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# Understanding First Nations Young Adults' Health Literacy

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Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Science

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UNDERSTANDING FIRST NATIONS YOUNG ADULTS' HEALTH LITERACY

(Spine title: Understanding First Nations Young Adults' Health Literacy)

(Thesis format: Monograph)

by

Ebony Rempel

Graduate Program in HRS

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Science

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## Abstract

Relative to non-First Nations, Inuit, and Métis (FNIM) Canadians, FNIM people have poorer health status. A qualitative investigation of the health literacy skill and the health information (HI) needs of young FNIM adults was conducted. Eight single mothers living on-reserve were interviewed. Data analysis generated four main themes along with the subthemes of: (1) Traditional Health (TH), (i) Traditional Health Culture Excised, and (ii) Wanting to Know More about TH; (2) Health Information Needs of First Nations young Mothers; (3) Access to HI, (i) Asking the Doctor / Telehealth (ii) other Female Family and Friends; (4) Online Accessibility, (i) HI Online, (ii) Social media, and (iii) Navigation and Computer Skills. Although participants expressed a lack of confidence in their computer skills, they did use social media to access HI. While TH practices were valued, there was a lack of understanding and lack of access to TH practices.

*Keywords:* First Nation, Inuit, Métis, Aboriginal, Indigenous, Health Literacy, Health Access, Health Preferences, On-Reserve, Canada, Ontario, Online Health Access, Traditional Health

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## Introduction

One of the major tenets of health promotion involves supporting individuals to assert more control over their health (World Health Organization [WHO], 1986). Understanding and comprehending health information is a fundamental skill that enables individuals to function within a health care system that advocates and increasingly expects individuals to play an active role in promoting and maintaining their own health (Forsyth, Maddock, Iedema, & Lassere, 2010). According to the WHO (1986), “health is defined as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. What determines health depends on many factors. The Public Health Agency of Canada (2012) has developed 12 key determinates of health that include: income and social status, social support networks, education and literacy, employment / working conditions, social environment, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, gender, and culture. These determinates of health do not exist in isolation from each other rather the combined influence of these determinants shape people’s condition of health (Public Health Agency of Canada, 2012).

The Canadian Constitution Act (1982) recognises three separate groups of Canadian Aboriginal peoples; First Nations, Inuit, and Métis, (FNIM) (Aboriginal Canada Portal, 2002; Leatherman & Sutherland, 2010). Without clarification, the use of a single term such as ‘Indigenous’ or ‘Aboriginal’ that aggregates many distinct populations is inappropriate given the unique heritage, language, cultural practises, and spiritual beliefs represented among more than one million self identified FNIM people living in Canada (Iseke-Barnes & Sakai, 2003; Vass, Mitchell & Dhurrkay, 2011). In this

work, ‘First Nation, Inuit, and Métis (FNIM)’”, will be used to identify native Canadians when referenced concepts and information do not provide adequate detail to accurately distinguish the population(s) or to purposefully reference an aggregated group of native Canadians. Otherwise individuals / groups will be referenced based on the specific group or area they reside or how the individual person wishes to be addressed.

According to the 2001 Canadian census, there are over one million self-reported FNIM peoples living in Canada and the majority of these peoples are living on-reserve with nearly half of them under the age of 25 (Statistics Canada, 2001). FNIM peoples in Canada are burdened with inequities that come from underlying health disparities related to a history of social, economic, and cultural upheavals (Adelson, 2005; Angell & Parkins, 2010; Doessel, Travers, & Hunter, 2007; Dyck et al., 2002; Frohlich, Ross & Richmond, 2006). In fact, FNIM peoples experience poorer health status compared to non-native Canadians as evidenced by higher rates of chronic disease, injury, diabetes, sexually transmitted infections (STIs), and cervical cancer in women (Anand et al., 2001; Baker et al., 1998; Davis et al., 2002; Frohlich et al., 2006; Institute of Medicine, 2004; Leatherman & Sutherland, 2010; National Cancer Institute’s Health Information National Trends Survey, 2005).

The federal government is responsible for and provides health promotion programs and public health services for FNIM peoples (Health Canada, 2004). Provincial governments provide universal insured health services to all citizens, including all FNIM people (Health Canada, 2004). In the Territories, the federal government has transferred almost all health services to the territorial governments, with the exception of some health promotion and disease prevention programs among FNIM (Health Canada, 2004).

Health is a socially constructed concept and shaped differently by cultural ideals and practices (Adelson, 2005; Smylie, Williams, & Cooper, 2006). FNIM culture includes many distinctly different ideologies compared to non-native Canadian culture, specifically with respect to traditional healing and medicines (Adelson, 2005; Royal Commission on Aboriginal Peoples, 1996; WHO, 2001). Traditional healing and health among FNIM peoples involve an understanding of the intersections of mental, physical, and spiritual well-being (Royal Commission on Aboriginal Peoples, 1996; WHO, 2001). It is challenging to achieve consensus among all FNIM traditional medicine and healing practices because each community may have different practices depending on the history of that localized area (Martin-Hill, 2009). Despite the differences, traditional methods of health and healing include knowledge, skills, and practices that are based on FNIM cultures that promote mental, physical, and spiritual well-being (Royal Commission on Aboriginal Peoples; 1996; WHO, 2001). The traditional FNIM healing practices and medicines are an important source of health information for FNIM peoples (Martin-Hill, 2009). Traditional health practices value the wisdom of tribal Elders who hold cultural and traditional knowledge and are responsible for educating youth (Cohen 1998; Nauman, 2007). Seeking advice from Elders, participating in healing ceremonies, using traditional plant material for healing, and traditional rituals are all ways that FNIM peoples may access health information, maintain, and promote health (Martin-Hill, 2009).

The expectation that people will advocate for themselves and participate in self health promotion is predicated on their literacy and health abilities (Canadian Council on Learning, 2007; 2008; Nutbeam, 2000; 2008). Health literacy skills are important in a health care system that is dominated by chronic disease (Nutbeam, 2000; 2008).

Similarly, the ability to access and understand traditional FNIM health information is dependent on adequate health literacy skills (Nutbeam, 2008; Wilson & Rosenberg, 2002). The Canadian Public Health Association (CPHA) Expert Panel on Health Literacy has created a definition that looks at health across the life span and states that:

Health literacy is the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course (Rootman & Gordon-El-Bihbety, 2008, p. 11).

Nutbeam (2000), a health literacy expert, explains health literacy in a way that moves beyond basic reading, writing, and comprehension skills. Nutbeam (2000) defines health literacy as:

The cognitive and social skills which determine the motivation and ability of individuals to gain access to and understand and use information in ways which promote and maintain good health. (p. 263).

Nutbeam (2000) models his way of thinking about health literacy as a typology of functional, interactive, and critical health literacy. Functional health literacy is the ability to obtain and comprehend health related material and services for health care (Nutbeam, 2000; 2008). Interactive health literacy includes the ability to develop personal skills including an enhanced self efficacy in order to act appropriately on information to improve the health status of individuals and / or community (Nutbeam, 2000). Lastly, critical health literacy involves advanced cognitive skills that support the critical analysis of information to enhance personal and collective control over social and political action (Nutbeam, 2000). In this ever-changing field of health and health information, the need

for accurate and timely health information is crucial (Kickbusch, 2001). Accessing traditional FNIM healing and medicines information may be an advantageous source of health information for FNIM peoples (Martin-Hill, 2009).

Yet troubling are the Canadian results of the International Adult Literacy and Life Skills Survey (IALSS) (Organisation for Economic Co-operation and Development [OECD] & Statistics Canada, 2005), an international survey of adults (aged 16 to 65), capturing information on prose literacy, document literacy, numeracy, and problem solving skills. The results of this survey indicated that 48% of Canadian adults' assessment scores reflected limited general literacy skill (levels 1 to 2) (OECD & Statistics Canada, 2005; Statistics Canada, 2005) which means that they require very simple, straightforward information within familiar contexts (Strucker, Yamamoto, & Kirsch, 2005). According to this survey, 35% of Canadian adults function at level 3 general literacy skill, which is the minimum skill level required to successfully function within our knowledge-based economy (Statistics Canada, 2005). People with general literacy skills of a level 3 performance or above have been associated with positive outcomes such as enhanced opportunities for lifelong learning, increased economic success, and independence (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993; Murray, Kirsch, & Jenkins, 1997; Tuijnman, 2001). Level 4 / 5 is the highest general literacy proficiency (OECD & Statistics Canada, 2005). Approximately 17% of Canadian adults function at levels 4 and 5 (Statistics Canada, 2005), requiring an increasingly higher skill such as the ability to integrate a number of sources of information to solve increasingly complex problems. Concernedly, results from the IALSS indicate that that 60% of Canadian adults have limited *health* literacy skills (Canadian Council on Learning, 2007; 2008).

Gaining and accessing health information is fundamental to promoting and maintaining health (Institute of Medicine, 2004; Kickbusch, 2008; Nutbeam, 2000). Current evidence points to a positive correlation between health status and health literacy skills (Canadian Council on Learning 2007; 2008; Davis et al., 2002). For example, individuals with low health literacy are 2.5 times more likely to report poor health than those with high health literacy skill (Canadian Council on Learning, 2008). Current evidence suggests that those with the ability to access and understand health information have better self-care practices, improved disease state knowledge, greater coping skills, and engage in healthier lifestyles (Donelle & Hoffman-Goetz, 2008; Robinson & Graham, 2010; Squellati, 2010). Those with limited health literacy tend to have lower health status typified by increased health problems, fewer years of education, lower incomes, and an overall lower socioeconomic health status (Adelson, 2005; Davis et al., 2002).

There is very limited literature available in regard to FNIM peoples' health literacy in Canada. The United Nations Human Development Index, which measures health through longevity, educational achievement, and adult literacy, ranked FNIM people in Canada 63rd in the world (Inuit Tapiriit Kanatami, 2004), meaning that FNIM living conditions and quality of life can be similarly compared to that of third world conditions (Indian and Northern Affairs Canada, 2008a). In addition, results from the IALSS indicate that FNIM peoples' average literacy skills were limited which means that they require very simple, straightforward information within familiar contexts (OECD & Statistics Canada, 2005).

In an environment where access to health information and services is increasingly multifaceted and complex, health literacy skills are foundational to self health care and promotion (Canadian Council on Learning, 2007; 2008; Nutbeam, 2000; 2008). Health literacy skills such as reading, writing, listening, speaking, numeracy, critical analysis, communication, cultural understanding, and interaction skills, are important in order to access relevant and credible information and services to function within an increasingly complex society (Nutbeam, 1999; 2000; 2008; Shohet & Renaud, 2006; Squellati, 2010).

A popular and important avenue for accessing health information and services is through the Internet (Hesse et al., 2005). Health information needs can encompass a wide variety of issues and gaining this information online can be an efficient and effective route (Hesse et al., 2005). According to the Canadian Internet Use Survey (2010), more than two-thirds of Canadians use the Internet at least once per day and approximately half of Canadians spend five or more hours per week online (Statistics Canada, 2010a). The Health Information Nations Trends Survey (HINTS) showed that although people prefer to talk to a doctor to get their health information (50%), 49% reported going online first with only 11% going to their doctor first (Hesse et al., 2005; Nelson et al., 2004). eHealth is a new term defined as:

As an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide

by using information and communication technology. (Eysenbach, 2001, p.e20)

Social media and online networking sites incorporate new technologies that can be accessed from virtually everywhere via the use of smartphones, tablets, laptops, or other similar devices (Boyd & Ellison, 2007). Online social networking sites are also becoming important channels of health information, especially for the younger population (18-30 years of age) who tend to be the most frequent online social network users (Lenhart, Purcell, Smith, & Zickuhr, 2010). The term Health 2.0 reflects, in part, these online social networking sites that provide Internet users the opportunity to connect and build relationships using the interactive, communicative, and social aspects of the technologies for health enhancement purposes (Avery et al., 2010).

Health 2.0 is defined as:

... applications, services and tools [that] are Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers, that use Web 2.0 technologies and / or semantic web and virtual-reality tools, to enable and facilitate specifically social networking, participation, apomediation, collaboration, and openness within and between these user groups (Eysenbach, 2008, p. e22).

Health 2.0 reflects the interactive nature of health information and service access of Web 2.0 (Eysenbach, 2008). The interactive nature of Health 2.0 is changing health care practices and empowering health care consumers (Eysenbach, 2001; 2008). In addition to information from health care providers, Health 2.0 introduces new channels of communication and interactive health care processes (e.g., consumer reviews, blogs, or

podcasts) to guide information seekers to sources of credible, trustworthy online health information (Eysenbach, 2008; O'Conner, 2008; Townes & Rogers, 2011).

The number of people using the Internet to access health information is increasing rapidly; however some Canadians may be disadvantaged because they are without the skills to utilize the Internet to gain relevant and appropriate health information (Horrigan & Rainie, 2002; Viswanath & Kreuter, 2007). For example, Canadians that are older, with less income, and with less education tend to be disadvantaged in terms of online information access (Lenhart et al., 2010; Viswanath, 2006). Furthermore, people with low or limited literacy and / or health literacy skills are less likely to navigate the Internet and to attain and understand information that is available online (Berland et al., 2001; Viswanath & Kreuter, 2007).

To date, health literacy frameworks and practices assume a western socio-cultural context and tend not to take into account FNIM culture and customs (Smylie et al., 2006). Limited literacy and Internet navigational skills may preclude FNIM Canadians (and the majority of non-native Canadians) from benefiting from a variety (e.g., online) of health resources (Smylie et al., 2006). This highlights the need for research to assess the health literacy skills of FNIM populations and to explore how culture and traditional health and healing shape health literacy skills among FNIM populations. Understanding how and what types of health information FNIM adults access is an important factor of their health literacy and therefore their overall health.

### **Understanding Health Information Needs through a Health Literacy Framework**

Health Promotion is a process, which enables people to take control over their own health (WHO, 1986). Authors of the Ottawa Charter for Health Promotion provided

a list of health prerequisites and strategies for promoting health and specified attention to cultural factors as significant to positive health outcomes (Health & Welfare Canada, 1996; WHO, 1986). Addressing health needs in a culturally relevant and meaningful way is essential to addressing the health issues among FNIM peoples (Marks, Cargo, & Daniel, 2007).

Rates of chronic disease, injury, and hospitalization are all higher within FNIM populations (Baker et al., 1998; Institute of Medicine, 2004; Leatherman & Sutherland, 2010). Relative to the general population, the poorer health status of FNIM people in Canada is reflected in diabetes rates that are three to five times higher; suicide rates that are five to seven times higher in FNIM youth; and higher age-standardized mortality rates (Health Canada, 2009a; Leatherman & Sutherland, 2010). In particular, FNIM women have an average life expectancy of 76 years compare to 81 years for non-FNIM women (Pederson, 2001). FNIM women experience higher rates of circulatory problems, respiratory issues, diabetes, hypertension, and cervical cancer than the rest of the Canadian female population (Pederson, 2001).

To successfully manage chronic health issues, Canadians require the ability to access, understand, evaluate and communicate information to promote, maintain and improve health; to develop adequate health literacy skills (Rootman & Gordon-El-Bihbety, 2008). In fact, gaining and accessing health information is fundamental to promoting and maintaining health (Institute of Medicine, 2004; Kickbusch, 2008; Nutbeam, 2000). Current evidence suggests that those with readily available health information have better self-care practices, improved disease state knowledge, greater coping skills, and engage in healthier lifestyles (Donelle & Hoffman-Goetz, 2008;

Robinson & Graham, 2010; Squellati, 2010). Yet as previously mentioned the majority of Canadian adults (48%) have limited general literacy skills (Statistics Canada, 2005; Strucker et al., 2005) and 60% of Canadians do not have the necessary health literacy skills to effectively manage their health and are significantly challenged in terms of managing their general activities of daily living (Canadian Council on Learning, 2007). In fact, individuals with limited health literacy are 2.5 times more likely to report poor health than those with high health literacy skill (Canadian Council on Learning, 2008; OECD & Statistics Canada, 2005).

Given the limited literature regarding FNIM health literacy skills, the intent of this study is to begin to address the gap in the research literature regarding the health literacy skills of young FNIM adults. Specifically, the purpose of this research is to investigate and gain an understanding of the health literacy skills and the health information needs of FNIM young adults living on-reserve. The results of this study are intended to create knowledge and insight into the health literacy skills of this unique community of Canadians. A better understanding of the health issues among FNIM young adults and the identification of their health information needs and access preferences may have implications for the development and dissemination of educational materials and services that align with their needs. It is anticipated that the outcomes of this investigation will contribute to the limited knowledge of health literacy among FNIM young adults.

### **Literature Review**

The literature reviewed for this study was accessed through online database searches of Scopus, CINAHL, and PubMed as well as online grey literature sources

inclusive of Health Canada, Aboriginal Canada Portal, community reserve websites, firstnations.ca, and Statistics Canada.

Table 1: Literature Review Search Terms

Search Terms used for literature review:				
To specify population:		To specify topic of interest:		To specify origin:
“First Nation” Inuit Métis Aboriginal Indigenous Indian	AND	“Health Literacy” “Health Information” “Online Health” “Health Information Access”	AND	Canada Ontario

### **First Nations, Inuit, and Métis People in Ontario**

Aboriginal and / or Indigenous peoples of Canada are people who live in Canada and self report as North American Indian, First Nation, Inuit, or Métis. Status or Registered Indians are those people that are entitled to be registered under the Indian Act. Over one million self-reported FNMI people live in Canada including those that reside on-reserve and off-reserve and fall under 50 different culturally and linguistic distinct groups (Health Canada, 2009b; Reading, Kmetc, & Gideon, 2007). Nearly half of the FNMI people are under the age of 25 (Health Canada, 2009b; Wilson, Rosenberg, & Abonyi, 2011). The 2002 Indian Register of Canada revealed that of the nearly 1.3 million people reporting FNIM ancestry, more FNIM live on-reserve (60.3%) than live off-reserve (39.7%) (Health Canada, 2009b).

In Ontario, there are close to 300,000 FNIM peoples, 65.3% are identified as First Nation, 30.4% as Métis, 3.5% as Inuit (Statistics Canada, 2006a). Ontario has the largest FNIM population in Canada (Statistics Canada, 2006a). About 20% of the FNIM population live on-reserve (Statistics Canada, 2006a). There are 206 reserves and

settlements in Ontario; these communities are located all over the province ranging from the south of the city of Windsor to the shores of Hudson Bay (Statistics Canada, 2006a). Some of these reserves are located close to urban centres and are relatively accessible to urban conveniences and services, while one in four reserve communities are situated in more remote and / or isolated communities and face many accessibility challenges, and can only be reached by air (Health Canada, 2009a; Statistics Canada, 2006a). In relation to this research, the reserves located near London Ontario are of particular interest. There are five reserves that are located near London, Ontario which include: (1) Chippewas of Kettle & Stony Point First Nation, (2) Chippewas of the Thames First Nation, (3) Oneida Nation of Thames, (4) Munsee-Delaware Nation, and (5) the Six Nations reserve. The Six Nations reserve has the largest population of First Nations peoples in Canada is located just northeast of London (Health Canada, 2009a).

### **First Nations, Inuit, and Métis Culture in Canada**

With respect to health, FNIM people exhibit cultural differences quite distinct in many ways from non-native Canadian culture (Adelson, 2005; Smylie et al., 2006). Ideologies, values, and norms are part of all cultures and are different within each FNIM community (Bird, 2011). FNIM cultures have a long history of rituals and traditions including ceremonies, a diversity of languages, and ‘the teachings’ from Elders (First Nations Health Council, 2012; Lavoie et al., 2010; Maar & Shawande, 2012). In contrast to the predominant western biomedical model of health, FNIM peoples’ traditional model of health takes into account all aspects of life and environment, including the physical, emotional, and spiritual aspects (Folke et al., 2002; Reading et al., 2007).

Traditional concepts of health, healing practices, and medicines are difficult to define as many of the traditional health practices are unique to the community and to the localized area (First Nations Health Council, 2012). Stewart (2007) states that FNIM models and practices of healing include: storytelling, advice from Elders, interconnectedness with family and community, healing circles, and ceremony. The WHO (2001) defines traditional medicine as:

The total sum of knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement of treatment of physical and mental illness (p. 1).

The Report of the Royal Commission on Aboriginal Peoples (1996) includes a summary of interviews with FNIM peoples across Canada about their past and current health and defines traditional healing as:

Practices designed to promote mental, physical and spiritual well-being that are based on beliefs which go back to the time before the spread of western 'scientific' bio-medicine. When Aboriginal peoples in Canada talk about traditional healing, they include a wide range of activities, from physical cures using herbal medicines and other remedies, to the promotion of psychological and spiritual well-being using ceremony, counseling and the accumulated wisdom of Elders (p. 348).

Generally, traditional methods take on a holistic approach to balance spiritual, emotional, physical, and social aspects of health and life (Cohen, 1998; Martin-Hill, 2009). There are many different types of traditional healing ceremonies including

dancing, singing, spiritual praying, and traditional healing (Cohen, 1998; Nauman, 2007). Ceremonial healing usually involves communicating with a spirit of disease through prayer and ritual along with a healer / Elder / medicine person and a patient (Cohen, 1998). For example, sweat lodge ceremonies are where a patient and the healer pray together while standing in hot water filled with red-hot stones (Cohen, 1998). Sweating ceremonies are considered deeply spiritual and the healing properties are founded in Mother Earth's healing energy of the heat (Maar & Shawande, 2010; Nauman, 2007). A survey with 99 First Nation students by Wyrostok & Paulson (2000) indicated that participation in sweat lodge ceremonies was associated with better mental health. Drumming is another native traditional healing method (Cohen, 1998; Nauman, 2007). The sound of the drum is said to mirror Mother Earth's heartbeat and listening to the beat can be a spiritual connection to Mother Earth (Nauman, 2007).

Herbalism, the practice of using plant based material as a source of medicine, is another traditional therapeutic method used by FNIM people in Canada (Cohen, 1998; Green, 1992; Winston, 1992). Depending on the geographical location of the FNMI community, different herbs (e.g., Sage, Sweetgrass, Cedar, and Lavender) can be used for spiritual purposes such as the cleansing and / or purification of one's soul or disease management (Cohen, 1998; Maar & Shawande, 2010; Martin-Hill, 2009; Nauman, 2007). Herbal remedies are generally used to manage illnesses such as cardiac symptoms, fevers, inflammation, pain, and infection (Cohen, 1998; Nauman, 2007). There are over 300 known medicinal herbs used to support health, and often the herbs are used in conjunction with ceremonies, music, and dance (Cohen, 1998; Green, 1992; Winston, 1992).

Elders are people that hold the traditional knowledge regarding cultural beliefs and practices (Maar & Shawande, 2010; Martin-Hill, 2009). As guardians of cultural practices, Elders are an important part of traditional health and healing (First Nations Health Council, 2012; Martin-Hill, 2009). Within communities, Elders are perceived as having great wisdom and are given the responsibility to educate others about traditional knowledge and protocols in each region; they also are responsible for the protection of traditional ceremonies, the environment, and traditional FNIM knowledge of health and healing (First Nations Health Council, 2012). According to Stiegelbauer (1996), Elders hold the knowledge of ‘the teachings’ which are traditional ‘understandings’ of FNIM culture. The intent of ‘the teachings’ is to show how and why it is vitally important to know who you are, as an individual connected to the world we live in. Elders’ knowledge is passed down from generation to generation to sustain the traditional beliefs and practices, and to support the community and the understanding of ‘the teachings’ (Stiegelbauer, 1996). ‘The teachings’ or way of living of the Elders will vary depending on their expertise, but all of ‘the teachings’ involve some aspect of traditional knowledge and / or culture (Stiegelbauer, 1996). FNIM peoples consult with Elders for advice about life and traditional knowledge because the Elders are viewed as teachers or experts on the FNMI community vision of life (Stiegelbauer, 1996; Wrostok & Paulson, 2000).

The traditional practices of health and healing were the focus of discussion among traditional healers in British Columbia in October 2011. The Traditional Healers’ Gathering brought First Nation Traditional Healers together to share traditional healing programs and knowledge (First Nations Health Council, 2012). The Traditional Healers of this gathering reviewed multiple methods of traditional health and healing used within

many of the FNIM communities (First Nations Health Council, 2012). Some of these traditional strategies for good health included: practicing ceremonies, youth and Elder involvement, traditional foods and culture, and medicines such as: teas and plants, providing education and giving children more knowledge, providing language and culture programs, treatment centres, and clinics (First Nations Health Council, 2012).

Incorporating traditional methods of health and healing within the lives of FNIM peoples is associated with several positive effects (Gunn, Pomahac, Good Striker, & Tailfeathers, 2010; Smylie et al., 2006). For example, encouraging results were found by Gunn et al. (2010) in a study where cultural components were incorporated into the education (i.e., determinant of health) of FNIM students who were falling behind in school. In this study, researchers reviewed 16 funded projects within the Alberta Initiative for School Improvement program and found that involving Elders and FNIM parents in a meaningful way, and integrating and focusing on FNIM culture, language, and history, the students were more likely to remain in school. Evidence suggests that teaching FNIM language creates a shared common world view, a belief of the interrelatedness of life, and the importance of honouring mental, physical, emotional, and spiritual medicines of life (Smylie et al., 2006). Western biomedical constructs conflict with FNIM traditional health and healing practices and conflicts with FNIM traditional healers (Jervis, 2010).

### **Health Status of First Nation, Inuit and Métis Canadians**

Recognizing the intersecting social, economical, political, cultural and medical issues that determine health, significant events within the history of FNIM peoples have shaped the health of FNIM individuals and communities within Canada (Public Health

Agency of Canada, 2012). FNIM peoples in Canada have been subjected to colonization which (Indian and Northern Affairs Canada, 2008b; Reading et al., 2007) involved outsiders (non-natives) taking FNIM peoples' land and dominating the common society, that resulted in the abolishment of FNIM societal and cultural norms and alienating them from their traditional ways of life. In the late 18<sup>th</sup> century newcomers to Canada (of mainly European ancestry) introduced microorganisms and diseases that were foreign to FNIM peoples (Adelson, 2005; Gracey & King, 2009) and created a situation where FNIM peoples were burdened with infectious disease (Gracey & King, 2009). As well, from 1874 to 1996 the Canadian government implemented a mandatory program of education for all FNIM children (Barlow et al., 2008; Milloy, 1999). FNIM children were forced into residential schools operated by the Canadian government with the intent to assimilate and integrate FNIM peoples into mainstream Canadian society. Practices at the residential schools forbade the use of native language, teachings, and cultural practices and mandated the adoption of a foreign religion and the use of only English or French languages (Barlow et al., 2008; Barman, 1995; Battiste, 2004). Even until 1996, FNIM children were taken, even forcefully removed from their homes, and separated from their families (Barman, 1995; Battiste, 2004; Milloy, 1999). In many instances, the children were marred by accounts of sexual, mental, emotional and physical abuse by staff and teachers at the schools (Barman, 1995; Battiste, 2004). The government imposed residential school policy resulted in many FNIM people leaving behind their land, resources, and culture to adapt to the western ways; they were prevented from speaking their language and their culture, heritage, and ancestors were discriminated against (Adelson, 2005; Barman, 1995; Battiste, 2004; Indian and Northern Affairs

Canada, 2008b; Morrissette, 1994). These historical injustices, particularly the destructive legacy of the residential schools have created intergenerational trauma and continued cycles of abuse among FNIM peoples (Kirmayer, Simpson, & Cargo, 2003). Post traumatic stress syndrome, loss of language, and loss of traditional cultural practices are some of the negative impacts which continue to shape experiences of ill health and health disparities among FNIM peoples (Adelson, 2005; Indian and Northern Affairs Canada, 2008b; Kirmayer et al., 2003). To this day FNIM communities are still healing from the impact of residential school and rates higher than the population average of substance abuse, violence, crime, child apprehension, disease, and suicide persist (Barman, 1995; Kirmayer et al., 2003). The consequences of these events and others have negatively affected the physical, social, emotion, and mental health of FNIM peoples (Adelson, 2005; Gracey & King, 2009).

Health inequity refers to the disadvantage of a group due to systematic disparities in health that are deemed to be unfair and stem from injustices in the distribution of resources and processes that influence health care and health status (Braveman & Gruskin, 2003). Health inequities, such as: self reported health status, mortality and morbidity persist among FNIM people in Canada (Adelson, 2005; Gracey & King, 2009; Jervis, 2010; Loppie-Reading, & Wien, 2009). FNIM peoples have limited autonomy with respect to their health issues and health care, which was lost when FNIM peoples had to leave their land, culture, and traditions (Adelson, 2005; Newbold, 1998). The biomedical model of health, characterized by situations where health care providers prescribe treatments for specific ailments, is inconsistent with FNIM health beliefs that model a more comprehensive understanding of health and wellness (Adelson, 2005).

The prevalence of chronic disease and self reported poor quality of life among FNIM people is greater relative to the non-native Canadian population (Adelson, 2005; Lavoie et al., 2010; Newbold, 1998; Reading & Nowgesic, 2002; Salehi, 2010). Prior to 2011 the Canadian Census, a nationwide survey conducted every five years, provided a cross-sectional statistical picture of the lifestyle, health, educational, work habits, and lives of Canadians including Canadian FNIM peoples. Similarly, the First Nations Regional Longitudinal Health Survey (RHS) is a national health survey focusing on First Nations peoples and is conducted every four years. The 2002-2003 RHS completed over 22,000 surveys across Canada and reported on 238 First Nations communities. The 2001 Canadian Population Census and the 2002-2003 First Nations Regional Longitudinal Health Survey revealed that First Nations people in Canada are more likely to experience poor outcomes in almost all areas of health (Assembly of First Nations, 2003; Statistics Canada, 2001).

Epidemiological evidence indicates that the potential years of life lost from injury among First Nation peoples was three and a half times higher than the national average; rates of pertussis (whooping cough), rubella (German measles), tuberculosis, shigellosis (intestinal infection), and Chlamydia (sexually transmitted infection) were at least double than that of the rest of the non-native Canadian population (Assembly of First Nations, 2003; Leatherman & Sutherland, 2010). As well, relative to non-native Canadians, FNIM's hospitalization rates were higher for all conditions except cancer (Baker et al., 1998; Institute of Medicine, 2004; Leatherman & Sutherland, 2010). Life expectancy is considerably less for FNIM people living in the Inuit-inhabited areas of Canada (80% of whom are Inuit) (Adelson, 2005; Leatherman & Sutherland, 2010). In addition, FNIM

women have an average life expectancy of 76 years compared to 81 years for non-FNIM women (Pederson, 2001).

There is extensive documentation of the comparatively poor health status and obvious health inequities within Canadian FNIM communities (Angell & Parkins, 2010; Doessel, Travers, & Hunter, 2007; Dyck et al., 2002). In a study conducted on First Nations people from the Six Nations Reserve of the Grand River, Ontario, Six Nations people had higher rates of cardiovascular disease, diabetes, smoking, obesity, and glucose intolerance compared with people of non-native heritage from surrounding cities in Ontario (Anand et al., 2001). In fact, hospital admission rates in Ontario, for ischemic heart disease are declining except in Native communities where ischemic heart disease has doubled (Shah, Hux, & Zinman, 2000). Similarly, a prospective survey of all women admitted for childbirth to the Saskatoon Royal University Hospital in 1998 tested for gestational diabetes mellitus revealed that the rates of gestational diabetes mellitus among FNIM women was twice that of non-FNIM women in Canada (Dyck et al., 2002). Researchers investigating the differences in the determinants of health of FNIM and non-FNIM Canadians living with HIV / AIDS, found that FNIM are disproportionately affected by HIV / AIDS among those of a younger age with lesser education, greater unemployment issues, and greater homelessness (Monette et al., 2011). Furthermore, behavioural practices that detract (e.g., smoking, illicit drug use, poor nutrition) rather than enhance the health of FNIM people also contribute to existing health disparities (Health Canada 1999; Loppie-Reading, & Wien, 2009). The social determinates of health, specifically education, adequate income, and cultural practices are given limited

consideration and attention within the 'medical culture' that dominates the Canadian health care community (Health Canada 1999; Loppie-Reading, & Wien, 2009).

### **Health Issues of On-Reserve First Nation, Inuit, and Métis Peoples**

The Public Health Agency of Canada details a number of issues that influence the health status and health outcomes of Canadians (Public Health Agency of Canada, 2012). These include: income and social status, social support networks, education and literacy, employment / working conditions, social environment, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, gender, and culture (Public Health Agency of Canada, 2012). Social determinates of health can shape the experience of health negatively (e.g., poverty, homelessness) or positively (e.g., well educated, safe and secure occupation settings) (George, 2012). Information on health and health issues for FNIM people living on-reserve is limited, however results from the Aboriginal Peoples Survey indicates that on-reserve FNIM communities reported a lower likelihood of having seen a physician and were more likely to rank their general health as fair or poor compared to those living off-reserve (Newbold, 1998; Tait, 2008). The Report of the Royal Commission on Aboriginal People (1991) showed on-reserve communities experience heightened social problems compared to off-reserve communities related to increased family violence (44% vs. 36%), suicide (36% vs. 34%), sexual abuse (29%, vs. 20%), rape (16% vs. 13%), alcohol abuse (73% vs. 56%), and drug abuse (59% vs. 43%). Additionally, relative to off-reserve FNIM peoples, on-reserve FNIM communities tend to have lower socioeconomic status typified by low levels of education, income, and employment (Anand et al., 2001; Bollman, & Reimer, 2009; Maar, Seymour, Sanderson, & Boesch, 2010).

The 1991 and 2001 Aboriginal Peoples Survey indicated that on-reserve FNIM people report higher rates of diabetes (8% vs 6%) and reported poorer health status and lower health-care utilization patterns than off-reserve FNIM peoples. Of those factors that determine health, evidence from the Aboriginal Peoples Survey also indicated that on-reserve FNIM groups had on average poorer socio-economical status and health behaviours (Statistics Canada 1993; 2003). For example, the median annual income for Registered Indians on-reserve is lower than that of the general Canadian population (\$10,631 vs. \$22,274) (Health Canada, 2009b). In addition, 62% of on-reserve peoples reported incomes of less than \$10,000 per year while only 50% of off-reserve registered Indians reported incomes of less than 10,000 per year (Statistics Canada 1993; 2003). The estimated life expectancy at birth for FNIM peoples on-reserve is 62 years for males and 69.6 for females compared to the total FNIM population which is 74.6 years for males and 80.9 for females (Statistics Canada 1993; Adelson, 2005). A significant risk to poor health reported by The Royal Commission on Aboriginal Peoples (1991) is the overcrowding housing conditions that exist on-reserves. The average on-reserve dwelling houses four people compared to less than three for the non-FNIM population (Statistics Canada 1993; Adelson, 2005). The unemployment rate for on-reserve peoples was 30.1%, compared to the total FNIM population of 24.6% in 1991 (Adelson, 2005).

Health Canada's: A Statistical Profile on the Health of First Nations in Canada (2009a, 2009b) reported on statistics from the First Nations Regional Longitudinal Health Survey about the educational level of on-reserve First Nations adults (Health Canada, 2009a; 2009b). This report indicated that the proportion of Registered Indians on-reserve holding a university certificate, diploma or degree is lower than the equivalent proportion

of non-native Canadians (5.1% vs. 22.7%) (Health Canada, 2009a; 2009b). Conversely, the proportion of Registered Indians on-reserve with less than a high school graduation certificate is higher than the equivalent Canadian proportion (48.6% vs. 22.5%). There are fewer registered Indians on-reserve that have graduated from high school by age 20 compared to all other Canadians (36.0% vs. 84.6%) (Health Canada, 2009a; 2009b). The Royal Commission of Aboriginal Peoples (1991) also reported that 40% of on-reserve FNIM peoples have a less than grade nine education, while only 16% of off-reserve peoples have a less than grade nine education. In addition, FNIM individuals who live off-reserve have better educational outcomes than those who reside on-reserve (Richards, 2008).

### **Young Adult First Nation, Inuit, and Métis Health**

The reported health data on FNIM young adults highlights suicide rates that are five to seven times higher in FNIM young adults compared to other young adults in Canada (Leatherman & Sutherland, 2010). Type 2 diabetes is increasingly prevalent in younger generations and tuberculosis cases have been reported among FNIM individuals at a younger average age than among other non-native born Canadians (Health Canada, 2009a). Young adult FNIM persons have been diagnosed with HIV at a younger age and exhibit a greater incidence of other STIs and the engagement in HIV risk behaviours than non-FNIM peoples (Public Health Agency of Canada, 2007).

The FNIM populations in Canada are on average much younger than the general Canadian population (Health Canada, 2009b; Wilson, Rosenberg, & Abonyi, 2011) meaning that there are more people being born and not living as long. Because the

average age of FNIM Canadians is young, there is a compelling need to attend to their health (Young, 2003).

### **Health Literacy**

There are a number of definitions of health literacy and the most widely used definitions are reported here. The U.S. Institute of Medicine's (IOM) report, *Health Literacy: A Prescription to End Confusion* (2004) defines health literacy as:

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Health literacy skills are inclusive of prose, numeracy, listening, speaking, and cultural knowledge (p.5).

The Institute of Medicine's definition focuses on reading and writing as influenced by cultural beliefs and practices. The Canadian definition of health literacy speaks to "...the ability to access, understand, evaluate, and communicate information as a way to promote, maintain, and improve health in a variety of settings across the life course" (Rootman & Gordon-El-Bihbety, 2008, p. 11). Nutbeam (2000) defines the concept as:

The cognitive and social skills which determine the motivation and ability of individuals to gain access to and understand and use information in ways which promote and maintain good health. (p. 263)

From this definition, health literacy is viewed as more than the functional aspects of being able to read pamphlets and make medical appointments but reflects a composition of reading, writing, listening, speaking, numeracy skills, and critical analysis, as well as social interaction, and advocacy skills (Nutbeam, 1999; 2000; 2008).

Nutbeam (1999; 2000) claims that, by improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment. In essence, health literacy constitutes the skills of reading, writing, listening, speaking, numeracy, and critical analysis that improve the ability of people to act on information in order to live healthier lives across the lifespan (Rootman & Gordon-El-Bihbety, 2008; Nutbeam, 1999; 2000; 2008).

Nutbeam (2000) frames health literacy as a typology of functional, interactive, and critical health literacy, which is the framework guiding this research. Functional health literacy is described as the ability to obtain and comprehend health related material and services for health care. Functional health literacy includes prose, numeracy, document, listening, speaking skills, and cultural knowledge that enables individuals to comprehend information, enhance knowledge, and function effectively within our increasingly complex health system (Nutbeam, 2000). Health education, understanding health facts and risks, the ability to read consent forms, medicine labels, and inserts are all forms of functional health literacy skills. Accessing information, understanding oral and written information within patient provider encounters, and acting upon necessary procedures and directions such as medication and appointment schedules are examples of functional health literacy knowledge and skills (Kickbusch, 2001; Nutbeam, 2000). Interactive health literacy includes the ability to develop personal skills including an enhanced self-efficacy in order to act appropriately on information to improve health status of individuals and / or community (Nutbeam, 1999; 2000). Interactive health literacy includes advanced cognitive and social skills that allow individuals to extract information, to derive meaning, and act on the health advice received within a supportive

environment (Kickbusch, 2001; Nutbeam, 2000). This level of health literacy is directed at improving personal capacity to be able to act on knowledge to improve self confidence and motivation (Nutbeam, 2000). An example of interactive health literacy includes encouraging students to develop specific skills as health consumers through education courses or online health community discussion groups (St Leger, 2001). Interacting with each other and discussing health material is indicative of interactive health literacy (Kickbusch, 2001; Nutbeam, 2000)

Finally, critical health literacy requires advanced cognitive skills and is directed at changing policies and practices that influence the social / health determinants of populations (Nutbeam, 2000). Critical health literacy skills include the ability to critically analyze information with greater autonomy and to use this information to create change or exert greater control of events and situations within the broader social context (Nutbeam, 2000). Here, the development of health education (e.g., activism knowledge and skills) that advocates for collective action on the social determinates of health reflects critical health literacy (Nutbeam, 2000). People collectively coming together to create changes in policy is an example of critical health literacy (St Leger, 2001). Critical health literacy skills support effective social and political action, benefiting an entire population (Nutbeam, 2000; St Leger, 2001).

Health literacy is influenced by level of education, early childhood development, aging, living and working conditions, personal capacity and genetics, gender, and culture (Nutbeam, 2000; Rootman & Ronson, 2005). Having adequate health literacy allows the public and personnel working in all health-related contexts to access, understand, evaluate and communicate information as a way to promote, maintain and improve health

in a variety of settings across the life course (Institute of Medicine, 2004; Kickbusch, 2008; Nutbeam, 2000; 2008; Rootman & Gordon-El-Bihbety, 2008). Health literacy skill is needed by providers, organizations as well as clients / patients. As an important health promotion strategy, health literacy is a means of enabling individuals to exert greater control over personal, social, and environmental determinants influencing their health (Institute of Medicine, 2004; Kickbusch, 2008). Much of the literature available on health literacy skills is focused on the client / patient (Gazmararian, Parker, & Baker, 1999; Safer & Keenan, 2005; Scott et al., 2002). Physicians often believe their patients' literacy level to be higher than it is and this creates problems where patients do not fully understand health instructions and health care advice (Gazmararian et al., 1999; Safer & Keenan, 2005; Scott et al., 2002). Effective health communication is fundamental to successful patient-provider relationships (Davis et al., 2008). Only recently has the influence of health literacy skills of the health care provider gained greater recognition within the published literature (Schillinger et al., 2003; Williams, Davis, Parker, & Weiss, 2002).

### **Health literacy among Canadians.**

The International Adult Literacy and Skills Survey (IALSS), conducted in 2003 interviewed adults aged 16 to 65 to capture information on prose literacy, document literacy, numeracy, and problem solving skills. The IALSS, a large scale survey collecting data from many countries scored health literacy into 5 levels. Level 1, the poorest health literacy skill, is reflective of the ability to read relatively short text, locate or enter information and complete simple, one step tasks such as counting, sorting dates, or performing simple arithmetic (Canadian Council on Learning, 2007). Level 2 skill is

displayed in the ability to sort through information “distracters” (plausible but incorrect pieces of information), integrate two or more pieces of information, compare and contrast information, and interpret simple graphs (Canadian Council on Learning, 2007). Level 3 health literacy skill required individuals to integrate information from dense or lengthy text, integrate multiple pieces of information and demonstrate understanding of mathematical information represented in a range of different forms (Canadian Council on Learning, 2007). Level 4 skill involved multiple steps to find solutions to abstract problems, requiring the ability to integrate and synthesize multiple pieces of information from lengthy or complex passages and make inferences from the information (Canadian Council on Learning, 2007). Level 5 skill required individuals to search for information in dense text which has a number of distracters, make high-level inferences or use specialized background knowledge to understand complex representations of abstract formal and informal mathematical ideas (Canadian Council on Learning, 2007).

This IALSS reported that 48% of Canadian adults age 16 and over have limited general literacy skills (OECD & Statistics Canada, 2005). Furthermore, health based survey questions from the IALSS indicated that 60% of Canadians have limited health literacy (Canadian Council on Learning, 2007; 2008; OECD & Statistics Canada, 2005). The report by the Canadian Council on Learning (2007) indicated that the average health literacy score of all Canadians is 258 which corresponds to a level 2 on a scale of 1 to 5. People with level 2 health literacy skills are able to deal with very simple, clear material involving uncomplicated tasks and are especially challenged in dealing with our increasingly complex health care system (Canadian Council on Learning, 2007).

The Canadian Council on Learning (2007) report on the health literacy skill of Canadians reveals there are large differences in health literacy among different populations within Canada, specifically the elderly, immigrant and FNIM people have lower health literacy compared to the rest of Canadians (Canadian Council on Learning, 2007). Nationally, individuals living in the Yukon Territory demonstrated the highest level of health literacy while people living in Nunavut had the lowest health literacy; Ontarians' health literacy skill scores fall in the middle among all provinces and territories in Canada (Canadian Council on Learning, 2008).

**The influences of health literacy on health status.**

Current literature indicates that limited health literacy is associated with poor health outcomes and poor health status (Canadian Council on Learning, 2008; Institute of Medicine, 2004; Nutbeam, 2008; Paasche-Orlow & Wolf, 2010; Rootman & Ronson, 2005). Adults with limited health literacy are more likely to self report poorer health (Institute of Medicine, 2004; Rootman & Gordon-El-Bihbety, 2008; Rootman & Ronson, 2005; Squellati, 2010). Effective health literacy skills are linked to a reduction in disease morbidity, disability, and mortality (Rootman & Ronson, 2005; Squellati, 2010).

On average, people with limited health literacy skills tend to have limited education, low socio-economical backgrounds, greater chronic disease, and often report poorer overall health (Adams et al., 2009; Kickbusch, 2008; Pirisi, 2004). The shame, guilt, and stigma associated with limited literacy skills is a major barrier in improving health literacy (Adelson, 2005). Those with limited health literacy have less knowledge of disease management, and health-promoting behaviours, and overall have a lower health status (Rootman & Ronson, 2005). Furthermore, there are higher rates of

hospitalization among those with limited health literacy (Baker et al., 1998; Institute of Medicine, 2004).

A review of research articles published between 1996 and 2001 by Davis et al. (2002) found that people with inadequate health literacy skills are more likely to have health problems, live in poverty, and have fewer years of education. In addition this review of the literature also showed that an individual's health literacy may be an important predictor of disease risk (Davis et al., 2002). Research evidence indicated that adults with limited health literacy were less likely to engage in preventive health practices, had less knowledge about their medical conditions, were more likely to present with advanced stages of disease or illness, and experienced higher rates of disease mortality (Davis et al., 2002; Garbers & Chiasson, 2004). Individuals with limited health literacy have greater vulnerability to many health issues and documented evidence of ineffective use of health services, chronic illness, and susceptibility to preventable diseases and accidents (Canadian Council on Learning, 2008; Institute of Medicine, 2004).

Similarly, the Canadian Public Health Association (2006) suggested that people with limited health literacy may experience poorer health from barriers of prevention and self-care. These barriers for people with limited health literacy include:

Health information not presented in a way they can understand, providers [that] are not trained in clear verbal communication and how to work with people with health literacy barriers, "locus of control" ... with the provider, difficulty navigating the system and knowing what options are available, limited basic knowledge and skills for prevention and self-care,

not fully understanding how the body works, the condition and the treatment, difficulty advocating for themselves in the health system, practical supports for healthy lifestyle or self-care may be unavailable or inaccessible, and language and cultural barriers to prevention and self-care are present. (p.5)

Societal outcomes, improved quality of life, maintenance of functional independence, social equity, and improved community development and empowerment have all been associated with health literacy skills (Donelle & Hoffman-Goetz, 2008; Rootman & Gordon-El-Bihbety, 2008; Smylie et al., 2006). Paasche-Orlow & Wolf (2007) propose that health literacy influences outcomes at three separate junctures; access to health care, interaction between patients and health care professionals, and differences in self-care practices. Health literacy is related to the health system, culture, and society, and this intersection influences the health outcomes and the cost of health care (Paasche-Orlow & Wolf, 2007).

### **Health literacy of First Nations, Inuit, and Métis peoples.**

The United Nations Human Development Index, which measures health through longevity, educational achievement, and adult literacy, ranked FNIM people in Canada 63rd in the world which puts them in the same conditions as third world countries (Inuit Tapiriit Kanatami, 2004). Results from the IALSS indicated Canadians with FNIM status were more likely to have limited health literacy (Canadian Council on Learning, 2007).

Often used measures of health literacy such as the Rapid Estimate of Adult Health Literacy, The Test of Functional Health Literacy in Adults (Parker, Baker, Williams & Nurss, 1995), and the Newest Vital Sign (Shah, West, Bremmeyr, & Savoy-Moore,

2010), treat health literacy as a set of skills and measure it by testing for reading, writing, numeracy, and pronunciation which tend to ignore socio-cultural factors (Smylie et al., 2006). When attending to FNIM peoples' health literacy, certain cultural aspects have to be addressed (Antone, Archibald, & Blair, 2003). Smylie et al. (2006) suggests that FNIM health literacy skills include ideas of building family relationships, nutrition, FNIM language, and traditional ceremonies. Culturally-based approaches to health literacy are an important area of investigation in terms of better defining and measuring FNIM health literacy.

Issues of health literacy among FNIM peoples are not well documented in the research literature. The development of interpersonal and social skills which support people to change their health behaviours aligns with FNIM philosophies, culture, and oral traditions (Hulan & Eigenbrod 2008; Stewart, Riecken, Scott, Tanaka, & Riecken, 2008; Rootman & Ronson, 2005). The Canadian FNIM beliefs of health come from unique perspectives that depart from the medical model of health that dominates North American society. As it is currently defined and measured, the concept of health literacy does not recognize FNIM cultural differences in language, education, and health (Smylie et al., 2006). Special attention to FNIM culture is required to address issues of health literacy among FNIM peoples in a meaningful way. Health literacy interventions designed by non-FNIM individuals and without FNIM knowledge of way of life have produced limited success (Stewart et al., 2008). Until there is a measurement tool that looks at health literacy in ways that includes these socio-cultural factors, FNIM health literacy will be difficult to define and measure (Smylie et al., 2006).

### **eHealth literacy.**

The intensity and frequency of Internet use in Canada is increasing (Middleton, Veenhof & Leith, 2007). According to the Canadian Internet Use Survey from 2010, more than two-thirds of Canadians went online at least once per day and just less than half of Canadians were online for five or more hours per week (Statistics Canada, 2010a). The term eHealth defines an emergent field of online information technology and health and describes how users of the Internet including health care providers, patients, and the media gather health information from online resources. Eysenbach (2001) defines eHealth as:

The intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology. (p.e20)

Eysenbach (2001) explains that the 'e' in eHealth represents efficiency, enhanced quality, evidence based, empowerment, encouragement, education, enabling, extending, ethics, and equity. Eysenbach (2008) offers a model of eHealth communication, he calls Medicine (Health) 2.0 that moves beyond the traditional provider / expert as the main source of health information to include health care consumers or patients, and biomedical researchers as important health information sources. Health 2.0 applications, services, and tools are web-based services that involve the collective intelligence of health care

consumers, patients, health care providers, and researchers that use Web 2.0 technologies (Eysenbach, 2000; 2008; O'Reilly, 2005; Mandl & Kohane, 2008). Health 2.0 technologies facilitate five major themes of: (1) social networking, (2) participation, (3) apomediation, (4) openness, and (5) collaboration (Eysenbach, 2008).

The interactive capacity of Health 2.0 applications such as online social networking allows individuals to collaborate and form relationships with others (Eysenbach, 2008). Participation is another theme from the Health 2.0 model and involves the participation of consumers along with health care providers and researchers; for example, consumers, health care professionals, and researchers are able to connect with each other and communicate via use of an electronic health record or personal health record (Eysenbach, 2000; 2008; Hesse et al., 2010). Apomediation is the idea that agents or tools (e.g., consumer reviews, 'expert patients') serve to guide other online information seekers to high quality, credible online health information (Eysenbach, 2008; O'Conner, 2008). The social networking site Facebook™ is an example of an apomediated environment where members can help each other navigate through extensive information sources and provide information to each other (Eysenbach, 2008; O'Conner, 2008). Collaboration is the idea that groups of people that do not typically interact with each other (e.g., scientists and public consumers), can engage with each other to translate and share knowledge (Eysenbach, 2008). Openness is the theme that is associated with client control and use of information / service resources. Eysenbach (2008) argues that openness is about people having control of their health data and access to research data. Openness and collaboration engage scientists, the public, and health care

professionals to be involved in health and online health information sources (Eysenbach, 2008).

The use of the Internet and related technologies is increasing in Canada and particularly among those seeking information about health and health services (Rootman & Ronson, 2005). The Internet has improved public access to information and communication, and has changed the way we interact with others (e.g., health care providers and general public) regarding health issues (Atkinson, Saperstein, & Pleis, 2009; Eysenbach, 2008; McCray, 2005; Viswanath & Kreuter, 2007). Health information accessed via the Internet allows information seekers to review health information as needed and perhaps minimize the negative stigma experienced by those with limited health literacy skill (Bickmore et al., 2010). Technologies like automated telephone calls, integrated electronic health record systems, online patient portals, and computerized search agents increase opportunities for accessing health information and have the potential to advance health literacy (Paasche-Orlow & Wolf, 2010).

Growing evidence suggests that the Internet has changed people's relationship with health information and that online resources are an increasingly significant source of health information and services (Fox, 2011c; Eysenbach, 2008). Researchers with the National Cancer Institute's Health Information National Trends Survey (2005) asked over 5000 U.S. citizens about their health communication practices, health information preferences, risk behaviours, attitudes, and disease knowledge and reported that the Internet was the most widely used resource for health information. Atkinson et al., (2009) found, in their analysis of the National Cancer Institute's Health Information National Trends Survey, that people using the Internet to access health information were seeking

health information for themselves and others, were participating in support groups with those with similar health or medical conditions, and were purchasing medications or vitamins online.

People gain health information from a variety of sources including: TV, radio, friends and family members, health care providers, and increasingly more from the Internet (Viswanath, 2006; Viswanath & Kreuter, 2007; Eysenbach, 2008). However, online health information seekers tend to have higher income and higher education and those with less education and less income may be disadvantaged in terms of online health information access (Viswanath, 2006). Limited health literacy reduces access to health information and an individuals' ability to locate and evaluate relevant health information online (Viswanath & Kreuter, 2007). Ironically, it appears that individuals who experience the greatest disadvantages with respect to many of the determinants of health are the least likely to benefit from online computer technologies (Eng et al., 1998; Viswanath & Kreuter, 2007).

Yet results of a study investigating the use of online health information technology with participants with less education, less income, and lower health literacy indicated that patients were receptive to learning via computer technology (Bickmore et al., 2010). In a clinical setting, Bickmore et al. (2010) investigated the use of embodied conversational agents, which are virtual people on the computer screen that simulate face-to-face conversations with patients to help communicate health information. The researchers found that patients with limited computer and Internet skills were more accepting of computer tools and gathering information via online virtually created people compared to in-person nurse / patient interactions (Bickmore et al., 2010). Results from

this study demonstrate that people with little computer experience and limited health literacy were successfully able to use new technologies and understand the health information from the computer (Bickmore et al., 2010). Similarly, a study conducted in northern Ontario investigated the Internet as a potential health promotion tool among urology patients and found that patients who used the Internet to access health information assumed a more active role in their own health care and claimed that Internet access to health information influenced their treatment choice (Abara, Narushima, & Abara, 2010).

Robinson & Graham (2010) used an eHealth literacy measurement tool (eHEALS), with HIV-positive patients to determine whether an educational intervention of basic computer skills and online health information improved the participants' health literacy skills. The researchers reported that computer and online health education sessions enhanced the health literacy skills (e.g., computer / Internet information access) and confidence of low literate participants (Robinson & Graham, 2010). Although people with limited health literacy are less likely to access health information online relative to individuals with adequate health literacy (Viswanath & Kreuter, 2007), this research indicated that computer skill educational sessions are helpful in supporting low health literate people in gaining access to online health information (Bickmore et al., 2010; Robinson & Graham, 2010).

### **Social media.**

Seventy-five % of all Canadian adults use the Internet at least once a day and 70-80% of those individuals use the Internet in search of medical or health related information (Fox, 2011c; Statistics Canada, 2010a). A study of youth in Ontario showed

that study participants most frequently used online technology to find information about specific medical conditions and diseases (Skinner et al., 2003). Young adults, the largest population segment of computer and Internet users, tend to rely on peers, school, and the media for their health information (Lariscy, Reber, & Paek, 2010). Online social networking sites are web-based services that allow individuals to construct a public or semi-public profile within that online system, connect with other users through the use of pictures, words, and video (Boyd & Ellison, 2007). Online social media networking sites have attracted millions of users and serve to connect people based on shared interests, political views, or activities (Boyd & Ellison, 2007). Social media and online networking sites incorporate new technologies that can be accessed from virtually everywhere via use of smartphones (blackberrys, iphones, and other new-age phones with Internet capabilities), tablets, laptops, or other similar devices (Boyd & Ellison, 2007). These online social networking sites have the ability to support relationship development given the interactive, communicative, and social aspects of the technologies (Avery et al., 2010).

Gaining access to quality health information has the potential to increase individual knowledge and control over one's health, to serve as a means of maintaining a healthy lifestyle, to provide reliable information about particular problems, and to increase awareness regarding possible treatment options (Rieke, 2005). Active online social networks (i.e., Facebook™ and Twitter™) have been effective in facilitating better self-care practices, improved disease-state knowledge, coping skills, and engagement in healthier lifestyles (Donelle & Hoffman-Goetz, 2008; Fox, 2011c; Rieke, 2005; Robinson & Graham, 2010; Squellati, 2010). In fact, a recent U.S. survey showed that 23% of

online social network users have followed their friends' personal health experiences online (Fox, 2011c). Not only does online health information via social media networks support health care, but also serves as an effective way to gain support from family and friends in time of illness (Fox, 2011c; Squellati, 2010).

Currently, Facebook™ and Twitter™ are the largest social media information applications with more than 350 million users worldwide (Greene & Kesselheim, 2010; Liaw, Lau, & Dennis, 2010). Twitter™ is an online social network that allows people to post short messages known as tweets to others that are following or reviewing their account. Twitter™ has been used by individuals, including health related groups, to post messages concerning health issues and to also provide links to relevant health articles (Liaw et al., 2010). Participants of these online social networks have the ability to gain information, share experiences and tools for research, education, and fundraising through these online websites (Greene & Kesselheim, 2010). Seeking information from online social networking sites enables individuals to communicate with others of similar interests and feel supported through discussion concerning the information they gather (Liaw et al., 2010; Vance, Howe, & Dellavalle, 2009).

While primarily used for creating and maintaining social contacts, online social networks are evolving into important health information and services resources. Social media networks also serve a supportive function among family and friends (Liaw et al., 2010). Individuals can post online messages of health information and personal encouragement as a means of support to family, friends and even strangers; this kind of online communication is quick and can provide timely support to people in need (Liaw et al., 2010). Furthermore, health databases such as MEDLINE have enabled Facebook™

users to post links to published research on numerous health issues (Liaw et al., 2010; Vance et al., 2009). These links can be shared among multiple networks of friends and health professionals thereby integrating health information throughout the social networking sites. The development of this tool has allowed evidenced based health information to be uploaded online within peoples' social networks (Liaw et al., 2010).

### **First Nation, Inuit, and Métis eHealth literacy.**

Eighty eight percent of Internet users live in developed countries which accounts for 15% of the world's population (UNDP, 1999). Four out of five websites are in English, while only 10% of the people in the world speak English therefore excluding many people from accessing health information from online resources (Kickbusch, 2001). FNIM Canadians who collectively speak up to 60 different languages may be disadvantaged with respect to online health information access (Statistics Canada, 2004). Besides English, the native languages of Cree, Ojibway, Oji-Cree, and Mohawk (in Quebec) are the most frequently used languages by youth on a daily basis (Norris, 2007; RHS, 2002 / 2003). According to the RHS (2002 / 2003), FNIM language is important to FNIM parents and grandparents and is part of the FNIM culture. Despite the importance of language to FNIM culture, traditional languages are disappearing (Reading et al., 2007) and only one in four FNIM peoples speak a FNIM language (Norris, 1998; 2007). Yet language remains a symbol of culture and group identity and is not only just words people use to communicate, but it also connects people with their social, emotional, and spiritual beliefs (Norris, 1998). Language plays a major role in defining the culture of a group (Antone et al., 2003; Norris, 1998; 2007) and specifically, FNIM peoples' traditional languages are a key component in the creation of healthy individuals and

communities (Statistics Canada, 2004). Antone et al. (2003) explains the importance of FNIM language noting it is related to a sense of identity for FNIM peoples. Language preserves FNIM peoples' traditional knowledge about their culture (past and present) and enhances their capacity to take part in their traditions (Antone et al., 2003; Norris, 1998; 2007). Language influences how personal lived experiences are told and enhances the art of storytelling, a large part of traditional FNIM culture (Antone et al., 2003).

With more than half of North Americans using the Internet as an information source (Greene & Kesselheim, 2010; Guselli, 2010), it is important to look at how FNIM peoples of Canada are using the Internet for health related purposes. Introducing English based information technology to FNIM communities may not reach or be well understood by FNIM peoples (Kickbusch, 2001; Travers, Hunter, Gibson, & Campion, 2006; Hunter, Travers, Gibson, & Campion 2007). English-based online health information may fall short of expectations if individuals are lacking the experience or the desire to use these technologies because of the lack of cultural markers the new information technology may or may not have (Kickbusch, 2001). Concernedly, having access to Internet resources does not necessarily guarantee that the retrieved information is accessible in terms of individuals' understanding or comprehension of information / services (Adelson 2008; Newbold, 1998; Nutbeam, 2000).

While most people, even those with limited literacy skills, have indicated a desire to access online [health] information, (Eng et al., 1998; Miller & West, 2009; Robinson & Graham, 2010), as noted above, literacy challenges and Internet navigational skills may preclude those with limited health literacy from benefiting from online health resources (Adelson, 2008; Smylie, et.al., 2006; Viswanath, 2006). Health literacy,

inclusive of a person's ability to read and understand written and verbal information, assumes a western socio-cultural context (Smylie et al., 2006). Health literacy is reflected differently among FNIM peoples and goes beyond skills of reading, writing, numeracy, and pronunciation (Adelson, 2008; Smylie, et al., 2006). An understanding of health literacy among FNIM people should incorporate spiritual, emotional, mental, and physical elements. Smylie et al. (2006) suggests that building healthy family relationships, nutrition, and mother tongue language instruction can be a part of FNIM health literacy.

FNIM people are some of the most disadvantaged groups in Canada related in part to historical experiences of inequities (Frohlich et al., 2006; Smylie et al., 2006). Furthermore, lower-income individuals living in rural areas with limited or no Internet use are further disadvantaged in terms of health information access (Miller & West, 2009). While the Internet and social media technology are important avenues for information access for North Americans (Fox, 2011a), most available online health information is not constructed nor tailored for FNIM populations nor does it take into account their cultural and historical underpinnings (Iseke-Barnes, 2002).

Creating appropriate online health information that respects cultural and regional health indicators (e.g., FNIM websites specific to FNIM traditional knowledge and traditional health and healing) for FNIM people will help ensure the utility and usability of the information (McMahon, O'Donnell, Smith, Woodman Simmonds, & Walmark, 2010; Morrison, 2000). As such, FNIM world views must find representation in the health information provided (Iseke-Barnes, 2002). Maintaining cultural relevancy and

sensitivity of health information will help facilitate FNIM individuals' interest and engagement in their health (Kildea et al., 2009; Iseke-Barnes, 2002).

There are over 10,000 websites associated with FNIM culture and history of North America, some of which are social networking websites dedicated to providing virtual meeting places for conversations about topics specific to FNIM culture, like spirituality and healing (Iseke-Barnes, 2002). Differences in health literacy, privacy preferences, and lifestyle all impact how social networking is perceived and interpreted by the people who use these social network websites (Guselli, 2010; Lenhart et al., 2010). There is preliminary evidence of health related Internet and social media use in some FNIM communities (McMahon et al., 2010). Kuh-Ke-Nah or K-Net is the largest FNIM network in Canada (McMahon et al., 2010). It is a bulletin board and an online meeting space to converse and share information among FNIM communities (McMahon et al., 2010; O'Donnell, Milliken, Chong, & Walmark, 2010). The MyKnet.org network plays an important role in connecting people in many communities and providing a means for people to build and maintain relationships concerning health issues and information (Budka, Bell & Fiser, 2009). While the majority of MyKnet.org users are under 25 years of age, signifying a primarily youth-driven online social environment (O'Donnell et al., 2010), FNIM online activities can be an important means for communities to keep in touch and maintain a sense of community despite changing geographic locations (Budka et al., 2009).

Geographic location, the ability to obtain and comprehend online health information via the Internet or social media tools, and the capacity of people to use these technologies effectively are some of the barriers that restrict the access of FNIM

Canadians to quality health information (Eng et al., 1998). To date, there is limited information published on broadband connectivity needs, rates of information and communication technology (ICT) access, and use of Internet in rural and remote FNIM communities (Industry Canada, 2009; O'Donnell et al., 2010). Equitable access to high speed online connections is a major concern, especially since lack of or limited access to certain media inhibits the use of digital technology (Ginsberg, 2008). Equitable infrastructure and connectivity in communication technology has the potential to reduce the disparities regarding access to online services (Ramirez, 2007). To date, the research investigating how and to what extent FNIM people in Canada use Internet / online social networking health resources is limited. Research into FNIM health literacy skill would provide insight into the benefits, disadvantages, and opportunities to shape health information access using social media technology for FNIM peoples.

### **Research Purpose and Question**

The inequities that exist among FNIM peoples, exemplified by high rates of chronic disease (e.g., diabetes, HIV / AIDS), suicide, challenges to mental health, addictions, and lower age standardized mortality compared to the non-FNIM population, are extensively documented (Statistics Canada 1993; Chandler & Lalonde, 1998; Kirmayer et al., 2000; Young, Reading, Elias & O'Neil, 2000). Access to accurate, appropriate, and timely health information and services is fundamental to self care and self health promotion (Rootman & Edwards, 2006). The Internet and social media technologies have enhanced access to health information and services for many Canadians but alternatively may disadvantage individuals who have limited literacy, health literacy, and eHealth literacy skills (Viswanath, 2006; Viswanath & Kreuter,

2007). On average, FNIM peoples have limited health literacy skills that further disadvantages them in terms of accessing and comprehending health information online (Adelson, 2005; Smylie et al., 2006). Given the importance of information and service access to disease management, prevention and health promotion there is relatively limited published literature on FNIM peoples' health literacy skills. As such, the purpose of this study was to investigate and gain an understanding of the health literacy skills and health information needs of FNIM young adults living on-reserve. This research explored participants' preferred sources of health information and communication channels, and specifically the use of online social media for health information access. The research process was guided by Nutbeam's (2008) typology of functional, interactive and critical health literacy. Given the limited research literature on the health literacy skills of FNIM young adults this research explored the health literacy skills of on-reserve young adult FNIM peoples. The research question guiding this research was: what are the health information needs and health information access preferences of FNIM young adults?

## **Methods**

### **Study Design**

History shows that previous research with FNIM populations has had elements of discriminatory and unethical practices (Smith, 1999). All research with FNIM peoples should ensure the respect, the culture, heritage, customs, community, and history of FNIM individuals / communities (Canadian Institutes of Health Research [CIHR], 2010). Community-based research facilitates collaborative partnerships in all phases of the research and includes active participation from the participant (Israel, Schulz, Parker, & Becker, 1998). Community-based researchers recognize the community as an aspect of the research and this type of research is based on the shared values and norms within the community (Altman, 1995; Israel et al., 1998). Part of community-based research is the act of dissemination of findings and knowledge gained to all partners including the participants (Israel et al., 1998; Wall, 1995). In respect of the tenets of community-based research practices, research partnerships with FNIM communities were initiated through consultation with members of a community-based Aboriginal health clinic, Indigenous Services at a local university, and members of a First Nations reserve community (CIHR, 2010).

This study used a qualitative descriptive exploratory design guided by community based research practices (Lincoln & Guba, 1985; Sandelowski, 2000; 2004; 2010). The goal of a qualitative descriptive study was to provide a comprehensive understanding of human experiences as described through the participant's own words (Milne & Oberle, 2005; Sandelowski, 2000; 2004; 2010). Given the limited literature on FNIM peoples'

health literacy skills, a qualitative descriptive methodology fit well with this exploration of health literacy skills of young adult participants.

Health Promotion is a process which enables people to take control over their own health (WHO, 1986). With respect to this study, the researcher's ontology was a tentative realist stance. The researcher looked for a valid truth from multiple subjective meanings by developing a consensus among participants. A single deduction was interpreted of a cautious truth deemed only valid by the researcher and the knowledge gained from participants through reflexivity (Morrow, 2005). Epistemologically speaking, knowledge was understood by looking at the construction of meanings gained from multiple interviews and perspectives that were all taken into account. Embracing subjectivity by using it in the data through reflexivity was administered throughout the study as it was important for the researcher to be able to interpret meanings (Morrow, 2005). I, the researcher am a young adult female in similar age to the participants of this study and because of this may be able to relate to and feel for the participants because we are of similar age. However, I am not a mother and am non-native and realize that this may change the way I am received by the participants as well as how I interpret their stories. I may be looked at as an outsider to these young women and have not gone through the same life experiences as these women. I realize these difference and similarities and understand how data analysis may be influenced. I am an active social media user and I am comfortable using a variety of computer and information technology devices. Personal reflection, in the form of journaling, was considered when analyzing the data (Sandelowski, 2004). Throughout the time that this study took place; I recorded casual conversations and observations I had during my time on the reserve. In addition to having

the reflexive journal, I also had many meetings and conversations with my supervisor and advisory committee to discuss new findings, research questions, and the evolving themes. Throughout the analysis process, I reflected on the differences and similarities between the participants and myself. Reflexive journaling and discussions with my supervisor / advisory team supported the data analysis.

Ethics approval was obtained for this study through the Western University's university research ethics board (see Appendix A).

### **Participants**

First Nations' young adults with an on-reserve home address were invited to participate. For this study, self-identifying First Nation young adults (between 18-34 years of age) were recruited. The age range that characterizes 'young adult' has multiple definitions. Research by Lenhart (2010) defined young adults as 19 to 29 years of age (inclusive), whereas others have defined young adults as 18 and 34 years of age (inclusive) (Canadian Council on Learning, 2006). This study used the age range of 18 to 34 years to define the 'young adult' period of growth and development.

### **Sample Size**

First Nations young adult participant volunteers were recruited using purposeful sampling techniques (Koerber & McMichael, 2008). The purposeful selection of participants includes those that will provide relevance to answering the research question and the phenomenon under investigation (Sandelowski, 1995). Qualitative research has no specific rules for the determination of sample sizes, but guidelines suggest that a study's sample size should involve a sufficient number of participants to achieve an adequate breadth of perspective and a complete and accurate picture of this group (Elo, &

Kyngäs, 2007; Van Hulle Vincent, & Gaddyz, 2009). In this type of qualitative research, participant recruitment persists until data saturation occurs (Bowen, 2008; Francis et al., 2010; Guest, Bruce & Johnson, 2006). Saturation is reflected by the number of events, incidents, and experiences accounted for by the participants, not the amount of participants (Bowen, 2008; Guest et al., 2006). In this study data saturation occurred when no new categories or themes were identified from the collected data (Francis et al., 2010; Guest et al., 2006; Marshall 1996).

### **Inclusion / Exclusion Criteria**

Participant volunteers were included in the study if they fit the following criteria:

(1) Participants were between the ages of 18 and 34, (2) male or female, (3) self identified as Métis, Inuit, or First Nations, (4) self identified as living on a reserve in Ontario, and (5) will consent to research participation. Participants who did not understand, read, or write English, as to be able to properly understand and respond to the interview questions were not recruited.

### **Participant Recruitment**

Multiple sites were considered as potential locations for participant recruitment. Community-based research included the development of relationships with the community of interest. The researcher visited and met with a nurse at an off reserve Aboriginal health centre and with people working and currently involved at a local Aboriginal Friendship Centre. A First Nation's Student Centre and Indigenous Student Services were also contacted in two local post-secondary educational institutions. University faculty that currently conduct research with FNIM communities were consulted for their expertise in participant recruitment. The researcher also met with a

First Nation community worker that lived and worked in an on-reserve community health centre. There were many discussions about research direction and shared values and outcomes. All participants were recruited from one on-reserve community health centre. All participants were informed of the study via a letter of information and were required to provide signed consent prior to participating in the research. Recruitment / information flyers (see Appendix B and Appendix C) inviting interested participants to contact the researcher were distributed throughout Indigenous Services at the university and the community based Aboriginal health clinic. Participants were asked to inform other young FNIM adults about the study to create awareness about the opportunity to participate in the research (Goodman, 1961).

### **Data Collection**

Semi-structured interviews were conducted with participants to gain an in-depth understanding of participants' health literacy skills, specifically their health information preferences, and information access strategies. Demographic information including: age, place of residence and place of birth, education level, and income level were asked and recorded. Consistent with the chosen methodology, qualitative descriptive studies are directed towards discovering the experiences of participants in their own environments through semi-structured open-ended interviews (Sandelowski, 2000). The interviews explored participants' information needs and access behaviours as framed by Nutbeam's (2000) health literacy typology of functional, interactive, and critical health literacy skills. Health literacy is reflected differently among FNIM peoples and goes beyond skills of reading, writing, numeracy, and pronunciation (Adelson, 2008; Smylie, et. al., 2006). Particularly, an understanding of health literacy among FNIM people should

incorporate spiritual, emotional, mental, and physical elements. Smylie et al. (2006) suggests that building healthy family relationships, nutrition, and mother tongue language instruction can be a part of FNIM health literacy. Furthermore, topic of health information and health information seeking habits can be personal and the use of individually focused interviews rather than focus groups created a context of confidentiality that enhanced honest disclosure of personal experiences (Giacomini & Cook, 2008). Individual interviews allowed the participants to describe their experiences in their own words in confidential environments (Findlay & Ballinger, 2006). As interviews progressed, the researcher explored issues that had developed in previous interviews and revised questions to the interview guide as needed (Findlay & Ballinger, 2006). For example one interview question was, 'does your community have any websites that you access?', and asked probing questions for further clarification, e.g., If yes, 'what kind of websites do you access', if no, 'what kinds of websites are you aware of'. All interviews took place in a private area in an on-reserve community health centre. The participants were familiar with the centre and were free to leave at any time during the interview if necessary. All participants received a \$15.00 gift card. Interviews lasted approximately 60 minutes. A record of each interview was kept with the date, time, place, and unique identifier for each person. Each interview was audiotaped for later transcription. Immediately after the interview, the interviewer recorded a description of events and processes observed as well as reflective notes about possible emerging codes and themes (Guest et al., 2006; Marshall, 1996). An interview guide was used to facilitate the interview process and a copy of the interview guide and the interview questions can be found in Appendix D.

## **Data Analysis**

Data from the interviews was analysed simultaneously with data collection as both the collection and analysis of data shaped the development of the other. Analysis was done concurrently with data collection in order to permit emergent themes and inform the direction of the next interviews (Findlay & Ballinger, 2006). The researcher listened to the interviews in order to gain a general understanding of the scope and context of the data (Miles & Huberman, 1994). The researcher then transcribed the recordings by listening to the audiotaped interviews and typing out exactly what was said. This was completed immediately after each interview and the data was coded line-by-line. The researcher used the cut and paste function on her computer to organize codes (segments of data, i.e., sentences, words, or paragraphs) into categories that she kept in chart form (Miles & Huberman, 1994). Descriptive statistics provided an overview of the number of people living on-reserve, place of birth, education level, and income level. The iterative analysis of data continued until a thorough picture of the experiences, thoughts, and perspectives of the participants was developed. Descriptive qualitative data analysis was used to inductively generate data categories and themes that explained the type and process of health information access (health literacy skills) among First Nations young adults (Coffey & Atkinson, 1996; Sandelowski, 2000). By reading through several times, the researcher was looking for particular events and key words that captured the essence of the piece and created as many headings as necessary to capture participants perception of their health information needs (Elo & Kyngäs, 2007; Hsieh & Shannon, 2005).

Codes were inductively generated from the transcribed interviews and were refined as more interviews took place. This iterative process allowed the researcher to

review the data many times to properly conceptualize, raise questions, and provide answers within the data (Coffey & Atkinson, 1996). As categories were generated, themes emerged and as more interviews took place, the themes were reformed and adjusted accordingly. Research findings were documented by the use of excerpts within the interviews. The outcome of this research was a qualitative descriptive summary of the information in a way that best fits the data. The research team consisting of researchers involved in: sociology, Indigenous research methodology, health sciences, nursing, health literacy, and knowledge translation. The diversity of the advisory team created many collaborative discussions and scrutiny in terms of data analysis supporting the credibility of the research findings. Two researchers reviewed the data independently, and compared and discussed the findings; any analytic discrepancies were fully reviewed and discussed until consensus was achieved (Goldsmith, Bankhead, & Austoker, 2007).

Strategies focusing on rigor were performed throughout the interviews, not at the end of the study (Morse et al., 2002). During the participant interviews, the researcher reflected meanings and interpretation back to the participants to check for the accuracy (Morse et al., 2002). This form of verification that occurred continuously throughout the data collection and analysis was one of the strategies used to ensure rigor (Guba & Lincoln, 1981). If participants did not agree with interpretations, conversation about the meaning was discussed until understanding was achieved (Morse et al., 2002). The goal of this research was not to ensure exact reflection of participant experiences but to gain in-depth and accurate participant perceptions in relation to the research question (Sandelowski, 1993).

## Research Findings

Eight First Nation females volunteered to participate in the study providing insight into the health literacy skills and information needs among this group of young adult women. The young women participants ranged in age from 19-26 years and all participants were single parents of young children. The participants were recruited from a community health centre located on a First Nation reserve in Southwest Ontario. Prior to entering the community health centre, the researcher reviewed and discussed the research project with a health centre service provider who was instrumental in providing orientation to the health centre services and introductions to the health centre staff. This health centre offered a variety of programs and services including: mental health counselling and case management, art and play therapies, addictions counselling, support groups, family planning clinics, health promotion programs (e.g., healthy childhood development) and other community health services. The health centre employed nurses, a nutritionist, mental health workers, and community outreach health workers.

To capture the age range of 18-34 years the researcher attended programs such as 'Funs for Ones and Twos' and the 'Mom's and Dad's' program. The participants of these programs tended to be single mothers with young children. No male young adults volunteered to participate in the research and although male participants would have provided interesting insight into the health literacy skills and information needs of FNIM young adults, research on FNIM populations tends to lack a female perspective and focus almost solely on men (Adelson, 2008; Reading et al., 2007). Table 1 provides the demographic details of the eight female participants.

Table 2: Demographics of Female First Nation Participants

Age	Gender	On- or Off-Reserve	Education	Annual Income	Smartphone*
Range: 19-26 yrs Mean: 23 yrs	Female (100%)	On-Reserve (100%)	Elementary / some HS = 38% (n=3) HS Diploma = 50% (n=4) Some College = 13% (n=1)	Range: \$6,000-\$21,600 Mean: \$12,836	Yes (100%)

\*Smartphones are mobile devices that have advanced computing technology and applications which can include a built in camera, media player, GPS capability, and the ability to connect to the Internet (PC Magazine, 2011). All women in this study had a BlackBerry, iPhone, or other similar devices with telephone services as well as the ability to connect to the Internet.

Four themes with associated subthemes emerged from the analysis of the transcribed interview data and included: (1) Traditional Healing and Health, with the subthemes of 'Traditional Health Culture Excised', and 'Wanting to Know More about Traditional Health'; (2) Health Information Needs of First Nations young Mothers; (3) Access to Health Information, with the subthemes of: 'Asking the Doctor / Telehealth' and 'Other Female Family and Friends'; and the final theme of (4) Online Accessibility, with the associated subthemes of: 'Health Information Online', 'Social media', and 'Navigation and Computer Skills'.

### **Traditional Healing and Health**

Relative to the biomedical model of health that focuses on illness management, traditional FNIM methods of health and healing takes a holistic approach that can include: ways that connect people to their culture and traditions (e.g., spiritual

ceremonies of song and dance), consulting Elders for advice and healing, accessing sweat lodge ceremonies, and herbalism (e.g., the use of plant material to treat illness).

(Chrisjohn, 1991; Cohen, 1998; Maar & Shawande, 2010, Nauman, 2007; Wyrostop & Paulson, 2000).

### **Traditional health culture excised.**

In this study participants reported limited knowledge of traditional healing, medicines, and wellness practices. The young women prescribed to a biomedical model of health. In fact, participants were unsure of available traditional medicines and did not participate in traditional health / healing practices. Yet all participants expressed an interest in learning about their cultural traditions in health and healing. When asked about traditional health and healing practices, one participant stated:

*Oh, well like no, not really, like no special ways, I just do the normal stuff, like see my doctor, get checkups for my kid and you know, get the flu shot, that kind of stuff. (Participant 8)*

The participants interviewed in this study felt that there were no traditional health and healing services available to them and were unaware of who they could contact or where they would go to access traditional health and healing knowledge and / or services (even when living on-reserve). Furthermore, the young women did not understand or were uncomfortable asking what traditional health or healing services were available.

*I haven't really gotten into anything like that [FNIM traditional medicines or services], so I don't have any details or background of anything like that, they don't offer too many things like that down here. (Participant 2)*

*I guess I'm kind of unsure, for anything as in the practice or anything like that I am unsure, there is a lot of things like that I don't understand, like it is kind of at a loss for me, once again, I'm young and I don't know too much about my heritage. (Participant 1)*

As well, the young women felt that their life circumstance did not allow for additional learning about their traditional culture and healing practices.

*...like I try to do the language and stuff like that, but for me when I was younger, I had nothing to do, because I had nothing to do I dropped out of school and did the wrong things, and I just got back on track with trying to do the right things, a lot of things like... for me being an addict has messed with my memory. (Participant 1)*

For a variety of reasons, the young women had limited knowledge of traditional health and healing practices and were equally unsure where to access this information. The women in this study did not incorporate any traditional aspects of health and healing (e.g., ceremonies, herbalism or 'the teachings' from Elders) into their own health care practices.

### **Wanting to know more about traditional health.**

The young women in this study expressed a desire to learn about traditional healing and wellness and believed this was an important component of their culture.

*I think my heritage is important because so much is lost, I think it would totally be worthwhile if we were going to have any kind of practice or traditional medicines here. (Participant 1)*

*There should be more of it, like you know, like maybe they could bring in older traditional ways of healing and stuff like that, that would be neat to see, instead of just a doctor in a room with dream catchers. (Participant 3)*

The participants identified traditional health teaching by community Elders as a potential strategy to gain a better understanding of traditional methods of healing and medicines.

*...through some Elder, learn some teaching of healing and such, yes that would be nice to have here. (Participant 7)*

### **Information Needs of Young First Nation Mothers**

All participants in the study were single parents of young children. Getting information and care regarding their children's health was an important aspect of their health information needs. For example, one woman explained:

*Since I have been a mother, my number one priority is looking after my son, like I know I need to stay healthy but I can't think of anything that I do for myself [need for health information / services], most of my time and stuff is for my son. (Participant 7)*

*Thinking about my son, there is a chance that maybe he could get epilepsy too, so there is things to watch out for, things that I have been looking out for. (Participant 6)*

Personal health issues reported by participants included issues of mental health, methadone treatment for drug addiction, need for counseling services, withdrawal from addictive substances, and even some health preventive measures such as screening for cervical cancer. Yet participants in this study denied any personal need for health

information / services. When asked about their own health information and service needs the young women denied personal health information needs and this perspective was reflected in the following way:

*I don't really look up anything for myself, if I am sick I just suffer.* (Participant 3)

There was a sense among these young women of wanting to provide for their dependent children. The women described how their children and their children's health were their first priority. It appeared that the women minimized the need for personal health information / services and intensified their focus on the health [illness] needs of their children. When one of the participants was asked about health needs of her own, she responded:

*[For myself] I haven't seen my doctors in over two years... I haven't really used the doctor since then and with my son I haven't actually used or seen an actual doctor for about six months, because I don't really have many concerns about myself.* (Participant 2)

Regardless of their personal health status, the reported health information needs of the women focused predominantly on their children's health.

### **Access to Health Information**

Health information can be accessed from health care professionals, family and friends, through television, the Internet, newspapers and magazines, radio, and pamphlets and brochures. In this study, the participants described their main sources of health information as their family doctor or health care provider and female family and friends.

### **Asking the doctor.**

All participants indicated that health care providers, especially physicians, were an important source of health information. The participants viewed their doctor's guidance as trustworthy and even though many of the women reported having experienced traumatic situations with the conventional health system (e.g., in hospitals and off-reserve health centres), all participants indicated their physician (located outside of the reserve community) as an important source of health information. This information preference was discussed as follows:

*I prefer to go to the doctors and ask questions because they know more, well so does the Internet to, but I would rather just go and talk to my doctor. So when I am on the Internet, when I want to know a certain thing, I have to go online, type in that certain thing and when I read that certain thing, then it has something that I don't understand in there, then I have to type that thing in. But if I go to the doctors and don't understand a part then I can just ask and they can tell me and explain more. (Participant 4)*

Despite other avenues of health information access, getting the doctor's advice was always preferred.

*My kids are pretty frequently with their doctors, like as soon as I feel that they are sick, I call and take them in. (Participant 2)*

The participants preference for health care professionals reflects their perception of physicians and pharmacists as medical knowledge 'experts' and the young women sought confirmation from them about their health questions. This is expressed in the following way:

*I need the expert explanation to really tell me and show me what it is. (Participant 1)*

*A pharmacist, the one in our town ... he is really good, you know you ask him a question he will answer to his best ability and you know if he cannot answer he will tell me you know maybe you should go to a hospital and talk to somebody. (Participant 5)*

This idea of having the expert decide the best course of action and make sure things “were checked out” was a very important aspect of their health care behaviours.

### **Telehealth.**

Telehealth is a publically available, 24-hour telephone service where individuals can call and talk to a registered nurse. Telehealth is available in Ontario and is a free and confidential service that anyone can call to get advice on any health related issues from qualified health professionals. The young women in this study reported that Telehealth was an easy to access source of health information. They also indicated that Telehealth services were used in the evening and through the night when physician consults and services (e.g. day time office hours) were not available. This is expressed by the participants in the following manner:

*Telehealth, I sometimes use Telehealth, like there you can call anytime and ask questions and you actually talk to a Nurse. (Participant 8)*

*My son got a fever and he had been sleeping for four hours already and when I woke up he was really hot to touch, so I ended up calling telehealth to see what I should do, should I give him Tylenol or should I let him sleep. (Participant 3)*

Related to their preference for health professional or expert advice – these young women appreciated the idea that they were able to get expert advice but also speak with a trained health provider. In addition, all of the women participants reported having smartphones, so for them, access to Telehealth services was ‘in hand’ and relatively immediate.

**Other female family and friends.**

In addition to talking to a health care professional, the young women participants also looked to other female family members and friends for advice on health issues. Specifically, the women looked to their mothers and / or sisters for advice on parenting issues and the health of their children.

*I will ask my mom or something about something that is going on with my son, you know cause she had kids and like I would ask her. (Participant 7)*

*I get freaked out and think oh my god what if this happens to my daughter and you know I don't really know, but like I say I call my sister and ask her. (Participant 1)*

Being a parent constitutes significant information needs among all of the participants. Seeking advice from other female family members was a common theme throughout the interviews. While family physicians were the most prominent source of health information, it was clear that participants also consulted with their mom, sister, or female family members in addition to their doctor when the latter was not available or before they went to their doctor to have some background knowledge or opinion.

*For instance my sister has 3 kids and I am always asking her things, like what can [my daughter] eat and when should she eat people food and what kind of*

*adult food can she eat and at what age and like diapers and changing them and creams. (Participant 8)*

### **Online Accessibility**

Within a health system that increasingly expects people to understand disease processes, and play an active role in maintaining their own health, access to information via the Internet and Health 2.0 applications provides multiple avenues for individuals to address these expectations. Having the health literacy skills (reading, writing, media literacy, information literacy, and computer literacy) and confidence in order to navigate the complexity and scope of online health resources underpins the ability to benefit from the health information that is available online.

### **Health information online.**

Accessing health information online was a valued activity among participants. All women reported use of the Internet and had access to online services from their home using a personal home computer, laptop or smartphone or using the computers available in a community setting. Interestingly, all of the women interviewed were unaware of the website for the community health clinic they attended for parenting programs and expressed knowledge of very few online sites that would provide them with good health information. When searching for online health information the young women used the search engine Google™ as the main source of health information.

*I just go to Google™ and type it in and you know how that whole list comes up, I just click the one that looks most interesting and has the most information.*

(Participant 4)

The women did not seem to have any algorithm (or systematic searching process) when accessing health information online and reported a lack of confidence in using the Internet as a source from which to gain health information.

*If I was concerned or something I would always go straight to the doctors, I don't think I would ever go on the computer, because like I say I don't really understand how a computer works, let alone how I would go about asking certain questions, like if I could think of something I would have to ask my sister and that's almost it for everything because she knows how to put it and where to look and ask um, like I said I don't really understand the Internet or really how to work it. (Participant 1)*

Specifically, participants reported feeling unsure as to how to judge the trustworthiness or credibility of online health information. In contrast to all other participants, one young woman who had a college education did use the Internet to access health information:

*...a lot of the times I like going on to the parent's website... Parents Today that is what it is called. (Participant 3)*

### **Social media.**

Social media technology and applications (e.g., smartphones, Facebook™) were useful in terms of gaining knowledge from other family and friends and joining online social network groups. All the young women had a smartphone but ironically did not associate their ability to connect with others on social networking sites to gain health information with Internet use, even though they used them to access health related Facebook™ groups.

*(I use) Facebook™, I will post a few questions, because there are other moms on there that know some things. (Participant 3)*

Similarly, the young women in the study indicated that they used online social networks like Facebook™, to remain connected to and to communicate with family and friends. While female family members and friends were significant sources of health information, the women did not perceive Facebook™ (online social networking) communication with family and friends as a health communication channel. For example when asked about social media network and websites, one participant explained:

*Yes, I have Facebook™, but I don't really go on it that often, when I do it is just to check out someone's photos and see their status or change my status or something like that. (Participant 8)*

Yet in this same interview the participant mentioned that:

*I joined this one [Facebook™] group for Moms, I forget what it is called, it is not a really big group, mostly just my cousins and stuff, but we are all moms on there and usually trying to go about it alone and we sometimes talk about our kids and usually the things that we are getting frustrated with like what our kids are getting into and making a mess of like how to get rid of stains and well one time we were talking about my cousins' kid who was sick and suggesting things and if other people had a kid near the same age we would talk about things, it is good for me because I am just had my first kid so, you know, everything is so new to me. (Participant 8)*

Although Facebook™ was not perceived as an avenue to gain health information, this participant as well as others did go online and discuss health issues about her child and the children of other family and friends.

### **Navigation and computer skills.**

The young women claimed limited computer skills and a limited ability to navigate the Internet. Participants also reported a lack of confidence in their ability to recognize trustworthy online information. These feelings inhibited their use of the Internet to obtain health information. In this study, the young women were able to get online, but once online were unable to find websites that had health information they felt they could trust.

Most participants except for one individual with a college education had little confidence in terms of their health literacy skills to access, and find credible and trustworthily health information online.

*Anything to do with Internet I don't understand and I don't know... like I said I'm that type that I wouldn't understand, I could read things and somewhat understand, but I need the expert explanation to really tell me and show me what it is. (Participant 1)*

*I have to get others to help me use the computer, just to get online, I can't even do that. (Participant 5)*

Participants reported having limited skill in which to navigate and use a computer, including the Internet. In fact, participants thought that they would benefit from instruction in computer navigation and online information literacy to enable them to differentiate credible from less credible websites and information. Similar to their desire

to learn more about their traditional ways of healing and medicine, participants also expressed a desire to learn more about how to use computers and the Internet to access health information.

*Like to know which sites to go to and so it is easy for me... like I would like to use the Internet more and things, but like I would want someone to teach me more and how to use it. (Participant 7)*

*I would like to know more about the Internet and how I can use it day to day for looking into my health... if I had um, more knowledge about other things online like here what is going on I would use it more. (Participant 8)*

## Discussion

This study explored the health literacy skills and health information needs of young adult First Nations women. Demographic data and transcripts of interviews with eight young women generated four main themes with associated subthemes: (1) Traditional Healing and Health, with the subthemes of ‘Traditional Health Culture Excised’, and ‘Wanting to Know More about Traditional Health’; (2) Health Information Needs of First Nations Young Mothers; (3) Access to Health Information, with the subthemes of: ‘Asking the Doctor / Telehealth’ and ‘Other Female Family and Friends’; and the final theme of (4) Online Accessibility, with the associated subthemes of: ‘Health Information Online’, ‘Social Media’, and ‘Navigation and Computer Skills’.

All participants in this study were single female young mothers living on a First Nation reserve in southwest Ontario, Canada. The average age of the participants was 23 and their educational attainment ranged from elementary / some high school to a college degree. The average income for the participants in this study was \$12,836 annually. According to the 2006 Canadian census, the average income of the participants in this study was even lower relative to the reported 2006 annual income of \$18,962 for all FNIM people in Canada. Compared to all non-FNIM Canadians who made an average of \$27,097 annually, the annual income reported by the young women in this study is lower still (Statistics Canada, 2006b). In fact, in 2009 the low income cut-off for a single person in Canada was \$18,421 (Statistics Canada, 2010b). This cut-off is a threshold for which people have to devote a larger portion of their income to necessities such as food, shelter and clothing than the average family living in Canada (Statistics Canada, 2010b). Studies have indicated that health inequalities favour the people in high income brackets rather

than those with income at or below the low income cut-off (Humphries & Van Doorslaer, 2000; Raphael, 2002). People who live in disadvantageous circumstances because of their income have more illnesses, disability, and shorter lives (Raphael, 2002). The Royal Commission on Aboriginal Peoples Report (1996) indicates that both income and education among FNIM peoples in Canada are lower compared to the Canadian population. Research evidence that points to strong positive correlations among the factors of: limited education, low income, and limited literacy / health literacy is consistent with the findings from the young adult women in this study (Canadian Council on Learning 2007; 2008; Health Canada, 1999; Kickbusch, 2001).

A study conducted by the Department of Indian Affairs and Northern Development investigated the life context of FNIM single mothers in Canada (Hull, 1996). In this study, researchers examined demographic, social, and economic information from the 1996 Canadian Census data and created a profile of young single parent FNIM women in Canada (Hull, 1996). According to this study, there were twice as many single mother families among FNIM peoples than among the non-native Canadian population and 25% of FNIM young children lived in single mother families, compared to 14% of non-FNIM children (Hull, 1996). Hull (1996) also reported that all single mothers in Canada experienced disadvantages including low income and problems in the labour market; however, FNIM single mothers in Canada experienced these problems to a greater degree. It appears that a similar composition of challenges including economical, occupational, educational, and literacy / health literacy – were experienced by the young women in the current study.

### **Functional Health Literacy**

Nutbeam's (2000) model of health literacy, a typology of functional, interactive, and critical health literacy, was the theoretical framework guiding this research. While there were implications of functional and interactive health literacy, there were no themes that aligned with the aspects of critical health literacy. Functional health literacy involves the ability to obtain and comprehend health related material and services for health care. Functional health literacy encompasses prose, numeracy, document, listening, and speaking skills, and cultural knowledge that enable individuals to comprehend information, develop knowledge, and function efficiently and effectively within their health system (Nutbeam, 2000).

### **Traditional health and healing.**

One of the themes that emerged from the data is the concept of traditional health and healing among the participants. Attending to culture is an important aspect of health care delivery and the development of meaningful health information (Chandler & Lalonde, 1998; Kirmayer et al., 2000; Lalonde, 1996). There are many traditional health and healing methods among FNIM peoples, some of the common methods are: seeking advice from Elders; ceremonies consisting of sweat lodges, singing, dancing and drumming; and the use of plants and herbs to reduce illness (Cohen, 1998; Nauman, 2007). Yet in a recent meeting of FNIM Traditional Healers' held in British Columbia, there was expressed concern that the idea of traditional knowledge of health and healing was missing and FNIM peoples were not accessing traditional health and healing services (First Nations Health Council, 2012). Additionally the group of Healers were troubled about the disconnect and loss of culture / spirituality / identity and respect for traditional

knowledge and practices; the lack of trust, loss of unity family values, loss of trust and safety, and loss of laughter, and leadership and teachings (First Nations Health Council, 2012). Similarly, the young women in this study indicated a lack of awareness regarding traditional methods of health or healing at the community health centre or on the reserve where they lived. Despite their lack of awareness, the women did express a desire to learn more about their heritage and traditional health rituals in order to pass it down to their children. One of the ways the women suggested this could be accomplished was to incorporate consultations with Elders within the on-reserve community health clinic to teach clients and / or community members about traditional methods of health and healing. For example, a study of FNIM youth in British Columbia showed that communities are stronger and individuals exhibit better health outcomes when they incorporated traditional knowledge into their health care practices and had control over their own affairs (Chandler & Lalonde, 1998). The participants' home community offered traditional methods of health and healing at the health centre such as: classes that teach traditional art and traditional water ceremonies.

Many Canadians are accustomed to the biomedical model of health, which puts less emphasis on health promotion and alternative medicine (Carvalho et al., 2007) and gives precedence to disease and molecular biology (Engel, 2004). This model does not emphasize the social, psychological, or behavioral dimensions of health and requires disease to be dealt with separately from the social context (Bird & Rieker, 1999; Engel, 2004). Interestingly, the young women did not perceive the on-reserve community health centre as a source of 'medical' information / services. Instead of using the community health centre for 'medical care', they clarified their presence at the clinic as attending

health educational programs. Perhaps it is the biomedical model of health that these women hold that creates a situation of limited awareness of their traditional health practices and a broader understanding of the social determinants of health.

The layers of colonization, the impact of residential schools, and the cycle of ill health that persists to this day has created a situation of poor health status among FNIM societies (Browne, Smye, Varcoe, 2005; George, 2012; Gracey & King, 2009; Indian and Northern Affairs Canada, 2008b; Reading et al., 2007). Given this legacy, it is not surprising that the young women in this study view the biomedical model of health as the norm. It may be that the young women's lack of knowledge regarding traditional health and healing methods is situated in the long history of colonization. Issues that stem from colonization and racism go beyond the control of the individuals and communities and impact population health (George, 2012; Loppie Reading & Wien, 2009). Prior to European contact, FNIM societies had a variety of sophisticated traditional approaches to medicine (George, 2012; Robbins 1992). The continuous shaming of FNIM tradition and culture has now made those traditional approaches to medicine less relevant and practically non-existent within FNIM society (George, 2012).

### **Health information needs of young adult First Nation mothers.**

The ability to access (e.g., obtaining and understanding) health information is part of functional health literacy. Current evidence indicates that FNIM women have higher rates of mental health, suicide rates that are five times higher than the national average, higher age-standard mortality rates, and a five times greater risk of death from diabetes compared to the overall Canadian population (Statistics Canada 1993; Chandler & Lalonde, 1998; Kirmayer et al., 2000; Young, Reading, Elias & O'Neil, 2000). Yet the

young women in this study emphasized the need for health information related to child health / parenting issues rather than personal health concerns. Despite serious personal health concerns such as addictions and mental health issues, caring for their children and disregarding their own health problems was consistent among this group of young women. Similarly, researchers found that becoming a mother was a pivotal point in the lives of FNIM women and greatly influenced their health care focus (Van Herk, Smith & Andrew, 2010). The women in the same study recalled positive encounters with their health care providers because of the health care providers' perception of their strengths that were associated with being a mother. Because they were now mothers, the women in the study perceived themselves differently; they were now people with power and strength to be able to take care of their young children (Van Herk, Smith & Andrew, 2010). Particularly within FNIM cultures, mothering (i.e., the bearing and nurturing of children) can be a way to participate in community and give back to the sustainability of the community (Sunseri, 2008). The young mothers in this study may have felt similar in terms of the power and responsibility they held as single-parent mothers with dependent children. They may have felt that they were positively perceived by health care professionals because of their role as a mother and of their attentiveness to the health of their children perhaps at the expense of their own health issues.

### **Health information access.**

One of the themes from this research is access to health information. While there are no physicians on staff at the on-reserve community health centre accessed by the young women in the study, there are nurses, social workers, and mental health counselors to support the health needs of the community members. As previously noted, the

community health centre also offers several group-based health programs such as: art therapy programs, cooking lessons, and programs that address issues of parenting. The women in this study did not appear to access the community health centre for ‘medical care’ (they consulted with medical doctors off the reserve) but did attend health educational programs there. It could be that the biomedical perspective of health held by the women in this study prevents them from considering the community health clinic programs – ‘Fun for Ones and Twos’ program (a play based educational program for parents with young children) and the ‘Moms and Dads’ program (an educational program for parents or people about to become parents) as sources of health information.

Among the young mothers in this study, their preferred source of health information was health care professionals and specifically their family doctor. Similar to the findings of Baker and Daigle (2000) the young women in this study reported negative experiences with the health care system (e.g., hospitalization experiences). Yet despite these negative experiences the young women identified their family doctor as their most frequent and respected source of health information. One of the participants stated that she goes to the doctor for “every little thing” regarding her child. Browne & Fiske (2001) found similar results in their study with women from a First Nations reserve in British Columbia. The researchers indicated that sharing knowledge and power about health care concerns between the women and their physician was important in reducing the social distance between the patient and provider and allowed the women to become more involved in their own health care (Browne & Fiske, 2001). This same study by Browne & Fiske (2001) indicated the importance of FNIM women having a ‘good talking relationship’ with their health care provider and it is perhaps this verbal exchange of

questions and knowledge with a health care provider that supported the women's needs. Similarly in another research study by Vick & Scott (1998) that examined patients' preferences within the doctor-patient relationship, 'being able to talk to the doctor' was the most important quality within the clinical setting.

As well, the participants in this study used the Ontario Telehealth service as a source of health information or as a resource supplement to their family doctor. Telehealth Ontario is a free, telephone service available to any person in Ontario. Callers accessing the service speak to a registered nurse for confidential health related advice or general health information. Callers are asked to describe symptoms and answer questions regarding their health issue and based on this assessment, the registered nurse will advise self care, recommend a visit to a health practitioner or, give the phone numbers of helpful community resources nearest to the caller (Ontario Ministry of Long Term Care, 2012). The young women stated that they used Telehealth after hours, when their doctor was not available and felt confident that they were still able to get an 'expert' opinion. Similarly, in a study by Jennett et al. (2003) that looked at the socio-economic impact of Telehealth, it was indicated that First Nations peoples benefited from Telehealth services. This systematic review indicated that First Nations peoples had improved access to appropriate health care, especially mental health care from the use of Telehealth (Jennett et al., 2003).

Along with looking to a doctor / Telehealth for health care information, the use of other female family and friends was an important avenue of health information access for these young single mothers. Whether it was through texting, calling, or even social networking websites, the women expressed that talking to their female family members

about health issues was always an important source of information and support. As one of the determinates of health, social support networks which often include family and friends, are associated with better health outcomes and the ability to help solve problems and deal with hardships (Albrecht & Goldsmith, 2003; Public Health Agency of Canada, 2012; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). For the young women in this study, female family and friends, who were also mothers, were important sources of information on child-related illnesses, parenting advice, general health information, and social support. FNIM health beliefs are not individually determined but instead are based on the social, spiritual, and cultural beliefs of their family and their community (Iseke-Barnes & Sakai, 2003; Lewis, 2011; Vass et al., 2011). Including family in health care decisions is an important cultural practice that gives strength and support to the family to be able to manage current illness and prevent further illness together (Lewis, 2011). Family within FNIM culture is where identity is affirmed and valued, and where healthy lives are constructed (Sunseri, 2008). Consultation with family about health issues is consistent with FNIM health beliefs (Lewis, 2011; Maher, 1999; Reid & Mununggurr, 1977), therefore reasonable that these women would consult with other female family members about health issues.

**Online accessibility.**

Recent evidence indicates that the convenience of the Internet has created a situation where more people go online to get health information than those who go to see a doctor (Hesse et al., 2005; Nelson et al., 2004). Accessing health information online is one of the top five reasons why people use the Internet (Middleton et al., 2007; Statistics Canada, 2010a). Although accessing health information online was valued among

participants, most of the young women reported a lack of ability and confidence in locating and judging the trustworthiness of online health information. The Internet can be a very complex environment and the amount of health information available online can be overwhelming (Friedman, Hoffman-Goetz, 2006; McInnes & Haglund, 2011). Studies that looked at the readability of health information on the Internet showed that the majority of the websites (64%) were written at a college level (Friedman, Hoffman-Goetz, & Arocha, 2004; Smart & Burling, 2001) and a study by McInnes & Haglund (2011) found that online information regarding a variety of health conditions required, on average, a grade of 12 reading ability. Similar to the experience of the young women in this study, research evidence suggests that individuals with limited health literacy skills may be precluded from accessing online health information or feel overwhelmed by the complexity of the information available online (Viswanath & Kreuter, 2007). In contrast to all other participants in the current study, one young woman who had college degree did use the Internet to access health information. Research evidence indicates that one's level of education is associated with health literacy ability and Canadian adults with less than a high-school education exhibit poorer health literacy skills than those with higher levels of learning (Adelson, 2005; Canadian Council on Learning, 2007; Davis et al., 2002). It may be that individuals with higher educational attainment may feel more comfortable going online for health information (Viswanath, 2006). In contrast to the other young mothers in this study, the advanced level of education of this one participant may have contributed to her ability and confidence in using the Internet to gain information about health issues and services.

Participants in this study discussed issues of computer and Internet navigation skills as necessary to access reliable and credible information. In fact, growing evidence suggests that access to online health information may primarily advantage those that already benefit from greater income and higher education; potentially creating even larger differences in health disparities among different groups of people (Canadian Council on Learning, 2007; Viswanath, 2006; Viswanath & Kreuter, 2007). Essential health literacy skills include: competency in using computers / Internet, the ability to navigate through the complexity of online information and the knowledge and confidence to discern reliable from unreliable information (Cline & Haynes, 2001; McInnes & Haglund, 2011; Viswanath & Kreuter, 2007). The young women in this study reported their perceived challenges with computer / Internet skills and expressed the desire to develop their ability to use computers and navigate through the Internet to access online health information / services. Those without these foundational skills will be disadvantaged in their access to health information and services (McInnes & Haglund, 2011; Viswanath & Kreuter, 2007).

### **Interactive Health Literacy**

Interactive health literacy focuses on the development of personal skills aimed at improving self-care, motivation, and self-confidence in order to improve health status (Nutbeam, 2000). Interactive health literacy supports access to health information and services within a supportive environment (Nutbeam, 2000). Furthermore, adequate interactive health literacy supports individuals' ability to influence social norms and foster collective participation (Nutbeam, 2000; 2008). The ability to participate within online health care environments to enhance personal health care knowledge is an

important aspect of Health 2.0 (Hesse et al., 2010). Interactive health literacy is closely linked with many of the Health 2.0 applications such as health / disease blogs and social networking sites, some of which combine the data from the group participants to provide information on ‘best practices’ from the collective experience of the online participants. Health 2.0 is viewed as a paradigm-like shift in the way health care is delivered and experienced (Eysenbach, 2001; 2008; Klecun, 2010). Health 2.0 and its applications are changing health care practices and empowering health care consumers (Eysenbach, 2001; 2008) through increased participation and interaction in online networks and communities as well as enhancing the patient’s role from passivity to that of collaborator and contributor (Townes & Rogers, 2011). Some of the women in this study utilized Health 2.0 applications such as Facebook™ to connect with other mothers, family members, and friends for social support and about childhood illnesses, and parental issues. Similarly, a FNIM online social networking site, MyKnet.org, based in northern Ontario has revealed that having health services and related health information available through a social network does attract attention and youth did participate and join (Budka et al., 2009).

The young women’s use of online social networks to access and / or provide support and information is consistent with Eysenbach’s (2008) Health 2.0 framework. As a component of the Health 2.0 framework, apomediation describes a process of information / service access that includes but is not limited by health care experts (e.g., physicians) and makes use of the collective knowledge of others (e.g., participants within an online social network group) to recommend or guide information seekers to quality, credible online information. The social networking site Facebook™ is an example of an

apomediated environment where members can help each other navigate the information (Eysenbach, 2008; O'Conner, 2008; Klecun, 2010). The Health 2.0 framework predicts that participation in apomediated environments such as Facebook™ allows individuals to access health information that is accurate, timely, and tailored to their needs (Eysenbach, 2008). Participation in these online environments can contribute to personal empowerment and encourage greater involvement in personal health care (Eysenbach, 2008; O'Conner, 2008; Van De Belt, Engelen, Berben, & Schoonhoven, 2010).

Although the literature on FNIM youth and social networking is limited, youth in general are prolific social networking sites users (Boyd & Ellison, 2007; Lenhart, 2010; O'Keeffe & Clarke-Pearson, 2011). The 2009 survey administered by the Pew Internet & American Life Project found that 72% of online 18-29 year olds use social networking sites. This same survey found that young adults (18-29) accessed the Internet wirelessly by using a laptop or cell phone / handheld device. All the women in this study had a smartphone and some of the participants used them to access Facebook™ groups regarding health. Ironically, the women in this study did not associate their ability to connect with others within online social networking sites as ways to gain health information. Perhaps it is the biomedical model of health that these women hold and the need for the expert opinion as the main source of health information that did not allow them to think of the advice and information they are gaining online as valuable, credible health information.

As previously mentioned, all of the participants had a smartphone (blackberry, iphone, or other mobile device with Internet capability), access to a computer and the Internet either at their home or in their community. Despite available access, none of the

participants were aware of the website for the community health centre where they attended the health educational programmes (e.g., parenting groups). The young women in this study reported that they would use the community health centre website if it was easy to navigate and if there was relevant and easy to understand information. They also indicated that they would be interested in links pertaining to health information for young children, and specific health information regarding FNIM young adults.

### **Limitations**

As with all research, there are limitations to this study. First, the research was conducted in English, therefore only those who speak English were included. However, current data indicates that more FNIM peoples are proficient in English rather than FNIM languages and, the participants in this study spoke only English (Statistics Canada, 2004). Including participants whose preferred language is not English may have highlighted different or additional themes than those identified.

Secondly, the recruitment for this study was conducted through one health centre on a reserve within Ontario, Canada. Recruitment from other on-reserve communities may have produced different results given the unique cultural differences across different FNIM groups.

A third limitation addresses participant recruitment. The participants were recruited from an on-reserve community health clinic offering a number of personal health services and group programs. Single parent mothers tended to participate in the many group programs offered at the health centre that addressed parenting issues and fun for toddlers. There were no male participants in this study and therefore there was no male perspective on health information needs and access. This is both a limitation and an

opportunity for further research regarding the health literacy skills and information needs of FNIM young adult males. However, this research does add to the limited research available on FNIM females as current research in FNIM populations tends to lack a female perspective and focus almost solely on men (Adelson, 2008; Reading et al., 2007).

Lastly, this study focused on young adults living on-reserve. This investigation contributes to the limited research on FNIM peoples' health literacy skills yet gaining an understanding of the health literacy skills and information needs of off-reserve participants is an important area for future research.

### **Continued Exploration for Future Implications**

This initial study of First Nation young adults' health literacy and health information needs has generated a number of areas for further investigation of health literacy skills among FNIM people. This investigation has highlighted the need for further research regarding the integration of traditional health and healing practices with biomedical health methods within existing on-reserve community health centres. Research investigating an interdisciplinary approach to health care including traditional medicine within health care settings has shown to result in positive experiences for providers and clients (Maar & Shawande, 2010).

Enhancing the health literacy skills of young adults to involve traditional FNIM healing with medical practices may broaden FNIM youths' perspectives on health and empower them with the skills needed to effectively access and utilize health information. It is important to understand how and what types of health information FNIM peoples are accessing. Research looking at the reintegration of traditional FNIM cultural health and wellness practices into local and / or online FNIM health care communities is needed to

determine the impact of traditional health and healing practices on health information / service access among young FNIM peoples.

Research investigating the integration of FNIM cultural practices within online social networks and through social media applications needs to be explored as a potentially important health information dissemination strategy. In addition, important research includes: exploring young FNIM women's perception of social media sites (e.g. Facebook™) as sources of health information and determining where young single mothers go to for their personal health information / services. Findings from this study supports further investigation into creating opportunities for young FNIM women to increase knowledge of their traditional health and healing methods as well as their identity to FNIM culture. The health literacy skills of FNIM young adult men and older age groups of men and women on- and off-reserve needs to be investigated in order to fully understand the health information needs and access preferences within FNIM communities.

This research was framed using Nutbeam's (2000) typology of functional, interactive, and critical health literacy. Research on creating awareness of existing health information / services resources is needed. The young women attending the on-reserve health centre were unaware that the community health centre had a website. A participatory / community based research approach to the enhancement and marketing of the community health centre website would be warranted so that young mothers and other community members are aware of and find utility in accessing the community health centre website. In addition, the young women in this study requested educational support in developing their computer skills to confidently access online health

information. Intervention research focused on developing health literacy skills (e.g., computer skills, Internet navigation, and information critique) would be helpful to determine educational strategies that especially enhance the eHealth literacy skills among FNIM children and young adults.

While the women in this study indicated aspects of functional and even interactive health literacy there were no aspects of critical health literacy within this work.

An investigation into the critical health literacy skills (e.g., ability to advocate for changes within the existing system of health care and within the determinants of health) of FNIM young adults would be important given the health disparities experienced by FNIM peoples.

## Conclusion

Health literacy involves the capacity of individuals to obtain, process, and comprehend health information and services in order to make informed health decisions to enhance individual, community, and system health. Findings from this study of First Nation young single mothers point to the young women's functional and interactive health literacy skills. Family physicians and other health care professionals were the preferred source of health information among the young adult female participants in this study. In addition, these young single mothers also looked to other female family members and friends for support and information. The health information needs of these young mothers focused on the health of their young children. This is somewhat disconcerting given the self reported health issues of the young women participants and also concerning in light of the high prevalence of chronic disease (e.g., diabetes), suicide, mental health, and addictions issues among FNIM peoples.

For this group of First Nation young adults, traditional health and healing practices did not play a part in addressing their health information / service needs. Traditional health and healing methods were absent from the health practices of young on-reserve single mothers yet these women expressed the desire to know more about their traditional cultural practices. The young women recommended the integration of Elders into the services and programmes offered within their community health centre as a way to integrate traditional health and health knowledge and practices. Elders are the keepers of knowledge and traditional practices and therefore would be appropriate source of traditional health and healing education (First Nations Health Council, 2012).

In contrast to their interest in traditional health knowledge and practices, the young women in this study utilized communication technology and Health 2.0 applications to support their health information needs. The young women participated in online social networking sites with family and friends about health related issues and valued the use of the Internet to gain health information / services. Yet at the same time, they felt that they did not have the confidence to navigate the Internet and access credible, trustworthy information. These findings contribute to the concern regarding inequitable health information / service access and have implications for health interventions that enhance the health literacy skills of First Nation young adult single mothers.

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## Appendices

### Appendix A: Ethics Approval



**Use of Human Participants - Ethics Approval Notice**

**Principal Investigator:** Dr. Lorie Donelle  
**Review Number:** 18641E  
**Review Level:** Delegated  
**Approved Local Adult Participants:** 20  
**Approved Local Minor Participants:** 0  
**Protocol Title:** Understanding First Nations and Inuit Young Adults' Health Literacy: Health Information Needs  
**Department & Institution:** Nursing, University of Western Ontario  
**Sponsor:**  
**Ethics Approval Date:** January 18, 2012      **Expiry Date:** December 31, 2012  
**Documents Reviewed & Approved & Documents Received for Information:**

Document Name	Comments	Version Date
UWO Protocol		
Letter of Information & Consent	Young Adults - December 2011	
Letter of Information & Consent	Health Care Providers - December 2011	
Advertisement	Recruitment Poster for Young Adults	
Advertisement	Recruitment Poster for Health Care Providers	

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines, and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REBs as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number B1B-0000890.

Signature: \_\_\_\_\_

**Ethics Officer to Contact for Further Information**

_____	_____	_____
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*This is an official document. Please retain the original in your files.*

**The University of Western Ontario**  
Office of Research Ethics

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**Appendix B: Recruitment Flyer**

## Faculty of Health Sciences University of Western Ontario

### Participants needed for Research in Health Information Access

We are looking for volunteers to take part in a study on  
Understanding First Nations, Inuit, and Métis Young Adults'  
Health Literacy: Health Information Needs

Eligibility: Self-Identified Males and Females between the  
ages of 18 to 34 who can read and understand English.

As a participant in this study, you will be asked to  
participate in one personal interview one hour long.

For any questions, more information, or to participate in  
this study please contact

Ebony Rempel at (XXX) XXX-XXXX or xxxxxxxxxxxx@xxx.xx

Or

Lorie Donelle at (XXX) XXX-XXXX or xxxxxxxxxxxx@xxx.xx

## Appendix C: Letter of Information

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## Arthur Labatt Family SCHOOL OF NURSING

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### **TITLE OF PROJECT:**

Understanding First Nations, Inuit, and Métis Young Adults' Health Literacy: Health Information Needs.

### **Purpose of this Study:**

You are invited to take part in this study because you are a First Nations, Inuit, or Métis young adult between the age of 18 and 34. The purpose of this study is to explore and understand the health literacy and health information preferences of First Nations, Inuit, and Métis young adults who live on- and off-reserve (18-34 years old). The purpose of this letter is to provide you with the information you require to make an informed decision on participating in this research.

I am a Masters student in the Department of Health and Rehabilitation Sciences at The University of Western Ontario and you are invited to participate in the study called *Understanding First Nations, Inuit, and Métis Young Adults' Health Literacy: Health Information Needs*. This research investigates the health information needs and preferences of First Nations, Inuit, and Métis young adults between the ages of 18 and 34.

### **Research Procedures:**

With your consent to participate, you will be asked to take part in one personal interview session asking general questions about yourself, and specific questions about the health information and health services you use and how you access those services. The onetime interview is expected to last one hour. The interview will take place in a public location that is convenient to both the participant and the researcher. Your comments regarding health information and services will be audiotaped in order to establish an accurate record of your thoughts and comments during the interview session.

Young men and women are eligible to participate in the study if they are First Nations, Inuit or Métis young adult living either on- and off-reserve and are between the ages of 18-34 years old. Volunteer participants need to be able to understand, read, and write basic English to participate in order to be able to properly understand and respond to the interview questions.

### **Voluntary Participation in this Study**

You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your future (care/ academic status/ employment etc). You may also withdraw the information collected about you for six months after the data has been collected without any negative consequences. If you would like to withdraw from the study within six-months after your data has been collected, please contact the Principal Investigator by telephone or email. At the end of the study, a luncheon will be held to discuss results and get your feedback.

**Privacy and Confidentiality:**

Your anonymity and confidentiality are of utmost importance and will be protected at all times. Your name will not appear on any form. You will be assigned a fictitious name and the list will be kept confidential. Only researchers associated with this project will have access to the information. Information that is collected from you will be kept in a locked cabinet at the University of Western Ontario. Your name or specific personal identifiers will not be given to anyone at any time during the study. There will be no names associated in the conclusions of the research and the written report from this study will report information as a group and no single individual will be referred to or identified. In fact, the information you provide will be combined with information from all other participants. If we find information we are required by law to disclose, we cannot guarantee confidentiality. The records will be locked up for a period of ten years and then destroyed.

**Benefits and Risks:**

The anticipated risk to participants is extremely low. Participation in this study may be of no direct benefit to you, however benefits may include increased knowledge of sources of health information and health services. There are no anticipated economic or physical risks or discomforts from your participation. The primary benefit of this study is the knowledge and insight into the health literacy skill (health information and service access) of First Nations, Inuit, and Métis young adults that will be gained. A better understanding of the health issues among First Nations, Inuit, and Métis young adults and the identification of the health information needs and access preferences may have implications for the development and dissemination of educational materials and services that align with the needs of First Nations, Inuit, and Métis young adults.

**Compensation:**

If you decide to participate, you will receive a small payment in the form of \$15.00 gift card to thank you for your participation.

If you have any questions about the study please contact the investigators, Ebony Rempel at (XXX) XXX-XXXX or xxxxxxx@xxx.xx or Lorie Donelle at (XXX) XXX-XXXX or xxxxxxx@xxx.xx or the University of Western Ontario Office of Research Ethics at (XXX) XXX-XXXX or xxxxxxx@xxx.xx.

Sincerely,  
Ebony Rempel  
Email: xxxxxxx@xxx.xx

**CONSENT FORM****Research Participation Consent Form**

**Re:** Understanding First Nations, Inuit, and Métis Young Adults' Health Literacy: Health Information Needs.

I, (please print name) \_\_\_\_\_, have read the above information and have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Participant Name: \_\_\_\_\_ (please print)

Participant Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Person obtaining consent: \_\_\_\_\_ (please print)

Person obtaining consent signature: \_\_\_\_\_

Date: \_\_\_\_\_

*Please sign above if you; have read and understood the relevant information; understand that you may ask questions in the future; and that you indicate free and informed consent to research participation*

**Please keep a copy of this consent form for your own records in a safe place.**

## **Appendix D: Interview Questions**

### Sociodemographics

What is your age?

Do you live on-reserve or off-reserve?

What level of education do you have?

What is your annual income?

Were you born in Canada?

### *Interview Questions*

Please describe any First Nations, Inuit, and Métis (FNIM) traditional medicines, healing or wellness practices available in the city, town, or community where you currently live.

How does your personal culture associated with being FNIM influence your health information access?

Does your community have any websites that you access?

Do you have to a smartphone, Laptop, Computer or similar electronic device, if yes, how many and what of each do you have?

Where do you access health information online? What website do you go to? Why do you go to those websites?

What kind of health information do you use an electronic device to search for?

In concern of the use of these devices do you ever use any form of social media like any instant messaging system, Facebook™, Twitter™, text messages, etc.?

What do you primarily use these systems for, can you think of anything health related in the past 12 months that you used Facebook™, Twitter™, MySpace™ or an instant messaging system for?

Describe any services you access to gain health information.

*Health Information Sources*

In the past year, have you looked for information about a health concern or medical problem?

Describe any health conditions you may have.

Where have you sought your health information from?

Do you ever access the Internet for health information or medical information?

If yes, thinking about the last time you went online for health or medical information; did you go online to look for information related to your own health or medical situation or someone else's health or medical situation? (Fox, 2011a) \_\_\_\_\_

(Apart from looking for information online, there are many different activities related to health and medical issues a person might do on the Internet).

Have you gone online to find others who might have health concerns similar to yours? (Fox, 2011b) \_\_\_\_\_

Thinking about the last time you had a health issue; did you get information, care or support from a doctor or other health care professional? (Fox, 2011b)

\_\_\_\_\_

Did you interact with them online through the Internet or email, offline by visiting them in person or talking on the phone, or both online and offline? (Fox, 2011b)

\_\_\_\_\_

Thinking about the last time you had a health issue; did you get information, care or support from others who have the same health condition? (Fox, 2011b) \_\_\_\_\_

If yes, did you interact with them online through the Internet or email, offline by visiting them in person or talking on the phone, or both online and offline? (Fox, 2011b)\_\_\_\_\_

About how often do you use the Internet or email?

Do you have a computer or notebook at home or in your community?

Do you have an Internet connection at home or in your home community?

Where do you access the Internet?

On your laptop computer or notebook, do you ever use a wireless connection such as WIFI or mobile wireless broadband to access the Internet? (Fox, 2011c)

Does anyone in your household have a working cell phone?

Do you have a working cell phone?

Have you posted comments, questions or information about health or medical issues in an online discussion, a listserv, or other online group forum? (Fox, 2011c)

Do you ever use the Internet to use Twitter™ or another service to share updates about yourself or to see updates about others? (Fox, 2011c)

**Appendix E: Curriculum Vitae**

**Name:** Ebony Rempel

**Post-secondary  
Education and  
Degrees:** University of Ontario Institute of Technology  
Oshawa, Ontario, Canada  
2006-2010 BHSc

**Honours and  
Awards:** Queen Elizabeth II Graduate Scholarship in Science and  
Technology  
2011

**Related Work  
Experience** Teaching Assistant  
The University of Western Ontario  
2010-2012

Research Assistant  
The University of Western Ontario  
2011-2013