

**FIRST NATIONS LED TELEMEDICINE:
FROM ACCESS TO EFFECTIVE USE**

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ANDRÉS IBÁÑEZ MIGEOT

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ABSTRACT

FIRST NATIONS LED TELEMEDICINE: FROM ACCESS TO EFFECTIVE USE

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University of Guelph, 2009

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Starting from the observation that *non-technological* elements matter to the introduction of new technologies into rural and remote communities, this thesis explores the organizational relationships that facilitate the development of a First Nations telemedicine system in northwestern Ontario. Accordingly, it adapts an existing “community readiness for telemedicine” framework to the description of factors that distinguish First Nations contexts for innovation with telemedicine. From this understanding, a First Nations led telemedicine effort is analyzed, giving way to the possibility that First Nations leadership in the introduction and development of a telemedicine system, which builds local First Nations capacity, is a requirement for success.

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To the memory of Nora E.A. Cebotarev

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1. INTRODUCTION

One way to understand the significance of Information and Communication Technologies (ICTs) is through observing why people use them: ICTs eliminate geographical distance – and the time it takes to travel across it – as an obstacle to communication (Cairncross, 2001). An ICT is any electronic communication tool that can connect people to each other by enabling the electronic transmission of text, voice and image. Such communication capabilities mean that ICTs open new possibilities for all areas of activity. In the greater scheme of global communications, ICTs bring the possibility of the “decentralization of globalization” (Gage, 2002; Von Hippel, 2005) or, at least, the inclusion of the excluded in the process of globalization.

Through ICTs, people have the power to access, and potentially benefit from, and also contribute to, the knowledge and information being generated, shared, and exchanged over the global communications infrastructure. ICTs, in this way, embody an important technological change in the realm of communication: people can be passive receptors of information or they can generate and send information in multiple formats for various purposes. Theses such as the “information society” (Mattelart, 2003) or “network society” (Castells, 2000) summarize the general expectation that ICTs will expand the possibilities for communication in ways that are completely new. ICT-facilitated global information exchanges are already credited with transforming the global economy and the way in which economic value is generated (Castells, 2000).

It is evident in the literature that the economic dimension of ICTs is dominant. It is through this emphasis on the economic that a new *development* imperative for ICTs emerges: if these technologies enable globalization, then everyone should have *access* to them, especially those on the margins of existing opportunities and services that could be made available through ICTs (Richardson, 2000). The problem of facilitating access to ICTs has thus been an important way of understanding the challenges posed by, as well as the significance of ICTs.

While access is an obvious need – considering that much of the world lacks these technologies and, consequently, a voice and a presence in the emerging global information society (Cohen, 2006) – the link between access and positive change (i.e. the “decentralization of globalization”) is not self evident. There is, however, growing recognition that attention should be granted to the soft-side of ICTs, the human capacities needed to take advantage of ICTs.

Canada, a developed country that has pioneered the construction of an infrastructural foundation for the use of ICTs (Lee, 1997) is harbouring the birth of new ICT applications and services across its economy (Castells, 2000; Melody, 1996; Picot, 1997). In turn, the growing implementation of ICT-based services has triggered organizational adaptations across sectors (Melody, 1996). These are changes that can affect in a positive way the lives of urban populations who now have a digital alternative to physically going to the bank, to visiting a library, to visiting family, and to accessing specific services, such as those of a medical clinic or hospital. As change becomes the norm, rural and remote populations are also enjoying some of the same alternatives. A case in point is the development and

implementation of digital *telemedicine* (health care at-a-distance) networks and technologies in most provinces and territories (Lee, 1997; Picot, 1998; Alliance for Building Capacity, 2002), which has implicated the development of "e-health" services for rural and remote users (Gideon, 2000).

The Canadian context for the development of telemedicine is further made favourable by a political mandate: the guarantee of *universal access* to health care (Gideon, 2000; Jennet, 2003). Hence, for Canada telemedicine was "a natural fit" (Picot, 1998). This natural fit is evidenced by a combination of at least three major factors: one, a propitious political environment for infrastructural investment in digital telecommunications (Picot, 1998); two, geography, as it affects rural and remote access to existing services, including pre-existing telemedicine services (Pong, 2002; Jennett, 2003). And, a third factor: the potential advantages of telemedicine in dealing with structural challenges such as the need to maximize scarce human resources in the face of growing demand (Pong, 2002; Jennett, 2003). The digitalization of the country's telemedicine services can, in light of these compelling elements, be seen as a logical next step in their development (Gideon, 2000).

Though the health implications of telemedicine are still the subject of research in Canada (Alliance for Building Capacity, 2002) a glance at the growing presence of telemedicine in hospitals and in remote clinics suggests that there is a general appreciation of its potential and advantages at a political level, if not yet across all of daily medical practice. It is a fact that Canada's decision to support the development of digital telemedicine programmes in the mid 1990s (Lee, 1997; Picot, 1998) created the conditions for the emergence of new experiences in the

design of telemedicine services for rural and remote communities (Gideon, 2000).

In the Canadian case, First Nations communities are among remote communities that have "embraced" and are increasingly able to access health care services through telemedicine (Crossing Boundaries, 2005). Still, it is important to keep present that the expansion of telemedicine into First Nations communities presents unique challenges, as they have unique political circumstances and unique economic, social and health needs.

It is a common observation in anthropological and other social research at the First Nations community level that: a) no two communities are the same: geography and traditions vary, as does access to resources, degrees of community cohesion, vision, and specialized capacities; and, b) a community can present internal divisions with regards to politics, religion, language, culture, and any number of issues (Turner, 2003; Lemchuck-Favel & Jock, 2004; Lavoie, 2004). Such complexities can be understood from the experience of colonization that resulted in the deterioration and fragmentation of First Nations forms of organization and decision-making. Though such division and fragmentation is the subject of broad First Nations efforts toward rebuilding their nationhood, these efforts, in terms of unity of political action (Niezen, 2003), are uphill. It is also significant to this context that such divisions are, in effect, enshrined in Canada's *Indian Act*, which gives the Canadian state the attribution to determine who is and who is not an "Indian". First Nations organization and action – specifically their capacity to bring about change – is, thus, challenged by divergent interests and perceptions. First Nations that are engaged in introducing

technological innovations such as digital telemedicine into their communities see that such divergencies can become obstacles to change (NAN, 2005). In terms of effecting change in the health status of First Nations communities in Canada, the main challenge is the disproportionately high incidence of certain diseases, such as diabetes, and conditions such as substance abuse and mental health problems that resulted from colonization (Taylor, 2003).

In the remote First Nations context, telemedicine addresses, first of all, the issue of distance: the health services needed by remote First Nations are based in distant urban centres (Pong, 2002). With telemedicine in the picture, the possibility of accessing such health care is no longer only limited to the travel-availability of family doctors, specialists, nurses and other health care professionals, or to seasonal road conditions (Winter roads) and access to expensive air travel, in the case of isolated communities. Telemedicine is being introduced to First Nations communities whose health care access is conditioned by such geographical remoteness and isolation. Yet, while the health needs to address are easily identifiable by local health authorities, the adoption of digital telemedicine by First Nations users has not been automatic (Jennett, 2003).

My research effort is centred on learning about the process behind the introduction of telemedicine as an innovation in the specific context of remote First Nations communities in northwestern Ontario. Thus, I consider some aspects of the organizational dimension of telemedicine in the context of a unique case, that of Keewatinook Okimakanak Telemedicine (KOTM), which by virtue of its continued expansion and evolution has been hailed as a telemedicine success story (Canadian Society of Telehealth, 2007). This study is an inquiry into

the factors that matter to the introduction of a telemedicine programme into remote First Nations communities, but with the particularity that the example explored constitutes a First Nations initiative to self-manage a telemedicine programme. In this way, I am not specifically concerned with how the advantages of the technology may be changing health care. My focus is, rather, the human capacities that a First Nations organization deems necessary in “starting-up” a telemedicine service in remote First Nations communities.

1.1. GENESIS OF THE STUDY

This study began as part of an evaluation – commissioned by Keewaytinook Okimakanak, a First Nations tribal council – of the expansion of First Nations run telemedicine (in its pilot project phase, at the time) into additional remote First Nations communities. This evaluation involved gathering and analyzing community-level qualitative data that would complement other qualitative and quantitative data collected. This process was designed to respond to community needs and concerns while meeting the evaluation requirements of the funder, the government of Canada (Health Canada). In other words, the roots of this study are in an evaluation of a First Nations-led telemedicine pilot effort.

1.2. PROBLEM STATEMENT

A review of specialized literature on telemedicine yields few studies involving telemedicine services in First Nations communities, and fewer still offering ground level views of community-based First Nations-led telemedicine. There is a need for academic analysis of telemedicine in First Nations contexts,

and more specifically, of First Nations-led innovation with telemedicine. Accordingly, I explore a First Nations initiative for the adoption of telemedicine in remote First Nations communities.

1.3. GOAL AND OBJECTIVES

The goal is to explore the possibilities for, and the complexities of, First Nations led implementation of telemedicine services.

The objectives are:

1. To identify the contextual factors – in terms of culture – that matter to the adoption of telemedicine in First Nations communities.
2. To describe and analyze the organizational and individual functions, relationships, and skills involved in the introduction of telemedicine into First Nations community clinics.

1.4. METHODOLOGY

This is a qualitative study that employed participant observation, participatory workshops, and semi and unstructured interviews about the perceptions, approaches, and challenges that make up the experience of a First Nations initiative for the improvement of health care access and quality. The conclusions of this study are drawn from my analysis of community level qualitative data on emerging community and organizational relationships for the promotion of telemedicine, and on the review of relevant frameworks on and related to innovation with telemedicine.

1.5. STRUCTURE OF THE THESIS

The Literature Review (Chapter 2) explores the concept of “readiness for telemedicine”, and relevant literature on ICTs and telemedicine itself to highlight elements that apply to the objectives of this study. The goal of this chapter is to develop the concepts that will be used in the analysis of Keewaytinook Okimakanak’s introduction of telemedicine to remote First Nations communities. A Background chapter (Chapter 3) focuses on the issues around remote access to health care that contributed to the telemedicine option in this case. A Methodology chapter (Chapter 4) explains the circumstances that led to this study, the data collection process, and the process of data analysis. A Findings chapter (Chapter 5) presents the organizational and individual roles, relationships, and capacities involved in the process of introducing telemedicine to remote communities of the Nishnawbe Aski Nation. An Analysis chapter looks at the implications of the Findings. A Conclusions chapter (Chapter 6) presents the implications of the Analysis to the literature on First Nations involvement with telemedicine. This chapter also provides a summary of the factors that mattered to First Nations control over the implementation of telemedicine in the concerned remote communities, and distinguishes the characteristics of an emerging First Nations approach to telemedicine: achieving an *effective use* and cultural appropriation of the technology.

2. LITERATURE REVIEW

FIRST NATIONS TELEMEDICINE: FROM ACCESS TO EFFECTIVE USE

An ICT application can be understood, first of all, through a review of the fundamentals of an ICT. A First Nations understanding of an ICT application brings in elements that are often dealt with in the development sector. The latter's perspective on ICTs is useful to consider as far as it argues that, given the right circumstances, ICTs can and should benefit everyone, but especially the rural poor (Richardson, 2000).

This study looks at the introduction of telemedicine into remote First Nations communities by a First Nations organization. Given the complexities of an ICT application like telemedicine, this study necessarily recalls research that has applied the concept of organizational readiness to telemedicine (Jennett, 2003). This, in order to review the distinction between the technical and the human elements that have already been identified as being important to the introduction of telemedicine to health care organizations and local communities. Having explored these insights, I bring into my review Gurstein's (2003) "effective use" thesis. This is the notion that "access" to a new technology does not determine its adoption. That is, technological innovations have to make sense to those who would adopt them. I briefly explore this idea in contrast to Heeks' (2002) insights concerning the need for a "fit" between a technology and the "development objectives" of those who would adopt it. This exploration is meant to arrive at a definition of "effective use" that can put into perspective the established notion of organizational readiness as applied to telemedicine.

2.1. INFORMATION AND COMMUNICATION TECHNOLOGIES (ICTs)

ICTs are advanced electronic communication technologies that developed as the result of the “merging of three previously separate technology paths [...] information-dissemination technologies, communication-enabling technologies and informatics solutions [...] into one technological system” (ECLAC, 2003, p. 3). Through their communications multifunctionality, ICTs serve as access points to networks that enable people to connect to each other, in *real time* (Von Hippel, 2005). This means that, once connected, people can communicate without noticeable lags between emission and reception of voice, text or image that has been converted into electronic data, and reconverted into voice, text or image. A key aspect of ICTs is that the technologies on which ICTs are built are continually being developed toward simpler, more user-friendly tools, thus improving people's ability to capture, store and communicate data.

While questions about how ICT-enabled communication is changing the way people communicate is a matter of ongoing research, it is clear that the discourse around ICTs is predominantly about great expectations of change. In some contexts, ICTs have been called “the steam engine of our time” (Mia and Dutta, 2007, p. 3): the catalyst of a communications revolution that will lead to unprecedented economic growth. The steam engine comparison exemplifies a predominantly technology-centred, economic development discourse around ICTs, while stressing the magnitude of the change underway.

The literature surveyed points out that ICTs behave like an “engine” in the sense that they generate their own momentum and impetus for their *adoption* and continued improvement. This notion is justified by a number of

circumstances such as: “rapidly decreasing costs” (Bound, 2006, p. 108) resulting from economies of scale in the production and improvement of the digital technologies involved – which play a role in expanding access to ICTs; the emergence of digital networks that brings the possibility to marginalized groups to build decentralized relationships over system linkages that are “critical to innovation systems” (Bound, 2006, p. 108); these innovation systems – which transform information into knowledge, and knowledge into wealth – are in turn vital to an expanding global knowledge economy (Tapscott, 1996; Young, 1997, n.p; Gage, 2002; Bound, 2006; Mansell & Wehn, 1998; Von Hippel, 2005); and, similarly, as ease of use improves, ICTs move towards intuitive interfaces, which contributes to gradually eliminating the “need for manuals or translation”, furthering “the democratization of innovation” (Von Hippel, 2005, p. 121; Mia and Dutta, 2007), and of information (Gage, 2002).

The transformation taking place is described by Castells (2000) as the “rise of the network society” – a global society that is increasingly shaped by the exchange of information and knowledge, and by Melody (1996), who developed a framework detailing the major components, trends and possibilities of the emerging “information society”.

2.1.1 Melody’s (1996) Information Society Framework

Melody (1996) posited that a global information society would be one where innovation and development are interdependent - and would therefore be worth creating. The materialization of such a global information society, in turn, should be a central concern of policy-makers who develop policies that promote

investments aimed at creating sufficient demand to align both the supply of basic digital communications infrastructure and consumer demand for ICTs. Melody suggested that generating this demand would amount to a culture-altering change of *mega project* proportions that would, thus, call for a new model of development: “the potential benefits of information societies must arise from [a] radical institutional restructuring throughout societies” (Melody, 1996, p. 253). Such a change would require the closely coordinated intervention of industry and government on the infrastructural end, and of all sectors of society on the ‘content’ end to develop the services and products that would use the infrastructure. Accordingly, he presented a framework that emphasized “the fundamental importance of [developing] service applications in specific sectors, [and of] skill development at both producer and consumer levels” (Melody, 1996, p. 243). In this view, the problem is to achieve “*effective* [my emphasis] access , use, and benefit” through the adequate management of “issues of need, preparedness [readiness], affordability, skill, and priorities” (Melody, 1996, p. 249). Needs, level of preparedness, and priorities are specific to each context, reason for which “effectiveness” is measured by whether access and use lead to desired or meaningful benefit or change.

Melody identifies the fundamental infrastructural requirement of an information society as an *interactive* telecommunications system for the production and exchange of information and knowledge. In this interactive system, consumers demand services and products that drive innovation towards new digital services and products that are increasingly influenced by consumers' needs or, in other words, customization.

In conventional markets, making this interactive system possible means the massive reallocation of financial resources toward the development of the foundations of the information society: (a) the telecommunications facility system (transmission facilities such as fibre optics, cellular radio, and satellite; major switching equipment; and the actual terminals people use); (b) information content (value-added services and applications for new systems); (c) the equipment sector (the hardware and software that generate new applications and opportunities); (d) skills development “throughout all sectors to produce, apply, and use the new services; and (e) “comprehensive and coordinated” policy development at the national and international levels (Melody, 1996, p. 245) to facilitate access and opportunities to all nations. In effect, according to Melody, this shift represents the only possibility that “there might be sufficient benefits” to justify the large financial investments needed in building the foundations of an information society:

“[The] growth of [such] electronic services” goes hand in hand “with a shift away from the [...] supply side orientation of service development that [...] characterized the traditional approach to telecommunications” to a “demand-side orientation” focused on specific needs (Melody, 1996, p. 251).

According to Melody, such customized development will generate the demand needed to achieve the “cost savings, service improvements and new service opportunities” that can fully justify substantial initial investments (Melody, 1996, p. 255). Créde & Mansell (1998) observe, in agreement with Melody, that if ICTs are to yield enough benefits to justify their costs the expansion of access (network expansion) is a requisite:

Communication networks have what economists call network externalities, meaning that the value of a network increases disproportionately as it is extended [...] As population coverage is extended, the benefits of the network increase twice as fast as the rate of network expansion (Credé & Mansell, 1998, n.p.).

An implication of this argument is that those who own the infrastructural foundations of the information society, and those who have access to it, will be at an advantage over those who do not. Between both groups existing inequalities will grow. A 'digital divide' will separate them unless action is taken to equalize access to digital telecommunications infrastructure and ICTs. With this observation, Melody provides an entry point for the 'development' perspective on ICTs.

Melody's framework shows that the potential benefits of the technological change involved cannot materialize without policies to encourage telecommunications infrastructure development. Other writers (Mansell & Wehn, 1998; Castells & Ince, 2003; Mattelart, 2003; Gage, 2002) reinforce this warning. Mansell and Wehn (1998), however, step momentarily outside the hardware-centered discourse, arguing that the human dimension of technological change is also a fundamental requirement for the development of a global information society. Innovation with new technologies requires skills to make use of their capabilities:

There is a very high risk that these technologies and services will deepen the disadvantages of those without the skills and capabilities to make the investments required for building innovative 'knowledge societies' (Mansell & Wehn, 1998, p. i).

This insight implies that ICTs are not only new media, but, essentially, represent a new mode of communication that creates new needs (Gideon, 2000) that, in turn, demand new human capacities. The unpredictable nature of ICT-mediated change (Ramírez, 2007) demands a sustained capacity for individual and organizational learning in order to adjust to new needs. In this regard, as ICT-mediated communication continues to expand, the Development perspective on ICTs becomes more relevant, as pointed out by Credé & Mansell (1998):

The new modes [of producing and exchanging knowledge] are creating potential problems for existing educational and scientific-research institutions. Without changes in these institutions' approaches, many developing countries risk finding themselves locked into a mode of knowledge production that is increasingly less relevant to their specific technical, scientific, and economic needs (n.p).

ICT powered communication – and its *positive* consequences have, indeed, not reached everyone. This reality has placed “access” to ICTs as the obvious challenge in development thinking. At the same time, some authors have highlighted the limitations of an exclusive focus on “access” on the grounds this reflects an incomplete understanding of ICTs.

Warschauer (2002) writes that “meaningful access” to information, which he describes as the development of the skills that allow people “to fully participate in society and control their own destinies” (Warschauer, 2002, p. 5), is really where the problem of “access” begins. Mansell and Wehn (1998), writing from the ICTs for development camp, similarly argued that making ICTs available to people is simply not enough. Policies that focus on introducing ICTs not for their own sake, but as part of a larger purpose, such as facilitating

improvements in productivity, education, and the delivery of services are what is required to address uncertainties about the future. The next subsection discusses some approaches to this issue found in ICTs for Development literature.

2.1.2 *ICTs and Development*

Much as access to fertilizers and machinery were and continue to be the major goal of the *Green Revolution*, in the “communications revolution”, access to ICTs has been presented as the means that can help national economies “leapfrog” stages of development (Wilson, 2003). Change comes not, as in earlier models, by way of diffusion from ‘progressive’ to ‘laggard’ adopters, but by virtue of ever improving ICTs themselves. Nonetheless, development literature also includes less technology-deterministic interpretations that centre on the communicative function of ICTs, which I review in the next subsection.

2.1.2.1 *“Communication for Development”*

The literature on ICTs contains the argument that development sector policies focusing on a minimalist definition of “access” – that of merely making ICTs available – do not adequately address the human dimension of the *digital divide* (Gurstein, 2003). Access is without doubt part of “the first mile of connectivity” (Richardson, 2000), as people have to be exposed to the technologies if they are to adopt them. But access requires a next step. This is, an emphasis on communication – the “C” before the “T”. Communication aids access to the technologies, as communication is concerned with the actual function of ICTs: the transmission of digital data that can be used for any number

of purposes (Heeks, 2002), and which can facilitate “horizontal” communication and learning (Von Hippel, 2007).

A communication approach, rather than a technology-centred one, is able to identify context specific needs as the basis for adoption of ICTs. Communication in this sense means *user participation* in the design of ICT applications that can be articulated to address actual needs, making ICTs relevant and desirable in such specific contexts. On this basis, the United Kingdom’s Department For International Development (DFID) argued that “[improving] the quality of the content that is communicated, and [including] poor-people [sic]” in the design of applications should be a priority along with expanding access (DFID, n.d.). DFID called its approach Information and Communication for Development (ICD). The motivation of the ICD framework was to guide the resources invested in expanding access to ICTs toward comprehensive approaches to ensure the demand-driven use of ICTs (Roman and Colle, 2003). As Mansell and Wehn (1998) noted, what is less evident than the need for access, is this need for supporting not only the transfer of technical skills, but of supporting the development of locally relevant applications. The ICD frame shows that access can be more broadly problematized in terms of who uses ICTs and for what purpose(s).

2.1.3 *Intensive and extensive uses*

Noting that the communication and information storage capabilities of ICTs can be used in different ways, for different goals, Heeks (2002) proposes that ICTs – any ICT – can be given “extensive” and/or “intensive” uses. In the latter

case, ICTs are viewed as a platform for improving aspects of existing services and practices. In the former case, the focus is on exploiting the information storage and communication function of ICTs to create new applications and *generate* demand for new skills and services that can grow and be sustained. In a community development context, such new skills and services can represent an economic development opportunity and, in this sense, it can be safely assumed that the extensive use of ICTs leads to greater benefits (Heeks, 2002; Melody, 1996).

2.1.4 Access for effective use

Gurstein (2003) identifies the next step from "access" as effective use, which he defines as the "capacity and opportunity to successfully integrate ICTs into the accomplishment of self or collaboratively identified goals" (Gurstein, 2003, n.p.). Here, *capacity* refers to the 'soft' (skills, relationships, organizational functions) dimensions of ICT; those capacities that can be seen as prerequisites for the successful introduction of ICTs into any given organizational context. Likewise, *opportunity* refers to the existence of favourable circumstances and conditions for a "self or collaboratively identified" need for change. In the "effective use" of ICTs frame, going "beyond access" means determining what is to be done with the possibilities ICTs bring. Effective use is defined by specific contexts of application. In Gurstein's words, if ICTs "are [...] the means for the production, distribution, and sale of 'content'", then:

"[...] the challenge with ICTs is not simply to provide passive 'access' to the technology, but rather to provide the means by which individuals in their communities can find ways of making 'effective use' of these technologies for productive, wealth creating, and transactional as well as other processes (n.p.)

This proposal agrees with Heeks' (2002) notion of "extensive use" in that effective use is defined by how local groups interpret and appropriate the tools. Effective use is the way in which the effects that a technological innovation will have on a given social environment can be managed – or contested – in order to favour a controlled way of using that technology's capabilities. A technology – if viewed as a cultural product – can be appropriated according to what is locally relevant.

Access *can* give way to the "extensive" or effective use of ICTs, but it is the latter two concepts (extensive or effective use) that most explicitly address the nature of the adoption challenge. The next section introduces telemedicine, an example of an ICT application where effective or extensive uses can be shown to be key to successful adoption of change.

2.2 TELEMEDICINE

This study refers to the introduction of digital telemedicine to remote First Nations communities. In using the term 'telemedicine' I mean 'digital telemedicine'. Here, I do not refer to the relationship between the terms 'telemedicine' and 'telehealth', other than to note an observation made by Cervinskas (1984), who places the terms "telehealth" and "telemedicine" as being interchangeable, though she acknowledges that "some workers in the field take

exception to the term ‘telemedicine’ and advocate instead the term ‘telehealth’” to express the idea that “‘telehealth’ implies a broader range of health-related activities than ‘telemedicine’ does” (Cervinskis, 1984, p. 4). I take the view that the semantic difference is less important in the context of remote First Nations communities, given that most of what happens in telehealth and telemedicine is confined within the walls of a small rural clinic. Thus, telemedicine is clinical health care at-a-distance.

The federal authority on health care in Canada defines telemedicine (using the term "telehealth") strictly in such terms: “a patient getting a face-to-face examination by a remotely located doctor, through interactive video-conferencing” (Health Canada, 2005). In technical terms, telemedicine is an ICT application that allows the transmission of voice, vital signs and images electronically, securely and confidentially.

2.2.1 A Brief history of telemedicine in Canada

As early as 1977, there were clear ideas about what telemedicine could be, and foresight about how technological improvements in health care-at-a-distance could bring particular advantages for rural and remote populations:

The advantages of [telemedicine] are: patient travel and inconvenience can be reduced: decentralized sites can handle more complex cases: remote sites are more professionally attractive because the providers feel less isolated and part of a complete system, and because they feel more comfortable with difficult decisions when they have the ability to consult readily; and patient services can be facilitated and coordinated. The disadvantages are: it is expensive, and although telephone based systems are less expensive than television systems, even they can incur significant long-distance charges; it may be inconvenient and time-consuming to establish and carry out a

teleconsultation; and in many rural areas the telephone services are inadequate (Rockoff, 1977, p. 430).

Just over three decades later, with growing access to ICTs, broadband, and satellite connectivity, Canada was fertile ground for the development of telemedicine.

Jennett (2003) underscores that telemedicine can *make sense* from multiple user perspectives, as its principal use is to connect people to a most basic service: health care.

2.2.2 Telemedicine in remote First Nations communities

Health coverage for remote communities in Canada – many of which are First Nations (Lemchuk-Favel & Jock, 2004) – is limited by a combination of factors. On one hand is the fact that public health care faces challenges in terms of rising costs, linked to pressures derived from other ailments in the health care sector, such as the health status of the general population (Pong, 2002). On the other, remote coverage is limited by structural issues, such as deficits in the numbers of nurses and specialists (Lemchuck-Favel & Jock, 2004). In the particular case of remote health care, the high cost of travel to and between communities is, in fact, a major limiting factor to the provision of quality health care to remote populations. Opposite these costs, are those related to the implementation of broadband technologies for the development of ICT applications in areas such as health care. As one author points out, First Nations access to applications of new ICTs represents an uphill battle:

Because many [First Nations] reserves are geographically small and have a small economic and population base, the great majority does not have, and in all likelihood never will have, the capacity to offer a full range of government services. In reality, they will have to join together in regional governments ... in order to be able to offer the full range of services ... In many cases Indian ... governments will decide to contract with existing agencies to provide services (Purich, 1992, p. 430).

Turner (2003, p. 22) adds that given the uniqueness of First Nations settings, the question of capacity is interpreted more broadly, in the sense that until more First Nations people attain the training needed to serve as [health care] professionals, non- people are likely to remain involved – and in control. This is an issue, considering that even if non-First Nations professionals are highly skilled and sensitive to the culture within which they work, language – and by consequence, other cultural gaps – will remain a significant barrier to ‘quality of care’ (Turner, 2003, p. 22)

2.2.3 *First Nations-led telemedicine*

There is, at the same time, according to some studies (Turner, 2003; Lemchuck-Favel & Jock, 2004) evidence of a growing consciousness among First Nations communities of these needs. First Nation peoples are increasingly concerned with taking control over the management of, and decision-making about, issues and services that affect them. One of these is the realization that First peoples have the right to exercise ownership over any research conducted on and about any aspect of their lives, territories, history, and any other subject concerning them (Schnarch, 2004). In relation to health care, First Nation communities have also begun taking steps to build local capacity for the design

and application of evaluation research tools that can lead to locally desirable service improvements (Turner, 2003; Jennett, 2003). Though there is a practical purpose to this type of research, such as obtaining “community level health and capacity indicators that matter for First Nations people” (Jeffery, 2006 , pp. 44, 46), its implication is – as shown in the research by Schnarch (2004) – that First Nation communities have appropriated the concept of “intellectual rights” over any data, information, and knowledge of or about their distinct cultures. There is, in the appreciation of the First Nations, a “critical link between self-determination and control over information” (Assembly of First Nations, 2005, p. 1). Self determination is a subject of strategic importance to the First Nations. I do not explore it here, however.

The telemedicine community – made up of university-based experts, physicians, government, and industry – are beginning to recognize First Nations rights, as described earlier, and their implications. Their focus remains nonetheless centred on the need for building local capacities to facilitate the adoption of change, such as in the case of the introduction of telemedicine (Gideon, 2000; Alliance for Building Capacity, 2002; Jennett, 2003).

It is useful to recognize that ICTs have enabled the creation of telemedicine networks for sharing audio, video, still images, x-rays, and other medical communications that allow health professionals to diagnose and follow up with patients as needed, without having to arrange for travel (of the physician to the community or of the patients to the urban hospitals). Travel is expensive and can be taxing on patients and their families (Jennett, 2003). Telemedicine networks,

thus, provide the technologies that can address the major issues in remote health care effectively (Canadian Institute for Health Information, 2007).

Considering what has been explained in terms of the advantages that ICTs bring to communication-at-a-distance – and particularly to remote health care – the definition of digital telemedicine can be presented again. Digital telemedicine is, in essence, the possibility of a new environment for interactive communication in which aspects of how health care happens can be re-thought. In terms of the combination of the clinical health care application (telemedicine) and the ICT itself – which is designed to be applied in clinical environments and, therefore, introduces clinical health care requirements into the social environment in which it is placed – we can arrive at yet a more detailed potential definition of telemedicine. Telemedicine can be seen as a framework for clinical health care, where the supposed unpredictability of its impact, as an ICT (Ramírez, 2007), gives way to the certainty that it will compell certain adaptations by its *adopters*, and not necessarily the other way around, unless the conditions exist for its effective use (Gurstein, 2003).

The picture that emerges from the effective use possibility is one that qualifies the idea of unpredictability with the notion of the controlled application of the advantages of the technology for purposes that are locally meaningful. In the case of First Nations telemedicine, health care needs are significant enough to facilitate a “fit” between technology and local context, at least as far as access to health care is concerned.

Though, as with any other ICT application, the long-term outcomes or impacts of telemedicine on remote communities can not be predicted,

telemedicine is facilitating changes that can already be observed. Outside of the strictly clinical use of this ICT application, for example, the communication function of digital telemedicine opens the door to making the clinical consultation experience more amenable to the patients and their families. Families are able to see and speak with – and offer support to – their loved ones when they have to spend time in an urban hospital (Buckwater, et al., 2002). Telemedicine makes remote health care more appealing, as a working and living environment, to health care professionals, particularly nurses, who have the possibility to attend distance education sessions, and to consult with colleagues and physicians more easily (Rockoff, 1977, p. 430). Telemedicine, as other ICT applications, can thus be “tailored” (Buckwater, et al., 2002) to the specific needs of remote communities.

Though the effects of telemedicine in remote health care may be unpredictable, it is hard to find arguments against its introduction into the health care system. Turner (2003) notes that digital telemedicine improves the chances that First Nations health workers can be located and asked to help with medical consultations that require translation or other remote assistance. There is room to wonder what would happen if there were more First Nations people with the capacity to lend a hand in such situations involving clinical health care. The ‘effective use’ of ICTs argument, applied to remote health care, would point to the critical importance of coupling access to ICTs with policies that support the building of local capacity. The following section explores the idea of “community readiness” for the effective use of telemedicine. The assumption here is that such an approach is what the literature is pointing to, given that the undercurrent of

the effective use argument is that of user ownership over the technologies. In this sense, community readiness refers to the conditions necessary for the appropriation of telemedicine by local groups who – as Gurstein (2003) proposed – define their own priorities and goals from their own circumstances.

2.3 READINESS

Community preparedness to confront the need for change is referred to as “community readiness” (Jennett, 2003). Community readiness has many of the requirements of *organizational* readiness, in particular the institutional and *evaluation* supports that allow an organization to plan for change (Papineau & Kiely, 1996). From this organizational perspective, community readiness includes “adequate human resources, training, policies, funding and appropriate equipment” (Jennett, 2003, p. 261) or, in other words, the capacity to build partnerships to secure sustained support. In the realm of telemedicine, readiness frameworks are emerging that use the insights of other readiness research on the promotion of behavioural change within organizations. An example of this is the telemedicine readiness framework presented by Jennett (2003) – a community readiness framework for telemedicine that I will explore in more detail in relation to the question of effective use of ICTs. Community readiness address two fundamental requirements to making telemedicine accessible and relevant to the community: community engagement and building the necessary local technical capacities. I will summarize Jennett’s definition of readiness on the basis of these two fundamental requirements.

In a study on ‘readiness for telehealth’ in a remote community, Jennett (2003) identifies several “types” or different levels (individual, organization, community) of readiness, each with a distinct focus or question at its core. At the individual level, readiness can be defined as the possession of the appropriate technical and communication skills for operating a telemedicine terminal and conducting a tele-medical consultation. At the organizational and community levels, Jennett identifies two types of readiness: core readiness and engagement. The former refers to the combination of circumstances that generate perceptions of “genuine need”; the reason for change (Jennett, 2003, p. 260). Core readiness is achieved through the *participatory* assessment of needs and the support of a process of communication through which needs become clear and can be integrated into strategies for change. Here, it is necessary to clarify that by “participatory” I am referring to the collaborative and consultative processes that lead to community input into organizational decisions. That is, participation is an inherently limited approach to change (Hickey & Mohan, 2005). Core readiness, then, is what leads to what Melody (1996) refers to as “sufficient” demand (Melody, 1996, p. 253) – that which can provide solid justification for an investment of the magnitude demanded by telemedicine. Readiness calls for participation – or engagement – to ensure some degree of “buy in” that leads to commitment toward change by the community (or members of the community – *champions* of change that can aid in its diffusion). In its participatory dimension, a readiness approach allows community users to become familiar with, and later scrutinize, proposed change. Readiness, thus conceived, aims to facilitate a shift – from resistance or hesitation to one of acceptance and will to adopt change. This

is a process that centres on managing expectations by exploring change in terms of “projection of benefits, assessment of risk, awareness and education, and intra-group and inter-group dynamics” (Jennett, 2003, p. 261). The following *Table 2.1* describes the components that fall under each of these areas:

Table 2.1 – Communication challenges for Readiness (Jennett, 2003, p. 261).

PROJECTION OF BENEFITS	ASSESSMENT OF RISK	AWARENESS AND EDUCATION	INTRA-GROUP AND INTER-GROUP DYNAMICS
<p>Telemedicine could “relieve some of the strains” endured by remote health care services:</p> <ul style="list-style-type: none"> - Unnecessary <u>travel</u> and discomfort to patients. - Facilitate better access to services and information needed for <u>quality of care</u>. - Boost access to professional <u>education</u> opportunities for local health care workers. 	<p><i>For practitioners</i></p> <ul style="list-style-type: none"> - Demand on their <u>time</u>. Professional <u>liability</u>. - <u>Quality</u> of the information made available via telemedicine. <p><i>For patients</i></p> <ul style="list-style-type: none"> - Confidentiality - <u>Reliability</u> of diagnoses. - <u>Replacement</u> of existing healthcare options, including initial face-to-face contact with doctors and specialists. - Potential for <u>exclusion</u> of the poor or less educated. <p><i>For organizations</i></p> <ul style="list-style-type: none"> - Short term financial risk and long term sustainability. 	<p>All categories of respondent signaled resistance as a function of</p> <ul style="list-style-type: none"> - <u>lack of understanding</u> of its applications, benefits, and limitations. <p><i>For practitioners & administrators</i></p> <p>Finding <u>the right people</u> to help diffuse the technology through demonstrations.</p> <p>Diffusion as “<u>learning by doing</u>”.</p> <p>This to complement the provision of <u>information</u>.</p>	<p><i>For practitioners & administrators</i></p> <p>Local ‘<u>champions</u>’ critical to diffusing telemedicine.</p> <p>Uneven <u>levels of awareness</u> and knowledge of telemedicine within rural and remote health care organizations.</p> <p>Intra-group relations have to accommodate the <u>gradual diffusion</u> of this knowledge in order to encounter “the least resistance”.</p> <p><i>For patients & administrators</i></p> <p>Inter-group dynamics.</p> <p>Acceptability of telemedicine depends on effective <u>communication</u> (informing, consulting, listening, and cooperation) between all the ‘communities of practice’ involved.</p>

Jennett (2003) shows that the infrastructural aspect of telemedicine (telehealth) links to the communication dimension of readiness. Her findings show that potential users needed to understand what infrastructure would be necessary, and whether all infrastructure needs had been identified: “[...] levels of readiness among the practitioner, patient and public communities were higher if they perceived the structures surrounding [telemedicine] to be adequate” (Jennett, 2003, p. 261). Awareness is the first step to acceptability of telemedicine. Developing the right skills and capacities among members of the community, including health professionals who live there, only makes sense if the community is interested in using telemedicine. Community engagement seeks to integrate local perspectives on the projected benefits of telemedicine. Jennett shows, for example, that replacement of existing services and face to face contact with physicians are concerns that people will raise when presented with the telemedicine option.

The potential for the failure of the introduction of telemedicine to a community rises when the process of community engagement cannot connect with local concerns, or adequately evaluate and demonstrate – communicate – the need for change. This status is referred to as *non-readiness*. Non-readiness can be ascertained through a needs assessment that reveals the lack of need for change. It can also be revealed through a needs assessment that shows a community's “failure to recognize such a need” (Jennett, p. 261). Lack of awareness of need demands a communication strategy that engages people on the specific qualities of the technologies, rather than on vague notions of change. The second type of non-readiness – lack of awareness – offers the opportunity for

comparisons: presenting the challenges and opportunities, the risks, advantages, and potential benefits that other communities in similar situations have found with the implementation of telemedicine. It can be argued that a non-readiness situation of this type – which demands a communication strategy that can succeed in promoting “buy in” (Jennet, 2003) – makes room for effective use when it looks to articulate a local vision (goal), and support subsequent local capacity for action in its direction. That is, readiness and successful adoption of telemedicine depend on the development of local community and/organizational capacity to “learn”, in this case, how to use telemedicine, translate, and act, according to local priorities, learning to innovative in uses of the capabilities of the technologies.

2.4 EFFECTIVE USE: GOING BEYOND “ACCESS”

Several authors (Melody, 1996; Heeks, 2002; Warschauer, 2002; Gurstein, 2003) note that physical access to ICTs does not guarantee their *effective use* and, as a result, their adoption. The term “adoption” is key to understanding the challenge posed by the idea of effective use of ICTs in the development realm. Adoption is the desired outcome of the successful integration of ICTs into context-specific settings. If “to adopt” is the equivalent of “to accept” something as a given, then the *adoption* of a technological instrument or technological system can be described as the consequence of users passively accepting a technology. Feenberg (1995), a writer exploring “technology” from the critical perspective, argues that, as cultural products, technologies such as ICTs not only represent a given cultural framework (i.e., western, scientific, productive) , but

also impose ways of thinking and doing into the different cultural contexts in which they are introduced. In this argument, Feenberg also stresses that, paradoxically, the cultural implications of technologies are always “contested” by their users. Users of technologies will choose what technologies to use to the extent that they have such choice. In essence, then, the adoption of a given technology always involves some degree of contesting – or adaptation through practice – of its design. While Feenberg was referring generally to individual users of commercially available technologies, the idea that technologies represent contestable cultural frameworks has value for any exploration of the adoption and adaptation of complex technological systems, such as digital telemedicine.

Feenberg (1995) offers an insight that helps address the challenge of the successful introduction of technologies into new social environments. This is the possibility that meaningful use results partly from the unavoidable need to contest – adapt – the cultural design (purpose, assumptions) of technologies. This idea leads conveniently into the notion of “effective” use, which implies that introducing an innovation into a new local context requires not only local “perception of need”, but also the existence of “self or collaboratively defined goals” (Gurstein, 2003, n.p.). Such goals can reflect a strategic vision and capacity (Kaplan, 1999) to guide the development of context-specific applications where the users of ICTs address as many needs as can be tackled by the communication and information dimensions of the technologies. In conventional contexts, effective use can involve the challenge of *integrating* a technological innovation into an existing way of doing things. In a unique setting, such as that provided by the very complex health and cultural-political situation of First

Nations communities, effective use can be imagined to involve not the luke-warm contesting of meanings necessary for such integration, but the opportunity or possibility to support transformative change – or appropriation. That is, such a vision and specific needs may involve not the adoption of a technological innovation, but its adaptation to serve a self-defined goal or a vision for change (Feenberg, 1995). This implies that a technological innovation can (or will) either be rejected or, if it “fits” with a vision of change (Kaplan, 1999, Heeks, 2002), appropriated in its meaning or function. In this sense, the effective use of telemedicine can involve more than a process of familiarization with it through mechanisms like “iterative interaction” (Warschauer, 2002, p. 9). Effective use can mean more than the integration of ICTs into existing ways and situations that need to be improved rather than changed. Effective use, then, is the outcome of locally defined goals, and of ongoing learning and innovation in action. Thus, while it is evident that adoption and local appropriation are different challenges, it can be established that effective use is a goal common to both, and that it is as important as the goal of ensuring access.

2.4.1 “Virtuous cycles” for effective use

Warschauer (2002) presents a framework of effective use of ICTs by describing a relationship between a strategic vision for context-specific uses of ICTs “for social inclusion”, and the infrastructural and capacity development inputs that make such a vision possible:

A framework of technology for social inclusion allows us to re-orient the focus from that of gaps to be overcome by provision of equipment [the

digital divide] to that of social development to be enhanced through the effective integration of ICT into communities and institutions. This kind of integration can only be achieved by attention to the wide range of physical, digital, human, and social resources that meaningful access to ICT entails (Warschauer, 2002, p. 10)

Congruent with Melody (1996), Warschauer (2002) defines effective use as the result of “meaningful access”. Such access calls for the development of the human and organizational capacity to “access, adapt, and create knowledge” (Warschauer, 2002, p. 9). In this view, acquiring and exercising capacity requires infrastructure, access to content, literacy and education, as well as sustainable local organization. The cyclical relationship between these elements and innovation results as access to infrastructure and content yields new content that shapes innovation (context-driven applications). The idea of “meaningful” access implies that users develop a sense of ownership, a sort of social investment, over the technologies. This is the appropriation of the technologies' *raison d'etre* and their adaptation to locally defined priorities or goals. The appropriation of the meaning of a technology was described by Feenberg (1995) as an organically, naturally occurring process of familiarization with, and subsequent “contesting” of, the cultural “codes” of technology, which implies that technology is seen as a *cultural framework*; a set of exclusive rules and expectations (Turkle and Pappert, 1999).

Thus, going beyond access – beyond the *digital divide* seen merely in terms of the availability of technological instruments – demands the recognition that such instruments cannot, on their own, bring about meaningful change. It can be argued that meaningful change only comes through the appropriation of the

technologies. And that appropriation, in turn, is the result of effective use, which demands a process of learning that evolves at the pace of local experience, and which can be supported through strategies promoting community readiness for innovation.

At the centre of this learning process is the question that the users of the ICT will have: why should we use this technology? (Heeks, 2002). Community objectives are what will define what effective use means. The role of policy and of those who become involved in facilitating access to ICTs and their applications is, then, to recognize and support self defined objectives (Melody, 1996; Heeks, 2002; Gurstein, 2003). Such objectives, according to this argument, will yield demand for specific applications and, as a result, lead to the extensive use of the information and communication dimensions of the technologies to support the development of new, locally relevant skills and applications. The literature reviewed suggests that, where the digital infrastructure exists to facilitate its introduction (access), effective use is possible, preferable, and necessary for the sustainability of the innovation, but it requires readiness for the acceptance of change and for the extensive use of the technologies.

While remote communities have the right to the same services as everyone else (Richardson, 2000), the literature points to the difficulty that “justification” for the implementation of ICT infrastructure is not only an economic matter (cost) – that is, subject to there being “sufficient” demand and diversity of applications (Melody, 1996). Finding the ‘right people’ and developing the right skills to support locally defined goals is, also, an ongoing need if that sufficient demand is to exist.

2.5 SUMMARY OF CONCEPTS

Three major elements frame this thesis: one technical – a definition of ICTs; one practical – an exploration of the insights into organizational change as a challenge that is about access; and one definitional – about the human-cultural dimension of technological innovation:

- Information and Communication Technologies (ICTs).
- Readiness.
- Effective Use and Appropriation of ICTs.

ICTs:

Information and Communication Technologies are the digital instruments that facilitate ease of communication in the “information highway”. ICTs make possible the sharing of data and information across distance in multiple formats with which individuals and communities can pursue strategies to attain specific objectives.

Readiness:

The planned management of risk around the possibility of failure to accept and/or carry out change. Risk management takes place through education and capacity development to facilitate the acceptance and adoption of change. In change that involves the introduction of a new technology in a rural or remote context, such goals involve the development of specific technical and communication skills at the community level. Aside from the normal technical and communication skills required, the objective of a readiness frame in a remote

context – and particularly in culturally distinct settings – must include non-technical goals, such as supporting the building of local acceptability and ownership over the change. The goals of a readiness approach, in essence, are to develop:

Sustainable organization – A vision, and the capacity to build partnerships and secure the sufficient material and human resources to implement and sustain the work to achieve that vision.

Local capacity for action – Organization and local capacity to manage the infrastructural requirements of telemedicine, including capacity to evaluate, create, and improve services.

Effective Use of ICTs:

The effective use of ICTs refers to the successful application of their technological potential in a given context, by a group or individual, for the advancement of their self-defined goals. Effective use can involve the adoption or the adaptation of ICTs by an individual or group. Effective use of ICTs means that ICTs are used by people to address locally perceived needs and to support locally defined goals or visions. When ICTs are either adopted or adapted, effective use is determined by how ICTs become part of the local culture and/or organization in which it is introduced.

3. BACKGROUND

In this chapter, I present the context of the case study in terms of the history of Keewaytinook Okimakanak Telemedicine, and the implications of clinical health care in First Nations-led telemedicine.

3.1 KEEWAYTINOOK OKIMAKANAK: THE GENESIS OF FIRST NATIONS TELEMEDICINE

The story of Keewaytinook Okimakanak Telemedicine (KOTM) begins with the Keewaytinook Okimakanak (Northern Chiefs) Tribal Council (KO). Founded in Northwestern Ontario, in 1991, KO brought together elected Chiefs from six remote communities: Deer Lake, Fort Severn, Keewaywin, McDowell Lake, North Spirit Lake, and Poplar Hill. These communities, and the communities to which KO has been expanding telemedicine service, are spread out over a large territory – comparable in size to France – and, prior to the arrival of broadband, were only ‘fly-in’ or communicated by Winter roads over frozen lakes, and by the Band Office phone (Ramírez, 2004). For much of the year, their only physical link with the rest of the country was provided by airplanes small enough to land on their short airstrips (Ramírez, 2004).

The Council made the strategic decision to lead the introduction of digital connectivity in its territory in order to facilitate the development of KO-run digital communications applications in education and health care. In this way, the introduction of telemedicine takes place in the context of KO’s efforts to take full advantage of the broadband – the “broad bandwidth” infrastructure that allows audio and video to be exchanged at electronic speed, and which can be

divided and shared by multiple simultaneous signals – to which it has access as a result of negotiations with federal agencies.

The telemedicine initiative began with the participation of KO leadership in a telemedicine demonstration at a conference organized by KO in Thunder Bay, Ontario. This early exposure to the technology resulted in the creation of KO Telehealth (now known as KO Telemedicine), an organization that subsequently began working on expanding service beyond the first five pilot KO communities. KOTM prepared a Memoranda of Understanding (MOUs) between itself and individual communities covering the expectations and responsibilities to be met by each party upon the delivery of telemedicine equipment to remote clinics. A favourable climate for First Nations initiatives at the federal level has allowed KO to continue with the development of on-line services. The remainder of this chapter explores issues around the formation of KOTM.

3.1.1 KO and K-Net

The Keewatinook Okimakanak (KO) tribal council:

[...Is] part of the Nishnawbe Aski Nation (NAN), a regional organization representing the political, social, and economic interests of [forty nine] First Nations in northern Ontario, across an area roughly the size of France. NAN includes a population of approximately 25,000. The majority of this population is aboriginal and lives in remote communities with 300-900 inhabitants (Ramírez, et al., 2004, p. 2).

In the early 1990s, KO began exploring opportunities and “strategies to bring all the Nishnawbe Aski Nation communities together onto a [broadband network] (Keewatinook Okimakanak, 2002a, p. 3)”. The limited connectivity of the region, coupled with the lack of extensive telecommunications facilities at the

service of remote communities, made it clear to KO that government and the private sector had to be approached to bring about change. That change became the Kuh-ke-nah ('everyone, everywhere') Network (K-Net), created by KO with the primary objective of harnessing the opportunity presented by the Canadian government's strategy to make Canada "the most connected nation in the world by the year 2000" (K-Net, 2001; Industry Canada, 2008).

3.1.1.1 *The SMART Communities Project*

K-Net is a private broadband telecommunications network that serves remote First Nations communities in northwestern Ontario, providing service and support to other First Nations communities across Canada. It supplies access to ICTs, technical support and human resources for the development of 'e-applications' in different areas, including governance, education, and health (KO, 2001). This broadband network carries high-volume digital traffic: video, voice and text data. K-Net emerges in the context of the SMART Communities Demonstration Project, developed by Industry Canada, a federal agency mandated to provide incentives for research and development at the regional (provincial, territorial) level. In 1999, K-Net assembled a bid to become one of Industry Canada's Smart Demonstration Projects. K-Net's Kuh-ke-nah proposal won the national competition for the Aboriginal category" (Ramírez, et al., 2004, p. 7), benefiting the five KO communities who were in a position to take part in this effort: Deer Lake, Keewaywin, Fort Severn, Popplar Hill, Weagamow Lake. In this sense, The SMART Communities project – almost 5 million dollars and technical and capacity support in building a broadband network – laid KO's

infrastructural and “know-how” foundations for “harbouring” further funding opportunities for First Nations led innovation:

The investment and documented accomplishments have allowed K-Net to leverage additional resources. For example, K-Net has recently been selected as one of the Regional Managing Organizations for Industry Canada’s First Nations’ SchoolNet initiative, serving as a help-desk for aboriginal schools all across Ontario (Ramírez, et al., 2004, p. 7).

In 2002, the Council hosted a conference¹ attended by First Nations representatives from across Northern Ontario, and sponsored by KO’s partners, including the major players in the connectivity sector in Canada, both from industry and government². KOTM’s role in facilitating the introduction of telemedicine was, thus, defined by the conference objectives, which included, among others:

- To demonstrate the advantages of (digital communications) technology.
- To communicate the benefits of “SMART” First Nations communities³.
- To create awareness and to capitalize on the benefits of Information Technologies (IT).
- To create awareness of government initiatives and strategies for the development of connected communities.
- To share the lessons learned in the development and uses of Information Technology.

¹ The ‘First Nations Connect’ conference in Sioux Lookout, Ontario.

² See: <http://smart.knet.ca/conference>. Accessed July 20 , 2008.

³ Communities that had already been connected to broadband through the SMART Communities program of Industry Canada.

- To educate and inform decision makers of the importance of IT and how the technology could be used to preserve history, culture and language.
- To showcase new and innovative products.

The conference provided a space for First Nations leadership and community members to explore, together, the concerting of efforts toward connecting with each other and with the world.

3.1.1.2 *Navigating the State-First Nations “relationship”*

It is evident that the First Nations realized that ‘harnessing’ opportunities for sharing ideas, documenting and preserving culture and language, and the appropriation of innovative products and applications would have a greater impact in remote environments without ready, physical access to services (KO, 2002, p. 16). It is also evident, however, that the Kuh-Ke-Nah Network (K-Net) constitutes an example of how the First Nations would rather navigate rather than seek a course of gaining greater control over their future. That is, KO and its various initiatives do not signal a desire for fundamental change in nature of their relationship with the Canadian state. As such, this initiative for a First Nations owned and operated connectivity (broadband) signifies the securing of a virtual space for First Nations innovation, but does not point to the desire to seek such a change. If there is a KO strategy for change, it seems to be one centred on how the First Nations can access ICTs to control the use and customization of services to support local needs. The central mission of K-Net, thus, is framed in the language of the *digital divide*, and suggests that the long term goal is ensuring First

Nations control over services that impact the daily lives of the communities. That is, the goal is to navigate the Canadian-First Nations relationship rather than challenge it:

K-Net achieved these significant impacts because of a vision: the network's organizers understood that the educational, health, and economic development needs of the most remote communities in Ontario required broadband service— they could not be satisfied strictly with what regulators and commercial carriers had agreed to build. This cumulative experience led K-Net to compete for Industry Canada's Smart Communities Initiative, a national competition for a CAD \$5 million grant that had to be matched with an additional \$5 million from other sources. K-Net succeeded and was selected in April 2000 as the only Aboriginal Smart Community Demonstration Project for all of Canada (Ramírez, et al., 2004, p. 5).

It is important to recognize the fact that KO represents an option: one that frames First Nations interests within the possibilities offered by the Canadian state for improvements that do not affect the political *status quo* (Dyck, 1991; Niezen, 2003). KO works with elected Chiefs and Councils, and other elected and appointed local officials, as traditional expressions of local authority have been displaced.

Access to more health services, along with access to 'education' and to 'economic development' opportunities were, instead, possibilities that were immediately evident to the First Nations in their decision to "harness" an opportunity to introduce digital connectivity. Telemedicine, thus, could be developed as "a community project [that] the communities will take [...] where they need it to go" (KO, 2002b). Such a statement is significant from the standpoint of two distinct possibilities: one, that First Nations communities, and not health professionals within or outside of the clinics, are contemplated as the

true source of future direction for telemedicine. The other, that such a contemplation is indicative of a degree of political or strategic “sophistication” or innovation in light of a very complex web of interests and possibilities (Niezen, 2003).

3.1.2 KO Telemedicine

Muttitt, *et al.*, (2004) describes the genesis of First Nations Telemedicine as “an intensive [telemedicine] information and education program [that] included meetings with Health Committees, Band Councils, and the general public” (pg. 410). The authors refer to the KOTM/NORTH Network project as one of “the largest and most successful [telemedicine] networks in Canada”, and as one that has been built based on “a First Nations focus” that includes paying attention to “wellness and prevention” needs (pg. 411). This partnership leaves First Nations Band leaders and health care providers with the responsibility to promote and oversee the “growing of the service” within a First Nations focus in their own communities. The cited research qualifies this telemedicine experience as successful also in light of the fact that “prior to [KOTM], there was an assumption that [telemedicine] would have to be heavily sponsored and developed by the federal government” (pg. 411). That is, KOTM stands out as a First Nations managed effort, and an example of ‘self-governance’ in the health care domain.

The stated mission of KOTM is to:

[...] improve health for all First Nations communities through a sustainable First Nations [telemedicine] program that is holistic, community driven and culturally appropriate (KO, 2004)

Keewaytinook Okimakanak is recognized as the “pioneer” in the promotion of satellite and broadband connectivity for all the First Nations in Canada (Keewaytinook Okimakanak, 2002a, p. 8). This recognition does not simply reflect the fact that KO was the ‘first’ Aboriginal group to “develop a business case to maintain the network and service” (Ramírez, 2004, p. 6). KO Telemedicine (KOTM) was originally known as KO *telehealth*. Today, KO Telehealth (KOTH) is a specific area of intervention under the KOTM umbrella. KOTH works on training the local Community Telemedicine Coordinators, and provides and facilitates other capacity building efforts at-a-distance.

3.2 THE CLINICAL MODEL FROM A FIRST NATIONS PERSPECTIVE

The ‘clinic’ represents a cultural frame proper to the modernist (Western) approach to health and the body, as well as to the organization of power and control. In this respect, the term “clinical” corresponds to a *philosophy*: that which places the ‘patient’ – and in the commodified language of health care today, the ‘client’ – as the subject of treatment extended from a structure that organizes health care as the domain of professionals, the state, and the market.

In his well-known work *The Birth of the Clinic* (1974), Foucault engaged in an in-depth analysis of the clinical ‘way of knowing’, which he identified as the hitherto seldom contested power and authority of doctors and health

professionals over all health matters – the formation and institutionalization of control over ‘medical knowledge’. The clinical model is a system of enclosed and systematized knowledge (Foucault, 1974, p. 29) that “dogmatically pronounces its judgment” (Foucault, 1974, p. 30) [...] within an enclosed space [the clinic, the hospital, the doctor's office] in which it is controlled only by itself, in sovereign fashion [...]” (Foucault, 1974, p. 31)

The major features of the clinical model, in its genesis, include: the development of the practice of statistical supervision of health; the resulting pathological record (rather than personal histories) that allows for the control of information and generation of medical knowledge, and; public education to alter the consciousness of individuals (a behaviorist approach) to acquire medical consciousness (Foucault, 1974, p. 31).

The significance of the clinic to health, thus, is that it “isolates events by analysis [to treat] them separately” (Foucault, 1974, p. 110) “as it seeks *precision* in the statement and *regularity* in [...] describing the object” (Foucault, 1974, p. 113, emphasis in original). The clinical approach to health ultimately represents the western disassociation of interior and exterior; of humanity from the natural environment.

3.2.1 *Aboriginal notions of health: Implications for telemedicine*

The First Nations live and interact simultaneously in two distinct *worlds* (Leclair & Warren, 2007). While language, particular beliefs and practices survive, that experience of survival – to colonization – has partly transformed or “fragmented” cultural identities. Specifically in terms of health status, changing

ways of life have brought “colonial” health issues for which colonial remedies are justifiably sought. It is clear, from the concrete “health status” of First Nations populations (Pong, 2002), that improvements to their health are needed and can be made. However, what these are and how they should be implemented are questions about *health care approach* as much as about health status.

Morse, et al. (1991), through a study of Cree conceptions of health, established that the Cree use holistic and categorical definitions: “there is no ambiguity in the Cree system: the patient does not go to the healer to ‘see if everything is all right’; the patient goes to be cured” (Morse, et al., 1991, p. 1362). The authors of this study explored the mechanisms that constitute the ceremonial structure of the Cree health care experience, and outline their conclusions as a list of observed *contractual* relationships between healer and patient:

(1) the ritual component which purifies and opens the doors to the spiritual world; (2) the contract component in which the patient requests healing and the healer agrees to mediate with the spirit world to facilitate healing; (3) the treatment component which consists of pharmaceutical therapy and sweatlodge ceremonies; (4) the didactic component in which the healer educates the patient concerning the nature of the healing process and the efficacy of his treatment; (5) the closure component in which the healer brings an end to the therapeutic relationship but reassures the patient of the continued healing and support of the Great Spirit.

The authors place emphasis on the fact that the Cree credit “the Great Spirit” with the power to heal, and call attention to the sharp contrast of this belief with the “Western model in which the physician is considered to be the main actor” (Morse, et al., 1991, p. 1364). Morse, et al. (1991) concluded that clinical health care can become more sensible to the cultural needs of First

peoples, but not, however, “as long as [health professionals] assign curing to the physicians, caring to the nurses and counseling to social workers”. In their analysis, “rampant specialization” creates unnecessary distance between health care professionals and First peoples, “inhibiting [...] trust on the part of the patient” (Morse, et al., 1991, p. 1365). Morgan, et al. (1997) echo this sentiment in highlighting, with their analysis of the more extreme example of the Australian experience in the matter, that westerners (in this case, Euro-Australians) have had difficulty understanding and respecting cultural difference as an important issue affecting quality of care:

Despite increased access to resources and a heightening concern shown by health care workers, governments and the Australian people generally, Aboriginal people remain reluctant to use mainstream health services, and where they do the overall success rates remain low. Our claim is that this is due largely to three factors: A generally poor understanding of the way Aboriginal people think about the nature of reality... An inability to notice the extent to which this thinking shapes the practical, daily lives of Aboriginal people, and a reluctance to recognize that these beliefs and practices differ from those of mainstream European Australians in significant ways (Morgan, et al., 1997, p. 597).

The challenge of making western health care more culturally appropriate and, therefore, *accessible* to First peoples is as important as making the technologies for remote access available.

Keewaytinook Okimakanak Telemedicine addresses the pressing health care needs of a population grappling with illnesses brought about by colonization. Chronic health conditions like diabetes are linked to dramatic changes in lifestyle and diet. The transition from hunting, trapping, fishing and gathering – and the corresponding diet of fresh, natural foods – was completed with the propagation

of a sedentary condition in which access to food is limited to the highly processed (and highly priced) “edible food-like substances” (Pollan, 2008) flown in from the south. Diabetes, thus, is an emblematic health issue in telemedicine consultations in remote communities (KOTM, 2004).

4. METHODOLOGY

In this chapter I explain the genesis of this study, the research process undertaken in the communities I visited, and the mechanics for interpreting the data. I cannot begin this chapter before emphasizing that the interpretations of the data presented are mine and do not represent the opinions of those who also took part in the evaluation project from which this thesis emerged. In the final sections of this chapter, I discuss the conceptual and practical limitations to my research methodology.

4.1 THE RESEARCHER

I was introduced to KO Telemedicine through an evaluation project conducted for KOTM by researchers at the Centre for Rural and Northern Health Research (CRaNHR, Laurentian University) and the School of Environmental Design and Rural Development (SEDRD, University of Guelph). My field research was funded as part of this evaluation project. The funding for the latter was provided by Health Canada to Keewaytinook Okimakanak (KO), which subsequently mandated its Research Institute (KORI) to seek research capacity from CRaNHR and the University of Guelph.

I took part in this project under contract, and in the capacity of research assistant to the evaluation conducted by SEDRD and CRaNHR. My role was to help gather community perspectives on telemedicine that would be employed to inform changes and improvements in the quality of health care access made available to the communities via telemedicine. This experience as a research

assistant gave me the opportunity to meet with, and sometimes interview, community members, remote clinic nurses, local authorities, and members of KOTM.

I came to this study with the awareness that research in the social sciences has traditionally been conducted as an invasive, extractive appropriation of another's knowledge and/or information. I understand that documenting and analyzing the experience of a First Nations tribal council with the introduction of telemedicine to remote First Nations communities involves recording and interpreting a process that is *in motion* (Ramírez, 2006, personal communication), and is complex. I understand that beyond the appropriateness of the methods and the questions that guide the research, a researcher's interpretations can decontextualize the information used to arrive at them.

A different problem is what happens with the results of research. This is a question for the researcher. Research itself is about “confronting [...] the ideal with actual empirical evidence” (Cebotarev, 1999, n.p.). As an outsider to the context in which my research takes place, I view my research as my responsibility, and its conclusions as my conclusions. Finally, whether my conclusions are acceptable will depend on the quality of my questions, on the appropriateness of the methodology employed, and on the biases and interests of the reader.

4.2 CONTEXT OF THE FIELDWORK: VISITING THE KO COMMUNITIES

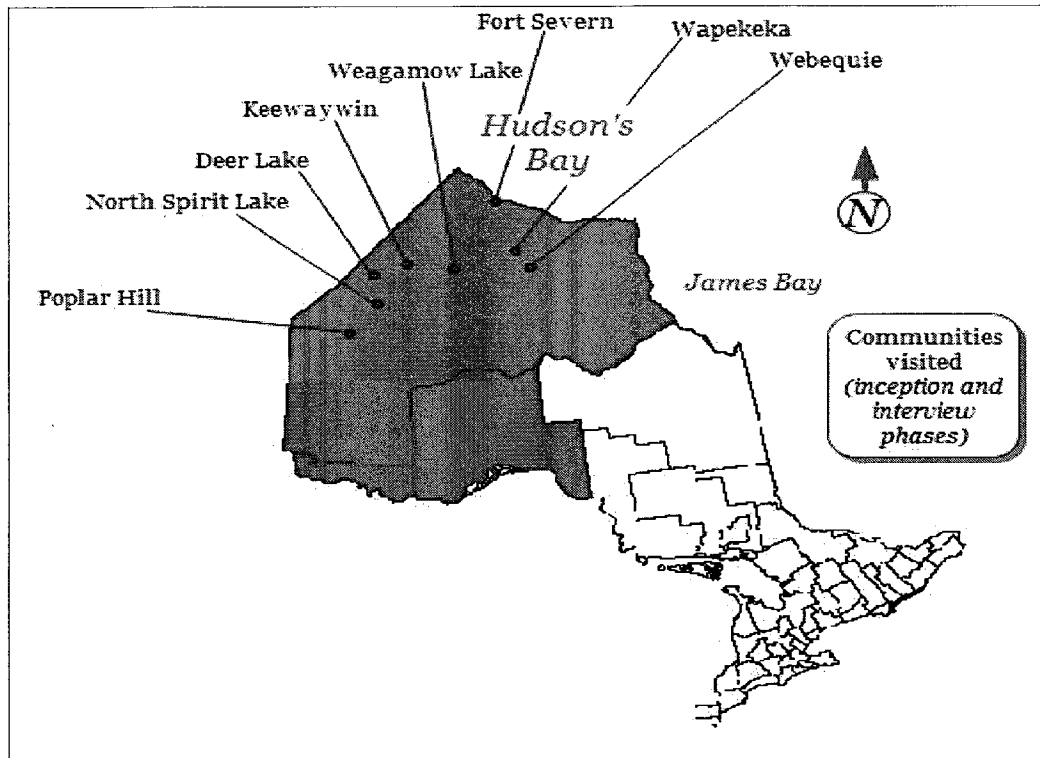
Though I did not have extensive stays in the communities, these did inform my appreciation of the meaning of the phrase ‘remote Aboriginal community’.

The basic infrastructural services that I as a visitor am accustomed to are largely absent from the First Nations reserve: adequate housing for extreme climates, a safe and reliable drinking water supply, roads and other public works, and complete health care facilities. Coming from a “Third World” perspective myself, I was surprised to encounter such “Third World” conditions in Canada.

In the particular context of the introduction of telemedicine into these communities, the most noticeable deficiencies were related to the material state and architectural design of the clinic buildings, and the availability of local capacity in health care. Every community visit made evident to me the important role that KOTM played in ensuring, to the full extent of the possibilities, the quality of telemedicine infrastructure and the availability of local capacity.

Over a period of over a year and-a-half, I visited eight of the twelve communities that began the expansion process in 2004. I made the attempt to visit communities that were at distinct levels of exposure to telemedicine – from no exposure to about one year. The names and geographical location of the communities I visited are shown in the following Map 1:

MAP 1 – Communities included the study



Map adapted from an illustration of KO's territory (shaded in) obtained from KO.

Out of the twelve communities that at the time of my stay in the region were taking part in KOTM's expansion, I visited eight, which I have listed on Map I. Of these, four are the sources of semi-structured interviews: Fort Severn, Wapekeka, Webequie, and Weagamow Lake. These were the communities in which longer stays were possible. The rest of the communities I visited: Keewaywin, Deer Lake, North Spirit Lake, and Poplar Hill, were part of my familiarization with the telemedicine system, and helped me gather qualitative data in other ways, such as through informal conversations, participant observation, health care facility tours, and participation in community events and activities.

4.3 COMMUNITY LINKAGES

In the absence of a formal protocol for arriving, meeting, and communicating with members of the communities visited for the purpose of the telemedicine evaluation – and for my own research – KOTM asked KO’s Community Liaison to accompany and introduce me to the authorities and clinical staff in each community that KO deemed important to include in the study. Through this process, it became clear to me that the informal mechanisms of communication were unique in each community, and that it would be useful to the research process to learn how to address people in their different roles – from Elders, Chiefs, and people in general.

Generally, however, the process involved meeting with the Chief and/or Band Council members to present myself, as the member of KOTM’s “evaluation team” who would be gathering community impressions of telemedicine, and as a university student wanting to document and analyze the introduction of telemedicine into the community. This basic presentation, along with the presence of KO’s liaison, became my standard approach to the first day or two in a community.

4.3.1 *Gathering the data*

This study relied on workshops with community health workers and community telemedicine coordinators; on semi-structured interviews with community members and remote clinic nurses, and on participatory observation of KOTM’s work with Community Telemedicine Coordinators (CTCs), remote clinic nurses, and community authorities. Information obtained from workshops,

interviews, and observations of the KOTM expansion process was complemented with telemedicine usage statistics, health status of the communities, and population figures, all data collected by KOTM and its partner non-governmental and state agencies. Community user perceptions of telemedicine are the backbone of the field research and, therefore, of the findings presented in Chapter 5.

4.3.2. *Inception visits*

There was an initial introduction period, of about two days, in which I met the local authorities, toured community facilities, and introduced myself and the purpose of my visit, at times with microphone in hand at social events or over community radio. Although not immediately apparent to the outside observer, each community receives its visitors differently. What could be “planned” about community visits depended in part on a previous knowledge of the people and local culture and the activities taking place in each community at the foreseen time of visit. Lacking more specific information and experience, it was necessary to rely on common sense and some “community expert” advice, from people at KOTM familiar with the communities, as to how to proceed with announcing my visit, inquiring about accommodations, and submitting interview requests. For all practical purposes, I relied on the CTC and sometimes the clinic staff for the arrangement of many aspects of the visits, starting with accommodations⁴ and

⁴ In most cases, I was reserved the 'visiting physicians' quarters in the clinic (shower, toilet, bedroom, kitchen, television, telephone, space and privacy).

the initial itinerary of activities, including introductory tours and pick up from and to the local airfield.

4.3.3 *Participating in the communities*

Access to community members was generally difficult outside of the clinic setting. Community visits never lasted more than an average of four days (in one case alone I was able to remain a fifth day, thanks to a mechanical problem with the daily flight scheduled to land at the local airstrip). The visit 'protocol' meant, furthermore, that access to individuals, particularly the elderly population, was not possible until often the latter few days of my stays, if at all. For this mix of reasons, taking part in community activities such as cutting wood, attending celebrations, going to church, or accepting dinner invitations became a crucial, yet unplanned strategic 'solution'. I state this along with the confession that I have a general tendency to never say no to dinner invitations or to community events (bingo games, celebrations, flea market sales).

4.3.4 *Planned events*

The structured or planned aspects of the field research took place almost exclusively in relation to the clinic and the Band Office. Upon previous arrangement, I attended in each community where interviews were done, a "telehealth open house" organized by the CTC (often as their own initiative for which they sought and obtained support⁵ from KOTM). Each one of these events was an opportunity to meet face to face with community members and to

⁵ KOTM would send refreshments and health food snacks for the Open House via airplane to the CTC.

establish contacts on a first name basis. Aside from meeting and helping me explore possible interview times, the clinic staff facilitated my familiarization with the scope of their operations and the resource margins they faced. Such field trips contributed to my general grasp of the impact that external factors, such as the difficulty of physically integrating a telemedicine unit into an already stretched health care facility, have on the relationship between the telemedicine project – embodied in the CTC – and the established health care workers. Information of this sort also helped me think about veins of questioning that I could possibly pursue with those eager to communicate their particular visions of local health care. I found that nurses, for example, were generally more willing to talk about the magnitude of the challenges they work with, and were comfortable exploring their thoughts on the introduction of telemedicine into their work environment.

4.3.5 *Semi-structured interviews*

An interview guide was initially developed prior to the first community visits with input from CRaNHR and KOTM. This instrument was flexible and not always employed, as I was asked by some potential interviewees to submit questions in advance, which I did, with the understanding that the questions were only a thematic guide. Some of the questions came from the evaluation of KOTM expansion (2004-2006), designed in part to meet the research needs of KOTM's funder, the Primary Health Care Transition Fund (Health Canada), but which included the objective of enriching that information with the results of my own work in gathering stories and points of view in the communities.

In general, there were few immediate positive responses to interview requests made of individuals through the CTCs. A few days would normally be needed to obtain an interview with a community member. The actual interviews differed from the questions included in the guide, particularly when discussing telemedicine with community members. On some occasions my questions were answered in the form of *stories* of a personal nature, which responded directly or indirectly to my questions. This form of presenting answers corresponded to the wishes of those interviewed, and presented no difficulties, as further questions could be asked.

The semi-structured interviews provided an atmosphere of greater comfort for the interviewee, as they allowed a degree of control over the interview process to be exercised by the participants. This advantage translated into the evolution of the interview towards the issues that were most significant to the participants. The interview guide is included in the Appendices section of this paper.

4.3.6 Administrative meetings

Because of my ongoing participation in administrative meetings, the organization held the expectation that for the duration of my involvement with the evaluation of the telemedicine expansion project (the main context of my presence there) I would be considered a member of their staff and included in all general staff meetings, as well as be subject to the directives of KOTM leadership. In terms of the significance of this information, attending regular administrative meetings facilitated a better grasp of the issues that matter to the organization in its work in support of community adoption of telemedicine. Aside

from this, the meetings also served as a source of data, such as that contained in the regular updates of some of the organization's administrative departments (Scheduling, CTCs, etc).

The meetings took place bi-weekly and often included the participation of external 'stakeholders' (such as the organization's funders and partners) through videoconference or by teleconference. As such, they were a showcase of the intra-organizational dynamics of decision-making, and of the organization's constant concern with the topic of the sustainability of the program.

As new communities were approached to join the service, I observed discussions about complementing KOTM's approach to telemedicine promotion with innovative tools such as the use of video vignettes documenting community telemedicine "success stories". At the same time, I was exposed to the every day operations of the organization, including the tele-training sessions with CTCs. These particular sessions gave me a sense of the level of commitment required on the part of the trainers to effectively communicate technical knowledge, and to adequately address concerns and questions coming from the communities through the CTCs.

4.3.7 *First Workshop: Community Health Representatives*

Prior to the beginning of my trips into the communities, and with the assistance of a KOTM staff member (the cultural liaison), I had an opportunity to gather impressions from community members (community health workers, and directors) and administrators of the telemedicine project regarding the challenge of expanding telemedicine service to all of Northwestern Ontario. Though the

attendance was not complete (not all community health directors could attend), the meeting served as an opportunity to discuss the level of meaningfulness that any research about telemedicine could ensure the communities. My presentation to the gathered was preceded by a brief card exercise centred on the objective of capturing the participants' expectations of research and researchers. Following the exercise, I explained my own research effort. During the discussion that followed the exercise and my presentation, participants suggested ways in which I could improve upon my approach. The ideas that emerged, and the fact that workshop findings were discussed during the workshop, allowed the data gathered to serve as a referent that guided me in interpreting new data.

This first opportunity to meet health care workers and authorities from the communities also gave me a glimpse into their apprehensions concerning the purpose my research (and my role as part of the evaluation). That is, I was confronted with questions about the “agenda” of the research, and with demands to provide evidence of how it would advance community interests. Participants reproached the absence of the rest of the researchers involved in the evaluation and were not satisfied that they (the researchers) were being represented by “a student”.

4.3.8 *Second workshop: Community telemedicine coordinators*

The second workshop consisted of a day-long workshop with the Community Telemedicine Coordinators (CTCs). A total of twenty four people, between CTCs and their “backup CTCs” took part. This figure, at the time of the workshop, represented the totality (100%) of the communities operating or

preparing operation of a telemedicine unit. The objective was to map the needs, opinions, and interests of the CTCs in order to understand “who does what and how”. The workshop involved the collective discussion of the expectations of all workshop participants, including my own, as a way to ensure that concerns were, at the very least, acknowledged and documented. This event also involved a visualization exercise for the collective ranking of practices and issues that the participants themselves identified as central to their work. The specific objectives of the workshop were to: 1) offer a space for CTCs to meet and to share their experiences on the job; 2) collect information needed for telemedicine evaluation purposes; and, subsequently; 3) to gather the perspectives needed for my research objectives.

The workshop took place in the context of a conference organized by KOTM in November 2004 and attended by Canadian Society of Telehealth members, as well as by representatives of Health Canada, INAC, North Network, and Industry Canada. KOTM had not initially contemplated holding a CTC workshop. Given that CTCs had little part in planning the event, as the initiative to hold a CTC meeting originated with CRaNHR and SEDRD, the objective of making the experience meaningful for CTCs was approached with a consultative strategy that involved holding a group exercise where the CTCs anonymously stated their expectations for the workshop through a visual (card) exercise. Participants summarized – in one idea per card – what topics or themes they wanted to spend their time exploring. These ideas were later used to steer further group work towards the meeting of those expectations that could feasibly be dealt in the

available time, and to propose an ongoing dialogue between CTCs and KOTM for addressing other issues.

Though the purpose of this event was to obtain the perspective of CTCs, it also gave CTCs a voice at a gathering that did not initially highlight them in the agenda. The workshop yielded information about how CTCs understand, plan, and execute their work as the local “experts” on telemedicine. See Appendices section for the *CTC Workshop Report*, which includes working questions, group exercises and results.

4.4 DIGITAL VIDEO AS A RESEARCH TOOL

Digital video was important in the gathering and analysis of information, both for my study and for the evaluation for which I was collecting data. The evaluation process looked to facilitate the collective analysis of information and findings, and for this purpose, it employed the skills of K-Net staff in the production of video vignettes that were shared on the web platform operated by KOTM. Video vignettes contained the “stories” that were emerging from the communities about their experiences with KOTM’s telemedicine service. I employed digital video in some of my own interviews with clinic staff and with members of the communities, and to gather images of telemedicine at work – some of which were used in the making of video vignettes explaining the evaluation process, as well in as demonstrating telemedicine. This made me an active participant in the expansion of telemedicine.

4.5 ANALYSIS OF THE DATA

It is important to emphasize that much time has passed since I carried out the fieldwork in 2004-2006. I have thus chosen to frame my study as a historical or 'hind-sight' analysis of a process I first documented then, and which I continued to monitor at-a-distance since. Given that the topic of my study is, after all, the *introduction* of telemedicine to First Nations communities under specific circumstances that remain in place, the initial impressions I recorded on the field remain valid as 'snapshots' of the process in an earlier stage of development – the introduction of telemedicine to additional First Nation communities from the original KO communities that founded KO Telemedicine. In this way, my re-encounter – through my notes and interviews – with the issues that surround the adoption of telemedicine allows me to analyze a particular stage in the still fresh history of this example of First Nations-run telemedicine.

When analyzing the data, the search for common themes was done in steps. Upon the transcription of recorded interviews and their first reading, I took note of the recurrent ideas emerging from answers to the questions that were in the question guide. For interviews where the question guide became less relevant, I followed the narrative provided and made note of the subjects that seemed to hold the most significance to the speaker. Afterward, I also took note of the recurrent and the new ideas each interviewee presented.

Several themes emerged, some of which were expected, given that many of the questions came from the evaluation framework with which I was working. These themes are presented in the Findings chapter.

4.6 LIMITATIONS TO DATA COLLECTION

4.6.1 *Community information*

The keys or codes of how communication flows in each community, as well as a correct appreciation of the importance (in terms of ownership and control) of what is being communicated and by whom, were not fully understood or known to me *a priori*. As an outsider and a “researcher”, I was limited by my lack of understanding of these codes. It was necessary to rely on the CTCs, as well as on KOTM staff, and on others in the communities, to reach and approach people that agreed to be interviewed. Visiting communities that have adapted to living and communicating in “two worlds” also created opportunities for confusion on my part regarding the proper forms for approaching different people in the community.

4.6.2 *Time frame*

In recording a ‘snapshot’ of the process of introducing telemedicine, this study is partially limited by its references to events that have since evolved in different ways. However, insofar as this study can be considered a ‘historical’ documentation of a process of innovation, it can contribute to a ‘qualitative’ baseline for analysis of how First Nations telemedicine has changed over time.

The data analyzed in this study was gathered primarily within the space of a year and a half, between July 2004 – during a week long ‘inception’ visit to the field – and March 2006 – in a subsequent four month stay in Northwestern Ontario in the context of work for Keewatinook Okimakanak Telemedicine. Since the data were collected, new developments have taken place in the areas

with which I was concerned. Since that time, the term ‘telemedicine’ (KOTM) has been adopted over the original, ‘telehealth’ (KOTH).

The time limitation on my stays in the communities, of less than a week, and the difficulty in returning to meet face to face with people with whom an interview had not materialized during my initial stays, meant that most interviews took place with clinic staff.

4.6.3 *Cross cultural communication*

Cultural limitations to analysis are expressed in the difficulty of accurately interpreting events across cultural difference. Being situated in ‘western’ values, I am not interpreting data from within. More importantly, perhaps, is the fact that the language barrier was a problem when attempting to interview people of more advanced age. There were instances where people were not entirely comfortable with communicating in English, or who did not feel at ease speaking with the help of a translator. These limitations were not present when interviewing clinical staff.

The local CTCs were generous in facilitating translation, in locating potential interviewees, organizing meetings with local authorities and in some cases, as introducing me to the community through a radio announcement or a community event. This assistance was crucial to obtaining access to people who otherwise it would not have been possible to meet, particularly elders and, in one opportunity, traditional healers. Yet, the translation effort of the CTCs – who are mostly younger people – was limited by their own knowledge of Oji-Cree, Cree or Ojibwe.

Aside from the unavoidable and more obvious language issue, there were other distances between myself and some of the people I approached or interacted with. It may be expected that during an interview with a “researcher” some people may feel compelled to give a certain answer. I cannot know if this was the case in my interviews, aside from deducing the meaning of reactions to my questions. Time was needed to create a minimum level of confidence and establish rapport with the interviewees, particularly with individuals who may have felt under the magnifying glass as health workers or under scrutiny in some way.

During the development of a context-specific “research protocol”, which was designed with the support of First Nations members of the KOTM organization, it was suggested that I share my interview questions ahead of time, with potential First Nations interviewees, to allow time for their familiarization with my intentions and the nature of my questions. This process determined that some times, due to traveling schedules, it was not possible to “wait” for the potential interviewees to accept or deny an interview. In only one case, and purely by accident, I was able to extend my community stay in order to conduct further interviews with interested community members (with whom I had held a ‘pre-interview’ conversation earlier during the visit). The end result of this situation is a low number of community-user (First Nations patients) interviews. This shortcoming, however, does not greatly impact my research, as the objectives centre on the people and approaches employed in the expansion of telemedicine.

4.7 LIMITATIONS TO DATA ANALYSIS AND THE CONCLUSIONS DRAWN

4.7.1 *Learning and generalizing from a “single” case*

While the number of communities I visited adds up to more than “a single case”, I consider that as *First Nations remote communities* in Northwestern Ontario they share a common set of challenges. In this sense, I find that academic reflexions on the generalizability of findings from a single case apply, in that First Nations communities face the same structural and political challenges. The data gathered represents, collectively, the First Nations remote community experience with the introduction of telemedicine.

The case study is not a unanimously accepted methodology. The more orthodox of social scientists question its scientific ‘worth’. Their objection to the case study rests on the idea that a single case cannot justify generalizations or serve to draw conclusions about similar cases, because these similar cases are not identical to each other or to the case being studied. Case study research is, in such perceptions, dismissed as incapable of offering transferable insights: they are viewed as static representations of particular – or unique – moments and places. A defense of the case study in response to this representation argues that it is precisely the uniqueness of a case which allows for new generalizable insights. Stake (2000) offers a clarifying response to this difficulty, arguing that it is necessary to, in the first place, concentrate on the particular case with no other goal in mind than attaining a “thick description” that allow readers with “interest in the case [to] learn more of it directly from the description, not ignoring comparisons with other cases [if these are possible] but not concentrating on comparisons” (Stake, 2000, p. 444, in Denzin & Lincoln, 2000). In other words, a

case study is the “observation of operations” in the case (Stake, 2000, p. 444, in Denzin & Lincoln, 2000) from which readers can learn and, if they so choose, find generalizable conclusions. While Stake (2000) outlines, through his typology of purposes behind the study of a single case, that there are many uses to a case study, he places the reader – not the researcher who must concentrate on providing a description and analysis of the case – as the final decision-maker with regards to the transferability or comparability of the specific elements of a case. In this sense, whether the case study objectives call for an *intrinsic* or in-depth understanding of the specific case, or for the *instrumental* purpose of providing new evidence – a ‘black swan’ (Flyvbjerg, 2006)⁶ – that can falsify an established claim and trigger the revision of theories, or whether the purpose calls for grouping cases into a *collective* study for understanding general trends, Stake (2000) points out that the first requirement is that the case or cases presented be accurate and detailed representations of specific, contextually dependent events. The advantage of the case study approach, and the basis from which, if so required, it can provide avenues for generalization, is the fact that it helps other readers or researchers “seek both what is common and what is particular about the case” (Stake, 2000, p. 438, in Denzin & Lincoln, 2000).

4.7.2 *Limitations of data analysis*

My goal was to document and analyze the “operations” in the introduction of telemedicine into First Nations communities. This was an exploratory study –

⁶ Flyvbjerg (2006) was citing Karl Popper’s analogy of the value of instrumental case study research to science. In this analogy, the assertion “all swans are white” would be disqualified by the proven existence of even a single black swan.

a case study – done as part of an evaluation project requested by KOTM and in which I took part as a research assistant. It is true that I did have the benefit of a ground-level view of the operation of KO Telemedicine, and had access to community perceptions about telemedicine. Furthermore, and this is key, I enjoyed the advantage of being introduced to many of the protagonists of this process in the communities and at KOTM. Because of this advantage, I generally had access to all “the right people” – those who were carrying the expansion of telemedicine forward: the ‘champions’ within the Band Councils, and in the communities themselves. This situation meant that in the eyes of the communities I would be associated with KOTM, who maintains good relations with its community partners. However, the fact that my access to the communities was controlled by others, the data I have, the amount and type of information that was accessible or that could be sought, may affect the scope and depth of the analysis of such data. The possibility that I could have employed videoconferencing more often to re “visit” communities for more data collection purposes, nonetheless, must be acknowledged. It remains a fact, however, that community visits – longer stays – are important when conducting an ongoing data gathering effort.

In analysing the data I opted to codify by “decanting” the basic factors or concepts that could be placed under clear themes that were corroborated through workshop consultations, where participants themselves drew collective interpretations of their statements. My data analysis contains much of my own interpretation as a member of a research/evaluation team, and a participant-observer at KOTM.

An obvious limitation to my data analysis is the fact that assumptions and biases accompanied my research and analysis processes. I gave, for example, equal weight to the different sources of data.

5. FINDINGS

As an initiative of Keewaytinook Okimakanak, the introduction of telemedicine into remote First Nations clinics can be described as an effort to advance the capacity of the First Nations to take greater control over their health care services. These findings focus on the capacity of a First Nations organization to contextualize telemedicine locally, ensuring that it acquires enough local meaning and relevance to be used effectively. That is, that telemedicine be successfully *adopted* rather than simply made *available*.

In summary, the chapter describes the importance of the cultural/organizational dimension in the introduction of telemedicine into First Nations communities.

5.1 LOCAL CAPACITY AND QUALITY OF CARE

5.1.1 *First Workshop: Community Health Representatives*

A first workshop, designed to discuss the evaluation from which this thesis emerges, was conducted with Community Health Representatives (CHRs) from the different communities engaged in telemedicine expansion. The workshop brought forth some of the major community concerns regarding the implications of introducing digital telemedicine. These ideas are summarized in Table 5.1.

It is necessary, first, to explain that the CHR is a well established component of remote community health care. In Canadian remote community health care practice CHRs are the articulators of a *holistic* approach to health care. In the context of First Nations communities, holistic care refers to care that

is responsive to the cultural needs, as well as the health care needs, of community users. In short, CHR supports the public health tasks of community-based health workers, which include prevention, education, and health research (KOTM, 2008).

It is also necessary to clarify that, when speaking of telemedicine, the term ‘users’ refers to those providing and those receiving tele-medical care.

Among the first CHR concerns to surface at the workshop was the fear that any cost savings resulting from telemedicine would eventually be at the expense of existing health care services, such as regular face-to-face consultations with a physician visiting and staying at the local clinic. At the workshop, CHRs asked (me) what guarantee KOTM could offer that any savings resulting from telemedicine – such as an averted emergency airlift to a hospital – would be subministered back to local health care. This was a question that surfaced among many community health workers during meetings between KOTM and other community representatives. Those at this workshop, upon hearing the phrase “costs versus benefits”, rejected it, condemned it, and instead proposed the phrase *quality of care* as the central theme of telemedicine expansion. It should be noted that this is precisely the stated mission of KOTM, and that KOTM staff show disposition to deal with this widespread concern. KOTM used the evaluation process, in this and at other meetings and workshops, to explain that it was not framing the expansion of telemedicine in terms of costs versus benefits, but was, instead, concerned with ensuring that any savings that could eventually be identified as the result of the implementation of telemedicine would be injected back into local health care (KOTM, 2005, personal notes). It is plausible

that this attitude of openness on the part of KOTM helped pave the way for the expansion of telemedicine into additional communities.

The following table displays the results of an intense discussion about what issues participants felt were most important when considering telemedicine as a health care option. The original “evaluation themes” I presented to the workshop – in representation of CRaNHR and SEDRD – were understood and agreed upon, with one major exception: the costs versus benefits theme, which had been reluctantly included upon the insistence of the funder as a final element of the evaluation of telemedicine in the first five pilot KO communities. This contested theme was immediately dropped. Participants gave emphasis, instead, to *quality of care*, a theme that was closer to the health care demands of the communities. The message clearly was meant for the funder soliciting hard data to justify continued telemedicine funding and expansion (Health Canada). The message is, to a lesser degree, also aimed as a reminder to KOTM that First Nations communities are clear about their basic expectations. What is most significant about this challenge is that KOTM took care to listen to the communities and to adjust the evaluation – which was needed to fulfill a contract requirement with the funder.

Table 5.1 – Community concerns (participants' ranking of issues)

Evaluation Theme	<i>Acceptability</i>	<i>Access</i>	<i>Integration</i>	<i>Capacity</i>	<i>Quality of Care</i>	
Community Concerns	Community Ownership	Community Ownership <i>(of resources and services)</i>	Community Ownership	Continuity <i>(decrease turn-over rate)</i>	Training <i>(of community health workers, to ensure quality)</i>	
	Confidentiality		Trust			
	Family Visits	Funding	Meaning <i>(local significance)</i>	New tools <i>(continue innovating)</i>		
	Education	Experience				
	Introduction to telemedicine <i>(Organizational support with capacity development)</i>	Physical Location	Community <i>(driven)</i>	Funding		
			NIHB <i>(Integration of existing services)</i>	Institutional support <i>(responsibility of the state)</i>		
			Language <i>(cultural appropriateness, translation of medical terms, procedures, and the clinical experience)</i>			
		NNADAP/NIHB <i>(integration of existing services)</i>				

The objection of community representatives to ‘costs-benefit’ criteria in the evaluation of First Nations initiated projects and services would resurface during conversations and some interviews with people in the communities. KOTM was working to facilitate a greater sense of community ownership over telemedicine, and in going to the communities learned of their concerns over the question of how to enhance what was already available. This effort showed KOTM the value that communities placed on face-to-face doctor visits, and on other health

services that it was feared would potentially be inadequately replaced by telemedicine. As one CHR who understood the advantages and limitations of telemedicine stated:

It has to be documented that [telemedicine] is not designed so that NIHB can cancel medical travel or physician visits to the community; [telemedicine] provides patients choice [...] to leave the community [and] travel out to see the doctor (Workshop participant, 2004).

KOTM was offered the idea that it work to ensure that any savings brought about by telemedicine would be reinvested in the communities. In effect, one of the ways in which such potential reinvestments were imagined was the improvement and development of local capacity in health care: First Response teams, CTCs, and other non-clinical services (Community health worker, personal communication, 2005).

Although it does not appear explicitly mentioned under the other themes, “capacity” was deemed so critical a need at the community level – considering the objective of improving health care – that workshop participants placed it as its own theme. Local capacity was identified as the principal mechanism to ensure acceptability of the service and the technology. In the same way, local capacity would also ensure the adequate integration of existing programs into the telemedicine option. That is, users will use the service because it is comfortable and inspires trust. In sum, local capacity was seen as the key to bring about a real improvement of the quality of care. In this sense, from a strictly health care perspective, local capacity is a critical area demanding urgent attention from all actors in the expansion of telemedicine.

5.2 FIRST NATIONS CAPACITY AND COMMUNITY ACCEPTABILITY OF TELEMEDICINE

5.2.1 *Second workshop: Community Telemedicine Coordinators (CTCs)*

The principal finding presented in this section is that local First Nations capacity is key to the acceptability of telemedicine among community members. Capacity refers to the individual skills and knowledge, as well as the conceptual frame (Kaplan, 1999), that enable and inform strategic or planned actions toward a set of – in this case – objectives related to the expansion of telemedicine.

This workshop was prepared for the twelve CTCs, and their accompanying “backup CTCs”, who were working at the time of data collection. This was the first time CTCs had been gathered in the same room. CTC perceptions about the skills and organizational support needed to introduce and promote telemedicine to the communities suggest that the CTCs are expected to become the “face” of telemedicine in the community, along with the nurses who live and work in the communities.

CTCs are in the unique position of being the best trained telemedicine users in the communities. They reinforce the training they obtain from KOTM, through regularly scheduled video and teleconferences, by creating peer to peer working relations as a complementary support network. CTCs exchange solutions to common challenges, such the technical aspects of the service, the medical terminology that is employed in telemedicine sessions, and help each other with the task of making the telemedical consultation a comfortable experience for local users. This task demands that CTCs are available and are able to answer questions, and know how to translate to local users, especially the elderly, key terms into Ojibwe, Cree or Oji-Cree.

CTCs prefer to solve problems collectively and ranked having access to more training and networking opportunities high on their list of tasks and needs. The following Table 5.2 reproduces the rankings on several of the tasks they themselves identified.

Table 5.2 – *Top ranked CTC tasks*

Rank	Task
1 st	Keep in regular contact with KOTM supervisor for reporting purposes. Communicate with other CTCs and KOTM for problem solving and training. Promote telemedicine through demonstrations (simulated consults).
2 nd	Make telemedicine consult comfortable to users: make it possible for family of user to be present; translate terminology (to Ojibway, Oji-Cree or Cree).
3 rd	Perform tasks to the satisfaction of physicians.
4 th	Attend educational and training sessions offered by KOTM over videoconference, and sometimes presentially.
5 th	Spend time in independent studying.

While participants felt that in terms of “importance”, reporting statistics to KOTM ranked first, they valued the resulting opportunity to contact each other through the network. CTCs are able to ask questions and solve on-the-job challenges. Other tasks ranked relate to investing time on the people that come to the consults, and in practicing with the equipment, and being ready to assist health care staff with its use.

This workshop provided the chance to learn about how CTCs actually do their job. One of the products of this workshop was a “wish list” that also reveals something about their on-the-job needs. In the last activity of the workshop,

though they did not rank these elements, CTCs discussed and grouped them into basic themes (which they named), and these were then discussed collectively. The results of this process are shown in Table 5.3.

Table 5.3 – CTC readiness

<i>Investing in People</i>	<i>Equipment</i>	<i>Basic Skills</i>	<i>Structure</i>
Promotion of telemedicine Communication People skills	IP phone	Ensured through certification	Full time hours More hours
Research	Technical support	Need ongoing training	More funding for position
Translating	Need more office space Need to have a supply of office materials	Writing and word processing Communication Maintaining up to date information	
More conferences		Being up to date on technology	

From the headlines of the above illustration it can be deduced that CTCs see their work as, first and foremost, encouraging the community's acceptance (trust) of the technology and of the telemedicine consult environment. Ultimately, it can be assumed that community users' trust of the telemedicine system as a whole can be impacted by how the CTCs perform.

Even without a ranking of these themes and their tasks, the topics and actions displayed suggest that CTCs feel that the certainty of a stable position – a dependable structure – helped them in performing their tasks, and in gaining the skills needed for performing them well. CTCs feel that without these supports,

they would be ineffective technical operators and, as a consequence, ineffective promoters of the service. This technical dimension is seen to be demanding, but not more important than having the capacity and support to deal with communicating with the community.

KOTM made a decision to employ CTCs on a full time basis in order to: raise the profile of the position in the eyes of potential CTCs and of potential users of the service; build trust in the service; and, as an added possibility, make a long-term contribution to the local economy. As a result, there has been a gradual recognition, and a gain in visibility, of the CTC as promoter and facilitator of telemedicine. The strategy of reinforcing the CTC position from a planning point of view (by KOTM) in this way is aimed at making telemedicine more accessible and acceptable to the communities. The CTC is valued, furthermore, as an additional human resource in the remote clinic, and as a dedicated resource for the customization (cultural adaptation) of health care⁷. Although many Chiefs and Councils made the decision to bring telemedicine into their communities, community members do not immediately or automatically become aware of such a decision. The community member who becomes the local CTC, therefore, is the first 'in' that KOTM, and the technology, have with individual community members.

Existing analysis of the importance of CTCs to the success of telemedicine offers a clearly defined set of tasks that should be handled by a community-based telemedicine 'expert' (see: Jennet, 2003). These include, promoting use of the

⁷ KOTM views the CTC as a direct, link, and 'local expert'; an investment in developing community level capacity. KOTM, thus, makes use of the videoconferencing function of the telehealth equipment – as well as the digital telephone – in bi-weekly tele/video conferences for 'training' and discussion.

telemedicine option, and ensuring that telemedicine is integrated 'into existing practice' (Jennett, 2003). The tasks that CTCs are expected to perform in a conventional (non-First Nations) telemedicine setting, however, do not contemplate the *value-added* services that CTCs in remote First Nations communities are both asked to perform (by KOTM) and those that they have begun developing on their own, through practice, through sharing with their peers/colleagues, which address more the specific contexts in which they work (how to translate medical terms, how an 'open house' went, etc.). CTCs channel community feedback (on a semi-structured basis, in pre-scheduled conferences or through questions to KOTM or to other CTCs before or after consults) for program improvement back to the telemedicine provider: demands, questions, impressions derived from their – and the patient's – own experience with the technology and with the system.

At the introductory stage of telemedicine, CTCs spend time in after hours activities, such as conducting 'open houses', attending community events to promote the services that are offered, escorting patients and assisting other community health workers in home visitations, making use of the local radio station to advertise telemedicine, and time spent at the clinic, also after hours, helping nurses acquaint themselves with the technology, in addition to attending meetings, etc.

The CTCs acknowledged a wide net of supporters in the community and beyond. Among many others, CTCs mentioned: members of their family; patients themselves – in terms of their willingness to take part in telemedicine; Community Health Representatives; the scheduling staff at KOTM; Chief &

Council for being accessible and willing to take part in demonstrations; Nurses, for offering their time, facilitating books and manuals of medical terminology, as well as their moral/emotional support; Physicians, for helping the CTCs feel comfortable in the telemedicine consult; Elders, who are important to them in a much larger sense; K-Net technical staff, and their back-up CTC. CTCs also valued the support of the Regional Telemedicine Coordinator (at KOTM) and of KOTM staff in general. The close involvement of the community, as well as that of KOTM staff, is clear from this list of supporters. What is also clear is that CTCs talk to a wide variety of community members and administrators in the telemedicine system.

At the introductory stage of telemedicine, however, CTCs generally expressed some concern over what they perceived was a gap in how their job or position was understood by those technically and administratively responsible for telemedicine. They see themselves in a process of learning through action, something that is created 'on the job' (CTC workshop, November, 2004). CTCs are the bridge between each community and KOTM staff. KOTM asks them to share information with the community and with health providers and the CTCs tend to take initiative in gathering community feedback about the service. While it would be difficult to say that all CTCs put forth the same level of commitment to their functions, it is clear that they do help KOTM in its effort to reach community members.

5.3 KOTM DATA ON TELEMEDICINE USE

5.3.1 *The importance of demonstrating usage: Top uses of telemedicine in pilot communities.*

KOTM, with the help of the CTCs, collects usage data and compiles monthly statistics, which are advertised on KOTM's website. This information is meant to be seen by anyone, but it is gathered in part to show funders and users that demand for the service exists.

Data collected over the first three years of the pilot phase of KOTM shows that the top three uses for telemedicine between the years 2002 and 2005, in the five pilot communities of the service, are: psychiatry, diabetes, and family medicine (KOTM, 2005, personal notes). The frequency of use, put into perspective by the size populations involved, shows that the number of people using these services grew with time. It also shows the types of health issues communities face, which the literature identifies as characteristic of remote First Nations.

5.4 INTERVIEWS

5.4.1 *Nurses: Local capacity demand compels new relationships*

Even at the early stages of telemedicine implementation, new relationships form to address the communication challenge of appropriating the technology. As has been documented in evaluations regarding the impact of computers and the Internet in First Nations communities (Ramírez, et al., 2003, p. 35), telemedicine creates a space for the exchange and development of skills and the sharing of

information. In the telemedicine setting, flow of information and skills development are conducted within an organizational structure that links communities through a local resource-person under centralized supervision: the Community Telemedicine Coordinator (CTC). Nurses were, in effect, advised by their supervising body, the Sioux Lookout Health Zone, that they were to help the community attain full ownership over the service by helping the CTCs become the 'local expert' (Personal communication, December, 2004).

CTCs complement their on-the-job experience by using the technologies at their disposal to support and reinforce their own learning. The CTCs are based in the remote clinic, but are linked to a digital network – digital phones, the videoconferencing function of the telemedicine unit – that, aside from enabling them to improve their skills in operating the technology, allows them to visit each other regularly and to rapidly establish an informal 'human' network. CTCs trouble-shoot technical issues, ask questions of each other about how to perform specific tasks – such as reporting to KOTM and filling out forms required by KOTM or its partner organization, NORTH network⁸ – but they also discuss personal matters as friends and share their ideas and proposals. This network has become an informal, but still working environment for flexible, peer-to-peer learning and a space for communicating and innovating. It is thus more than an on-the-job support tool and more than the pre-scheduled bi-weekly meetings for gathering community feedback.

Emerging relationships in the remote clinic form and expand around the presence in the clinic of the local CTC. Everyone involved with telemedicine in

⁸ The private network, based in Toronto, Ontario, to which KOTM connects for access to doctors and specialists.

the clinic must deal with the CTC. CTCs, however, are not confined to the telemedicine unit. In the clinics, where demand for the time and resources of the nurses at times overcome their capacity to respond, the CTCs take on various supporting roles. While in the clinical frame the CTC acts as a facilitator between community users and the health care provider, usually a physician or specialist at a hospital hundreds of kilometers away – in practice they also serve as a much needed extra resource for both the clinic and the community:

[The CTC] has already given us a list of [telemedicine] education things that are going on. I've taken a look at it, I've hung it here in the office and so far, this month, it seems to be basic first aid, which doesn't help us, but I'm hoping there's people like the First Responders, and the crisis teams, and the firefighters, that'll be great for the people in the community to get in on it. And just even people who have an interest of maybe getting a First Aid, like your people [KOTM] working in your Healthy Start program, your Baby's Healthy Start programs, you know, people that get your basic First Aid stuff (Nurse, personal communication, December 2004).

The main task of CTCs in remote community clinics that are being introduced to telemedicine could be broadly described as overcoming communication barriers in the promotion and operation of telemedicine (Whitten, et al., 2005). Among the specific job tasks for which CTCs are responsible is the preparation of the telemedicine equipment and the telemedicine room for the consultation. Most importantly, CTCs also work with the local nurses to prepare the individual requiring the medical consultation. This last stage may demand any of the skills CTCs have or are developing for the *cultural* acceptability of telemedicine – the cross-cultural communication dimension of the promotion and performance of telemedicine consultations. In the specific case of the telemedicine consult, the skills demanded would include

translation of the entire process from English to Oji-Cree to the patient – to the extent that their mastery of Oji-Cree allows. Additional supporting roles include the escort or accompaniment of individuals from their homes to the clinic and back or, in cases of emergency, driving the ailing persons to their emergency ambulance-flight.

5.4.2 *The CTC and the nurse*

Nurses – most of whom, at the time of the interviews (2005), were not First Nations, but had lived in the communities (the clinic or nursing station’s attached housing unit) an average of close to two years – were in general excited about telemedicine, and happy to be able to rely on CTC. From the moment that telemedicine arrived, they facilitated the new working environment which helped to gradually integrate telemedicine both physically – in reduced spaces, including converted toilettes and closets – and operationally, through the gradual increase in the number and types of telemedicine consults in which they participated. The perception they have of CTCs is rather favourable, but revealing of an aspect that was not immediately obvious to me, as their interviewer, from the start. As one nurse remarked: “we don’t need them [CTCs] around all day, but we appreciate that [they] want to learn from us” (Nurse in Charge, personal communication, January, 2005). Their level of acceptance of telemedicine can, therefore, be described as ‘high’. It is difficult to imagine, however, that nurses would be critical of the arrival of the CTCs, considering their importance to KOTM as both a new human resource and a new local employment opportunity. Nurses are without exception rather extremely busy people. Yet, they have grasped the

significance of the CTC, and of telemedicine as a whole, quickly. However, nurses did not immediately take to telemedicine as a new means of communication with their peers in other communities, preferring to continue to use the phone on their desks. Still, at the early stage of implementation, nurses were taking part in a few teleconferences and videoconferences per month, with their Health Zone supervisors (not with KOTM). It could be expected, given the initial favourable reception nurses gave to telemedicine, and all that came with it, including the CTCs, that nurses and CTCs (and through them, KOTM) may find many opportunities to innovate in their working relationship in yet unpredictable ways, but always in mutual support.

CTCs are responsible for training the nurses in the use of the telemedicine unit. This training is necessary to guarantee patient confidentiality in situations where non-medical professionals cannot be present. In such cases, the CTC only prepares the connection and the equipment for the consult.

The issue of patient confidentiality has been raised in relation to the telemedicine units themselves, in the sense that physical space (room) in a remote clinic is a scarce commodity in high demand. Most remote clinics consist of a small waiting area, a few shared offices, an examination/emergency room, a washroom, a kitchen/staff room, a closet or storage space, and a visiting physician guest room. Telemedicine means that, given the limited budget and waiting lists in place for the expansion or re-building of remote clinics, one of these spaces is going to be taken up with the telemedicine unit, independent of its suitability to meet telemedicine standards: doors that cannot be locked; privacy;

enough space for the CTC, nurse, equipment, and the patient; proper connectivity; proper 'telemedicine blue' paint for adequate illumination.

Such changes in the spatial distribution of functions within the clinics, at least for the foreseeable future, are permanent. In one community, a washroom was converted. In another, the storage room. In general, there is enough space that can be re-dedicated to ensure the minimum comfort necessary for telemedicine consults, but the issue does re-surface when family members are involved in accompanying patients in their telemedicine experience.

Nurses responded well to their training by the CTCs; they expressed no inconvenience in making time for their training. Most are very excited about having access to the telemedicine units, as they unequivocally understand the advantage of not having to verbally describe the conditions of their patients in order to enable the physician at the other end to sufficiently grasp the situation at hand in order to make an appropriate judgment⁹. Nurses do prefer to have the CTC deal with all of the technical details of telemedicine consults. They state that worrying about such details is impossible given the time and human resource constraints characteristic of the remote clinic.

The relationship that emerged at the early stages of the introduction of telemedicine between the CTC and the nurse was a complementary one, as it developed around the work of keeping the health of patients with chronic problems, and in the task of consultations and follow up consultations for non-emergencies. CTCs aid in making the visit to the clinic an efficient process that

⁹ In the absence of telemedicine, when insufficiently clear about a situation, a doctor must opt to have the patient undergo tests, which may involve the transfer of the patient to a hospital, by air, at a significant financial cost.

frees time for the nurses. In regards to this new advantage, nurses invariably state that any time saved – when other priorities or situations do not intervene – is needed for their intended role in the clinic: to be public health nurses working on health maintenance and prevention rather than on the handling of chronic health problems and frequent emergencies:

[Telemedicine] decreases the time I have to dedicate to arranging travel bookings, straightening out schedules, re-bookings, arranging escorts... our hands are in that quite a bit. Now with the [telemedicine], it's also easier for me to fill out a form and give it to [the CTC to take care of] (Nurse in Charge, personal communication, February 2005)

Well, since it's all come in [the equipment], I've had very little to do with it [...] It's just exclusively the CTC [...] and there again, unstable nursing population... How many nurses are you going to train? (Nurse, personal communication, January 2005)

I find that our [telemedicine] coordinators are quite handy at it. I personally find it a bit difficult... it's become more the coordinator's baby, and I just come in when there is a session in progress that requires confidentiality [...] I find that the person that helps me all the time with it is the [telemedicine] coordinator (Nurse, personal communication, December 2004)

The uncertain terrain of remote health care would appear less so with the introduction of telemedicine and the community-based CTC. Nurses, particularly those in the position of Nurse-in-Charge, are privileged participant-observers of the local health care situation. They have, like few others, a clear sense of the possibilities for telemedicine without a constant and reliable CTC presence. Nonetheless, the nurses remain firmly in charge within the walls of the local clinic.

The involvement of the CTC in the clinic produces change in the dynamic of space use, demanding that nurses give up some of it, for the CTC and for the equipment, something to which they pose no explicit or direct objections. There are only some concerns that are expressed in a half-kidding manner: nurses do not want telemedicine to *become* the clinic – to ‘take over’ the clinic. This reaction, though not generally expressed in the interviews, may hint to an underlying difference in the vision nurses have for the CTC and telemedicine – both of whom they welcome. These impressions suggest the possibility that as First Nations communities continue to develop local skills, remote community clinics will see more changes.

5.4.3 *The CTC and the community*

The CTC has also been recognized as a key factor in communicating local demands and feedback to KOTM. I have mentioned the bi-weekly meetings in which CTCs, as a group, speak with their KOTM supervisor to share, in a semi-formal videoconference environment, issues around the quality of services offered (Personal notes, 2005). In this way, the CTCs help KOTM ‘customize’ the service it delivers. The constant and intensive communications involved in preparing telemedicine consults, in reporting them, and in gathering community-level data and feedback about them, for example, allows for continuous observation of the community response and, as a consequence, for reflection that can lead to innovation. Prior to the introduction of digital communications media – the videoconferencing and teleconferencing capability currently in place – such a possibility was simply non-existent. Assuming that few innovations can result

from isolation, the new relationships that telemedicine facilitates are important to consider. It is to be expected that as telemedicine use grows, so will the level of community awareness about its advantages and shortcomings. The development of local expertise with telemedicine is thus viewed as a way to meet local demands.

CTCs are engaged members of their communities. Like other local health care workers, CTCs find themselves sometimes helping their own or extended family at the telemedicine consult. Some make frequent use of the local radio station, where/when available, proved to be an important forum and source of information, particularly the older generations, who take on much air time to converse and share stories. The situation of the local economies, marked by dependence, in many (if not all) cases, on federal transfers (bloc funding for the Band) also make the CTC position a valuable as new employment. Interestingly, at the time of my visits to the communities most CTCs were young women. Employment opportunities are rather difficult to create in the North and the option of working for KOTM, either as a CTC or a 'back up CTC' is welcome.

In the telemedicine experience of Northwestern Ontario, the CTC is the undisputed articulator of the process of innovation with the technology in the remote clinic and in the community:

There is more than just a technical role for the CTC to play. [The CTC] has to sell [telemedicine] to the community so the community feels comfortable using [telemedicine] here ... as being equal to [seeing a physician] in Sioux Lookout and doing the same process (Nurse-in-Charge, personal communication, February 2005).

The CTC helps KOTM manage the gaps left by the combination of limitations in connectivity and the scarcity of specialists available to attend health needs. The importance of this aspect of the ‘intelligence’ work performed by CTCs is further evidenced by the fact that KOTM has a permanent position in its staff for a Community Liaison, a position occupied by a knowledgeable First Nations staff member with connections and relationships established in most communities.

Though community members, in familiarizing themselves with the technology, are the ones who redefine telemedicine, the CTC plays a critical part in facilitating this process of familiarization and appropriation. Almost without exception, everyone involved in telemedicine in Northwestern Ontario – from nurses to community health workers – identifies the CTC as the key articulator of its appropriation in the communities. Between the later half of 2004 and the start of 2006, the CTCs had handled over 1,200 telemedicine consults, among a total of twelve communities – the first expansion communities and the original five KO communities, the majority of which have populations of under four hundred (KOTM internal records, March 2006).

In the introduction of telemedicine into the remote clinic setting, given the small size of the local populations, and the number of staff at the clinics/nursing stations, the Community Telemedicine Coordinator becomes more than the technical support instrument for the smooth operation of telemedicine.

5.5 EMERGING STRATEGY

5.5.1 *Strengthen First Nations capacity in communication*

The First Nations vision for telemedicine has its focus beyond the technical advantages of telemedicine:

The most visible part of this process has been the technology – delivering, installing and testing [telemedicine] workstations and building a private and secure network. But healthcare really is all about relationships and KO Health Services has been working hard to make sure that [telemedicine] has a human face (KO, 2002b)

The above quoted statement can be understood as part of a strategic approach to the long-term vision of First Nations control over matters that affect them. In this case, the statement specifically refers to making the telemedicine experience and its content culturally appropriate, which is not a minor aspect of the larger vision of First Nations capacity to exercise control.

For diverse reasons, the elderly are a difficult to reach segment of the First Nations population. While KOTM often highlights the benefits of telemedicine for those who are less mobile and in need of constant care, it is faced with the difficulty of overcoming different barriers that hinder their access to telemedicine. A major barrier is language. CTCs have adopted various methods of communicating to the elderly population the existence and benefits of telemedicine: announcements on the community's radio are a popular option. Home visits alongside home care workers are another. But, in spite of their best efforts, in many cases to the language barrier must be added the health status and reduced mobility of elderly community members.

There is awareness, among those involved in the work of telemedicine, about the potential of the “communicative dimension” (Thesis advisor, personal communication, 2008) of the videoconferencing side of the telemedicine unit to facilitate the search for new ideas and solutions to emerging issues (Ramírez, et al., 2003). In effect, the organizational capacity to manage the *customization* of services and, thus, the technology, constitutes an expectation in the First Nations understanding of telemedicine.

As the communities become aware of telemedicine primarily through the work of the CTCs, its significance begins to take form, as people begin to ask questions. One of the first queries with regard to telemedicine, once people have ‘seen’ what it can do (how effectively a ‘patient’ can be assessed by a doctor), was whether or not the doctor would still come to the community. While such questions are not entirely answerable at the pilot project or expansion phases, KOTM assumed them as real concerns and attempted at different times to address the issues directly, on behalf of the communities, with its funders, informing the communities of such efforts directly.

5.6 EMERGING ISSUES

5.6.1 *Learn about and address remote community concerns early and through official channels*

Questions or comments about the significance of telemedicine for existing services were common at the community level during the introduction phase of telemedicine. Will telemedicine mean the end of doctor visits to the community?

In the “expansion” communities, particularly where telemedicine had not yet been put to use, or had not yet arrived, this concern was voiced by people in positions of community leadership. As regularly explained (to me) by staff at KOTM, such worries are normally handled by KOTM, and not by the Community Telemedicine Coordinators. I did not encounter situations in which the CTC, as the “representative” of KOTM in the communities, had to answer such concerns. These concerns, which were widespread at the time, surfaced at consultative workshops, during some of the interviews I conducted with clinic and Band Office staff, and during informal conversations held during my community stays.

5.6.2 CTC Roles: Strengths and vulnerabilities

We have a lot to do here, what [KOTM] tells us, and what we know we have to do to promote the service and to make it work for the community (CTC, personal communication, January 2005).

The risks and opportunities associated with the CTC role are related to other community components of the proper functioning of telemedicine. It has been shown thus far that the CTC is at the centre of the community’s participation in the telemedicine system. Thus, in terms of the strengths of this ‘position’, it can be stated that the training of CTCs by KOTM make for a hard-to-replace investment. In effect, KOTM’s move to ensure full-time employment status for its CTCs is a move designed to strengthen the appeal that the organization already managed to generate around telemedicine as an interesting employment opportunity for people in the communities. Aside from this, KOTM is logically concerned with retaining CTCs as an investment that they can continue to

develop. Within the community, therefore, there is no other person capable – or certified (by NORTH Network as well as by KOTM) – to occupy this role. From a community relationships point of view, the strengths of the CTC role can be said to be derived from both the support they receive and from the perceptions that community members have of telemedicine. In this sense, CTCs are *relatively* isolated from internal disputes between ‘factions’ or other fissures or situations within that might otherwise affect their performance. I highlight that, in some communities, having the express support of Chief and Council is not necessarily a guarantee of – or precursor to – community acceptance.

The CTCs can be said to *help* advance First Nations control over health care and over the definitions and approaches to health care. This is a statement about the limitations of the CTC role, but also about their importance as a way to bring telemedicine to the communities. As an extra resource in the local clinic, they are indeed very valuable, considering the situations remote clinics have to deal with:

... [in the community we have] fifteen cases that should be monitored daily... they are teens with suicidal tendencies ... even teleconferences for case management as proper assessments are required... [and these are being provided more or less as needed] ... Medication can provide some relief... and a lot of times we miss [don't have] the tools that we can use to address [the effectiveness of treatment] ... they can create social problems [the mentally ill], like gas sniffing and drug abuse. If they could be assessed at an earlier stage they can become normal to an extent that they can be productive members of the community... Through telepsychiatry... in a single day [more patients can be seen]... Sometimes we wait up to six months and that's not helpful... sometimes we wait longer than eight months (Community Resource Worker, personal communication, 2006).

Current or future ‘vulnerabilities’ of the CTC aside, it is useful to remark that KOTM continues to offer education and training sessions through

videoconference – at times even in the context of a working/social gathering in one of the northern ‘hubs’ – to their community link, “which are really popular” (Personal notes, teleconference with KOTM and Health Canada, 2005).

Nevertheless, some risks exist at the start-up phase of the introduction of telemedicine. Relying on CTCs to familiarize community users with the system has some risks that are mainly associated with the issue of patient confidentiality. In communities of small population size, CTCs are likely related to many people or they will know many people. The challenge for the system is to ensure confidentiality during consultations, but also to address such concerns from the perspective of community users who are seen making use the services.

Other concerns regarding CTCs are related to the availability of people in the communities who are willing and able to take on this task. Ensuring that CTCs are well trained and will want to stay in their positions is part of the challenge of making telemedicine work in the communities.

6. ANALYSIS & DISCUSSION

PIONEERING FIRST NATIONS TELEMEDICINE

In this chapter, I take a comprehensive approach to the analysis of site-specific data: I interpret KOTM's role in pioneering a 'First Nations telemedicine' system and identify and analyze the new relationships for innovation that materializes at the local level (in the remote clinic and in the community) with the introduction of telemedicine.

6.1 KOTM: PIONEERING FIRST NATIONS TELEMEDICINE

The introduction of telemedicine into remote First Nations communities by a First Nations organization is an effort to develop an effective use of the technologies involved. In this sense, it can be argued that the most important likely result of this process is the emergence of a First Nations approach to telemedicine that "fits" with the needs and demands of First Nations peoples.

The immediate or most evident objective of the introduction of digital telemedicine services in First Nations communities was the necessity of recognizing and acting upon local health priorities (Fiddler, nd), many of which draw and require urgent attention given the disproportional impact of health issues affecting the First Nations in relation to the rest of the population of Canada (Pong, 2002). There is room here to add an interpretation; responding to urgent priorities makes the goal of "improving access" to quality clinical care a matter of necessity rather than long-term strategy.

6.1.1 *First Nations control: Doorway to “effective use”*

The First Nations can be said to exercise real control over digital connectivity by virtue of contractual agreements with satellite communications providers. These agreements have ensured First Nations access to dedicated frequencies, which carry telemedicine services to the communities. Having established control over connectivity has had a symbolic value for KO, but it also has a concrete value in that signifies a certain degree of independence or freedom from external intervention – at least in the virtual territory of digital communications. In this sense, K-Net’s securing of satellite connectivity sets a landmark in the advancement of First Nations led innovation as it reduces a dimension of First Nations dependence upon the Canadian state: infrastructural dependence on public funding. As KOTM builds partnerships with private communication networks, it is able to gradually increase its control over the development of local capacity.

The issue of control, in a health care context, surfaces with the arrival of telemedicine as an opportunity to discuss a new possible future for health care in the communities. In a way, community leaders, as well as many patients, are experts in the Canadian health care system. Particularly in the case of the former, in cases where some have been involved in negotiating funding for health care needs, there are ideas as to what needs to change or what could be improved: “I know more about health care than I know about [being] Chief” (Chief, personal communication, February 2005). Telemedicine opens the way (creates an opening) for a more detailed role for the communities in identifying needs and shaping health care services.

6.2 EFFECTIVE USE MEANS 'VALUE-ADDED' TELEMEDICINE

In earlier sections, I presented my understanding of how CTCs contribute to raising community acceptability of telemedicine. I showed that CTCs 'add value' to telemedicine by becoming skilled telemedicine operators. They add value to the telemedicine consultation by making it acceptable to community users. They add value by working to make telemedicine known in the communities as a good thing – an option that is flexible and versatile, in terms of the videoconferencing capability of telemedicine, which allows for family visits and other important communication. CTCs employ the “open house” strategy in promoting telemedicine. They promote the service through prepared demonstrations that take place regularly. CTCs perform a defined function in actual medical consultations. They learn new skills that then they put to use in their jobs. As a major human resource for telemedicine, CTCs are helping the First Nations-run telemedicine programme gain experience and improve. The CTCs demonstrate that developing local capacity is critical to the success of telemedicine in First Nations communities.

The findings presented earlier emphasize the importance of human relationships in the appropriation of telemedicine by the First Nations. The findings highlight a communication process rather than the advantages of an ICT application that 'enables' communication. To be precise, while the technology enables communication for innovation, the findings address more directly the emerging roles and new relationships that the introduction of telemedicine helps build within the remote clinics, the communities, and among these and KOTM – the organization that supports this process. While the findings do not provide a

definition of what First Nations telemedicine 'is', they do bring together examples of new human/cultural relationships with the technology that transform some of the traditional roles within the rural clinic.

The findings show a process of interpretation or translation of the symbolic meaning of telemedicine; witness KOTM's insistence, in the face of state bureaucracy, that CTCs are as important as the telemedicine equipment itself. The CTC was identified by nurses and by community members, as a key resource in making telemedicine politically and culturally acceptable to the communities. Politically, in the sense that KOTM is a First Nations organization that is putting within the reach of First Nations communities the possibility of tailoring telemedicine to their needs, while investing in building local expertise in the communities. In the aggregate, KOTM is contributing, as is the K-Net experience, in generating a new pool of skills and knowledge for further innovation and spin-off activities, such as helping other organizations and communities achieve a similar situation. Thus, KOTM has the potential – and even the vision – of making what in the literature is called the “extensive” or creative use of ICTs, rather than limiting itself to the passive adoption or “intensive” use of ICT for clinical health. Likewise, the CTC makes telemedicine culturally acceptable, because the CTC's job is to ensure a comfortable and appropriate environment within the walls of the clinic, as well as to channel community demands to KOTM. In this sense, the findings illustrate certain conditions that differ from those that created the remote clinic. KOTM and the CTC represent a new plausible future: the emergence of a First Nations health care system from the *appropriation* of telemedicine rather than its uncontested adoption.

The technology end of telemedicine – the digital network itself – presents some obstacles that KOTM has been working to mitigate. Bandwidth restrictions – the time and space available for ‘quality assured’ telemedicine events over broadband or satellite – make connectivity with specialists and physicians at hospitals a matter of careful planning. When a meeting is booked, the booking is understood as a ‘window’ of opportunity that must be used at that specific allotted connection time. Telemedicine units across the northwest of Ontario must connect with telemedicine units in hospitals whose connectivity may be under considerably more pressure (demand) than that at remote clinics. Competition for bandwidth is, therefore, not limited to the communities themselves, nor is it limited to the actual availability of ‘space’ for transmissions. The ‘human’ factor of connectivity – availability of scarce resources – is another relevant element. On the ‘human’ end of telemedicine, re-scheduling telemedicine consults is challenging and frustrating when physicians and specialists are already stretched in their availability. Additionally, at the time of the interviews, consultants, government representatives, and the doctors and KOTM staff themselves, made evident their concern that few health professionals were involved or keen to take part in telemedicine, for various reasons, not excluding the lack of a protocol for ‘adequate’ compensation¹⁰ (Personal notes, 2005). The technological and ‘human’ context has meant that CTCs are obligated to make sure that patients ‘show up’ for booked appointments (Personal notes, Evaluation Committee Meeting – KOTM, 2004). In a meeting that took place

¹⁰ It appears that the concern of some physicians was that a ‘telehealth visit’ to a community should be compensated in the same way (to the same amount) as a non-telehealth ‘face to face’ meeting with a patient.

between KOTM, NORTH Network, and Health Canada, concerns raised touched upon geographical distance as an issue that, in spite of telemedicine's communicative advantage still manifests itself: that of time zones. Though this latter concern is not overly dramatic in northwestern Ontario, there is a one hour time difference that separates the Western from the Eastern area of the region. The issue is that telemedicine consults must fit into physicians' availability, and a one hour time difference may signify some level of risk in terms of scheduling. As a result, there may be a need to establish a clear reference point, such as 'all times EST', for all specialists involved, whether they are connecting from Ontario or Manitoba. There are many roles involved in the telemedicine consultation, but the telemedicine consult event in the clinic finally depends on the CTC's preparedness and availability. The CTC must be available and ready at all times.

6.2.1 *The human dimension of telemedicine: Building new relationships for sustained effectiveness*

Emerging relationships in the community clinic, as well as in the communities themselves, following the introduction of telemedicine by KOTM and the CTCs, are creating a new environment for innovation. New capacities are needed, collaborative innovation and knowledge sharing is taking place, and as a result of this changing environment, the conditions for innovation and *action* are beginning to materialize.

CTCs are the networked local resource that links the communities to new sources of information and knowledge. KOTM is able to take the pulse of the

communities and monitor their experience with telemedicine, as well as learn of their demands. The growing importance of the CTC, and of telemedicine, within the clinic is complemented by good, supportive working relations with the community clinic nurses. The CTCs are able to then confidently explain and promote telemedicine as a health care alternative among the population. In this way, CTCs build community acceptance of the change, send community feedback to KOTM, and create favourable conditions for community members to make use of, and feel comfortable with the service.

Keewatinook Okimakanak Telemedicine is a unique case in the Canadian health care landscape because, as a First Nations organized and administered system, it represents the possibility of re-framing telemedicine beyond the “intensive” role – the existing clinical practice – normally assigned to telemedicine. The findings suggest that through a coordinated and community oriented strategy for its use, telemedicine can become Aboriginal or, more precisely, given its context, it can be 'customized' to meet local needs.

This concluding chapter discusses in a general, but integrated manner the potential implications of the KO telemedicine experience in relation to the principal themes emerging from the findings and the literature.

6.3 COMMUNICATION FOR INNOVATION

My findings describe how telemedicine was presented to remote communities following its successful introduction, by a First Nations organization, into five pilot communities. In this sense, I am not describing a process of diffusion – something that happens organically and which is difficult

to map out. Instead, I am presenting findings on the communication strategies and tools employed at the organizational and local community clinic level, to introduce and begin integrating telemedicine into the health care of remote communities. In this way, the findings relate the emergence of new relationships, new roles and functions, which were developed through the sustained and close support of KO Telemedicine (KOTM), the primary organization responsible for managing telemedicine for the First Nations in northwestern Ontario.

6.3.1 *Capacity to innovate*

Contrary to patronizing beliefs regarding the capacity of ‘traditional societies’ to organize themselves, and to innovate, the First Nations in Northwestern Ontario, in establishing the foundations for a First Nations run telemedicine system, provide an example of such innovative capacity. Since the ‘snow machine’¹¹ (snowmobile) and through to the Internet, the First Nations have been adopting, and adapting, ‘modern’ technologies to address their specific needs. The process of adoption of telemedicine shows through in the strategies employed by the First Nations to include local voices in the improvement of services, and is yet another example of the innovative capacity of the ‘traditional’ inhabitants of this region. To borrow an interesting expression, the First Nations are adept at “stealing [the] fast horses” among modern technologies (Leclair & Warren, 2007, p. 5). That is, the acceptance of a technological innovation does not signify the capitulation of conscious identity. To the contrary, it may even serve to reinforce it.

¹¹ Name given to the ‘snowmobile’ in northwestern Ontario. Comment made by Dr. Ricardo Ramírez (Personal communication, 2006).

6.4 DIGITAL VIDEO

Digital video has become particularly important to online communication. It is already critically important to digital telemedicine. In the context of the remote First Nations of Northwestern Ontario, the integration of video into existing web platforms (hosted by KNet), such as KO's internet highschool or the thousands of personal webpages, was a logical step. In the same way, telemedicine could only *go digital* and audiovisual.

An advanced telemedicine unit is made up of a central processing unit (a computer), a television screen (monitor), a digital videoconferencing unit (a digital camera that can be remotely controlled), and "peripheral" medical diagnostics equipment, all connected to the central processing unit (CPU). This central computer is connected to a secure broadband port, which transmits voice, video, and other electronic data – such as a pulse or a heart beat – in "real time" (as it happens) to another CPU. The receiving CPU then displays, for the physician doing the diagnosis, all of the information that the peripheral equipment earlier referred to captured and transmitted. Digital video capabilities, thus, only in part define telemedicine. Digital video, however, is also a separate element that can be used on its own, such as is done by millions of people when they record for posterity various events in their lives, such as birthdays and holidays. Digital video is inexpensive, easy to use, and easily shared over the Internet and easily edited on a computer with the adequate software (some of which is available free of charge, over the Internet). But returning to the subject of this study, digital video can be used as a strategic tool for the introduction of innovations. As an ICT, a digital video camera can serve as a unit for the capture

or documentation of information and knowledge. As such, it can serve as an educational tool, through its capacity to store and to reproduce captured (recorded) information. Canada boasts many examples of the use of video generally (decades before digital video was around) as an aid for the communication of community demands to political authorities. Digital video cameras can be employed to record and edit messages for any audience, which can then be distributed over the Internet, shared “live” at events, or targeted to individuals as “compressed” files over electronic mail (e-mail). If it is used as a way to communicate new ideas, digital video can serve to strengthen internal communication. KOTM, in partnership with another Keewaytinook Okimakanak organization, K-Net, use digital video to strengthen internal communication efforts. KOTM, with the help of K-Net videographers, produce video “vignettes ” that are included in the KOTM website for all the communities to see. What communities see is what telemedicine looks like, who is using it in the pilot communities, and perhaps the possibility that telemedicine is something that should be available. KOTM uses video vignettes with the expectation that video communicates better than written documents what KOTM hopes to accomplish – its organizational mission and its effort to bring telemedicine to more communities. Thus, KOTM looks to digital video as a vehicle for building a common vision or understanding of telemedicine as a valid and desirable option for communities.

6.4.1 *Digital video as a communication and decision-making tool*

Digital video, because it is so accessible and portable, can be used to support the collective management of information for decision-making at the community level. Though digital video offers this possibility, my observations on the field at the initial stages of the introduction of telemedicine suggest that a first option is to hold “open house” events at the community clinics. It would appear that once a telemedicine unit arrives – once it has been set up and it is ready to operate – an “open house” is more effective at “showing” what telemedicine actually looks like and what it can do. Nonetheless, digital video vignettes are always accessible over the Internet and they continue to be produced as visual documents designed to explain, to diverse audiences, including federal health care authorities, what needs justify change.

In effect, digital video is widely used by KOTM for its documentary power to communicate news, concerns, and demands to the authorities responsible for funding this particular First Nations-led telemedicine experience. During my stays in the communities, and with the consent of all persons who appeared in the images, I took part in the filming of the routines surrounding a telemedicine session. These images were sometimes used in the production of the digital video presentations that increasingly form part of official communication between KO, KOTM, K-Net and their funders. One of the workshops that I co-facilitated – the CTC workshop – was video recorded as a document of the event in which it was embedded. As with other events involving telemedicine, KOTM included a digital video vignette of the workshop on its public Internet site.

At the community level, digital video is generally the domain of the younger generations. It is, arguably, no accident that CTCs are mainly young people, as youth tend to respond to technology – and to change – differently than older generations. Older people can be discouraged from both by different circumstances, including those related to skills, but also perhaps “by ways of thinking that make them reluctant to join in” with others in experimenting and learning new things (Turkle & Pappert, 1990, p. 132). This is a challenge that falls outside of the scope of this study, but which is, nonetheless, important enough to note. Much more could be written about the advantages and potential of digital video, as these findings suggest, but the topic is too important and too large to be included here beyond its immediate implications for telemedicine in remote First Nation communities.

6.5 TELEMEDICINE AS STRATEGY FOR DEVELOPMENT

Telemedicine is a technology-system that has been widely accepted by the rural and remote health care community as a fitting ‘tool’ for improving care. In a way, telemedicine is also seen as more than ‘just a tool’. Its arrival brings new skills, and new communication capabilities to the communities. It also brings a new potential for change in every area of health care delivery and, in this sense, has raised it to the level of ‘strategic’ importance. Unacceptable levels of inequality in health care coverage; increasing costs due to changing demographics and health needs; and geographical remoteness itself have been powerful motivators of change. The context of telemedicine development is thus one that has drawn a large input of resources, both financial and human, ‘from

above' (including the federal government) and 'from below' (First Nations capacity development).

Telemedicine has been appreciated as a strategic opportunity by remote First Nations communities. The introduction of telemedicine into First Nations communities was initiated by KO, a First Nations tribal council with a vision – not just in terms of health care, where this vision becomes an obligation: to help in advancement of the quality of life of the communities by building capacity locally. The strategic dimension of telemedicine is that it can serve the objective of capacity development for community control over health care. It also introduces benefits that are not directly related to health care. Benefits also spread to the improvement of the communication capabilities of the communities, and the acquisition of new skills and experience that can have uses in the realm of community economic development, for example. Thus, First Nations telemedicine, as an opportunity, brings peripheral or non-medical advantages as well.

Keewaytinook Okimakanak's strategy of finding and investing resources to acquire connectivity responds to more than awareness about the need for change: it reflects a 'conceptual framework' for innovation. KO's vision is, therefore, critical in that it questions the present and decides to take advantage of a political opportunity to acquire the necessary financing for connectivity first, and then again for telemedicine later. KO Telemedicine represents a true First Nations initiative: it was KO and various community leaders who made the decision to embark on a telemedicine pilot project in the first place. Thus, I propose that the process of appropriation of telemedicine proper can emerge from KOTM's

approach toward the communities. As each community was asked to decide its participation, and what services to bring, there is a foundation for a process of appropriation to start. KO thinks of telemedicine as another way in which First Nations communities can advance toward strengthening not just access to services, but also the possibility that adding services onto the digital platform it manages (through K-Net) might lead toward greater community based capacities. Furthermore, building more ICT applications can help ensure sustained funding in the critical years that it will take to solidify a less politically and economically dependent First Nations presence and role in the digital communications revolution. KO Telemedicine holds the potential of becoming a unique experience of cultural appropriation of a 'modern' technology and, furthermore, the possibility of the critical adaptation of the clinical health model in the remote clinics.

The KO experience with acquiring telemedicine technology illustrates that First Nations communities begin engaging telemedicine fully once its meaning has been appropriated, once telemedicine represents something significant to them. The communities did not want to 'fit' into a telemedicine model, but rather, they expected KOTM to assure them that its presence would not cause the erosion of what was already available in terms of care. This fundamental requirement was dealt with through a process of meetings, demonstrations of the technology (what it is designed to do) and discussions between KOTM, its representatives, and communities' leadership. Communities were concerned with what letting telemedicine in would *really* mean. In every case, the communities were assured by KOTM that telemedicine would "improve" and expand care, but

would do so with their involvement and support as ‘partners’, and not at their expense. This process could thus be seen as addressing political concerns directly, as well as cultural concerns related to what telemedicine could do in specific areas such as mental health, which requires a higher degree of cultural awareness. They were thus looking to make sure that KOTM did not in effect represent non-First Nations interests. While the communities took well to the advertised advantages of the technology – particularly as a real alternative to the need for travel to hospitals far away from home – there were community voices that nonetheless wondered whether better access to conventional care was really all they, as First Nations peoples, should hope for. There is a sentiment in the communities – and within KOTM itself – that telemedicine must facilitate meeting community needs and demands. Some First Nations voices go further, arguing that telemedicine should reflect traditional health care knowledge. In such cases, the meaning of the technology – its cultural framework – will stand critically contested.

6.6 FIRST NATIONS TELEMEDICINE

In the particular case of KO telemedicine, the communications function of the technology serves as an instrument for strengthening local capacity, and for facilitating the flow of health information and community feedback (through the CTCs) – two types of information that then help the KOTM improve the system. One possible implication of this First Nations telemedicine experience is immediately evident. The presence of telemedicine in the communities creates the possibility that the technology will become familiar to the communities to the

degree that First Nations users will begin to raise demands that may challenge the cultural frame of the technology: clinical health care at a distance.

Communities have already challenged KOTM based on the perception that telemedicine was not brought in to serve the First Nations first. This attitude – which was not an objection to clinical health care per se – was present in most of my interviews in the communities. By challenging KOTM to guarantee community control over what telemedicine would mean to existing health care services, they were manifesting mistrust in their ‘relationship’ with the state.

Only after KOTM stated unequivocally that telemedicine would serve community interests first – obviously without violating the rules of the game as laid out in the contractual relationship between KO and the Canadian state – did telemedicine really become a new element in the First Nations landscape of possibilities and opportunities. In effect, this explicit assurance formed the basis for the ensuing relationship between KOTM and expansion communities and, consequently, also formed the basis for the locally meaningful or effective use of the technology.

In a First Nations context, telemedicine can be linked with many other concepts: digital communications; new employment option in the communities; virtual classroom (for training and sharing ideas); virtual informal network (CTCs visit each other from their respective telemedicine offices); timely health assessments (that may avert unnecessary trips to the hospital); and in a larger scheme, the gradual accumulation of local expertise and capacities that can, if so decided, be ‘exported’ and developed further for the benefit of First Nations economic and cultural development.

6.7 CONCLUSIONS

In this study, I have explored the case of Keewaytinook Okimakanak Telemedicine (KOTM). I have argued that its significance is that KOTM initiated and supports a process for the building of *effective uses* – meaningful uses – for telemedicine in First Nations communities. By building trust through ensuring that telemedicine would respond to community needs and not replace or take away existing services, the communities accepted to join the system. The role of local capacity was also central to this process, as it not only facilitated local familiarization with and acceptance of the technology, but also demonstrated to community members that KOTM meant to improve the responsiveness of the local clinic to their particular, case-by-case needs.

As local users of the technology – particularly within the clinic environment – have become familiar with many of its advantages, a network of support for training and capacity development (including peer support in the case of the CTCs) has emerged. This process of familiarization, then, opened the possibility for further innovation. The presence of the ICT itself motivated many actors in the community health care context to imagine other possible ways in which it could be used.

While the telemedicine side, rather than the ICT side, is at the centre of the communication effort conducted by KOTM, the fact that the communication effort has been First Nation managed and has involved local talent in the production of video vignettes, the collection of usage statistics by locally employed CTCs who also help in providing the logistical services necessary for community clinics to participate, it could be argued that KOTM represents a

unique learning and innovation environment. This unique environment ensures that the local communication efforts undertaken are effective at promoting the service, as well as in addressing concerns, and operating appropriately. The positive response of nurses and local actors to the introduction of telemedicine is the result of the ability of the organization in charge of its operation to show the benefits of the technologies as well as provide a learner-centred implementation model.

This effectiveness, or search for “effective uses” of telemedicine, is possible because of two major elements: a) a sufficient degree of First Nations control over the system and its inputs (people resources and financial resources allocated for health care in the communities), and; b) an emphasis on building local capacity through a First Nations managed learning and innovation environment. In other words, “effective use” in the case presented is the result of a (long-term?) strategy for First Nations control over the holistic – administrative, political, educational – implementation of a telemedicine system. The implication of this conclusion is that “effective use” is a concept that goes necessarily further than a conventional readiness framework, because it invites a political question: who should control the process of innovation? The communities or the sponsoring institutions? In a First Nations led process, the answer – the goal – is self-evident.

6.8 A CHALLENGE FOR FURTHER RESEARCH

This study analysed the organizational and cultural dimensions of First Nations innovation with telemedicine. These dimensions were explored through

the experience of the introduction of First Nations led telemedicine – KOTM – into First Nations communities.

I did not address, as was made clear from the beginning, the difficult question of how telemedicine, as an advanced ICT, may be changing local understandings and, consequently, organization around health care. Such concerns require a longitudinal approach that is beyond the scope of this research.

Likewise, while there were some allusions to social and political aspects of this telemedicine experience, namely the political dimension of health care in remote First Nations communities, I did not fully address the nature of the relationship between the Canadian state and the First Nations communities in terms of how it conditions the development of First Nations innovation with telemedicine. The reaction to the notion of measuring the benefits – and the possible benefits – of telemedicine in the communities according to financial criteria illustrates the importance of this political dimension.

There are also methodological concerns that can be raised from a reading of the limitations of this study. For example, that this study is born out of a participatory evaluation process. This participatory evaluation, conducted over many months, did include many community concerns and perspectives: it helped KOTM gain a better appreciation of the needs of the communities. It also gave KOTM the opportunity to advance with the expansion of its coverage to the communities. It is ultimately true that this study is focused primarily “on technical matters [...] rather than broader questions related to social impact” (Cain, et al., 2007, p. 459). There is a need to look at the political dimension of

First Nations innovation with telemedicine in the context of the relationship that the Canadian state has maintained with the First Nations. For the more adventurous among researchers, such analysis could intersect with observations into how the technology may be re-shaping the way people understand and organize health care in rural and remote contexts.

Lastly, and in relation to the possibilities for culturally-specific telemedicine, it would seem that there is a need to question the dominance of market terminology to refer to ICT applications like telemedicine. The possibilities for First Nations led telemedicine can perhaps be better understood through a less restrictive lens.

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APPENDICES

Appendix A	Guiding questions
Appendix B	Readiness for telemedicine adoption
Appendix C	CTC Workshop Report

APPENDIX .A.

Guiding questions for interviews with community members, nurses and health workers, and CTCs

Members of the community

Introduction of Telemedicine into the community

1. Are you interested in TM? Why/Why not?
2. How did you first hear about TM?
3. What were your first thoughts about TM?

Acceptability of telemedicine

1. How did Telehealth come to this community?
2. Do you agree with/like where TM is located?
3. Have you made use of the service? If not,
4. Do you see yourself using the service? Why/Why not?

Quality of care

1. Who do you speak to about your health?
2. If you have used telemedicine, how did you feel during your TM consult?
3. Who did you expect to find at the TM consult?
4. Did your experience coincide with your expectations?
5. Did the doctor understand your needs?
6. (If translation was necessary) Was there a translator present?
7. How were you contacted?
8. How long did your last consult last?
9. How long did you wait for your appointment? (hours/days/weeks)

Integration to existing services and access to health care

1. Will TM affect health care in the community?
2. What should TM do in the community?
3. How do you feel about the arrival of TM here?

Nurses

Introduction to telemedicine

1. Who introduced you to telemedicine?
2. How will Telemedicine affect this community?
3. How do you explain TM to a member of the community who has never used it before?

Acceptability

1. How would you rate the technology's interface? Why?
2. Who helps you with the technical aspects of the technology?
3. Are you satisfied with the level of support you have for using the technology?
4. How did you become introduced to TM?
5. Who do you use it with?
6. What component of TM are you most comfortable using?
7. How would you describe the quality of the connection/ audio/ video images?
8. What alternatives to TM exist?
9. Who provides the alternative(s)?
10. How do the alternatives compare to TM?
11. What services do you currently provide through TM?
12. Who are the users? (each service)
13. Who provides the service (each service)
14. When do you provide these services (on TM)?
15. What other services do you need to provide?
16. What other services do you expect you will be able to provide through TM?

Integration

1. How do you feel about the quality of health care you are able to offer to the community?
2. What difficulties or obstacles can you observe in the delivery of health care?
3. How does telemedicine affect your experience living and working in the community?
4. Were you involved in its arrival to the community? If yes, how?
5. How does TM fit with existing health care practice here?
6. How does TM affect working relationships at this clinic/nursing station?
7. Are you willing to increase your use of TM?
8. What obstacles/challenges exist to the integration of TM here?
9. What is needed for these challenges to be dealt with properly?

On CTCs

1. Are CTCs helping to provide Quality of care? If not, why not. If yes, how.
2. Do you have a say in who becomes a CTC?
3. Are you involved in training the CTCs?
4. How often/when do you interact with your CTC?
5. What challenges do you see in relation to the role of the CTC at this clinic?

CTCs

1. How do you help explain TM to a member of your community who has never used it before?
2. How do you explain your work as a CTC?
3. How often does training for TM take place?
4. Who provides the training?
5. Are you satisfied with the training?
6. Who helps you with training?
7. What do you need in order to improve your training?
8. What are the challenges you face as a CTC?
9. Who do you speak to when you need help doing your job?
10. How would you rate/describe your experience so far?

APPENDIX .B.

Actor	Stage 1 – Readiness							Stage 2 – Start-up				Stage 3 – Adoption						
	Needs assess	Business Plan	Champions	Create vision	Technology	Standardization	Connectivity	Partnerships	Hiring	Training	Integration	Translation	Client escorts	Scheduling	Referrals	Education	Promotion	Evaluation
KO		X	X	X	X		X	X										X
K-Net		X	X	X			X	X						X			X	
KOTM	X	X	X	X	X	X		X	X	X		X	X	X	X	X	X	X
Partners (private & government)		X	X	X	X	X	X	X	X							X	X	X
Band Councils (Chief & Council)			X		X		X	X	X			X	X				X	X
CTCs			X			X				X		X	X	X			X	X
Nurses			X			X						X	X	X				X
Specialists/GPs			X			X					X						X	
Community Health Workers			X			X					X		X					
Clients/family												X						X

Source: KOTH (KOTM) evaluation, 2005.

APPENDIX .C.

**CTC Workshop Report
First Nations Telehealth Workshop
Sioux Lookout, ON, November 17 -18th 2004.**



**DRAFT REPORT
SUBMITTED FOR COMMENT**

This draft report includes a summary of objectives and results from the day-long workshop held with Community Telehealth Coordinators from twelve First Nations communities.



The workshop was divided into two parts:

Part I was a “talking circle” of brief introductions and a reconfirmation of our purpose at the workshop through a card exercise of “expectations” for the meeting.

CTCs sharing opinions on the value of each of the tasks they perform on the job.

Part II involved working in small groups (of 3 or 4 people) to explore the complexity of the CTC position. Group work was complemented with a collective sharing and individual categorization of results. A ranking of preferences was also conducted towards the end of the workshop. Facilitators and participants agreed to share and comment on this report of the workshop before these are included in the evaluation/thesis.

Workshop Objectives

- Offer a space for CTCs to meet and to share their experiences on the job.
- Collect information needed for Telehealth evaluation purposes.

Part I: Expectations

Participants offered their individual expectations for the workshop. These were then collectively classified into three themes and displayed throughout both sessions (morning and afternoon) as a reminder of common goals. The facilitator explained that given time constraints, only part of the expressed expectations for the workshop would be covered, taking any remaining expectations as a recommendation for future objectives. As the workshop progressed, it became apparent that Team Building would be the one expectation that the group could achieve and 'take home'. Training and a better understanding of the job of the CTC emerged strongly in the afternoon exercises, which may be interpreted as an indication of participant ownership over the content of the workshop.

The three themes under which participant expectations were grouped include: Team Building, Community Responsibilities, and On the Job Training (see Table 1 – Participants' Expectations).

Table 1 – Participants' Expectations

Team Building	Community Responsibilities	On the Job Training
<ul style="list-style-type: none"> ● Meet other CTCs and learn more about telehealth ● Meet anyone involved with telehealth ● Meet new people ● Learn to talk with others more easily ● Make friends 	<ul style="list-style-type: none"> ● Understand health issues in the communities ● Better understanding of telehealth ● Learn more about telehealth 	<ul style="list-style-type: none"> ● Need more training and information ● More resources/skills ● Learn from other CTCs ● Learn more about telehealth equipment ● Learn about how to deal with equipment problems

Part II: Group Work

Group work took place around four questions

- What are the different jobs you do as a CTC?
- Who else helps you with telehealth jobs in the community?
- Which jobs are the most important?
- What do you need to do your jobs better?

Small groups were formed by assignment. Once formed, the groups remained the same for the duration of the workshop in order to facilitate communication and allow each group to build relationships. Roles were assigned internally (note taker, presenter, time keeper) and these tasks were performed efficiently. All participants were reminded by the facilitator that, this being their workshop, they could choose to spend extra time on questions of particular interest to them. The response was positive and all questions were dealt with by the groups. Collective sharing and classification of the information produced could not be completed for all questions, as priority was given to the ranking of jobs described by CTCs. This decision was made with the justification of meeting some of the expectations about “learning” that were expressed in Part I of the session. This ranking can be observed in Table 2 – Job Ranking.

CTC Jobs Ranking Results

Table 2 – Job Ranking

Job Theme	Administration	maintenance & testing	Communication	Promotion	Community needs	Working with physicians	Education & training	Preparation & organization
Job Ranking	Weekly reports	Keep workplace tidy	Contact other CTCs for help	Encourage individual users	Translation	Using TH	Attend ed. meetings	Organize demo sessions
	Fax work plan	Equipment checks	KO for day-to-day issues	Research TH on internet	Contact patients for appointments		Train nurses (1 on 1 training)	Plan clinical and education sessions
	Filing paper work	Equipment checks with other CTCs	Attend workshops	Promote TH	Inform clients		Learn new equipment	Advertise sessions
	Design workplan	Equipment checks (EC)	CTC meetings	Be a resource with info on TH	Transportation (travel arrangements)		Work with other HC workers	Set up sessions
	Doing surveys		Call KO for info on TH				Using computers	Arrange space use for TH
	Photocopy forms							
	Planning							
No. of votes	32	25	26	21	26	3	40	23

Participants collectively classified the information obtained from the exercise into eight themes, and proceeded to individually rank each 'job' with a mark (on a sticker) from 1 to 3. For the purposes of this exercise, one (1) signified 'most important' and three (3) 'least important'. The stickers on each individual card were used to calculate its ranking, where the denominator corresponded to the number of stickers on the card and the numerator corresponded to the sum of the numbers on the stickers. Table 2

above illustrates the results of the ranking in descending order. The total number of 'votes' was calculated for each of the eight themes, yielding a general idea of the weight the participants gave to each.

Note that the themes with the highest number of votes are: 1) Education, 2) Administration, and 3) a tie between Communication and Community Needs. The Education column on Table 1 illustrates the sort of needs the participants outlined as critical to their jobs, most important of which is that of 'attending meetings', as participants feel that the opportunity of sharing experiences face-to-face helps them learn and problem-solve a great deal.

One of the highest ranked cards in the exercise (all twelve CTCs placed a sticker with either a '1' or a '2' under this heading, for a final ranking of 1.6) was that of 'translation' of medical and technical concepts and clinical jargon to the clients who are not fluent in English. Community Telehealth Coordinators discussed this particular issue in Part I of the workshop, when thinking about their expectations coming into the workshop. Their intention in including this concern in the list of 'On the Job Training' topics earlier in the workshop was to draw attention to the difficulty they face in this regard. More training and support in this area is a high priority, as they consider this aspect of their job to be the top 'community need'.



Under the 'Administration' column, preparing weekly reports rated as an important task, as this is an opportunity to communicate concerns to KO Telehealth staff. At the same time, reporting in this fashion is valued as another skill in itself.

Weekly reports were mentioned as a challenge by some participants who would prefer more training in the use of a word processor, typing, etc. Having the opportunity to meet and keep contact with other CTCs facilitates problem solving as a 'team' and also ranks high on participants' preferences, which are listed under the 'Communication' column. Participants expressed a desire to meet again in a gathering tailored-made for CTCs, as they felt that this particular workshop gave them a chance to talk about their experiences and learn from each other, in some cases "for the first time".

The conclusion of Part II of this workshop focused on the question “**What do you need to do your jobs better?**”, under a tight time limitation. Groups continued to work on this last task, writing down individually on cards what basically amounted to a wish list that was grounded in their job experience.

Given the time constraint, participants did not have time to classify the results of their group work into themes. A working classification based on a general discussion among all present is presented here to help identify common priorities.

<i>Investing in People</i>	<i>Equipment</i>	<i>Basic Skills</i>	<i>Structure</i>
Promote	Phone	Certification	Full time
Research	Support	Training	More hours
Communicate	Office space	Writing and word processing	More funding for position
Translate	Office materials	Typing	
People skills		Challenges	
More conferences		Up to date information	
		Up to date on technology	

Participants understand their work as, first and foremost, building the community's acceptance of the technology, but acknowledge that this represents a challenge considering that some or many of the skills and other needs are not always available. CTCs value the opportunity to help each other on day-to-day matters, but also see a need for a greater investment by the organization in its front-line community workers. There clarity among the participants about their individual on-the-job responsibilities, and a realization that the demands on, and importance of, their work to the community justify full time employment.

The participants acknowledge a wide net of supporters in the community and beyond. Among many others, CTCs mentioned: members of their family patients themselves who give feedback, and community members who attend events for the promotion of telehealth; Community Health Representatives; schedulers at KOTH; Chief & Council; nurses, who help them become familiar with the clinic environment; physicians, who help them become comfortable and confident using the equipment and helping at consultations; elders, on whom they call for support with some tasks, such as translating clinical terms and concepts; K-Net staff, with whom they resolve technical issues; and their back-up CTC. The participants also value the support of the Regional Telehealth Coordinator, with whom they are in contact for technical support; and KOTH staff, with whom they interact through video and teleconferences on a regular basis. The involvement of the community, through the CTCs, becomes apparent from this list of supporters.

Some CTCs express a slight degree of frustration over what they perceive is not a well understood position, especially in regards to their employment status.

At the end of this workshop, CTCs expressed support for an invitation to come together again, perhaps in 2005, for a follow up workshop to continue discovering common challenges, as well as to build stronger relationships with the organization. There was also the feeling that the CTCs could be a stronger advocate for telehealth through a better understanding of their roles on the part of all involved, and through the sharing of this information with the community and health providers. All participants made clear their enthusiasm for this particular opportunity (workshop) and thanked the facilitators and conference organizers for the invitation to take part. A short video of the conference is available on the web:

http://streaming.knet.ca/telehealth/tele-intro_300k.wmv

The facilitators would like to express their thanks to KOTH and to K-Net for their support of the workshop. Special thanks to the CTCs for sharing their concerns, experiences, and ideas with the evaluation team.