nations, 2004; Canada Health Infoway, 2007; Kakepetum, 2005).

This chapter will provide a context for the thesis research: first, it provides a background and definition of the telehealth concept. Second, it contextualizes telehealth development in Canada from the perspective of decision makers and it orients' telehealth within the international literature. Third, it provides a systematic literature review of telehealth in First Nation communities<sup>37</sup> to orient the reader on the gaps in research.

## **Background on Telehealth: A Historical Context**

### ***a. Definition***

Telehealth<sup>38</sup> is commonly defined as the delivery of health care services using information communication technologies (ICTs) to enable sound, data, and direct video connection over a vast geographic distance, often in the form of videoconferencing, but increasingly changing to include many clinical services such as robotics in surgery

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<sup>37</sup> The reader may question why this literature review is based on telehealth in Aboriginal communities instead of rural and remote communities. The literature review is mindful that there are several distinctions between health care service delivery in Aboriginal communities and other rural communities in Canada: culture, service delivery structure, and political jurisdiction, which means that types of challenges and opportunities for telehealth usage will be distinct, though the technology may be the same or similar to rural and remote communities.

<sup>38</sup> As mentioned in the introduction, telehealth is under the umbrella of ehealth or e-health (a much larger category of health information technologies used to facilitate health care services and education).

(Marohn & Hanly, 2004; Satava, 2005). In the literature on telehealth<sup>39</sup>, the term has become an umbrella that encompasses medical services (diagnostics such as radiology, psychiatry and ophthalmology) and health care services (such as peer-to-peer practitioner consultations and health education for patients and practitioners) (Rous, 2004). The term telemedicine, though similar to telehealth, is much older and for some, much more restrictive, often focused on the clinical or curative aspect of the connection between patients and physicians rather than including such services as health education (Maheu, et al., 2001: p. 3), family visits via videoconferencing, and peer-to-peer consultations.

### ***b. History of Telehealth in Canada***

The use of information and communication technologies in the delivery of health care services and support has a long history. In the late 1870s, the first recorded use of the telephone for health care occurred between a drugstore and twenty-one physicians in Connecticut (Reisman & Stevens, 2002); in 1955 two televisions were used to facilitate communication between health care providers in consultations (Demiris & Toa, 2005); in 1975 Newfoundland began its telemedicine program, using telephones to connect health care providers together (Muttitt, Vigneault, & Loewen, 2004)<sup>40</sup>; and in the 1980s in Alberta, Dr. Watanabe, with the University of Calgary, established the first viable telehealth connection to support rural physicians in Dumbrell (Cradduck, 2008).

The growth of modern telehealth programs in the province has been facilitated in large part by policy and decision makers: government, non-governmental bodies, researchers in universities (particularly in the area of technology and organization evaluations and policy recommendations) and the technology industry. The general public, particularly in the First Nation communities I visited, were unaware of telehealth technology except for health care administrators making the decision to include particular telehealth programs in health care services. Policy and decision makers implemented

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<sup>39</sup> Telehealth also falls under the umbrella of e-health, which includes electronic mediated health care services such as electronic medical health records, Internet health information, and diagnostic image transmission (Canadian Society of Telehealth, 2005: p. 5).

<sup>40</sup> Muttitt et al. (2004) the Telemedicine Centre at Memorial University was established in 1975 under the guidance of Dr. A. M. House. Today the centre is called the Tele-health and Educational Technology Resource Agency (TETRA).

telehealth across Canada in patches according to provincial frameworks then slowly developed and established guidelines.

Modern telehealth began in earnest with the development of Canada's Information Highway, a wider policy initiative in the 1990s that enabled Canada to be a player in the knowledge economy. The Federal Government, in collaboration with industry leaders and researchers from universities, supported the Information Highway Advisory Council (IHAC), which steered Canada's Information Highway development. The National Broadband Task Force further provided vision for Canada's knowledge economy, including the vision of telehealth in Canadian society (National Broadband Task Force, 2001). Other non-governmental bodies, such as CANARIE (Canada's Advanced Research and Innovation Network) was established in 1993 in collaboration with research institutes and industry leaders to provide connectivity to universities, colleges, schools, government labs, research institutes, hospitals and other organizations (CANARIE, 2002).

A specific initiative for health care, Canada's Health Infoway was established in 2001 with a mandate to create a pan-Canadian interoperable electronic health records for 50% of Canadians by the end of 2009.<sup>41</sup> To achieve this goal, Infoway invested in the development of health information and communication technologies to develop electronic health records, telehealth, and public surveillance systems (Health Canada, 2007a). The 1990s was a period that focused on establishing connectivity, but Canada did not want to leave First Nation communities behind and according to INAC, they were connecting schools (Indian and Northern Affairs Canada, 2002) and later an initiative to provide connectivity to other First Nation organizations was attempted through Industry Canada's Broadband for Rural and Northern Development (BRAND). The vision of a content filled band width with ethical standards was never far from the imaginations of decision-makers.

Over the years, the literature on telehealth has focused on implementation challenges associated with technology, connectivity (Health Canada, 2001), organizational structure (Jennett, Yeo, Pauls, & Graham, 2003), resources (Hailey &

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<sup>41</sup> Electronic health records are a part of the many e-health solutions that western nations are developing and using to facilitate effective and efficient access to health care services.

Jennett, 2004; Jennett, Watson, & Watanabe, 2000), ethical guidelines (AETMIS), 2008; National Initiative for telehealth Guidelines, 2003), policy and evaluations (Scott, 2006).

**Table 3.1: Milestones in Telehealth Development in Canada**

Type	Name of Report / Document	Purpose
Technology	• Broadband Task Force (2001)	• Establish vision for development of broadband technology
Telehealth Guidelines	• National Initiative for Telehealth (NIFTE, 2003)	• Establish a frame of reference, guidelines for ethical telehealth practice
Health care	• Kirby Report • Romanov Commission	• Recommend telehealth to broaden access to health care in rural and remote locations
First Nations Health care	• Agenda for Restoring and Improving First Nation Health	• First Nation communities advocate the use of telehealth in enhancing health care services

In the above chart, some of the key reports have established a foundation for the establishment of telehealth as a permanent service within Canada's health care system. In many ways telehealth requires the coordinated efforts of many policy makers and stakeholders in many different areas – a framework for not only imagining its use, but also for considering the logistics of cost allocations<sup>42</sup> and ethical standards (National Initiative for telehealth Guidelines, 2003).

It is important to note that while it may appear that health care services are moving from face-to-face encounters to technologically mediated encounters, the advances in connectivity may sometimes appear to displace old technology, but they could also work in tandem with face-to-face encounters. For example, telephone medicine continues to play a significant role in connecting health care providers to their patients and colleagues in rural and remote communities (Stacey, Nororani, Robinson, Joyce, & Pong, 2004). Telehealth, connected through the Internet, is being utilized in conjunction with old technologies such as telephone, fax, and store and forward technologies.

### **c. Telehealth Utility: Defining Function and Potential**

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<sup>42</sup> I discuss the complexity of allocating costs to telehealth usage in the following chapter on the structure of health care service delivery in Aboriginal communities.

With the advancement in wireless technologies and fibre optics to handle the large volume in data, videoconferencing has been used to address health care providers' need to visually connect to patients and their colleagues, while maintaining the use of the telephone.<sup>43</sup> The challenge for considering what technologies *do* and what they *can do* are often blurred: what it can do often depends, to some degree, on what users imagine it does. Technology designers often create technologies for a specific function, but users may or may not use the technology for its designed function. For example, some technologies such as videoconferencing (comprised of a camera, a screen, and Internet connection) can be used for several applications: meetings between various locations, education, and patient consultation, but users may not use it for all these applications out of choice or structural limitations or they may use it to take still pictures and circumvent the intended purpose of interactive audio and visual exchange.

The chart below, while not exhaustive, provides a broad perspective on the types of telehealth services being studied in the literature. All the services require some form of Internet connectivity: real time videoconference requires wireless or fibre optics enabled speeds greater than 1.5mbps (videoconferencing capability is at 1.5mbps) and higher for robotic surgery; other applications that require lower bandwidth such as home telehealth applications for electrogram readings or other simple data are dependent on dial-up connectivity using telephone lines. Each type of telehealth involves different peripherals (electronic devices plugged into the telehealth unit that provide digital, visual, or audio health information) and interfaces to enable a particular function; some are converged into one piece of technology, while others are stand alone technologies.

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<sup>43</sup> In the Northwest Territories, the tele-care center is operational and valuable in patient care (Howard Research & Management Consulting, 2006).

**Table 3.2: Some Examples of Telehealth Services**

Telehealth Name	Function	Medical / Health Service
<b>Tele-consultation</b>	Videoconferencing	<ul style="list-style-type: none"><li>• Clinical consultations</li><li>• Administrative meetings</li><li>• Family visitations</li><li>• Health education</li><li>• Health promotion</li></ul>
<b>Home Telehealth</b>	Monitoring / Assistance / Continuing care (provide care in the home using technology)	<ul style="list-style-type: none"><li>• Monitoring chronic disease (heart, diabetes)</li><li>• Videoconference counseling sessions</li></ul>
<b>Tele-robotic Surgery</b>	Surgery	<ul style="list-style-type: none"><li>• Perform surgery at a distance</li><li>• Example: pilot project in Canada using Robotic arms to operate on a woman in Thunder Bay (Anvari, McKinley, &amp; Stein, 2005)</li><li>• Other projects in submarines and battle fields (C. M. R. Marohn &amp; E. J. Hanly, 2004)</li></ul>
<ul style="list-style-type: none"><li>• <b>Tele-otology</b></li><li>• <b>Tele-radiology</b></li><li>• <b>Tele-dermatology</b></li></ul>	Images of human body parts transmitted (examples: ear, eyes, skin)	<ul style="list-style-type: none"><li>• Diagnosis acute inflammation of the middle ear</li><li>• Diagnosis using x-rays or ultrasounds</li><li>• Diagnosis of the skin using images</li></ul>

In the chart above, each type of telehealth application is associated with different technologies requiring different types of skill sets to operate; some are more user friendly than others. Below are some images that capture elements of technological convergence, but it also captures the diversity of telehealth technology in various settings to illustrate the types of telehealth technologies that some communities are using.<sup>44</sup>

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<sup>44</sup> There were no examples of home telehealth in the communities visited. As a result no images are being presented here.

### Images 3.1 of Telehealth Technology



- A) Tandberg Videoconferencing Equipment (located in Fort McMurray Hospital) enables telehealth consultations, education between physicians, administrators, and patients. This technology is situated in a front of a room with a conference table and chairs. It is comprised of a television screen, video camera, and wired to the wall to ensure connectivity speed greater than 1.5mbps.
- B) Physician Cart located in Fort McMurray Hospital: This cart is a mobile unit equipped with wireless technology, television screen, camera, and it has the ability to transmit ECG readings. While it is an older technology, it was still being used.
- C) This is an example of first generation video-conferencing equipment, located in a First Nation community. It has attachable peripherals to provide clinical exams. The white machine is a diabetic foot scan. The telehealth set up is comprised of a television screen, a camera, and it is wired to the wall using six telephone lines called ISDN 384 and the older version is called switch 56. This telehealth technology was located in the physiotherapy room with a few movable chairs.
- D) Physician Cart located in Fort McMurray Hospital: Newer version of the cart above with higher bandwidth capabilities and easier mobility.

All the telehealth technologies are used in particular settings (conference room, patient's room) and each of the technologies and their peripherals are intended for a particular setting and purpose. This, however, does not mean that all of its users would agree with the technology's capacity to fulfill their intended purposes or that they were satisfied with its operation (Courtney, Demiris, & Hensel, 2007). Consequently, how technologies are designed, how users use technologies in everyday health activities, and how users

perceive technologies may diverge, creating opportunities for exploring how these realms intersect.<sup>45</sup>

## **Telehealth Use in First Nation Communities**

### ***a. The International Context: The United States and Australia***

Telehealth has been rigorously pursued in countries with vast geographic space and limitations in health care resources as a means of addressing both primary and specialist health care needs. In a survey of 12 telehealth projects across Canada, Jennett et al. (2000) indicate that telehealth has the potential for enhancing access to specialists, providing more opportunities for diagnosis and continuing medical education. There are some case examples that have tested this hypothesis, confirmed the potential for telehealth, but also highlighted the challenges for telehealth use in the United States, Australia, and Canada.<sup>46</sup>

In the United States, the earliest clinical telehealth project called STARPAHC (Space Technology Applied to Rural Papago Advanced Health care) was developed to serve First Nation communities from 1973 to 1977 (Fuchs, 1979; Henceroth, 1978). It involved several collaborators: NASA (National Aeronautical Space Administration), the Papago Reservation (now called the Tohono O'odham Indian Nation), the Indian Health Service, and the Lockheed Missile and Space Company (Freiburger, Holcomb, & Piper, 2007). While the project was not sustainable, its early successes and failures offer insight into the use of communication technology for medical purposes. However, many of the challenges that health care providers faced then were also experienced two decades later in Canada's telehealth pilot projects in First Nation communities such as: high staff turnover, technical difficulties, jurisdiction and billing issues (Fuchs, 1979; Health Canada, 2001).<sup>47</sup>

Two decades later in Alaska, some success stories of telehealth usage emerged in part due to the advancement of telehealth technology, but perhaps also due to the

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<sup>45</sup> The opportunity to observe users using telehealth technology is further examined in the three cases studies in the last three chapters, offering us a perspective on design, function, and use.

<sup>46</sup> Alaska and Australia both involve private and public health care service systems, while Canada is public.

<sup>47</sup> These challenges are examined further in the discussion below.

increasing amount of training that health care providers were receiving. The Alaska Federal Health care Access Network (AFHCAN) has a history of using telecommunications (telephone and fax) to facilitate health care assistance due to its vast geographic space, lack of physicians, and high cost of health care (McDowell Group, 2007). In 1996, a store-and-forward<sup>48</sup> tele-otology program using a video otoscopy camera and the Internet was implemented to address the high number of patients with chronic otitis media, acute inflammation of the middle ear. In 1997, the AFHCAN implemented the tele-radiology program (the use of radiant energy such as x-rays or ultrasounds to diagnosis disease), reducing diagnostic wait times from between 9 to 21 days to 24 hours, which quickly became one of the most successful telehealth applications (Patricoski, 2004). As well, applications for otolaryngology, audiology, dermatology, and cardiology grew 50% from 2003 to 2004 (p. 373). These telehealth services rely on the use of digital images transmitted from remote communities to the referring hospital, enabling not only rapid diagnostic times, but it also alleviated unnecessary travels for consultations (Kokesh, Ferguson, & Patricoski, 2004). The literature indicates that telehealth plays a role in rural and remote communities in Alaska by providing small communities access to physicians, whose service they may not normally be able to retain; it also provides physicians the ability to consult with specialists and continue their medical education and training (Report of the Alaska Physician Supply Task Force, 2006).

In Australia, the story is similar: vast geography, many rural and remote communities, limited health care resources, and the possibility for telehealth to play a role in enhancing health care services. In 1995, ophthalmologists from Perth, 2000 – 3000 Km away from Kimberly, made periodic visits, but they could not alleviate the rising number of end-stage diabetic retinopathy that led to blindness. The use of the fundus camera reduced the ophthalmologists' need to see their patients face-to-face by enabling health care workers in Kimberly to take digital images of the eye and forward them to the physicians (Murray, Metcalf, Lewis, Mein, & McAllister, 2005; Yugesan, Constable, & Chan, 2002). The desire to reduce travel, increase diagnostic effectiveness

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<sup>48</sup> A store-and-forward system uses e-mail: an image of the problem is forwarded to the expert and the expert responds via e-mail.

and efficiency, and provide better patient care was also found in another case: 70% of Aboriginal children had chronic otitis media, but there was a shortage of otolaryngologists. Otolaryngologists used tele-learning to educate Aboriginal health care workers in remote locations on ear anatomy, physiology, hearing, otoscopy and telemedicine, which significantly provided better care for young children (Eikelboom, et al., 2003).

From the international perspective, the telehealth projects enabled and enhanced health care services that would otherwise be costly or very difficult to access from a remote location. Most of the international experiences with telehealth in Aboriginal communities have been based on store and forward technology requiring users to email digital images such as retinal scans, ultrasounds, and x-rays to specialists; these telehealth applications have been proven to increase diagnostic efficiency, particularly in Alaska and Australia (Kokesh, et al., 2004). However, as Internet technology improved in early 2000 to enable interactive two-way video conferencing in real time, more attempts have been made to test telehealth technology's capacity for consultations and meetings (Nissen & Tett, 2003; Smith & Ferguson, 2004; Starren, et al., 2005). As Telehealth technology changes, the possibility of providing different types of services to rural and remote communities have created persistent questions of its cost-effectiveness, organizational structure, technical, and network challenges, and the need to understand health providers and patients' perspective of telehealth usage (Jennett, et al., 2003; Kerr & Norris, 2004; Khazei, Jarvis-Selinger, Ho, & Lee, 2005; Martinez & Villarroel, 2004; Starren, et al., 2005). These issues are the same issues faced by First Nation communities in Canada.

### ***b. The Context of Telehealth in First Nations Communities in Canada***

Often in Canada, policy makers invoke the need for health care services based on the vast geography and the limited resources for the implementation of telehealth (Assembly of First Nations, 2005a; Health Canada, 2005a; Report of the National Broadband Task Force, 2001a; Romanow Commission, 2002). Ho and Jarvis-Selinger's (2006) environmental scan of telehealth usage across the country have been implemented in all the provinces and territories, but they vary according to funding, human resources,

technology solutions, and the number and type of programs being offered. These differences reflect Canada's emphasis on provincial control of health care services. Most of the telehealth systems began their operation within the last seven to eight years, except Newfoundland's system which is the oldest, but not necessarily with the most integrated or number of telehealth services provided. In Quebec, Ontario, Alberta, and Nunavut, the number or percentage of telehealth consultations have steadily increased from one year to the next due to a combination of possible factors: 1) an emphasis on providing specialty programs such as programs aimed at children and youth in rural and remote communities; 2) an increase in the number of telehealth installations in rural and remote communities; 3) telehealth service provided to other provinces or territories such as the case in Alberta (Provincial Telehealth Committee, 2006); and 4) an incorporation of telehealth services to Aboriginal communities (Muttitt, et al., 2004).

According to Ho and Jarvis – Selinger (2006), the technology solutions in some telehealth systems such as the ones in Newfoundland, Nunavut, and Quebec are comprised of an audio system and a video system, enabling two different types of applications: one for videoconferencing and the other for teleconferencing. As well, the types of peripherals attached to telehealth systems such as digital cameras, stethoscopes, exam cameras, otoscope, dermascope and many other technologies vary according to the type of service being provided within the communities. In the area of connectivity, the problem that many provinces experience is that telehealth technology is a mixture of older ISDN (Integrated Services Digital Network) (a series of telephone lines used to carry information) and newer broadband technologies based on wireless or fiber optic connections (enables connection speeds greater than 1.5mbps), which means that bridging technology is needed to ensure both systems can communicate with each other (Canadian Society of Telehealth, 2001). For example, in Alberta, telehealth is in the process of migrating to newer technologies from ISDN to fibre optics in the Alberta SuperNet, a broadband grid connecting all federal and provincial government offices in 421 communities. The Alberta Government indicates the migration process is a change not simply in technology, but in the way telehealth is delivered: more connectivity speed means enabling more and newer health care services such as tele-surgery (Provincial Telehealth Committee, 2006).

### **c. Differentiating Telehealth Use from Telehealth Implementation in First Nation Communities**

Across Canada, the variety of telehealth applications has grown and so has its acceptance as a form of health care service delivery, but whether these services are supported and how these services are used in First Nation communities is still questionable. There are a number of challenges in considering telehealth in First Nation communities, particularly, jurisdiction. Telehealth use also involves negotiation, sometimes on a program-by-program basis, between Health Canada's First Nations Inuit Health Branch (FNIHB), the province or regional authority, and the First Nation communities.<sup>49</sup> These challenges mean that telehealth connectivity and implementation in First Nation communities may not necessarily mean telehealth is being used, particularly if health care programs are not established or funded.

One example of significant First Nations telehealth connectivity is in Alberta. The existing broadband grid provided by the Alberta SuperNet enables First Nation communities to connect their health care facilities; in particular, telehealth with speeds of 10mbps (very fast Internet speeds that would enable real time videoconferencing and other bandwidth challenging applications such as streaming video). FNIHB in Alberta, through the Alberta's First Nations Telehealth Program (AFNTP), has connected (or is in the process of connecting) forty-one telehealth units in the First Nation communities to the Alberta SuperNet's point-of-presence and it will continue to focus its resources on clinical training and health education (diabetes and nutrition) to improve health care workers' knowledge. One of AFNTP's goals, through tele-learning, is to facilitate higher quality of health care services and reduce health care workers' isolation in the First Nation communities by connecting health care practitioners with external expertise using a combination of videoconferencing applications and a website forum (First Nations Inuit Health Branch (FNIHB), 2004). However, the AFNTP program, like other telehealth

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<sup>49</sup> This may seem that telehealth is a special case in health care services, but to understand telehealth services in Aboriginal communities requires some understanding of the way health care services are delivered in Canada (more on health care services will be covered on chapter 5).

programs in First Nation communities across Canada, is subject to First Nations' governance of health.<sup>50</sup>

The other extensive telehealth connectivity project is in northern Ontario: First Nation communities in Sioux Lookout have established a telehealth network called KO-Telehealth Network to address their health care needs. The KO-Telehealth Network (KOTH)<sup>51</sup> is seeking to provide both Western medical service and traditional medicine (2005a). As far as this author is aware, KOTH is the only telehealth system offering an integration of Western and Indigenous ways of healing. The Yukon Telehealth Network and KOTH both offer tele-visitation between family members and patients who have been transferred outside the community. According to the KOTH (2005b, 2005c), tele-visitations was expected to increase between the years 2004 to 2006.<sup>52</sup> The ability to access traditional healers and connect with family members during periods of illness enable First Nation peoples in the Sioux Lookout communities to better control and meet their health care needs.

As of December 2007, Canada Health Infoway has decided to provide 100% funding for telehealth in First Nation communities to connect to provincial telehealth systems, but only 75% for independent telehealth projects – all welcome news for the Assembly of First Nations (Canada Health Infoway, 2007).<sup>53</sup> However, connectivity does not negate the fact that physicians and nurses are in short supply; it is only one type of solution to the vast disparity of health care challenges. Some of these concerns are similar to those challenges found in Health Canada's (2002b) pilot projects across Canada in five First Nation communities from 1998 to 2001. On the positive side, the pilots revealed that the implementation of telehealth increased access to external expertise and fostered greater confidence in local practitioners' judgment and care (p. 42). Telehealth reduced 30% to 40% of potential transfers by enhancing the capabilities

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<sup>50</sup> In chapter 5, I discuss the structure of health care services in Aboriginal communities and the connections to telehealth.

<sup>51</sup> KOTH has now been changed to KOTM (KO - telemedicine).

<sup>52</sup> The log, however, only indicates tele-visitation up until September 2005, but from April to September 2005 eighteen tele-visitations were logged compared to nineteen tele-visitation sessions in the fiscal year from April 2004 to March 2005.

<sup>53</sup> In chapter 5, I discuss further the implications of Infoway's telehealth funding on jurisdictional challenges.

of local practitioners (p.43); this was all very good news to continue on the course to providing telehealth services in First Nation communities.

However, the final report also indicated that telehealth was not sustainable or usable in all First Nation communities; the key issues for sustainability is that “telehealth is about people, not technology” (p. 97). According to the report, this means that professional relationships are at the heart of operational and sustainable telehealth services. Effective telehealth services appear to be premised on several key cornerstones based on the development of various relationships:

- 1) Established trusting relationship with local health care providers;
- 2) The ability of telehealth providers to build excellent rapport and trust with chronically ill patients’ (usually established when specialists visit the community);
- 3) Creating health care teams between rural and urban centers across geographic distances;
- 4) The willingness of telehealth providers in urban centers to provide health care services;
- 5) The willingness of stakeholders to collaborate together (p.97-98).

The report further indicated that due to the existing health care environment in First Nation communities, telehealth was susceptible to inefficiency stemming from the shortage of health care providers and the high rates of staff turnover like all other health care initiatives (p. 99). Despite the shortage and instability of health care staff, the report was optimistic that telehealth “successfully” deployed would improve the stability of health care teams in First Nation communities.<sup>54</sup> The notion of what constitutes as being successful is challenging, since success must be considered in the context of First Nation communities. As well, successful implementation does not equal successful usage in health care practice. Health Canada (2001) recognizes the need for the users involvement in telehealth operation, but the report does not mention important aspect of telehealth use: 1) it does not provide recommendations for how these different users (patients, administrators, nurses and doctors) should be engaged; and 2) there is no recognition of

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<sup>54</sup> The perspective that telehealth facilitates the stabilization of health care teams will be further discussed in the case study comparison and discussion.

how health care practice may change with the introduction and sustained use of telehealth technology.

Overall, the actions of different levels of government in Canada suggest strong support for telehealth's potential to reduce health care costs by decreasing the need to travel to consult with physicians, particularly for those applications that thrive on digital imagery such as retinal screening for diabetes, radiology, dermatology, and cardiology (Ho & Jarvis-Selinger, 2006). The elderly may particularly appreciate being cared for within their own community and patients who normally must brave treacherous weather conditions will also benefit. Tele-learning for education purposes also reduces costs to the health care system by enhancing local expertise and decreasing the need to travel. As new technologies such as fiber optics enable broadband connectivity, video-conferencing for clinical consultations will likely become more common.<sup>55</sup> Currently, there is little or no cost-effectiveness study involving First Nation communities that would factor in the travel time, costs, and social implications of telehealth over a sustained period of time.<sup>56</sup> As well, the same difficulties and challenges found in Health Canada's pilot projects may still exist today in Canada.

In the above discussion on the definition and description of telehealth in Canada, Australia, and Alaska, the reader is given an understanding of the historical push and deployment of telehealth in First Nation communities. The context is largely from a health care systems' perspective (the federal and provincial government, various non-governmental bodies such as CANARIE, and some health technology assessments). In many ways, the discussion highlights the consistent rationale for telehealth deployment: telehealth technology enables services to be provided over a vast geographic distance; reduces the high cost of health care service delivery; and leverages the lack of human resources in First Nation communities. The discussion positively affirms that telehealth's potential to enhance health care service delivery is real, since most decision makers,

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<sup>55</sup> In Canada, Dr. Anvari's tele-robotic surgery has become the ultimate use of broadband technology (Anvari, et al., 2005).

<sup>56</sup> In studies involving non- Aboriginal communities, however, some telehealth applications requiring video-conferencing may not be saving the health care system money due to high initial investments for telecommunication fees and equipment, but it is proving to be highly efficient in facilitating care (Sicotte, Lehoux, Van Doesburg, Cardinal, & Leblanc, 2004). This may likely change as telehealth applications mature (Hailey & Jennett, 2004). In Jong's (2004) work on the management of suicide in remote northern communities, the travel costs saved was \$140,088.

academics, and communities would agree that some access to health care is better than none at all. However, the way in which telehealth is conceived, implemented, and assessed also shapes the degree of its success or failure. When we consider the success and failure of telehealth, we cannot simply consider the economic viability, albeit a significant aspect, nor simply user satisfaction, but there is a need to include an evaluation of the social, political, organizational and cultural context of telehealth usage as well (Whetton, 2005). This discussion provides a backdrop for the next section on the review of the literature on telehealth in First Nation communities.

## A Review of the Literature on First Nations' Telehealth

The discussion above establishes a map of telehealth implementation and, to some degree, usage. My focus in this section is on the types of questions, methods and findings covered in the literature. It is, of course, difficult to complete a systematic review of the literature when there so many different telehealth applications and communities (rural, remote, urban, and professional settings) in the literature. To identify the relevant literature, I performed an initial scan of the literature using such keywords as “telemedicine”, “telehealth”, and “underserved” in the Medline database.<sup>57</sup> The search yielded 222 articles, after duplicates were removed. I subsequently replaced the keyword “underserved” with a combination of “rural” and “remote”, but more articles were offered.<sup>58</sup> Hence a different approach to examining the literature was necessary.

I refined the search by using the following words: “Aboriginal”, “First Nation”, “American Indian”, “Indian”, “Native”, “Aborigine”, “Indigenous”, “telehealth”, and “telemedicine”. The search was conducted in the Medline database<sup>59</sup> covering the years

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<sup>57</sup> The database included Global Health (1910- Oct. 2007), Ovid Medline (1950 to November 2007), and Ovid Healthstar (1960- Oct.2007).

<sup>58</sup> Using the words “rural” and or “remote” yielded roughly 1,494 articles. The problem, of course, is that in Canada, the United States and Australia, First Nation communities also belong in the underserved population with non First Nation rural communities. First Nation communities, however, have unique jurisdictional lines of responsibility, cultural heritage, and the experience of colonization that distinguish them from other underserved communities (Savin, et al., 2006).

<sup>59</sup> The database included: Global Health (1910- Oct. 2007), Ovid Medline (1950 to November 2007), Ovid Healthstar (1960- Oct.2007).

2000 to November 2007.<sup>60</sup> The search yielded 42 articles, but journal articles on electronic health records, India, editorials and commentaries were rejected which left 21 articles for review.

Finally, in the last stage, the articles were read and categorized. If any of the articles referenced First Nations' telehealth, they would be included but none were found. In the chart below, I have organized and summarized the articles according to the research question, methodology, and summary of findings. Out of this analysis came a two-fold categorization of the articles: first, a group of articles focused on the structure of telehealth often made comments about cost-effectiveness, technology, and human resources; second, a group articles focused on user perceptions often mentioned user satisfaction. In both categories of research, there were several historical and literature reviews; these articles have been used to summarize the state of each area of research.

**Table 3.3: Summary of Articles on Telehealth in First Nation Communities**

Authors	Research Question / Problem	Methodology / Method	Summary of Findings and limitations
<b>Summative Studies / Literature Review / Historical Account</b>			
Barry <i>et al.</i> (2006)	A historical account of diabetic screening in Western Australia, detailing the challenges and opportunities for tele-ophthalmology	Historical account of tele-ophthalmology using statistical information noting changes in service, number of patients, and dollars spent on eye exams to make the case for tele-ophthalmology.	* Problems using tele-ophthalmology involving technology * Increase number of patients screened * Reliance on culturally trained community health representatives to assist specialists in remote communities * High quality and timely diagnostics
Hudson (2005)	Description of the Alaska Federal Health care Access Network (AFHCN) (implemented to address health care communication needs following the history of communication technologies commencing since the mid 1950s)	Description of AFHCN's communication services to 248 sites with 38 partner organizations. Chronicles the project's focus on: user needs (health care aides and physicians), focus on primary care, scalable telemedicine system (include local wireless telemedicine units, wireless technology, dial-up / broadband connectivity, computer systems at the center)	* <b>Preliminary results</b> in the AFHCN project: 1) saves time (timely consultations and radiology diagnostics); 2) improve health care quality (early diagnostics prevent deterioration of patient health); 3) save money (tele-consultation alleviates the need to travel) p. 465 * <b>Limitations in the project:</b> 1) involve the user (health care staff, organizational needs); 2) shift from deployment to usage and operation; 3) need for cooperation, clinical needs of the technology; 4) develop comprehensive training * <b>Future research:</b> consider technology design for sustainability, cold weather environment
Sherry (2004)	Asks the question: what is the role of telehealth in health care service delivery in remote Aboriginal communities in Alaska given the high rates of chronic disease, rise in population, and lack of financial	Retrospective review of existing telehealth programs	* The need to develop an innovative telehealth / telemedicine network that reflects the needs of Aboriginal communities involving multiple organizations

<sup>60</sup> As well, a search through the Cambridge SocioIndex and Academic Search Premiere was made, but these two databases did not yield any articles outside of the ones found in the Medline database.

	resources to meet health care needs and sustain health care technologies?	
Patricoski (2004)	Asks the question: what is the history of telecommunication in health care services? Is it possible that the Alaska Telemedicine Testbed Project (ATTP), using low bandwidth connectivity, would prove useful to health care providers?	<p><b>Methodology / Method:</b> Review of different telehealth projects in Alaska and each of their contributions</p> <p><b>Findings:</b></p> <ul style="list-style-type: none"> <li>* AFHCAN successfully uses telecommunication for new telemedicine technologies / programs to enhance health care services (radiology, otoscopy for ear disease, and other services) (Since Mar. 2001 to 2004: 19,000 clinical cases, 3000 training cases, 76,000 digital images transmitted, &amp; 6,000 ECG tracings (p. 373)</li> <li>* Demonstrates structured approach, but many health care centers have also developed their own programs to meet health care needs e.g. the Alaska Medical Center's provision of real-time pharmacy service to St. Paul Island (p. 375)</li> <li>* <b>Limitation:</b> Continuous examination of systems issues (reimbursement, data standards, inter-network operability, and efficacy studies) p. 379</li> </ul>
Muttitt <i>et al.</i> (2004)	Can telehealth be used to alleviate the disparity in First Nations' health care services due to distance, travel cost, and resource limitations? What are the challenges to telehealth use?	<p><b>Methodology / Method:</b> Review of telehealth projects in Canada</p> <p><b>Summary of Existing Lit Findings:</b></p> <p>Limitations to telehealth use:</p> <ol style="list-style-type: none"> <li>1. geography (increase cost for technology implementation);</li> <li>2. technical infrastructure (variation in connectivity);</li> <li>3. human resources (requiring highly skilled personnel to coordinate telehealth sessions);</li> <li>4. cross jurisdictional services;</li> <li>5. readiness (availability of resources, technical and organizational ability to adopt or 'buy-in' into telehealth);</li> <li>6. government, community, &amp; health care champions (leadership in telehealth projects to influence government, organizations, and communities to contribute to success);</li> <li>7. needs driven (focus on clinical staff use to ensure buy-in);</li> <li>8. integration (mesh telehealth with health care service delivery – workflow and resources)</li> <li>9. sustainability (many telehealth projects have limited time frames and funding)</li> </ol>
Jennett <i>et al.</i> (2003)	<ul style="list-style-type: none"> <li>* What are the socio-economic benefits of telehealth use?</li> <li>* Most telehealth studies have focused on feasibility, costs and estimated cost savings, and with an allusion to social benefits</li> </ul>	<p><b>Method:</b></p> <ul style="list-style-type: none"> <li>* Comprehensive literature review of the socio-economic studies involving pediatrics, geriatrics, First Nations, home care, mental health, radiology, renal dialysis, rural / remote health services, and rehabilitations</li> </ul> <p><b>Findings:</b></p> <ol style="list-style-type: none"> <li>1) access to health care services; 2) access to mental health services within community may lead to improvement in quality of life; 3) information should be delivered in culturally appropriate way; 4) need for further First Nations research, connectivity, and increase awareness of telehealth</li> </ol> <p><b>Limitation:</b> No socio-economic studies were completed on First Nations community</p>
Sheahan (2002)	* Does a primary health care model utilizing videoconferencing reduce clinician burn out?	<p><b>Methodology / Method:</b></p> <ul style="list-style-type: none"> <li>* Review of health care services for Aboriginal communities in the Far West Health Service</li> <li>* Project planning for telehealth (tele-psychiatry services)</li> </ul> <p><b>Findings from the project plan:</b></p> <ul style="list-style-type: none"> <li>* Changes in the health care services need to involve several levels: 1) develop skills and support for health professionals; 2) enable health professional education and training; 3) enhance connection between remote health organizations and urban centers</li> <li>* Videoconference will play significant role in enabling the changes in the Far West Health Service</li> <li>* Must include community involvement in developing appropriate child and adolescent mental health service (as well as educating the community on these matters)</li> <li>* Augment psychiatry services with other health services (nutrition, drug abuse), education (drama / music, North American Indigenous schools), &amp; crime prevention</li> </ul>

Case Study: Patient Perspectives			
Savin <i>et al.</i> (2006)	Can tele-psychiatry reduce the shortage of child / adolescent psychiatrists in rural and remote Aboriginal communities?	Case studies using interviews / sessions with children and their families.	<ul style="list-style-type: none"> <li>* Aboriginal patient, families and psychiatrists quite receptive to tele-psychiatry service</li> <li>* Diagnostic accuracy is consistent with face-to-face interactions</li> <li>* Lower cost for tele-psychiatry service compared face-to-face psychiatry service</li> <li>* Success of service dependent on culturally sensitive psychiatrist with exceptional record of Aboriginal health care</li> </ul>
Shore & Manson (2004)	How effective is it to treat an Aboriginal patient with post traumatic stress disorder (PTSD) via telehealth?	<p><b>Methodology / Method:</b> Clinical case study involving the use of telehealth technology: diagnosis, treatment, and support group via telehealth consultations</p> <p><b>Findings</b></p> <p><b>1. Patient:</b></p> <ul style="list-style-type: none"> <li>* Patient gained better management of anger and irritability</li> <li>* Developed better coping mechanism through support group</li> <li>* Patient desires to participate in cultural and traditional activities, but hindered by his fear of crowds</li> <li>* Patient became more comfortable with the technology over time (becoming very active and enthusiastic in telehealth support group due to feelings of privacy and confidentiality (p.240)</li> <li>* Telehealth offers a less intrusive means of assessment (p. 241)</li> </ul> <p><b>2. Community:</b></p> <ul style="list-style-type: none"> <li>* Require community participation in supporting emotional and spiritual difficulties arising from war</li> <li>* Aboriginal traditional practices may blend western practices in PTSD</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>* Modern day veterans do not believe in PTSD</li> <li>* Patient is confused about which explanatory model to embrace (traditional, community, or biomedical)</li> </ul>	
Data Analysis			
Murray <i>et al.</i> (2005)	How effective was the fundus camera in assessing retinal screenings for type 2 diabetes in Perth?	<ul style="list-style-type: none"> <li>* Statistical examination of the last 5 years of existing data on ophthalmologist's evaluation of fundus camera images of the eye (p. 521)</li> </ul>	<ul style="list-style-type: none"> <li>* Quality of fundus camera images was highest beginning in 2002 when Polaroid film was used</li> <li>* Of the 1, 589 patients 21% had diabetic retinopathy. 2,587 episodes of retinal screening were conducted</li> <li>* Operators of the fundus camera felt it was user friendly</li> </ul>
Fisher <i>et al.</i> (2003)	* Does the implementation of telemedicine increase the employment duration of health care providers in rural Alaska communities?	<p><b>Methodology / Method:</b></p> <p>Gathering of statistical information on employment start and termination dates:</p> <ul style="list-style-type: none"> <li>* 25 test communities for approximately 1 year</li> <li>* 996 participants (doctors, nurses, community health aides)</li> <li>* Use SAS software to analyze data</li> </ul> <p><b>Findings:</b></p> <ul style="list-style-type: none"> <li>* Community health aides retained jobs longer than physicians and nurses, primarily because they are recruited from Aboriginal communities</li> <li>* Nurses and Doctors on average retained their jobs for under 2 years, but in federal institutions doctors retain their jobs on average of 3 years (p.432)</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>* These results only indicate minimum retention days not necessarily days employed</li> <li>* Unable to test hypothesis of whether telehealth would extend the length of employment in rural communities in Alaska (p.432)</li> <li>* Results from the study suggest that health care organizations may allocate a larger budget to recruit nurses rather than doctors (p.433)</li> </ul>	
Descriptions of Project Development and Evaluations			
Dick <i>et al</i> (2007)	What does a PAR approach to facilitating telehealth skills and knowledge development among health care providers,	<p>Participatory action research focus on:</p> <ol style="list-style-type: none"> <li>1) Increase community member access to health</li> </ol>	<ul style="list-style-type: none"> <li>* Develop process to identify and solve the access to health care resources using multimedia</li> </ul>

	administrators, and planners involve?	care resources; 2) provide technical training to develop health care resources; 3) promote capacity building and sustainability at the local level.	
Shore & Manson (2005)	* How does one develop psychiatry services for Aboriginal veterans with post-traumatic stress disorder in rural Aboriginal communities using telehealth?	Three cases involving different reservations focused on tele-psychiatry for Aboriginal war veterans involving 6 stages of development: 1) identify needs and develop model, 2) infrastructure survey, 3) partnership organization, 4) structure configuration, 5) pilot implementation, 6) solidification – integrate tele-psychiatry into clinical services	<p><b>Project development findings:</b></p> <ul style="list-style-type: none"> <li>* Varying time periods to implement technology in each case</li> <li>* Lack of local resources (pharmacy, onsite medical / psychiatric services, substance abuse treatment, 24hr. emergency psychiatric backup), but this requires multi-organization partnerships</li> <li>* Variation of the diffusion of innovations approach (focus on rural communities, concerns multiple organizations, and offers guide to future clinic creation and process description) (p. 979).</li> </ul> <p><b>Limitations:</b> Fail to address economic factors (possibility of decreasing, but also increasing cost due to treating more patients) p. 980.</p>
Baquet et al. (2005)	How does one establish a robust and sustainable infrastructure to promote cancer awareness in ethnic minority communities?	Collaborative participatory research approach involves multi-stage development (technology / facilities/ partnerships / research): grass roots involvement to determine research relevance (p.199).	Telehealth related results in multi-dimensional infrastructure and research project: <ul style="list-style-type: none"> <li>* Incorporate telehealth use as a part of its institutional network between universities for research and in rural communities for cancer screening, education and health promotion</li> <li>* No results on the efficacy of telehealth in cancer project, most of the article focuses on the entirety of the MSPCN</li> </ul>
Rowlandson & Associates (2005)	<p><b>Problem:</b></p> <ul style="list-style-type: none"> <li>* How to develop a sustainable and holistic model of health care services for First Nation communities in Sioux Look Out, Ontario</li> </ul> <p><b>Method:</b></p> <ul style="list-style-type: none"> <li>* Collaborative model involving multi-level partners using a scalable model (interoperable with Federal and Provincial health services)</li> </ul> <p><b>Findings:</b></p> <ul style="list-style-type: none"> <li>* Enabled community needed telehealth services</li> <li>* Reduced unnecessary travel</li> <li>* From 2002-2005, the number of tele-education / training sessions increased significantly; the number of clinical telehealth sessions increased moderately compared to tele-education services (p. 16)</li> </ul> <p><b>Network Limitations</b></p> <ul style="list-style-type: none"> <li>* Sustainability in network infrastructure, community participation, and health care services integration is challenged by limited resources</li> <li>* Other challenges: 1) change from face-to-face service required change management strategies; 2) community's initial concern of breaching privacy and confidentiality; 3) health care providers' concern over diagnostic accuracy, workload &amp; workflow</li> </ul>		
Nissen & Tett (2003)	* Can tele-pharmacy provide pharmaceutical support to providers and patients in remote communities?	* Analysis of analogue enabled video-phone interactions between dispensing doctors, depot pharmacies, and Aboriginal medical services	<p><b>Findings:</b></p> <ul style="list-style-type: none"> <li>* Satisfaction survey: 1) users felt that the pharmacist had role to play in case conferencing, patient counseling, support for new grad doctors; 2) improved relationship between health care providers and pharmacist; 3) all participants were disappointed and frustrated with technical difficulties</li> </ul> <p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>* Only 10 video-phone interactions were recorded over 6 months</li> <li>* Technical problems prevented patient – pharmacist interaction</li> </ul>
Eikelboom (2003)	* Can tele-otology enhance care for Indigenous children in rural and remote Australia by increasing the speed of diagnosis and removing barriers to access?	<p><b>Method:</b></p> <ul style="list-style-type: none"> <li>* Train Aboriginal community health care aides (using DVD and video)</li> </ul> <p><b>Project Findings:</b></p> <ul style="list-style-type: none"> <li>* 90% of the community health care aides responded well to the training</li> <li>* At the end of the course, participants were comfortable using video-otoscope</li> </ul>	

		(p.221) * The negative comments were associated with the practice standards of video-otoscope (p.221)	
Dever (2000)	* What is the role of low cost communications in the redevelopment of the Indigenous physician workforce among the Freely Associated States of Micronesia (FASM)?	* Documentation of the use of low cost communication in the FASM	<b>Findings:</b> * The equipment size and the high cost of long-distance calls are real challenges to operation * E-mail access and the Internet assist in enabling less expensive communication between the FASM medical community (store-and-forward distance medical consultations) such as x-rays, CAT scans, digital photos, videos of patients, ECGs.
<b>Cost-effectiveness studies</b>			
Whited <i>et al.</i> (2005)	What is the comparative cost-effectiveness using tele-ophthalmology system and clinic-based ophthalmoscopy examinations? How costly and accurate are the exams?	Used agency-specific cost-effectiveness decision model using TreeAge Pro Suite 2004 software to develop decision trees.	<b>Findings:</b> * Tele-ophthalmology is the most effective and least costly for detecting proliferative diabetic retinopathy based on the assumption of maximum labor and equipment use (p.650) * Improved patient access to eye exams * Improve service by shortening length of examination, lower labor costs, averted travel costs (p.649) * Prevention of type 1 diabetes in HIS increase by 1%, 5%-10% in the Department of Defense (p.649)  <b>Limitations:</b> * Economic model does not reflect how equipment is used in actual practice (p.650) * Does not include social costs (travel and loss of productivity)
Jin <i>et al.</i> (2004)	* Does a mobile diabetes clinic improve the standard of care in remote locations and increase the rate of compliance to diabetes guidelines?	* Cost-effectiveness evaluation based on mobile diabetes clinic in Aboriginal communities * Involves mobile clinic implementation, monitor and report of program delivery, assessment of client satisfaction and program cost-effectiveness	<b>Findings:</b> * Of the 339 patients 44% would have required an escort person for medical travel * Client satisfaction based on 386 surveys of the 402 people: 93% agreed it was very convenient and 95% would use the clinic again * More cost-effective to use mobile clinic compared to traveling to access care <b>Limitation:</b> * Further cost reduction calculations need to include: Internet connectivity for transmission of retinal eye scan

## Discussion of the Literature Review

The 21 articles reviewed here fell into several categories: 1) summative studies or literature reviews or historical accounts of telehealth (seven papers); 2) case study research (two papers); 3) data analysis derived from existing telehealth programs or projects (two papers); 4) descriptions of projects or evaluations of projects (five papers); 5) and cost-effectiveness studies (two papers). Many of the papers on telehealth in First Nation communities fell in the first category of summative studies or literature reviews, followed closely by papers completed on telehealth projects and evaluations of projects.

I will discuss some of the similarities and differences amongst all the papers, followed by an examination of the gap in telehealth research.

First, all of the authors in the articles reviewed here indicate that First Nation communities in remote and rural communities have high health care needs, but they lack sufficient health care services to address them. Telehealth in each of these articles is a potential instrument to bridge the gap between deficient resources in remote First Nation communities and the available resources in urban centers. In each of these cases, the telehealth projects are tested as pilots (whether the projects become a critical component of continuous care in the clinics or hospital is unknown). All the authors indicate that telehealth facilitates much needed medical services; some articles also reveal the degree which telehealth facilitates access to medical services such as ophthalmology, pharmacy, electrogram and mental health services.

Secondly, in terms of approach, those under the categories of project development and evaluation and data analysis tend to approach the telehealth discussion or project implementation from a diffusion perspective:<sup>61</sup> they begin by acknowledging the gap between health care services, followed by telehealth technology implementation in one or several communities to determine how remote First Nation patients or communities would respond, they then glean statistical or survey information from patients and health care providers or obtain patients' perspective of their telehealth experience. In most of the studies, researchers began their studies at the same point in time as the telehealth implementation, but they did not return to examine how telehealth was or was not being used. The Alaska telehealth projects offer the longest continuity of discussion, with much of the information presented as a historical background for examining new telehealth technologies (transitioning from telephone, store-and-forward, to higher

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<sup>61</sup> The diffusion perspective is based on Rogers' *Diffusion of Innovations* written in the 1950s. The core idea of early diffusion theory is that external factors from outside a community such as technology, resources, or finances stimulate modernization (Melkote & Steeves, 2001). Although other researchers were developing ideas around the diffusion of innovations, Rogers' work synthesized many of the prevailing ideas and significantly propelled diffusion theory in the United States. However, this perspective failed to account for the many different cultural contexts in which new innovations are used. Rogers' understanding of technology diffusion separated decision makers from an understanding of user needs and the users' social, political, and economic environment. This disconnection effectively made the social world of technology interaction into a question of managerial effectiveness and, in some cases, positioned researchers as market evaluators to assess the psychological connection between technology choice and user acceptance. Many technology projects failed in developing countries and the diffusion perspective declined in the 1980s.

bandwidth applications such as videoconferencing). In other projects that examined telehealth over periods greater than three years, the telehealth technologies being used varied with the programs offered, but very little is known about how health care practices facilitated technology change and conversely how technologies facilitate changes in health care practice (Dever, 2000).

This thesis research will examine telehealth use at the post-implementation stage.<sup>62</sup> It offers a unique opportunity to consider other questions not found at the pre-implementation and implementation stage of technology. Decision makers are often concerned with structural questions (sustainability, return on investment, and technical soundness -- addressed in the third point below). While these structural concerns do not diminish at the post implementation stage, other questions arise and become equally pressing: the users' role in shaping telehealth in health care practice; changes in relationships between users; and changes in health care practice. As well, at the post-implementation stage, researchers can examine whether community collaboration and consultation (Baquet, et al., 2005; Dick, et al., 2007; Rowlandson & Associates, 2005) was addressed and how concerns of confidentiality and sustainability were implemented into health care practice. Consequently, the post-implementation stage of telehealth offers a unique research opportunity to consider structural and user concerns.

Thirdly, most of the articles are concerned with reducing costs, diagnostic accuracy, user friendly technology, and sustainability (Barry, et al., 2006; Hudson, 2005; Rowlandson & Associates, 2005; Muttitt, et al., 2004; Nissen & Tett, 2003). The structural focus and findings in each of these areas of concerns demonstrate strong evidence of proof: diagnostic accuracy (Savin, et al., 2006) or user friendly technology or comfort (Eikelboom, et al., 2003; Jin, et al., 2004; Shore & Manson, 2004); in other areas such as cost-effectiveness, the challenge of ascertaining cost-benefits in every project is much more difficult (Jin, et al., 2004). The articles that discussed jurisdictional concerns were primarily from Alaska and Canada (Muttitt, et al., 2004; Patricoski, 2004).<sup>63</sup> The concerns that telehealth content (clinical or educational wise, not the implementation of

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<sup>62</sup> Two communities in the thesis research have been using telehealth for several years; they are at the post-implementation stage. One community is at the pre-implementation stage of telehealth.

<sup>63</sup> Patricoski (2004) and Muttitt's (2004) article is a review of telehealth in Alaska and Canada rather than data collected from interviews or surveys.

telehealth technology itself) be delivered in a culturally appropriate manner was mentioned several times (Barry, et al., 2006; Jennett, et al., 2003; Savin, et al., 2006; Shore & Manson, 2004).<sup>64</sup> Most of these findings reflect an organizational, policy, and health technology evaluations' perspective which is concerned with efficiency and effectiveness. While it is important to understand the structural constraints of telehealth implementation in order to maximize organizational return on investment, the research does not contribute new insights or provide a First Nation community's perspective of telehealth. The thesis research will provide an alternative perspective from science and technology studies, in particular from telehealth users in First Nation communities, while still being engaged with structural concerns.

Fourthly, some authors clearly indicate that telehealth technology may change health care practices by increasing human resources (Barry, et al., 2006; Fisher, et al., 2003), enhancing relationships (Nissen & Tett, 2003), changing workload and workflow (Rowlandson & Associates, 2005). However, none of the authors mentioned what aspects of professional relationships were enhanced and what the implications are, if any, of involving other trained professionals to assist in health care services – that is – not only does telehealth mediate the health care experience, but other professionals mediate health care delivery that would normally be carried out by a physician. Shore and Manson's (2004) work illustrated how tele-psychiatry may transform face-to-face interaction to a mediated interaction. This opens a vast array of challenging questions: should face-to-face encounters be incorporated? Could health care professionals miss key body language, including eye contact (most cameras do not enable an eye to eye contact between patients and physicians), that would facilitate a better encounter with the patient? How does the lack of physical presence within a community impact the other health care services? What are the First Nation communities' perceptions of virtual care? These questions compel us to consider what constitutes successful telehealth usage in First Nation communities. This thesis research will consider changes in health care

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<sup>64</sup> Shore and Manson (2004) were the only authors who examined the challenges of integrating culturally appropriate content with a western medical model for the patient. They discovered that sometimes the integration of two models of health care may be conflicting and the patient must then select from the two models that best reflect the patient's cultural frame to meet his psychiatric health needs.

relations as telehealth is used in health care practice and the dynamics between users and technology.

Fifthly, most of the authors approached telehealth from a case study perspective. Of the literature reviewed, most of the authors either reviewed or described a particular telehealth case or project. Case studies are often presented as the most suitable methodology for understanding the complexity of telehealth use in health care service delivery. For example, Shore & Manson's (2004) work on the role of telehealth on post-traumatic stress disorder (PTSD) relies on a case study to perform an in-depth examination of the patient's health and his perceptions of telehealth, incorporating the relation between his community context and the personal dimension. Compared to other telehealth user research, Shore and Manson's work offers us more than a satisfactory evaluation of telehealth; it provides the patient's perspective on telehealth, while revealing the social context of PTSD treatment.

Compared to other case studies, few authors provided as rich of an explanation as Shore and Manson's work. Other case studies often reflected Health Canada's (2001) pilot projects, with much of the findings oriented from a structural perspective: the communities' use of telehealth varied depending on technology, health care policies, organizational needs and users concerns. This thesis research uses a case study approach based on the telehealth users' perspective, which may provide an opportunity to re-examine; test the findings of previous studies; and reconsider the role that telehealth plays in health care service delivery. Ethnography will be used to capture the rich contextual description of the telehealth users in health care settings to provide an understanding of their routines.

The literature review reveals that most telehealth research is conducted from the perspective of medicine, organizational studies, and technology evaluations. As such, most of the findings support organizational needs to understand the structural constraints of telehealth implementation, but very little is known about the role telehealth users play in integrating telehealth into health care practice. This gap in the literature can be addressed using the social construction of technology and Giddens' structuration theory to understand the role users play in incorporating telehealth in health care practice.<sup>65</sup>

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<sup>65</sup> The social construction of technology and Giddens' structuration theory is discussed in chapter 3.

This alternative theoretical perspective and focus on telehealth users offers a new understanding of telehealth use in First Nation communities.

## **Concluding Comments and the Need for Further Research**

Over the last seven years of the literature on telehealth in First Nation communities, researchers, policy makers, health care providers and First Nation communities realize telehealth may play a role in providing health care services to remote communities. Much of the telehealth projects in the literature are pilot projects, but some of them have become a part of continuous care, as examined in historical reviews of telehealth in Alaska, making telehealth a potential technology to address the gap in health care needs. However, the literature on telehealth does not reveal how health care practices changes – that is – what health care providers must do in their everyday work in order to integrate telehealth into their routine nor does the literature offer a substantial understanding of how technologies facilitate changes in health care practice. The integrated relationship between health care providers, patients' as users and telehealth technology in health care practice is a fascinating area of research that needs further exploration.

With the exception of Shore and Manson's (2004) case study of one posttraumatic stress disorder patient, we do not know whether tension rises at the juncture at which western health technology is used and First Nations' culture, healing, and communities intersect. Most of the literature on telehealth recognize health disparities in First Nation communities, but do not seem to recognize the cultural difference – if any—between telehealth use in mainstream populations and organizations and First Nations' health care centers and communities. The question is not one of whether First Nation communities are resistant to telehealth technologies, but rather if they accept these technologies, how do communities, health care providers, and patients shape their use in health care practice? What do telehealth technologies do in First Nation communities? The paucity of an agent centered perspective in the literature is largely due to a managerial focus on technology diffusion rather than considering how individuals and First Nation communities use technology. The danger of ignoring the agency of telehealth users in

First Nation communities may be that it perpetuates paternalistic views, academy included, that decision makers and policy makers know best: top-down technology implementation into a community to “solve” health care service delivery gaps. The above questions serve as the fundamental basis for this dissertation: in particular examining the users’ role in shaping telehealth in health care practice.

As well, from the literature review, it is clear that a case study approach would offer an opportunity to consider the findings and examine telehealth use in greater detail and depth. The literature also indicates that a collaborative community approach with First Nation communities would enable them greater ownership in the research process that would facilitate the knowledge translation from the academy to health care work in First Nation communities.

# Chapter 4 - Research Methodology: Into the Field

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## Introduction

This thesis research was designed to explore the role of telehealth in First Nation communities, while aiming to be relevant to the communities. The research project uses case studies employing mix methods to develop the research and gather the data. Case study research was used because it is highly descriptive, relying on thick descriptions and in depth research into a particular phenomenon in its natural context within a specific time and space (Hancock & Algozzine, 2006: p. 15-16). Ethnography as a methodology may fit case study research because it enables the researcher to gather rich qualitative data using interviews, observations, and journals over a period of time (R. E. Stake, 2005). A community based participatory action research (CBPAR) approach was used to collaborate with First Nation communities. According to Tedlock (2000), Participatory Action Research approach may be paired with ethnography when researchers work with disadvantaged or marginalized communities as a means of empowering or giving these communities voice in the research process and making research relevant to the communities they study (Foley & Valenzuela, 2005). However, this thesis does not purport to use critical ethnography since community collaboration was at the front end of the research process.

The objective of this chapter is to provide the reader with an understanding of the definitions and descriptions for each step of this research process. The chapter is divided into three sections: first, a description of the PAR process, highlighting the process for building a collaborative partnership with the First Nation communities; second, a description of the case study design; and third, a description of the ethnography methodology and its methods that I used to gather the data.

## **Developing Collaborative Research using Community Based PAR**

### ***a. A Description of PAR and its Variations***

In the past, research in First Nation communities has predominantly benefited researchers and their institutions with little or no knowledge being returned to the communities (Ryan, 1995; L. T. Smith, 2004). The thesis research seeks to collaborate and involve First Nation communities in the research process.<sup>66</sup> The process of collaboration draws its principle from a community based participatory action research (CBPAR).

There are as many types of PAR approaches to research as there are disciplines; it is not a new approach to research, but it definitely continues to be the most challenging, given the iterative process of engaging communities and completing research. There are two traditions of action research and in both traditions, there are limitations and challenges to realizing social change: action research and participatory action research (Freire, 1970; Lewin, 1945). First, the tradition based on Lewin's (1945) action research methodology, emphasizes a cyclical process of solving a particular problem identified by a group of individuals within an organization. The process involves planning, action, observation, reflection or evaluating the actions, and back to planning again. These steps for action research have been modified over the years to include participatory inquiry for workplace studies and participatory design of technologies (Baskerville & Myers, 2004). Some realize that action research may affirm the existing power structures, while particular processes may change (Hammel, 2000).<sup>67</sup> Action research was initially localized within a particular group or organization rather than extended into the greater community.

The second tradition, follows Paulo Freire's (1970) participatory action research (PAR) is a critical approach for engaging community members for the purpose of emancipation and action in redistributing power in the areas of social, political and economic life by re-examining and redistributing knowledge (Kemis & McTaggart, 2000). The participatory element of the PAR appeals to democratic processes that

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<sup>66</sup> See Appendix A: the research proposal sent to Athabasca Tribal Council.

<sup>67</sup> In workplace research using participatory inquiry, the methodology facilitates changes in the workplace, but these processes may also re-entrench or strengthen the same power dynamics between workers and managers in a more efficient way once the problem has been solved.

include individuals on the margins, which assists policy makers in understanding and seeking solutions to social, economic, health and other challenges; however, it requires political will and the mobilization of economic resources to ensure these solutions are not simply on paper. For many, it is not enough for community members to participate in research or in the community clubs (Putnam, 2000) (since social networks are often horizontal rather than vertical), individuals must also have access to physical, material, and financial resources (Baum, 2005; Bourdieu, 1985; Wakefield & Poland, 2005). This aspect of PAR research is the most challenging and sobering, that while we researchers seek to engage communities for social change, it is a small component of macro changes.

Both traditions emphasize a cyclical process of solving a particular problem identified by a group of individuals and it has been used in variety of fields (workplace studies, participatory design of technologies, health, education and many others (Baskerville & Myers, 2004; Hammel, 2000; Kemis & McTaggart, 2000; Wakefield & Poland, 2005) to address social, economic, health and political inequalities (Blanck, Ritchie, & Schmeling, 2003; Mehra, Bishop, Bazzell, & Smith, 2002). Most PAR researchers engaged in social change are not exclusively action or PAR researchers. Rather, some researchers use a combination of action research and PAR approaches. This is the case in participatory methodologies that combine technology design with emancipatory goals under the rubric of PAR (Balcazar, et al., 2004).<sup>68</sup> Despite differences in terminology usage, most authors agree that the degree or variation of PAR methodology researchers use is based on the degree of power or control that community members have within the research process (Minkler & Wallerstein, 2003: p.5).

The PAR principles can be adopted on a continuum of low to high degrees of PAR principles, but researchers must be cognizant of the power differential in this continuum and not assume PAR means granting participants the same power as the researcher (this is discussed further below). The table below illustrates this continuum.

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<sup>68</sup> Other disciplines have adopted various other terms to signify the interchangeability between action research and PAR. In community health promotion, the respectable term is “community based participatory research” (Hammersley & Atkinson, 1983: p. 4-5).

**Table 4.1: The Continuum of Participant Involvement in PAR Implementation**

Level PAR	Degree of Participant Control	Amount of Collaboration	Degree of Commitment
No PAR	None	Minimal	None
Low	Participant advisers	Advisory board	Minimal
Medium	Responsibility in some meetings and representation in research process	- Advisory role - Reviewers - Consultants - Possible contractual agreement	- Multiple commitments - Some ownership in the research process
High	- Equal partners - Leading partners	- Active researchers - Research leaders	- Full commitment - Full ownership of the research process

Source: (Balcazar et al., 2004: p. 19).

At the highest level where PAR methodologies are adapted, community participants become active partners and researchers who take full ownership and responsibility for the research process, while academic researchers are the catalysts or facilitators. This, of course, is the ideal situation: individuals are empowered to find their own solutions to their problems within the community context (Wallerstein & Duran, 2003: p. 32).

According to the range of PAR approaches outlined by Balcazar et al. (2004), the type of PAR process this thesis research uses would be considered in the medium to low range of participant involvement given the consultative role the First Nation communities play, the agreement established between the First Nation communities and myself, and the report provided to Athabasca Tribal Council. I outline the PAR process undertaken in this research in the next section below.

There are a number of reasons that may prevent researchers from using PAR at the highest range of participant involvement. First, research and action in PAR may change the dynamics of communities, which may conflict with Indigenous peoples' desire to reclaim their voice (Joseph M. Kaufert, 1999; Maher, 1999). Second, PAR practitioners may find that some Indigenous cultural practices conflict with western notions of health and well being (L. T. Smith, 2004; Struthers, 2003; Warrawee'a, 2004). Third, while there is a possibility that community member participation in PAR may rebalance or give power back to the communities that have been repressed by Western cultures, the duration of time needed to accomplish this task may not be viable (Ryan, 1995; Sanchez & Almeida, 1992). These contentious issues compel researchers and communities to thoughtfully negotiate the degree of community involvement and action.

There are also practical obstacles to using participatory research methodology that may intervene in the process of designing a PAR study, such as:

- Gaining entry and developing participatory relations
- Researchers struggling to relinquish control of the research project
- Lengthy commitment to research process.
- Unintended consequences of research (Sanchez & Almeida, 1992)

These practical limitations to PAR methodology hinder the completion of PAR research with community partners.

***b. Implementing Community Collaboration: Setting up the Project***

As mentioned at the beginning of this chapter, there are two elements of the research process: 1) developing a research project that is relevant to First Nation communities; and 2) answering the research question: is there a role for telehealth in First Nation communities? Why or why not? Both of these concerns demand different approaches. A timeline for both of these processes were initialized is provided below.

**Table 4.2 Telehealth Research Time Line (Mar. 2006-Dec. 2007)**

Dates	Tasks	Comments
<b>Phase #1: Theoretical concepts development</b>		
<b>Phase #2: Research team building and ethics approval</b>		
<b>Mar-Nov. 2006</b>	<ul style="list-style-type: none"> <li>• Seek ethics approval from ATC and University of Calgary</li> <li>• Meet with First Nation communities</li> <li>• Health Directors and administrators to discuss the approach in the research project</li> </ul>	<ul style="list-style-type: none"> <li>• Collaborative approach based on PAR</li> </ul>
<b>Phase #3: First Nation Community “A” begins collaborative research process</b>		
<b>Jan. - Mar. 2007:</b> Community “A”	<ul style="list-style-type: none"> <li>• Visit the First Nation community to establish research scope</li> <li>• Train participants on research methodology</li> <li>• Develop telehealth workshop for the community</li> <li>• Observe health care services and telehealth sessions</li> <li>• Conduct interviews with end-users</li> </ul>	<ul style="list-style-type: none"> <li>• Sharon will make bi-weekly progress reports to the Administrator of ATC</li> <li>• At the last meeting of the month, some preliminary findings may arise</li> <li>• Report preliminary findings</li> <li>• Telehealth workshop developed for all First Nation communities in ATC.</li> <li>• Presented with the Alberta SuperNet Alliance on Feb. 12 &amp; 13 2007 at 2 sites</li> </ul>
<b>Phase #4: Community “B” begins collaborative research</b>		
<b>* Mar.-June. 2008</b> (this community implemented clinical telehealth and I made subsequent visits in 2008 to interview all the telehealth users again)	<ul style="list-style-type: none"> <li>• Visit the First Nation community to establish research scope</li> <li>• Train participants on research methodology</li> <li>• Develop telehealth workshop for the community</li> <li>• Apply lessons learned from Community “A”</li> <li>• Conduct interviews with end-users</li> </ul>	<ul style="list-style-type: none"> <li>• Sharon will make bi-weekly progress reports to the Administrator ATC</li> <li>• At the last meeting of the month, some preliminary findings may arise</li> <li>• Report preliminary findings</li> </ul>
<b>Phase #5: Community “C” begins collaborative research</b>		
<b>Mar. – Apr. 2007</b>	<ul style="list-style-type: none"> <li>• Visit the First Nation community to establish research scope</li> <li>• Train participants on research methodology</li> <li>• Develop telehealth workshop for the community</li> <li>• Apply lessons learned from Community “A”</li> <li>• Conduct interviews with end-users</li> </ul>	<ul style="list-style-type: none"> <li>• Sharon will make bi-weekly progress reports to the Administrator to ATC</li> <li>• At the last meeting of the month, some preliminary findings may arise</li> <li>• Report preliminary findings</li> </ul>
<b>Phase #6: Complete Dissertation</b>		
	<ul style="list-style-type: none"> <li>• Maintain on-going communication with First Nation communities</li> <li>• Follow-up on telehealth usage in the communities</li> <li>• Submit report to ATC and participating First Nation communities after the completion of dissertation</li> <li>• With the guidance of ATC and First Nation communities, disseminate findings to appropriate health care policy makers and other sources</li> </ul>	

The initial plan for the research in the communities was divided into four week time spans, which would enable me to gather qualitative information from interviews,

observations, and journals. However, the timeline was not rigid but flexible to accommodate some of the community needs such as developing a telehealth project or adding another community to the research. Once research was underway, the communities' initiative to develop a telehealth project<sup>69</sup> involving their physician and the participation of Fort McKay meant that the research in community "A" was extended into the second week of March. Fort McKay's inclusion arose out of the chief's consent in late February 2007 and the University of Calgary's Biomedical Ethics Board subsequently approved the community's inclusion. This proved to be an excellent opportunity to respond to the needs and direction of the communities' concern with telehealth. This flexible framework was developed in response to Athabasca Tribal Council's desire to ensure that any member community could join the research process during the course of my work as a means of being inclusive. Consequently, the timeframe is not rigid, but fluid.

### **c. Community Consultation and Collaboration**

Before beginning my field research, I used a community based PAR process to inquire about the relevance of telehealth in First Nation communities. I contacted and visited several rural and remote First Nation communities across the province in three treaties (six, seven, and eight) to query whether they would be interested in developing a research partnership with me based upon their years of telehealth usage. Some of the community leaders that I knew through previous projects had moved onto other positions or were either not interested or unfamiliar with my work, making it difficult for the community to ascertain who I was and therefore, difficult to accept my research proposal. At the end of several months of seeking community partners across Alberta, the communities in Treaty 8 – Alberta, in particular Athabasca Tribal Council (ATC) and their CEO responded with an invitation to explore the possibility of developing a research partnership. The community of most interest to my research was Fort Chipewyan, one of the first communities to participate in Health Canada's 1998 pilot projects and a member of ATC. The CEO of ATC asked me to send a two page research proposal to him. I sent a general description and letter to the CEO in November of 2005 and he asked me to

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<sup>69</sup> A great detail of this telehealth project will be discussed in the analysis chapter. The telehealth project involved Fort McKay, Fort Chipewyan, the doctor for the two communities, First Nations Inuit Health Branch – Alberta, and Barrington Passage of Nova Scotia.

contact ATC's Health Director to consider what the communities might like to see arise out of the research project. Subsequently in February 2006, I contacted ATC's Health Director to have a meeting between Dr. Edna Einsiedel (my doctoral adviser) and me for February 17, 2006, eleven months prior to the actual research project commenced to discuss the research project.

From the minutes of this meeting in Edmonton, which the Health Director of ATC contributed to, some very keys issues were brought up.

- ***Privacy and confidentiality:*** ATC's Health Director wanted the assurance that the participants' identities were not disclosed unless they indicated otherwise. I mentioned that before research could commence the University of Calgary would need to approve all research methodologies and methods (participant confidentiality being a part of this process).
- ***Researcher and University Intent:*** In the letter to community leaders, I had stated that the telehealth research was specific to my dissertation; it was exploratory, given the research question and the purpose of the research was to facilitate health care service development through community collaboration using a PAR approach. At the meeting, the Health Director wanted the University of Calgary's intentions in telehealth research be clearly stated in the proposal to ATC. Dr. Einsiedel clarified the role of the university in regards to research and the position of the supervisory committee.
- ***Research benefits to the communities:*** I had stated in my initial two page proposal that the communities would receive a practical report of the findings and a copy of the dissertation. I had also indicated in the letter that I would try to facilitate other benefits to the community such connection to other information sources: The Alberta SuperNet Research Alliance. At the meeting, the Health Director commented that a clearer contribution to the health care programs such as diabetes, programs under the National Native Addictions Prevention Program (NNAPP), mental health, and continuous care could be facilitated.<sup>70</sup>

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<sup>70</sup> I, however, indicated that measurable benefits to these programs could not be ascertained.

- ***Expanding the research topic:*** In my proposal, I had specified that the research would seek to answer whether telehealth could play a role in First Nations' health care. At the meeting, the Health Director indicated that telehealth could be considered in a variety of areas such as economic, education, and community development. As well, he indicated that the dissertation research should include impact studies or yardsticks for assessing health technologies in ATC. I responded such assessments would require additional research exploration.

All of these issues could not be immediately resolved except during the research process, but the Health Director was eager to take a firmer proposal to all the chiefs in ATC for approval by April 2006. At the end of the meeting, I drafted a clearer proposal addressing the ethical issues including: 1) methodological approach and measures to ensure confidentiality and privacy; and 2) the position of the university in the research project. The other issues such as direct benefits to programs could not be forecasted nor could the direction of the research to include other realms such as economic, education and community development be predicted. With the revised proposal, I received ethics approval from three out of the five chiefs<sup>71</sup> in May 2006, inviting me to commence research in their communities as soon as I had received ethics approval from the University of Calgary. Ethics approval from the University of Calgary's Faculty of Communication and Culture and the Conjoint Research Board was delayed for several months due to ethical concerns around patient interviews. Ethics approval was subsequently sought from the Office of Biomedical Ethics at the University of Calgary, which was granted in January 2007.

During this gap of approximately seven months between the chiefs' approval and the University of Calgary's approval, I sought additional input and clarity about the research focus from each of the individual communities that approved of the research: Athabasca Chipewyan First Nation, Chipewyan Prairie First Nation, and Mikisew Cree First Nation. I felt the best way to achieve this was to meet the health representatives

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<sup>71</sup> One of the chiefs did not think the research project was applicable to his community due to its proximity to an urban centre and the fourth community, Fort McKay, sought to be included during the research process in February 2007; the Office of Biomedical Ethics at the University of Calgary granted approval shortly after receiving a letter from Fort McKay's chief.

from each of the communities.<sup>72</sup> From October 16 -17, 2007, Dr. Einsiedel and the Health Director from ATC graciously accompanied me on the visits to the communities to hear the community representatives' concerns before research commenced. Each of the meetings involving Dr. Einsiedel, the Health Director from ATC, the community representative and myself lasted between one and half to three hours; they were not audio taped nor were there any formal questions presented to the community representative. I did, however, take notes on each of the visits to ensure that I captured the essence of the meeting, so that I was aware of the issues and concerns that the community representatives raised.

Below, I have categorized each of the community's<sup>73</sup> concerns prior to the research commencement in January 2007:

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<sup>72</sup> In Fort Chipewyan, the two First Nation communities (Athabasca Chipewyan First Nation and Mikisew Cree First Nation) are governed by a board comprised of their representatives, which facilitated the direction of health care service delivery for both First Nations.

<sup>73</sup> As I mentioned in above section case studies, Fort McKay did not consent to join the research process until mid-February, so no preliminary meeting to ascertain the communities concerns were made. Instead, Fort McKay joined the research process with the intent of developing the telehealth project between the physician and their community.

**Table 4.3: First Nation Communities' Concerns Prior to Research**

Name of the Community	Concerns
Fort Chipewyan (includes 2 First Nation communities)	<ul style="list-style-type: none"> <li>• Telehealth has been a part of health care services since 1998 in Fort Chipewyan. What will your research do for this community?</li> <li>• Who will be involved in this research project (elders, community members)?<sup>74</sup> Will you provide compensation for their involvement?</li> <li>• How can telehealth enhance existing health care services?*</li> </ul>
Chipewyan Prairie First Nation (Janvier) <sup>75</sup>	<ul style="list-style-type: none"> <li>• Will telehealth replace existing health care providers?*</li> <li>• Will health care become impersonal?*</li> <li>• What can this research serve? Who will this research serve?</li> <li>• Will health care services be relocated to Conklin?<sup>76</sup> *</li> </ul>

\* Questions captured in the research process and explored in the analysis. They are discussed more in the research design section.<sup>77</sup>

The health directors in Fort Chipewyan and Chipewyan Prairie First Nation presented several interesting questions to consider during the visit, but not all these were directly related to the research proposal. One community health director clearly had issues with how health care issues were being addressed at the federal level, which required intervention from all the First Nations in ATC as a collective with other First Nations in Alberta. Other concerns were associated with the role the University of Calgary played in the dissemination and ownership of the information gathered. These concerns were subsequently addressed by the Health Director from ATC and Dr. Einsiedel. The preliminary visit to the communities established a common ground and trust to explore the telehealth research proposal. During the research process, the health care directors and the health care providers in the communities continued to ask questions, but these

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<sup>74</sup> These were the types of questions that community leaders in Athabasca Chipewyan Prairie and Mikisew Cree First Nation asked; one of their concerns was that if elders participated in the research process, a financial compensation be given for their time.

<sup>75</sup> Telehealth had not been implemented in the community at the time of the discussion, but when research commenced, telehealth had been implemented.

<sup>76</sup> Some questions such as this issue about the possibility of relocating health care services were aimed at the Health Director from ATC. During the conversation, he often answered the community Health Directors while Dr. Einsiedel and I remained silent. However, I responded to those questions specifically addressed to me.

<sup>77</sup> Some of the preliminary questions the health directors had affirmed both the need to use a collaborative approach to research and the research questions. The questions in Fort Chipewyan were largely focused on participation and compensation, but their last question of how telehealth can enhancing existing services is interesting given the community has had telehealth for the longest time. The questions in Chipewyan Prairie First Nation, a community without telehealth services, reflect the anxiety of obtaining telehealth services. These questions are better answered in the analysis of the data from Fort Chipewyan and Fort McKay.

questions were related to the development of a telehealth project to examine the possibility of retaining medical services with their physician (he was relocating to Nova Scotia). The clinical telehealth project was developed using PAR, first as an exploratory process with Fort Chipewyan and Fort McKay, followed by a formal project proposal to First Nations Inuit Health Branch of Health Canada. The development of this project coincided with my dissertation research on the role of telehealth.

The chart below summarizes the stakeholders' involvement in the initial research process. As the research progressed, the number of stakeholders remained relatively similar, but the individuals from each organization or community's concerns and roles were clarified during the research process.

**Table 4.4: Summary of Stakeholder Involvement**

Stakeholder Name	Initial Type of Involvement	Objective in Telehealth Research
Sharon Mah	<ul style="list-style-type: none"> <li>• Researcher</li> </ul>	<ul style="list-style-type: none"> <li>• Contribute to relevant research in health</li> <li>• Completion of PhD dissertation</li> </ul>
University of Calgary	<ul style="list-style-type: none"> <li>• Institutional support and guidance</li> </ul>	<ul style="list-style-type: none"> <li>• Production of ethical research</li> </ul>
Athabasca Tribal Council	<ul style="list-style-type: none"> <li>• Collaborator</li> </ul>	<ul style="list-style-type: none"> <li>• Development of healthy communities</li> <li>• Development of skills</li> </ul>
First Nation Community	<ul style="list-style-type: none"> <li>Fort Chipewyan, Fort McKay, Janvier</li> <li>• Collaborator</li> </ul>	<ul style="list-style-type: none"> <li>• Development of healthy communities</li> </ul>
FNIHB	<ul style="list-style-type: none"> <li>• Institutional support</li> <li>• Collaborator</li> <li>• Funding</li> <li>• Technology</li> </ul>	<ul style="list-style-type: none"> <li>• Development of healthy communities</li> <li>• Enhance technology reach and utility</li> </ul>
Peripheral Stakeholders	<ul style="list-style-type: none"> <li>Northern Lights Health Region, Government of Alberta</li> <li>• Institutional support</li> </ul>	<ul style="list-style-type: none"> <li>• Health care provision outside the communities</li> </ul>

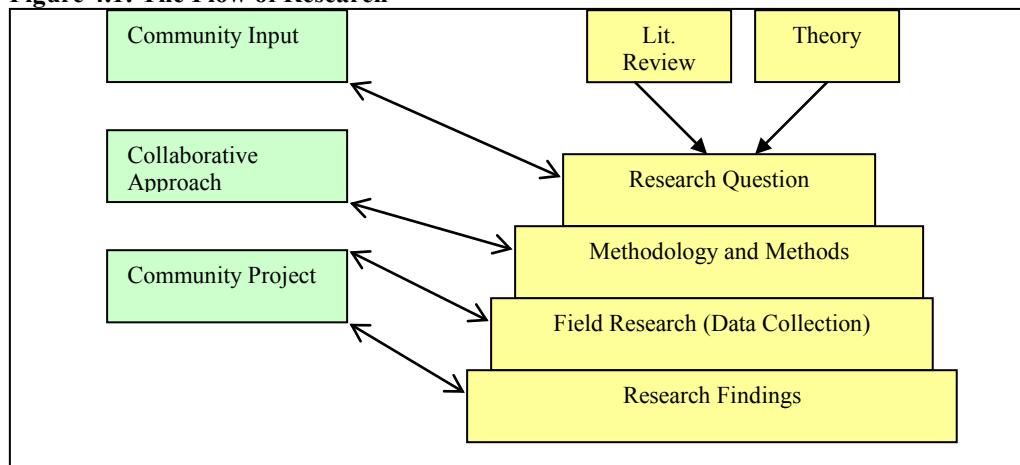
The objectives of the stakeholders in the third column became more refined in the research process. The common goal amongst all stakeholders was to contribute to the development of healthier First Nation communities. However, how this goal is obtained may vary as different actors have limited resources and competing demands. The complexity of using a technology within First Nation communities transcends the simple relation between user and technology.

## Telehealth Research Design

### a. Description of Case Study Research Design

The research design, in the diagram below, illustrates the community consultative process and the research process to answer: what is the role of telehealth in First Nation communities?

**Figure 4.1: The Flow of Research**



In the above diagram, the reader can imagine that information from the left side, representing each First Nation community's input and involvement sought throughout the research process, flows into the right side, representing the thesis research.

The dissertation research is based on case studies design, which can have multiple interpretations and contradictions, not necessarily *always* distinguished along the lines of disciplinary differences of what comprises a case study (George & Bennett, 2005; Gerring, 2007; R. E. Stake, 2005; Yin, 1994). Researchers agree the number of participants does not determine whether something is defined as a case; rather the way in which we approach the information has theoretical and methodological implications to define what a case study is (Hancock & Algozzine, 2006; R. E. Stake, 2005). While there are different approaches to case study design, this research follows an interpretivist approach – that is – the “case study concentrates on experiential knowledge of the case and close attention to the influence of its social, political, and other contexts” (R. E.

Stake, 2005p. 444). The method of data collection is secondary to understanding the case itself.

The interpretivist perspective, of which this dissertation follows, draws upon a rich contextual understanding to not only tell a story, but, through the thick description, often using diverse methods including ethnography and interviews, enable the researcher to distill his or her own conclusions (Flyvbjerg, 2006; George & Bennett, 2005; Ruddin, 2006; R. E. Stake, 2005). Both types of case study research may also contribute to theoretical development by providing insights into a particular phenomenon or by providing small steps to grand generalizations (Gerring, 2007; R. E. Stake, 2005; Yin, 1994). Given that causal approaches are increasingly including qualitative methods to understand a phenomenon; it is possible to conceive that interpretivist case studies can benefit from including quantitative data to tell a significant aspect of the research narrative.

In both causal and interpretivist approaches to case studies, more than one location can be selected; this is called cross-case or multiple case studies to examine a particular phenomenon (Yin, 1994: p. 45-46). In causal approaches, researchers select many cases or empirical units based on variables that may differ in each case for comparison whereas interpretivist approaches may only select a few sites or locations (Ragin, 1992). In causal approaches, the rationale for multiple-case study design would be selected if the following conditions are met: 1) there are independent innovations at different sites; and 2) these innovations reveal similar results (a literal replication) or contrasting results for predictable reasons. If the results of the multiple case studies occur as predicted then it supports the initial suppositions and if they do not then new cases need to be examined (Flyvbjerg, 2006; R. E. Stake, 1995). In the interpretivist approach, cases are *not* selected to represent a general population or phenomena as sampling would lend itself, but the researchers make selections based on what can be gleaned from the case to modify generalizations or theories (Flyvbjerg, 2006; R. E. Stake, 2005: p. 44). Single case studies are completed for entirely different reasons than multiple case studies design. However, multiple case studies approach may be selected even if common characteristics are not known in advance and the case may not be similar or dissimilar with redundancy; the cases are chosen to better understand a phenomenon

(Gerring, 2007; Hancock & Algozzine, 2006; Ragin, 1992; Yin, 1994). Causal and interpretivist approaches select multiple case studies for different reasons, but both approaches may use mix methods to better understand the phenomenon such as a combination of qualitative and quantitative methods.

This dissertation follows an interpretivist case study design used in the social sciences as means of understanding a particular phenomenon bounded by space within a specific timeframe (Aboriginal Canada Portal, 2008). This means that this dissertation research is focused on one particular phenomenon: to understand what the role of telehealth – if any -- in each community health care center in Athabasca Tribal Council from January 2007 to June 2008. The *case* communities are: three First Nation communities in ATC (Fort Chip, Janvier, and Fort McKay). The *space* is in each health care clinic of the three First Nation communities within Athabasca Tribal Council, Alberta. The *timeframe* is: January 2007 to June 2008.<sup>78</sup> The relevance of this timeframe is both serendipitous and timely given: 1) ethics approval was finally granted after many complications in January 2007; 2) Athabasca Tribal Council was in the process of working with Northern Lights Health Authority<sup>79</sup> and First Nations Inuit Health Branch - Alberta on telehealth services for the communities within its jurisdiction; and, as the ATC Health Director advised in earlier meetings; and 3) community members would be traveling less than the summer months to enable a better observation of health care in the communities.

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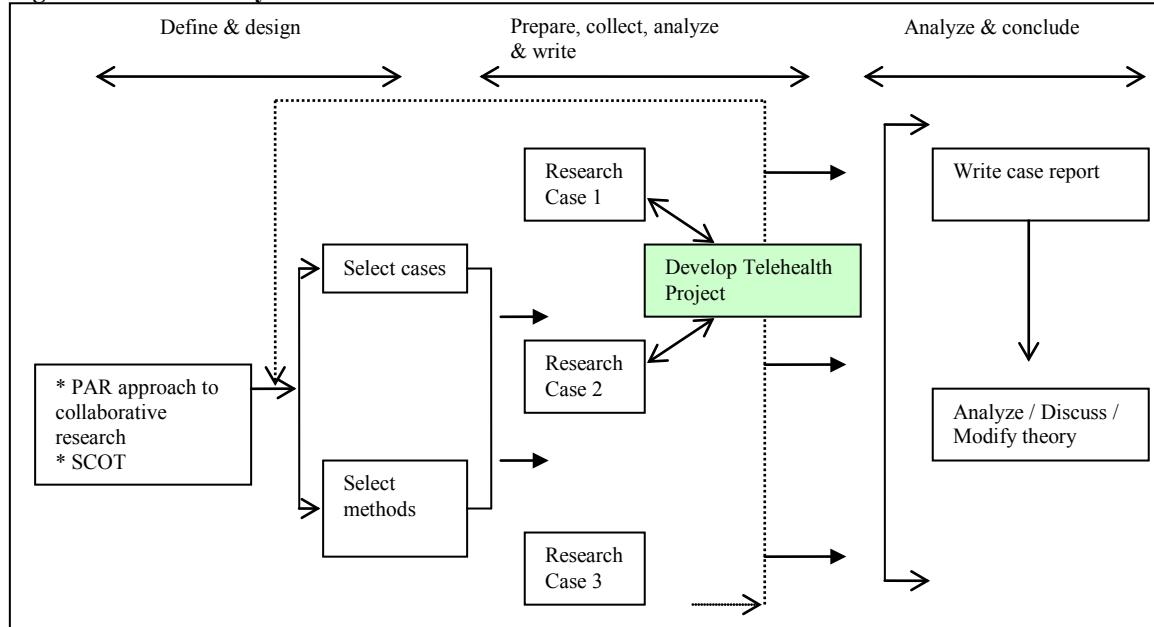
<sup>78</sup> The initial timeframe was January 2007 to April 2007. However, telehealth development in one community continued to progress; these innovations significantly contributed to an understanding of telehealth in the First Nation community. Consequently, the time was changed to accommodate the exploration in telehealth development in the community.

<sup>79</sup> As of Spring 2008, the Stelmach government in Alberta amalgamated the regional health authorities into one governing structure.

### **b. Thesis Research Design: Summary of Case Study Research Flow**

The structure of the case study design summarized below is an iterative approach to research.<sup>80</sup>

#### **Figure 4.2: Case Study Research Flow**



Source: Modified version of Yin's case method (1994: p. 49).

The case method in the above diagram suggests that each case was independent of the other, but the common links between all three cases is the same physician working in all three communities (all are within the same tribal council and regional health authority).

Two of the three communities were interested in exploring the possibility of retaining his services via telehealth after he left Alberta, enabling lessons learned in each case to be applied to the project's development. As well, the collaborative development and investigation of the possibility of enhancing telehealth services to clinical consultation with their doctor in Nova Scotia fed back into the understanding of telehealth in case one and two.

<sup>80</sup> While the diagram appears linear, the flow from start to finish has been proven otherwise. For example, at the start of the research many of the preconceived theoretical ideas were based on SCOT, but as research commenced many questions around use and structure arose and Giddens' ideas on structuration were explored then utilized during the research. Similarly, during the analysis of the research, the process of examining the data required consistent re-examination of the theoretical concepts.

### **c. Research Questions**

Telehealth has been implemented in a considerable number of First Nation communities across Alberta and indeed across Canada, but little research has been conducted to 1) understand whether telehealth is being used. Is there a role for telehealth in First Nation communities? Why or why not? 2) If telehealth is being used, who or what shapes telehealth usage in health care settings? 3) How do these work practices and contexts shape and is shaped by telehealth usage? These research questions provide direction for this thesis research.

### **d. Rationale for Telehealth Research in Consideration**

The literature review revealed several assumptions and they are briefly summarized below:

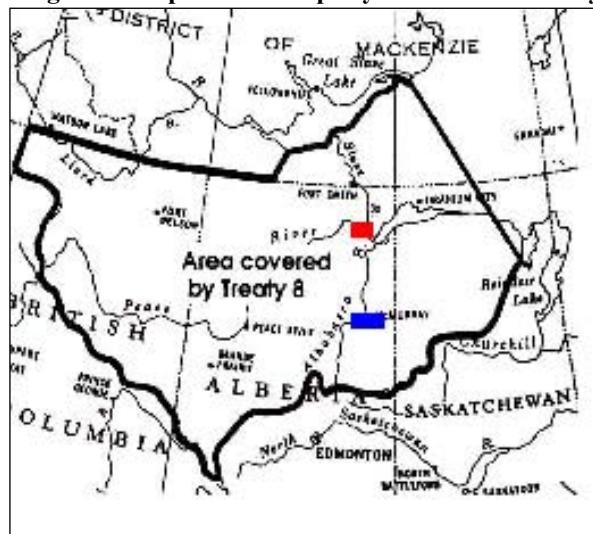
- *Telehealth Implementation:* The diffusion of telehealth is based on the rationale that the vast distance, the lack of health care providers, and the high cost health care provision compel a technological solution to the disparities in health care services in First Nation communities. Health care administrators and policy makers suggest that telehealth will facilitate solutions to the health care gap between urban and rural communities. FNIHB operationalized this belief by dispersing telehealth into First Nation communities.
- *Success of Telehealth:* Is telehealth being effectively used in First Nation communities? Many research projects have, in one form or another, observed or been involved in the implementation of telehealth, but little research has been completed to investigate whether telehealth changes health care practice and whether health care practices shape the use of telehealth practice.

## **Case Studies Selection: Community Selection Criteria**

The community selection process was initially based on Health Canada's (2001) previous pilot projects involving five First Nation communities in Canada. Given that

five communities in Health Canada's (2001) study were the first communities to receive telehealth services in the late 1990s, it was important to understand if telehealth had been appropriated to some degree within one of these communities' health care practices. Fort Chipewyan was one of the communities chosen to receive telehealth services in the late 1990s.

**Images 4.1 Map of Fort Chipewyan and Fort McKay**



**Red square:** the location of Fort Chipewyan  
**Blue rectangle:** Fort McKay is to the west and Chipewyan Prairie First Nation (Janvier) is to the east of the city of Fort McMurray. Treaty 8 spans across northern British Columbia, the Northwest Territories, Alberta, and Saskatchewan. The treaty 8 area is the home to the Dene, Cree, and Chipewyan people.  
Source: Alberta Source<sup>81</sup>

Once the community was selected, the question of whether time and location played a role in facilitating the appropriation of telehealth in First Nation communities became an interesting question as well. In summary, the criteria used to select the communities are:

- Remote, isolated or semi-isolated community;
- State of telehealth use or implementation;
- Community residing within the tribal council;
- Research supported by the First Nation community Chief;
- Research supported by Athabasca Tribal Council;
- Research supported by Health Directors.

Below, the three First Nation communities selected for this dissertation research had the support of the CEO of Athabasca Tribal Council, his associate, the Health care Director of ATC, the Chiefs and the health care directors within each community. This research endeavor involves four First Nations in three communities.

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<sup>81</sup> [http://www.albertasource.ca/treaty8/eng/The\\_Treaty/i\\_treaty\\_8\\_map.html](http://www.albertasource.ca/treaty8/eng/The_Treaty/i_treaty_8_map.html)

**Table 4.5: Summary Table of Community Characteristics**

<b>Community Name</b>	<b>Population</b>	<b>Distance from Urban Centre (Fort McMurray)</b>	<b>Duration and Mode of Travel from Fort McMurray</b>	<b>Date of Telehealth Implementation</b>	<b>Internet Connectivity Status</b>	<b>Nursing Staff</b>
Fort Chipewyan (Mikisew Cree and Athabasca Chipewyan First Nation)	* 728 Aboriginal Peoples	291Km Or 188Km to Fort Smith NWT	~9.5hrs drive via winter road or fly in	1998	Yes (ISDN)	5
Fort McKay	**521	66.5Km	~1.5hrs drive	2004	Yes (Broadband)	2
Chipewyan Prairie (Janvier)	**271	123Km	~2hrs drive	2007	No <sup>82</sup>	1

\* Aboriginal Canada Portal (2008a)<sup>83</sup>

\*\* Statistics Canada (Tedlock, 2000: p. 455)

Fort Chipewyan (Fort Chip) is located 291Kms from the closest urban center (Fort McMurray) requiring 9.5hrs drive over a winter road of ice, frozen river, sand, and muskeg or a fly-in trip of about 45 minutes. Alternatively, many residents of Fort Chip have driven to Fort Smith (population of about 2,800Kms) in the Northwest Territories for weekend grocery shopping or other diversions. Chipewyan Prairie First Nation (Janvier) is 123Kms away from Fort McMurray and while there is a concrete road, it is narrow and slippery in the winter. Fort McKay is the closest to Fort McMurray (about 67Kms), but this road passes many oil and gas plants with large tankers and lumber vehicles congesting a narrow road, making commuting in and out of the community treacherous and time consuming. The oil sands surrounding these three First Nation communities in northern Alberta provide economic opportunities for the communities, but they also challenge the ecosystem, particular for Fort Chipewyan residents dependent on wild game for food in the winter months. Economically, Fort McKay has reaped the benefits of being located in the heart of oil saturated lands; many companies assist in the

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<sup>82</sup> At the time of the research, Janvier had received the telehealth equipment, but Health Canada had not connected the technology.

<sup>83</sup> The 2006 Census did not have population figures for Athabasca Chipewyan First Nation or the community called Fort Chipewyan, but it has population figures for Mikisew Cree First Nation. Indian and Northern Affairs have a census figure of 463 people for Athabasca Chipewyan First Nation, but this only accounts for the Aboriginal peoples, not the many inhabitants in Fort Chipewyan. The figure given to me by the former Health Director of Nunee Health was about 750 people in 2007, so I have chosen to use the Aboriginal Canada Portal figure.

establishment and support of community efforts such as the Elders' Lodge. Janvier is the least economically viable of the communities. At the time of research, telehealth connectivity had not been implemented in the health center, but the technology had been delivered. The community was chosen to consider what health care providers' expectations were of telehealth and to understand the obstacles or opportunities were for telehealth usage prior to implementation. The communities' participation in the research process has been described above in the participatory action research section.

## **Undertaking the Research: Data Collection**

### ***a. Description of Ethnography***

This research is based on a combination of ethnography and PAR to collect data and engage First Nation communities in research. Ethnography involves participant observation: the researcher (ethnographer) listens, observes, and in some ways participates in the everyday activities of the people s/he is studying. Ethnographers are outsiders “wearing insiders’ clothes” gradually learning the people’s language and behaviors (Hammersley & Atkinson, 1983: p. 6), providing a unique perspective of everyday life often called naturalism premised on the appreciation or respect of the natural world (Hemment, 2007).<sup>84</sup> The emphasis on understanding activities within the context of the event or situation operates as an explanation for what is occurring (Hammersley, 1995: p. 23). However, some ethnographers are not satisfied with providing a description of what they observed; rather they want to make their research relevant to the communities / groups by engaging in their particular concerns or struggles, which may seem to fit with a PAR approach to research (Foley & Valenzuela, 2005: p. 218). This form of ethnography is called critical ethnography.

There are several strands of critical ethnography; all of these strands are based on a much more reflexive understanding of power differential between the researcher, the community, and the social and political context of the study (Averill, 2006). According to Foley and Valenzuela, some are more willing to reflect on the researchers' co-

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<sup>84</sup> Naturalism is in contrasted to positivism, a reliance on quantitative methods of obtaining data through surveys, experiments or tests.

constructive capacity within their ethnographic research while others are less so. The combination of participatory action research with ethnography means the researcher becomes a broker for the disenfranchised (p.220). The degree of collaboration is dependent on the degree of community based participatory action research (Wallerstein & Duran, 2003), but the common thread is an interactive engagement between the researchers and her collaborators. Action ethnography is based on its precursor, critical ethnography, which attempts to situate the ethnographer within the research process while completing relevant community research that benefits the communities.

This research uses ethnographic observations of day to day activities to understand telehealth usage. It does not purport to undertake critical ethnography since the degree of PAR was limited to the initial consultation and collaboration process with all three communities. However, the research did facilitate the development of the physician-patient telehealth consultation project in Fort Chip and Fort McKay.

### ***b. Method of Data Collection and Analysis***

After establishing a collaborative partnership with the First Nation communities, I used a series of methods to gather the data. Illustrated in the diagram below is the process of data collection. The semi-structured interview questions were developed prior to beginning the research process, but some questions were modified or added based on observations and conversations made in the community health centers. The process of completing the research and my reflections was recorded in journal entries. Based on the PAR process of research, the community could take action to further develop telehealth with Health Canada's First Nations Inuit Health Branch.

#### ***b.1. Interview Telehealth Users***

A total of 63 interviews were conducted with health care providers, administrators, staff, and patients. All participants were informed of the research objectives, their ethical rights and asked to read the consent form before the interview

commenced.<sup>85</sup> The interviews were based on a semi-structured question model, lasting between half of an hour to one and a half hours.<sup>86</sup> Semi-structured questions were used to enable the researcher to follow the various tangents participants may raise to explore particular problem (Ansary, Perkins, & Nelson, 2004). During the course of the interview, if clarifications were required in the respondents' answers, subsequent questions were asked, but I also gauged the participants comfort with answering particular questions. The shortest interviews were completed by those individuals who were either very short in their answers and they fail to elaborate with follow up clarification questions. However, some participants used the open ended questions to elaborate and told stories to illustrate their answers. At the end of each interview, I wrote in my research journal, noting the particular interactions. All these interviews were transcribed for analysis. A chart below documents the number of participants involved in the interview process.

**Table 4.6: Summary of Participants in Research Project by Community**

Type of telehealth users	Fort Chip	Fort McKay		Janvier	Total Interviews
		Round1	Round2		
Health care providers	10	4	4	4	22
Administrators	7	3	*overlap <sup>87</sup>	5	15
Patients	0	0	26	0	26
<b>Total Interviews</b>	<b>18</b>	<b>7</b>	<b>30</b>	<b>9</b>	<b>63</b>

Each of the three communities consented to the first round of interviews and research observations, but based on PAR, the communities decided whether to develop or enhance telehealth within the community. If the community proceeded to develop telehealth, I assisted in facilitating the process and contact with Health Canada. As well, I returned for a second round of interviews and observations to note the changes in telehealth practice. Fort McKay was the only community that decided to proceed forward with clinical telehealth and the chart above indicates that two sets of interviews were completed.

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<sup>85</sup> To ensure that the language of the document did not pose a barrier to comprehension, I also went through the consent form with each participant.

<sup>86</sup> See Appendix B for a list of the research questions.

<sup>87</sup> In round two of the research process in Fort McKay, administrators were not interviewed since they did not use telehealth.

### ***b.2. Participant Observations***

The health care administrators provided a desk for me to work in each of the health care clinics, which enabled me to observe the life of the clinic from open to close. Only one community, Fort Chipewyan, had formal staff meetings and I made notes of some of these encounters. As well, I had the opportunity to observe some aspect of the community's life. The observations and conversations that I had with individuals throughout the day provided opportunities for me to understand the nuances of clinical practice and they offered insights for future interview questions.

### ***b.3. Journal***

I made notes of my observations and conversations throughout the day, which provided rich details and reflection for case descriptions. These notes often formed the basis for my nightly journal entries as a means of reflecting on the research process and considering what participants may or may not have said during the interviews. They provided points for analysis, an understanding of the community, and personal insights into working with First Nation communities. I often returned to these notes when reviewing the data in the cases.

## ***c. Analysis of the Data: An Deductive and Inductive Approach***

Given the wealth of data collected during the research process, a theme approach to data analysis will be used to examine the data. Many researchers using interviews as a form of data gathering use theme analysis to examine recurrent themes (Krueger, 1998; Onishi & Gjerde, 2002; Schostak, 2006). Some have used an inductive approach, looking at the data and deriving themes from the data, or grounded theory (Corbin & Strauss, 2008). Others have examined interviews from a deductive approach, using existing theories and the research questions to guide the development of themes (Schostak, 2006). However, some researchers use both deductive and inductive approaches to examine their interview data, a combination of theory based theme development and inductive discovery of themes in interview data (Fereday & Muir-

Cochrane, 2006). This analysis uses a combination of both deductive and inductive analysis of the interview data.

From a deductive perspective, the research was oriented around two theoretical frames: social construction of technology (SCOT) and Giddens' structuration theory. In the SCOT approach, questions were based on an understanding of the social context of the technology use of the telehealth user (patient, administrator and health care provider); in particular, the questions explored four areas of the users' context: the location of the community, work responsibilities, perception of health and the state of the community's health, opportunities for continued health education and perceptions of technology use. All communities undertook the questions based on a SCOT perspective, but only one community, Fort McKay completed the questions based on Giddens' structuration theory which focused on telehealth use and the different contexts of telehealth use (the patient's role required a few different questions than those developed for health care providers). However, my observations of the routines and interactions in the all three communities could be understood from Giddens' theoretical lens.

In the charts below, I summarize some of the themes and provide a few sample questions to illustrate the theoretical perspective I was trying to address.

**Table 4.7: Questions Based on SCOT and Giddens' Theoretical Frame**

Theoretical Connection	Theme	Sample Questions
Feminist Approach to SCOT: Who is the user?	Location / Geography	<ul style="list-style-type: none"> <li>• How long have you lived in this community?</li> <li>• Why do you like living in this community?</li> </ul>
Organizational context	Work responsibilities (Based on Giddens' notion of rules and practice)	<ul style="list-style-type: none"> <li>• Tell me about your work routine in a normal day.</li> <li>• What are your work responsibilities?</li> </ul>
Relevant and irrelevant groups of technology users? Network of choices?	Perception of community health and health context	<ul style="list-style-type: none"> <li>• What does being healthy mean to you?</li> <li>• Who do you talk to about your health concerns?</li> <li>• What are the health care needs of the community?</li> <li>• Integration of indigenous healing with Western medicine?</li> </ul>
Opportunities for technology use: organizational context	Opportunities for continuing education	<ul style="list-style-type: none"> <li>• Do you have opportunities to continue your health education? If so, please describe what these are. If no, please explain why.</li> </ul>
Users' choices and actions	Perception of Technology use	<ul style="list-style-type: none"> <li>• What types of communication technology do you have at home?</li> <li>• How comfortable do you feel using these technologies?</li> <li>• Have you used telehealth?</li> <li>• Describe your first telehealth experience?</li> <li>• If you could tell your family and friends about telehealth, what would you say?</li> </ul>

**Table 4.8: Questions Based on Giddens' Theory**

Theme	Sample Questions
Telehealth use in health care service (Rules)	
a. Work routines / practices using telehealth	<ul style="list-style-type: none"> <li>• What do you (patient) notice the doctor doing differently?</li> <li>• What aspects of telehealth are beneficial or not beneficial in work?</li> </ul>
b. Telehealth consultations	<ul style="list-style-type: none"> <li>• What aspects of telehealth consultations is the same or different from face-to-face consultations?</li> <li>• Have you noticed patient care changing?</li> </ul>
c. Maintaining relationships	<ul style="list-style-type: none"> <li>• Do you feel your relationship with your doctor is the same or different? Please explain.</li> </ul>

An example of a deductive process of coding may start off with examining the question: what aspects of telehealth are beneficial or not beneficial in your work? The primary code for the participants' answer involves work routines or practices using telehealth.

The participant may or may not offer such details as their perception of telehealth in their work, what they found difficult about the technology or presenter in their work, or they may suggest changes to telehealth. Under the category, of perception, other subthemes may rise. These codes are grouped and tabulated and presented as the findings in chapter 6 of the case descriptions. If there is a common response, such as the participants' recommendations for improving health care, these answers can be grouped and ranked. The participants' rich answers provide fertile ground for inductive coding, where new codes are added, revised, or changed based on the participants' answers.

The interviews were coded using the open source software called Weft QDA (qualitative data analysis), used for coding qualitative data such as interview transcripts, field notes, and written text.<sup>88</sup> The process of coding that I used was:

- 1) Interviews were read in their entirety before coding.
- 2) A codebook (a set of common codes) for round 1 of the research was developed after coding several interviews or until no new codes arose from examining the data. This codebook was applied to all the interviews in round 1 of the interview process.<sup>89</sup> New codes were added to the codebook when considering the interviews in round 2 for Fort McKay.<sup>90</sup> This could be considered codebook 2. Weft QDA enabled me to code for central, subthemes, and sub-sub themes (i.e. creating a tree of themes off the central theme), tagging phrases, sentences, and sections of text under particular headings across interviews. Tagging these texts enabled me to compare, contrast, or reject coded text that may not be similar as the others. As well, reading the text under a particular category and comparing it to journal entries provided a greater understanding of the nuances of the interview.
- 3) All the themes with their attached texts were then analyzed: first, for consistency between texts and second, for the meaning of the text. The themes or findings from data were then organized and summarized in each of the cases (discussed in chapter 6) and analyzed in chapter 7.

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<sup>88</sup> For more information on WEFT QDA see <http://www.pressure.to/qda/>

<sup>89</sup> The semi-structured interview questions in appendix C were used in all three communities.

<sup>90</sup> See Appendix D for the questions asked in round 2 of the interviews in Fort McKay.

I coded all text relevant to telehealth research. This means I did not code texts where participants talked about other participants and the community from a very personal and private manner that did not have relevance on health care or telehealth research.

## **Concluding Comments**

This is a multiple case study design following an interpretivist approach to research, which relies on a community based participatory action research process to involve health care providers and other stakeholders. The thesis research uses ethnographic methods to capture an understanding of telehealth usage in First Nation communities. All three components enable the research process to fulfill the two objectives of this research: 1) making research relevant to the communities it engages; and 2) enabling the researcher to answer the question: what is the role of telehealth in First Nations' health care services? The next chapter will provide the reader an understanding of the policy context in which telehealth operates in First Nation communities, followed by chapter 6 which employs observations and interview data to provide a detailed description of the context in which telehealth is used in each of the three cases.

# Chapter 5 - Policy Perspective: Health Care Services in First Nation Communities

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## Introduction

Often in determinist perspectives of technology, technology is black boxed and seen as the instigator of change, but Hughes (1983) and Cowan's (1987) work revealed that technologies are embedded in larger systems that shape their use and function. The discussion of the potential or existing role that telehealth may or may not play in First Nation communities would not be complete without an understanding of the way First Nations' health care services are structured and provided in Canada. This chapter provides an understanding of the health care system, commencing with an outline of the historical development of health inequalities and its persistence in Canada's struggling health care system. The growing First Nations population and the obvious statistical gap between health care needs and access to health care services in these communities are provided as compelling evidence to consider alternative methods for addressing the health care service gap in rural and remote First Nation communities.<sup>91</sup>

Academic research (Muttitt, et al., 2004; L. Nissen & Tett, 2003; Patricoski, 2004), countless government reports from Health Canada and its affiliated branch, First Nations Inuit Health Branch (FNIHB) (2002b, 2003a), and the Assembly of First Nations (AFN) (2005c) have all advanced the same reasons for deploying telehealth services in First Nation communities to address the gap in health care services and resources. However, this research needs to consider: 1) how all these stakeholders' roles may mold the jurisdictional boundaries of a health care service that defies time and space; and 2) how the social context of health care services (their limitations and strengths) may play a significant role in shaping a new technology's use, all the while being cognizant that the

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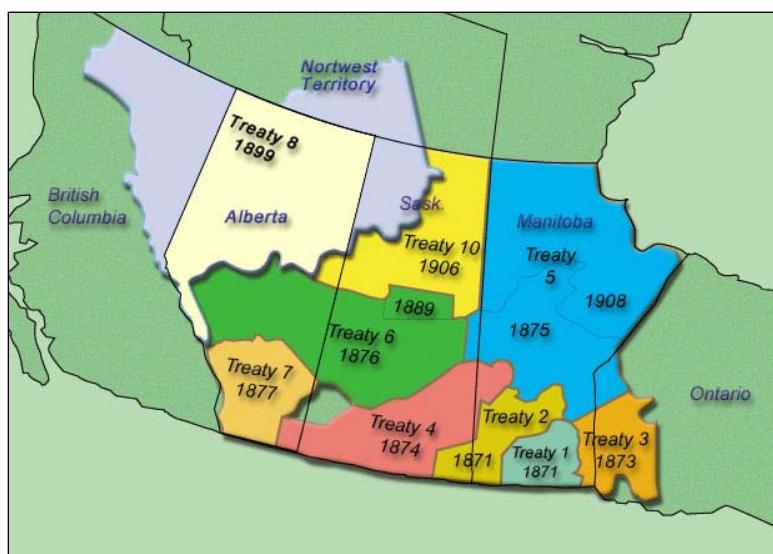
<sup>91</sup> In the literature review, the technology system was briefly discussed to contextualize an analysis of telehealth in Canada.

evidence, the gap, and realities of First Nations' health inequalities may still persist in the face of new technology. The jurisdictional obligations of First Nation health care services continues to be debated and into this fray, the issue of telehealth services in First Nation communities muddies an already cloudy subject when it attempts to address the gap in rural and remote First Nation peoples' health care needs.

The purpose of this chapter is to provide the reader an understanding of the context in which telehealth services exists, namely a flavor of the complexity of health and health care services in First Nation communities. It also serves as a background chapter for the next chapter on the case studies of telehealth in First Nation communities.<sup>92</sup> The chapter is divided into three sections: 1) the historical development of health care services in First Nation communities; 2) the structure of health care programs; 3) the gap between First Nations' health needs and health care services; and the possible role telehealth may play in health care service provision.

## A Brief History of the Contributing Factors to First Nations Health in Canada

The history of First Nations' health care has contributed to the current state of health in First Nations communities today: the burden of overcoming colonization and the struggles for access to health care services have left a vivid scar on the communities (Wesley-Esquimaux & Smolewski, 2004).



**Images 5.1 Map of the First Nations' Treaties in Canada**

The first set of treaties (one to five) was signed between 1871 and 1875 and the last set of treaties (six to eleven) was signed between 1899 and 1921. The treaties **not** shown on this map: Treaty 9 is in northern Ontario and Treaty 11 is in the Northwest Territories.

Most of the treaties are in western Canada and they contained most or some of the following elements: peace, a governing structure, reserves or the surrender of lands, the type of material goods or cash payments, and promises of education for First Nation peoples.

**Source:** Treaty 8 - Alberta<sup>93</sup>

<sup>92</sup> The case studies in the next chapter contain individual descriptions of each community.

<sup>93</sup> <http://www.at8ha.ca/> (Downloaded Jan. 2004).

With the signing of the treaties<sup>94</sup> mapped in the above, and the subsequent forms of colonization,<sup>95</sup> the Government of Canada participated in the creation of residential schools that traumatized generations of First Nation peoples. Until the 1960s, the Government of Canada, along with Christian churches (Protestant and Roman Catholic), carried out attempts to assimilate First Nation peoples through residential schools, a means of cultural genocide, which severed the cultural, spiritual, and social bonds between First Nation youths from their families and from the knowledge of their elders (Bastien, 2004: p. 26-27). The loss of close kinship bonds eroded First Nation peoples' sense of identity. In Canada, there are about fifty First Nations' languages, but in the 1990s only two languages (Cree and Ojibwa) had a significant number of speakers (over 500 speakers) (Ponting, 1997).<sup>96</sup> However, the 2006 Census on First Nation Peoples reveal this trend is slowly reversing; the number of First Nations' language speakers has grown to over 200,000 people with relative growth in such languages as Cree, Ojibwa, Blackfoot, Dene, and Mi'kmaq, all with over several thousand speakers (Statistics Canada, 2008f).

Aside from the institutions of colonization,<sup>97</sup> First Nation communities also struggled to access health care services. Some First Nations people contest that the Government of Canada *acquired* the responsibility for First Nations' health care services with the signing of Treaty 6, created in 1876 that covers a region in central Alberta and Saskatchewan, promising a medicine chest and other necessities. However, the government did not specify health care services in other treaties (Dickason, 1992; Hildebrant, et al., 1996; Waldram, Herring, & Young, 2004).<sup>98</sup> Treaty 6 covers a region between, what is now, Edmonton and Calgary, extending to the east borders of

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<sup>94</sup> With the revival of Aboriginal voices in the 1990s, there have been many challenges to the meaning of treaty. According to Goodstriker (Crowfoot, 1997), there is no word for treaty that invokes the meaning of the surrender of land. The Blackfoot's signatures in Treaty 7 referred to *istsist aohkotspi or iitsinnaihtsiiyo'pi* (the time we made a sacred alliance) (p. 4). Sacred alliances of peace are between equal nations, binding for all time or "as long as the sun would shine and the rivers would flow" (p. 15). These two different interpretations of the meaning of treaties have had significant ramifications on governance.

<sup>95</sup> Colonization was not without resistance, Aboriginal peoples struggled to shape policies according to their needs (B. Minore & Boone, 2002).

<sup>96</sup> As of fall 2005, the Government of Canada promised to award \$2 billion to Aboriginal peoples to compensate for the residential school experience.

<sup>97</sup> Residential schools, the reserve system and the electoral system changed the way First Nations educated their children, developed their communities, and sustained and governed themselves.

<sup>98</sup> What a medicine chest entails, however, is open to interpretation: is it access to full health care services or is it some access to drugs and medication?

Saskatchewan. In the early 1900s starvation and the onslaught of infectious diseases (influenza and tuberculosis) decimated the First Nations population; the Federal Government was slow to respond to the health needs of First Nation communities (Fumoleau, 2004).

When health authorities did respond, many communities experienced the imposition of health care protocols that seemed to suggest invasive disregard for the overall health of the communities rather than compassionate intervention. During outbreaks of tuberculosis, the government removed individuals from their communities and placed them in hospitals; many did not return home (O'Neil & Kaufert, 1996). A Western medical model of healing had been transported into a culture that did not comprehend its scientific values nor did health authorities recognize First Nation peoples' perceptions of health and illness (Reid, 1982). These twin blind spots made seeking treatment a confusing ordeal for First Nation peoples<sup>99</sup> -- and – today, some individuals and families continue to be suspicious and cautious of health authorities.

In 1962, the federal government created the Medical Services Branch<sup>100</sup> and incorporated the Indian Health and Northern Health Services (Health Canada, 1999). In 1974, the Minister of National Health and Welfare tabled the *Policy of the Federal Government concerning Indian Health Services* to provide health care services to many First Nation communities, though it argued that it did not have any treaty responsibility to do so since health care remained the jurisdictional responsibility of the provincial governments (Health Canada, 2007d). The Policy effectively enabled communities to have access to federal funds for health care services in the provinces they reside in, but it created a jurisdictional separation between provincial health care services and federally controlled funds and programs (B. Minore & Katt, 2007). The tension between each First Nation community's health care needs, provincial health care services and federal funds and programs continue to play a significant role in how First Nation communities obtain and receive health care services.

The structure of First Nation health care services has evolved over the years with increasing control of health care governance being transferred to First Nation

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<sup>99</sup> Today, health care practitioners are aware of the cultural barriers to effective health care in Aboriginal communities, calling for interdisciplinary teams (Health Canada, 2007f).

<sup>100</sup> The name was changed to First Nations Inuit Health Branch in 2000.

communities.<sup>101</sup> A number of significant policies were created to enable First Nations' control of health care services. In 1989 the Cabinet in the Canadian government approved the transfer of federal resources for First Nations' health care programs to First Nation communities. A few years later, the Royal Commission on Aboriginal Peoples (1993) called for changes to Aboriginal health and in 1996 an action plan was created (Indian and Northern Affairs Canada, 1996) called *Gathering Strength*, which moved control of health care services towards a community based and community controlled model. *Gathering Strength* (1996) advocated that the future of First Nation peoples lay in developing "a new relationship based on mutual recognition, mutual respect, sharing, and mutual responsibility" (p. 6); First Nation peoples would become partners with the Canadian government in providing health solutions. The action plan advocated that existing health services be reformed and transformed from a centralized government model:

- Reorganization of health and social services under Aboriginal control;
- A human resources strategy to prepare First Nation peoples to design and staff services;
- Reform of mainstream institutions to make them more responsive to First Nation peoples; and
- Urgent action to achieve minimum standards of safe housing, water supply and waste disposal.
- Political empowerment and economic development must complement this health strategy (p. 8).

While the above objectives remain tangible possibilities, in the last decade since *Gathering Strength*, the change in government, the escalation of health care needs and cost have challenged the federal government's willingness to fund them (Assembly of First Nations, 2006).<sup>102</sup>

The history of First Nations' health is embedded in this historical context of colonization, commencing with the signing of the treaties and the struggle to access health care services. The deprivation of self worth and identity led to the deterioration of many First Nation people's lives. The beginning of change, a turn towards rectifying the horrors of the past, lies in First Nation people's empowerment to regain control over each domain of their lives, one policy at a time. The Royal Commission on Aboriginals peoples was one of the significant markers recognizing the need for change and one of its

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<sup>101</sup> The transfer of control would enable communities to decide how to spend their resources and prioritize their health concerns.

<sup>102</sup> Some communities have received some assistance, but this has usually arisen out of immediate emergencies such as the water contamination in Kashechewan, a First Nation in Northern Ontario.

outcomes was increase legitimization for self governance in the form of jurisdictional changes to the delivery of health care services that enabled First Nation peoples to govern their own health.<sup>103</sup>

## **Health Care Services Structure in First Nation Communities**

In the past, a western model of health care services delivery in First Nation communities was controlled by the Federal Government, in particular the Medical Services Branch, but in 1989 the Federal Government initiated the Indian Health Transfer Policy<sup>104</sup>. The Transfer Policy often has two conflicting definitions of what “transfer” entails: 1) as administrative structure that provides a mode of reallocating financial responsibilities for a select number of programs from the federal government to First Nations and Inuit communities in Labrador, embraced by First Nations Inuit Health Branch of Health Canada; and 2) as a structure to foster self governance, embraced by First Nations and Inuit communities (Lavoie, et al., 2006: p. 2).<sup>105</sup> In both cases, the word “transfer” involved the shift of responsibilities for managing health care resources or programs to First Nations and Inuit communities. To qualify for transfer status, communities must demonstrate 1) the Band Council’s resolution to enter a transfer agreement; and 2) the band must have a successful record of financial and program management (Health Canada, 2005bp. 6).

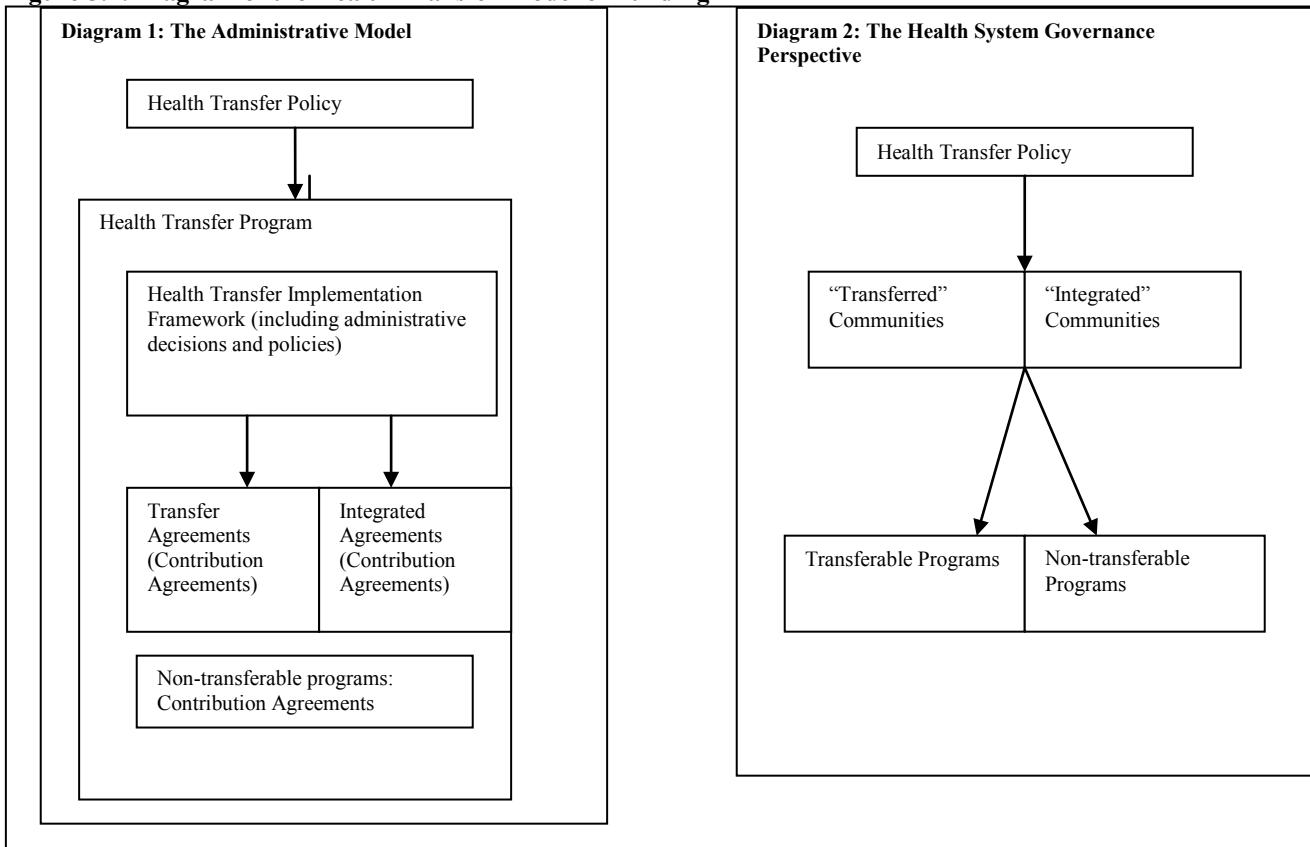
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<sup>103</sup> These changes are reflected in the transfer agreements between First Nation communities and Health Canada which is discussed below.

<sup>104</sup> The Health Transfer Policy is above and beyond the agreement between the provinces and the federal government to provide health care services; this means that any Aboriginal person has the right to access health care services in any community or province, but where specific reserves are established, the federal government, and at times the provincial government, has responsibility for ensuring health care services.

<sup>105</sup> Lavoie et al. (2006) work followed two of Gibbons and Associates (1995; 1992) evaluations on the transfer policy.

**Figure 5.1: Diagram of the Health Transfer Model of Funding**



Source: Adapted from (Lavoie, et al., 2006)

In diagram 5.1, the **administrative model** is a perspective based on the types of administrative decisions, policies, and agreements that enable FNIHB to provide resources to transfer responsibilities to First Nations and Inuit communities.

Administration is then the policy mechanism enabling the transfer of responsibilities for health care delivery. In diagram 2, the **Health System Governance Perspective**, often embraced by First Nations and Inuit communities, is the lens that communities view themselves through, as either transferred or integrated communities (Lavoie, et al., 2006).<sup>106</sup> Those communities who have *transfer agreements* have entered contribution agreements with FNIHB on the standards and condition in which programs must be delivered, but communities can shift funds according to their health care needs and priorities. *Integrated agreements* (formerly called Integrated Community-Based Health Services Approach) are mechanisms that enable communities to establish their own

<sup>106</sup> The reader may be concerned that a number of references are government documents and those by Lavoie et al (2006), but aside from Lavoie et al (2006) no other researchers have completed any current peer-reviewed close examination of the transfer policy.

health care structure with some flexibility on resource allocation, but communities share the responsibility of health care delivery with FNIHB. In some cases, *multi-department agreements* are established between FNIHB and the department of Indian and Northern Affairs Canada (INAC) to provide services (Health Canada, 2007b).

Table 5.1: Signed Transfer Agreements as of June 2007				
Region	Transfer Agreements to date	# of First Nations and Inuit Communities	Total # of First Nations and Inuit Communities	% of First Nations & Inuit Communities
Atlantic	15	14	40	35%
Quebec <sup>107</sup>	24	22	28	79%
Ontario	24	38	124	31%
Saskatchewan	20	56	85	67%
Alberta	5	4	58	7%
<b>Total</b>	<b>158</b>	<b>279</b>	<b>609</b>	

Chart adapted from Health Canada (2007f).

As of June 2007, the total number of *transfer agreements* that have been signed is 158 with 279 communities out of 609 communities and 139 communities have signed *integrated agreements*; this means roughly 46% and 33% of First Nations and Inuit communities have assumed *transfer* and *integrated* responsibilities for health care service delivery (Health Canada, 2007f). Most First Nation communities who sign *transfer agreements* do so to manage and control the financial resources – meaning the community can allocate resources according to their priorities. Communities who enter into *integrated agreements* establish a management structure for health services, but FNIHB delivers these services (Health Canada, 2007b). For example, the cases in this study have all three forms of health governance. Fort Chip is a full transferred community: the nursing station manages and hires their nurses while allocating their expenditures as they see fit. Fort McKay, on the other hand, has an integrated agreement: the community manages their nursing staff and some of their programs while FNIHB delivers some of their health services.<sup>108</sup> Janvier is a community that does not meet

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<sup>107</sup> The First Nation communities that signed the James Bay and Northern Quebec Agreement (JBNQA) are excluded in these numbers. The JBNQA area has a population of roughly 10,000 people and it was signed in 1975 (Ciaccia, nd).

<sup>108</sup> In Fort McKay, FNIHB has a contract with Northern Lights Health Region to provide public health services to the community. See more discussion of their health structure in the description of the second case in the next chapter.

FNIHB's requirement for transfer status, so nurses are provided and managed by Health Canada.

In the chart above, Alberta has the least number of First Nation communities who have transfer status, 7% compared to 79% in Quebec. Communities have also assumed *transfer* responsibilities for treatment centers and hospitals: 19% (11 out of 58) National Native Alcohol and Drug Abuse Program (NNADAP) Treatment Centers and 40% (2 out of 5) hospitals<sup>109</sup> (Health Canada, 2007f). The programs and services that are eligible for transfer are found in table 5.2 below:

**Table 5.2 Eligible Health Programs and Services Under the Transfer Approach**

- Brighter Futures
- Building Health Communities – Mental Health Crisis Management
- Building Healthy Communities – Solvent Abuse
- Canada Prenatal Nutrition Program (excluding Development Funds)
- Community Health Promotion and Injury / Illness Prevention
  - Community Health Representatives
  - Community Nursing
  - Nursing Training
  - Support Services to Community Health
  - Health Education
- Community Health Primary Care
  - Community Nursing (Limitations apply in some provinces because of the absence of applicable legislation)
- Dental Therapy (Limitations apply in some provinces because of the absence of applicable legislation)
- Environmental Health Program
- Health Careers (excluding bursaries and scholarships)
- Health Services
  - Operations and Maintenance of Facilities and Residences
  - Communicable Disease Control
  - Health Board and Health Coordinators
- National Native Alcohol and Drug Abuse Program (NNADAP)

Adapted from Health Canada

The table reflects the type of services that can be *transferred* into the control of First Nations and Inuit communities. Consultative, coordinative and supervisory positions may also be transferred. Health Canada, through the First Nations and Inuit Health Branch, also supports *non-insured health care benefits* for eligible First Nations – a limited series of services such as prescription drugs, glasses, dental, medical transport, crisis intervention and mental health counseling (Health Canada, 2008). In the list above, there is no mention of transferring physician or hospital care (a large part of the budget) responsibilities to First Nation communities. Under the Canada Health Act, the

<sup>109</sup> Three hospitals in First Nation and Inuit communities were also closed (2006).

provinces provide access to a family physician and specialist care. However, many First Nation communities do not wait for physician care to arrive in their communities; they actively seek and hire a family physician. They often compensate her time for travel and time away from home above and beyond provincial remuneration for medical services to provide services to their communities.

In 2005, an evaluation of the transfer program was conducted and while researchers acknowledged the structure provided greater flexibility for health care services, it found that health services within the structure was severely underfunded to meet the needs of the communities (Lavoie, Forget, & O'Neil, 2007). The 2006 evaluation echoed the findings of previous policy research that the transfer agreements were simply a means of off-loading responsibility onto communities without increasing the financial compensation needed to sustain and improve health and health care programs (Cook, 2003).<sup>110</sup> The transfer policy framework attempted to give qualified communities greater control over health care services, but many gaps still existed in health care service funding (Lavoie, Forget, Rowe, & Dahl, 2009).

In 2005, the *Blueprint on Aboriginal Health: A 10 Year Transformative Plan* initiated by the Martin Liberal Government in partnership with the provinces and First Nations' leadership would have addressed some of these funding issues with \$5.1 billion along with jurisdictional policy changes to enable an administrative mechanism to meet the needs of First Nation communities, paving the road back to healthier communities. While it was not legally binding, it would have established overarching principles and distinctive frameworks to engage First Nation communities (Health Canada, 2005ap. 3).<sup>111</sup> These plans along with the establishment of the *First Nations and Inuit Health Program Compendium* (Health Canada, 2007c) in 2007 would have refashioned the health care structure and the provision of funds within transferred communities. However, funding was slashed to \$800 thousand in 2006 by the Conservative Government, diminishing the necessary funds to make the *Blueprint on Aboriginal*

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<sup>110</sup> According to Cooke, Beavon, and McHardy (Health Canada, 1999), federal expenditures for education, health, and development has not increased per capita for on-reserve status Indians.

<sup>111</sup> The *Blueprint* includes discussion for health care services to Métis peoples where as the transfer program is restricted to First Nations and Inuit peoples (or status Indians).

*Health* workable and, once again, the vision of addressing health inequalities remains unmet.<sup>112</sup>

## **The Gap between Health Care Needs and Health Care services**

The gap between health care needs and existing health care services is wide. The overall health of an individual is sometimes difficult to ascertain due to its multidimensional character (physical, spiritual, economic etc), but to define community health sometimes defies definition due to its intricacies. Definitions in of themselves are often limiting, failing to include the obscure, the individual outside of the norm, and sometimes what is considered healthy for a community may actually be quite detrimental to an individual. However, one can say with absolute certainty that it is challenging for an individual to be healthy without a healthy community. Among health care policy makers the notion of health determinants is one way of defining health: the complex interplay between social and economic factors, the physical environment and the individual's behavior (Public Health Agency of Canada, 2003). The report, *Gathering Strength*, indicates that health care expenditures are not meeting health care needs. The data below is provided as a contextual understanding of the social, economic, and physical environment of rural and remote First Nation communities to compel us to consider whether these environments are being adequately addressed.

### **a. Population Growth**

The 2006 Census on Aboriginal Peoples, the survey divided the population survey into several groups: Aboriginal, Inuit, First Nation and Métis. Each grouping reported significant increases in population compared to the last decade and to the non-First Nations' population. In the chart below, the percentage of First Nation peoples increased by 45% from 1996-2006, which is six times the rate of increase compared to the non-Aboriginal population. For those identifying themselves as First Nations, the increase was 29% (Statistics Canada, 2008b). Statistics Canada attributes the significant changes

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<sup>112</sup> CBC (2003b) indicated that such a move could open the possibility of pitting urban Aboriginal peoples against rural and remote communities for resources, since the public only sees the lump sum provided to Aboriginal peoples rather than the actual sum provided per person.

in population due to a number of factors: higher birth rate and an increasing number of people comfortable with identifying themselves as First Nations.

**Table 5.3: Size and Growth of Aboriginal Population by Identity, Canada**

Aboriginal identity 2006	Percentage change from 1996 to 2006
Total population	9
Aboriginal identity population	45
First Nations people	29
Métis	91
Inuit	26
Multiple and other Aboriginal responses	34
Non-Aboriginal population	8

Statistics Canada, 2008 (p. 10).

Considering the total First Nations' identity population, much of the growth occurred in urban cities. As well, 60% of those individuals identifying themselves as First Nations people lived off reserves compared to 40% living on reserves. The 2006 Aboriginal People Census also indicates that First Nations were more likely to live in homes requiring significant repair and these homes were often overcrowded (more than one person per room) (Statistics Canada, 2008b: p. 8). These statistics indicates that while health resources need to be directed to remote and rural First Nation communities, an increasing amount of resources should also be allocated to address the rising needs of urban First Nation peoples. This creates an increasing competition for scarce resources allocated to First Nations people.

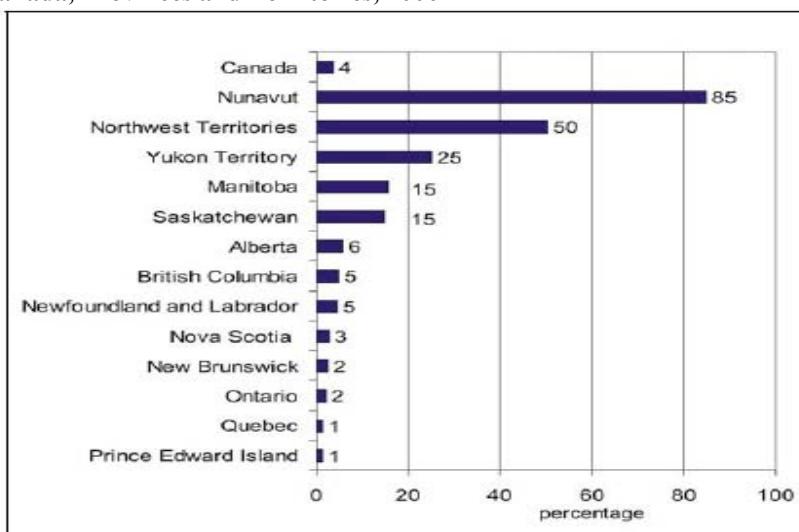
In the chart below, a breakdown of the Aboriginal population reveals that Alberta ranks third at 16% of First Nation peoples after Ontario at 21% and British Columbia at 17%.

<b>Table 5.4: Number and Percentage of Population Reporting Aboriginal identity, Canada, Provinces and Territories, 2006</b>		
<b>Provinces and territories</b>	<b>Number</b>	<b>Percentage of overall Aboriginal Population</b>
Canada	1,172,790	100
Newfoundland and Labrador	23,450	2
Prince Edward Island	1,730	0.1
Nova Scotia	23,175	2
New Brunswick	17,655	2
Quebec	108,430	9
Ontario	242,495	21
Manitoba	175,395	15
Saskatchewan	141,890	12
Alberta	188,365	16
British Columbia	196,075	17
Yukon Territory	7,580	0.6
Northwest Territories	20,635	2
Nunavut	24,920	2

Source: Statistics Canada (2008b: p. 11).

While the most number of Aboriginal peoples may reside in Ontario, British Columbia, and Alberta, they only comprise a very small percentage of the provinces' population. In the figure below, Aboriginal people represent 6% of the Alberta population.

**Figure 5.2: Percentage of Aboriginal People in the Population, Canada, Provinces and Territories, 2006**



Source: Statistics Canada (2008b: p. 11)

The increasing population growth means a greater percentage of the individuals in First Nations will be younger: the median age among Aboriginal peoples is 27 years old compared to 40 years old among non-Aboriginal peoples – a gap of 13 years. The youth (those 24 years and younger) comprise 48% of the Aboriginal population compared with 31% in the non-Aboriginal population (Statistics Canada, 2008b: p. 14); the potential for economic growth lies within the youth, but resources must be adequately invested to develop this potential. The rising youth population also means that health care services such as pediatricians, nutrition, and public health (vaccinations) are needed to reflect this trend.

#### **b. Breakdown Health Canada First Nations Geographic Categories**

Often times, the geographic location of First Nation communities influence access and availability of health care services. Health Canada (1999) has divided First Nations and Inuit communities into four categories of accessibility based on transportation and communication.<sup>113</sup>

1. *Remote-isolated*: No scheduled flights, minimal telephone or radio services, and no road access, reflecting 3% of the total number of First Nations communities.
2. *Isolated*: Scheduled flights, good telephone services, and no year round road access, which reflects 17% of the total number of First Nations communities.<sup>114</sup>
3. *Semi-Isolated*: Road access greater than 90 km to physician services, reflecting 14% of the total number of First Nations communities.<sup>115</sup>
4. *Non-Isolated*: Road access less than 90 km to physician services, reflecting 66% of the total number of First Nations communities.<sup>116</sup>

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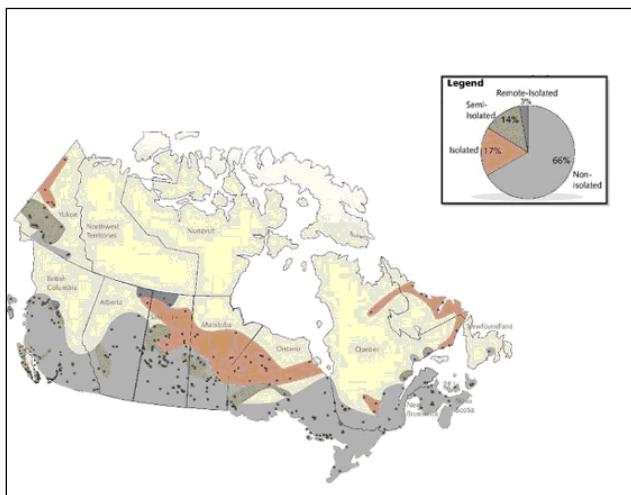
<sup>113</sup>The Northwest Territories and Nunavut are not included in categorization list of First Nation and Inuit communities. The Medical Service Branch has transferred universal health services and facilities to each of the respective governments as of 1997 (Report of the National Broadband Task Force, 2001b: p. 1).

<sup>114</sup> According to this definition, Fort Chip would be considered an isolated community.

<sup>115</sup> Janvier would be considered a semi-isolated community.

<sup>116</sup> Given Fort McKay is less than 90Km away from physician services, the community would be considered a non-isolated community. However, the community has a health centre and receives full time nursing services.

**Images 5.2: Map of First Nation Communities by Geographic Designation**



In the map to the left, the majority of First Nation communities in Alberta are classified as non-isolated with a few classified as semi-isolated and remote-isolated.

**Source:** Health Canada (1999: p. 11).

Health Canada determines the type of services First Nation communities receive based on the geographic categories in the above. Based on these categories communities are designated as health care offices, health centres, or nursing stations. Health office designation is for non-isolated communities, with a part-time nurse, primarily focused on health education. Health care centre designation is for semi-isolated communities with full time nurse(s) providing public health services. Nursing stations provide full clinical services, including 24 hour emergency medical services (Waldrum, et al., 2004).<sup>117</sup> Despite the fact that 66% of First Nation communities are considered non-isolated, most First Nation communities are geographically rural and it is challenging to obtain consistent health care services because neighboring rural communities are also understaffed (Health Canada, 2007e).

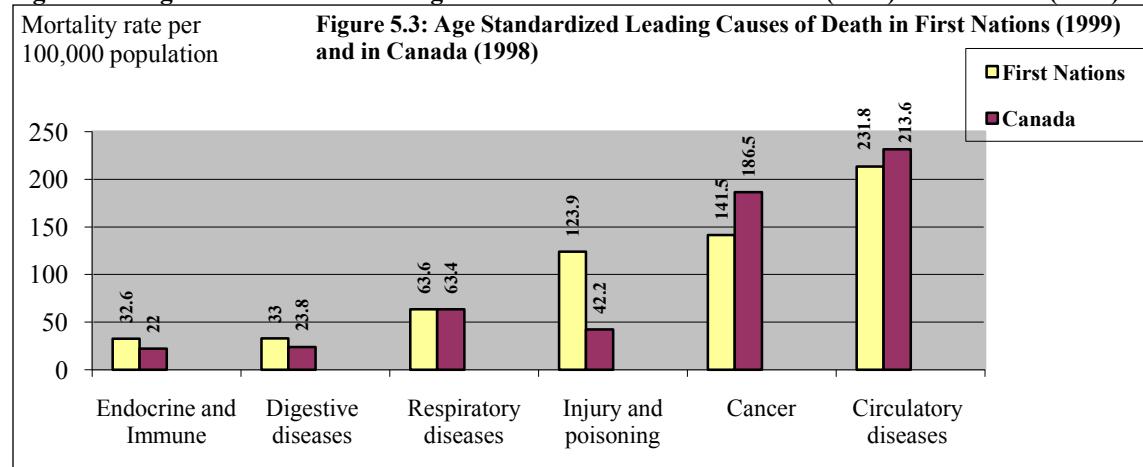
*c. Burden of Disease in First Nation Communities*

The burden of disease in First Nation communities has not shown substantial reduction since the Royal Commission on Aboriginal Peoples in the 1990s. In the early 1990s, the Royal Commission on Aboriginal peoples (1993) indicated that First Nation communities were in a state of crisis marked by violence, disorder, and despair (Brant, 1993; LaRocque, 1993). Some of these serious issues can be manifested in the health of

<sup>117</sup> Of the three communities, Fort Chipewyan is the only community with a nursing station and a health centre. Janvier and Fort McKay both had health care centres.

First Nation peoples. According to Statistic Canada (2003)<sup>118</sup> First Nation communities face higher rates of infectious diseases<sup>119</sup>, infant mortality, and deaths due to diseases arising in their most productive adult years from 20-44 years of age (p. 29).

**Figure 5.3: Age Standardized Leading Causes of Death in First Nations (1999) and Canada (1998)**



From Statistics Canada (2003), p. 32

The bar graph illustrates what policy makers are all too familiar with, significant disparity between First Nation communities and the rest of Canada in the area of endocrine and immune diseases (1.5 times higher), digestive diseases (1.4 time higher), and injury and poisoning (3 times higher). Endocrine diseases such as type 2 diabetes have been on the rise across age groups in First Nation communities for the last decade (Canada, 2000; Dean, Young, & Flett, 1998; Young, Szathmary, Evers, & Wheatley, 1990). As well, rising health problems such as addictions to drugs and alcohol are severe (Anderson, 2007; Assembly of First Nations, 2004; Callaghan, Cull, Vettese, & Taylor, 2006). The other significant difference is found in deaths due to injury and poisoning, which is highest among those between the ages of 20 to 44 years old (Statistic Canada, 2003, p. 31). Overall, First Nation peoples have poorer health compared to the rest of the Canadian population.

<sup>118</sup> At the time of writing this dissertation, the 2006 census data for Aboriginal health had not been published.

<sup>119</sup> According to Health Canada (2005b) the infectious diseases most prevalent and advanced among Aboriginal peoples compared to the Canadian population are: Chlamydia (7 times higher), pertussis (3 times higher), and shigellosis (almost 20 times higher) (p. 7).

*d. Expenditures and Access to Health Care Services*

Given the above data on the social, economic, and physical environment of the First Nation communities in Canada, the amount of resources needed to address the health disparities in First Nation communities should match health care needs. However, if one could compare the gross expenditures with population growth, the rural and remote locations of First Nation communities, the low rate of employment and education and disease or illness in First Nation communities, the health care expenditures will likely not match the pace of growth and decline in First Nation communities. In 2000, Health Canada (2000) citing Green et al (1997) indicated that health care service delivery was likely to increase from 2.4% in 1996 to 7% of the provincial budget in 2016 for diabetes, factoring in the projected rate of disease such as diabetes and its various complications to increase during the 20 year span: cardiovascular disease – 10 times, strokes – 5 times, dialysis – 10 times, blindness – 5 times (p. 22).<sup>120</sup> The AFN (2004) indicated that a sustainable financial base for health care services will require a minimum investment of \$182 million plus a 10 -12% increase per annum (Jacobs, Blanchard, James, & Depew, 2000: p. 300). Health Canada's projected expenditures do not match AFN's projected expenditures for health care services. These numbers seem daunting, but possible given that many First Nation peoples do not commence treatment until the individuals begin to notice their symptoms are impacting their lifestyle due to the difficulty of access (Mill, 2000; National Aboriginal Health Organization, 2003). This means that First Nation peoples tend to have greater deterioration in health. For example, in one case study, First Nation peoples with diabetes in Manitoba were more likely to be admitted to hospital with serious complications (circulatory disorders, infectious diseases, peripheral neuropathy, and renal disorders) (Health Canada, 2000). This combined disease trajectory means higher costs for care and treatment.

Aside from the higher rates of disease, rural and remote First Nation communities are geographically dispersed, adding to the cost of transportation.<sup>121</sup> When asked in a poll to rank the type of care that was difficult to access, First Nations people indicated

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<sup>120</sup> By population rate alone, Health Canada's projection in 2000 would have been a disastrous. Lavoie et al. (Lavoie, et al., 2007) documented that actual spending in two First Nation communities exceeded the transfer payments to the communities.

<sup>121</sup> Health Canada pays for the transportation cost for patients (a driver, vehicle, and hotel costs for overnight stays).

that the top five most difficult type of care to access were the following: midwives (59%), obstetricians / gynecologists (52%), mental health workers (45%), pediatricians (43%), optometrists (37%). The smaller and the more remote the communities, the more difficult these services were to access. The least difficult to access are nurses (17%) and community health representatives (20%) (J. K. Scott & Kieser, 2002). This means First Nation peoples requiring care must travel greater distances to access specialist health care services.

In First Nation communities it is difficult to recruit and retain health care workers: most physicians and nurses are non-First Nation with short-term contracts. The short-term contracts are due partly to inconsistent funding, but largely due to burnout. In rural and remote communities, one physician serves 800 people compared with one physician for every 200 in urban centers (Bruce Minore, Boone, Katt, Kinch, & Birch, 2004: p. 364). The consistent turnover has not only compromised the health of First Nation peoples, but escalated costs for retraining new recruits. First Nation peoples facing crisis are often reluctant to tell their story to a new care giver and new care givers often lack the expertise to deal with the magnitude of the health issue, so patients often discontinue treatment or counseling (Assembly of First Nations, 2005a). The turnover rate also reduces the likelihood that new programs can be effective as mature expertise often leaves the community.<sup>122</sup> As well, the professional networks between health care practitioners managing individual cases are weakened and patients' information may be misplaced or contradictory as a flow of health care providers stream in out of First Nation communities (Kakepetum, 2005).

## **Opportunities and Challenges for Telehealth in First Nation's Telehealth**

In the discussion above, the history of the factors contributing to First Nation peoples' health, the jurisdictional debate over health care responsibilities and the gap

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<sup>122</sup> The collection of stories from nurses working in remote areas of the Yukon, Northwest Territories, Nunavut, and Alberta in Scott and Kieser (2002) reveal the challenges of isolation and the magnitude of health care needs. Most nurses are stretched beyond their training and suffer from burnout at the end of the contract period. Although all the nurses mentioned how much they loved the people and their jobs, very few returned and remained nursing in the Aboriginal communities.

between health care needs and health care services provide the context for the implementation and use of telehealth services. Given this complex context, one would be foolish to suggest that telehealth can be the only solution. There are many social, economic, and political rifts that will require serious attention and care. Indeed some of these same issues will act as barriers to telehealth operation. The role telehealth can play will be dependent on the First Nation community's health care needs, the type of transfer agreements in place for telehealth, and the resources and technology available. As well, one must take into consideration the relative newness of telehealth: some regions and provinces have different technologies (telephone lines, satellite, cable, fiber optics),<sup>123</sup> organization structure, policy, and human resources are still being formulated and shaped as new telehealth applications are being implemented. AFN, Canada Health Infoway (2007) and other First Nation communities, particularly the KO-Telehealth Network (CBC, 2007), indicated that telehealth was a valuable tool to improve health care services and provide visitation for family members who had relocated outside the community. The AFN recognizes the potential of telehealth and it proposes that 170 First Nation communities across Canada receive telehealth services.

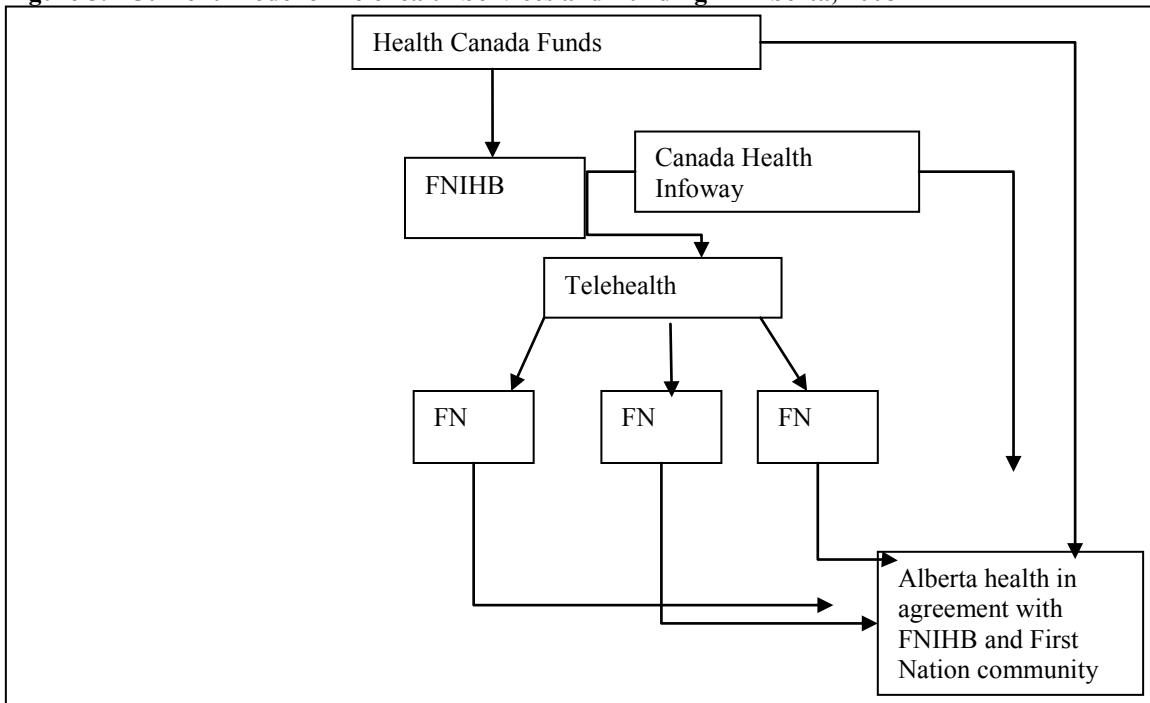
However, like other health responsibilities, it is not clear who funds telehealth all the time. At the time of research in Alberta, tele-learning and telehealth connection for the services were provided by FNIHB.<sup>124</sup> At the end of 2007, Canada Infoway declared that it would fund 100% of the telehealth services to First Nation communities connecting to a provincial network and 75% to communities maintaining its own network (Canada Health Infoway, 2007). The fact that 100% funding is allocated for collaborations with the province and stand alone networks will only receive 75% of funding seems to penalize First Nations' self managed networks. From this announcement, the model for telehealth delivery would resemble the model below.

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<sup>123</sup> The type of technologies in place affects the type of applications that health care providers can access. For example, interactive video-conferencing requires synchronous broadband (1. 5 / 2.0 to 30 Million bits of information per second) for live video and sound transfer between locations. The greater the distance and more traffic (users exchanging information) the more bandwidth is required to maintain live feed between locations. The transfer of information from technologies such as wireless (satellite) to fiber optics networks can be made compatible through a bridge offered either by the FNIHB or a telephone company.

<sup>124</sup> Two of three of the communities in this study received telehealth funding for tele-learning services; Janvier did not have telehealth connectivity at the time. For more discussion see the cases in the next chapter.

**Figure 5.4 Current Model of Telehealth Services and Funding in Alberta, 2008**



Prior to Canada Health Infoway's announcement in December 2007, FNIHB – Alberta often acted as the middle liaison to connect health education services offered by the province. However, with Canada Health Infoway's announcement to fund telehealth services, communities must enter into agreements with provincial health services, further complicating the already muddy jurisdictional boundaries of who is responsible for what particular services. If First Nations connect to provincial health services, will Canada Health Infoway pay for health services or just connectivity or both connectivity and health services? What will be FNIHB's role? Canada Health Infoway's funding conditions seem to compel all stakeholders to work together and this collaboration may maximize scarce resources, but it may also leave First Nations and the provinces carrying more of the financial burden to cover the cost of telehealth access.

## Concluding Comments

The history of First Nation peoples and their health began with a drastic decline in their population size when they became wards of the Government of Canada. Over the last two decades, the attempt to grant First Nations people greater control over their communities and health care services has not been without complications: jurisdictional

debate and ambiguous qualification criteria for health care services have created gaps that have left communities and people without proper access to care. The case in point to illustrate the grayness of First Nations' health policy is Jordon: a four year old boy who died in 2007 in a Winnipeg hospital while federal and provincial governments debated who should pay for his treatment (CBC, 2007). First Nation communities, policy makers, and researchers suggest that telehealth may play a role in bridging the gap in health care services, but this service will likely be subject to jurisdictional challenges as well.

# Chapter 6 – The Role of Telehealth in Three First Nation Communities

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## Introduction

The previous chapter provides a context for understanding the health care system in which First Nations' telehealth is situated. The purpose of this chapter is to present the findings of the research within the context of each of the First Nation communities in this study. The findings are the themes that arose out of the interviews coupled with the observations and insights made during the research. Following the tradition of ethnography, this chapter is a rich description of the social context of telehealth usage in three First Nation communities.<sup>125</sup>

## An Overview of the Social Context of First Nation Communities

The overview of the three communities here serves to provide an understanding of the socio-economic context of the communities.<sup>126</sup> The three communities involve four First Nations located in northern Alberta near the Athabasca River. They are a part of a one tribal council, a gathering of five First Nation communities, one of which did not choose to be a part of this research project due to its close proximity to Fort McMurray and its reliance on medical services in the city. These communities govern themselves independently of one another, but for political, social, economic, education or health reasons, the chiefs from each of the communities may collaborate in the tribal council to address their mutual interests.<sup>127</sup> At the time of research, one of the benefits of being in a part of Athabasca Tribal Council was the development of a telehealth initiative with

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<sup>125</sup> The larger theoretical analysis of the data is provided in chapter 7.

<sup>126</sup> The health context of Aboriginal communities was provided in the previous chapter on Aboriginal healthcare policy.

<sup>127</sup> Some communities, however, opt not to join other First Nations communities in a tribal council for various political, social or economic reasons. At the time of study, one such community in Alberta was Big Stone First Nation.

Northern Lights Health Region.<sup>128</sup> These communities are also a part of the larger municipality of Wood Buffalo, which is comprised of ten rural communities. According to Statistics Canada (2008h), the 2006 Census indicates that the municipality had a population of 51,496, a 26.3% increase in population from 2001 to 2006. Of the total population size of Wood Buffalo, 5,365 people are of Aboriginal identity.

The population increase could be attributed to the booming oil and gas economy and the significantly younger population in the region due to migration and birth rates; 19% of Alberta's population is under the age of 15 years old compared to the national growth of 15% (Statistics Canada, 2008g). In Wood Buffalo, the growth in the youth population is nearly twice the national rate at 24.1%, but slightly lower than the rest of the Aboriginal population in Alberta at 31.1%.

**Table 6.1: Demographics of Aboriginal Peoples in Comparison**

Category	Wood Buffalo (Aboriginal Population)	Alberta (Aboriginal Population)	Alberta Population	Canada
Education Level - 25 to 64 years old (No certificate, diploma, or degree)	24.9%	34.6%	*15.4%	*15.4%
Percentage of Population below 15 years old	24.1%	31.1%	** 19%	** 17.7%
Unemployment Rate	7.9%	11.1%	***4.3%	***5.2%
Average earnings	\$50,971	\$29,466	****\$43,964	****\$41,401

Source: (Statistics Canada, 2008h), \* Source: (Statistics Canada, 2008d), \*\* Source: (Statistics Canada, 2008g), \*\*\*\* Source: (Statistics Canada, 2008c), \*\*\*\* Source: (Statistics Canada, 2008e),

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<sup>128</sup> The telehealth initiative with Northern Lights Health region is discussed further in the case descriptions.

### **Images 6.1: Road to Fort McKay through the Oil Sands Industry**



Source: Mah (2007) The road to Fort McKay is lined with Syncrude's development; as well Suncor and many oil companies extract and process the oil sands deeper in the region. The picture on the left is Syncrude's refineries and the picture to the right is one of many tailings pond where water used in the oil extraction and processing procedure ends up. In 2008, 500 ducks died in one of these tailings pond causing an uproar across the province, forcing Syncrude to change its practices and invest in migratory bird conservation (Syncrude, 2008).

While the oil sands development around the Fort McMurray area is not the central focus of this dissertation, it impacts the First Nation communities' social, economic, health, political and environmental life.<sup>129</sup> The oil sands near the remote community provide many of its community members with employment; in some cases, industry also invests in the First Nation communities' economic development, provides financial compensation, or establishes infrastructure in the community (Suncor, nd; Syncrude, 2007). The oil sands development in northern Alberta is an economic gift to First Nation peoples whose lands are rich with oil, but its production is hazardous to their health. Many of the participants in the interviews mentioned concerns over water, respiratory problems, cancer, and skin problems. In the last two years of conducting field research for this dissertation, there have been numerous documentaries, newspaper articles, and television news stories related to the oil sands development and First Nation peoples' health concerns, particularly about Fort Chip.<sup>130</sup> These concerns, challenges, and problems shaped some of the encounters between health providers and their patients over telehealth in Fort McKay.

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<sup>129</sup> According to Government of Alberta (2008), second only to Saudi Arabia, producing 47% of Canada's crude oil (Alberta Energy, 2008).

<sup>130</sup> Some of the primary concerns among the communities are water contamination, the abnormalities in the fish and wild life due to heavy industry activity, cancer (Canadian Broadcasting Corporation, 2007) and, during the research many community members mentioned the fear of respiratory problems associated with the oil sands industry. Throughout my research, a number of media stories involving one or all the First Nation communities were regularly in the newspapers, television, radio and a documentary short was created soon after my departure from Fort McKay in 2008 about the community's doctor.

## **Case 1: Fort Chipewyan**

### **Introduction**

In the first case study, the telehealth research in Fort Chipewyan (commonly referred to as Fort Chip) lasted from the end of January until mid March. As outlined in the methodology chapter, Fort Chip was chosen because it one of the original telehealth pilot projects in First Nation communities in the late 1990s. Of the three communities in this study, Fort Chip had been using telehealth for the longest duration of time, allowing us to understand how duration may contribute to the incorporation of telehealth into health care practice.

Of the three communities, I spent the most number of consecutive days observing and interviewing the participants in Fort Chip.<sup>131</sup> The case description here is based on the interviews and observations of telehealth use in the Nursing Station. Firstly, the reader is provided with the context of telehealth use: the community background, a description of the everyday activities and challenges in the Nursing Station are necessary to understand the circumstance under which telehealth is being used. Secondly, a brief description of the participants and their reasons for working in Fort Chip contextualizes the participants themselves followed by the participants' perspective of community health. Thirdly, the case follows the participants' approach to changing and addressing health challenges in Fort Chip. Lastly, the reader is provided with a description of the participants' use of technology and telehealth.

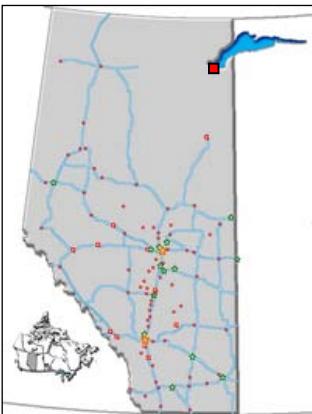
### ***Community Background***

From a geographic perspective, Fort Chip would appear to have the most urgent need for telehealth since it is the furthest north of Fort McMurray compared to the other two communities. It is a fly in only community three seasons of the year in the spring, summer, and fall. Fort Chip is also one of the oldest European settlements in Canada

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<sup>131</sup> During this time, I tried to understand the environment for the research and, at the request of the Health Director, engage the Nursing Station in a PAR process to develop a physician to patient consultation project, separate from this dissertation research. This side project helped me to understand some of the jurisdictional challenges of establishing telehealth service involving the Northern Lights Health Region.

which is comprised of non-Aboriginal peoples and two First Nations (Mikisew Cree and Athabasca Chipewyan).<sup>132</sup> Its geographic location at the western tip of Lake Athabasca has been one of the reasons Fort Chip is exposed to constant change over the decades:



European settlement during the fur trade and, in recent times, due to its isolation, new innovations like telehealth.

Statistics Canada's *Community Profiles for Aboriginal Communities* does not have a clear community demographic for

**Images 6.2: Map of Fort Chip** the municipality of Fort Chipewyan. However, the search through the database indicates that Fort Chip is included in the Wood Buffalo municipality (Statistics Canada, 2008h). This makes it difficult to ascertain the exact breakdown of population demographics within the community since Wood Buffalo is comprised of ten rural communities and one urban center, Fort McMurray. According to Statistics Canada, Mikisew Cree First Nation has a population of 153, a decline of 26.8% since 2001. There were no population statistics for Athabasca Chipewyan First Nation, but Wikipedia indicates that Fort Chip has a population of 1,200 and other sites indicate between 700 and 1000 people. At the time of my research, the Health Director at Fort Chip indicated the population was around 1200.

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<sup>132</sup> According to the Health Director of Fort Chip, the Nursing Station provides health care services to status and non-status Indians as well as the rest of the residents in Fort Chip.

**Images 6.3: Fort Chip at Sunset**



The left picture is taken from the Athabasca Lodge overlooking the Athabasca River (a place that many people go to ice fish) and the picture to the right is Nunee Health Board (a few weeks into the research many northern lights were seen flashing above this building).

## A Day in the Nursing Station in Fort Chipewyan

### a. Location

During the entire period of my field research in Fort Chip, I was fortunate to have lived with one of the nurses in the community, offering a unique perspective on the everyday life and challenges of nursing in the community. The temperature during my stay from the end of January to the end of February frequently dropped well below -30°C and with the wind chill factor it was unimaginably cold for this Calgarian. It was too cold to trek the short distance to the Nursing Station from the residence (picture to the left) until the thermometer climbed towards -20°C, but even then it often warranted snowboarding pants to walk the 15 minute distance. I did not see many people walking anywhere between January and February.

**Images 6.4: Fort Chip Residence and Food Prices**



The three pictures above were taken in 2007 in Fort Chip. The cost of groceries was very high.

One of the most important aspects for healthy living is the ability for people to obtain affordable nutritious food, but the cost of nutritious food in Fort Chip was very expensive: 2L of milk was \$9.00; a 4lb bag of oranges sold for \$9.99; and a head of cauliflower was \$8.25. Similarly the previous week, I had paid for a similar bag of oranges for \$2.99 at the Real Canadian Super Store in Calgary. The cost of canned foods was about a third more expensive than in Calgary.<sup>133</sup> During my stay, I also realized that Internet connectivity was spotty and not easily repaired.<sup>134</sup>

In Fort Chip, the Health care services were situated in three separate buildings rather than a single complex governed under the Nunee Health Board, a council comprised of community members from the two First Nations in the community (Mikisew Cree and Athabasca Chipewyan First Nation). At the time of the field research, the Nunee Health Board was the only organization to provide fully transferred<sup>135</sup> health care services independent of much of Health Canada's governance. My description here is focused on the Nursing Station, the location of the telehealth equipment and the site of everyday clinical health services. The administration building is quiet compared to the Nursing Station; it houses the Nunee administration and community health. The third building is the Healing Center; it housed counseling services and Native traditional healing practices.<sup>136</sup> Each of these buildings operated under Nunee, but its everyday operations were autonomous of each other with some opportunities for collaborative efforts.

### ***b. The Nursing Station***

The Nursing Station is open from 8:00 AM to 4:30 PM. From about 8:00 AM to about 10:30 AM, many of the health care providers and staff were busy catching up on paper work, following up on patients, calling various specialists outside of Fort Chip,

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<sup>133</sup> On two separate occasions when I was in Fort McMurray for meetings with ATC and Health Canada, I stocked piled a significant amount of groceries for the remainder of my two months in Fort Chip. The nurse that I resided with did the same and she purchased things for the staff. Many of the staff at the Nursing Station often drove to Fort Smith for groceries, stock piling winter food supplies (canned and frozen foods) for the winter.

<sup>134</sup> Throughout my stay in Fort Chip, I maintained contact with friends and family via an Internet program called Skype. However, these connections often began well, but after twenty minutes the images became increasingly fuzzy.

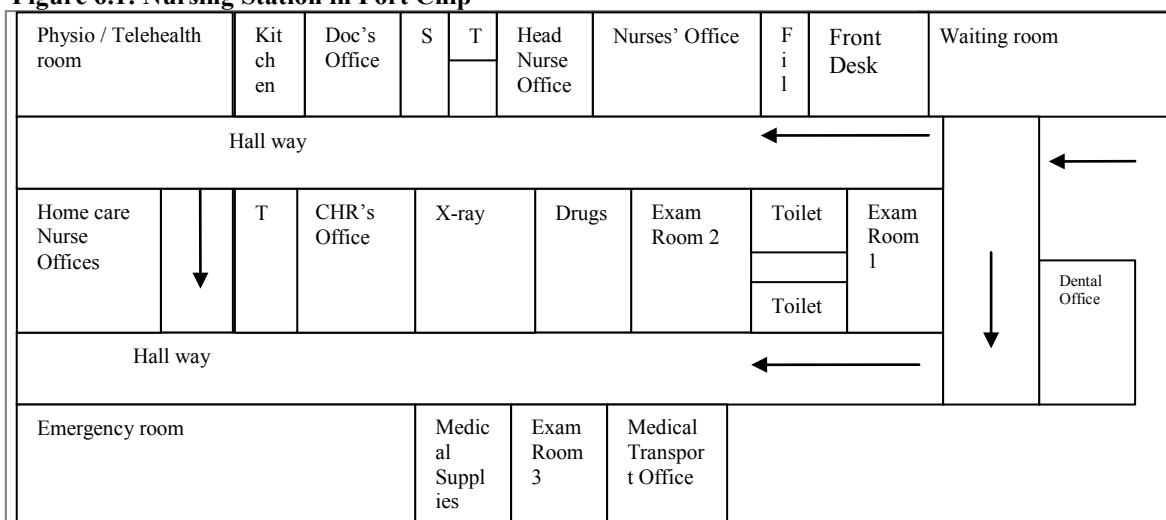
<sup>135</sup> The implications of full transfer status are discussed in the previous chapter.

<sup>136</sup> I was fortunate to have participated in a traditional pipe ceremony and healing class.

checking on labs or preparing their patients' appointments. Some ate breakfast and had coffee while doing this preparation work. A few patients may trickle into the Nursing Station, but for most of the first few hours of the morning, the health care staff was preparing or catching up on paper work.

For its relatively small physical structure, the Nursing Station had a complete array of services to enable its autonomy for basic clinical services: a stock of medication, the only such facility in my research, an emergency medical van, several clinical exam rooms, an emergency room, telehealth / physiotherapy room, and an x-ray room.

**Figure 6.1: Nursing Station in Fort Chip**



In the above diagram, two structures in the building have not been drawn: the basement where the wireless network is established and the garage where the medical evacuation van and medical transport are housed (located across from the physiotherapy room). T represents toilet and S represents storage room.

In the diagram above, most of the offices are located on the upper area and the assessment or examination of patients are located in the center and lower half of the diagram. The waiting room, like all the waiting rooms in this study, contained literature (pamphlets) targeted at First Nation peoples on almost every aspect of health care services offered by Health Canada. Some of the pamphlets addressed diabetes, addictions, HIV, smoking, and pregnancy.

#### **c. Flow of Activities and Work in the Nursing Station**

At the Nursing Station, the phone calls usually escalated after 9:00 AM and tapered off near closing time, 4:30 PM; there were often two to three staff members

receiving phone calls at the front desk. They routed the phone calls to the nurses and scheduled patient appointments for the various health services provided by the community. They also ensured patient files were organized and connected patients to medical transportation, a taxi service offered to members without vehicles, to and from the Nursing Station. When asked whether there was a possibility of implementing an automated telephone system to route the calls, individuals responded that the risk of a patient terminating their call during an emergency when faced with an automated service far outweighed the advantages of its usage.

The chart below illustrates the various visiting health care professionals that provided health care services at the Nursing Station.

**Table 6.2: Frequency of Health Care Services in Fort Chip**

Type of Service	Frequency
Family Physician	2 days / week
Dentist	5 days / month
Dental Hygienist*	1 day / month
Optometrist	1 day / year
Physiotherapist	1 day / bimonthly

\* The dental hygienists contract ended in Mar. 2007, one month after I completed my field research; Nunee could not employ a dentist and a dental hygienist. This is one of the most sought after health care service in all the First Nation communities I visited.

Each of the health care providers in the above chart have their own appointment books and for some services such as the dentist or dental hygienist, they were often fully booked weeks in advance of her visit. When health care providers visited the community, Nunee covered their travel costs and accommodations. The staff at the Nursing Station readily prepared and assisted the visiting health care professionals in completing their clinics. The busiest days at the Nursing Station were the days that the visiting health professionals offered their services, which frequently required later evenings for the nurses to complete their paper work.

The telephone ringing throughout the day was the most consistent noise in the Nursing Station; its silence was strangely incomprehensible. One terribly cold day when the thermometer plunged to -35°C, the phones were silent, slowing down the normal bustling day. The lines were down and the only form of communication was radio. The fax machine, which regularly churned out lab results, was also at a standstill. For emergencies and medical transport communication, the medical transport drivers and the nurse on-call relied on the radio. The nurses frequently stayed at the Nursing Station

charting well after closing, particularly on Tuesdays and Wednesdays when the physician visited for clinics. He, the physician, often skipped lunch or grabbed food during the flow of patients moving in and out of his office. At lunch (12:00 PM to 1:00 PM), the treatment nurses often frequented a restaurant known for its beautiful scenery overlooking the Athabasca Lake.

After lunch, the nurses returned to the station and many patients would be waiting to see them. The nurses frequently conferred with each other about common patients, discussed ethical issues (medication, patients' choices and other pressing concerns) and their programs. The number of registered nurses (RNs) fluctuated between 2005 and 2007, but the number of patients stayed the same or increased with additional laborers arriving in the community, adding to the existing tension and friction over the schedule for vacation and on-call nights.

Tuesdays was the busiest day at the Nursing Station: lab work was sent out on Air Mikisew, the physician arrived in the community on the 10:30 AM flight to start work at 1:00 PM. However, his patient assessments were often interrupted by phone calls so his patients were compelled to wait longer. The doctor's Tuesday clinics often commenced with regular routine meetings with the nursing staff to discuss the patients' files and concerns (lab results, changes in health or questions that nurses had), but frequently, the team also discussed strategies for engaging the patient's health. At these meetings, a team approach towards health care was evident, divided along scopes of practice or responsibility (programs headed by a particular nurse), but collaborative on common patients seen by different nurses. Complex cases involved more discussion and frequently tension arose. After the team was briefed, health care providers began or continued their various tasks and the physician completed his patient assessments.

There were moments of reprieve for the staff members; they often had an extra cup of coffee, joked with other staff members, smoked outside, downloaded music or videos, and completed courses on-line.<sup>137</sup> These moments were not rare, but were a part of the everyday flow of work in the Nursing Station. During my research observations, I noticed that most of the nurses left work at closing time, but on rare occasions a few late

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<sup>137</sup> Internet access at the nursing units was often unreliable. It took nearly two months before a technician fixed the connectivity problem at the unit I was living in.

evenings were spent charting. When the station was closed, the telephone system directed all phone calls to the on-call nurse's resident or radio; shifts were split between evening and night. During my stay, some phone calls involved minor health concerns such as the common cold and still others involved family members advocating for emergency attention (one man called to request the immediate evacuation of his nephew to Fort McMurray for stomach pains). Other times, these emergency calls reflected the degree of health problems in the community: a woman had cut herself, but before the nurse could assess her over the phone, the phone went silent. The nurse called the police to find the woman, but no such person could be located in the community. Often the on-call nurses saw their patients at the Nursing Station after assessing them on the telephone or radio. If these cases were beyond their scope of practice, they contacted the physician on his cellular phone.

However, while there was routine in the day-to-day life at the Nursing Station, the typical day was also subject to unexpected possibilities (different health programs, health care professionals visiting or emergencies). The variations in the work required the staff to be flexible, one of the many reasons that the nurses loved their work, but this variation also created stress.

#### *d. Challenging Issues in the Health Care Center*

The everyday activities of the Nursing Station in Fort Chip would not be complete without an acknowledgement of the persistent issues that preoccupied the staff's conversations. While there were many challenges related to health care work, geographic, and human resources issues, the two challenges I mention here affected the operation of the Nursing Station and the community itself.

The first challenge began prior to my arrival: a young woman was criminally charged and convicted for fraudulently posing as a nurse. Her departure to jail and subsequent release into the community became headline news in the newspapers; it also created confusion in the community as patients tried to ascertain whether she was a nurse or not and the fears of taking the wrong medication. Her colleagues attempted to manage the problem and risks created by her work by carefully reviewing all of her patients'

charts and the prescriptions ordered for patients. The criminal charges, speculation, and subsequent conviction in this woman's case was not only fodder for conversation, but it created a sense of unease amongst the nurses because they had failed to spot obvious clues such as her inability to assess patients, her confusion over prescriptions, and her general unprofessional practice. The woman's departure left a cloud hanging over the real work that some of nurses diligently undertook. Shortly after the completion of my field research in Fort Chip, another nurse was criminally charged for the theft of narcotics. The ramifications of these nurses' actions cannot but challenge the fundamental trust that patients place within their health care providers.

The second pressing issue in the Nursing Station at the time of my research was the investigation of the unusual rates of cancer in the community. The question that scientists, policy makers, health care providers, and community members were anxious to answer was: is there scientific evidence to link cancer to the oil and gas industrial development downstream from Fort Chip? Was the number of cancer cases unusually high? At the time of my research, this issue hung over the Nursing Station as the media made this remote community's issue a primary topic over the airwaves and in people's living rooms. The doctor involved in all of the media discussions worked in Fort Chip and due to his media advocacy and involvement, the alarm of unusually high rates of cancer compelled policy makers and scientists to investigate whether this was true.<sup>138</sup> The media continued to be preoccupied with his perspective of health well after my departure from Fort Chip: in 2009 an award nominated documentary short called "Downstream" was shown in Calgary. Throughout the research process his relation to the media, Health Canada, and the College of Physicians and Surgeons continually created a certain amount of controversy and also stress for the Nunee administration, the Nursing Station and for the doctor himself.<sup>139</sup> The community was involved in making their concerns visible to policy makers in Ottawa, the media, and to the oil and gas

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<sup>138</sup> In November 2008, the report, conducted by independent scientists including two Canadian Aboriginal researchers, indicated that there was higher than normal rates of cancer in Fort Chip between 1995 and 2006. The report also indicated that some cases of cancer warranted follow-up, but the report did not suggest that the cancer was linked to the environment in Fort Chip. Instead, the report suggested further studies were required (Canadian Broadcasting Corporation, Feb.6/2009).

<sup>139</sup> I noted in my journal that on Jan. 23, 2007, he was facing so much stress that the nursing staff was concerned about his health.

industry, but the doctor's continued media advocacy undermined their ability to control who speaks for the community.<sup>140</sup>

During the research process, the eye of the media on the environmental challenges in the region seemed surreal, but the reality of the environmental challenges was confirmed by several incidents: a nurse caught a fish covered with boils while ice fishing in the Athabasca River – an increasingly common occurrence. As well, when I first met the health director, she mentioned that the community was seeking an independent scientist to test water contamination. The Head Nurse indicated that in the summer of 2006, due to community advocacy, Health Canada officials visited Fort Chip to calm fears of contaminated water.<sup>141</sup> These incidents illustrate the community's persistent environmental concern.

In sum, the special circumstances surrounding this research process in Fort Chip highlights the crisis points in a community that provides a dynamic lens on the disruption of the everyday work routines in a health care setting.

## The Participants

In this research process at Fort Chip, the participants were administrators and health care providers who had much experience working in First Nation communities and some of them were community members from Fort Chip. At the time of the research, 18 interviews were conducted with permanent staff members<sup>142</sup> working at the Nursing Station: the visiting physician, six nurses, five community health representatives or members of the community licensed to assist the nurse, and administrative staff. The

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<sup>140</sup> The tension of *working with the community* and *for the community* is a difference of perspective and power that First Nations have been struggling with throughout the history of colonization (L. T. Smith, 2004). The Health Director indicated the chiefs wanted to speak on behalf of the community. She mentioned that the next contract for physician service would confine the doctor's role to providing medical care for community members, unless directed otherwise by Fort Chip. She hoped this would be a preventative measure.

<sup>141</sup> Health Canada's water tests focused on measuring bacterial levels rather than heavy metals in the water. The Health Director was concerned about heavy metal contaminants as well as bacterial levels.

<sup>142</sup> The two medical transport drivers did not agree to be interviewed.

chart below captures all the participants included in the interview process except for addictions counseling in the Healing Center.<sup>143</sup>

**Table 6.3: Number of Health Care Staff in Fort Chip**

Type of Health care Staff	Number of Permanent Staff	Represented As
Homecare	1 RN, 4CHR	H, CHR (Dar1, E2, J3), Personal Assistant (PA)
Treatment	1 NP, 3RN (should have 4), doctor	T (1, 2, 3), (D)
Public Health	1 RN, 1CHR	P
Medical transport	1 CHR, 2 drivers	MT
Administration	2 receptionists, 1 telehealth coordinator, 1 Director of Health	R(1,2), TC, Ad1
Physiotherapy	1 CHR	

The number of community health representatives (CHRs) has remained fairly consistent, providing a sense of stability; some CHRs have worked in the community for over ten years. However, out of the five nurses (RN), only two nurses had more than five years of service in the community, the rest had less than five years of service; the Head Nurse and the two treatment nurses had all worked for less than two years in the community while the nurse practitioner (NP) had worked in Fort Chip for four years. Throughout the research, one of my observations in the community health care centres was that the termination and relocation of nurses from one community to another created instability and discontinuity in community health care services as communities struggled to provide services (the participants mention this in their interviews further in the discussion below).

#### **a. Residing in Fort Chip**

All the community members who worked in the Nursing Station had, at some point in time, left the community only to return years later to care for elderly parents or family. They found jobs in the community and most worked in the community for a longer duration of time than most of the nurses. The nurses reside in the community for several reasons: one, the commute to Fort McMurray is expensive by plane and time

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<sup>143</sup> On hindsight, it may have been beneficial to conduct interviews with the health care professionals in the Healing Center. However, the focus of the research was on telehealth in the Nursing Station since the Health Director was curious about the possibility of patient to physician telehealth consultations.

consuming, not to mention hazardous on the ice road; two, most of the nurses have partners who live and work in the community.

Travel represented the greatest obstacle to many residents and health care providers in Fort Chip. During the interview, some of the community members indicated that a permanent road north to Garden River may be built in the near future, an opportunity for inexpensive transportation of goods into the community. However, many also feared that the road would enable the transportation of dangerous drugs into the community. Some participants indicated that the community was already facing drug addictions to marijuana and other illegal drugs, making Fort Chip an increasingly dangerous community to live in.<sup>144</sup>

***b. Participants' Perspective of Community Health Concerns***

The participants, all health care providers and administrators, at the Nursing Station were concerned about a number of health care challenges in Fort Chip. In the chart below, I have summarized and ranked their health concern according to their answers to the question regarding what their health concern was in the interview. They also mentioned how these health care concerns could be addressed below.

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<sup>144</sup> Some of the participants felt Fort Chip was safer than cities like Fort McMurray and Edmonton due to the availability of drugs. These participants did not mention that some community members in Fort Chip had drug problems.

**Table 6.4: The Top Most Mentioned Community Health Concern**

Rank	Health Concern	Steps for Change
1	Diabetes	<ul style="list-style-type: none"><li>• Education and health literacy</li><li>• Self responsibility</li><li>• Increase number of nurses</li><li>• Connection to specialists (endocrinologists)</li><li>• Health programs (increase number, enhance capabilities, and foster utilization)</li></ul>
2	Addictions to drugs and alcohol	<ul style="list-style-type: none"><li>• Collaborated management of prescription drugs (pharmacies, Health Canada, Chiefs, and College of Physicians)</li><li>• Self responsibility</li><li>• Increase number of nurses</li><li>• Traditional healing</li></ul>
3	Seasonal infections	<ul style="list-style-type: none"><li>• Health literacy</li><li>• Hand sanitization</li></ul>
4	<ul style="list-style-type: none"><li>• Water quality</li><li>• Cancer</li></ul>	<ul style="list-style-type: none"><li>• Collaborative partnerships with other First Nation communities to assess problem</li><li>• Enhance screening system</li><li>• Health literacy</li></ul>

Out of all the possible health problems, most of the participants<sup>145</sup> mentioned that Type 2 diabetes is the most problematic health concern in the community. One of the clinical nurses estimated that 10% of the population had Type 2 diabetes or approximately 107 cases existed in the community. She suggested that increasing the surveillance and implementation of health awareness programs would counter these challenges.

The second most mentioned health challenge in Fort Chip was addictions to alcohol, prescription medication, and drugs amongst the elderly and the young. According to some participants, the type of addiction varies according to age: the elderly are addicted to alcohol and prescription medication while the young are often addicted to illegal street drugs and prescription medication. The physician indicated that in the mid 1990s the Northern Lights Health Region, along with Athabasca Tribal Council, and all the chiefs from the First Nation communities in the region, met to address prescription medication abuse.<sup>146</sup> There is an Alcohol Anonymous organized in the community, but

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<sup>145</sup> There is a possibility that participants' perception of health and illness is affected by the number of cases they see in their job or roles within the Nursing Station. This may predisposition them to suggest certain health concerns were more urgent than others. Many of the health care providers have described health care operating on a reactive model, rather than a preventative approach in Fort Chip.

<sup>146</sup> To counter the abuse of prescription medication, the physician consciously limits his patients' prescription to a one week period to prevent drug stock piling.

one participant commented that family members often bear the brunt of caring for the addict.

Third, the other health problems are seasonal. One nurse indicated that during the summer months, asthma, allergies, accidents due to alcohol, violence or collisions are much more prevalent. During the winter season, people flood the Nursing Station with emergency calls as the first symptoms of the common cold circulate and fears of influenza escalate, compelling the Nursing Station to provide town hall discussions.<sup>147</sup> Patient fears of influenza were common phone calls at night, but some on-call nurses would triage on the telephone and decide not to see a patient if s/he thought the patient could be seen in the morning during working hours.<sup>148</sup> The notion of rights and utilizing resources effectively was often a hot topic, since patients seen after hours were significantly more costly than during regular clinic hours.

Lastly, from my observation cancer was one of the most pervasive topics in the media and in the Nursing Station. However, only a few participants mentioned it during the interviews. During my research, many participants at the station made passing comments about their suspicion that cancer was linked to the water quality: there were fears of eating the fish from the Athabasca Lake, a necessary supply of food given the high cost of groceries.<sup>149</sup> Despite these fears, the community's desire to solve their water supply challenges went unresolved: Health Canada continued to state the water quality was satisfactory. The nurse responsible for testing water quality indicated that in her nine years of experience, she had only seen one boil water advisory in Allison Bay and a few times in Dog Head involving private water cisterns (both are reserve areas surrounding or within the greater community of Fort Chip). She said that these tests measured fecal and bacteria levels, not heavy metals in the water.<sup>150</sup>

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<sup>147</sup> The fear of influenza is not unwarranted given epidemics contributed to the decimation of Aboriginal populations and significantly altered the social structure of Aboriginal communities (Waldrum, et al., 2004).

<sup>148</sup> In reaction to the nurse's decision, some community members filed complaints to the Nunee Health Board because they felt it was their right to be examined by a medical professional regardless of the time.

<sup>149</sup> There were several people who mentioned they had fished two tailed fish from the Athabasca River.

<sup>150</sup> During my stay, I used a Brita filter. In the Nursing Station, like all the other Health Centers in this study, bottled water was provided for the staff. This, however, should not be seen as unusual given many places of employment have bottled water in their building.

In sum, the participants' health care concerns reflected similar concerns as the other two communities: diabetes and addictions. However, what is noticeably different is that health care providers are concerned about seasonal infection (reflecting the community's lack of understanding) and the water quality (the possible connection to cancer).

## **Addressing the Health Challenges in Fort Chip**

As discussed in previous chapters, policy makers, decisions makers, and First Nation communities often believe that telehealth may enhance health care services in First Nation communities. According to the participants, many recognized that there are definite proactive preventative measures for addressing the health challenges in Fort Chip. From their comments, several approaches on how to affect change in the health of the community were obvious: education, traditional healing and reorganizing health care practice.

### ***a. Education and Prevention***

Many of the participants, particularly the nurses, recognized that they were reacting to the health problems (diabetes, addictions, and seasonal health challenges) rather than proactively focusing on health promotion and disease prevention. According to one of the nurses, this form of reactionary health care has created unrealistic expectations of health care providers to provide expedient care to address all the patients' problems without any responsibility for their health. As a result, nurses indicated that they often either saw patients for trivial matters or acute illness.

Up until less than half a year ago, the health programs supporting health promotion and disease prevention were understaffed. One participant indicated that health program continuity required effective program development in the face of high staff turnover, but this was often difficult because programs were often staffed by a single nurse. As a result health programs often commenced and ended with staff turnovers. For such programs as diabetes, it was not problematic since the program was well entrenched and several nurses were involved. The Nursing Station has employed other educational endeavors such as collaborations with the local school to reach a larger population.

However, most nurses felt they educated patients on a one-on-one basis, which was very time consuming.

In the Nursing Station, the educational literature was displayed in the waiting room, but whether patients and family members actually read and comprehended this material was another matter.<sup>151</sup> The CHR translating for elderly patients said that most did not comprehend the information provided or how medications worked. She used an example to illustrate the patient's perspective: taking one Aspirin does not reduce the headache, so they consume more pills or quite taking Aspirin altogether. She indicated that these types of patients generally do not adhere to the doctor or the nurse's request to come back into the clinic for follow-up visits when the drugs fail to perform or have unbearable side effects.<sup>152</sup>

In sum, while all the nurses in the interviews acknowledged the need for health promotion and individual responsibility, they also recognized that much of it has not been successful due to a variety of reasons: lack of patient comprehension and literacy, lack of staff and time, and lack of programs. However, what they did not mention was the manner in which these health educational or promotional efforts were delivered. Did the nurses provide culturally appropriate information? Could the patients modify their behavior with the resources at their disposal? If they recommended patients eat a nutritious diet, they would encounter barriers to accessing quality food. As well, as much as health promotion and patient empowerment was desired it was difficult to assess. At the heart of patient empowerment lies the individuals' ability to trust and believe the information provided to them. This is difficult when two nurses in the community were criminally charged for stealing narcotics and for fraudulently posing as health care professionals.

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<sup>151</sup> During my research throughout the three communities, I did not observe any community members selecting a pamphlet and reading it.

<sup>152</sup> At a health education seminar on tuberculosis for nurses in the ATC region and in informal conversations with the nurses at the Station, this form of health literacy is one of the most problematic issues facing tuberculosis patients and those on antibiotics because patients do not understand medications need to be completely consumed to effectively address their illness.

## b. Work Practice<sup>153</sup>

The work the participants undertook varied with their experience, educational attainment, responsibilities, and roles. The chart below summarizes some of the participants work responsibilities and what they hoped to accomplish in the near future to achieve their professional goals. The chart is provided to contextualize the existing responsibilities of staff members and how these may change as telehealth is incorporated into their work routines.

**Table 6.5: Participants' Work Responsibilities**

Staff	Work Responsibilities
<b>Homecare</b>	
RN – H1	<ul style="list-style-type: none"> <li>All homecare patients, oversee CHR work team and administration</li> </ul>
CHR 1	<ul style="list-style-type: none"> <li>Diabetes patients (vitals and home visits)</li> </ul>
CHR 2	<ul style="list-style-type: none"> <li>Diabetes patients (vitals and home visits)</li> </ul>
CHR 3	<ul style="list-style-type: none"> <li>Translator, physiotherapy assistant</li> <li>Enhanced responsibilities: Telehealth coordinator</li> </ul>
Personal Assistant	<ul style="list-style-type: none"> <li>Translation</li> </ul>
<b>Public Health</b>	
RN – P1	<ul style="list-style-type: none"> <li>Maternity health, environmental health, communicable diseases (but not STIs), disaster planning and acute services</li> <li><b>Enhanced responsibilities:</b> Injury prevention and health promotion</li> </ul>
<b>Clinical / Treatment</b>	
NP- T1	<ul style="list-style-type: none"> <li>Diabetes surveillance, women's health (paps and swabs)</li> <li><b>Goal:</b> Incorporate more tests (mammograms, bone densitometry scan &amp; etc.)</li> </ul>
RN – T2	<ul style="list-style-type: none"> <li>Administrative responsibilities and on-call duties</li> <li><b>Goal:</b> Maximize human resources for efficient Station</li> </ul>
Physician	<ul style="list-style-type: none"> <li>Patient care</li> <li><b>Goal:</b> Public advocate for cancer investigation</li> <li><b>Goal:</b> Future telehealth clinical consultations</li> </ul>
RN – T3	<ul style="list-style-type: none"> <li>Well women, well babies, chronic cases, on-call duties</li> <li><b>Enhanced responsibility:</b> Future telehealth clinic nurse</li> </ul>
RN – T4 <sup>154</sup>	<ul style="list-style-type: none"> <li>On-call duties</li> </ul>
Transportation (BM)	<ul style="list-style-type: none"> <li>Coordinate, arrange and follow-up on transportation and accommodations for patients and their family between services and Health Canada</li> </ul>
<b>Administration</b>	
Reception 1	<ul style="list-style-type: none"> <li>Reception, telehealth, assistant to nurses</li> <li><b>Goal:</b> Changing jobs for something less stressful</li> </ul>
Receptionist	<ul style="list-style-type: none"> <li>Reception, assistant to head nurse</li> </ul>
Telehealth coordinator	<ul style="list-style-type: none"> <li>Resigned her job</li> <li><b>Future changes needed to existing job role:</b> More telehealth coordination with clinical work</li> </ul>
Administrator (Ad1)	<ul style="list-style-type: none"> <li>Administration of health care services</li> </ul>

<sup>153</sup> In this section a brief discussion of changing practices in the Nursing Station is provided, but the policy implications will be examined in the chapter on the cross case comparison and analysis.

<sup>154</sup> This nurse had five years of nursing experience in Nunavut before taking a leave of absence and being hired in Fort Chip.

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|--|---|
|  | • <b>Goal:</b> Develop telehealth and enhance future health care services |
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Of the nurses in the Nursing Station, the homecare and public health nurse have worked in Fort Chip for more than five years, enabling them a longer duration of time to establish and implement health care programs and work flow. As well, the nurse practitioner had four to five years of experience in the community, but her work was disrupted for a lengthy time when she switched from being an employee of Health Canada to being an employee of Nunee Health Board. The nurses working in Fort Chip generally have a high rate of turnover, but the community health representatives (CHRs) have often been employed for longer duration of time. Some participants indicated that telehealth may be incorporated into their work (discussed further below). Others focused on changing existing practices, emphasizing that the constraints require innovative approaches to using human resources to enhance health care services. Both of these options would change the existing flow of work and responsibility within the Station.

In sum, the changes in health care staff challenge the stability of health programs at Fort Chip. Given the existing load of work on health care staff any incorporation of telehealth into their work will likely affect how they perform their jobs.

#### *c. Benefits and Challenges of Work in Fort Chip*

Many of the participants work in Fort Chip for various reasons. Community members work in the Nursing Station to be close to their family and friends, but it is also an opportunity to assist in improving community health while being financially well compensated. For some of the nurses, the benefits of working in a northern rural remote First Nation community are: practicing the full range of nursing instead of specializing in one area; being able to care for an individual throughout his or her life; and they enjoy the autonomy of their practice (without the consistent presence of a physician). It is, as one nurse, put it “very difficult to get bored”. As well, some of the nurses acknowledged that the cost of housing was lower in rural and remote communities.<sup>155</sup> These benefits made nursing work a desirable job.

When asked about the negative aspects of working in rural and remote communities, few openly responded except to say that patient self care was challenging.

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<sup>155</sup> The cost of housing was lower, but, as mentioned earlier, the cost of food was not.

However, the tension and stress of working in an isolated community was obvious to an observer. Fort Chip's rural and remote location also hindered social entertainment and community involvement: the movie theatre closed long ago and the recreation center was damaged by fire. In the winter, ice fishing and snowmobiling were available, but if the health care providers did not develop friendships in the community then they were socially isolated. The nurses were often not only each other's strongest support in the workplace, but, for some, they are each other's friends. The lack of social support for the nurses beyond their immediate work relations, particularly for those new to Fort Chip, meant that some were unable to balance the stresses of work.

In sum, many of participants enjoyed working in Fort Chip: the rural and remote community setting enabled nurses to practice the full range of nursing skills. For community members, many returned home to care for family or to be close to friends.

#### ***d. Changing Work Practice in the Nursing Station***

While the nurses felt health education was important, they also recognized that reconfiguring the fundamental ways of health care work was necessary to address the health challenges in the community. These changes involved the way health care programs were implemented and the way human resources were managed. During the research, Fort Chip health care providers attempted to make these changes and some of these practices were immediately observable.<sup>156</sup>

One of the clinical nurses made some concrete suggestions on how nursing should focus on prevention at the Nursing Station: first, nurses needed time to develop, plan, and implement their programs. Second, clinic time and health program schedules should be separated to prevent programs being offered during clinic hours. The nurses' work in their respective health programs would increase surveillance facilitating prevention while the physician focuses on treatment. These nurses acknowledged that the financial budget may not support additional nursing staff, but a change from "putting out fires" to prevention and health promotion would maximize existing human resources.

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<sup>156</sup> The nurses had granted me permission to record the duration of their full day discussion, but only the morning session was recorded. Due to the number of interviews conducted in Fort Chip there was insufficient time and money to fully transcribe the eight hour meeting. Instead, the observations and notes from the meeting have been used to inform the examination of the interviews.

To address the changes in practice within the Nursing Station, a meeting was held on February 6, 2007. The nurses decided that they would immediately implement a half day for program development, planning, and implementation. The Nursing Station closed for half the morning on Thursdays and patients were scheduled to see the nurse after lunch. These changes produced several results: it reduced the flow of patients; enabled more time for planning health programs; provided more time for follow-up with lab work and specialists. As well, during the meeting, a number of significant questions about the operation of the Nursing Station were presented: first, should the Nursing Station be doctor or nurse driven?<sup>157</sup> Second, are nurses practicing within their scope of practice? Many nurses practice in the north because they could exercise their full range of skills with littler physician involvement. However, some feared that telehealth may inadvertently make northern nurses a “handmaiden to the doctor” – contrary to their existing autonomy.<sup>158</sup> Lastly, what can nurses do to enhance practice while practicing within their scope? The answer to this question seems to lie in maintaining more telephone / telehealth consultation with the physician.

Other suggestions for improving work in the Nursing Station included: reducing or eliminating over-the-counter medications at the Station to reduce the number of patient visits. As well, the nurses themselves felt increasing the number of nursing staff would also improve patient care. At the time of the research, the treatment nurses often took holiday leave and contract nurses were hired to fill in their position. Instead of disrupting work in the clinic, these intermittent contract nurses, and the occasional doctor, provided much reprieve and collegiality for the staff nurses at Fort Chip.<sup>159</sup>

In sum, the participants' indicated that existing health care services could be better managed by developing and implementing health care programs that focused on

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<sup>157</sup> At the time, according to one of the participants, the Station was nurse driven because the doctor was only available on Tuesdays and Wednesdays; the nurses bore the brunt of the treatment work while consulting with the doctor on some patients throughout the rest of the week.

<sup>158</sup> At the time of my research, three of the four treatment nurses were taking classes to upgrade their RN status to the level of Nurse Practitioner because of the changes to Nursing Practice in Alberta. This would enable them to prescribe some drugs and work more independently from physicians. When I informally asked why some of they did not want to just get an MD designation, many responded that they became nurses because it was a different practice from being a physician; they enjoyed being nurses. As well, the financial cost of returning to school was beyond their capacity. All three of the nurses were working full time and taking on-line courses to complete their requirements.

<sup>159</sup> During my research stay, three contract nurses provided intermittent service and one physician provided two locums to alleviate the staff personnel.

prevention rather than simply being treatment oriented. The Nursing Station reconfigured their time allocation to adjust to this approach. The participants, while seeing the benefits of telehealth in health care prevention and patient consultation, were wary of whether telehealth usage would modify the existing autonomy of the nurses and increase their work responsibilities. What is uncertain in this discussion on work practices is the degree that CHRs and receptionists would facilitate telehealth use, and conversely, if there are immediate implications on their work.

## **Technology Use**

Most of the participants were familiar with the computer and various programs to complete their job tasks. High speed Internet access, however, was temperamental at the residential nursing units and most residents in Fort Chip did not have access.<sup>160</sup> Most of the participants indicated that they only used the Internet and computer for work related purposes, but a few were enrolled in continuing education courses. Of the six nurses, three of them were intent on either finishing or working on their Nurse Practitioner designation on-line. Many of the participants indicated that they received continuing education through telehealth, on-line courses, or, as with the case in the tuberculosis seminar hosted by Health Canada, attended it in person in any number of the northern communities or in Edmonton including Fort Chip. The reasons they preferred on-line or telehealth educational courses over onsite were related to the lack of time, financial constraints, and travel. Some courses that participants mentioned they were actively seeking were: wound care, drug information, nursing, business and computers.<sup>161</sup> As well, participants could attend the local Keyano College to upgrade their skills.

In sum, most of the staff personnel in the Nursing Station Fort Chip were continuing their education on-line and off-line. They were familiar with some of the capabilities of the Internet, computer and telehealth for educational purposes. One

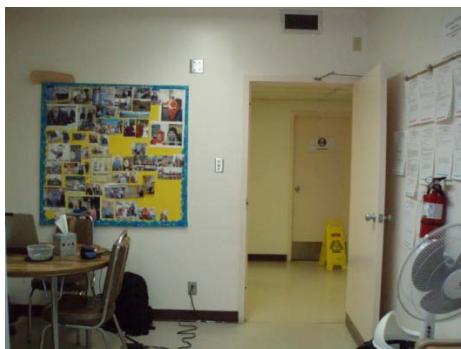
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<sup>160</sup> At the time of research, SuperNet connectivity was established and the provincial and federal offices received high speed Internet access. However, as I had mentioned before connectivity often faltered below -30°C and this was soon remedied through some conversations with Health Canada, the Internet provider, and Axia (the company managing the SuperNet).

<sup>161</sup> Other courses that could not be accessed were: massage therapy.

participant mentioned that there were many tele-learning opportunities for administrators, nurses, and paraprofessionals such as the CHRs. However, there were no courses on how to use telehealth.

### Telehealth in Fort Chip



**Images 6.5 Telehealth Setup at Fort Chip 1**

The path towards telehealth usage in Fort Chip operates separate from the rest of the Nursing Station: the phone calls are not routed through the front desk since it has its own telephone line, coordinator, and schedule. The site for telehealth operations is comprised of three different spaces: the kitchen where tele-learning sessions are posted; the coordinator's office is to the left of the bathroom across the hall in the picture above. The telehealth information sessions posted in the kitchen (site of morning coffees, farewell parties, personal conversations, and temporary office space) range from psychiatry to diabetes. The third site of telehealth was the physiotherapy room.



Left: setting up the new system.



Right: New system and the old system

In the pictures above, the old telehealth system is a simple TV with a camera mounted on top of the screen with a series of telephone lines connected to the system.

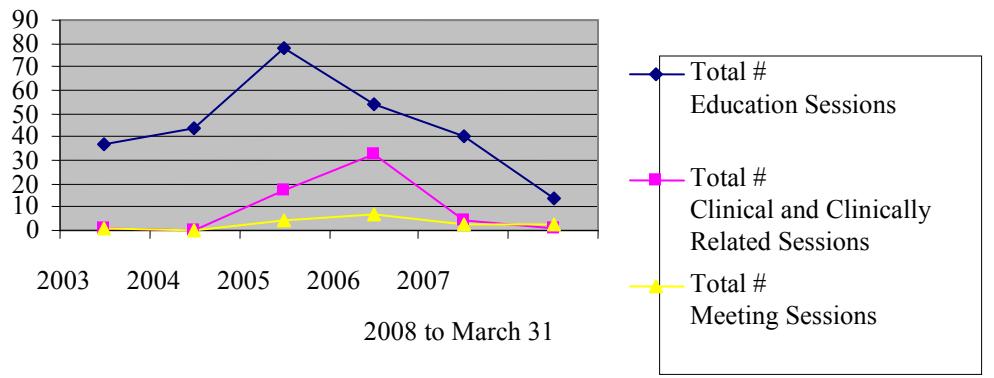
The telehealth equipment is situated at the front of the room among the physiotherapy equipment; upon entrance into the room one could imagine the physiotherapy patients staring at the traditional TV with the large screen. A week prior to my departure, a flat screen telehealth system was delivered to the Nursing Station; it was set up in the physiotherapy room (picture on the right).

However, as the reader can see in the above photos, the exam table and the chairs for the telehealth participants were about two to three feet away from the equipment on the picture to the left. When the patient sat down, the new large flat screen TV was significantly above the viewer's eye level. If there were more than three or four telehealth participants in the room, individuals had to sit on the exam table or among the physiotherapy equipment. At the end of the day, however, the large flat screen TV, as many of the staff members called it, was wheeled away to the storage room a day after it was set up because there was no connectivity. The location and design of the telehealth equipment is important to consider because, for some participants, it became a barrier for telehealth usage.

#### **a. *Telehealth Usage***

During my two months of field research, telehealth was rarely used: several times for diabetes learning (patients initially registered, but did not attend); and twice for conference meetings related to this project. In the graph below, telehealth usage has fluctuated over the years in Fort Chip. In the telehealth logged by FNIHB, there are three types of telehealth sessions: education, clinical and meetings.

**Figure 6.2: Fort Chip Telehealth Session Type Comparison**



Source: FNIHB, Alberta to Mah (2008)

Of the three types of telehealth sessions, meetings have stayed relatively the same from 2003 to March 2008. Education sessions and clinical sessions have declined the most. Between 2003 and 2005, education sessions increased from 38 to 80, more than 50% increase, but from 2005 to 2007, the decline was almost equal to the rise in usage. From 2007 to 2008 the trend seems to indicate an accelerated decline in telehealth usage, but this is unknown since all the numbers for 2008 were not provided at the time. Clinical sessions also followed a similar pattern: a rise in telehealth usage from 2004 to 2006 than an accelerated decline from 2006 to 2007.

One of the reasons for the decline in telehealth usage may be due to Health Canada's nursing staff reshuffle from 2005 to 2006.<sup>162</sup> Two participants indicated that this reshuffle disrupted the health care programs being offered at the Nursing Station. As well, at the time of observations, the Nursing Station was in the process of re-establishing and developing new health care programs – potentially drawing health care staff's attention away from telehealth to other health care areas. The lack of staff may have decreased program availability for health promotion and therefore patient interest in telehealth education sessions. In 2006, the telehealth coordinator quit her job and the CHR for physiotherapy acquired the role as telehealth coordinator in addition to her existing responsibilities. As well, health care programs such as enhancing patient awareness of diabetes through telehealth sessions on healthy eating may have also

<sup>162</sup> At the time of research, Fort Chip had gained complete control over health care services (including hiring nursing staff). However, prior to 2005, Nunee may have had only partial control which explains why some of the nurses were Health Canada nurses.

increased the number of times telehealth connectivity was recorded by FNIHB, but not whether individuals attended. All these factors may explain the changes in the telehealth log.<sup>163</sup>

*b. Participants' Perspective of Telehealth*

While my observations indicated that telehealth was not used very often, many participants had used telehealth at one point or another. In the chart below, I have summarized the participants' comments and perception about the positive and negative attributes of using or accessing telehealth.<sup>164</sup>

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<sup>163</sup> However, as I mentioned earlier, connecting to the sessions does not confirm the attendance of patients, health care providers, or administrators.

<sup>164</sup> The nuance of seeing something positive suggests a contribution or enhancement and negative as something deficient or lacking.

**Table 6.6: Fort Chip Participants' Positive Perceptions of Telehealth**

<b>Telehealth Attributes</b>	<b>Positive</b>
<b>Access to Services</b>	<ul style="list-style-type: none"> <li>• Can access clinical services (useful during Christmas and New Year period travel is challenging) (D, T3, T1)</li> <li>• Relieve the short supply of physicians and offer choice (D, T2)</li> <li>• Use telehealth more for clinical (x-rays) (Ad, P1)</li> <li>• Limitless applications and possibilities to available 24/7 (D)</li> <li>• 2 consultations with orthopedic surgeon without traveling (H1)</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Existing workload prevents time to use telehealth for learning (P1)</li> <li>• No clinical consultations (T2)</li> <li>• Question: what about the need to touch your patient (S) ... much of what is needed to make a diagnosis is based on the patient's history and a pair of reliable hands on the other end, which can be observed via video (D)</li> </ul>
<b>Access to information</b>	<ul style="list-style-type: none"> <li>• Can access information, educational, and support services without flying out (TP, PA, CHR1, CHR3, T3, H1, T3, P1, D)</li> <li>• Learning sessions enabled NP to make a diagnosis (T1)</li> <li>• New way of delivering possible physician services to community (CHR3)</li> <li>• Similar to videoconferencing for education; the experience was comfortable (D, R2)</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Information presented too advanced for the community members and staff ... too many sites connected to answer questions (TC)</li> <li>• Redundant information presented (PA)</li> <li>• People prefer to travel to Fort McMurray or Edmonton because they can include a shopping trip (T1)</li> </ul>
<b>The Human Factor: Staying Connected</b>	<ul style="list-style-type: none"> <li>• Can see the other person (TP)</li> <li>• Can visit family members (TP, D, PA, Ad, CHR2, R2) (used to visit her dad because of the fog unable to fly out in spring)</li> <li>• The human interaction factor: talking to someone or "the person laughs ... it's a real person" (P1, T3, D) (D: informing the family members of sick grandmother in FM in FC, there were tears and hugs at the end), trust in the physician (D)</li> <li>• Quality of information is dependent on the speaker (T3)</li> </ul>

In the chart above, the participants' perspective of the positive outcomes of telehealth use was based on their desire to access health care services and information and staying connected to people. The type of health services some participants indicated that they have accessed through telehealth in the past are: orthopedic surgeon when the patient could not travel; the doctor consulted a family in Fort Chip at his patient's end of life process; family visits to reduce patient isolation in urban hospitals. As well, many participants mentioned that telehealth played a role in information provision and as a support to enhance their health care practice. Telehealth's ability to bridge geographic distance, reduce travel and connect individuals to families, services, and information

compelled two participants to consider it as a possible alternative to face-to-face physician service in the community.

There are, however, some challenges with trying to use telehealth programs: lack of time for participants to use telehealth (heavy workload); frustration with redundant information; and inappropriate or jargon filled information sessions. According to one participant, these challenges can be mitigated by the presenter: when the presenter is real – that is – s/he laughs – the presenter becomes a real person on the screen.

The participants also had negative perceptions of telehealth and telehealth usage. The chart below illustrates the participants' negative perceptions were focused around cramped physical space, the human factor, and the frustrations with the technology system.

**Table 6.7: Participants' Negative Perspective of Telehealth**

<b>Negative Attributes</b>	
<b>Space</b>	<ul style="list-style-type: none"> <li>• Lack of space for a dedicated telehealth room (learning services) ... existing space not very professional sitting on physiotherapy beds (R, TC, T3)</li> <li>• Conflict with physiotherapy, so must book around it (TC, CHR3)</li> </ul>
<b>The Human Factor</b>	<p><b>Awareness:</b></p> <ul style="list-style-type: none"> <li>• Not enough people know about telehealth (CHR3, Ad1)</li> <li>• Not enough people are in the habit of using it (Ad1, CHR2, T3)</li> </ul> <p><b>Organization:</b></p> <ul style="list-style-type: none"> <li>• Lack of communication between coordinator and interested participants (CHR1)</li> <li>• Lack of human resources for coordination (CHR2)</li> <li>• Lack of preparedness or organization (T2)</li> <li>• Sessions get cancelled because of only one person connecting, so would only use it if she had to (PA)</li> </ul> <p><b>Interaction:</b></p> <ul style="list-style-type: none"> <li>• It's not personal communication; telehealth can create a barrier to talking. People don't know how to interact via telehealth (when to speak, ask questions, laugh) (T3)</li> <li>• Technology can disrupt communication (push the wrong button) (T3)</li> <li>• People are camera shy (CHR1, T2, Ad2)</li> <li>• Lack of confidentiality (many witnesses to a single event) (CHR3)</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• People don't show up for their sessions despite signing up (CHR1, CHR3)</li> </ul>
<b>Technology System</b>	<ul style="list-style-type: none"> <li>• Frustrating technology failures to connect have been numerous; it is unreliable and inconsistent = wasted time and effort (T1, T2, T3, R, P1, H1)</li> <li>• Sound and image quality and consistency (cutting out or fuzzy or squiggle lines like a poor TV connection), connection falters, need to see people's faces (including all the participants that join from elsewhere) (TP, CHR3, PA, T3)</li> <li>• Requires a lot of phone conversations to correct problems with different administrators in Health Canada, technical companies etc (T2)</li> <li>• Nursing Station paralyzed by poor Internet connectivity (T2, H1)</li> <li>• What is the cost for a compatible technology system (SuperNet connection and LSDN)? (Ad1)</li> <li>• Telehealth unit fixed in one location, not mobile (H1)</li> <li>• Can be intimidating, not a desk unit (H1)</li> </ul> <p><b>Human Factor:</b></p> <ul style="list-style-type: none"> <li>• Can't see who is talking in sessions (H1)</li> </ul>

The lack of space shaped how participants viewed their telehealth experience.

The participants' indicated that the cramped space prevented tele-learning and meetings from being professional, particularly when they had to sit on beds and other props to view the screen. Situating telehealth in the same room as physiotherapy also meant that if people were in physiotherapy sessions, others could not use telehealth. For some individuals, the solution to the lack of space was either to purchase a mobile telehealth unit or create a separate space for telehealth.

The other challenge for telehealth usage involved human factors. The human factor challenges are organizational in nature, the lack of community awareness, and the human interaction over telehealth are problematic. At the organizational level, one participant indicated that telehealth sessions were poorly coordinated and communicated to potential users about session availability, causing missed opportunities or cancelations. Some participants indicated that community members were not aware of telehealth sessions being provided and others, if aware, were not familiar with the technology. One participant mentioned that the lack of preparedness occurred at both sites: Fort Chip and the interacting site. While these organizational issues were not severe, they produced disruptions, disappointments, and frustrations. Participants attributed some of these feelings to the failure of staff and patients to develop telehealth routines and habits of use.

The other type of human factors that several participants observed was their interactions with other telehealth users: lack of personal communication or active involvement in the learning environments. She noted that telehealth created a barrier in the communication exchange: people often did not know when to ask questions, speak, or laugh. Several other participants mentioned that people were aware of the camera and they became “camera shy”. Consequently, where the intent of telehealth was to enable visual and audio communication, participants’ lack of familiarity with the technology and self consciousness, instead, produced silence.

Lastly, many of the participants were frustrated with the technology because it disrupted human interaction; they found the technology unreliable and inconsistent: failure to connect, poor connection leading to blurry images and poor sound quality and user error in pushing the wrong button. At the time of the research, telehealth connectivity was not fully optimal since two of the six LSDN lines were not functioning. As well, Internet connectivity over a period of several weeks was dropping every few seconds. Several participants associated Internet connectivity to the SuperNet and the overall performance of telehealth, not realizing the two operated on separate systems: telehealth was connected through TELUS.<sup>165</sup> T2’s frustration with repeated efforts to find a technician to fix the Internet connectivity spilled over to her regard of telehealth as

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<sup>165</sup> At the time of research, FNIHB’s plan was to switch telehealth from LSDN lines to SuperNet connectivity; it just had not done so quite yet.

just another example of problematic technology. Overall, while telehealth presented participants with many opportunities, the technical challenges hindered their regard of its ability to mediate information, support and health care services.

### **c. Improving the Telehealth Experience and Usage**

When participants were asked how telehealth could be improved, participants responded that telehealth could be improved in a variety of ways. They made suggestions that focused on enhancing the overall telehealth experience during a session, on the user herself, trouble shooting, organization, and raising awareness.

**Table 6.8: Fort Chip Participants' Recommendations for Changing Telehealth**

Telehealth Experience	Ways to Improve
Experience	<ul style="list-style-type: none"> <li>• <b>Technology set-up:</b> TV could be higher (eye level), permanent cameras to capture the entire room</li> <li>• <b>Room:</b> space to sit together, space that is telehealth specific, a boardroom; need a new building</li> <li>• <b>Improving Comprehension:</b> <ul style="list-style-type: none"> <li>• Sessions should be taught in Cree or Chip</li> <li>• Presentations should be paced and explained to increase comprehension</li> </ul> </li> </ul>
User Initiative	<p><b>Awareness:</b></p> <ul style="list-style-type: none"> <li>• Increase personal phone calls to inform and less posters,</li> <li>• target all age groups not just the elderly, including those who don't understand</li> <li>• More promotion to raise awareness</li> </ul> <p><b>Individual motivation:</b></p> <ul style="list-style-type: none"> <li>• Sessions need to be specific to the community's needs,</li> <li>• Need to frequently use it, develop a habit</li> <li>• Individual initiative to use technology on both ends ... ex. patient wanted to see doctor and showed up for sessions</li> </ul>
Troubleshooting	<ul style="list-style-type: none"> <li>• Technician on-hand to ensure telehealth is operational</li> <li>• Train all the users, so everyone can troubleshoot</li> <li>• Fail proof it to ensure time is preserved</li> <li>• Need to test pilot telehealth applications</li> </ul>
Scheduling / Organization	<ul style="list-style-type: none"> <li>• Multiple sessions, but only one can be seen at a time</li> <li>• Coordinate times of availability for connection to specialist and Fort McMurray hospital ... requires contract to a doctor willing to serve Chip residents</li> <li>• Will the doctor be available for telehealth outside of clinic in Fort Chip?</li> <li>• Applications: x-rays sent to radiologist, but who will receive it?</li> </ul>

The participants' made suggestions on how the telehealth experience could be improved and these can categorized according to: improving the technology set up, the location of telehealth sessions, and the comprehension of the sessions. First, telehealth set-up could be improved to enhance visual quality by: a) changing the camera settings to

the users' eye level; b) mounting permanent cameras mounted on the wall to visually capture everyone in the room; c) displaying everyone from the various sites on the screen (at present the system only enables the presenter's site, creating a disembodied experience with multiple voices); d) improving the connectivity in order to enhance the quality and consistency of the audio sound and image. Participants indicated that often the sessions would begin well, but the audio and image distortion is often distracting. Second, three of the participants indicated that telehealth requires a dedicated room to maintain a sense of professionalism. Lastly, a participant suggested that telehealth sessions require modification for elders to ensure comprehension such as: Cree or Chip language presence; culturally appropriate explanations; slower pace of information delivery.

The participants recognized that technology may fail even with the best of organization and intentions. The view towards how to fail proof telehealth was split. On the one hand, participants' recommendation to train all users to reduce disruption or time wastage due to technical delay seemed to place technology solutions into the hands of the users. On the other hand, several participants indicated that telehealth users could troubleshoot, but it was not within their job responsibilities. These telehealth users suggested that a technician oversee Internet technology and telehealth to ensure optimal function rather than, as another participant indicated, waste her time (better used for gaining health information or providing health service to the patients). Several participants illustrated their previous experiences with troubleshooting telehealth: calling the TELUS operator<sup>166</sup> and relying on the former telehealth coordinator. To avoid future problems with telehealth consultations for patients, the administrator and physician indicated that test piloting a few sessions to anticipate potential problems would be beneficial.

The other type of suggestions participants made were organizationally related: first, select telehealth sessions according to community need in cases where concurrent sessions were offered. At the time of the research, sessions were selected according to the programs being offered and individual health care staff preference. Second, organizational agreements must be in place to ensure patient consultations with specialists

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<sup>166</sup> As mentioned earlier, the telehealth system in Fort Chip relied on telephone lines.

from other hospitals were available. These types of application require agreements between organizations to share and support health care services across jurisdictions.<sup>167</sup> These types of organizational challenges hindered telehealth usage in Fort Chip.

Lastly, participants made recommendations pertaining to telehealth users themselves. Several participants indicated that telehealth usage was related to individual initiative and motivation. One participant mentioned that the lack of usage was due to the lack of awareness; she wanted to raise awareness through information posters, phone calls, and personal conversations. The participant also mentioned that to increase telehealth usage, the Nursing Station needed to expand its demographic target to include, not just the elderly, but the young as well. The participants recognized that the most important aspect to increasing usage was developing habitual telehealth usage both at the Nursing Station and other health care centres – without which participants indicated that telehealth would remain simply a novelty.

Many participants understood the barriers to telehealth usage: space, human factors, and the technology system. However, they also had insightful suggestions on how to overcome these challenges to foster regular usage of telehealth in health care practice, particular at the level of the individual, organization, and technology system.

### **Summary of Fort Chip Case**

Fort Chipewyan's rural and remote location near the heart of Alberta's oil and gas industry is significant in understanding the community's health issues. First, the health challenges facing the community may be environmentally related (cancer). Second, the difficulty in accessing health services may exacerbate the severity of health conditions, particularly in delaying diagnosis and treatment. Third, the participants' concern that nurses may be practicing beyond their scope of practice due to the shortage of health care providers and the health care needs in the community. The community's ability to provide health care services, like many northern communities, is hampered by high staff turnover due to stress and isolation. Up until 2007, the physician in Fort Chipewyan had worked in the community for seven years and during that time there have been significant changes in nursing staff retention, affecting the type of health care programs offered and

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<sup>167</sup> At the time of research, several stakeholders acknowledged and were attempting to resolve some of the jurisdictional challenges surrounding telehealth services for First Nation communities in the ATC region.

their ability to effectively educate and empower patients. Many of the health care staff mentioned that a dual approach to health care was needed: a combination of health care promotion and patient self initiative to actively tackle diabetes and addictions. These three concerns provide some of the context in which telehealth is or is not used.

Many of the participants mentioned that telehealth played a role in facilitating access to health care services, education for staff and patient, and an opportunity to stay connected to family and other professionals. For the participants, telehealth could reduce isolation, the need to travel, and enable services not accessible in the community. However, they were frustrated with telehealth operation and their experiences such as the lack of physical space afforded to telehealth, technology failure, and human factors such as the lack of telehealth awareness, organizational preparedness and the limitations (cultural, language, visual and audio cues) placed on human interaction over telehealth. These frustrations are reflected in the participants' infrequent use of telehealth in Fort Chipewyan. According to FNIHB's telehealth log, Fort Chipewyan has had periods of relatively high and low technology use.

The participants made a number of recommendations to remedy the infrequent telehealth usage by involving the users, the nursing station and external bodies such as FNIHB. They suggested that changes to the space afforded to telehealth work, telehealth set-up, troubleshooting technology failure, providing community needed services, and enabling cross jurisdictional access to services. Some of the participants recognized that if these changes were made, it would only be effective if telehealth users were motivated to use telehealth and if they developed a habitual routine.

In Fort Chip the case of telehealth is one of yet unfulfilled possibilities and potential: its remote location suggests telehealth use would be ideal for obtaining information and health care services (including connecting to families for tele-visits). However, as the participants have indicated, telehealth use has been shaped by the lack of space, the complexities of human interactions over telehealth, and technology function (or malfunction). The participants indicate that it is possible to change telehealth use through a combination of simple and extensive changes in the organization and scheduling of telehealth programs, personal interactions, as well as technological capabilities.

## **Case 2: Chipewyan Prairie First Nation (Janvier)**

### **Introduction**

At the time of the research, Chipewyan Prairie First Nation or as many call the community, Janvier, was the only community in this study that did not have active telehealth. As part of the agreement between Athabasca Tribal Council and the chiefs of the communities, the research would investigate whether there was a role for telehealth in health care service delivery in First Nation communities. Janvier was one of the communities interested in understanding whether telehealth could play a role in their health care service delivery. The case description below is a synthesis of the interviews and observations made in April 2007 beginning with an understanding of the social and economic background, followed by mapping out the Health care Center, the site of research, and an understanding of the participants. The second aspect of the description is the participants' perspective of the community's health, the health care needs, the participants' work responsibilities, and lastly an understanding of the participants' technology use, including telehealth.

### **Community Background**

Of the three First Nations communities in this study, Janvier, statistically in 2006, had the smallest population at 271, a growth of 7.5% from 2001 of 252 (Stats Can 2006).<sup>168</sup> The community is located approximately 1.5hrs from Fort McMurray. In the chart below, the 2006 Census indicates that the population of Janvier has a significantly higher percentage of individuals without any education certificate, diploma, or degree at 83% of population compared to 34.5% of the Aboriginal population in Alberta and 15.4% of the general population in Canada. The community also has significantly younger population with 30.1%, a low median income of \$19,008, and a much higher

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<sup>168</sup> The statistical figure is often not the real population figure in Aboriginal communities, since it is common for people to relocate seasonally to live with relatives and friends. All the interview participants indicated that the population of Janvier was well over 600 people. Unfortunately, according to the health directors, the statistical population number is the basis for health care fund allocation.

unemployment rate at 18.2% compared to 11.1% of the Aboriginal population in Alberta and 5.2% of the general population in Canada. However, Janvier had a very high percentage (71.6%) of the population that spoke their native Chipewyan language compared to 18.8% of the Aboriginal population in Alberta. By statistical accounts, the community of Janvier is a young community, rich in their Aboriginal language heritage, but poor in economic and educational status.

**Table 6.9: Janvier Education Demographics**

Category	Janvier	Alberta (Aboriginal Population)	Canada
Education (No certificate, diploma, or degree)	83%	34.5%	*15.4%
Percentage of Population below 15 years old	30.1%	31.1%	** 17.7%
Knowledge of:	Aboriginal Lang: 71.6%	18.8%	N/A
	English only: 26.4%	76%	
Labour force unemployment	18.2%	11.1%	***5.2%
Median earnings	\$19,008	\$21,010	****\$41,401

Source: Statistics Canada 2006

**Images 6.6 Health Center in Janvier**



Left: The road leading into the community and the houses facing this modern Health Center (R). During my research stay, the road was very quiet except for the few vehicles traveling to the health centre.

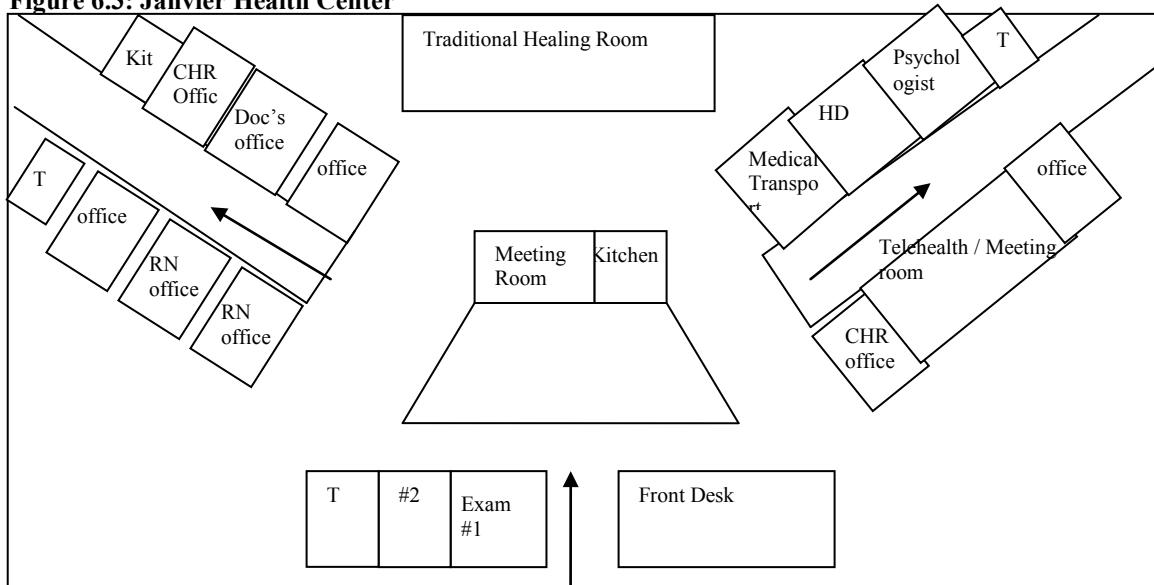
### A Day in the Health Care Center in Janvier

In April 2007, a time of occasional heavy snow falls, I completed the rest of my field research in Janvier. The nurse in the community kindly picked me up for the daily long drive at approximately 8:00 AM for two weeks and we arrived at the health care

center at approximately 9:30 AM, but on heavy snow fall days we arrived in the community at approximately 10:00 AM. The Health Center had normal operating hours between 8:30 AM and 4:30 PM. Unlike the drive to Fort McKay, we did not encounter any Diversity buses shuttling laborers back and forth to work; indeed, the single lane highway from Fort McMurray to Janvier, surrounded by woods and, at the time, a few oil and gas exploration projects, was noticeably quiet. During the April snow, the nurse and the Health Center were on the alert for accidents along this road, but this would have been better facilitated if the nurse's satellite phone could maintain a continuous signal throughout the drive – creating a possible emergency should the nurse encounter difficulties. In the case the nurse did not arrive at work, the health care staff's plan was to send a search team for her.

A few years before my research commenced, the road to Janvier from Fort McMurray was made of dirt, making the drive a hazardous journey. The roads inside the community were made of dirt that turn into mud slush in spring weather. From a visitor's perspective, there were only a few houses built randomly on unfenced properties along the road to the Health Center – lending the impression that only a few families resided in the community. However, most of the homes were built further into the woods, undetected in my initial drive into the community.

**Figure 6.3: Janvier Health Center**



In the above diagram, the Health care Center is built with offices to the left and right; each side requires a key for access. The diagram depicts a building capable of

housing many staff members' offices, but most of these are empty: traditional healing, physician's office and one of the RN's offices. The building resembles a bird with open wings with a brightly painted exterior. In the center of the building, a large spacious meeting room with a small kitchen acts as a communal meeting place and information center. Posters on diabetes, sexually transmitted infections, and nutrition are decorated on the walls with information pamphlets ready for community members on all the tables surrounding the room. Often times, staff members, clients and their family members enjoy coffee or snacks in the room.

By the time the nurse arrives at the Health Care Centre, many of the staff are working, and while the pace of work and the people in the building seem relaxed, the concerns migrating through the doors are not. Unlike Fort Chip, there is only one receptionist to field phone calls. Due to the fact that the nurse and I arrive 1.5 to 2 hours after everyone starts work, I was unable to observe the morning rituals.<sup>169</sup>

## **Reasons for Residing in Janvier**

Out of the nine interviews completed with the participants in Janvier, seven individuals lived and worked in the community. Most of these participants indicated that they lived in the community for a variety of reasons: family, work, having a home, being a community member and they enjoyed the quieter life. One participant said that her treaty status enabled her to own a home; her reason was based on economic need, a dependence on government funding rather than a matter of choice.<sup>170</sup> The other two participants, the nurse and the psychologist, commuted to work from Fort McMurray and Edmonton respectively. They indicated that they chose to work in Janvier because their professional goals: being a community nurse and the ability to practice his specialization in Aboriginal mental health and addictions.

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<sup>169</sup> I did not reside in the community because there were no homes built to house health care professionals for the duration of their work.

<sup>170</sup> She mentioned that her children continued to live on the streets because they did not have treaty status to own a home. At the time the woman married her non-Aboriginal husband, the Indian Act removed her Indian status and her children were not considered status Indians. In 1985, amendments to the Indian Act enabled her to obtain her status. If Parliament enacts Bill C-31, it would entitle the grandchildren of women who lost their status to register for status if their parents obtained status.

The chart below illustrates the type of health care services provided by the participants and their years of service in the community.

**Table 6.10: Health Care Staff in Janvier**

Type of Health care Staff	# of Permanent Staff and designation /title	Years of Health Service <sup>171</sup>
Homecare, public, and community health nurse	1 RN	9
Community Health Representative	1 CHR	27-30
NNADP / Health Director	1 Counselor	7
Medical transport	1 Coordinator	20
Addictions Psychologist	1 MA	2.5 years
Social worker assistant <sup>172</sup>	1 Diploma	~20
Odd jobs staff	1 Grade 7	17
Receptionist	1 Grade 12	3 months
Janitor	1	14

Overall, the participants from the Health care Center provided a substantial number of years of health care service in the community, not to mention some individuals worked in other capacities before health services such as education and forestry, meaning that many individuals have witnessed the community's transformation over the years as community members and service providers.

## **Perception of Community Health**

The participants' perception of Janvier's health is complex. From the participants' perspective, the health of the community is intricately intertwined with some aspect of the community's political, economic, and social state; as well as with the individual's own initiative in maintaining a healthy lifestyle. The chart below summarizes the participants' perception of community health and their suggestions for change.

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<sup>171</sup> Six months prior to the commencement of my research, the doctor terminated his nearly thirteen years of service to the community due to allegations of double charging. However, upon questioning all three community Health Directors, this allegation was unfounded. They indicated that it was common to pay a fee for the physicians' travel time and time away from home. At the time of my research, there was no physician service in Janvier.

<sup>172</sup> At the time of the interview, the social work assistant was not employed at the Health care Center, but she regularly visited.

**Table 6.11: Janvier Participants' Top 5 Community Health Concerns**

<b>Rank</b>	<b>Perception of Community Health</b>	<b>Steps Towards Change</b>
1	Addictions (drugs & alcohol) <ul style="list-style-type: none"> <li>• Violence</li> </ul>	<ul style="list-style-type: none"> <li>• More health care staff</li> <li>• Be an advocate for First Nations' health and change</li> <li>• Coordinate effort between providers and individual</li> <li>• Community unity and involvement</li> </ul>
2	Lack of treaty rights <ul style="list-style-type: none"> <li>• Lack of resources</li> <li>• Housing</li> </ul>	<ul style="list-style-type: none"> <li>• Treaty status</li> </ul>
3	Youth and education	<ul style="list-style-type: none"> <li>• Community involvement</li> </ul>
4	Elderly care	<ul style="list-style-type: none"> <li>• Build a seniors' home</li> <li>• Build a new hospital in the area</li> </ul>
5	State community environment	<ul style="list-style-type: none"> <li>• Individual initiative</li> <li>• Political leadership</li> </ul>

More than half the participants recognized that addictions led to poor job performance and sustainability, lack of social cohesiveness in the community, violence, and familial dysfunction. The psychologist indicated that addictions have eroded relationships and caused violence, abuse, and accidents. He commented that familial relations that bonded individuals together in times of distress have been so badly eroded in some families that many could no longer support one another. As well, the taboos around relations, particularly incestuous sexual relations between first cousins, brothers and sisters, fathers and daughters, sons and mothers may be eroded when individuals lose control due to their addictions. Several participants indicated they no longer spoke with some family members because of the individuals' addictions.

My observations and conversations with the participants confirmed the potential for violence in the community. On April 10, 2007 the Health care Center was locked down because a known violent schizophrenic patient was being sought by the police for the questioning in the possible death of a child in the community. From the conversations I had after the incident, the community had experienced several incidents of violent deaths over the last few years.

Aside from addictions and violence, some participants indicated that many community members were homeless and landless because they lost their treaty status (meaning they could not acquire a home from the band or obtain basic services). If community members did own homes, they were often not well maintained for two

reasons: first, home repairs were difficult to obtain due to the distance from Fort McMurray and; second, the community lacked an efficient sewer and clean water system.

The third most mentioned problem was not related to health as much it was related to the overall health of the community. Some participants indicated that they were concerned by the youths' lack of desire to complete their education and their tendency for late night parties and rowdy behavior, creating an atmosphere of chaos and fear.

The fourth concern was the lack of elderly care. Participants indicated that the elderly were often neglected and isolated in Fort McMurray nursing homes, without community or family support around them. One participant envisioned building a seniors' home in Janvier and the possibility of collaborating with industries around the community to build a full treatment health care clinic to meet the needs of the people in the area.

Lastly, a participant indicated that the community environment was problematic: garbage littered throughout the community often ended up in the mouths of young children and dogs. The participant associated the litter in the community as an indicator of people's apathy towards cleanliness.

Overall, many of the participants recognized that the environmental, housing, and social problems in the community are multifaceted, requiring strong political leadership in the community, individual initiative and responsibility, additional resources from the government, and a coordinated effort between the various social and health care services in the community. One participant noted that Janvier's existing community health has improved with the paved road, which has enabled regular health care provider visits; as well, in the case of emergencies, community members could be transported to the Northern Lights hospital in Fort McMurray.

## **Health Care Needs**

### ***a. Burden of Illness***

The perception of community health is also closely related to the health care needs of the community. Throughout my research stay and in the interviews, several

health care problems were identified: first, drug and alcohol abuse. Only a few people indicated that increasing addictions counseling and programs were necessary to address the problem in the community. Second, several participants mentioned that diabetes was problematic in Janvier. Third, infectious diseases such as TB, syphilis and gonorrhea seemed to periodically overwhelm the health care staff. The nurse was regularly swabbing and taking samples into the lab at Fort McMurray, to the extent that often times, she could not attend to all her homecare clients. For the nurse, at the time of my research stay, it was one of the darkest periods of health care crisis in the community.

***b. Human Resources and Organization***

The lack of health care staff to manage the health care needs in the community was obvious and without a physician or a nurse practitioner, community members were compelled to travel 1.5 – 2 hours to Fort McMurray. The participants themselves offered varying perspectives of whether existing health care services were addressing the health needs and how these resources (monetary and human) could be deployed. First, community members could fill these positions by undertaking further studies to advance the health of the community. Second, some participants indicated that the existing reliance on family members to care for the sick was making those individuals ill. Third, another person indicated the community was in a difficult position –receiving more government funds created dependence while at the same time criticizing the lack of oil and gas royalties for lands surrounding their community. Lastly, one participant indicated that despite the community's Native Alcohol and Drug Abuse Program and the psychologist's services, many community members were not utilizing them. The participant mentioned that community members fail to comprehend the significance of counseling to change destructive behaviors. Instead, some community members only sought counseling at the point of crisis, not prior to or after the crisis. All the participants indicated that more human resources, in the form of health care professionals such as a physician, dentist, and additional nurses, from outside of the community were needed to care for elderly patients and treat diabetes in the community.

The lack of staff became much more pronounced in spring 2008 when the nurse was placed on a three month stress leave by her doctor. This was understandable given

her daily commute and her client load. At the Health Center, there were two vacant offices for nurses, but she occupied all three offices to perform different tasks. A few years prior to the research, Health Canada had employed three nurses in Janvier. The nurse left in the community often partnered up with the receptionist, the odd jobs person, or the CHR to complete home visits to the elderly. The lack of staff was also evident in the number of job tasks individuals shared, requiring them to change or adapt according to the demand. Like the two other communities, many of the participants could do more than one job.

From the interviews, the participants indicated that the lack of staff was due to the lack of funding and the changing political dynamics in community leadership. One participant indicated that she left her job in the Health care Center after the previous community leadership was elected and only returned when new leadership was elected in the community. The changes in leadership resulted in a number of staff changes: the termination of the physician's services in the community; the psychologist who had worked in the community for the past decade retired and he was replaced by the psychologist I interviewed; termination of the medical transport assistant's job; and a few months later when I commenced my research, the first Health care Director I communicated with also resigned her job. As well, Janvier has not had a dentist visit the community in the last nine years and a few years ago, the person performing traditional healing also stopped working in the community. These changes in staff reduced the number of health care service offered and altered the human dynamics in health care services.

Funding and organizational effectiveness are connected to the access of health care professionals both outside and inside the community; as well as the ability of health care programs to build capacity within the community. With the termination of physician's services in Janvier, it lost the ability to treat patients and the Health Center became health promotions oriented: the nurse in Janvier could no longer administer simple antibiotics or even provide pain killers. As well, unlike Fort McKay and Fort Chipewyan, Janvier does not have transfer status. This means nurses are employees of Health Canada rather than employees of the First Nation. The former Health Director at Janvier did not reveal the reasons why Janvier was unable to gain transfer status or how it

lost transfer status. She did mention that funds were not properly managed, one of the criteria for gaining transfer status.<sup>173</sup> During my research, two Health Canada nurses visited Janvier to assist the local nurse with immunizations and homecare visits. However, the assisting nurse mentioned that since she is not the local nurse, she must be sensitive to the way health care programs are practiced in the community.

## **Work Responsibilities**

### **a. Routines**

The chart below illustrates some of the participants' work responsibilities; they are recorded here as a means of situating future telehealth work.

**Table 6.12: Janvier Health Care Work Responsibilities**

<b>Health care Staff</b>	<b>Work Responsibilities</b>
Homecare, public, and community health nurse (N)	<ul style="list-style-type: none"> <li>• Homecare</li> <li>• Public health</li> <li>• Transport lab samples to Northern Lights hospital</li> <li>• Well Child Program</li> <li>• Coordinate client and family transportation and accommodations</li> </ul>
Community Health Representative (CHR)	<ul style="list-style-type: none"> <li>• Environmental health (water sampling)</li> <li>• School presentations on STIs</li> <li>• Assist the nurse</li> </ul>
NNADP / Health Director (Ad)	<ul style="list-style-type: none"> <li>• Addictions counseling</li> <li>• Management of the Center</li> <li>• Head Start program</li> </ul>
Medical transport (MT)	<ul style="list-style-type: none"> <li>• Scheduling patient transportation</li> </ul>
Addictions Psychologist (C) (P)	<ul style="list-style-type: none"> <li>• Counseling in 3 locations (Janvier, Conklin, &amp; Edmonton)</li> </ul>
Social worker assistant <sup>174</sup> (SA)	<p>Formerly worked as</p> <ul style="list-style-type: none"> <li>• Health Director</li> <li>• Medical Transportation</li> </ul>
Odd jobs staff (O)	<ul style="list-style-type: none"> <li>• Greeting people, answering the phone, photocopying, cleaning</li> <li>• Visiting patients</li> <li>• Assisting CHR &amp; nurse</li> </ul>
Receptionist (R)	<ul style="list-style-type: none"> <li>• Photocopying, writing letters, answering phone</li> <li>• Assist the nurse</li> </ul>
Janitor (J)	<ul style="list-style-type: none"> <li>• Cleaning</li> <li>• Assist the nurse</li> </ul>

Job responsibilities are often not clear cut. For example, the receptionist's response to my question of what her job entails is typical of receptionists work:

<sup>173</sup> See chapter 5 for more information on the structure of health care in First Nation communities.

<sup>174</sup> At the time of the interview, the social work assistant was not employed at the Health care Center, but she was expecting to be re-employed in the Health Care Centre.

photocopying, taking messages, writing letters and directing calls to the nurse. Upon further inquiry this set of responsibilities changed during a crisis and a lack of staff in the Health care Center; she often assisted the nurse.<sup>175</sup> Some participants such as the janitor, receptionist, and odd jobs person may have unspecified, but normalized job tasks such as assisting the nurse on homecare visits and at the Health care Center. As mentioned earlier, the nurse also performed a job usually meant for two nurses: homecare and community health. However, performing two roles means she is often unable to complete them to the full extent. The CHR doubled her job by performing environmental health (water sampling), school presentations on sexually transmitted infections, and assisting the nurse on public health tasks such as immunization. The medical transportation worker performed her job plus the job of her previous clerk. The NNADAP counselor was also the Director of the Health care Center. Many of the individuals completed tasks beyond their initial specified job descriptions which have become normalized in their day to day work. In other work environments, taking on additional job tasks may be seen as individual initiative towards skills enhancement, but here it was the norm.

Given the participants' multiple job tasks, it was not surprising to hear that there were very little routine in the participants' daily work. The NNADAP counselor, nurse, and psychologist indicated that their work was dependent on encounters of the moment or whatever problem entered the Health care Center. The psychologist reasoned that there was a tendency or natural desire to be an activist and begin changing things, but without patient and community trust one was powerless to affect any change. He often waited for his patients to show up, no appointments needed, so as not to enforce a schedule or an action plan onto a community. The NNADAP counselor also worked in the same manner, no appointments necessary. The nurse followed health programs: communicable disease, the immunization program, well child and homecare are mandatory programs. She, however, did not mention if there were specific days for each of program. The CHR indicated that she had a Monday routine for water sampling in the community. Overall, most of the participants emphasized their job flexibility rather than their routines, the need to respond to changes in their work environment.

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<sup>175</sup> In most communities, community health representatives with educational training assist the nurse.

**b. Benefits and Challenges of Working in Janvier Health Care Center**

Most of the participants have worked in the community for many years. The reasons they continued to work in the community laid in the benefits and the challenges of the job. The nurse indicated that as a community nurse she had the opportunity to understand the entire patient context (their friends, family) over a long period of time, which granted her the opportunity to see incremental changes in peoples' lives. She mentioned that her work team had become like a family, just by the sheer number of hours she worked with them during the day. She also enjoyed the autonomy to change small things in her practice, a sense of empowerment that enabled her to be an advocate for Janvier. Most of the participants felt their comprehension of the culture, language, and professional skills contributed to the wellbeing of the community in a tangible way.

The challenges of working in the community, however, created stress as well. The nurse indicated that it was important to debrief with her co-workers and other health care professionals outside of Janvier. Other participants performing more than one job often felt the pace and amount of work was overwhelming. For one participant, the lack of routine in her daily work was challenging, forcing her to respond to the most urgent demand. Participants mentioned that the clients themselves could be difficult, especially those individuals with a history in the criminal justice system or with social services or individuals who were drug and alcohol abusers. These challenges obviously did not deter the very committed health care staff at Janvier, who's years of service totaled 117 years amongst the nine participants.

**c. Work Practices and Change**

The most notable changes in work practice have involved the nurse's scope of practice and the number of clients the psychologist sees<sup>176</sup>. Nearly all the participants noticed that the nurse no longer performed the same tasks she did while the physician was providing health care service to the community. The nurse indicated that these changes were due to a combination of factors: first, the doctor's termination of service,

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<sup>176</sup> The psychologist indicated that he was not practicing counseling to the extent of his scope due to two factors: one, patients were not familiar with the meaning of counseling and two, patients often stopped when their life circumstances improved.

which meant he could no longer supervise her work. Second, the re-definition of nursing work in the Alberta Professions Act changed; this altered the types of work all nurses and nurse practitioners could perform, enforced by CARNA (College and Association of Registered Nurses of Alberta). Prior to the Alberta Professions Act, northern nurses in Fort Chip and Janvier had more latitude in what they could perform. As of 2005, however, northern nurses were subject to the same scope of practice as the rest of the nurses in Alberta. The nurse in Janvier, like many of the nurses in Fort Chip, wanted to practice their extended scope of practice, but under the new rules, they needed to have a nurse practitioner (NP) designation. The definition of what entails as RN and NP work has delineated the profession in northern nursing practice. It has placed many RNs in the uncomfortable position of practicing a limited scope of practice, continuing their education to acquire the NP designation, or challenging the exam to be grandfathered into the NP designation.

At the time of the research, the nurse had not acquired the NP designation, but she considered the possibility of continuing her education or challenging the exam to be grandfathered into the NP designation. The changes in her scope of practice meant that many people in Janvier who needed a physical examination had to drive to Fort McMurray to see a physician. While this may seem an easy task, the nurse indicated that not all community members have vehicles and some individuals mentioned that Fort McMurray was a tempting place for recovering addicts trying to achieve sobriety. On the other hand, one of the unintended positive benefits that arose from the limitation of the nurse's practice was the time afforded to her to access emails and visit FNIHB's on-line One Health site. She indicated, however, that it did not outweigh the benefits of being able to practice her full scope of practice.

#### *d. Continuing Education*

All the participants with para-professional or professional designations attended workshops within their scope of practice: the psychologist on Aboriginal peoples and addictions; the transportation coordinator attended annual workshops; the NNADAP worker also attended an annual workshop in Edmonton or Slave Lake for two to five

days; the CHR went to workshops on water sampling; the nurse attended workshops with the other northern nurses from Fort McKay and Fort Chip.<sup>177</sup> The nurse had completed a workshop on transporting biological hazardous material, which enabled her to drive swab samples to the Northern Lights Hospital in Fort McMurray. She indicated that traveling for several days interrupted her work schedule, but incorporating a telehealth workshop into her work day would likely be impossible. The social work assistant had changed jobs as result of continuing education. She was looking forward to using her education in the Health care Center. However, one participant indicated she preferred traveling to the workshops because they were a forum for renewing and reconnecting with colleagues from outside the community. Three participants did not attend workshops and they had no desire to continue their education: the person doing odd jobs, the receptionist, and the janitor.

Overall, three factors affected whether individuals would attend workshops: first, the relevance of the workshops to their work; second, available funding for travel outside the community; and third, available time to complete the workshops. These conditions were particularly true for the nurse. Some participants in Janvier could foresee telehealth playing a role in facilitating continuing education.

## **Technology Use**

The Health care Center in Janvier was wired with high speed Internet access through the Alberta SuperNet, but it did not have a wireless network. From the interviews, all the participants were familiar with using the telephone, and fax machine. Several participants indicated they used the computer for work: entering data for transportation, accessing email, or government sites for work. One participant indicated that she played on-line games, completed banking transactions and searched the web for personal interest information. Another participant indicated that if she could, she would avoid the computer altogether because she was never sure if the information she sent arrived at the designation it was intended. Overall, people were familiar with the use of day to day technologies.

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<sup>177</sup> I initially met the nurse from Janvier on a workshop on TB in Fort Chip in January 2007.

## **Telehealth in Janvier**

At the time of the research, FNIHB of Health Canada had just delivered the telehealth equipment, but it was not connected, so the equipment was placed in storage. There were discussions of developing telehealth connectivity; the cost would be absorbed by FNIHB. Of the participants interviewed, only four people were familiar with the concept of telehealth: the psychologist, the nurse, the NNADAP worker / Acting Manager of the Health care Center, and the receptionist. The rest of the participants had not heard about telehealth, so a short explanation and video was provided. The participants who were familiar with telehealth all gained their knowledge from previous work encounters for educational purposes: working with the Head Start program and tele-learning lessons in other First Nation communities or urban centres. All the participants demonstrated an interest in developing tele-learning applications for the community.

### ***a. Barriers and Opportunities: The Human Element***

While none of the patients had used telehealth in Janvier, one participant, who had some telehealth use experience, anticipated barriers and opportunities for the technology within his own field.<sup>178</sup> He foresaw several anticipated human barriers that would hinder telehealth from being an effective tool for counseling: first, he indicated that many patients lacked an understanding of counseling; second, the personal nature of one-on-one patient interaction; third, the psychologist's need to observe nonverbal communication cues necessary for understanding patients.<sup>179</sup> The opportunities he foresaw for telehealth in Janvier were: first, as a means of enhancing individual care through group therapy (individuals connecting with other individuals) or; second, as an educational tool for bereavement or postpartum depression. Overall he was skeptical of using telehealth for counseling purposes because he felt Aboriginal peoples' tendency towards shyness and telehealth's tendency to depersonalize interactions. In emergency

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<sup>178</sup> Here the health care provider's own perspective of telehealth and the First Nation community may be a barrier to telehealth use.

<sup>179</sup> There are several studies where telehealth has been successfully used for counseling First Nation peoples (Savin, et al., 2006; Sheahan, 2002).

cases, however, if a counselor was not available or if clients were unable to attend due to lack of transportation access then telehealth may be a last resort to accessing care, but this type of care, for the psychologist, is of a lesser quality than face-to-face interactions.<sup>180</sup> This perspective of telehealth as a secondary tool for education and as a tool for emergency is common amongst policy makers as well, but it has become increasingly a tool to bridge the gap in health care resources.

***b. Barriers and Opportunities: Structural Constraints***

The discussion above on the participants' work practices revealed that there was very little work routine. The lack of routine was due to the community member's habit of dropping or walking in for service. This is in contrast to telehealth's need for organizational coordination and schedule. As well, one participant indicated that human resources were already limited, so adding extra responsibilities to an individual's workload may be overwhelming. However, she mentioned that the receptionist could be trained to coordinate telehealth, since she was computer literate. Aside from organizational structure and human resources, the nurse mentioned that Janvier had no dedicated telehealth room, but she suggested a room for information, similar to a library, would suit Janvier. These structural constraints may hinder telehealth from becoming a regular routine in the community.

***c. Barriers and Opportunities: Opportunities***

The nurse indicated that telehealth was an untapped and potential opportunity that had not yet been experimented with. The possibility of facilitating health care service and information, particularly in providing information on such topics as West Nile's virus, diabetes, and smoking. Many participants wanted to see if telehealth could be used to access a doctor, dentist, or a nurse since these services were missing in the community.

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<sup>180</sup> In the underlying conversation with the psychologist, any form of mediation was a disruption of the personal connection between counselor and client.

## **Summary of Janvier Case**

Of the three First Nation communities in this research, Janvier was the only community without an active physician or telehealth services. However, the context for telehealth implementation and use seems to suggest that the community could use telehealth to access health care services and information. While the community was not remote, its road access time of approximately 1.5 - 2 hours east of Fort McMurray made the commute to access services particularly challenging in the winter. The participants indicated that there are a number of social, economic and health challenges that were intertwined: addictions to drugs and alcohol, the lack of care for the elderly, family dysfunction, the lack of education, and violence. As for the burden of illness, addictions and diabetes were some of the expressed concerns, but the community was also fighting sexually transmitted infections such syphilis and gonorrhea and vigilantly testing for tuberculosis as well. Many of the participants mentioned that more health care professionals such as nurses and a physician was needed in the community since the Health Center had experienced a significant decline in staffing. As a result of the changes in staffing, many individuals often worked in several positions, some trained through experience and others periodically upgraded their skills through education seminars outside the community.

Most of the participants were familiar with computer technology to perform work tasks, but very few use it for personal applications. Only four participants were familiar with the concept of telehealth, two of them gained an understanding of telehealth through using videoconferencing for education. According to the participants, the primary challenges for telehealth usage in the community were the human factor (personal interactions via video) and structural constraints, but there were also opportunities for telehealth to enhance the staffs' knowledge about a variety of topics such as diabetes, West Nile virus, and smoking. One participant suggested that telehealth was like a train, a vehicle that has the potential to carry materials in and out of the community. It could bring opportunities into the community or create hardships for the community.

## **Case 3: Fort McKay First Nation**

### **Introduction**

Fort McKay is the only First Nation community in this study that has undergone two rounds of interviews for this research, following the pattern of telehealth use. In the first round of interviews conducted in March 2007, following Fort Chip, participants indicated that telehealth in Fort McKay was a sporadic and often forgotten learning tool. The second round of interviews was conducted between May and June 2008, after the community informed me that telehealth was being used as a medium for physician to patient consultation.<sup>181</sup> In both of these rounds, interviews and observations were made around the health care staff and their work in the Health care Center in Fort McKay. In the second round of interviews patients were included in the interview process due to the implementation of physician to patient consultation arising from this dissertation research process. Ethics covered both rounds one and two of the research.<sup>182</sup> In round one, only the health care staff was interviewed since they were the primary telehealth users. In round two of the research both patients and health care staff were interviewed. The case description below is a synthesis of the interview and observations collected, beginning with an understanding of the community background, the health care staff and lastly, the technology and telehealth use in Fort McKay. The theoretical analysis of the case is reserved for chapter 7.

### **Community Background**

Fort McKay, named in 1912 after Dr. Williams Morrison McKay, the first resident doctor in Alberta, is home to the Dene, Cree and Chipewyan people (Fort McKay, 2008). It is located approximately 67 Km northwest of Fort McMurray Alberta with a population of 521 people, an increase in population of 19% since the 2001 Census

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<sup>181</sup> The physician to patient consultation was implemented as a result of the PAR process I completed with Fort McKay. I assisted the community by providing information and completing a preliminary report on telehealth in First Nation communities. Fort McKay completed a separate survey to examine the users' satisfaction with telehealth consultations in October 2008; these findings were presented at the Canadian Society of Telehealth's annual conference.

<sup>182</sup> The actual project planning, however, is not included in the ethics coverage.

(Statistics Canada, 2008a).<sup>183</sup> The community lies in the heart of oil and gas development; the road leading into the community is surrounded by Alberta's largest oil sands development companies.

**Table 6.13: Fort McKay Community Demographics Based on 2006 Census**

Category	Fort McKay	Alberta (Aboriginal Population)	Alberta	Canada
Education: 25-64 years old (No certificate, diploma, or degree)	63.3%	34.6%	*15.4%	*15.4%
Percentage of Population below 15 years old	25%	31.1%	** 19%	** 17.7%
Knowledge	Aboriginal Lang: 43%	18.8%	N/A	N/A
	English only: 57%	76%		
Unemployment Rate	19.1%	11.1%	***4.3%	***5.2%
Median earnings	\$44,320	\$21,010	****\$43,964	****\$41,401

In the chart above, Fort McKay's social challenges reflected many of the other First Nation communities in the Wood Buffalo region: 25% of the population was below the age of 15 years old, compared to the wider Alberta (19%) and national (17.7%) population. As well, 63.3% of those who were at their peak economic earning potential lacked educational certificates, diplomas, and degrees, nearly four times the wider Alberta and national rate of 15.4% and double the Aboriginal population in Alberta of 34.6%. The unemployment rate in Fort McKay was comparatively very high at 19.1% -- triple the national rate of 5.2% and four times the rate in the wider Alberta population.<sup>184</sup> However, the median earning in Fort McKay of \$44,320 did not reflect this social trend; it was higher than the wider Alberta (\$43,964) and national median earnings (\$41,401). In the pictures below, Fort McKay had both crippling poverty and great prosperity. Fort McKay has a statistically larger population who spoke their native language, 43%, compared to 18.8% of the Aboriginal population in Alberta. According to Statistics

<sup>183</sup> Some of the participants estimated that there were over 700 people living in Fort McKay.

<sup>184</sup> Perusse (2008) indicates that the high unemployment rate may due to the fact that the Aboriginal population is significantly younger than the rest of Alberta and Canada.

Canada (2008), Aboriginal languages are being revived across Canada and Fort McKay showed great promise.

**Images 6.7 Health Center at Fort McKay**



Left: The first picture is the one that greets visitors entering Fort McKay, the Métis area is the most impoverished image of the reserve. Right: the Professional Building, one of the most impressive buildings I have seen on my research, is complete with a gathering room overlooking the river in the rear and the Health Center.

### A Day in Fort McKay's Health Care Center

I shadowed the homecare nurse on her daily work routine throughout most of my research. The commute, north from Fort McMurray to Fort McKay along highway 63, was approximately one hour plus or minus 10 or 15 minutes depending on the activity on the road. The road towards Fort McKay was congested with many trucks, logging haulers heavy with trees, land moving machines on the side of the road (amazingly these vehicles are sometimes the size of malls and houses), buses operated by Diversity shuttling oil and gas workers to their various work destinations. There was also an unmistakable odor passing through Syncrude.<sup>185</sup> During the research, many of the participants mentioned the road towards Fort McKay was being expanded. In spring 2008 an additional road lane was added, reducing the travel time on the return trip to Fort McMurray by approximately twenty minutes.

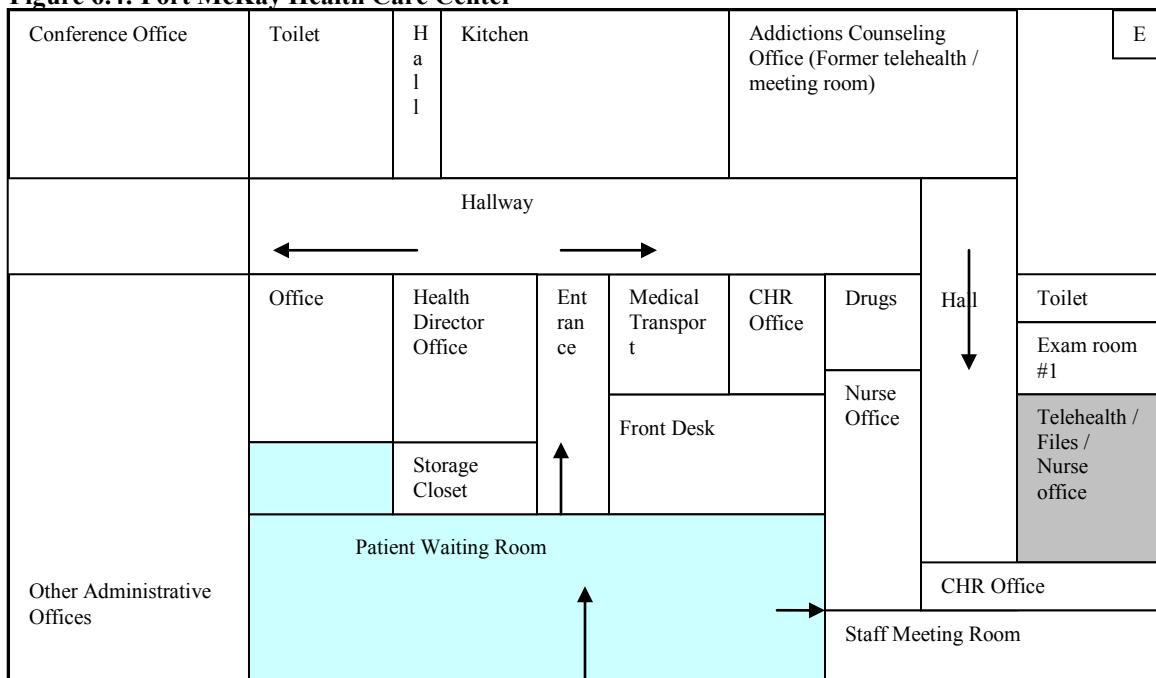
In the above picture to the right, the Health Care Center was located over the bridge at the entrance of the community by the river as a part of the professional building. To the far right of the picture, out of camera sight, was a beautiful white tepee set-up during the spring, picnic tables and a makeshift shelter were used for various community

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<sup>185</sup> In the spring of 2008, 500 ducks landed and died in these same tailings ponds, causing not only an uproar in Canada, but in Fort McMurray.

functions. While the picture shows a beautiful building, the parking lot was a large mud pool -- especially after all the snow melted or a thunder shower; the community was eagerly anticipating new funds to cement it. The professional building where the Health care Center is located houses other administrations including the band office and a large meeting room facing the river, decorated with Aboriginal art, a room well used by companies hosting community meetings usually on the topic of oil and gas resource development.

**Figure 6.4: Fort McKay Health Care Center**



The Health care Center has partial transfer status, meaning it manages the resources allocated to the community for health care services under particular Health Canada stipulations.<sup>186</sup> The Health care Center is focused on public health, but given the public health nurse's training and connection to the Northern Lights Health Region, her scope of practice in Fort McKay was much broader than Janvier. From the diagram above, the health care services were located to the right side of the diagram; a sign, in the right hallway leading to the nurse's offices, boldly stated "Nursing Zone". The left side of the diagram illustrates administrative offices. Access to the entrance of the health care

<sup>186</sup> While I was there in 2008, three auditors secluded themselves in staff meeting room assessing Fort McKay's programs. According to one participant, the community has worked hard to re-organize the management of its resources.

unit was controlled by the front desk; patients must be buzzed in to see the nurse or the physician on his Monday clinics. The patient may then proceed to turn right and access the various services.

## The Participants

The health care center at Fort McKay offered a limited number of services to the community members and like the previous two communities in this research, the services were provided by health care staff from Fort McMurray or outside of the region. The chart below illustrates the daily staff on duty.

**Table 6.14: Number of Health Care Staff**

Type of Health care Staff	Number of Permanent Staff	Years of service
Homecare	1 RN, 1CHR	4
Public Health	1 RN, 1CHR	13
Medical transport	1 Coordinator	1.5
Addictions Counselor	1	1
Physician	1	7

\* Staffing varied from 2007 to 2008. In 2007, at the time of my observation, there were no CHRs. In 2008, a CHR and a nursing student were hired to assist N1 with her daily homecare clients and another CHR was hired to complete water sampling.

At the time of the research, the public health nurse (N2) had been working the longest length of time in Fort McKay -- 13 years. The home care nurse (N1) had been in the community for four years. Prior to her work in Fort McKay she had worked as a Health Canada nurse in the First Nation communities surrounding Fort McMurray. After working in Fort McKay, the Health Care Center decided to hire her from Health Canada; under the transfer program N1 became an employee of Fort McKay rather than Health Canada. N2, on the other hand, was an employee of the provincial government in what was formerly the Northern Lights Health Region (NLHR). Fort McKay, through Health Canada, engaged in contract negotiations to pay for her services as an employee of NLHR, which enabled her to work in the community for thirteen years, the longest number of years of service in one community in this research project.<sup>187</sup> Under N2's

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<sup>187</sup> When I further inquired about the history of N2's work in Fort McKay, she indicated that the NLHR had sent her to provide service to Fort McKay because there was no nurse in the community. According to N2, the Medical Service Branch (Health Canada) did not contact her directly until a much later period of time.

contract the number of hours committed to commuting was included in her work whereas the hours that N1 spent commuting were not counted in her job.

Between 2007 and 2008 Fort McKay experienced staffing fluctuations and changes: the health director resigned in 2007 and two subsequent new hires followed her; the homecare CHR resigned in 2007 and a new CHR was hired, but the new CHR had to take a stress leave a few months following the commencement of her work; maternity leave forced the medical transport coordinator job shuffle; the 2007 addictions counselor left for a different job and a new person was hired for 2008; a new nurse was hired in 2008, her job task included water sampling, but it was difficult to determine if there were other job tasks and whether she had settled into a routine. As well, the front desk received two new faces. In the job shuffle, the two RNs (N1 and N2) remained consistent in their work, but they have received additional job tasks due to the utilization of patient to physician consultations over telehealth. The fluctuations in staff affected available services: new employees had to be trained or existing employees had to adjust to new responsibilities.<sup>188</sup> In an interview with the former health director, she mentioned she could do every job in the Health Care Centre, except the nurse's job, enabling the Health Care Centre to continue operations when staff was sick or departed. This "woman-of-all-trades" understood that it was difficult to retain qualified staff.

*a. Flow of Work or Activities in Fort McKay*

Every day N1 and I arrived at the Health care Center at approximately 8:50 AM. She would unlock all the office doors in the area designated nursing, check for telephone messages, and prepare for the day (a list of homecare patients to visit, pack her medical bag with the patients' new medicines or medical instruments such as the blood glucose meter for monitoring blood sugar levels in patients with diabetes). The homecare visits often lasted 15 minutes and, on some visits, twenty to thirty minutes depending on the degree of health care concerns that the patient has. During these visits, patients were friendly and invited the nurse into their home with ease. She assessed their health, talked about their concerns, and most of the time told jokes. When she completed her homecare

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<sup>188</sup> According to N1 the oil sands industry was a competitor for health care staff personnel.

visits, she drove back to the Health care Center and completed charts on the patients or contacted the physician. Sometimes he was available and other times he returned the nurses' calls soon after, but it was always very timely.

As for N2's day, she arrived at the Health Care Centre between 9:30 AM and 10:00 AM to see drop-in patients for vaccinations and various health care concerns. Her work ended at approximately 3:30 PM and, on the drive back to Fort McMurray, she dropped off the lab samples at the hospital. N1, on the other hand, often did not leave Fort McKay until 4:30 PM. As with the other First Nation communities, the telephone in Fort McKay Health Care Centre was often ringing: patients made appointments or contacted the nurse for various reasons and, if necessary, they contacted the doctor. When telehealth was operationalized this procedure did not change, since the doctor remained on-call to the community throughout the week.<sup>189</sup>

In the chart below, I have listed the types of health care services being provided by visiting health professionals to Fort McKay.

**Table 6.15: Frequency of Health Care Services**

Type of Service	Frequency
Family Physician	1 day / week
Dental Hygienist	1 day / month
Mental Health Therapist	2 day / week

The doctor regularly visited on Mondays from approximately 10:00 AM to 3:00 PM;<sup>190</sup> the entire health care staff would assist him in patient consultations, including an additional nurse,<sup>191</sup> to take the patients' vitals, prepare charts, follow-up on labs, and fax labs. After he completed his visit, the nurses compiled their task lists to ensure all follow up visits and labs are noted. On Tuesday mornings the nurses often completed the remainder of the charts and worked on their own programs. While I was completing my research, the dental hygienist and mental health worker did not visit the community. The nurse and the Health Director indicated that the dental hygienist worked at the school once a month, but sometimes twice or three times a month depending on the work

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<sup>189</sup> The nurses made calls to the physician while he was in Nova Scotia.

<sup>190</sup> As mentioned earlier, this physician provided service to Fort Chip and to Janvier – that is – prior to the termination of his contract in Janvier.

<sup>191</sup> The additional nurse is his wife; she accompanied him on his trips to Fort McKay, including when telehealth was operationalized for patient consultation.

needed. Fort McKay also hired a dental hygienist from Edmonton to work in the Health Center four times a year.

**b. *Health care Staff's Perception of Health care Challenges***

Based on the interviews in the first round of research, the staff members indicated that health care challenges were a combination of a heavy burden of illness and a lack of health human resources. The chart below illustrates the participants' top five most pressing health concern in Fort McKay.

**Table 6.16: Fort McKay Participants' Top 5 Community Health Concerns**

Rank	Health care Problems	Steps Towards Improvement
1	Addictions to drugs and alcohol	<ul style="list-style-type: none"><li>• Tighter measures on prescription drugs</li><li>• Increase counseling services</li><li>• Use telehealth to maintain family contact during treatment</li></ul>
2	Chronic illnesses due to smoking (cancer & respiratory problems)	<ul style="list-style-type: none"><li>• Nursing home</li><li>• More nurses and Trained CHRs</li><li>• Health promotion and prevention</li></ul>
3	Poor nutrition (all age groups particularly the youth) leading to diabetes	<ul style="list-style-type: none"><li>• Increase diabetes screening (using SLICK program)</li></ul>
4	Water quality, dental hygiene, eczema	
5	High cost of health care delivery	<ul style="list-style-type: none"><li>• Health promotion as first line of defense, treatment secondary</li><li>• Use telehealth to access to specialist care</li></ul>

In the interviews with the health care staff in Fort McKay four out of the five individuals interviewed indicated that addictions to drugs, prescription and illicit drugs, as well as alcohol was the most challenging health problem. In the second phase of the research process with the patients, many of them mentioned that they were concerned about addictions, particularly the ease of access to highly addictive prescriptions such as Tylenol 3, 4, and 5s. Some of the patients told stories about their own family members: daughters, sons, grandchildren, and friends who were addicted to pills or alcohol. Some of these individuals were saddened by the erosion of their family as they became isolated or by their behavior towards them or other family members. As well, chronic illness due to smoking (cancer and respiratory problems), poor nutrition leading to diabetes, eczema,

dental hygiene and water quality were some of the other health concerns that health staff and patients mentioned were problematic in the community.

Most of the participants also mentioned that human resources, particularly trained nurses and community health representatives (CHRs), were necessary to address the health challenges in the community. However, according to one administrator, telehealth could be used to augment access to health care specialists or, as another indicated, used to maintain a connection to family members while patients were undergoing therapy for drug addictions. For both participants, using telehealth in the long run may or may not reduce the cost of accessing health care services. Lastly, N1 indicated that an overall plan to restrict prescription medication was necessary to ensure patients did not see more than one doctor to obtain drugs that feed their addictions. According to one participant, the health problems in the community cannot be solved by a single solution, but a combination of patient and community initiative through education and health care professional involvement.

### ***c. Work Practice and Job Responsibilities***

In round one of the research process, some of the health care staff often said they were tired or stressed from their busy workload. Some of the health care staff could perform, or did perform, more than one job task: the Health Director could fill in any position except the nurse's role and the NNADAP worker also worked in family services. Both of the nurses expressed how difficult it was to maintain their own practice because of the number of clients they were responsible for: the homecare nurse had approximately forty clients and the public health nurse mentioned that she was constantly trying to stay abreast of the immunization records. She, like the public health nurse in Fort Chip and Janvier, called the parents to remind them of the children's immunization. N2 could also screen for sexually transmitted infection. At the time of the first round of interviews, there were no CHRs to assist the nurses, so the homecare nurse (N1) had to complete visits on her own. Both of the nurses' job tasks also included reporting to their employers, Fort McKay through Health Canada and Fort McKay through the health

region; each of these different allegiances required inputting data into the respective national and provincial databases.

In the second round of the research process, a CHR and a summer nursing student had been hired to provide homecare while N1 performed the duties of Health care Director, telehealth operator, and homecare nurse. The summer student, while providing N1 a reprieve from the extensive workload, was not at the time, a permanent solution. N1 continued to express how difficult and challenging the workload was since acquiring the role of Health Director. The changes in practice arising from telehealth are discussed below, but the stress of changing routines was obviously felt by both of the nurses, particularly N2 whose mannerisms and interactions with patients and the telehealth technology was stilted rather than smooth and continuous like those found in her interactions performing immunizations.

#### ***d. Benefits of Working in Fort McKay***

While both of the nurses daily commuted to Fort McKay and bore heavy work case loads, the least attractive aspects of the job, both nurses are given gas, a vehicle, and a cell phone to complete their work. N1 and N2 appreciated the fact that they could understand their clients within their family and community contexts on a daily basis. In many ways, they have been accepted into the community and their clients were comfortable talking to them. Often, many clients casually told their life story, challenges, and concerns to these trusted nurses. Most of the health care staff enjoyed the challenges and diversity of work possibilities offered by Fort McKay, but they also suggested that they were making real contributions to the health and wellbeing of the community.

In sum, the fluctuation in staff at the Health Center affected the work load of health care providers: each of the nurses incurred more work tasks with the same number of patients, meaning they must either: a) increase the rate of work or, b) decrease the number of patients they see in a day or, c) work longer hours. The nurses have commented that they often did not leave the community for education purposes because upon their return an insurmountable amount of work waited for them.

## **Technology Use**

In Fort McKay, the health care staff was familiar with the use of various technologies to accomplish their daily work. In many ways these technologies also fulfilled the distance gap between health professionals in urban centers and rural and remote communities: fax machines used for transmitting patients' lab results to the physician's office; cell and land line phones used for maintaining contact with the physician, other colleagues, booking appointments; and computers were used for accessing health information from FNIHB's One Health site or email as well as for inputting data into Health Canada or the Alberta Government's database. Due to the partial transfer status of Fort McKay, each personnel had to input data into different computers: Health Canada provided N1 a computer for data entry, but N2 had to input her data in Fort McMurray due to her affiliation with the Northern Lights Health Region. Indian Northern Affairs provided a computer for the Health Director, so she could regularly input and access information.<sup>192</sup> At the time of the research, each of these computers' could only be accessed or serviced by the respective government departments, but in 2008 Fort McKay tried to provide service for all the computers. Overall, the health care staff at Fort McKay was familiar with information technologies and some were more comfortable using new technologies than others.

## **Telehealth in Fort McKay**

**Images 6.8 Telehealth Setup at Fort McKay**



Left: new and old system in then meeting room. Center: telehealth in nurse's office. R: patients' chairs to view telehealth

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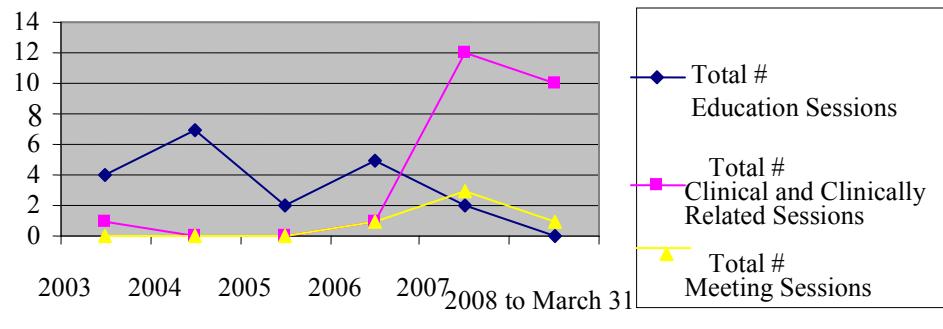
<sup>192</sup> The division over which government or government branch provided the computers reflects the jurisdictional challenges of health care services in First Nation communities.

In the first round of interviews, participants indicated that telehealth could be used to access services not otherwise found in Fort McKay. Telehealth during this period was being used for tele-learning purposes. In the second round of interviews, telehealth was being used for patient consultations (one of the outcomes from the preliminary collaborations of this research project). Prior to 2007, telehealth was located in the photocopier / meeting room, but in 2008 the room became the Native Addictions Alcohol Drugs Program and the telehealth equipment in the above center picture was moved into N1's office. In 2007, FNIHB had delivered and set-up the new flat screen telehealth system, the same one used in Fort Chipewyan and Janvier. The week that I began my field research, the staff had mixed feelings about its presence: some commented that it was an extravagant use of money since the old system was in working order and others felt the large screen would enable more people to be involved in conference calls or learning programs. One of the participants was concerned that technology solutions may replace funding for health care staff within the Health care Center. Despite this concern, the health care staff at Fort McKay clearly saw a role for telehealth in health care service delivery and enhancing work skills.

*a. Telehealth Usage*

According to FNIHB's records of telehealth use in Fort McKay, prior to 2007 telehealth was primarily used for education purposes, but it followed an erratic pattern of use, rising then falling equally. Telehealth for meetings was minimally used and peaked in 2006. In 2007 telehealth use for patient consultations jumped significantly with the development of the project as the doctor relocated to Nova Scotia, but its incline seems to coincide with the decline of telehealth for education purposes.

**Figure 6.5 Fort McKay Telehealth Session Type Comparison**



Source: FNIHB to Mah (2008)

There are two possible explanations for this statistical shift from tele-learning to increasing patient to physician telehealth consultation use. First, the focus on telehealth consultation may mean there are less available resources (time, attention, interest, and staff) to continue education endeavors. Second, staff may no longer embrace the benefits of tele-learning opportunities, but this is unlikely since the first round of interviews revealed that all of the health care staff had used telehealth for learning purposes. The decline in telehealth use as a learning tool may likely be due to staff turnover and the Health care Center's focus on physician to patient consultations, shifting the amount of time for learning to patient consultation, meaning the existing staff had more work to complete and less time for education endeavors. Third, physically moving the telehealth equipment to N1's office signified a shift from a learning environment to a consultation environment. Lastly, prior to 2007, the old telehealth system was located in the meeting room, several individuals indicated they were comfortable and knew how to use it: the Health Director, NNADAP worker, N1, and the receptionist, who declined to be interviewed but mentioned during an informal conversation that she knew how to operate the telehealth system. When the new telehealth system was relocated to N1's office for patient consultations the only individuals who had access to the telehealth system were N1, N2, and the nursing student. The shift from tele-learning to patient consultation meant time and resources had been dedicated to consultations, but the machine's function and design as a learning tool had not changed. In the discussion below, the participants'

views and experience with telehealth are provided to elucidate a deeper understanding of the changes in telehealth use.

***b. Tele-learning and Patient Consultations***

In the interviews with the health care staff in round one, health care staff had used telehealth for learning purposes and their perspective of the technology prior to patient consultation is important to note here. In round two of the research, telehealth was used for patient to physician consultation, but some of the same problems, challenges and opportunities that the health care staff had experienced continued to be carried over into existing telehealth consultations. In the chart below, the reader may note that patients are anonymized as “P”, “M” for male, and “F” for female followed by the number of their interview.

**Table 6.17: Round 2 Research, Patients' Perspective of Telehealth Consultations**

Telehealth Attributes	Health care Staff Perspective Prior to 2007	Implementation of Patient Consultation (staff & patient perspective)
		Round 2
	<b>Round 1 Positive</b>	
Access to Information	<ul style="list-style-type: none"> <li>• Access information to enhance skills (NNADAP, N2)</li> <li>• Convenience without travel (N2)</li> </ul> <p><b>Challenges:</b></p> <ul style="list-style-type: none"> <li>• Redundant or lack of relevant information (NNADAP)</li> </ul>	<ul style="list-style-type: none"> <li>• N/A (tele-learning services were not accessed at the time).</li> </ul>
Maintaining a connection	<ul style="list-style-type: none"> <li>• Use for meetings (N1, N2, Ad2)</li> <li>• Desire to retain physician's services (N1, N2, Ad1, Ad2)</li> <li>• Contact with communities (N2)</li> </ul>	<p><b>Driving Factors to using telehealth:</b></p> <ul style="list-style-type: none"> <li>• Don't want to lose doctor (PF4, PF7)</li> <li>• Convenience (PF15, PF2, PF4, PF5, PF8, PM9, PF2, PF21, PF22, PF3, PF6, PF8, PF16)</li> <li>• Need their meds (PF8, PF5)</li> <li>• Shortage of physicians (PF2, PF21, PF22)</li> <li>• High travel cost (PF16, PF2, PF16)</li> </ul>
Technology System		<p><b>Function</b></p> <ul style="list-style-type: none"> <li>• Enable close examination of rash, wounds and infection (N1, N2, PF10)</li> <li>• Enable audio of fetal heart rate (N2)</li> <li>• Looking forward to new functions (listen to heart, see the ear) (N2, D)</li> </ul>
Human Factor: Trust	<p><b>Round 2</b></p> <p><b>Trust:</b></p> <ul style="list-style-type: none"> <li>• Doctor is not there, but he knows your history &amp; you (PF17, PF21, PF3, PF16, PF4, PF5, PF10, PF21, PF3, PF14, PF17, PF19, PF2, PF21, PF22, PF7, PM1, PM9)</li> <li>• Skills and knowledge of patient (N1, N2, D)</li> <li>• He makes me feel comfortable (PM18)</li> <li>• The nurse is there (PF3, PF4, PM18, PM11, PF11, PF19, PF7, PF8, PM1)</li> </ul> <p><b>Relationship:</b></p> <ul style="list-style-type: none"> <li>• Physical exam needed (PF10, D, N1, PF14, PF15, PF5)</li> </ul>	
<b>Negative Attributes</b>		
Cost	<ul style="list-style-type: none"> <li>• Cost allocation to other needed community resources (Ad1)</li> </ul>	<ul style="list-style-type: none"> <li>• Time = money, so limit session time (PF15)</li> </ul>
The Technology System	<ul style="list-style-type: none"> <li>• Blurry images (N2)</li> <li>• Unable to connect (N2)</li> </ul>	<ul style="list-style-type: none"> <li>• Glitchy, poor audio quality, lag time, obstructs interaction (N1, N2, D, PF10, PF21, PF3, PF8, PM1, PF21, PF9, PF7, PF8 )</li> <li>• Shared connection: competing bandwidth (N1)</li> <li>• Need new portable system with hand held drivers (N1, N2, D)</li> </ul>
The Human Factor	<ul style="list-style-type: none"> <li>• Need telehealth coordinator to organize sessions (N1)</li> </ul>	<p><b>Displacement:</b></p> <ul style="list-style-type: none"> <li>• Nurses compensate for lack of physician presence (describing, speaking, touching, interpreting) (PF15, PF3, PF8, PM9, PF14, PF2, PF4, PF5, PF8, PM11, PM18, N2, PF10, N1, PF19)</li> <li>• Seeing but being recognized, but by voice (PM18)</li> <li>• Not a hands on experience (PF11&amp;PM11, PF3, PM1)</li> <li>• Back-up physician to examine (D)</li> </ul>

Prior to 2007 and the implementation of patient to physician consultation in Fort McKay, the health care staff indicated that telehealth could enable access to information and people. The health care staff saw and experienced the potential for telehealth to enhance their work skills, meet with colleagues, and provide training information – it was a valuable resource to their work. However, they had also experienced technology failures and they feared the high cost of technologies in communities would substitute remuneration for qualified staff. Two participants had also indicated that telehealth could be improved by providing learning sessions relevant to their community and hiring a coordinator dedicated to working with telehealth.

After the implementation of telehealth for patient to physician consultation, all three nurses, including the summer nursing student, learned to operate the telehealth equipment, but N1 gained the responsibility of troubleshooting and telehealth organization. The doctor established telehealth consultations on Mondays from 10:00AM to 1:00PM with onsite face-to-face consultations every six weeks for three day durations beginning at approximately 9:30AM to 3:30PM. N1 indicated that the average number of patients seen over telehealth was approximately 19 and the daily number of face-to-face consultations ranged from 28 to 30 patients for three days. This means that the average amount of time the physician spent with telehealth patients was about 9 minutes (including the nurses' assessment time). The average amount of time he spent with patients during onsite visits was about 13 minutes (without the nurses' assessment). This would indicate that he spent more time with each patient during onsite face-to-face consultations. During the interviews with patients, they also indicated they spent more time talking with the doctor during onsite visits.

In the chart above, the participants revealed several reasons they wanted to use telehealth: it was more convenient than driving into Fort McMurray and waiting to see a physician; travel costs for those without vehicles and non-band members was exorbitantly high; some individuals also mentioned that there was a shortage of physicians, making it difficult to find a doctor; some patients mentioned that they needed to see the doctor to fill their prescriptions; and still others wanted to retain their physician. These are some of the common push factors for telehealth use. The deeper reason patients wanted to continue to see their doctor over telehealth was based on a

relationship of trust; they suggested that his skills and understanding of their complete medical history would be effective regardless of distance communication. As well, while he was not physically present, they trusted the nurses to care, provide them with the necessary information, interpret, and describe what the doctor needed to know to ensure their consultation was successful. While some patients viewed the care of the physician being displaced onto the nurses as a function of telehealth operation, it also became evident that this displacement was acceptable for the majority, but there were a few dissenting voices. Several patients indicated that telehealth consultations should not be done with nurses as the hands, eyes and mouth of the physician; that role belonged to the physician himself. They did not trust the nurses less, but they mentioned that physician consultations must be done with the physician physically present. In fact, one community member passionately argued whether Aboriginal peoples were receiving telehealth service because they were a less important population and therefore less deserving of regular onsite visits. However, for the majority of the patients, the sense of trust and rapport developed between themselves and the health care team enabled telehealth to provide them with the care they needed. This same trust and rapport was the root of the relationship that enabled the nurses and the doctor's work interactions. The nurses mentioned that they trusted the doctor's understanding of the patients' cases and the doctor trusted the nurses' observations and touch. The doctor indicated that if technology interfered with the opportunity to "see" the patient or if he had any doubts about the telehealth consultation, he would refer the patient to see a physician in Fort McMurray. Trust enabled the telehealth consultations to become an acceptable experience for patients and health care providers.

The health care team also indicated that the positive aspects about telehealth technology was its ability to magnify skin conditions such as rashes and, while the system was not explicitly designed to "listen" to fetal heart beats, the microphones were sensitive enough to enable the physician to hear the heart beats. The participants' positive perspective of telehealth was often tested during technical difficulties. At the time of the second round of research, patient consultations had been operational for approximately six months. According to the health care staff, the worst technology problems occurred on all the Mondays I was in the community to observe telehealth

usage. The participants noticed the glitchy reception (fuzzy, blurry lines, poor audio and video quality) and lag time between visual and audio exchange. The technology failure produced several different types of unintended consequences illustrated in the box below.

**Table 6.18: Unintended Consequences of Technology Failure**

<b>Outcomes of technology failures</b>	<p><b>Rely on other technology:</b></p> <ul style="list-style-type: none"> <li>• Poor audio or visual, rely on phones (N1, D)</li> <li>• Waiting for new cart, connection to SuperNet (N1, N2, D)</li> </ul> <p><b>Physical exhaustion:</b></p> <ul style="list-style-type: none"> <li>• Creates fatigue (psychedelic experience, disjointed, requires more concentration) (N1, D)</li> <li>• Preference for face-to-face consultations (N1)</li> <li>• Feeling like he was stuck in a void (PF21)</li> </ul> <p><b>Efficiency and Quality of Service:</b></p> <ul style="list-style-type: none"> <li>• Repetition in talk (N1, N2)</li> <li>• Fewer patients to see (N1, D)</li> <li>• Poor quality service because of communication challenges (D)</li> </ul> <p><b>Focus</b></p> <ul style="list-style-type: none"> <li>• It did not matter, the purpose was accomplished (PF10)</li> </ul>
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First, when poor audio or visual quality was encountered, the nurses quickly telephoned the physician to continue the consultation. The switch from telehealth communication to landline to cell phone or landline to landline was seamless. During one consultation, the nurse continued to show the physician a patient's rash and during the intermittent blurry lines while talking to him on the phone. He waited several minutes and finally received one clear image and proceeded to prescribe the appropriate medication. The technology challenges also made the health care staff desire a dedicated Internet connection or a connection to SuperNet. Second, it became quite obvious that the poor audio and visual transmission produced physical and mental fatigue on those engaging or observing the communication exchange. The doctor called it a psychedelic experience, a patient said it appeared the doctor was caught in a void, and N1 said it was exhausting. Third, the quality of the patient consultation was affected in several ways. N1 and N2 found that they were often repeating themselves or changing their speech patterns to accommodate the poor connection, this reduced the speed at which patients could be seen by telehealth and therefore the total number of patients seen on a bad day. The doctor indicated that he would not be providing the type of care patients needed if the connection remained poor and part of his fear was alleviated by asking another physician in Fort McMurray to

provide a second opinion. Lastly, one patient indicated that despite poor technology connection, the purpose of seeing the doctor was accomplished. This purpose, however, needs to be evaluated in light of the physician's concern for quality of service.

### *c. Conversation and Talk*

The participants, while being impacted by both functional and poor technology connections, often times attempted to modify their own actions to ensure that telehealth communication continued to be comprehensible. In the chart below, the areas of modifications are listed: body positioning, technology, and talk.

**Table 6.19: Modifications of Behavior to Use Telehealth**

<b>Actions accommodate technology</b>	<p><b><u>Body Positioning:</u></b></p> <ul style="list-style-type: none"> <li>Lifting legs (body positioning) (N1)</li> </ul> <p><b><u>Technology Modifications:</u></b></p> <ul style="list-style-type: none"> <li>Changing telehealth set-up to compensate closer distance to monitor (N2)</li> <li>Use camera from old system</li> </ul> <p><b><u>Talk:</u></b></p> <p><b><i>Conversational turn-taking</i></b></p> <ul style="list-style-type: none"> <li>Conversation turning taking emphasized, more pauses &amp; waiting (PF10, PM1)</li> <li>Getting the point through (PM1, PF3)</li> <li>Slower pace and more repetition (N1, PF17)</li> <li>Listen closely (D, PF10, N1)</li> <li>Ignore conversation because can't hear (PM9)</li> <li>Lack of eye contact (PF5)</li> <li>Can't understand what he's saying (audio quality) (PF8, N1)</li> <li>Waiting (conversation turning taking emphasized, more pauses) (PF10, PM1, N1)</li> </ul> <p><b><i>Back stage Talk</i></b></p> <ul style="list-style-type: none"> <li>Not personal or private because everybody is there (PF15, PF8)</li> <li>Backroom talk (directions to nurses are also observed by patients) (PF8)</li> <li>Awkward, multiple conversations (PF19)</li> </ul> <p><b><i>Rapport</i></b></p> <ul style="list-style-type: none"> <li>Free to talk with him (joking, laughing, small talk) (PF5, PF10, PF13, PF19, PF21, PF22)</li> <li>Normal conversational volume as if I'm talking to him face-to-face (PM18, PM20, PF19, PF14, PF16, PF17, PF19, PF21, PF3, PF6, PF7)</li> <li>Shorter conversation due to time crunch (PF15)</li> </ul>
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In many ways, the health care team and patients altered their body positions, the technology and their conversation style to enable a comprehensive telehealth experience. The camera on the new telehealth unit could not be easily extended to acquire a view of the rash on a patient's leg, the nurses and the patient attempted a minor acrobatic feat to

enable the physician to see it. As well, while the camera provided with the new telehealth unit was standard, N1 discovered it was not as adequate for the job as the camera from the old telehealth unit. These minor adjustments in body position and technology enabled participants to see each other.

The most obvious modifications that participants made were in their talk. The participants noted that during telehealth interactions, they often emphasized their words, slowed the pace of talking, and were conscious of conversational turn-taking (waiting for one person to finish speaking, followed by another, with no interruptions). This conversational turn-taking involved more waiting time for the participants to finish speaking rather than a more fluid dialogue; this is marked by what participants call waiting or listening harder, and more repetition during poor transmission in order to get the point across. The challenges of telehealth communication was obvious for some participants: one participant noted that there was no eye contact, while another said he completely ignored the conversation until the nurse spoke directly to him because he could not hear the conversation and still two other participants indicated that they could not understand the doctor when he did speak. Mediating communication via video and audio did not only change the dynamics of how individuals communicated, but it also disengaged telehealth users. One participant (PM9) emphasized that during face-to-face communication he could exert himself physically to persuade the doctor to give him what he wanted. This lack of physical presence frustrated PM9 because he felt he could be ignored. The doctor also indicated that telehealth, given the limited time frame, eliminated all the superfluous talk and allowed the health care team to get down to business of simply addressing the health concern of the moment. However, during the course of assessing telehealth patients for consultation, the nurses continue to talk to the patients about various matters. It is possible that the lack of physical presence combined with limited time creates a sense of physical distance between patient and physician.

Some participants found that telehealth decreased the parameters of conversation: first, there was little privacy because there were many people in the room. This was particularly obvious for staff members who used the physician's services; their health care issues became known to the nurses attending the session. Second, the conversations normally reserved between physician and nurse that occurs away from patients were

sometimes occurring in front of the patient. As well, some patients thought there were multiple conversations occurring at the same time. While this type of conversation did not lessen the regard the patients held for the nurses or the doctor, telehealth created a flattening of spatial dimensions that transgressed dimensions of talk between professionals and lay peoples.

However, there were many participants who felt their conversational rapport was smooth and unhindered by telehealth mediating their conversations, they indicated they joked, laughed, and engaged the doctor in small talk about the weather or the community. Other participants indicated that talking to the doctor was as normal as talking to him face-to-face with the exception of perhaps the consultation times being shorter. For these participants, the trust that they had established with their doctor carried them beyond the technological glitches that often times obstructed communication. In sum, telehealth, while for some represented an opportunity to consult with their physician, posed some challenges that compelled many participants to change the way they conversed with each other.

#### ***d. Participants' Perspective of Telehealth***

In the above discussion, the focus was on telehealth use, but participants' perception of telehealth in the delivery of care is also important. What does telehealth mean to participants aside from a tool to access health care? Does this perception shape their use of the technology? Often times, participants did not know what the term telehealth referred to, but they often asked whether it was the "TV" in the nurse's room. Several participants thought the "TV" seemed unusual: one simply did not talk to the TV (PF13, PF5, PF11, PF9, and PM11). The unusual nature of talking to a TV when the person was not physically present also posed a challenge to what could be deemed as the provision of care, particularly for PF11 and PM11 whose expectations of what constitutes a normal patient physician interaction was usurped by a dominant TV screen. PM18 indicated that many Aboriginal elders may find the concept not only unnatural but also problematic to pay for something that is not tangible as in the case of paying for cellular phone connection because it appears the phones function by "air". Another participant (PF4) thought the TV was similar to the telephone, a piece of technology that a person

could use to communicate with. Television also magnified the communication experience, both visual and audio communication is sent to the receiver, the doctor, but because telehealth had an embedded screen showing the participants, the participants saw themselves interacting with the doctor. For some people, they ignored the depiction of themselves, but one person (PF10) commented that she initially was shocked by her hair and weight; she said it required some effort to ignore the image of herself on the screen. Lastly, the most interesting comment about telehealth came when the technology was not operating at an effective capacity: one participant (PF19) blamed poor reception on the weather, similar to interrupted services for TV and telephone. The participants associated telehealth to other technologies they were familiar with to comprehend what telehealth technology could do.

### **Summary of Fort McKay Case**

In Fort McKay, there have been several changes in the Health care Center involving staffing and the addition of patient consultations over telehealth. These changes have also increased or changed some of the staff's job responsibilities and patterns of work. According to the health care staff at Fort McKay, the primary health care challenges the community faces are: addiction to drugs and alcohol, smoking causing cancer and respiratory problems, and poor nutrition leading to diabetes. Some of the patients in the second round of research indicated that their primary concern was water contamination from the oil and gas industry. These health concerns, while pressing, are not necessarily being addressed by the tele-learning services being provided since some of the information is repetitive, but the health care staff generally found learning services did enhance their working knowledge.

With the doctor's relocation to Nova Scotia, Fort McKay implemented telehealth for patient consultations to retain his services in the second phase of telehealth usage. Some of the challenges found in tele-learning services continued to be obvious in patient consultations such as the need for a reliable connection to prevent blurry images and poor audio quality; it became much more obvious and obstructive when there was poor connectivity. Patients continued to see the doctor because it was more convenient than

driving to Fort McMurray to find a physician, especially since there was a shortage. For some individuals who were non-band members the cost of travel was prohibitive. While these were compelling reasons for seeing the doctor over telehealth, one of the most important finding in this case was that many patients used telehealth because they trusted the doctor's knowledge of their medical history and the health care team's abilities to provide excellent health care. Trust was the underlying factor that also enabled the health care team to work together through challenging technical difficulties and large patient loads during each telehealth session. The other finding in this case that is important to consider is telehealth users often altered their actions, communication, and some technological adjustments to ensure their telehealth experience continued to be acceptable.

## **Concluding Comments**

Each of the three cases above illustrated different approaches to telehealth use. Each of the communities was selected to consider the role telehealth may play in health care service delivery with varying degrees of the following characteristics: health care autonomy; duration and stage of telehealth use; and geographic remoteness to an urban center. At the same time, the cases provide ample opportunity to consider some of the issues that the literature on telehealth explored such as the structural constraints of telehealth and the role of users in telehealth appropriation from a SCOT and structuration theory perspective. The proceeding chapter, a theoretical analysis of the three cases, will provide the reader a deeper discussion of these issues.

# Chapter 7- Analysis: The Role of Telehealth in First Nations' Health Care Services

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## Introduction

In the previous chapter, three cases of First Nation communities' telehealth usage or the lack of usage was documented. In the descriptive account, we see the users' role in shaping telehealth in the health care centres. This chapter analyses the empirical findings in light of the theoretical frame based on SCOT and Giddens' structuration theory to answer these questions: 1) what is the role of telehealth in First Nation health care service delivery? 2) What or who shapes the use of telehealth in health care settings? 3) What are the implications of telehealth on work practices and health care relationships? The thesis questions challenged the underlying assumption in the literature and amongst decision makers that there is a uniform role for telehealth in all First Nation communities. Much of the assumptions lie in FNIHB's strategy to implement telehealth in all First Nation communities in Alberta for tele-learning.

There are several findings from the case study in the previous chapter: first, there is a role for telehealth in First Nation health care service delivery, but this role (as a mediator for health information, physician consultations and a connection site for colleagues and families) is based on each community's health needs. However, the obstacles to telehealth utility in all three communities confirm some of the findings in the literature: structural constraints such as policies, technology design<sup>193</sup> and resources shape how telehealth is used in health care services (Health Canada, 2001; Jennett, Yeo, Pauls, & Graham, 2003; Hailey & Jennett, 2004; Watson & Watanabe, 2000; R. Scott, 2006). Second, health care providers and patients both use and do not use telehealth. The research uncovered the complexity of actively using telehealth – that is – the choice

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<sup>193</sup> DeSantis, Snyder and Poole (1994) suggest rules and resources are inscribed into the technology. When actors are moved to use the technology, these structures are engaged for a variety of possibilities.

to use telehealth is tinged with the users' position as health care provider or patient; as well as the larger context of technology usage and operation in rural and remote communities.

This chapter will examine the tension between structural constraints and user agency at the policy level and at the level of the users' everyday interactions. The discussion is divided into three parts: first, I will provide a look at the role that institutional actors play in shaping telehealth usage, particularly through the provision of resources and as developers of rules in the form of policy. Second, I will examine the users' role in shaping telehealth usage despite the obstacles and constraints they encountered. Lastly, I will discuss the unintended consequences of participants using and not using telehealth. The reader will note that I have made some conclusions for future telehealth development in each of these sections, since it seemed logical to follow the analysis without reiterating the reasoning behind them. I make an overall recommendation in the last chapter of this thesis research.

## **Structural Constraints Shaping the Role of Telehealth**

Giddens' (1984) defines structure as being comprised of rules and resources that enable and constrain the everyday activities of individuals. At the micro level of everyday life, structure is evident in the routines and interactions that individuals engage in. At the macro level, the resources shape what type of telehealth services are made available for First Nation communities while the rules governing health care create the lines of jurisdictional debate. Outhwaite (1990) reminds us that Giddens' concept of structure is not separate from everyday actions; rather, rules and resources are connected to individual's choice to act or not to act. Structure is recreated in the individual's actions and as she uses telehealth (Orlikowski, 2000), her actions may be constrained or enabled by the resources and rules governing telehealth operation. However, this is also not the only structure that is at play in telehealth operation in First Nation communities. The precarious nature of First Nations health services delivery is comprised of federal and provincial services; the jurisdictional challenges around the rules governing health services and the resources offered by the province may hinder some communities from seeking their own direction in developing different telehealth applications. The

discussion below examines the rules and resources that enable and constrain First Nation communities' actions in telehealth usage.

### ***Resources Shaping the Role of Telehealth***

The roles that telehealth played in the three case communities were: as mediator for information exchange, as a connection site for families and professionals and as a mediator for clinical services (patient to physician consultation). At the time of the study, the telehealth structure for First Nation communities in Alberta was established by FNIHB and its primary focus was on enhancing education for health care providers and patients. Fort Chip, Fort McKay, and Janvier (when connected) could access any of the tele-learning programs offered. This approach of "first come, first serve" on the telehealth schedule would enable health care providers and community members to enhance their health care knowledge.<sup>194</sup> For clinical services and connection to others, the First Nation community, depending on their transfer status and health care facility designation, could also access telehealth programs by developing partnerships with other institutions. Fort Chip, as a community with full transfer status and clinical capabilities as a nursing station, has developed partnerships in Fort McMurray and Edmonton to access telehealth services such as physiotherapy, diabetes education, family visitations<sup>195</sup> and others.<sup>196</sup> At the time of research, Fort McKay, as a community with partial transfer status, developed physician consultation services with their doctor in Nova Scotia. Both of these communities could act within the range of their health authority.<sup>197</sup>

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<sup>194</sup> Some of the participants in Janvier indicated this is one of the assets that telehealth could bring to their health care services.

<sup>195</sup> As a connection site to meet others, tele-visitation must be developed with the hospitals, care facilities or other organizations.

<sup>196</sup> At the time of research, the Health Director was considering contracting a local physician in Fort McMurray to provide telehealth consultation. However, she reasoned that it would be more beneficial to hire a physician to fly into the community and pay him for his telephone consultations since telehealth was not a reliable technology.

<sup>197</sup> At the time of research, the tribal council was preparing to enter into a memorandum of understanding with Northern Lights Health Region to provide primary health care service to all three communities via telehealth. FNIHB had been one of the supporting partners in an application to Canada Health Infoway for funding. However, when I asked the Health Director of Fort Chip if the community would participate, she responded Fort Chip has full autonomy of its services and can choose not to participate in the tribal council's telehealth efforts. Fort McKay's Health Director also indicated that it had control over its physician service and responded in the same manner as Fort Chip. The need to state the community's autonomy suggests the community's desire to establish their own health goals and objectives.

The structure of telehealth services reflected the larger health care services system for First Nation communities. As a result, some of the limitations and constraints that the telehealth structure had reflected the larger constraints in the health service delivery structure: most communities were categorized as non-isolated which means FNIHB<sup>198</sup> focused on health promotion rather than on clinical or treatment services (Waldrum, et al. 2004). The potential benefits of such a system may include providing an organizational structure to manage telehealth, technology training for communities, and funding. However, it also means, the perpetuation of a system that may not reflect First Nations' immediate interests, needs and goals. First Nation communities lack access to basic medical services (Health Canada, 2007). While receptive and willing individuals may benefit from increasing access to health information, tele-learning is a long term health project. Some of the immediate health needs reflect studies on health challenges in First Nation communities such as treatment for diabetes patients (Canada, 2000; Dean, Young, & Flett, 1998; Young, Szathmary, Evers, & Wheatley, 1990) and the need for counseling services for addictions (Anderson, 2007; Assembly of First Nations, 2004; Callaghan, Cull, Vettese, & Taylor, 2006). These services will require federal, provincial, and community level collaborations. As a result, institutional actors need to engage in a consultative process with First Nation communities, so they can actively make changes to the existing telehealth system to reflect their health care needs.

**Conclusions:** First, tele-learning sessions need to be tailored to the communities' health challenges, so they should be periodically reviewed for community relevance and interest. Second, most of these concerns require education, but some also require treatment. Diabetes was the paramount concern in the communities and participants indicated that tele-learning services were focused on this problem. However, community members also require treatment: in the First Nation communities without physician services, retinal eye exams akin to those offered in Australia using telehealth (Murray, Metcalf, Lewis, Mein, & McAllister, 2005; Yugesan, Constable & Chan, 2002) or a mobile diabetes clinic or tele-ophthalmology may decrease the length of time for diagnosis (Jin et al. 2004). As for the participants' concerns with mental health and drugs

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<sup>198</sup> Giddens' (1984) does not examine the difference between individual agents and institutions as agents. While institutions are comprised of individual agents, they are often acting in the interest of the institution. This needs to be further examined.

and alcohol addictions, Savin et al (2006) and Shore & Manson's study both indicate that telehealth has been used to connect patients to traditional healers, psychiatrists, and counselors. This is one area that is worth exploring with First Nation communities who lack access to counseling services.<sup>199</sup> The other health concerns require a combination of education, socio-economic development, and the involvement of many organizations. Lastly, given the geographic location of the communities, water quality connected to cancer were concerns that seemed pervasive in Fort Chip and Fort McKay. The participants indicated that they lack sufficient understanding of the connection between cancer and their water quality. This needs to be addressed in a compassionate, informative, and unbiased scientific process from a third party that all stakeholders can trust.

Lastly, institutional actors (including First Nation community leadership) need to consider the existing health care services in the communities before implementing telehealth services. Often the health care concerns in the community reflect the lack of health care services. The high rates of chronic illness in First Nation communities can be reduced by increasing access to primary health care services (Mill, 2000). Telehealth can facilitate this service by connecting access to a nurse practitioner or family physician to support nurses in communities such as Janvier. Janvier lost their physician services due to a number of community related problems. The community leadership must focus on managing their financial and human resources and, if need be, seek assistance and counsel from other First Nation communities on the course of action that would benefit their community.

In sum, institutional actors, play a significant role in shaping the role that telehealth plays in First Nation communities by providing particular telehealth programs and technology to the communities. While communities themselves may attempt to develop collaborations with provincial authorities, their transfer status (which affects the degree of control over programs and financial resources) may constrain the types of partnerships they can create to access particular telehealth services. As a result, a

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<sup>199</sup> Canada Health Infoway (2011) indicates that its objective is to fund 40% of communities north of 60 with telehealth service support for mental health and drug addiction services. However, funding must be broadened to include other First Nation communities outside the territories that struggle with mental health challenges.

coordinated effort between all levels of health provision must be made to address both learning and treatment opportunities. Resources, however, are simply one side of structure, rules for telehealth must be developed to coincide with the vision for service provision.

### ***Rules: Jurisdictional Challenges and Limitations***

According to Giddens (1984), structure involves rules and resources. In this study, the usage of telehealth was shaped by structural constraints, particularly the lack of clarity around resource management and rules or policies governing telehealth operation. This finding confirms past research on telehealth in Alberta that identified the limitations of existing telehealth policy in such areas as data stewardship (risk management, liability, human resources, reimbursement, and funding), operational (privacy and to some degree documentation), and inter-jurisdictional (inter-jurisdictional billing, locus of consultation, and billing) policies (Health Telematics Unit, 2004: p.5). The jurisdictional challenges, however, are not clearly explained by Giddens' structuration theory: what happens when multi-organizations with different responsibilities are connected and no rules apply to the event that is unfolding? What happens when neither organization claim responsibility for the event unfolding?

In this study, some of the participants mentioned that the lack of clarity regarding jurisdictional resource responsibilities, particularly technology and billing for physician services, created a sense of apprehension to use telehealth for physician services. Given that Fort Chip had full autonomy of their health resources and Fort McKay had some autonomy, both questioned whether FNIHB would continue to be responsible for financing new telehealth technology and connectivity or whether this would become another transferred program (transferred into the control of First Nation communities). The Health Directors indicated that if there were ***no*** additional funds for telehealth then First Nations may fail to provide needed health care programs by shifting funds to telehealth. Given this type of scenario, and the uncertainty of their future responsibilities, Fort Chip questioned whether it was financially feasible to expand telehealth to include physician consultations. Jurisdictional responsibilities include resource responsibilities: if the First Nation community has transfer status but does not gain additional

resources<sup>200</sup>, then according to Giddens, it only possesses half of what comprises structure. In the end, if telehealth does become a part of the transferred programs, structural change may be stalled without additional resources to include new technologies or innovations to care.<sup>201</sup>

The second jurisdictional challenge observed in this study involved billing for physician consultations from outside of the province to local communities. There are two challenges here: first, billing practices and second, insurance and care responsibilities. Regarding billing practices, can a doctor with an Alberta license and insurance charge for services from outside the province? Fort McKay telehealth users successfully skirted around Alberta's vague billing codes by launching a patient to physician consultation service. Alberta's Schedule of Medical Benefits (2008) indicated that billing must be for<sup>202</sup> a "patient in attendance at an designated RHA<sup>203</sup> telehealth site at the time of video capture" (s1.10, pdf#1). It also did not specify whether a "medical consultant" was a specialist, a family physician or a nurse (p.16, pdf#3).<sup>204</sup> The doctor, however, did not encounter any difficulties billing Alberta Health and Wellness for seeing First Nations patients via telehealth while he was onsite in his Nova Scotia office.<sup>205</sup> Does this mean other doctors located outside of Alberta can follow the same path as the doctor in Nova Scotia? FNIHB's Telehealth Director mentioned the extreme scenario: will doctors located in other countries such as India follow the same example? In this case, policy development lagged behind technological advancements and usage.<sup>206</sup> The billing codes

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<sup>200</sup> Here I am not suggesting there is only one way of increasing resources, but from whatever means – taxes, increases in transfer dollars, capital development or etc.

<sup>201</sup> Canada Health Infoway continues to fund innovative technological projects across the nation, but these projects must also include funding to hire technicians and support personnel to repair and maintain the technology.

<sup>202</sup> Alberta Health and Wellness did not respond to my repeated request for information about jurisdictional issues. FNIHB also was uncertain of the jurisdictional challenges associated with billing issues.

<sup>203</sup> First Nation communities are under federal jurisdiction, but for health care services they are considered a part of a regional health authority. First Nations people can obtain medical care from the province just like any Albertan. However, health care services on reserve are under FNIHB (Health Canada).

<sup>204</sup> FNIHB was supportive of the telehealth consultations, but it anticipated trouble with Alberta Health and Wellness because the patients were not at a designated RHA nor was the doctor a traditional specialist billing for services.

<sup>205</sup> The doctor retained his license in Alberta and acquired one in Nova Scotia with each of the province's College of Surgeons and Physicians.

<sup>206</sup> I return to the discussion on structure and agency after the answering the questions presented by this thesis.

reflect jurisdictional territory over resource management, but at the level of First Nation community, they reflect an intersection of jurisdictions for health service access: federally situated communities accessing provincial services. If Alberta Health and Wellness closes this door, it will curtail family doctors from practicing outside the province, terminate Fort McKay's ability to maintain physician services, and perpetuate their own inability to provide physician services in rural and remote communities (Minore, Boone, Katt, Kinch, & Birch, 2004).<sup>207</sup> However, by doing so, Alberta will also succeed in controlling who can provide family physician services.

Regarding care responsibilities, there are some concerns when a physician provides health care services outside of the province. First, who is responsible for the practice of appropriate care: the nurse in Fort McKay assisting or the physician in Nova Scotia completing the consultation? The doctor obtained insurance for his practice in Nova Scotia and Alberta; he assumed he was responsible for the care of his patients despite being at a distance. At the time of research, some of the provinces anticipated this very concern.<sup>208</sup> In Ontario, the Registered Nurses' Association of Ontario (RNAO) (2007) indicated:

The registered nurse has the knowledge, skill and expertise to provide necessary safe and effective care to the clinical encounter. That level of expertise and knowledge cannot be replaced by “training” a less qualified individual to answer calls. It is precisely because the potential risk is higher when there is no opportunity for direct contact with the patient that a skilled clinician is essential. The RNAO supports the ability of nurses to provide telehealth care for a patient during a clinical consultation. In Alberta, CARNA (2008) indicates that “telehealth services that registered nurses provide include, but are not limited to, health assessment and triage, provision of health information, health counseling and teaching” (p.4). CARNA outlines the RN’s role as a support to the physician in health assessments and triage while also supporting and educating patients. In CARNA’s (2008) outline, the nurse’s role as a

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<sup>207</sup> Currently, specialist services are provided over telehealth and this may be route that family physician services follow if there is a real demand. In any case, the billing codes will need to clarify who can bill for services.

<sup>208</sup> At the time of research, I could not find what the College & Association of Registered Nurses of Alberta (CARNA)

supporter and educator for health in face-to-face interactions is carried over into telehealth interactions.

After using telehealth for patient to physician consultations, the nurses indicated that their supportive role for the physician and patients carried over to telehealth. However, these additional job tasks added to their workload and created additional stress. The physician providing care to Fort McKay would agree with RNAO: the nurses in Fort McKay provided him the best assistance. If, however, he conducted patient consultations via telehealth in an unfamiliar community with its nursing staff, he would need an understanding of their skills before he could be comfortable with their ability to assist him. Despite being at a distance, he felt responsible for the care provided to his patients.

***Conclusions:*** To ensure health care providers are aware of their professional responsibilities using telehealth for patient consultations, each licensing body in each province must provide a clear statement of responsibility. As well, they need to stipulate how this responsibility is translated into practice such as establishing a standard for telehealth training when using telehealth for patient consultations.

In sum, the role that telehealth played in First Nation community health care services was shaped by institutional actors who provided resources for telehealth operation, but this structure may neglect First Nations' health interests. Some of the structural constraints uncovered in this study revealed that transferred communities were wary of progressing with telehealth services if it did not mean additional funds were provided. The lack of resources to support new innovations means telehealth cannot stand on one leg of structure. As well, continued usage of telehealth for out of province family physician - patient consultations present a challenge to Alberta's billing codes. However, exercising provincial power to change the billing codes may also limit First Nations' access to physician care. These types of structural constraints not only shape the number of telehealth applications made available to communities, but its future utility. According to the HTU (2004), "policy, at least in theory, determines the rate and direction for healthcare initiatives" (p. 7). The direction of First Nation telehealth in Alberta will depend on these policies.

## **Users Shaping Telehealth Usage: Defining Agency**

In the above discussion, much has been discussed about the structural constraints that shaped telehealth usage. Very little, however, has been mentioned about the users' role in shaping telehealth usage. In this study three scenarios were observed: users who used telehealth as designers intended; users who avoided or sporadically used telehealth; and users who modified telehealth. Giddens (1984) defines agency as "doing", the observable performance of an actor. According to Giddens agency is enacted through the person's encounters<sup>209</sup> with other individuals, so the relationship a person builds or changes also changes the social system the person moves through: the individual participates in the structuration process. By using technology to connect to others, the user participates in supporting, recreating, and perhaps even changing the social structure that she is in (Star, 1991; Winner, 1993).

In the case of Fort McKay, users modified the limitations of telehealth and used it for physician consultations to meet the community's health care needs. Consequently, in some instances, users actively engaged the limitations of an implemented telehealth system and, might I add, the opportunities it presented without expending significant resources to organize the telehealth system. These users discovered that the human factor limitations, technological difficulties and space challenges were not barriers to telehealth usage. The users appropriated the technology into their work routines, changed how telehealth was used to fit their goals, and some changed their existing patterns of work to create new structures for telehealth usage. These new rules and routines, though unwritten, became their norm for telehealth.

However, what happens when users choose not to act or sporadically act? Is both a form of agency? Giddens (1984) indicates that when an actor involuntarily reacts to something, such as the blinking of an eye, it is not agency. Given Giddens' perspective, acting when needed would be considered a form of agency, but he does not mention willful inaction (knowingly avoiding telehealth usage when the individual could use telehealth). Kline (2005) indicates that resistance is a form of agency; resistance to technology is a common approach to the process of social and technological change.

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<sup>209</sup> According to Giddens (1984) encounters are the single or series of events that can become a part of routines.

Instead of embracing the dichotomy of resistance as acts of irrationality or heroism, he views resistance as transformative. Historically, resistance in capitalist markets have involved inaction, the refusal to work or participate in production, or overt action against technology which have signified the users' perspective of technology and their relation to work (Grint & Woolgar, 1997). Consequently, technology users may resist the conventional ways of using telehealth to meet their goals or refuse to use telehealth (both can be considered willful forms of agency).

Some participants used telehealth as it was intended, but their experiences led them to sporadically or altogether avoid using telehealth. They acknowledged telehealth's potential to reduce travel, enable access to various services, provide them with learning opportunities not readily available in their communities, and connect them to colleagues, friends, and family. However, the participants' experiences with telehealth were disappointing and often times, frustrating. Consequently, the possible role that telehealth could play in the communities and the way this role was enacted in the health care centres in the First Nation communities was not what stakeholders intended: it was not regularly used. Giddens (1984) indicates that normalizing actions into peoples' routines in a social system provides stability, but the users in Fort Chip and Fort McKay had not used telehealth routinely. Instead the unintended consequence of implementation was that most of the participants in this study used telehealth sporadically or not at all for long periods of time.<sup>210</sup>

The data from FNIHB-Alberta's telehealth scheduler<sup>211</sup> suggests that between 2003 and 2008, Fort Chip's telehealth connections were focused primarily on educational services with some clinical and meeting connections. Fort McKay's telehealth connection was erratic in the same period. According to this log, telehealth connection has been on the decline since 2005 in Fort Chip perhaps due to staff turnover, changes in

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<sup>210</sup> Until Fort McKay started physician consultation, telehealth was sporadically used. The problem with sporadic use is that users do not gain familiarity with the technology, which means that each time they use the technology they must go through the process of learning again how to use the technology (a time consuming and somewhat unsettling process).

<sup>211</sup> The FNIHB-Alberta telehealth scheduler, a log of all telehealth connections, only had data starting in 2003. The communities did not have a log of their telehealth connections.

health care programs or, as participants indicated, the lack of attention to user needs.<sup>212</sup> In Fort McKay, telehealth was on the decline until physician consultation services commenced in 2007.

In sum, users demonstrated agency by shaping telehealth in First Nation communities by engaging the limitations of its design and delivery structure. However, as the reader will read below, the technology design, available applications, and structure also shaped users' ability to appropriate or integrate the technology into their routines. Some users clearly did not appropriate telehealth; rather, they used the technology when they needed to or altogether refused to use telehealth.

### ***Relevant Groups: Health Care Providers and Patients***

Pinch and Bijker's (1987) examination of the bicycle revealed that the relevant groups' needs provided the impetus for changing the bicycle design. Oudshoorn and Pinch (2005) indicate that identifying or labeling the user of a technology often excludes other possible users, since designers focus on these particular groups. In this study there are two conceptions of the relevant groups: at the level of the community and at the level of individuals. First, in the literature on telehealth, the conception of the relevant groups of telehealth users can be summarized by the following: rural and or remote communities requiring health care services. First Nation communities fit this relevant group based on geography and the lack of health care services and support. The underlying assumption is that First Nation communities would receive information and services from urban centres: the flow is unidirectional rather than a reciprocal flow of health services and information. At some point in time, decision makers and researchers will need to consider that First Nation communities can also enhance our understanding of health and healing. They can be our teachers and educators; the flow of information can be mutual. Telehealth can become a medium for the mutual sharing of information: the re-conception of relevant groups may include urban centres, not simply as providers of information and services, but as receivers as well.

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<sup>212</sup> The telehealth scheduler at FNIHB logs every connection with the communities. However, as mentioned in the case study, this does not necessarily mean that community members or health care providers are present during the session.

Secondly, relevant groups are conceived at the individual level. In the literature on telehealth, three relevant user groups were identified: health care professionals needing work support (Sheehan, 2002; Dick et al, 2007; Dever, 2000), health care organizations and systems requiring economic sustainability (Jennett et al. 2003; Murray et al. 2005; Fisher et al. 2003; Baquet et al. 2005; Rowlands & Associates, 2005; Whited et al.; Jin et al. 2004) and patients needing health care services (Sherry, 2004, Muttitt et al. 2004, Savin et al. 2006; Shore & Manson, 2004, 2005; Nissen & Tett, 2003; Eikelboom, 2003). These three conceptions of the relevant users as health care providers, institutional actors, and patients identify users in the health care system. Giddens (1987) suggests that the actor's position in the social system affects the degree of power and responsibility that she has to exercise particular actions. Consequently, when the actor uses telehealth, her position or role in the health care system contributes to how she may use the technology. In the discussion above, institutional actors' involvement in shaping telehealth usage has been examined; this discussion here will examine providers and patients as the other two relevant groups.<sup>213</sup>

Do health care providers and patients have different telehealth needs? In this study, users made several modifications to: human factors, technology and space needs. The health care providers in all three communities were primarily comprised of professionally trained women from outside the communities. The patients interviewed in Fort McKay were also primarily comprised of female status and non-status Indians.<sup>214</sup> While the discussion on human factors, and technology and space needs apply to both types of users, patients frequently placed more emphasis on human factors and health care providers placed greater emphasis on telehealth fitting into their work routines. Both groups of users were observed using telehealth in the health care centres. The other

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<sup>213</sup> This means that often times the user's other identifiers as male, female, mother, father, friend, and perhaps even their cultural background seemingly disappear under the label of health care provider or patient. The singular dimension of the user as health care providers, staff, administrators, and patients is problematic, and a limitation in this study. According to Giddens the actor draws from her knowledge to change the social system. This knowledge can be taken from multiple contexts. Most of the participants in this study were women: as nurses, patients, health administrators and staff. There were very few male patients that volunteered to be interviewed for this study. As result it is difficult to compare whether males and females had different perspectives and experiences with telehealth.

<sup>214</sup> The government administrators that I spoke with for this research project were male. It would have been beneficial to interview these administrators to understand their construction of telehealth in First Nation communities.

group of users that I did not interview in this research was the telehealth educators connecting to the communities. I will discuss the differences and similarities between needs below.

### ***Human Factors Needs Shaping Technology Usage***

Many of the health care providers in Fort Chip indicated that their desire and ability to use telehealth was hindered by their negative experiences with human factors such as the lack of conversation development. Often we forget that telehealth is a mediator for human interaction and connection, so the lack of conversation development hinders relationship formulation. In the study, the lack of conversation led participants to focus on the technological problems rather than the people they were meeting. Giddens (1984) suggests that when an individual uses technology such as the telephone, co-presence (managing spatial relations) is limited to audio communication, but given telehealth enables both visual and audio expressions, the users' telehealth experience enables them a form of face-to-face encounter. The users must be able to manage co-presence in their human encounters to enable the flow of health related activities. In Fort Chip, health care providers indicated that their feelings, questions, and interests were not acknowledged during the tele-learning sessions. According to Giddens' structuration theory, telehealth users failed to manage co-presence, which means full presence (the users feeling that they were being perceived and understood) was not achieved. The users expected to be engaged in some form of conversation and the lack of acknowledgement made them spectators in their learning experience. From Goffman's perspective (1986), the educator via tele-learning and the participants in the communities had failed to establish, and or maintain, the rules surrounding conversations. Conversations form the basis in which culture, trust, respect, and information are communicated.

The study confirms Health Canada's (2001) previous study on telehealth usage in First Nation communities: trust and relationships between health care providers and community members are essential to telehealth operation and viability. In many ways, telehealth sessions are opportunities for personal and professional encounters. The

mediated form of communication does not lessen the individuals' need for assurance that their presence, needs and feelings are acknowledged. The patients in Fort McKay and the health care providers in Fort Chip mentioned that when the person they were communicating with interacted in a personable and friendly manner (laughter, jokes, and personal greetings), they felt the other person related to them as a person.

The patients in Fort McKay often mentioned that they communicated well with their doctor regardless of technical difficulties and obvious disruptions; they saw it as an opportunity to continue an existing relationship. They mentioned that the doctor understood their medical history, provided an excellent level of care, and navigated them through the medical system. Several patients recounted their experiences of having cancer or some unknown illness that their doctor discovered and provided quick intervention that healed them. Consequently, patients responded to my questions of technology failures with statements of trust in their doctor; they ignored the technical difficulties in their interactions. For them, the telehealth mediated physician relationship was better than the choice of going to Fort McMurray to sit waiting for hours to see a doctor who did not know them. The patients had a doctor who understood them and advocated for them; this was worth overlooking the technical difficulties.

In Fort McKay, the participants who used telehealth successfully understood that telehealth enabled two-way communication – requiring each person to acknowledge their relationship and their role in the health interaction. When users encountered poor technology design or malfunction, providers and patients increased the volume of their voices and repeatedly reiterated their words. When telehealth failed to be clear, the nurses and doctors used their cell phones and landlines to overcome the static. The users were also cognizant of rapport and conversational turn-taking. Similarly, poor communication, disruptions in the natural flow of conversational turn-taking and the inability to establish a sense of trust, eroded the ability to build relationships.

Relationships are based on trust.<sup>215</sup> Giddens (1984) indicates that trust enables individuals to bracket an event without evaluating every risk, which would paralyze an encounter (p.3). For those that perceive telehealth as a medium to broadcast information,

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<sup>215</sup> This finding also verifies the findings in Health Canada's early telehealth pilot projects that the success of telehealth usage is based on establishing trust between community members and health care providers.

a relationship is not necessary, but the receiver of the information will likely choose other means that are more optimal, less time consuming, and a flexible source of information that does not require scheduling an appointment or an evaluation of the trust relationship. These encounters with other users over telehealth reveal that communication forms the basis of the structuration process. Users must make a coordinated effort between different locations to simultaneously meet. Relationships enable users to use telehealth.

**Conclusions:** While mediated communication is never as clear or personal as a face-to-face conversations, the participants' concerns about privacy and confidentiality, components of trust, should compel decision makers and health care providers to take additional measures to ensure patient information is protected by removing those uninvolved in the telehealth session; this includes the telehealth coordinator, if s/he is not a translator, and the nurse. Patients should also be assured that their information is confidential. As well, several health providers commented that the tele-learning sessions were jargon laden for patients or overly repetitive for health care professionals. If FNIHB aims to fully utilize tele-learning opportunities, it must re-organize the sessions not as information sessions, but as educational endeavors. This means: a) equipping information providers with teaching skills; b) educating educators about the importance of language, conversation, and cultural protocols when talking to patients; and c) developing a curriculum for providers that reflects the communities' health needs. These three changes to human contact will change tele-learning sessions from information sessions to periods of learning and interaction.<sup>216</sup>

In sum, many participants suggested that positive human relations were the basis of formulating routine telehealth usage. When they did not encounter other telehealth users, usually through tele-learning, that acknowledged their feelings and needs, they were less likely to use telehealth again. Without positive human relations, users responded to telehealth in one of two ways: 1) avoidance or 2) using only when necessary or needed. Both of these types of responses would lead to telehealth being sporadically used.

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<sup>216</sup> In the discussion below, participants indicate the type of telehealth sessions would be most beneficial to their communities.

## ***Technology and Space Needs***

The discussion above revealed the challenges that users encountered with other users. This section examines technology and the spaces needed for telehealth utilization; both are examined here since users often associated their telehealth experience or needs with the space that it occupied. The participants encountered two technology problems when they used telehealth: first, challenges associated with other technologies connected to telehealth and second, inappropriate technology design. Both forms of technology problems shaped users' experiences of telehealth and how they responded.

The first technological problem users encountered was that telehealth, while being embedded in the health care system full of structures, was also embedded in technology systems: technologies are connected to other technologies, which enable their functionality. Hughes (1983) indicated that technology shapes the function and productivity of other technologies. Poor and inconsistent Internet connectivity led health care providers and patients to view telehealth as unreliable and, in some cases, disuse. For health care providers in Fort Chip, the perception of telehealth as unreliable led the users to distrust the technology. Consequently, the meaning of telehealth was not simply tied to its functionality and the benefits that users knew existed, but whether they could trust it. If a user experienced sustained disappointment and frustrations with the technology, these incremental failures to connect, see or hear the other person via telehealth then their expectations of telehealth diminished.

In Fort McKay, health care providers and administrators soon realized that telehealth connectivity was operating on the same system as desktop computers; they attempted to disable desktop connections to the Internet to improve telehealth connection.<sup>217</sup> While SuperNet connectivity was being implemented in the communities, no one was available to immediately repair telehealth malfunctions.<sup>218</sup> The delay in developing stable connectivity and the lack of resources to address malfunctions likely led to disuse and telehealth being perceived as an unreliable technology.

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<sup>217</sup> This was not possible since the health centre was in the same building as other services.

<sup>218</sup> As mentioned in the case description of Fort Chip, SuperNet connectivity was not "cold" proof, so it frequently dropped. This took some time to repair for two reasons: 1) it was remote and resources could not be immediately deployed to repair it; and 2) FNIHB and AXIA could not determine if the problem existed externally or internally within the nursing station.

Secondly, there were two obvious telehealth design challenges: the new units were not designed for the space needs of the communities or the work context of the health care providers. According to Latour (1992), when we look into the black box of technology we will see the social world. The social world that designers imagined for the new telehealth units in the communities seemed to involve spacious meeting rooms, chairs spaced at a distance from the monitor, and telehealth users facing the monitor. In contrast to the design of telehealth, the social world of First Nation health care centres resembled scarce resources and small cramped rooms with poor sound proofing. The space in which telehealth was housed shaped users experience of telehealth. Consequently, health providers in Fort Chip mentioned that the technology was uncomfortable to use in the physiotherapy room; patients and health providers in Fort McKay mentioned the nurse's office lacked privacy; and administrators and health providers in Janvier promptly stored the new telehealth unit because the room was not secure from theft. The users wanted to renovate or build alternative spaces and rooms that were sound proof, darkened without windows to improve visual images, and securely locked. In the end, users attempted to circumvent the poor technology design by making changes to its set-up, using an old teleconferencing camera, using the telephone when they could not comprehend the person, changing their own speech, and body positions during telehealth interactions.

As well, telehealth was based on scheduled appointments that required human coordination and stable work routines to enable point to point meetings for all telehealth applications. With the exception of Fort Chip, most of the health care providers in Fort McKay and Janvier had little routine. They were, in the words of one nurse, on a reactive model of responding to the most urgent demand entering through their doors. In Janvier, the psychologist indicated that community members preferred to drop-in when they needed to. This drop-in basis meant that health care providers needed to be flexible. In Fort McKay, aside from physician consultations over telehealth which occurred on Mondays from 10:00 AM to 1:00 PM, health care providers indicated they were too busy to attend tele-learning sessions. In Fort Chip, the division of job tasks and the setting for

care varied,<sup>219</sup> making it difficult for nurses to attend tele-learning sessions. All these nurses, like the nurse in Fort McKay and Janvier, mentioned they did not have time to attend tele-learning sessions because their work routines were overwhelming. The problem was that the existing design of the telehealth unit for learning fit some contexts, but not others. Pinch and Bijker's (1987) concept of relevant technology groups suggest one design did not fit every user group; rather bicycle designs had to be changed to meet the needs of different groups of users.

Given poor technology design and the lack of regular work routines some users may have turned to the Internet as their source of educational material. Cowan (1987) indicates that individuals tend to select a technology based on the number of choices offered by the technology. Nearly all the nurses in Fort Chip were pursuing NP designations using on-line courses, accessing on-line journals, and websites. The Internet may have provided them with more educational choices than telehealth, making the computer a more optimal choice. Consequently, the nurses may have avoided using telehealth as a learning medium because they were receiving far better choices on the Internet. However, at the time of research, community members in Fort Chip and Fort McKay did not have high speed Internet connection. They had fewer or no other options aside from television or print media.

**Conclusions:** Telehealth designers must work with First Nation communities to develop technologies that fit their community contexts, particular for home care patients and those working outside the health care centre. These users are often the ones that require the most assistance. As well, given the existing technologies implemented in the communities, decision makers must develop a plan to address users' frustration with technology problems, including a guide for troubleshooting and a help desk to clearly assist individuals. Often users in the study simply wanted to understand the technical problem and when it could be repaired. Some of the administrators did not know who to contact for equipment failures because FNIHB personnel passed them along to various individuals. Others felt frustrated because FNIHB did not inform them of when telehealth was being implemented in their facilities; it simply arrived in their health care

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<sup>219</sup> The home care nurse worked in the homes with chronic mobile challenged patients; the treatment nurse prescribed medication and educated patient with chronic illnesses; and the public health nurse undertook water samples and vaccinated patients.

centres, making some of the staff feel disrespected because FNIHB did not recognize that: “it’s our health centres”. The staffs’ sense that First Nation health centres are separate entities from the government needs to be communicated to government contractors and workers.

The problem for large institutions that contract some aspects of their work out is that actors may become disconnected from the source of action – that is – actors who know or understand the challenges may not be able to carry out the change. Giddens (1984) indicates that the closer one is to the intended action, the more power one has on influencing the outcome of the action. For example, the administrator who contacted FNIHB to ask why the Internet was dropping and then passed along to several individuals before being told they could not fix the problem. When the problem was identified as being external to the Nursing Station, it took time for FNIHB personnel to contact AXIA (the company managing the SuperNet).<sup>220</sup> This problem demonstrates that the solutions to the technological challenges involve integrated technology systems and multi-organizational collaborations that require significant clarity in communication and responsibility between organizations.<sup>221</sup>

In sum, the participants’ perception of telehealth was shaped by the larger telehealth system and the space in which the technology was used. While some users did not comprehend that telehealth was a part of an integrated technology system, direct communication would have resolved some of their frustration. As well, this study reveals that users often associate their telehealth experiences with the space or room in which telehealth occupies; it shapes the atmosphere for telehealth interactions.

## **The Unintended Consequences of Telehealth Use**

Giddens’ structuration theory mentions the unintended consequences of an actor’s actions: some of the secondary results arising from the initial encounter with telehealth.

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<sup>220</sup> Axia then had to send their technical team to resolve the matter.

<sup>221</sup> But, even with the best effort, sometimes jurisdictional gaps may still leave institutional actors baffled and paralyzed to change policies. Giddens’ (1984) structuration theory does not explicitly state how different social systems with similar or competing goals negotiate responsibilities, particularly when these responsibilities are beyond their purview nor does he consider how actors outside these systems may influence systems or change policies. The negotiation of responsibilities and the mobilization of resources is often a muddy terrain.

The secondary results may be that users inadvertently support the social, political, and economic structures that gird the technology's development or operation (Winner, 1993; Star, 1991). The participants' action to use or not use telehealth has implications on First Nations' health and the providers' work practices.

### ***Implications on the Rural First Nation Communities***

This discussion on the role of telehealth would not be complete without a brief discussion of the unintended consequences of telehealth usage. In many ways, while telehealth is designed for the purpose of facilitating First Nation communities' access to health care services, the usage of the technology also affirms the disparity of health care. For First Nation communities, two particular unintended consequences were observed that signify the deep divide between those who have access to health services and those who still need health care services. First, the patients who found their telehealth consultations with their physician to be on par with the quality of care they would expect from a face-to-face interaction consistently referred to how much they trusted their doctor and nurses. This means that telehealth is indeed a medium for relationships, not simply a tool to access care. This quality of care is based on the trust relations established between the community and their health care providers. If the nurses in the community had been temporary nurses, the expression of trust by patients may have been less. Trust is needed to effectively work in the First Nation communities; it cannot be over-emphasized given the history of colonization (Vukic & Keddy, 2002).

Second, patients used telehealth to access a service that was not available in their community, but it also means it is a temporary solution. Is telehealth a temporary solution to long-term needs? Of the 26 patients interviewed in Fort McKay, 24 of them indicated that they accomplished their objective of maintaining a relationship with their physician. However, two patients out the 26 patients interviewed asked two very challenging questions: "why do we have to use telehealth? We want to see a doctor like everyone else. Is it because we're Indians?" At the heart of these questions was the notion that by using telehealth, First Nations were again second class citizens; telehealth provided health care services to bridge the gap, but these services were less than what the average Canadian received. These two participants saw telehealth not as a tool to obtain

their health care services, but as an indicator of what the community still lacked; it was a political object that symbolized their community's marginalization in the health care system. As I spoke with these two participants, they indicated they were proud of their heritage, their community, and the people providing the health care services in the community, but they wanted to be treated fairly; they wanted to see a doctor face-to-face.

### ***Implications of Telehealth Use on Nursing Work and Knowledge***

Much of the above discussion has examined how users' action shaped telehealth to achieve the users' telehealth objective. Here, I'll examine the unintended consequences of the providers' access to information or their presence facilitating patient consultations on their work and knowledge. When telehealth was first implemented in rural and remote communities, including First Nation communities, one of the benefits of telehealth was that it supported health care providers (Sheehan, 2002; Dick et al, 2007; Dever, 2000) to enable the retention of a health care work force (MacLeod, et al., 2005). However, many of the participants also had to change their work routines to accommodate telehealth and they added more job tasks to their role as a nurse.

In all three communities, many health care providers indicated that there was very little routine in their work. However, one of the unintended consequences of using telehealth was that it demanded a certain degree of routine. In Fort Chip, the lack of telehealth routines disrupted the normal flow in health care providers everyday activities; the users' inability to form stable expectations of telehealth due to technology malfunction and the lack of administrative support at the time of operation made users distrust the process of using telehealth. The findings on the need for routine coordination suggest that the routines health care providers developed in their work and the patients' experiences in health care services are transplanted or carried into new technology usage interfaces. The users' prior structured experiences in their every day health care environment shaped their expectations of telehealth mediation (Orlikowski, 2000). At the level of every day interactions, structure reproduces structure with modifications as users identify the structures that are incongruent with their needs. This may also mean that it is more difficult to introduce radically new processes unhinged from other processes in the health care environment.

The participants in Fort Chip indicated that they wanted to coordinate telehealth sessions, raise awareness, and motivate others to regularly use telehealth. While these suggestions would indicate that users need a telehealth coordinator to establish a schedule or routine for telehealth activity, Fort McKay did not have one during their physician consultations.<sup>222</sup> The two nurses in Fort McKay accepted new telehealth responsibilities when they recognized that it would assist patient consultations. They incorporated telehealth work into their existing work. Aside from the telehealth technology, patients were familiar with the triage process. The physician then returned to the community every six weeks for face-to-face consultations. The team at Fort McKay developed a routine they were comfortable with. At the micro level of telehealth activity, participants created routines that sustained the technology activity because they recognized the need for patients to continue physician consultations. In Fort Chip, telehealth was not as vital to the community as it was in Fort McKay. Some of these nurses had extended scopes of practice that enabled them to prescribe medications as NPs or under the supervision of the doctor working in the community. They also mentioned they felt very busy and some felt overwhelmed by the amount of work due to the shortage of nurses in the communities. Consequently, the work context for technology usage is also relevant to users' decision to use telehealth or not.

Secondly, while many recognized the benefits of telehealth, some also feared that telehealth would displace their professional skills or add unwanted job tasks to their burgeoning workload. The nurse who vehemently claimed she was not the doctor's hand maiden felt if she assisted the physician during telehealth consultations with patients, it obliterated the need for her skills. Telehealth offered users the possibility of enhancing their knowledge, but in some instances it may also reduce their ability to practice their skills. This finding is unusual given the telehealth literature has often only considered the possibility of enhancing knowledge and skills, not limiting one's skills, which would be reason enough not to actively pursue physician consultations via telehealth.

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<sup>222</sup> But even if a telehealth coordinator was needed, it may not be feasible given the lack of human resources within all three communities. Instead what is more likely to occur is that individuals, performing other jobs, will become proficient at operating telehealth and act as the coordinator. This becomes their routine whether they have time for it or not. For small communities such as Fort McKay and Janvier, individuals often oscillate between jobs. However, adding another job task to an individuals' existing work load may increase burnout and stress.

As well, patients in Fort McKay indicated that while they trusted their nurses, they also acknowledge the usual doctor's examination was replaced with the hands of their nurse when using telehealth. Several patients indicated it was no longer a "hands on experience". This change from the hands of the doctor to the hands of the nurse means that knowledge and skill transfer must equally match this responsibility. The doctor in Fort McKay indicated that if he was not familiar with the nurses' skills, he would not be able to complete telehealth consultations.

**Conclusions:** In the future if First Nation communities have a stable Internet connection, what may be feasible, encourage participation, and learning is if educational programs were moved to on-line technology that enables educators and participants to log on through their desktop computers. The on-line technology, such as Elluminate,<sup>223</sup> could facilitate the individuals' work schedules in the small communities without significant disruptions in the work of those providing the service. The user could select from any number of possible tele-learning sessions in Canada and join the site at her convenience without utilizing a telehealth scheduler in each province. Health Canada, through FNIHB, could develop a large selection of learning options based on health care needs in First Nation communities from across the nation that would offer various educational programs for both patients and health care providers. This would reduce duplication of tele-learning services in each province. The ideal technology would enable participants to engage in the conversation either through voice or text; the user could also have the option to be seen or not. This suggestion reduces the need for coordination, increase program selection, facilitate greater participation, and takes into consideration the health care providers tight schedules. However, in the immediate future, for tele-learning, those who know how to use telehealth should teach those who do not since changes in staff require periodic re-training.

In sum, the unintended consequences of using telehealth have ramifications on the work routines and knowledge development of nurses. In many ways, changes to work routines accommodate and enable telehealth operation in the larger structure of the health care centres. However, where the work routines are disrupted and users can no longer

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<sup>223</sup> Elluminate is a web conferencing technology that enables audio and visual participation in live time (see <http://www.elluminate.com/>).

formulate expectations of telehealth, the users come to distrust the technology. This disruption of expected routines prevents telehealth from being incorporated into the larger structure of health care services. As well, the users who regard telehealth as a limitation to their knowledge expertise also view telehealth as a limitation to their practice; telehealth then becomes a limitation to their agency in nursing practice.

## **Concluding Comments**

The analysis here reveals that the role of telehealth in First Nation communities lies in the users' ability to integrate telehealth into the larger structure of health care service delivery in their communities. The users' agency is exercised in the most obvious way: overcoming structural constraints (resources and rules), poor technology design, space limitations by engaging other telehealth users in the structuration process. Every communicative encounter with another telehealth user is an act to negotiate telehealth's role in real time.

As a result, institutional actors may implement technologies into communities, but users decide if these resources (telehealth programs and applications) will be used. The study reveals that users must see a real need for telehealth to integrate the technology into their work or health seeking habits. If users do not see the need, users often refuse, avoid or use telehealth only if needed. These behaviors are also forms of agency that have great implication on institutional actors' investments. In the long run, decision makers will need to consider how telehealth will be funded in First Nation communities: will the shift towards Infoway funding give those communities with transfer status greater control of their resources? Will this shift increase the responsibilities of communities without necessarily granting them more resources to manage needed services? While these questions could not be answered in this study, what we have learned for now, particularly for communities such as Janvier, is that the health needs of the community can be mirrored in appropriate telehealth programs. However, this must involve the community's input into identifying their telehealth needs. In this way, communities can participate in developing telehealth that fits their needs.

# Chapter 8: The Role Constructed by Structural Constraints and Users

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## Introduction

In the literature review, some studies on telehealth in First Nation communities recommended the need to incorporate cultural protocols into the interaction with First Nations people. Other studies emphasized the structural constraints of telehealth operations such as human resources, cost-effectiveness and technology challenges. In chapter five on the policy of First Nation health care services delivery, telehealth is situated in the larger policy context of health care service delivery, an imperfect system requiring the negotiation of financial control, access to services, and the responsibility of care between Health Canada and First Nation communities. The literature review on telehealth and the health care policy discussion reveal that telehealth is bound and framed by structural constraints (resources, policy, and technology<sup>224</sup>). What was missing in the literature was an understanding of the role that users play in using or shaping telehealth in health care service delivery.

The selection of the three First Nation communities based on geography and telehealth implementation time revealed that these two criteria did not play a significant role in determining whether First Nation communities used telehealth or not: Fort McKay appropriated telehealth into health care service delivery despite being closer to an urban centre and having the technology for a shorter length of time. The existence of telehealth in a First Nation community does not guarantee its usage: structural constraints, technology, space and human factors may hinder telehealth usage. The study found that some users responded to these challenges by making modifications to their actions and to the technology to acquire their telehealth goals. The study revealed the role users play in shaping and appropriating the technology in health care centres.

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<sup>224</sup> While Giddens (1984) does not directly talk about technology, it can be considered a resource (one aspect of structure) used to accomplish work. Orlikowski (2000) reminds us that Giddens' concept of resource in the structuration process is that technology must be used to become a part of the social system.

This chapter brings to conclusion the study on telehealth in the three First Nation communities by addressing several important areas: first, the empirical findings and the theoretical implications of the research; second, the limitations of the study; third, an overall recommendation to policy makers and stakeholders of telehealth; and lastly, some possible new queries for future telehealth research.

## **Research Findings and Theoretical Implications**

### *a. Relevance of Findings to Telehealth Literature*

The main argument of this thesis has been: users play a significant role in shaping telehealth usage in First Nation communities and in turn technology shape users' interactions. The research indicates that while institutional actors may implement technologies, users decide how and for how long the technology will be useful to them. In the process of using technology, users encounter all the structural constraints such as the rules and resources girding telehealth operations. These rules are found in the lack of policies facilitating telehealth operation at the level of the day-to-day telehealth activities, in the form of work routines. The lack of rules opened questions around billing practices and the possible challenges governing the scope of practice for physicians and nurses facilitating telehealth encounters. In the long run, policies must consider jurisdictional boundaries, funding for telehealth and its connection to transferred communities' control of resources. Will telehealth be included as a part of the transferred package or will this continue to be a separate entity partially funded by Infoway and FNIHB? Without adequate telehealth funding, telehealth will continue to be decided by those who may know what First Nation communities' health needs are, but not necessarily what the community's telehealth needs are.

The study also revealed that users' routines, another form of structure, played a role in structuring telehealth into every day operation. These routines were malleable and two communities deliberately restructured their health services to facilitate telehealth and maximize the health care programs in the community. In the examination of the structural constraints shaping telehealth, decision makers must consider users' needs and

the needs of the communities before formulating and implementing telehealth programs (particularly tele-learning sessions).

In this study, we see users exercising their agency by making changes to technology design and the space allotted for telehealth by adding different technologies and changing their communicative behaviors to ensure telehealth was functional. This means that implemented technologies can be used to meet community needs, but users will shape the technology. As the previous case study conducted by Health Canada (2001) indicated, relationships and trust between users were vital to ensuring telehealth would be used. While relationships were established prior to physician consultations with patients in Fort McKay, users indicated that the educators' language choice and tone affected the participants' feelings of being acknowledged and involved in tele-learning sessions. This reveals that co-presence management in telehealth encounters require the same diligence as face-to-face encounters. Decision makers will need to review how tele-learning sessions can facilitate active participation and dialogue between educators and users in the communities.

Overall the research on telehealth revealed that while structure plays a role in shaping technology usage, users and technology also mutually shape each others' actions. Indeed what we observe is that implemented technology structures fail to become a part of the users' routine activities when users fail to incorporate telehealth as a part of their work or health seeking habit. From a users' perspective, the technology may not have offered them the right design, routine, or content (culturally appropriate, educationally simulating, and technically viable), but if the content is appealing, users will actively engage in shaping the technology to meet their needs.

### ***b. Theoretical Relevance and Implications on Relationships***

In this study, I have applied a SCOT perspective and Giddens' structuration theory to consider both user agency and social structure in technology usage. While some have also applied SCOT and Giddens' structuration theory to the study of technologies (Orlikowski, 2000; Barley, 1986; Poole & DeSantis, 2004; Greenhalgh & Stone, 2010), these studies tend to ignore the encounters individuals have with each other

as they do their work. One of the most interesting points in Giddens' structuration theory is the encounters individuals have with one another and the need for garnering trust.

While Greenhalgh and Stone (2010) suggest that Giddens' structuration theory lacks an empirical way of studying technology, I approach the study of technology by observing individuals' day-to-day routines in health care centres to ensure my research would include a broader discussion of users' encounters with technology, other users as well as the existing routines within the health care centres. The research is concerned about the social context of technology usage in First Nation communities, since this has been largely ignored in the telehealth literature.

The findings in the research reveal insights that are theoretically relevant to the study of technology, particularly interactive technologies, in social systems that require human-to-human communication. Applications of Giddens' structuration theory or the practice lens (Orlikowski, 2000) do not discuss the interactions or relationships between individuals as they negotiate technology usage. In the three communities, telehealth had the potential to mediate meetings between two or more users for the purpose of education, clinical consultations, visitations, or meetings. Telehealth simply provides a space for users to simultaneously engage in an activity for a short period of time during the regular hours of operation in the health care centres. Health care providers must be willing to take time from their daily work and for patients, time out of their day to meet with others on telehealth. In Fort Chip and Fort McKay, telehealth was primarily about coordinating a time for users to connect with people. When the technological connection occurs, the user either sees an effortless space created for her to talk, listen, and see the other person or she encounters the technology (all the problems associated with trying to connect with the other users such as fuzzy images, noise, static, and a host of challenges).

The object of study may appear to be simply the point at which individuals encounter and connect over telehealth, but telehealth was designed for human communication, so what happens to enable communication during telehealth usage? My observations in the three communities suggest that health care providers establish their work routines and gain trust through repetitive encounters in their work, but these encounters also reveal their colleagues' competence. Patients also gain an awareness of their providers' abilities and establish trust relations. However, if relations begin at a

distance, they may be unable to observe and engage the person repeatedly to ascertain their providers' knowledge and skills; this may create strains in trust. Telehealth encounters are by nature distant, but given enough repetition an understanding of the practitioners' skills and knowledge is possible. The central problem is whether users will use telehealth enough times to establish trust relations. In Fort Chip's history of telehealth usage, the participants would often cease to use telehealth before trust could be built or substituted face-to-face encounters for telehealth encounters due to their inability to trust the technology. The preference for face-to-face encounters is much more expensive, but it may prove to be more effective if community members feel their health concerns and needs are being addressed. Consequently, this may be the reason why participants in Fort Chip did not incorporate telehealth into their everyday work routines and the reason why tele-learning was not routinely used.

In the chapter on health care policy, we see that First Nations health has been a continuous struggle to overcome colonization and the experiences of broken promises and trust. While Giddens (1984) indicates that motivation is something that cannot be measured, only action is obvious, the participants from Fort McKay's motivation to continue telehealth usage is evident in their comments about trust and the desire to maintain a relationship with their physician. It is the desire for relationships that telehealth is being used. It is possible that no amount of coaxing or reminding the patients to attend telehealth could establish a routine, a familiar pattern of usage, unless trust is established first.

One of the ways trust can be gained is through an understanding of a patient's culture. Through much of the previous chapter on the analysis, the reader may have noticed that much of the behavioral modifications that users failed to enact or enacted involved speech and language usage. In Fort Chip, the concern among some users was not that tele-learning sessions were not available, but that these sessions were incomprehensible. On the other hand, in Fort McKay patients and health care providers continued to use telehealth despite technical disruptions. It is possible that the trust patients developed for their physician extended beyond his excellent set of medical skills

and knowledge:<sup>225</sup> he could communicate in a manner which elicited trust. Giddens (1984) does not examine the cultural component of trust or trust development between people of different cultures and the ways common ground and understanding is reached, particularly in health. The patients mentioned that they could easily banter with him or joke around. In First Nation communities, the usage of humor in the maintenance of relationships may be a vital part of sustaining trust.

The finding on how users mutually shape the technology during telehealth usage means that relationships can be “carried on” as if the person was in the same space as another. What the findings do not reveal is: how do these communicative practices frame an understanding of the medical problems from a First Nations’ and Western medical perspective? What cultural practices are enacted in telehealth usage? In this study, I have only observed how individuals communicate to overcome technological and human factor constraints, not what was said during the physician consultation with patients. These types of questions frame the limitations in the research.

### **c. Research Contribution to Telehealth Research**

This study on telehealth in First Nation communities makes several important contributions to telehealth studies. First, the research reveals that user satisfaction with technology is based on a sociotechnical ensemble. In the telehealth literature, user satisfaction was often affiliated with the technology rather than telehealth in its entirety (content, technology design, policy, institutional actors, health care context, and other users’ involvement). The study revealed that each community’s different sociotechnical contexts provided users with a different telehealth experiences for users.

Second, the study indicates that different relevant groups require different sociotechnical ensembles. Health care providers require:

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<sup>225</sup> According to Barnes (2001) the act of doing, recognized by groups of individuals, may or may not encompass a set of technical skills or tacit knowledge to perform an action whose theoretical knowledge may or may not be known to the actor. His examples illustrate that any practice involves a collective of individuals rather than an individual performing his / her action: vegetarianism is not based on scientific knowledge, but has customs that are observed by many individuals throughout society; acupuncture is a technique performed by an individual in Western society without much of its theoretical and religious foundations; and the cavalry performs coordinated actions with other members at the same time based on both technical and theoretical knowledge.

- mobile telehealth units for clinical work;
- hand held devices for nimble camera movement, high resolution camera to capture images and other devices for specific diagnostic endeavors;
- dedicated high speed Internet access;
- appropriate health policies to facilitate telehealth access (billing regulations, licensing and insurance for scope of practice and etc.);
- help desk to assist with technical problems; and
- technology training to use the equipment.

First Nation communities, as a relevant group, require:

- community specific tele-learning programs that address their health needs;
- patients must be able to develop and maintain their relationships;
- regular training to keep abreast of technology change; and
- sound proof rooms for privacy.

Tele-learning instructors require:

- training to communicate health educational material to health care providers and patients in a culturally or professionally appropriate manner;
- and technology training to use the equipment.

These three different types of users require different sociotechnical ensembles.

Consequently, user satisfaction is much more complex than whether users like using telehealth or whether they are willing to use the technology to access health care services. Instead users' satisfaction with telehealth services must also be understood in the context of the users' work in the health care system and the type of relationships they maintain or develop.

Third, this research contributes to telehealth research by using a collaborative community based participatory action methodology to engage First Nation communities and mix methods to collect the data. The case study utilizes thick description to provide a rich understanding of the users' telehealth context in First Nation health. This enables a broader understanding of telehealth usage compared to previous research on telehealth in First Nation communities. The study reveals the point at which community health care needs, users' needs, and the structure of health shape how telehealth can be used or limited.

Lastly, this research utilizes Giddens' structuration theory and SCOT to provide a fresh perspective on telehealth usage. This theoretical frame enabled an understanding of the mutual shaping of health care work and health care routines on telehealth usage. We see the role that users play in shaping telehealth, but we also see how the users' work and

health care routines and technology design shape telehealth usage. These contributions enrich an understanding of telehealth in First Nation communities.

## **Limitations of the Dissertation Research**

While the cases expand an understanding of the role that users play in shaping telehealth in health care settings, there are also limitations to this research. First, the scope of the research is limited. While I made observations of the interactions within a social system, I have not examined the health care structure from a post-colonial perspective. In this light, the agency of First Nations people to choose or to refuse telehealth may be acts to develop greater independence or acts against the dominant structure of health care. As well, the colonial relationships between health care providers, administrators, and patients reflect relations of power (Browne, 2003). This thesis does not consider how these relations reinforce systems of control, emancipation or praxis. In the Fort McKay case, we can see the trust developed between patients and their nurses or physician, but this discussion is not situated in the larger realm of colonialism.

Second, there are three methodological limitation of this research. A) It did not develop a fully participatory action research approach. Due to limited resources and time, this research, while fulfilling the agreement between the communities to return the knowledge back to the communities in a report, has not retained the essence of PAR by developing projects that would enable communities to participate in new telehealth programs and technology design. B) It would have been beneficial to interview patients in Fort Chip. However, at the time, telehealth was not functioning and the patients that were scheduled to use telehealth for diabetes education canceled or did not show up. Consequently, the patients' perspective is largely represented by users' in Fort McKay. C) While I wanted to reside in all three communities for the same duration of time, both Fort McKay and Janvier did not have homes for me to stay in. As a result, the observations of these two communities' life are absent in this thesis.

Lastly, the interviews were conducted primarily with users in all three communities, but the research would have benefited from possessing a broader

perspective of the institutional actors' role in shaping telehealth. Interviews with such organizations as FNIHB – Alberta, the then Northern Lights Health Region, and Alberta Health and Wellness would have provided a deeper understanding of the strategies, policies, and funding for telehealth programs in First Nation communities.

## **Future Research Questions**

While I see the limitations in this thesis research, I also see opportunities for future research. First, this research has touched on policy implications of First Nations telehealth usage and the intersection with health care services, but no funding numbers has been provided. First Nation communities with transfer status such as Fort Chip and Fort McKay may glean much from understanding the financial costs and benefits of telehealth usage for tele-learning, family visitation and patient consultations, particularly in the long-term when chronic patients may increasingly rely on specialist consultations. A cost-effective study would be beneficial for communities.

Second, other researchers in the telehealth literature have noted that cultural approaches to telehealth should be included, but no one has provided research on the details of the cultural approaches to telehealth. In anthropological studies of Aboriginal health care, some foundations of cultural communication with Aboriginal peoples in palliative care have been established by Kaufert and O’Neil (1995) and Kaufert and Lavallee (1999). They indicate Aboriginal peoples’ approach to death, grieving, and dying must inform how health care providers communicate and provide care. Their work and the glimpse of the cultural and communicative dimensions of telehealth engagement in this study should compel future investigations on culturally mediated telehealth interactions. Specifically, what type of cultural protocols should educators, administers, be familiar with when talking to First Nations people? What aspects of care and education should change to better reflect First Nations’ world views to ensure quality of care is enhanced?

Third, SCOT highlights the difference between women’s approach to technology in everyday life compared to men’s. The fact that many of the health care workers, staff, administrators, and patients were predominantly First Nations women in this study suggests a gender bias towards telehealth usage, health care work, and health. Future

studies may consider exploring the gendered dynamics in telehealth usage in First Nation communities to uncover the social and economic context of First Nations women's contribution to health in rural and or isolated communities.

Fourth, there were a number of unmentioned actors (First Nation communities, governmental and non-governmental organizations)<sup>226</sup> that have shaped the course of telehealth development and usage. An understanding of how different actors enacted policies and the negotiations between regional health authorities, First Nation communities, and professional standards of practice in nursing and medicine would provide a broader perspective on the institutional actors' role (s) in shaping telehealth usage.

Lastly, as First Nation community members seek care via telehealth, the normal trajectory of seeing the doctor or nurse in the community followed by a visit into an urban centre may be changing. This change has ramifications on how First Nations receive care and whether there are gaps in services. A study following First Nations' trajectory of care would provide a perspective of their experiences in the health care system, particularly as they move from federal to provincial services. This type of study would document the social, economic and policy challenges of obtaining care.

## **Recommendations to Enhance Telehealth Use in First Nations**

This study reveals several important findings for First Nation communities hoping to implement or in the process of utilizing telehealth in health care service delivery. First, while there may be funding for telehealth, it is vital that communities assess their resources, health care practice, and, most importantly, understand how their community members use existing health care services. Deploying telehealth into a community that has little health care resources may deplete both human and capital resources. As well, community members may indicate a positive perspective of telehealth, but their health care routines may not facilitate telehealth. The macro perspective of community health, telehealth structure, and the telehealth users' (health providers and patients) context is

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<sup>226</sup> The Canadian Society of Telehealth (CST) plays a significant role in drawing industry, government, and communities together. At annual CST conferences, one sees a host of actors involved in the telehealth industry.

important and relevant for understanding how telehealth will be used in everyday health care routines.

Second, telehealth users, particularly health care providers in First Nation communities must be trained to use the telehealth equipment. When technology fails in the community, relying on one person to consistently troubleshoot may be difficult. This training must include technical knowledge as well as the human ethics of using telehealth (the rules governing confidentiality and the scope of practice should be clear to health care providers). Ongoing training may be necessary for communities with high staff turnover. Telehealth utility is based on knowledgeable telehealth users, particularly health care providers whose relationships with First Nations' patients enable community members to access quality care.

Third, FNIHB in collaboration with First Nation communities must develop tele-learning programs that are based on a curriculum to reduce redundancy in information and expenditures. A national First Nation tele-learning program would be ideal to increase the number of tele-learning opportunities and reduce capital resources. As well, tele-learning educators must be provided with an understanding of how to teach relevant information to different telehealth users: health care providers and patients are two different types of users that have different information needs. As such, tele-learning programs must be tailored to fit the different users' educational and cultural background.

Lastly, the research indicates that telehealth users find innovative ways of shaping telehealth when the programs or goals are based on community health needs. This means that telehealth project expansion or additional development into patient physician consultation and tele-learning will gain greater utility when communities are not only consulted but involved in the process of developing programs and technology. For example, six months after physician consultations had commenced in Fort McKay, the technological limitations with the new telehealth unit in Fort McKay meant that the community needed to obtain a smaller, more mobile unit with a peripheral to hear the heart. If Fort McKay had been consulted prior to the implementation of the new telehealth unit, decision makers may have discovered the users' needs and avoided the need to change technologies.

Often decision makers' desire for efficiency has led them down the path of diffusing technologies into First Nation communities by applying the same programs and the same technologies at the time, but these projects have historically been proven to be ineffective. Instead a participatory model with the possibility of scaling up is the best approach. This approach avoids duplications, costly errors in creating distrust (not only between users themselves, but between users and the technology).

In sum, the recommendation this project makes to decision makers is to work closely with communities to ensure telehealth technology and content reflect the communities' needs. As well, this close partnership will enable communities to advise decision makers about culturally appropriate telehealth programs.

## **Concluding Comments**

Many decision makers and First Nation communities have focused on the role that telehealth could play in alleviating the shortage of health care services in First Nation communities. While telehealth does have the potential to play a role in First Nations' health care service delivery, it is not the panacea for meeting all of their health care needs. In this study, we see that the role of telehealth in First Nation communities can be understood by examining the larger context of health care service delivery. The structural constraints and the users shaped how telehealth was appropriated in the health care centres.

This thesis contributes to the literature on telehealth by providing a perspective of the users' role in shaping telehealth in First Nation health care services. By using a SCOT approach and Giddens' structuration theory, the research revealed that relationships are essential in telehealth interactions and how users communicate with each other. In the end, when some of the users encountered structural, technological, and human factor constraints, they overcame these barriers because users' wanted to stay connected via telehealth. Telehealth met a specific health care need within the community that was difficult to replace.

However, the deeper question for First Nation communities is: does telehealth enable greater autonomy over their health care services? The answer to this question is likely much more complex. We see in this study that structure replicates structure as

actors utilize telehealth in their everyday health care routine, so while control is possible, emancipation from the existing health care structure is not entirely feasible. Telehealth is very much a part of the larger health care system. As such, First Nation communities will need to evaluate on a community by community basis of how telehealth fits into their health care service delivery structure. Community members must take an active interest in the opportunities and resources available to them. Decision makers will need to work with First Nation communities on how to develop telehealth programs that reflect their health care needs because without deliberate collaboration, First Nation communities will continue to be recipients of technology instead of active users.

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## **Appendix A: Summary of Dissertation Research Proposal for ATC**

### **Contact Information:**

Sharon Mah (PhD Candidate)  
Communication Studies  
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Calgary, AB T2M 1N4  
Email: [mahs@ucalgary.ca](mailto:mahs@ucalgary.ca)  
Phone: [REDACTED]

Dr. Edna Einsiedel (Professor and Advisor to Sharon)  
Communication Studies  
University of Calgary,  
2500 University Dr. NW  
Calgary, AB T2M 1N4  
Email: [einsiede@ucalgary.ca](mailto:einsiede@ucalgary.ca)  
Phone: 403-220-3924

Across Canada telehealth, the mediation and delivery of healthcare services and information, using broadband technologies such as satellite, wireless, cable, and fiber optics, is being implemented to address healthcare needs in rural and remote First Nation communities. In Alberta, the First Nations and Inuit Health Branch (FNIHB) will implement telehealth in 41 First Nation communities. Many First Nation communities are eager to take advantage of the new technologies to address their healthcare needs by accessing information, training, and education and clinical services. In First Nation communities, the accelerating rate of diabetes, the increase in population, and the lack of physicians and nurses all contribute to higher medical service needs.

Although many policy makers believe the future of healthcare service needs reside in obtaining telehealth connectivity, many issues need to be explored. The existing studies on telehealth examine healthcare operation, feasibility and sustainability, technology implementation, and cost-benefits analysis. These studies are important in understanding how telehealth can exist within Canada's healthcare system; however, these types of studies do not address: 1) First Nation communities' involvement in appropriating technologies that reflect their interests; 2) how the dynamics of the person-to-technology impacts healthcare practice; and 3) how telehealth may be used for other communication endeavors in First Nation communities. Without an understanding of how telehealth shapes healthcare practice or how telehealth users shape telehealth in First Nation communities, there is a danger that technologies will not only fail to meet First Nation community expectations and needs, but also fracture the relationships between healthcare providers and First Nation communities.

My dissertation research will consider telehealth technology in First Nation community healthcare practices. In particular, I am interested in answering the following questions in my collaboration with First Nation communities:

- 1) How do telehealth users use telehealth technologies in the healthcare practices of First Nation communities?
- 2) How do telehealth users appropriate telehealth?
- 3) What, if any, are the social, political, and economic impacts of telehealth in First Nation communities?

### ***Methodology***

I will use participatory action research (PAR) methodology. The process that PAR practitioners take is research, action and education for social change. Although there are a variety of different PAR approaches, generally the principles that are common to all participatory methodologies are:

- It is participatory.

- Researchers and community members cooperate and engage in a collaborative and equal partnership.
- Participants and researchers engage in a learning process.
- Participants are empowered and gain greater control of their community issues in the research process.
- There is a balance between research and action.

These principles will be used to guide the research process. The methods that will be used to conduct the research are: interviews, focus groups, observations, and participant involvement in assessing healthcare needs. (Please see the ethics document on how participants' privacy and confidentiality will be preserved in the research process).

### ***Significance of the Research***

My dissertation research will contribute to an understanding of how First Nation communities can appropriate telehealth technologies and how healthcare practices in First Nation communities may be shaped through telehealth. To this end, my research will contribute to the First Nation communities in several ways: 1) provide an understanding of how medical knowledge, practice, and telehealth technology mutually shape each other in First Nation communities; 2) show how telehealth users enact this knowledge in practice; and 3) empower participant First Nation researchers to use telehealth to enhance social and human capital.

### **Addressing ATC's Questions:**

#### ***1. What type of Research will you be doing with the ATC First Nations?***

This is primarily a constructivist approach (community perspective) using qualitative research methods; however, quantitative data may be used, such as government statistics, in the written dissertation. I will be completing collaborative research with ATC First Nations, which means that First Nations interests and participation is my first and foremost concern.

#### ***2. Who from the First Nations will you be working with?***

I will be working with telehealth users. Telehealth users may be healthcare providers (traditional healers, doctors, nurses, community health representatives, counselors, administrators and etc.) and patients (patients and their families who consult healthcare providers using telehealth).

#### ***3. How long will your research take?***

My goal is to complete my dissertation by Fall 2007. This timeframe includes the collaborative community research, writing, and some dissemination of the research findings.

#### ***4. How much time will your research take in the communities?***

The maximum amount of time I have allotted to collaborate with the First Nation communities (if there are 5) is no more than 1 year. Of course, this does not mean I will cease to associate with ATC's future interests. Rather the 1 year timeframe is established as flexible timeframe to manage unforeseen circumstances that may hinder or open new opportunities for research; in particular if the community makes suggestions to

include specific issues in the research process. If the communities are willing and ready to collaborate, the research should take between 1-2 months per community. If there are 5 communities, then a minimum of 5 months is needed to complete the research process.

### **5. *What amount of work will be required by ATC First Nation people?***

Many researchers who use participatory action research methodology to collaborate with various communities suggest leaders in the community decide the extent community members will participate. Consequently, the community members can be very active in creating their own research agendas, developing new approaches, or the researcher can decide what is needed.

To answer the questions above I will need: a) to talk with telehealth users either individually or in groups once or twice a week for 1 hour; b) observe the interactions in the healthcare clinic around telehealth. Now, this may involve patients in some communities, but if patients do not consent to my observation of their use of telehealth than I will leave this portion of the research out; c) evaluate the healthcare needs in the communities.

Each of the First Nation's healthcare director or community leaders will be encouraged to participate or to act on the findings of the research. For example, if telehealth users discover there are healthcare needs that can be addressed in the course of the research, they may encourage leaders to act upon the new findings. The outcomes of the research lie largely in the hands of the community; Sharon Mah's role is to provide information and expertise for the community to consider in their community healthcare decisions. This means if the First Nation's objective is to take action during the research process, Sharon will work with the participants and leadership to see their community achieve their objectives.

### **6. *How will ATC First Nations benefit from the research you are undertaking?***

The concrete benefits that ATC First Nations will see are as follows:

- a. Gain a greater awareness and use of the role of telehealth in healthcare
- b. At the end of the thesis research, a practical report and a copy of the thesis research synthesizing ATC's telehealth system in Alberta will remain in the First Nation communities.
- c. As well, every effort will be made to facilitate any recommendations that First Nation communities would like to communicate to policy makers.

The intangible benefits that ATC First Nations may see arise out of the research process are as follows:

- a. Enhancing social and human capital among healthcare providers, patients and their families through education
- b. Community health development through the collaborative efforts of the participants
- c. Changes in healthcare practices in First Nation communities
- d. Other benefits may arise as each First Nation community may have different issues they would like to see addressed in the research process.

## **Appendix B: Health care provider and Patient Consent Form**

You have been invited to join this research project because you are either a frontline healthcare provider in your community or a community member using telehealth to access healthcare services. If you have any questions regarding the ethics of this research you may contact any of the individuals listed on this page.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form. This research project has been approved by Athabasca Tribal Council and the University of Calgary's Health Research Ethics Board. Please find the relevant contact information below.

<b>Principle Investigator</b>	<b>Co-Investigator</b>
Dr. Edna Einsiedel (Professor) Communication Studies Faculty of Communication and Culture University of Calgary Email: einsiede@ucalgary.ca Phone: (403) 220-3924	Sharon Mah (PhD Candidate) Communication Studies Faculty of Communication and Culture University of Calgary Email: mahs@ucalgary.ca Phone: (██████) █████ - █████

### **First Nation Community Contacts:**

<b>Athabasca Tribal Council</b>	<b>Athabasca Tribal Council</b>
Roy Vermillion CEO Athabasca Tribal Council 9206 McComick Dr. Fort McMurray, AB T9H 1C7 Email: roy.vermillion@atc97.org Phone: 780-791-6538	Patrick Mercredi Health Director Athabasca Tribal Council 9206 McComick Dr. Fort McMurray, AB T9H 1C7 Email: patrick.mercredi@atc97.org Phone: 780-791-6538

## **Background to the Research: A Community Based Approach to Understanding Telehealth in First Nation Communities**

Across Canada telehealth is being implemented to address healthcare needs in rural and remote First Nation communities. Telehealth is the mediation and delivery of healthcare services and information using broadband technologies such as satellite, wireless, cable, and fiber optics. In Alberta, the First Nations and Inuit Health Branch (FNIHB) will implement telehealth in 41 First Nation communities. Many First Nation communities are eager to take advantage of the new technologies to address their healthcare needs by accessing information, training, and education and clinical services.

This study is an opportunity for healthcare providers and patients to discover their communities' healthcare needs, health assets, and best practices to implement and use telehealth.

### ***Purpose of the Research***

This dissertation research will consider telehealth technology in First Nation community healthcare clinics or centers. The aim of the research is three fold:

- 1) To understand the role of telehealth in medical knowledge, practice, and First Nation communities;
- 2) To show how telehealth users enact this knowledge in practice; and
- 3) To empower participant First Nation researchers to use telehealth to enhance social and human capital.

### **What do I have to do to Participate?**

No you do have to participate. Your participation is voluntary.

In this research project, all the healthcare telehealth end-users will be involved in interviews, focus group discussions, and observations. Patient telehealth end-users will be involved in interviews and observations. Below are some directions on how each method will be used.

### ***Directions for Participating and Withdrawing from the Research Process***

- 1) This project will last one month or four weeks.
- 2) You may withdraw from the research process any time prior to the analysis of the data in January 2007. If you decide to withdraw from the research process, please inform Sharon Mah of your intentions and she will discard by deleting or shredding any information you have contributed to the research process.

### ***Focus Groups***

Over the course of the 4 weeks research project, the researcher will contact you (the healthcare provider) for a series of weekly focus group discussions.

- 1) The researcher will invite you to the focus group at a convenient time.
- 2) The focus group discussion will last no more than 1.5 hours and be audio taped.

- 3) If there are deeper issues that arise out of the focus groups that warrant individual interviews, the researcher will contact you to explore these questions.

### ***Interviews***

Over the course of the 4 weeks research project, the researcher may contact you for a series of weekly interviews if there are deeper issues that arise from the focus group discussions.

- 1) The researcher will contact you for interviews at a convenient time.
- 2) The interview sessions will last no more than 1 hour.
- 3) The focus groups will be audio taped.

### ***Observations***

There are two areas of observation: first, ATC has approved for Sharon to make general naturalistic observations of the healthcare facility (the providers and patients every day comings and goings).

The second aspect of the observation method involves close observation, which requires the patients and the healthcare providers consent. Sharon will observe how healthcare providers set-up and interact with other healthcare professionals from locations outside the First Nation. As well, she will observe patients interacting with healthcare providers from healthcare facilitates outside of the First Nation.

- 1) Prior to the observations, the researcher will contact the healthcare providers (both in the community and in the remote location) and the patients to coordinate the best time for observing the telehealth sessions.
- 2) She will not interact with patient or the healthcare provider (connected through telehealth) during the telehealth session; instead she will observe their interactions.
- 3) She may take some notes on a note pad during the course of the observation. (The patients' telehealth information will remain anonymous and confidential).

### **What type of Personal Information will be collected?**

Personal information related to telehealth usage will be collected in this research project. If you decide to take part in this research project, please put a check mark on the corresponding line(s) that grants me your permission to:

I grant permission to be audio taped:

Yes:  No:

I grant permission to be video-taped or photographed for academic, community, or government publications/ presentations:

Yes:  No:

I wish to remain anonymous:

Yes:  No:

I wish to remain anonymous, but you may refer to me by a pseudonym:

Yes:  No:

The pseudonym I choose for myself is: \_\_\_\_\_

You may quote me and use my name:

Yes:        No:       

You may quote me or paraphrase me anonymously:

Yes:        No:       

### **Will my Records be Kept Private? What Happens to the Information I Provide?**

If you choose to remain anonymous, I will keep your identity confidential. This completed consent form will be kept separate from any other information you give the researcher. Please note the ID number printed in the right hand corner of this form. All your future information that you give to the researcher will be identified only with this ID number and the information will be kept in a locked filing cabinet in a locked room. All the information gathered that identifies you will be stripped away to ensure your anonymity. Only your researcher will have access to ID and identifying information. Your name and contact information will not appear in any reports of the completed study.

In the focus group discussions, there is limited anonymity and confidentiality since your colleagues will see and hear what you say or recommend. Consequently, only the researcher can ensure she will not disclose your information.

The information gathered from the research methods will be analyzed as an aggregate for Athabasca Tribal Council to maintain the communities' anonymity. Any information gathered will be analyzed in the writing of the research report to ATC and the researcher's PhD dissertation, which will be available to the public. The data may also be re-analyzed in academic presentations, journals or conferences or recommendations to government or presentations made to First Nations communities.

### **What are the Risks and Benefits of Participating?**

#### ***Participant Benefits***

Indirectly, you will benefit from this research process by having the opportunity to work with your peers to solve, identify, and analyze telehealth problems.

#### ***Benefits to the First Nation Communities:***

The concrete benefits that ATC First Nations will see are as follows:

- 1) Gain a greater awareness and use of the role of telehealth in healthcare
- 2) At the end of the thesis research, a practical report and a copy of the thesis research synthesizing ATC's telehealth system in Alberta will remain in the First Nation communities.
- 3) As well, every effort will be made to facilitate any recommendations that First Nation communities would like to communicate to policy makers.

The intangible benefits that ATC First Nations may see arise out of the research process are as follows:

- 1) Enhancing social and human capital among healthcare providers, patients and their families through education
- 2) Community health development through the collaborative efforts of the participants

3) Changes in healthcare practices in First Nation communities  
Other benefits may arise as each First Nation community may have different issues they would like to see addressed in the research process.

### ***Risks to Participation***

There may be some socioeconomic risks in participating in this research project, since the information will be written in a report to Athabasca Tribal Council and made available to its member First Nation communities. If ATC and the First Nation communities decide to heed the participants' recommendations arising from this research project, the participants' jobs or work environment might change or the medical service delivery may change.

**Will I be Paid for Participating or do I have to Pay to Participate?**  
There is no financial rewards for participating in this research project nor do you have to pay to participate.

***If I Suffer a Research-Related Injury, Will I be Compensated?***  
This is not a clinical test. There are no physical or psychological tests involved.

In the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by the University of Calgary, the Calgary Health Region or the Researchers. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

### **SIGNATURES**

Your signature on this form indicates that you have understood 1) to your satisfaction the information regarding your participation in the research project and 2) agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time prior to the analysis of the data in January 2007. If you have further questions concerning matters related to this research, please contact: Dr. Edna Einsiedel: (403) 220-3924.

If you have any questions concerning your rights as a possible participant in this research, please contact The Ethics Resource Officer, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's Name: (please print)

Participant's Signature \_\_\_\_\_ Date:

Researcher's Name: (please print)

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

The University of Calgary's Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records. The researcher has also kept a copy of this form for her reference.

## **Appendix C: Semi-Structured Interview Questions**

These questions are one-on-one with the telehealth users and it should take no longer than 1.5 to 2 hours. The interview will be audio taped and it will be transcribed.

### **A. Health Status:**

- 1) What does being healthy mean to you?
- 2) What do you do to keep healthy?
- 3) How often do you visit the doctor or some other healthcare provider such as a nurse, therapist, counselor or Indigenous healer?
  - a. Are these visits helping you to be healthy?
- 4) What are your family's health concerns?
- 5) Do you think your health concerns are being met in the community?
  - a. If no, what do you think needs to happen, so your health care needs can be met?
  - b. If yes, what resources in the community keep you and your family healthy?

### **B. Healthcare Service and Resources**

- 1) Who do you talk to about the health concerns in your family or community?
- 2) Where do you go to when you have a health concern?
- 3) Do you use books, the Internet, or other information sources to learn more about your health concerns?
  - c. If so, why or why not are these sources useful to you?
- 6) How do you feel about your face-to-face consultation with the healthcare provider?
- 7) What type of healthcare services do you wish your community could provide?
  - a. Do you think this type of service might be facilitated by telehealth?

### **C. Other Technology Use**

- 1) What type of communication technologies do you have at home? (computer, Internet, phone, television – satellite)
- 2) What communication technologies do you use throughout your work day?
  - a. Why are these technologies important to your work?
- 3) How comfortable do you feel about using the computer and the Internet to access information?

### **D. Technology Interaction**

- 1) Have you used telehealth in previous health visits?
  - a. Do you like using telehealth?
  - b. Why or why do you not like using telehealth?
- 2) Tell me about your first experience with telehealth.
- 3) What do you think would have improved your consultation in telehealth?
- 4) What, if any, benefits do you see telehealth providing?
- 5) If the makers of telehealth were sitting here, what advice would you give them to make it better?

- 6) If healthcare policy makers were sitting here, what would you tell them to do to improve healthcare Aboriginal communities?

### **Sample Healthcare Provider Semi-Structured Interview Questions**

These questions are one-on-one with the telehealth users and it should take no longer than 1.5 to 2 hours. The interview will be audio taped and it will be transcribed.

#### **A. Personal Background Information**

- 1) Do you live in this community? How long have you lived and worked in this community?
- 2) What are your work responsibilities?
- 3) What are some personal benefits and costs to working in this community?
- 4) Do you have opportunities to continue your healthcare education?
  - a. If yes, how often do you continue to update your healthcare knowledge?
  - b. If no, why is this difficult to do?
- 5) What other sources of continuing healthcare education do you access? Do you find these sources helpful?
- 6) Over the course of your career in Aboriginal healthcare delivery, have you ever used Indigenous knowledge to care for your patients?
  - a. What are your reasons for or against incorporating Indigenous knowledge in your care practice?

#### **B. Community Health Status**

- 1) In your opinion, what are the community's healthcare needs?
  - a. Over the course of your work in the community, how have these healthcare needs changed?
- 2) What are your suggestions for meeting these healthcare needs in the community?
- 3) Do you think the community has the resources to address these healthcare needs?
  - a. What resources does the community possess or need in order to address the healthcare needs in the community?

#### **C. Other Technology Use**

- 4) What type of communication technologies do you have at home? (computer, Internet, phone, television – satellite)
- 5) What communication technologies do you use throughout your work day?
  - a. Why are these technologies important to your work?
- 6) How comfortable do you feel about using the computer and the Internet to access information?

#### **D. Telehealth Usage**

- 1) How often do you use telehealth in the course of 1 week or 1 month?
- 2) Do you feel you have adequate training using telehealth?

- a. Explain how this training did or did not benefit your current use of telehealth.
- 3) What are the most challenging aspects of using telehealth technology?
- 4) What makes telehealth a “good” or “bad” technology to use?
- 5) What other programs do you wish you could access by telehealth?
- 6) If the designers of telehealth were sitting here, what advice would you give to them to make telehealth better?
- 7) If you were to have a meeting to make telehealth function better in the clinic, who would you invite from the community or from the urban hospital?
  - a. What would you tell each of the people attending?
- 8) If you were to have a meeting with the healthcare staff, who would you invite?
  - a. What would you tell each person to do to make telehealth function better in the clinic?
- 9) If healthcare policy makers were sitting here, what would you tell them to do to improve healthcare Aboriginal communities?
- 10) What do you think healthcare will look like in 2 years, 5 years or 10 years from now?

## **Appendix D: Round 2 Interview Questions in Fort McKay**

### **Patient Interview Questions**

- 1) When you are sick, who do you talk to? Why do you talk to this / these people?
- 2) What made you come to see the doctor?
  - a. When you have a headache / stomach, do you take medicines for it or do you wait to talk to the nurse first? Why do you do this?
- 3) What is it about telehealth that you like and do not like?
- 4) When you talk to the doctor through telehealth are you able to tell him everything that is worrying you?
- 5) Do you think your conversations with the doctor have changed in any way?
- 6) How has your relationship with the nurses stayed the same or changed through the telehealth consultation?
- 7) Why do you prefer to see the doctor? Will you continue to do so by telehealth? Why or why not?
- 8) Are there things you do differently when seeing the doctor by telehealth compared to face-to-face?
- 9) Do you also come in to see the doctor when comes to the community?
- 10) When you come to the telehealth consultation, is there anything you do that is different than meeting the doctor face – to – face?
- 11) What do you notice the doctor or nurse doing differently?
- 12) If you could tell your family members about telehealth, what would you say?
- 13) When you see yourself on the screen, what are your thoughts?

### **Interview Questions for the Doctor**

- 1) When you are communicating with your patient, do you feel you are able to address all his health concerns that you would say face-to-face?
- 2) What aspects of the telehealth consultations are different compared to seeing this person face-to-face? What aspects of your patient encounter has stayed the same or changed?
  - a. When you are communicating with your patient, what are you most aware of?
  - b. What do you do make sure this communication is going to be effectively understood?
  - c. How often would you say that culture, technology, and distance play a role in how you modify your communication? Has this changed with telehealth usage?
- 3) How do you prepare (activities) for a telehealth consultations?
- 4) You have been using telehealth for a little over 6 months, what would you say are your primary concerns?
  - a. Given you have 2? Practices, how do you feel about managing your practice?
  - b. What makes telehealth a great or not so great tool for your work?

- c. If you could make changes to telehealth, what would you do?
- d. Although it has only been a little over 6 months, have you noticed any changes in your health care team? What are these changes or consistencies?

### **Interview Questions for the Nurse**

- 1) What has nursing been like since you started using telehealth? How has it changed or remained the same?
  - a. What aspects of patient care has changed or remained the same?
- 2) What aspects of telehealth are good or problematic in your work?
  - a. What opportunities or barriers does telehealth create?
- 3) In your work, what would say are the changes that you have had to make in order for telehealth to work in Fort McKay?
  - a. Are you doing more work, the same amount, or just different work during the telehealth interaction?
  - b. What is different or the same?
- 4) Are you able to communicate effectively with the doctor during the telehealth sessions?
  - a. Was there a time / case when it would have been more helpful if the doctor was face-to-face with you / the patient?
  - b. What are the communication adjustments you have had to make with telehealth? (eye contact, speaking up louder etc.)
- 5) When you see yourself or your patient on the screen, how do you feel?
- 6) How do you feel your rapport with the patients and the doctor with telehealth?