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**Health Websites in Aboriginal Context:
Principles of Conception based on a User-Centered Approach.
The Case of the Sioux Lookout District**

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**Health Websites in Aboriginal Context:
Principles of Conception based on a User-Centered Approach.
The Case of the Sioux Lookout District**

By

Marie-France Gratton

Directed by

Dr. Dominique Ferrand

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II. Abstract

This thesis aims to establish the principles that should govern the conception of health websites in Aboriginal context. For Aboriginal Canadians in remote communities, it is essential to gain accurate, reliable and relevant access to health information. Health websites customized to the preferences of users and to the cultural particularities of Aboriginal culture are a possible means to vehicle this information to them.

A user-centered approach is used to gather data on the preferences of presentation types and content on health websites for Aboriginal people. Remote focus group sessions were conducted using videoconferencing. Different Web presentation types, mainly videos and text-based Web pages, from Diabetes and COPD websites, are presented to the users during the focus group sessions. A qualitative data analysis is done to examine user preferences and what factors have an influence on those preferences.

Key findings include: (1) the type of disease being presented on the websites has an influence on the preferences of users; (2) the preferences of users vary based on the different disease aspects presented; (3) the different factors related to the living location, such as the limited access to healthcare and the Internet, the inaccessibility of certain foods and the diversity of cultures of the different remote communities also affect the preferences of users; (4) users prefer websites to contain elements related to their culture.

The findings of this research have allowed for the development of the principles for the conception of health websites. Health website owners should apply these principles to use the appropriate presentation types, add content that is more meaningful to its target audience, and reorganize the content so that the most relevant information is more easily accessible to the users.

As a consequence of conducting qualitative research, the main limitation of this research is the small sample size. Future research should be conducted with a larger sample size that is more representative of the general population and of the heterogeneity of Aboriginal culture to confirm the results of this study.

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Chapter 1: Introduction

The government of Canada has taken several initiatives to connect Aboriginal people to the Web, in an effort to provide all Canadians with equal access to information. One of these major initiatives is the *Connecting Aboriginal Canadians* initiative, which is part of *Canada's Aboriginal Action Plan*. This plan aims to create jobs, promote growth and stability, and improve the quality of life for Aboriginal People (INAC, 2000). As part of this plan, the *Connecting Aboriginal Canadians* initiative was taken with the goal that new information and communication technologies will support Aboriginal socio-cultural and economic development objectives (Alexander, 2000).

Although the quality of life and the social conditions of Aboriginal Canadians are continually improving, they are much lower than that of the average non-Aboriginal Canadian (National Aboriginal Health Organization, 2008). Furthermore, there is a need to improve the expertise and resources required to deal with serious social issues present in Aboriginal communities, including health matters (INAC, 2000). Aboriginal people suffer a significantly lower health status than the general population (National Aboriginal Health Organization, 2008). Some significant health problems that Aboriginal people are faced with today are family violence, suicide, respiratory diseases, diabetes, tuberculosis, alcoholism, to name a few (National Aboriginal Health Organization (NAHO), 2003; Silverman, Goodine, Ladouceur, & Quinn, 2001). For these reasons, it is crucial that Aboriginal Canadians in remote communities gain accurate, reliable and relevant access to information and social services.

At the same time, it is also important that the information systems that will be created to connect Aboriginal people will be adapted to the Aboriginal culture. Failing to do so can limit access to information for Aboriginal people, as stated by Alexander: "External information systems can destroy indigenous cultures if information fails to be tailored to meet community needs and support the survival of individual cultures. Indigenous peoples must join the Information Age" (Alexander, 2000). Aboriginal people's active involvement in the creation of information systems is the key to ensuring the cultural sensitivity of such systems (Alexander, 2000).

1.1 Problem Statement

The prevalence of specific diseases in Aboriginal people and the limited access to healthcare due to the remoteness of most communities make it essential for these people to get the most information possible about those diseases. Customized health websites are a possible means to vehicle this information to them. However, to our knowledge, to date there is only one study that looks at the cultural-sensitivity of health-related websites targeted to Aboriginal people (Friedman & Hoffman-Goetz, 2007). In addition, no studies have been conducted that examines the preferences of Aboriginal people for online content and presentations for health-related websites. This brings about the general research question for this thesis:

What principles should govern the conception of health websites in Aboriginal context?

The concept of "principles" can be defined as the guidelines and criteria to abide by for the conception of health websites. The "conception" is the design of the blueprint for a website taking into account the set of factors susceptible to modulate its definition.

From this general thesis question are derived several more specific questions:

- In Aboriginal context, what are the preferences of Web presentation types for content on health websites?

The concept of "presentation type" is defined as a means of displaying information on a website. Examples of how information can be presented are forums, the language of presentation, and different media formats such as video, text and images.

- What conditions of access to health websites in Aboriginal context must prevail?
- What factors related to the living location will have an effect on the preferences of content and presentation?
- What are the cultural characteristics that should be displayed on health websites in Aboriginal context?

This research will aim to provide a set of recommendations derived from the answers to these questions to establish the principles governing the conception of health websites in Aboriginal context.

1.2 Context and Scope of Research

The work for this research is conducted in partnership with K-Net, the telecommunications services department of Keewaytinook Okimakanak (KO), a tribal council of six First Nations in northwestern Ontario. K-Net, based in Sioux Lookout, provides telecommunications services to First Nations in northwestern Ontario and the people of the Sioux Lookout district. The Sioux Lookout district, an area of northwestern Ontario consisting of 23 remote First Nations communities, was chosen as a focus for this research. Because of the remoteness of the communities in the district, access to healthcare and the Internet is an issue. For this reason, improved access to health information on customized Websites is vital to the First Nations people of this region.

This study concentrates on health-related websites with information on Diabetes and COPD (Chronic Obstructive Pulmonary Disorder, which includes Emphysema and Chronic Bronchitis) as a high rate of First Nations people from the Sioux Lookout district suffer from these two chronic diseases (Statistics Canada, 2004). These two diseases are also prevalent in all Aboriginal people (National Aboriginal Health Organization (NAHO), 2003). There is much to learn from the First Nations of the Sioux Lookout district regarding access to health information on the Internet. Past and current issues in the region have emphasized the need for improved access to healthcare and health information (Fiser, Clement, & Walmark, 2006), however little research has been conducted on the preferences of how this information should be delivered.

Because of the remoteness of their communities, the limited access to healthcare and the specific Aboriginal health issues of the region, online health websites are essential to the people of the Sioux Lookout district, however, it is unclear how these websites should be built so that the information is relevant to them. Moreover, it is essential to see if Internet access issues should be taken into account when building

these websites and to what extent cultural factors should be included in these websites.

1.3 Objectives of the Research

The objectives of this research are aligned with the research questions and aim to help build websites that will deliver health information to Aboriginal people in remote communities. Three major objectives for this thesis are identified.

The first objective of this thesis is to determine the preferred type of presentation for content on health websites in Aboriginal context. The goal is to determine whether or not this preference will be expressed regardless of the disease and regardless of the disease aspect that is being presented on the health websites.

The second objective aims to determine if the factors related to the living location have an influence on Aboriginal people's preferences of content and presentation type on health websites. Major factors that are related to the living location are the level of access to healthcare and the level of access to the Internet.

The third objective is to explore to what extent cultural elements should be included in health websites in Aboriginal context. The goal is to determine how culture can be integrated into the design of a health website in order to appeal to Aboriginal people.

1.4 Importance of the Topic

In order to help build websites that will deliver health information to Aboriginal people in remote communities, this research will develop understanding about the preferences of different Web presentation types as well as content on health websites that will be useful for Aboriginal people in the country. The results of this research could possibly be used to establish principles to build health websites that are more meaningful, appealing and useful to Aboriginal people.

Understanding the preferences of presentation types and content will allow for websites to be customized according to those preferences. For instance, if Aboriginal people relate better to video, then text-based Web pages that are targeted to Aboriginal people should be converted to video in order to reach them. Moreover, knowing what type of content is important to them will allow website owners to add content that is more meaningful to its target audience or reorganize the content so that the most relevant information is more easily accessible, such as directly on the homepage.

Furthermore, websites could be modified to be more culturally sensitive by understanding what cultural elements users would like to see on the websites. For instance, adding cultural images of objects or people, putting some background music, adding content relating to their beliefs about health and medicine, or even translating the content into the local language of the users are a few examples that could possibly make health websites more attainable to the target audience.

1.5 Research Methodology

A user-centered approach leads to the study of the preferences of users. Based on this approach and our literature review, a research model is developed. The model suggests that there are contextual influences on the preferences of online health information for users in Aboriginal context: Aboriginal health issues, access to healthcare, culture, living location, and Internet access. Furthermore, the model shows that when exploring the preferences of online health information for users, two dimensions have to be considered: the preferences of the content and the preferences of the presentation of that content.

In order to explore the preferences of users regarding Web content and presentation types, content from Diabetes and COPD websites had to be chosen to present to the participants. In order to determine what disease aspects would be presented to the users, three medical doctors were consulted. Three content categories, corresponding to the different disease aspects of Diabetes, and three content categories for COPD, were used as part of this research.

Two empirical models including the retained content categories were then created, one for the participants viewing COPD Web presentations and one for the participants viewing Diabetes Web presentations. Hypotheses were then derived from these models to be tested.

Based on the user-centered approach, two questionnaires were developed to be used during focus group sessions. Both questionnaires contained the same questions but one was customized for the COPD group and the other was customized for the Diabetes group.

This research was conducted under the VideoCom project, which investigates the use of video communications and other information and communication technologies by and for remote and rural First Nation communities, in partnership with First Nations organizations. The VideoCom research protocols were approved by the research ethics boards at the University of New Brunswick and the National Research Council. The specific research protocol and questionnaires used for this study were approved by the First Nation research partner KORl - the Keewaytinook Okimakanak Research Institute.

Data were collected during remote focus group interviews using videoconferencing technology with twenty-two people from nineteen different First Nations in the Sioux Lookout District. Participants were recruited with the help of the K-Net partners.

Each participant was connected to the videoconference from their own community. In total, five focus group interviews were given, with three groups viewing COPD websites and 2 groups viewing Diabetes websites. Following the Web presentations, participants were asked several questions by the interviewer for group discussions and were also given the time to fill-in a questionnaire on paper. A qualitative analysis of the participant's responses was then conducted using NVivo.

1.6 Research Contributions

This thesis focuses on the principles that should govern the conception of health websites in Aboriginal context. This thesis will:

- discover users' preferences of different types of health Web presentations
- examine the reasons why users prefer one presentation type over another. More specifically, look at whether the following elements have an influence on the preferences:
 - the type of content being presented (different diseases and different aspects of the disease)
 - the living location (remote community or city)
 - the level of access to healthcare in their community
 - the level of access to the Internet
 - certain cultural characteristics of the users
 - specific health issues of the remote communities
- obtain information on what other types of content users would like to see on the websites
- learn more about other ways that the users would like the content to be presented
- determine how the websites could be made more culturally sensitive
- employ a user-centered approach in Aboriginal context.

This thesis also has innovative methodological contributions. First, the data collected from the participants was done through multi-site videoconferences, thus allowing to reach remote and dispersed populations and simulating a focus group setting from a distance. This resulted in major cost and time savings. Second, through these videoconferences multiple techniques were used to communicate with the participants and to collect data, including group discussions, individual questionnaires, and the showing of Web presentations. The coordination and control of these different techniques during the videoconferences, requiring much planning and organization, were accomplished successfully and have proven to be suitable for qualitative research.

1.7 Organization of the Thesis

This thesis is organized into seven chapters, including this introduction (Chapter one).

The second chapter provides a thorough literature review of the research that has been conducted on the evaluation of the quality of health websites. Two main approaches used to evaluate the quality of health websites are described. The first section examines the criteria-based approach for evaluating the quality of health websites and the second section describes a user-centered approach.

The third chapter explains what culture means for Aboriginal people in Canada, elaborates on how history has influenced their culture and their health today, and demonstrates the strong ties between Aboriginal culture and health.

Chapter four describes the current situation of the First Nations in the Sioux Lookout district by providing the geography and demographics of the region, giving an overview of the health issues prevalent in the region, examining the level of Internet connectivity of the region, and looking at the availability of healthcare and health information for the people of the region.

The fifth chapter outlines the framework for this research, exposes the research model and empirical models, and defines the methodology used for this research. The sampling and data collection procedures are described. The questionnaires used during the interviews are provided in Appendix I.

Chapter six is a detailed analysis and discussion of the findings from the data collected during focus group interviews and a validation of these findings against the empirical model.

The thesis ends with a conclusion (Chapter seven) that summarizes the background on this study, discusses the findings of this research and provides some recommendations for the principles that should govern the conception of health websites targeted to Aboriginal people. It also specifies the limitations of this study and offers some thoughts for possible future research.

Chapter 2: The Evaluation of the Quality of Health Information Websites

Canadians are increasingly using the Internet to access health information. A 2008 article that examines adults' use of the Internet to access health information based on the results of the 2005 Canadian Internet Use Survey (CIUS) demonstrates that 35% (8.7 million) of Canadians (excluding residents of the territories, inmates of institutions, residents of Indian reserves, and full-time members of the Canadian Forces) went online at home to search for health information in 2005 (Underhill & McKeown, 2008). Due to the nature of health information it is crucial that users have access to accurate, reliable, relevant, and easily accessible health information. With the large amount of health information found on the Internet, it is becoming more important to ensure the quality of these health websites (Harland & Bath, 2007).

This research will attempt to establish the principles that should govern the conception of health websites in Aboriginal context. In order to do so, a literature review of what has been previously done regarding the evaluation of the quality of health websites is undertaken. There are several studies focusing on this theme (Childs, 2005; Curro et al., 2004; Dragulanescu, 2002; Friedman & Hoffman-Goetz, 2007; Harland & Bath, 2007; Kim, Eng, Deering, & Maxfield, 1999; Purcell, Wilson, & Delamothe, 2002; Williams, Nicholas, Huntington, & McLean, 2002a). This chapter concentrates on the different approaches used for such an evaluation. It reviews the literature evaluating different aspects of the quality of health websites and describes the past studies that use different methods of evaluation.

The literature can be categorized by the approach that was used to evaluate the quality of health websites. Two main categories most prevalent in the literature were identified: a criteria-based approach and a user-centered approach. The first section looks at the criteria-based approach, provides examples of studies that have used this method to evaluate the quality of health websites, and highlights the criteria most commonly used for evaluations. The second section describes the user-centered approach and explains when this approach has generally been used in past studies.

2.1 Criteria-Based Approach for Evaluating the Quality of Health Websites

The criteria-based approach consists of the examination of a website to determine if it meets the different criteria of what constitutes a quality health website. This can be done by using a tool such as a pre-defined checklist or through the form of a questionnaire, where each question represents a quality criterion to be measured. This approach has been widely developed and used by different researchers and organizations (Williams, Nicholas, Huntington, & McLean, 2002a). Two different types of criteria-based tools have been identified in the literature to assist in the evaluation of the quality of health websites: generic tools and specialized tools.

2.1.1 Generic Tools for Evaluating the Quality of Health Websites

Generic tools contain only criteria that can be used to assess any type of health-related website, regardless of the disease that is presented. For example, criteria that would only apply to a specific disease would not be found in a generic tool. Generic tools can be distinguished by their objective of use. Some of the generic tools have been developed with the goal of being used to help standardize the quality of information, while others have been developed to be used for specific studies.

2.1.1.1 Generic Tools for Specific Studies

A study by Kim et al. (1999) conducts a review of published criteria for evaluating health-related Web Sites. The study compiles a list of 29 generic tools from published articles or organizations' websites that contain criteria for the evaluation of Health Web sites. Of these 29 tools, the authors identified 165 different criteria, which were all grouped into specific categories. Table 2.1 summarizes these groups and which criteria each one encompasses as well as the frequency in percentage in which each group was referenced in the literature (Kim et al., 1999). A more recent study that also compiles a list of the criteria found in the literature did not identify more criteria than the ones listed in the Kim et al. list (Childs, 2005).

Criteria Groups	Frequency (%)
Content of site (includes quality, reliability, accuracy, scope, depth)	30
Design and aesthetics (includes layout, interactivity, presentation, appeal, graphics, use of media)	22
Disclosure of authors, sponsors, developers (includes identification of purpose, nature of organization, sources of support, authorship, origin)	20
Currency of information (includes frequency of update, freshness of data, maintenance of site)	14
Authority of Source (includes reputation of source, credibility, trustworthiness)	11
Ease of Use (includes usability, navigability, functionality)	9
Accessibility and availability (includes ease of access, fee for access, stability)	9
Links (includes quality of links, links to other sources)	5
Attribution and documentation (includes presentation of clear references, balanced evidence)	5
Intended audience (includes nature of intended users, appropriateness for intended users)	3
Contact addresses or feedback mechanism (includes availability of contact information, contact address)	2
User support (includes availability of support and documentation for users)	2
Miscellaneous (includes criterion that lacked specificity or were unique)	33

Table 2.1: Frequency of specific criteria categories for the evaluation of health-related web sites (Kim et al., 1999)

The most frequently cited criteria were related to concepts of information quality and accuracy, design and aesthetics, disclosure of authors or sponsors, currency of

information, and authority of source. The study provides a synthesis of all the criteria used by different authors. Although several criteria seem to be recurring from one tool to another, the abundance of tools containing different criteria shows that there doesn't appear to be any consensus on the appropriate criteria to use to evaluate the quality of health Websites (Childs, 2005; Kim et al., 1999).

A recent literature review by Harland and Bath (2007) showed that there is a lack of validation of tools for the quality of health Websites. The tools that are being used may not be suitable to assess the quality of health Websites. Some researchers fear that the lack of validated tools may actually cause Websites to be wrongly evaluated as quality Websites: "...while the proliferation of tools to evaluate the quality of information on websites means that a wide choice of tools is available for people to assess the quality of health information on the web, concerns have been expressed that this may actually cause harm to patients and the public" (Harland & Bath, 2007). Kim et al. (1999) state that generic criteria should be agreed on and a generic tool for assessing the quality of health Websites should be developed (Kim et al., 1999). However, these criteria would need to be validated to ensure that they actually do correlate with good quality Web sites (Childs, 2005; Harland & Bath, 2007).

2.1.1.2 Generic Tools for the Standardization of the Quality of Health Websites

Organizations have developed generic criteria sets to be met in an attempt to help standardize the quality of health Websites (Centrale Santé, 2001; DISCERN, 1999; Health on the Net Foundation, 2007a; Internet Healthcare Coalition, 2003). The most cited example is the Health on the Net (HON) Foundation, which has established a code of conduct, the HONcode, that is meant to encourage Web site developers to comply with a series of criteria when presenting health information (Health on the Net Foundation, 2007a).

The HONcode addresses two main concerns with health information: the reliability (the relevance and accuracy of a document) and the credibility of the publisher of the information. The site provides a list of quality criteria to be met and also provides a questionnaire that Web site developers can use to verify their compliance with the

criteria. Web site developers can also apply for an HONcode accreditation and display the HONcode active seal on their Website. This accreditation is completely voluntary, which means that the organization does not approach companies to get accredited, the companies must do so if they wish (Health on the Net Foundation, 2007a).

Another example of such an organization is the University of Oxford's Institute of Health Sciences, Division of Public Health and Primary Health Care, which has created the DISCERN instrument (1999), a checklist to allow users to assess the quality of health information online. DISCERN concentrates on evaluating the content of Websites and does not provide any means to measure the appropriate presentation of the information as a lot of literature already exists for this. The instrument consists of a series of 15 questions, each asking the evaluator to rate on a 5-point scale how much a quality criterion has been met by the website, and also contains a 16th question asking the evaluator to provide an overall quality rating of the website (DISCERN, 1999).

Netscoring, a similar checklist developed by Centrale Santé, a French organization, has provided a list of 49 criteria to assess the quality of online health information (Centrale Santé, 2001). However, a recent article published on the HON website indicates that the Haute Autorité de la Santé (HAS), a French governmental organization, has chosen HON to be the official certifying body of all French health websites. France is the first country to adopt a standard to ensure the quality of its health websites (Health on the Net Foundation, 2007b).

IEEE-USA states that they endorse the Health Summit Working Group (HSWG)'s "Criteria for Assessing the Quality of Health Information on the Internet", but the link provided to access those criteria is inactive and a search on the Internet produced no relevant results (IEEE, 2000). Another such example is the Internet Healthcare Coalition criteria, which can be found in Internet archives, but nowhere else on the Web (Internet Healthcare Coalition, 2003). A very recent initiative is the European Union's eHealth Quality Criteria for Health-Related Web Sites. The Website where these criteria could be found has also been recently archived and is no longer being maintained (European Commission, 2007).

These examples show that several initiatives to develop standards for the quality of health websites referenced in the literature do not seem to have survived. It is not clear why these initiatives are no longer active today. To the exception of France, despite the existence of such generic tools, no tool has yet been adopted by the mainstream population as a standard to develop or evaluate health Websites and no attempt has been taken to enforce the use of these tools (Curro et al., 2004; Jaffery & Becker, 2004; Oermann, 2003). This may be due to the lack of agreement on the proper criteria to evaluate the quality of a health Website (Childs, 2005).

2.1.2 Specialized Tools for Evaluating the Quality of Health Websites

Specialized tools can be used to assess the quality of disease-specific health websites or section of a health website (Bath & Bouchier, 2003; Harland & Bath, 2007). They include criteria that measure aspects of quality that are specifically relevant to the disease being presented on the website being evaluated. Specialized tools may or may not include generic criteria in addition to the disease-specific criteria.

A study by Harland and Bath (2007) evaluates the quality of websites containing information on multiple sclerosis using three generic evaluation tools and compares the results with those of a specialized tool designed specifically to evaluate multiple sclerosis information. The study showed that the tools did not yield the same results. The highest quality websites identified using the generic tools were not always the same as the ones identified using the multiple sclerosis tool. The authors suggest that the criteria used in generic tools are limited in that they can't be tailored to users' specific multiple sclerosis needs. Examples of disease-specific criteria found in this tool are such questions as "does the site contain information about balance and walking problem?" or "does the site contain information about memory problems?". These types of questions could not be included in a generic criteria set. However, the research did have limitations. The sample of websites used for the evaluation was small and only one reviewer was used to evaluate the websites. It is therefore not possible to determine whether or not the tool is more suitable to measure the quality of websites containing information on multiple sclerosis than generic tools (Harland & Bath, 2007).

A study by Bath and Bouchier (2003) questioned the use of generic tools to assess the quality of websites providing information on Alzheimer's disease. The study involved the development of a specialized tool that combined both generic criteria as well as disease-specific criteria to be used uniquely to evaluate websites containing information on Alzheimer's disease. The tool was then used to evaluate a sample of websites with information on Alzheimer's disease and the results were compared with those obtained using generic tools. The results showed that generic tools could not include criteria that would be most relevant to people with Alzheimer's disease and included criteria that were completely irrelevant to people with this disease (Bath & Bouchier, 2003).

In the evaluation tools in the two studies discussed above (Multiple Sclerosis and Alzheimer's website evaluation tools), all of the non-generic questions started with similar phrases as "Does the site have information on..." or "Does the site provide advice for..." (Bath & Bouchier, 2003; Harland & Bath, 2007). For example, "Does the site give information on what to expect in the different stages of Alzheimer's disease?" (Bath & Bouchier, 2003). All of these non-generic questions asked whether or not precise information relating to a specific disease was presented on the website. Both the generic and specialized evaluation tools appear to measure different aspects of quality. Therefore, tools that combine both generic and specialized criteria could potentially be useful to evaluate more aspects of quality of health websites than tools that contain either generic criteria or specialized criteria (Bath & Bouchier, 2003). However, a disadvantage of tools that contain specialized criteria, when compared to generic tools, is that they cannot be used to measure any type of health-related websites as they contain information that is not relevant to all diseases.

2.2 User-Centered Approach for Evaluating the Quality of Health Websites

User-centered approaches can be used to evaluate the quality of health websites. The user-centered approach involves actual or potential users of the website in the evaluation process, taking into account their perceptions and wishes, often expressed by their preferences, as indications of quality. This can be done by conducting interviews with the users, observing users while they use the website, or

involving users as partners in the evaluation process (Williams, Nicholas, Huntington, & McLean, 2002b).

In the next three sections, we look successively at: the different components that are the focus of a user-centered approach (user's needs, perceptions and culture), the different studies that evaluate the cultural sensitivity of health websites, and the various studies that employ a user-centered approach to evaluate different aspects of quality.

2.2.1 Users' Needs, Perceptions and Culture

The studies using only criteria-based approaches are not involving users in the evaluation process. Sellitto et al. believe that the untrained users are not in a position to assess the quality of information. The authors suggest that when we are talking about the quality of information in the context of healthcare, it is safer to rely on experts' opinions than on users that are not medically trained (Sellitto & Burgess, 2005). However, with the abundance of information that users can find on the Internet, it is crucial to develop websites that will attract and retain the target audience. In order to do so, the website must respond to the users' needs. Evaluation methods that do not take into consideration users' needs and perceptions are likely to be ineffective (Childs, 2005; Harland & Bath, 2007).

Therefore, the target audience appears to be an important factor to consider when assessing the quality of health Websites. What constitutes a quality health website might be different for different types of users. Medical doctors may want scientific facts whereas patients may prefer simple explanations and more practical information (Purcell et al., 2002). As discussed earlier, the use of a simple generic checklist developed by professionals to assess the quality of health Websites may not be sufficient. Although a professional may feel that certain health information is useful to a user, it becomes useless if the user does not have enough interest in the website to remain on the site. As Dragulanescu argues, a website that delivers information is considered to be of quality only if it meets the stated needs of users. (Dragulanescu, 2002)

According to some authors, culture has an influence on users' perception of websites. Singh et al. (2006) studied German, Chinese and Indian cultures to determine whether consumers would perceive websites that were adapted to their respective cultures to be more effective, in terms of presentation, navigation, purchase intention, and attitude towards a site, than websites that were standardized. The results of the study showed that consumers from all three cultures preferred websites that were adapted to their culture. It also shows that culture has an influence on consumer beliefs, attitudes, and intentions to purchase on the web. Therefore, the authors found that the perceptions of a website may be influenced by culture (Singh, Fassott, Zhao, & Boughton, 2006).

Thomson et al. (2007) affirms that while health is important to all human beings despite their cultural background, the dissemination of health information online should take into account the cultural differences of users. A person's cultural views on health can influence their perception of the quality of health Websites. The perception of risk related to disease, emotions of fear or embarrassment, the level of communication with physicians, and social stigmas may be influenced by a person's cultural view on general health matters or specific diseases, which in turn, can influence health information seeking on the Internet. (Thomson & Hoffman-Goetz, 2007)

2.2.2 Evaluating Cultural Sensitivity

A recent study by Thomson and Hoffman-Goetz (2007) looked at the cultural sensitivity of web-based patient decision aids for cancer screening and treatment for diverse cultural groups. The researchers used the Cultural Sensitivity Assessment Tool (CSAT) to assess the cultural sensitivity of decision aids that specified African Americans as their target audience. This tool was specifically designed to assess the cultural sensitivity of cancer print material for African Americans. Even though a tool was used to evaluate cultural sensitivity, as opposed to a more user-centered approach, the tool was developed in collaboration with an advisory committee consisting of health professionals as well as lay persons from African-American communities (Texas Cancer Information, 2008; Thomson & Hoffman-Goetz, 2007).

Some limitations were found with the CSAT tool. In a study by Friedman and Daniela (2006) that used the CSAT tool to assess the cultural sensitivity of cancer information in ethnic print media for different cultural groups found the tool had limitations in the level of cultural sensitivity characteristics it can measure. They found that the tool can be valuable to assess the sensitivity of more surface characteristics of culture, such as the appropriateness of graphics or the use of familiar expressions. However, the tool is not appropriate to measure the sensitivity of deeper historical characteristics of culture, such as beliefs about death, traditional medicine and symbolic representations of health and illness. (Friedman & Hoffman-Goetz, 2006)

Because of the limitations of the tool, Thomson and Hoffman-Goetz (2007) also used the Cultural Sensitivity Assessment Checklist (CSAC). This checklist, proposed by Friedman and Daniela, was designed to be used in combination with a tool like the CSAT tool to measure more deeply rooted cultural characteristics. The tool can be used to assess information that is targeted to any cultural groups. However, the CSAC tool has not been tested for reliability and validity (Thomson & Hoffman-Goetz, 2007). Therefore, this leads to wonder whether a single generic tool can actually capture the deeply rooted cultural characteristics that would make a site culturally sensitive for all cultures, especially if no users of different cultures were involved in the development process of this tool. (Friedman & Hoffman-Goetz, 2006; Thomson & Hoffman-Goetz, 2007)

A recent user-centered study that assessed the cultural sensitivity of breast cancer information on the Web for older Aboriginal women found that Aboriginal women preferred to have culturally relevant cancer information. A quote from an Aboriginal woman interviewed states just that: "If we're not used to it and it's not geared specifically to the Aboriginal women, it won't matter to us". Some women also emphasized that the cancer information should include spiritual beliefs, traditional healing methods and story telling, all important cultural practices of Aboriginal people. The authors concluded that for online breast cancer information to be culturally sensitive, they should incorporate health attitudes and behaviors of Aboriginal women (Friedman & Hoffman-Goetz, 2007). The results of this study suggest that cultural sensitivity needs to be taken into account when looking at the

quality of health Websites. To my knowledge, this is the only study to date that looks at Aboriginal people's opinions of the cultural relevance of online health information.

This study however did have some limitations. The researchers used a convenience sample of Aboriginal users living in Southern Ontario to conduct their interviews. As the Canadian Aboriginal population contains several different cultures, unique cultural needs of the different communities must be taken into account. A convenience sample does not recognize the heterogeneity of Aboriginal people in Canada and the results could be biased. Therefore, generalization of the results to the whole Aboriginal population is unrealistic (Friedman & Hoffman-Goetz, 2007).

2.2.3 User-Centered Approaches to Evaluate Different Aspects of Quality

User-centered approaches have been used to evaluate different aspects of the quality of health websites, such as the usability (defined below), the readability (the degree of ease with which the text can be read), the usefulness (having practical utility), and the relevance (the degree in which the user's information needs are satisfied) (Friedman & Hoffman-Goetz, 2007; Gilbert, Temby, Julie Rae E., & Rogers, 2005; Williams, Nicholas, Huntington, & McLean, 2002b; Williams, Nicholas, Huntington, & McLean, 2002b).

Some studies that take a user-centered approach for evaluating the quality of health websites focus mostly or only on usability (Gilbert et al., 2005; Williams, Nicholas, Huntington, & McLean, 2002b). Jakob Nielsen (2006) states that usability is a component of website quality, but a usable website does not necessarily equal a quality website. As such, the quality of a Website cannot be assessed completely by simply evaluating if the site is usable or not. As defined by Nielsen, usability looks at how a Website's user interface is easy to use and encompasses the following 5 quality components: learnability (ease of use the first time a user goes on the site), efficiency (speed in which the tasks can be accomplished), memorability (ease in remembering how the site functions the second time a user goes on the site), errors (the number of errors users make, the severity and how easy is it to recover from them), and user satisfaction with the site (Nielsen, 2003).

A study by Gilbert et al. (2005) uses 3 different methods to evaluate the quality of a teen sexually transmitted disease (STD) prevention Web site. The researchers first evaluated the site's content and quality, then assessed the usability of the site, and finally conducted an online survey on their site. For the usability aspect of the study the researchers take on a user-centered approach. An observational study was conducted with 14 teens, where each was interviewed, observed as they performed searches on the site and interviewed once more to assess satisfaction of the site. The ease of finding information, navigation, and interaction with the site to obtain information was assessed. Although the study did involve the participation of target users, the user-centered approach was only used for the usability assessment part of the study (Gilbert et al., 2005).

Similarly, another study by Williams et al. (2002) emphasizes the importance of including users in the evaluation of the quality of a Website. This study also focused mostly on the assessment of the usability aspect of quality with their user-centered approach. They did however also consider the comments and the opinions of users on the readability and the relevance of the information on the site, which are other aspects of quality. The method consisted of observing users while they navigated on the Website, followed by interviews about their experience. As participants were asked to chat freely about the site and their views on it in order for the observers to more easily capture usability issues, other comments not relating to usability, such as relevance of information were also made by the participants and noted by the observers (Williams, Nicholas, Huntington, & McLean, 2002b).

User-centered approaches can also be used to assess other aspects of the quality of websites. For example, a recent study by Friedman & Hoffman-Goetz (2007) adopted a user-centered method to assess older Aboriginal women's opinions of the usefulness and cultural relevance of breast cancer information on the Internet. The method consisted of exploratory semi-structured interviews with Aboriginal women. The women interviewed were asked about their opinions and were also asked to provide recommendations for improvements to the health websites studied. The results of the interviews provided insightful information on the quality of cancer websites from the target audiences' point of view (Friedman & Hoffman-Goetz, 2007).

Harland et al. (2007) believe that having so much health information available on the Internet has caused a paradigm shift. Patients are now empowered because they can look up information more easily from several sources before meeting with their physician. They now show up at their doctors well-informed about their condition. Before the advent of health information on the Internet, patients had to rely only on their doctor's expert point of view, or get a second opinion. However, today, patients have the option of taking a more informed decision on their health, based on the information that they find on the Internet, as well as their doctor's opinion. However, if users are not consulted when creating these health Web sites, then we are again back to the old paradigm of "experts know best" (Harland & Bath, 2007).

Williams et al. (2002) suggest that a different method of evaluation should be used depending on the type of Website that is being evaluated. They identify five different types of Websites depending on its purpose: information dissemination, commerce and advertising, education and training, entertainment, and communication. These types are not mutually exclusive, meaning that most sites will contain elements of each type. However, there is usually a specific purpose for the site that falls into one of these five types. In the case of health information Websites, the main purpose would be to disseminate information, although some sites will also incorporate a communication aspect, such as the ability to chat with other users or with professionals or the possibility of sending email enquiries (Williams, Nicholas, Huntington, & McLean, 2002a).

Williams et al. (2002) suggest that the aim of an evaluation of health information Websites would be to look at any or all of the following: information quality, usability issues, site facilities (multimedia, communication links), and relevance of the material for the target audience. Depending on what is the aim of the evaluation, a different method or a combination of methods would be used (Williams, Nicholas, Huntington, & McLean, 2002a).

Indeed, the difficulty in agreeing on an appropriate set of criteria for assessing the quality of health information Websites may be because a simple checklist tool cannot be enough to capture all the components that make a quality Website. "The logical conclusion must be therefore that the broader the website types an evaluative framework attempts to encompass, the more general the criteria have to be to

include each possible function of the site” (Williams, Nicholas, Huntington, & McLean, 2002a). Users’ preferences should also be taken into account and the actual user behaviors should be observed through other methods such as user studies.

Both approaches to the evaluation of health websites have their limits. The limits of the criteria-based approach include the lack of validation of existing tools and the lack of agreement on the proper criteria to use. In addition, a limit of generic tools is the fact that they cannot be tailored to users’ disease-specific needs. Conversely, a limitation of specialized tools is that they cannot be used to measure any type of health-related websites as they contain criteria that are not relevant to all diseases. A limitation of the user-centered approach is the fact that users that are not medically trained cannot be in a position to evaluate the quality of the health information presented.

Both approaches measure different aspects of quality (Williams, Nicholas, Huntington, & McLean, 2002a). Quality is evaluated in this study through a user-centered method by looking at the relevance of the content and presentation on health websites for the users based on their preferences.

Chapter 3: Aboriginal People in Canada and Culture

Canada is known for its cultural diversity. It is one of the most ethnically and racially diverse countries in the World (Pendakur & Hennebry, 1998). Aboriginal People in Canada contribute to this multiculturalism as they are a culturally diverse group (Assembly of First Nations, 2002; Canadian Heritage, 2004). In fact, Canadian Heritage states that there were more than 56 Aboriginal nations speaking more than 30 languages at the time of European settlement. Diversity was a part of Canada even before the Europeans set foot on this land. Living among different cultures comes with its challenges (Canadian Heritage, 2004).

Aboriginal people have a different perspective on life that they want to share with Canada. As Merle Assance-Beedie said: "We have something they do not know about — we have our teachings, our value systems, our attitudes, our clan systems and on and on and on....Let's educate them. [...] They educated us to a point where we almost forgot who we are. Now it is time we educate them, people to people. We are different. We have a different perspective on life and all creation. We have many wonderful things to share. We have different and wonderful teachings to share that are simple to live by, reasonable, sensible, for the good of all within the community, full of respect. These have remained a mystery to mankind until now" (INAC, 2006j).

Understanding another culture is not easy and takes time. Canadians are slowly learning to respect the differences of others and to relate to one another, in order to live in harmony. Today, Canada is working to try and heal the relationship it has with its Aboriginal people. The 5-volume report of the Royal Commission on Aboriginal People that was published in 1996 was a start to this process. The report identified the legal, political, social, economic and cultural issues that need to be addressed to ensure the survival of Canada's Aboriginal people. Following this report, the federal government developed Gathering Strength: Canada's Aboriginal Action Plan, a plan to work in partnership with Aboriginal people to improve health, housing and public safety, strengthen economic development and assist with the implementation of self-government (Canadian Heritage, 2004).

Because this research is conducted in Aboriginal context and that a hypothesis on the role of culture on preferences is proposed, this chapter covers the background on

Aboriginal People in Canada and their culture. The terminology related to Aboriginal people is defined in the first section. The second section goes into the details of defining the concept of culture. The third section paints a picture of what culture means to Aboriginal People in Canada based on the literature and on concrete examples from specific Aboriginal people testimonies. The influence that the history of Aboriginal People has had on their culture and their health today is described in section four. Finally, the last section explains how Aboriginal culture and health are strongly related.

3.1 Terminology related to Aboriginal People

Before defining what culture is to Aboriginal people in Canada, a lot of terminology that is used in Canada in relation to Aboriginal people must be defined. Indian and Northern Affairs Canada (INAC) has provided a terminology guide on their website to define the several words relating to Aboriginal People in Canada. "Aboriginal People" in Canada is a collective name that refers to the original peoples of Canada and their descendents and includes three different groups: Indians, Métis and Inuit. All three groups have unique heritages, languages, cultural practices and spiritual beliefs (INAC, 2005).

Indian describes all the Aboriginal people in Canada that are not Métis or Inuit. Today, the term Indian is considered to be outdated and is only used in certain circumstances such as when discussing rights and benefits. The term "First Nation" is now more currently used (INAC, 2005).

There are three groups of Indians in Canada: Status Indians, Non-Status Indians, and Treaty Indians (INAC, 2005). This categorization of Aboriginal People has been done by Euro-Canadians. As Hedican (1986) has observed in one northern Ojibwa Indian community, such categorization as Status Indians, Non-Status Indians, and Treaty Indians do not have a cultural analogue in the world of the northern Ojibwa. By definition, Status Indians are Indians that are registered on the Canadian federal government Indian Register and therefore are entitled to certain rights and benefits under the Indian Act. These benefits may include on-reserve housing benefits, education, and exemption from federal, provincial and territorial taxes in specific

situations (INAC, 2004). Indians must meet specific criteria in order to be entitled to register. People who consider themselves Indians but are not recognized by the government as Indians under the Indian Act are referred to as Non-Status Indians. Finally, Treaty Indian is a term that describes "Status Indian who belongs to a First Nation that signed a treaty with the crown" (INAC, 2005).

Although the term First Nation is used to replace the term Indian since the 1970s, the term is widely used yet it does not have a legal definition. Some First Nation communities also use the term to replace the term "Indian Band". A band is a body of Indians with its own governing council, declared as such for the purpose of the Indian Act, in order to benefit from the lands and money set aside by the Federal government. Bands usually share common values, traditions and practices (INAC, 2005). For the purpose of this research, the term "First Nation" will be used to refer to an Indian as defined above, and the terms "First Nation Band" or simply "Band" will be used to refer to an Indian Band.

Métis is a word of French origin that means "mixed blood". It is used to describe people with mixed First Nations and European ancestry (INAC, 2005).

Inuit, which means "the people" in the Inuit language Inuktitut, are Aboriginal people that live in Arctic Canada, primarily in Nunavut, the Northwest Territories, and northern parts of Quebec and Labrador. Inuit are not covered by the Indian Act; however, the laws affecting Indians also apply to Inuit since 1939 (INAC, 2005).

Some First Nations live on reserves, which are a part of land that have been reserved for use and benefit by a First Nation Band. A First Nation Band can have more than one reserve. Inuit do not live on reserves; therefore, the term "reserve" does not apply to them. Rather, the terms "Inuit community" or "communities in the Arctic" are used. Some First Nations also prefer to use the term "First Nation community" instead of the term "reserve" (INAC, 2005). For the purpose of this research the term "First Nation community" will be used.

Aboriginal People are also divided into culturally diverse nations sharing a language and a culture. All people that identify themselves as Aboriginal are part of a nation, whether they live in First Nation communities, Inuit communities or in urban areas.

Aboriginal nations are mostly concentrated in one geographical location. Some examples of Aboriginal nations are Cree (Nituuhuiyuuch), Algonquin (Mamiwinnik), Inuit, Malecite (Wulust'agooga'wiks), and Mamac (Mig'maq) (Lepage, 2005). The Assembly of First Nations states that as a general rule, most Aboriginal people prefer to be referred to by the specific nation to which they belong (Cree, Ojibway, Oji-Cree, etc), instead of generally being referred to as First Nations or Aboriginal people (Assembly of First Nations, 2002).

Several First Nation bands are organized into tribal councils, which represent the interests of these bands. For example, the Keewaytinook Okimakanak (KO) tribal council is composed of 6 First Nation bands (Deer Lake First Nation, Fort Severn First Nation, Keewaywin First Nation, McDowell Lake First Nation, North Spirit Lake First Nation, and Poplar Hill First Nation) located in the North-Western part of Ontario. The tribal council board of directors is composed of the Chiefs of the 6 member First Nations bands. All of the KO First Nation members are from the Oji-Cree nation (Keewaytinook Okimakanak, 2008b).

In the Canadian 2001 Census, nearly 1 million (976,305) people identified themselves as Aboriginal (Statistics Canada, 2001). In the 2006 Census, the number has surpassed the 1 million mark, with 1,172,790 people identifying themselves as being part of an Aboriginal group. This represents 3.8% of the population, an increase of 18.7% since 2001, and 45% since 1996. Of this number, about 60% reported they were North American Indian, 33% reported they were Métis and 4% reported they were Inuit (Statistics Canada, 2008).

3.2 Culture

Culture is one of the most complicated words in the English language (cited in (Martin & Nakayama, 2004), p.75). Several different definitions of the concept exist. Alfred L. Kroeber and Clyde Kluckhohn proved this by defining the word "culture" in 164 different ways (cited in (Durrer, 2006), p.11). However, some definitions are more appropriate for this study. Hofstede defines culture as "the collective programming of the mind that distinguishes the members of one group or category of people from another" (Hofstede, 2001).

To better grasp the difference between groups, Hofstede uses Guilford's definition of personality for an individual and applies it to a group. Guilford's definition of personality is "the interactive aggregate of personal characteristics that influence the individual's response to the environment" (cited in (Hofstede, 2001), p. 10). From this, Hofstede defines culture as "the interactive aggregate of common characteristics that influence a human group's response to its environment". The comparison of culture with personality highlights the fact that culture helps to differentiate one group from another by its uniqueness, just like personality is unique and differentiates one individual from another (Hofstede, 2001).

An intriguing aspect of culture, on top of it being a complex phenomenon, is that the members of a group often "practice" it at a subconscious level (Martin & Nakayama, 2004). Often, it is only when individuals are faced with or immersed in a culture that is different from their own that they can compare, see the differences and better understand their culture (Martin & Nakayama, 2004). Travelers can easily get a culture shock when visiting a country for the first time, as it can be difficult to understand another culture without living it.

A core element of culture is values. Values are simply defined by Merriam-Webster dictionary as "something (as a principle or quality) intrinsically valuable or desirable" (Merriam-Webster, 2007). In a more elaborate way, Rokeach defines having values as having "an enduring belief that a specific mode of conduct or end-state of existence is personally and socially preferable to alternative modes of conduct or end-states of existence" (Cited in (Hofstede, 2001)). For instance, a person that values perseverance might frown upon a quitter as they consider perseverance to be personally and socially preferable to quitting.

Hofstede (2005) believes that our basic values are acquired at the early stages of our lives, in the first 10 to 12 years. For example, we learn what is dangerous versus safe, abnormal versus normal, or evil versus good. Children growing up in the same family will most likely develop similar values as their siblings or parents because they learn by imitating the people that they admire around them. Likewise, people living in the same country or cultural region most probably share common values (Hofstede & Hofstede, 2005).

Hofstede (2001) uses values, as well as three other manifestations of culture to explain the concept: heroes, rituals, and symbols. He illustrates this concept in a diagram that he calls the "Onion Diagram" (figure 3.1). The Onion Diagram demonstrates that values are at the core of culture. The word "Practices" crosses the layers of Rituals, Heroes and Symbols. These three manifestations of culture are considered practices and are therefore visible to an outside observer. The cultural meanings of these practices, however, are not visible. The cultural meanings depend on the person interpreting these practices, and therefore, their true meanings can only be explained from an insider (Hofstede, 2001).

Symbols are depicted as the outer layer of the Onion Diagram because they can easily be copied from one culture to another. Symbols represent words, gestures, images, and objects that embody a specific meaning or importance to people that share the same culture. Language is considered to be a cultural symbol. Other examples are colors, emblems, and styles.

Heroes symbolize persons, alive, dead, real or imaginary, who demonstrate qualities that are considered to be valued in a culture. Cultural hero examples could be Wayne Gretzky (alive) for Canadians, John F. Kennedy (dead) for Americans, or even the cartoon Asterix (imaginary), for the French (Hofstede, 2001).

Rituals can be defined as ceremonies, acts or a series of acts that are done by people of a specific culture (Merriam-Webster, 2007). Rituals help individuals feel like they are part of the collective group of a culture. Examples of these are marriage ceremonies, ways to greet people, or offering gifts to someone on their birthday. Values are invisible to an outsider, unless these values are manifested in behavior or through the three manifestations described above (Hofstede, 2001).

Culture is not static, it changes over time. As the world evolves, people evolve and their culture changes. Older people's culture differs from younger people's culture, as they have lived in a different time. The outer layers of the onion, symbols, heroes and rituals, are more easily changed than the core values since these are acquired when we are young. Therefore, although the practices in a society may vary, the values are more stable (Hofstede & Hofstede, 2005).

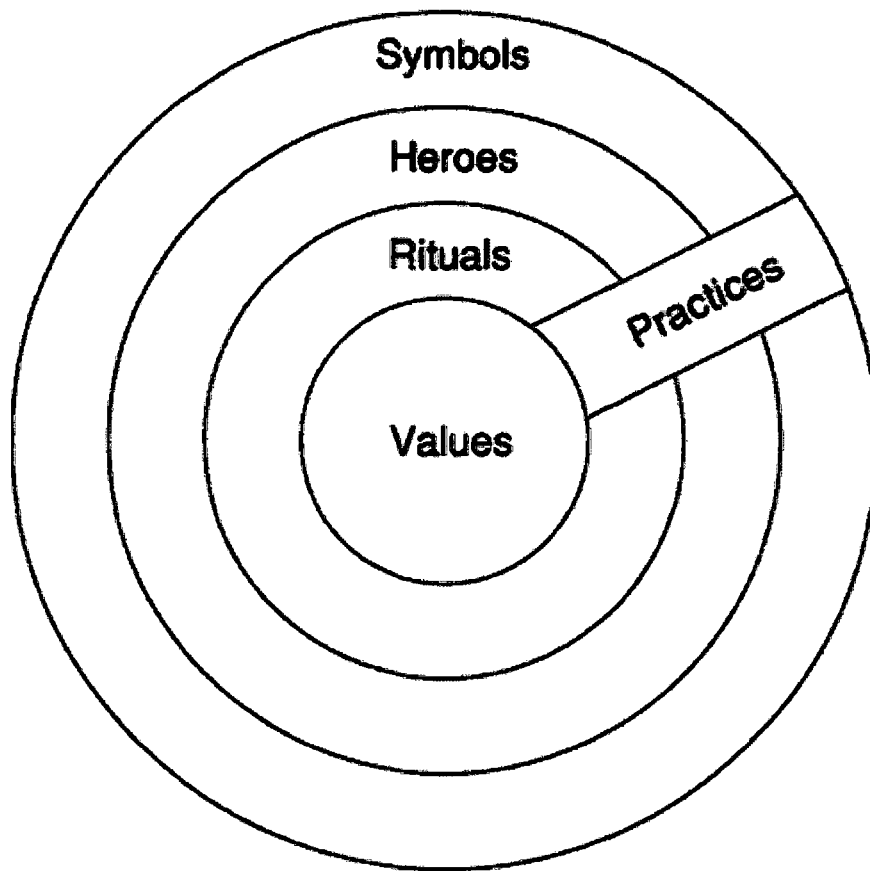


Figure 3.1: The "Onion Diagram": Manifestations of Culture at Different Levels of Depth
(Hofstede, 2001)

The concept of "sharing a culture" applies to societies. However, in his study of cultures, Hofstede (2005) applies the concept to nations. Although nations are composed of groups with different cultures, a nation also has its own culture. Nations are built by sharing practices that encourage integration, such as a common language, a national education system or political system. As put by Hofstede, "many nations do form historically developed wholes even if they consist of clearly different groups and even if they contain less integrated minorities" (Hofstede & Hofstede, 2005). Therefore, there exist different aspects of cultures within a single nation.

3.3 Aboriginal Culture

Aboriginal People in Canada are culturally diverse. The Assembly of First Nations identifies 633 First Nation Bands in Canada among the Aboriginal group known as First Nations. More than 50 cultural groups and more than 50 languages are represented among these First Nations (Assembly of First Nations, 2002). As described by Hofstede's definition of culture, each Aboriginal culture possesses its own values, heroes, symbols, and rituals. The difficulties in defining the concept of culture, as well as the diversity among the Aboriginal communities, make it inappropriate to define a homogeneous Aboriginal culture. However, despite the cultural heterogeneity of Aboriginal people, there are cultural characteristics that are unique to Aboriginal people and that unite all Aboriginal cultures together (INAC, 2006h).

INAC describes Aboriginal culture as "a way of life shaped by intimate relationships with the land, reinforced by a world view attributing life and spirit to all elements of the biosphere, and expressed in ethically ordered behaviors in social, economic and political spheres" (INAC, 2006h). The traditional Aboriginal culture is a way of life and a way of knowing that can be manifested in different ways in the various Aboriginal communities. Each community has its own rituals, ceremonies, cultural practices, and beliefs, however all Aboriginal people share a common way of life that is holistic, acknowledging the emotional, spiritual, physical, and mental aspects of life (Assembly of First Nations, 2002; Hill, 2003; INAC, 2006h).

The medicine wheel is a fundamental symbol of several Aboriginal cultures that symbolizes their holistic way of life and way of knowing. There exists a variety of medicine wheels that are used for different purposes by different Aboriginal cultures. However, all the medicine wheels are in the form of a circle, separated by four quadrants, each representing an element of a holistic view. No one quadrant is complete, nor is it more important than the others. The four quadrants together symbolize the concept of wholeness. The medicine wheel shows that in the Aboriginal way of knowing, there must be balance and harmony between the four dimensions. All four are equal and necessary parts of a whole. The symbols used for the four quadrants vary. For example, the four quadrants could be represented by the four

stages of life: childhood, youth, adulthood, and elderhood, or by the four elements: fire, earth, air, and water (Dapice, 2006; Orr, 2000; Roberts, Harper, & Bull, 1998).

For example, Dapice (2006) describes a medicine wheel that includes all races and all life, including two-leggeds, four-leggeds, winged things, plants and medicines (figure 3.2). The four quadrants represent the four aspects of a person: mental, emotional, physical, and spiritual. Through this medicine wheel, a person learns that they will lack wholeness if they focus on a single aspect of these four quadrants. Mental, emotional, physical and spiritual balance must be achieved for the well-being of a person. (Dapice, 2006).

Kind et al. (2005) describe how Aboriginal ways of knowing can be applied to education. Gabriel, a Coast-Salish artist, visited 3rd and 4th grade classes to introduce the First Nations culture through drumming, storytelling, dancing, and learning. Arts were used with the students to facilitate holistic ways of knowing, experiencing, and understanding, by balancing learning through their minds, their bodies, their emotions, and their spirit. The artist developed the student's minds by sharing traditional stories, dances, legends, symbols, ways of living and history. Their learning was embodied by dancing, feeling the rhythm of the drum and connecting to the heartbeat of people. Emotions were felt during the dancing and singing. Finally, the students connected spiritually by sharing with the class their own family traditions (Kind, Irwin, Grauer, & De Cosson, 2005).

Also very apparent in Aboriginal cultures is their strong ties to the land and their profound spiritual beliefs (INAC, 2006c; National Aboriginal Health Organization, 2008). In Aboriginal cultures, the land is indispensable to existence. Their entire lives are shaped around the land's natural resources, including their socialization, their governance, and the nourishment of their bodies and spirits. This intimate relationship is reinforced by the sense of duty of Aboriginal people to safeguard and care for the many historical and cultural symbols and landmarks that generations have left behind. Sacred objects dedicated to ritual use, storytelling and songs symbolize Aboriginal spirituality (INAC, 2006c; National Aboriginal Health Organization, 2008).

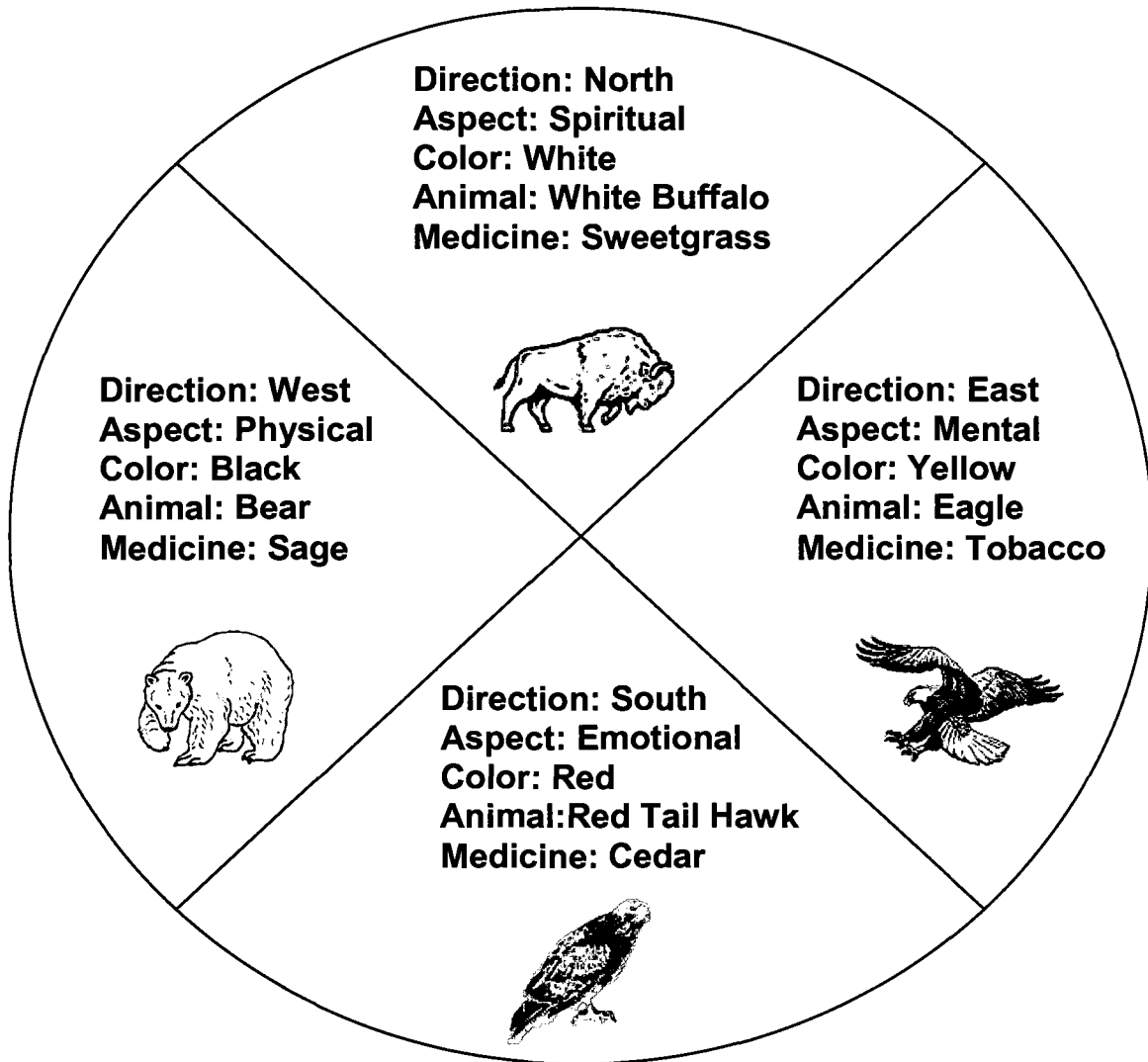


Figure 3.2: The Medicine Wheel (Dapice, 2006)

"We Are One with the Land" (2007), a book on the history of Kitchenuhmaykoosib Inninuwug (KI), a Cree community in the North of Ontario, whose people speak Ojibwe, describes the many ways in which this Aboriginal community traditionally practiced a holistic way of knowing. The physical and spiritual were evident aspects of the traditional way of life. The people of KI have a very strong connection to the land and live in balance and harmony with it. The people of this community believe that the land can provide them with everything that they need to survive, as long as they care for it and protect it. Hunting, fishing and trapping were an integral part to their survival and are still very present today. Other traditional activities such as

drumming, songs, and dances still remain today. They incorporated the spiritual in every detail of their lives, and respected the land that was given to them by the Creator (Hiebert & Heinrichs, 2007).

As can be seen by all these examples, the holistic way of knowing concept of Aboriginal culture can be applied to all aspects of life.

Language is also a fundamental part of the Aboriginal culture. Language allows to communicate and to transfer knowledge in cultural terms that can be lost in translation. As Hofstede classifies language as a cultural symbol, language can be said to embody a specific meaning or importance to people that share the same culture (Hofstede, 2001). For Aboriginal people, language ensures the survival of their world view, the wisdom of their ancestors and their ways of life (INAC, 2006i).

Family and community are also important aspects of the Aboriginal culture. The meaning of the word "family" has a broad meaning to many First Nations, where all members of the community are considered as family, linked through a common ancestor. Family is considered to be a central part to the survival of the Aboriginal culture (INAC, 2006f). Children are valued as much as Elders. Elders, who are "keepers of tradition, guardians of culture, the wise people, the teachers" play a central role in the education of members of their community, passing down their knowledge from generation to generation (INAC, 2006g). Children on the other hand "bring a purity of vision to the world that can teach their elders. [...] They renew the strength of the family, clan and village and make the elders young again with their joyful presence" (INAC, 2006f). The concept of sharing with and learning from other family or community members is fundamental to the Aboriginal culture.

3.4 Aboriginal History in Canada and its Consequences on Culture and Health

The history of Aboriginal People in Canada has played a significant role in shaping their culture and health today (INAC, 2006h). Aboriginal people have had to adapt to a different way of life and to sharing land with Euro-Canadians. Aboriginal people lived all over Canada long before the Europeans first set foot on this land. They had their own cultures, languages, political organizations, and trade and economic

systems (Assembly of First Nations, 2002). However, with the arrival of the Europeans, their way of life was completely disrupted. Aboriginal people gradually lost control of their land and in this process, became more and more disconnected with several of their symbols of history and culture. As Aboriginal people cultures are closely tied to the land, this loss has been tremendous for them (INAC, 2006h).

According to Indian and Northern Affairs Canada (INAC), a series of events in the history of Aboriginal people after the arrival of the Europeans to Canada have contributed significantly to the present situation of Aboriginal people. Among the actions of the past, three areas of federal policies are considered among the most unjust policies imposed on Aboriginal people, that still have negative consequences today: the Indian Act, the residential schools policy, and the relocation policies (INAC, 2006d).

The Indian Act, still an existent policy today, was created in the 19th century under the assumptions that Aboriginal societies were inferior and could not make decisions on their own and with a hidden agenda to assimilate. It infringed on the lives and cultures of Aboriginal people. "It subjected status Indians to prohibitions and penalties that would have been ruled illegal and unconstitutional if applied to other Canadians (INAC, 2006d)."

With the residential schools policy, children were taken from their homes and sent to schools away from their land, families and cultures, discouraging any contact with the outside world and preventing them to speak their native language in an attempt to assimilate the children and to mold them into the ways of the dominant European, Christian society (INAC, 2006d). Lots of abuse took place in these schools, from starvation, to beatings, to verbal abuse. The damaging effects of this policy on thousands of Aboriginal people are still felt today (INAC, 2006b).

The relocation policies forced the physical displacement of Aboriginal communities from their homes, away from traditional hunting and fishing territories. The separation of Aboriginal people from their land has caused cultural, social, political, economic and health problems that are also still suffered to this day (INAC, 2006c). Cultural knowledge and symbolic places from their native homeland links Aboriginal people with their past and their future, and taking them away from this land has

caused them great stress that has had effects on their health, both physically and psychologically (INAC, 2006c).

These are examples of the many intentional acts of assimilation and ongoing racism towards the Aboriginal population by Euro-Canadians that have forced them to change their way of living and give up many of their cultural beliefs and practices. This history has had a harmful impact on the emotional, spiritual, mental and physical health of Aboriginal people today (Dapice, 2006; Hiebert & Heinrichs, 2007; INAC, 2006d).

For example, INAC's special report on suicide considered culture stress (i.e. the loss of confidence in the ways of understanding life and living that have been taught within a particular culture (Chenier, 1995)) as a major factor in the high rates of suicide in Aboriginal young people, linked to the cumulative impact of assimilative policies of the past that have caused young people to have low self-esteem, have negative images of their culture, and engage in self-destructive behavior (INAC, 2006d). The following are among the most significant health problems that Aboriginal people are facing today: family violence, suicide, high levels of infectious and chronic diseases, tragic levels of childhood deaths, youth injuries and adult disabilities, diabetes, tuberculosis, pneumonia, homicide, alcoholism and substance abuse, and nutritional problems (National Aboriginal Health Organization (NAHO), 2003; Silverman et al., 2001). Aboriginal people suffer a significantly lower health status than the general population (National Aboriginal Health Organization, 2008).

3.5 Aboriginal Culture and Health

The forced abandonment of many cultural practices includes the way in which Aboriginal people practiced medicine. Christian missionaries considered traditional healing methods as witchcraft and other non-Aboriginal people ridiculed it. The Indian Act outlawed healing methods and elders and healers were prosecuted for practicing traditional medicine (INAC, 2006e).

Traditional medicine has generally been defined as the healing beliefs and practices of specific Aboriginal societies, before any contact with Europeans were made.

However, traditional medicine has also been used to describe these same healing beliefs and practices that have gradually changed over the years since the arrival of the Europeans, but that are still shaped by cultural worldviews and values. Several people dislike the term "traditional", as it was only introduced by Europeans to differentiate between Aboriginal medicine and European medicine. Many Aboriginal people prefer to simply use the term "medicine" (Hill, 2003). The term "alternative" has also been used to describe traditional medicine. This suggests that traditional medicine is considered to be an alternative choice to the biomedical practices of the dominant society (Johnston, 2002). The term "alternative" is most often used by Canadians to refer to other types of therapy which have become more popular nowadays, such as chiropractic care, massage, and relaxation techniques (National Aboriginal Health Organization, 2008).

For the purpose of this research and for clarity, the term "traditional" will be used to refer to the Aboriginal ways of practicing medicine.

As Aboriginal people are culturally diverse, they are also very much different in the way they practice traditional medicine (Johnston, 2002). However, like in culture, Aboriginal people are similar in the way in which they approach the whole concept of health and healing. The cultural concepts of holism, balance and harmony are very much visible in their views on health. The physical, mental, spiritual, and emotional aspects of a person must be balanced in order to be healthy. This is generally contrary to the Western view on medicine, in which emphasis is mostly placed on biomedical concepts only (Johnston, 2002; National Aboriginal Health Organization, 2008).

In the book on the history of the KI community, "We Are One with the Land" (2007), the authors describe a traditional practice, the vision quest, that was part of their way of life at the time and that is also present today. The vision quest consists of a fast that every boy and girl was expected to make at a point in time while they were growing up. They would spend some time alone in the woods for a few days without eating or drinking, in a quest to form a relationship with a spirit entity. This spirituality was a crucial element in maintaining a balance in each individual and therefore staying healthy (Hiebert & Heinrichs, 2007).

Some examples of traditional methods to restore and maintain balance in a person include healing circles, sweat lodges, herbal medicines, spiritual ceremony, songs, dances, feasts, and the transfer of knowledge from elders (Hill, 2003; National Aboriginal Health Organization (NAHO), 2003). Aboriginal medicine is strongly linked to their relationship with the land and it is said that the diverse environments in which Aboriginal people live, shape the medical expertise and practices of the different communities. The different climates, landscapes, plants, animals and the differences in culture and language found in Aboriginal communities influence the way in which they practice medicine (Hill, 2003).

The literature has also emphasized the importance of traditional medicine in cultural identity. Culture is fundamental for Aboriginal people to be healthy. "The loss of culture and language has resulted in profound feelings of despair, grief and depression, which have been linked to alcohol and drug abuse, violence and family breakdown". Language is essential for the transfer of the complex Aboriginal knowledge on medicine and cultural identity can give people a feeling of self-worth (Johnston, 2002; National Aboriginal Health Organization (NAHO), 2003).

Despite all the efforts of assimilation, Aboriginal traditional medicine is still being practiced in many communities (Johnston, 2002). In fact, Aboriginal people can be seen as true survivors, as many cultural practices are still practiced today, some that have been maintained, and others revived (Hiebert & Heinrichs, 2007; McMillan, 1988). In their report on the overview of traditional knowledge and medicine, NAHO states that 72.1 percent of 276 Aboriginal women respondents in 2003 reported consulting traditional healers (National Aboriginal Health Organization, 2008).

The holistic views on health and healing of Aboriginal people are more and more accepted by the mainstream population (National Aboriginal Health Organization, 2008). The Report of the Royal Commission on Aboriginal People in Canada has shown that the federal government has acknowledged that the acts of colonization has caused much harm to Aboriginal communities that are still felt today and that things much change. One of ways that this can be done is by introducing programs that promote traditional medicine (INAC, 2006a). "Indigenous medicine provides a vehicle through which to express individual and cultural identities and to take a

stance in relation to a history of colonization and ongoing power relationships with the dominant society” (Johnston, 2002).

The National Aboriginal Health Organization (NAHO), an Aboriginal-designed and – controlled body, has put traditional medicine as central to its mandate to influence and advance the health and the well-being of Aboriginal People (Hill, 2003). Other organizations and governmental bodies are creating programs to promote traditional medicine. For example, the Métis Addictions Council of Saskatchewan (MACSI) has a 28-day program for in-patient treatment that has a traditional healing component administered by community elders following cultural protocols. Examples of practices are cleansing ceremonies and sweat lodge ceremonies (National Aboriginal Health Organization, 2008). The increasing interest in the development of programs that recognize traditional medicine has been to help restore the health of Aboriginal people by bringing them back to their culture. As Alma Brooks from the Wabanaki Medicine Lodge in New Brunswick says, “The only way for our people to heal is to go back to those original instructions that were given to us, go back to the sacred fires, go back to the wisdom and knowledge that was given to us, and apply that to our lives today (INAC, 2006a)”.

Dapice explains how an Aboriginal person can achieve health, positive change, and growth in each aspect of the medicine wheel today. For the mental aspect elders must pass on knowledge to youth, for the spiritual aspect, a person must reconnect to creation, the earth, the sky, and nature, for the emotional aspect, counseling and therapy must be linked to cultural symbols and beliefs, and finally for the physical aspects, a person must look at the way ancestors ate and exercised (Dapice, 2006). Pastor Chapman of the KI community also agrees that going back to old ways would be a good thing: “There is hope for the native people even if there will be difficult times. I see that they would go back to eating things they ate in the past. There were herbal medicines too that people knew. They were all good for the body” (Hiebert & Heinrichs, 2007).

With the presence of both practices – traditional and biomedical - Aboriginal people will be able to choose which practice works best for them. In the past, when faced with the option of using traditional medicine or European medicine, Aboriginal people have responded differently (Johnston, 2002). One pattern of response has been to

use traditional medicine for “Aboriginal diseases” and European medicine for “European diseases”. Another pattern of response has been to use traditional healing to help Aboriginal people deal with the chronic health problems that are so present today in their communities (Johnston, 2002). No matter how Aboriginal people respond to these new programs, there is a need to show that there exists more than one way of healing (INAC, 2006a).

However, as Aboriginal people are now faced with diseases that they did not know before the arrival of the Europeans, and with the changing nature of disease, traditional ways have to be adapted (Hill, 2003). In the end, one of the key things to consider is that any health program should be developed to be fully inclusive of Aboriginal people and their diversities (National Aboriginal Health Organization, 2008).

All things considered, the discussed matters highlight the complexity associated with the search for health information on a website in Aboriginal context. The preferences of presentations of information on these sites are susceptible to be linked to the cultural particularities and to the specific aspects of the diseases that touch Aboriginal people. These matters also have implications in terms of the method developed to guide this research, which have led to the choice of a user-centered approach described in chapter 5 of this thesis.

Chapter 4: The First Nations Communities in the Sioux Lookout District

To determine whether health Web sites are culturally sensitive this research is conducted in partnership with K-Net, the telecommunications services department of Keewaytinook Okimakanak (KO). KO is a tribal council of six First Nations in northwestern Ontario.

K-Net, based in Sioux Lookout, provides telecommunications services to First Nations in northwestern Ontario and the people of the Sioux Lookout district. The Sioux Lookout district, an area of northwestern Ontario consisting of 23 remote First Nations communities, was chosen as a focus for this research. Because of the remoteness of the communities in the district, access to healthcare and the Internet is an issue. For this reason, improved access to health information Websites is essential to the First Nations people of this region.

This chapter describes the current situation of the communities of this district in respect of health matters, internet connectivity and ICT infrastructure, and access to health care services and health information. First, a description of the geography and demographics of the region is given. The following section provides an overview of the health issues present in the Sioux Lookout district. The third section looks at the Internet connectivity of the region. Finally, the last section provides details on the availability of health information for the residents of the communities.

4.1 Sioux Lookout District Geography and Demographics

The Sioux Lookout district consists of 23 remote First Nations communities across 385,000 square kilometers in northwestern Ontario, with community populations varying between 100 and 2000 people. The 23 First Nations are grouped by four Tribal Councils (Independent First Nations Alliance, Keewaytinook Okimakanak/Northern Chiefs, Shibogama First Nations Council, Windigo First Nations Council), to the exception of two communities, Sandy Lake and Mishkeegogamang, which are independent First Nation bands (Fiser et al., 2006; Nishnawbe Aski Nation, 2007b; Northern Nishnawbe Education Council, 2008b). Figure 4.1 shows a map of the Sioux Lookout district and to which tribal council each First Nation is affiliated

with. Note that one First Nation community is not depicted on this map, the Koocheching First Nation, which is part of the Windigo First Nations Council and is located 65 km north-east of Sandy Lake (Windigo First Nations Council, 2007).



Figure 4.1: Map of Sioux Lookout District First Nations in Northwestern Ontario (Northern Nishnawbe Education Council, 2008a)

Most communities can only be accessed by air, some have temporary winter road access and only one community has year-round road access (Fiser et al., 2006). The district is represented by the Nishnawbe Aski Nation political organization, which represents 49 First Nation communities throughout Ontario. The people of the Nishnawbe Aski Nation speak Ojibway, Cree, or Oji-Cree (Nishnawbe Aski Nation, 2007a), however the people of the Sioux Lookout district mostly speak Oji-Cree or Cree. Although English is also spoken by many, Aboriginal languages appear to be an important part of the people of these communities (Fiser et al., 2006; Statistics Canada, 2004). For example, the community profile of Deer Lake of the 2001

Aboriginal Peoples Survey reports that 96 percent of adults and 85 percent of children in Deer Lake can speak or understand an Aboriginal language. In addition, 85 percent of adults say it is very important to keep, learn or re-learn an Aboriginal language. Eleven percent say it is somewhat important (Statistics Canada, 2004)¹.

As described in Chapter 3, the negative effects of colonization and residential schools are still felt today by all Aboriginal people, including the people of the Sioux Lookout district. For instance, tests have shown that First Nations students from grade one to eight in the district are on average, at least two grades behind the average Ontario student in vocabulary, reading, and math. Furthermore, the unemployment rate is significantly high. For example, the 6 communities of the KO tribal council (Deer Lake, Fort Severn, Keewaywin, McDowell Lake, North Spirit Lake, Poplar Hill) had an unemployment rate of 36 percent in 2000 (Fiser et al., 2006). The community profiles of the 2001 Aboriginal Peoples Survey of Deer Lake, Sandy Lake, and Lac Seul reported that the unemployment rate was at 24.5, 21.0, and 26.9 percent respectively (Statistics Canada, 2004). Health issues in the district are also prevalent and will be described in the next section (Fiser et al., 2006).

Because unemployment rates are so high, traditional practices such as hunting, trapping, and gathering are still being practiced today, which in a way, has helped the people preserve their cultural background (Fiser et al., 2006). In fact, several other cultural practices, such as traditional dances, feasts, and, songs, are still seen in the Sioux Lookout communities. Sioux Lookout First Nations show signs of holistic cultural beliefs, which is described in Chapter 3 as being a common view on life for all Aboriginal cultures. For instance, Ursula Heller from Big Trout Lake said: "Along with the practical aspects of the native culture, the spiritual and moral values of the Cree heritage are taught. An animal killed for food or for its fur is treated with respect" (Hiebert & Heinrichs, 2007). Another example showing the presence of culture in the Sioux Lookout District is the Legends site (<http://legends.knet.on.ca/>) for the people of this region that provides traditional Oji-Cree legends presented in both English and Oji-Cree in a multimedia format and written in syllabics -- an alphabet allowing to write Aboriginal languages (Hiebert & Heinrichs, 2007; K-Net, 2008).

¹ Note: At the time this thesis was written, the data related to the unemployment rate from the 2006 Aboriginal Peoples Survey (APS) was not available.

4.2 Health in the Sioux Lookout District

Like the majority of Aboriginal people, health is one of the critical issues that the people of the Sioux Lookout district are facing. In terms of resources, communities do not have enough general practitioners and specialists to treat all patients. Patients must often be flown to the nearest town of Sioux Lookout or cities of Thunder Bay and Winnipeg to reach a hospital. As all communities in the Sioux Lookout district are remote, access to these locations is costly. For example, one-way air trips to Sioux Lookout, Thunder Bay or Winnipeg cost at least CAD400\$ and up to CAD1000\$ (Fiser et al., 2006).

Among the diseases and health problems most common to all Aboriginal people, there are some that are widespread in the Sioux Lookout district: type II diabetes, heart disease, obesity, addiction, mental illness, depression, self-inflicted injuries and suicide. Many also suffer certain health conditions that require special attention, especially in schools, such as deafness, speech impairments, dyslexia, and fetal alcohol syndrome (Fiser et al., 2006).

Community-specific statistics on health and disease is limited (Smylie, 2001). However, data is available on the communities that participated in the 2001 Aboriginal Peoples Survey. To illustrate the health issues the Sioux Lookout district people are facing, Statistics Canada reports some data in the 2001 Aboriginal Peoples Survey Community Profile on the Lac Seul First Nation community. Out of 470 adults (population 15 years of age and over), more than half (56.5 percent or 266 adults) reported that they had one or more long-term health condition, with 17 percent of adults having diabetes, 17 percent having respiratory problems, 27.7 percent with high blood pressure, heart problems or effects of stroke, and 10.6 percent with communicable diseases (table 4.1). Out of 230 children (population under 15 years of age), 52.2% (120 children) reported having a long-term health condition. Data is also available for the Deer Lake and Sandy Lake First Nations communities (tables 4.2 and 4.3) (Statistics Canada, 2004)².

² Note: At the time this thesis was written, the data related to long-term health conditions from the 2006 Aboriginal Peoples Survey (APS) was not available.

Characteristics	Lac Seul 28
Long-Term Health Conditions (diagnosed by a professional):	
Adults	
% of adults with one or more long-term health conditions	56.5
% with diabetes	17.0
% with cancer	x
% with respiratory problem (asthma, chronic bronchitis, emphysema)	17.0
% with high blood pressure, heart problems or effects of stroke	27.7
% with communicable diseases (Hepatitis, TB or HIV/AIDS)	10.6
% with other long term health condition	19.1
Children	
% of children with one or more long term health conditions	52.2
% with allergies	17.4
% with asthma	17.4
% with ear infections or ear problems	21.7
% with a learning disability	x

Table 4.1: 2001 Aboriginal Peoples Survey Lac Seul Community Profile – Long-Term Health Conditions (Statistics Canada, 2004)

Characteristics	Deer Lake
Long-Term Health Conditions (diagnosed by a professional):	
Adults	
% of adults with one or more long-term health conditions	43.5
% with diabetes	10.9
% with cancer	x
% with respiratory problem (asthma, chronic bronchitis, emphysema)	13.0
% with high blood pressure, heart problems or effects of stroke	21.7
% with communicable diseases (Hepatitis, TB or HIV/AIDS)	x
% with other long term health condition	21.7
Children	
% of children with one or more long term health conditions	30.0
% with allergies	x
% with asthma	x
% with ear infections or ear problems	x
% with a learning disability	x

Table 4.2: 2001 Aboriginal Peoples Survey Deer Lake Community Profile – Long-Term Health Conditions (Statistics Canada, 2004)

Characteristics	Sandy Lake 88
Long-Term Health Conditions (diagnosed by a professional):	
Adults	
% of adults with one or more long-term health conditions	47.4
% with diabetes	16.2
% with cancer	x
% with respiratory problem (asthma, chronic bronchitis, emphysema)	8.1
% with high blood pressure, heart problems or effects of stroke	27.3
% with communicable diseases (Hepatitis, TB or HIV/AIDS)	x
% with other long term health condition	23.2
Children	
% of children with one or more long term health conditions	44.3
% with allergies	12.9
% with asthma	12.9
% with ear infections or ear problems	27.1
% with a learning disability	x

Table 4.3: 2001 Aboriginal Peoples Survey Sandy Lake Community Profile – Long-Term Health Conditions (Statistics Canada, 2004)

The statistics on health problems for the communities in the Sioux Lookout district show that health is a critical issue for the people of the region. The limited access to healthcare increases the magnitude of this problem. Because of the health problems and the limited access to healthcare, it is crucial that people gain better access to health information. One way to do this is through the Internet. Although Internet connectivity is also a problem in the region it is slowly improving, as discussed in the next section.

4.3 Internet Connectivity of the Sioux Lookout District

Crompton (2004) identifies the biggest barriers to Internet adoption as being cost, access to computers or the Internet, lack of skills or training, living in a rural location, being a member of a minority ethnic group and speaking a minority language. All of these characteristics are predominantly relevant to many Aboriginal people. Living in a rural area brings about some of the barriers listed above, such as high costs and accessibility. For example, it is less profitable for Internet service providers to invest in rural areas than in urban areas, because of the costs of offering this service and the sparse population density results in having less potential subscribers. The lack of competition in rural areas can therefore bring the cost of

Internet access up. Furthermore, rural residents may not have the necessary infrastructure to connect to the Internet, such as cable or a telephone line. The cost of connection for users may be also higher in rural areas because of long distance charges or more expensive types of connections like satellite (Crompton, 2004).

The government of Canada's *Connecting Aboriginal Canadians* initiative as part of *Canada's Aboriginal Action Plan* was taken with the goal that new information and communication technologies will support Aboriginal socio-cultural and economic development objectives (Alexander, 2000). However, "although the "Connecting Canadians" initiative of the late 1990s promised to help "Canadians to become the most connected people on earth", large gaps in service still remain" (The Ontario Rural Council, 2007).

The Sioux Lookout district First Nations communities are all remote; therefore, access to the Internet is a definite challenge. For example, in 1999, communities such as Keewaywin and North Spirit Lake had a single payphone for approximately 150 residents. Despite these challenges, an initiative of the KO tribal council brought about K-Net (Kuh-ke-nah Network), a carrier class broadband network, that as of 2006 connected 40 communities in the Nishnawbe Aski Nation, including the 23 First Nations communities of the Sioux Lookout district. Kuh-ke-nah is an Oji-Cree term meaning "for everyone, everywhere". Broadband connectivity has also allowed for residential access. The whole network consists of both terrestrial and satellite links that combine video, voice and data services that require broadband and high-speed connectivity (Fiser et al., 2006).

The network is managed by the ICT branch of the KO tribal council, K-Net Services, from its headquarters in Sioux Lookout and offices in Balmertown, Fort Severn, and Thunder Bay. However, each community band office owns and manages its own Municipal Area Network (MAN) to allow for each to address their broadband local challenges and priorities, such as economic development or promoting health online. This decentralized approach to the management of the local loops is based on traditional First Nations values that "encourage resource pooling, knowledge sharing, and respect for local autonomy" (Fiser et al., 2006).

K-Net initially received funds from Industry Canada as part of its SMART Demonstration Projects, and later from Fednor and the Northern Ontario Heritage Fund, who were also project partners. K-Net also partnered with Telesat and Industry Canada's National Satellite Initiative under the C-Band Public Benefits Transponder agreement to provide satellite connectivity to remote First Nations communities (Fiser et al., 2006). The C-Band Public Benefits Transponder agreement is a component of Industry Canada's National Satellite initiative that was created to deliver affordable 28 MHz satellite capacity to supply broadband services to remote communities. These broadband services include telehealth, tele-education, e-commerce, and videoconferencing (Industry Canada, 2006).

The broadband connections in the communities allowed for the development of the KO tribal council telehealth program in 2002 (now KO Telemedicine) with the goal of enabling remote health consultations and therapies over the network. This is done to reduce the frequency residents need to leave their home communities to get proper medical attention, reduce costs associated with providing health care in remote communities, and to deliver more medical services to the communities to help deal with widespread health issues. Twenty-five Nishnawbe Aski Nation communities participate in the program, including all communities in the Sioux Lookout district. The telehealth program is funded by Health Canada (Fiser et al., 2006).

The telehealth applications are accessible at the community nursing stations, which are like medical clinics in remote First Nations communities. Telehealth is conducted through a VPN tunnel, maintained by K-Net, that is connected to a network linking hospitals across Ontario, to allow for the secure transmission of private and confidential information. Each telehealth station provides a videoconferencing unit, and peripherals such as an otoscope, a stethoscope, and a patient view camera. These technologies allow for meetings, training sessions, therapy sessions, patient examinations, digital transmissions of X-rays, and more, to be conducted with a medical professional at a distance, all over the network (Fiser et al., 2006).

As part of the several services that K-Net offers its members, one of them is to deliver training and programs to help enable communities to be self-sufficient in terms of computer and telecommunications expertise (Keewaytinook Okimakanak,

2008a). This is consistent with their decentralized approach to the ownership and control of local loops.

In 2006, K-Net had thirty-eight thousand email account holders and over eighteen thousand individuals and groups hosting sites on My K-Net. Given that the Sioux Lookout district's population is approximately 20,000, K-Net estimates that email penetration is nearly at 100% in the region (Fiser et al., 2006). Therefore, communities that are connected through K-Net appear to be very active in terms of Internet usage. The fact that K-Net is locally owned has significantly lowered the costs of providing Internet service, which may contribute to the high participation rate (Industry Canada, 2004).

4.4 Health-Related Websites for Sioux Lookout District Residents

The 2002 National Aboriginal Health Organization's (NAHO) national Public Opinion Poll on Aboriginal Health and Health Care in Canada was an Aboriginal-defined and – controlled process. The results provide a snapshot of opinions and general perceptions of the respondents on various health and health care issues, such as perceived personal health and satisfaction with the health care system. In the First Nations component, the majority of respondents (85%) thought that more information on health related topics available in communities would be a good way to improve Aboriginal health (table 4.4) (First Nations Centre - National Aboriginal Health Organization, 2003). Health related Websites is one way to help increase the amount of information in communities. The KO Telemedicine website (<http://telemedicine.knet.ca/>) offers live Webstreaming events for health training and education. The videos are recorded and archived on the site for later access. The site also offers links to external health-related websites. Aside from these videos and external links, the website does not offer additional text information on health-related topics (KO Telemedicine, 2008b).

A multitude of websites exist that offer information on health issues. For instance, Web MD website (<http://www.webmd.com/>) offers both text-based and video-based information on health. MD Kiosk website (<http://www.mdkiosk.com/>) offers an alternative in text-based health information by specializing in online videos of health

topics. Healthedia website (<http://www.healthedia.com/>) provides health blogs, podcasts, and videos from health professionals. The Public Health Agency of Canada provides a section on its website targeted for Aboriginal people that contains information on diseases that are prevalent in people with Aboriginal ethnicity (<http://www.phac-aspc.gc.ca/chn-rcs/aboriginal-autochtones-eng.php>). The question arises whether or not these websites are adapted to Aboriginal culture.

To date there is only one study that looks at the cultural-sensitivity of health-related websites targeted to Aboriginal people (Friedman & Hoffman-Goetz, 2007). In this study on the assessment of the cultural sensitivity of breast cancer information for older Aboriginal women, an Inuit woman expressed her frustration with diet recommendations on health Websites: "About diet, they emphasize eating fruits and vegetables which is not what the Inuit eat...so for somebody from the north, this is irritating...we don't get them up there!" (Friedman & Hoffman-Goetz, 2007). Health related Websites often emphasize the importance of a healthy diet, which is high in fruits and vegetables. Fruits and vegetables are not as accessible in Northern and remote areas of Canada. For example, in Sandy Lake three bananas cost CAD\$2.56 and two tomatoes cost CAD\$4.15 (Fiser et al., 2006). For that reason, recommending that First Nations people that live in these areas eat a lot of fruits and vegetables can be very frustrating.

In the same study, another woman spoke about how traditional medicines should be included in the cancer information on the Web directed at both Aboriginal and non-Aboriginal people: "There's a cure out there for us, especially among our traditional people. I'm sure they have some knowledge of it with all their herbs and medicines in the bushes. It would help a lot of people whether you're Native or non-Native" (Friedman & Hoffman-Goetz, 2007). These are just a couple of examples of how health websites may need to be adapted to the specific conditions of its various target audiences. The results of the study found that the Aboriginal women preferred to read and related better to the culturally specific breast cancer websites (Friedman & Hoffman-Goetz, 2007).

A website built and maintained by local people, such as the KO telemedicine website, could be a candidate for delivering health information, as complementary to its archives of health videos, customized for the needs of the people of this region. As

discussed in the chapter on the evaluation of health websites, the dissemination of health information online should take into account the cultural differences of users (Friedman & Hoffman-Goetz, 2007; Singh et al., 2006; Thomson & Hoffman-Goetz, 2007). People that are transmitting information over the webstreaming on the KO Telemedicine website are from the outside and may not understand the particularities of the region. Therefore, offering health information on the website that is tailored to the specificities of the Sioux Lookout district residents could be beneficial. In addition, if this information is culturally sensitive, then it may appeal more to the residents. According to the majority of the respondents in the First Nations component of the Public Opinion Poll on Aboriginal Health and Health Care in Canada, culture appeared to be an aspect that could play an important role in improving the health of Aboriginal people (table 4.4) (First Nations Centre - National Aboriginal Health Organization, 2003).

First Nations Ideas to Improve Aboriginal Health	Percentage of total respondents
More information on health related topics available in the community	85 per cent
Increased funds for health care services	84 per cent
Better housing	84 per cent
Better translation and interpretation services in the health care system	83 per cent
Decreased use of drugs and alcohol	82 per cent
Better relations between Aboriginal and non-Aboriginal peoples	80 per cent
Developing culturally-relevant/responsive health care programs	80 per cent
Revival of Aboriginal cultures and traditions	75 per cent
Increased use of Aboriginal languages	72 per cent
A return to Aboriginal medicines and healing practices	67 per cent
Aboriginal control of health care services	66 per cent

Table 4.4: First Nations Ideas to Improve Aboriginal Health (First Nations Centre - National Aboriginal Health Organization, 2003)

For instance, in the NAHO poll, 80% of respondents thought that developing culturally-relevant/responsive health care programs would help improve Aboriginal

health. An increased use of Aboriginal languages (72% of respondents) and better translation services in the health care system (83% of respondents) were also important for the respondents. Seventy-five percent also believed that the revival of Aboriginal cultures and traditions as a good way to improve the health of Aboriginal people. Furthermore, 67% of respondents thought that a return to Aboriginal medicines and healing practices would be a good idea (First Nations Centre - National Aboriginal Health Organization, 2003).

In this thesis, we suggest that providing more information on health related topics in communities would contribute to improving Aboriginal health. We question whether dissemination of this information in a culturally sensitive manner, by increasing for example the use of Aboriginal languages and providing information on Aboriginal cultures, traditions, medicines and healing practices lead to improved Aboriginal health. The research model and hypotheses of this thesis take into account these various cultural aspects which are gathered under the term of context.

The end of this chapter concludes the review of the main components of our thesis. Chapter 2 provides a literature review of the evaluation of the quality of health information websites. Chapter 3 describes Aboriginal people in Canada, what culture means to them, and how it relates to health. The present chapter provides a detailed description of the First Nations in the Sioux Lookout district as this region was chosen as our scope of research. In the next chapter, we present the research method of our study.

Chapter 5: Methodology

The present chapter describes the methodology used to gather data for this research, which aims at establishing the principles that should govern the conception of health websites in Aboriginal context. The organization of this chapter is as follows.

Research in Aboriginal context necessitates a user-centered approach. The fundamental reasons of this choice of approach are examined with an analysis of the conditions that must be respected when conducting research in Aboriginal context. Consequently, this research examines user preferences to establish the principles of conception.

A research model for online health information in Aboriginal context is defined based on the analyses of preceding chapters. The research model outlines the link between the preferences of online health information and the particularities of the Aboriginal context. It also takes into account the impact of the variability of the disease aspects on those preferences.

Derived from the research model, two empirical models are presented, each focusing on a disease included among those considered to be the most prevalent in Aboriginal communities. The empirical models identify the specific dimensions from which are collected the data used to test the hypotheses.

The next section provides a list of the web presentations and the process of their selection. The user-centered method adopted to gather data is then described in detail. The questionnaires used are provided in the appendix. Finally, the process to recruit participants is explained, followed by the details of the participant demographics.

5.1 Research in Aboriginal Context

Historically, Aboriginal people have had feelings of discontent, skepticism, or even contempt and distrust towards researchers conducting studies in Aboriginal communities or on Aboriginal subjects. Among several other reasons, these views are a result of research being conducted by non-Aboriginals using paternalistic approaches, which are irrelevant to community needs, don't include Aboriginal people in the process, and that lack respect for Aboriginal ways of doing research, cultural differences and cultural appropriation of information (Bennett, 2004; S. Perley & O'Donnell, 2006; S. Perley & O'Donnell, 2005). As Bennett states, "Academic reputations [...] have been built on the backs of Aboriginal subjects and at the political and economic expense of Aboriginal communities" (Bennett, 2004).

Colonization and assimilation practices have also contributed to shaping the relationship that Aboriginal people have with non-Aboriginal researchers in general (S. Perley & O'Donnell, 2006). As Smith (1999) puts it, "the term 'research' is inextricably linked to European imperialism and colonialism. [...] it stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful" (Smith, 1999). Johnston (2002) explains how some researchers are using the dominant culture's ways of doing research which may create some biases. For example, some researchers have shown a condescending attitude toward native healers and healing, and fail to recognize traditional medicine as a legitimate way of healing (Johnston, 2002).

In the past decade, research relating to Aboriginal people has begun to change. The results of the Social Sciences and Humanities Research Council's (SSHRC) Dialogue on Research and Aboriginal Peoples have shown that a paradigm shift is beginning to emerge in the approaches that are being taken to research relating to Aboriginal people (McNaughton & Rock, 2003). Aboriginal people are no longer seen as research objects, but are increasingly being seen as researchers, experts, and partners in research. The results of SSHRC's dialogue suggests a new approach to Aboriginal research that is focused on joint promotion of knowledge opportunities, such as establishing partnerships with Aboriginal communities and supporting research on Aboriginal systems of knowledge.

Another complementary approach that focuses on issues of equity has also been suggested (McNaughton & Rock, 2003). The goal of the equity approach is to correct situations that prevent Aboriginal researchers to fully develop their research potential. Examples of such situations are research that lack respect of Aboriginal people's knowledge traditions and research that lack benefits to Aboriginal communities (McNaughton & Rock, 2003).

Seven programs have also been proposed as a result of SSHRC's dialogue. An example of one of these proposed programs is the Aboriginal Knowledge Systems (AKS) Program (McNaughton & Rock, 2003), in which Aboriginal knowledge would be gathered and restored and its application in relation to other non-Aboriginal knowledge traditions would be explored. "[...] non-Aboriginal people especially need to have an opportunity to understand the ways in which Aboriginal knowledge traditions are distinctive yet complement non-Aboriginal traditions" (McNaughton & Rock, 2003).

The "CIHR³ Guidelines for Health Research Involving Aboriginal People" (2007) has also recently been published. The intent of these guidelines is "to promote health through research that is in keeping with Aboriginal values and traditions". Researchers who are funded by Canadian Institutes of Health Research (CIHR) should adhere to these guidelines when they are conducting any research involving Aboriginal people. The guidelines were developed by a multi-disciplinary committee and through ongoing consultations with Aboriginal communities through the ACADRE (Aboriginal Capacity and Developmental Research Environments) network. The ACADRE network is a "unique university-based resource with links to academic research communities and partnerships with regional First Nation, Inuit and Métis communities" (Canadian Institutes of Health Research (CIHR), 2007).

Researchers have also shown signs that a paradigm shift is occurring regarding Aboriginal research (Averweg & O'Donnell, 2007; S. Perley & O'Donnell, 2005). For instance, Perley and O'Donnell (2005) published a methodology for engaging New Brunswick First Nations in ICT (Information and Communication Technologies) research that could also be useful for research in other Aboriginal communities

³ CIHR: Canadian Institutes of Health Research

across Canada and in the rest of the world. The methodology consists of five approaches to research:

- Building a relationship, partnerships and collaborations with First Nations
- Developing First Nations' priorities for research
- Developing researcher's self-awareness of how their upbringing and education have shaped their cultural biases, motives and perspectives
- Integrating the political, socio-economic and historical contexts of the research
- Expanding the borders of the researchers' academic discipline, methodologies and theories (S. Perley & O'Donnell, 2005)

The paper also explores ways to engage First Nation communities in New Brunswick in RICTA, a Canadian network of Research on Information and Communication Technologies with Aboriginal communities. The authors state that to engage New Brunswick First Nations in RICTA, an understanding of and a desire to integrate the five themes listed above in all aspects of the research process must be achieved (S. Perley & O'Donnell, 2005).

Averweg and O'Donnell (2007) have published a draft Code of Ethics for Community Informatics (CI) Researchers, relevant to Aboriginal communities, that is meant to evolve. The objective of CI research is "the formulation of knowledge or insight into the means to enable and empower communities through the use of Information and Communications Technologies" (Averweg & O'Donnell, 2007). The Code of Ethics contains a list of standards of conduct for CI researchers that can be applied to research in Aboriginal communities and also contains a section for ethical guidelines for research involving Aboriginal communities specifically. Researchers are encouraged to contribute their experiences to help in the development of this Code of Ethics (Averweg & O'Donnell, 2007).

Aboriginal communities have come to a point where they will "no longer tolerate colonial intrusion by researchers" (Bennett, 2004). These new initiatives to promote new ways of doing Aboriginal research have become essential today to decolonize research and to engage Aboriginal people in research. Several questions come to mind when a researcher conducts Aboriginal research: "Whose research is it? Who owns it? Whose interests does it serve? Who will benefit from it? Who has designed

its questions and framed its scope? Who will carry it out? Who will write it up? How will its results be disseminated?" (Smith, 1999).

Researchers working in or with Aboriginal communities must choose approaches to research that include members of the communities, allowing them to contribute throughout the whole research process (Bennett, 2004; Smith, 1999).

One model of research, participatory research, has been recognized as favorable to Aboriginal research. Participatory research is collaborative in nature and enables Aboriginal researchers involved in the research to voice their opinions, share their knowledge, have more control over every step of the research process, and build local skills in their community (Bennett, 2004; Smith, 1999).

Participatory research is an approach "that replaced the exploitative elements of the dominant research paradigms" (Bennett, 2004). It allowed for non-Aboriginal researchers and Aboriginal people to work together. Researchers must also go beyond simply choosing an appropriate model of research. They must change their attitudes, actions and ways of thinking: "[...] espousing and emancipatory model of research has not of itself freed researchers from exercising intellectual arrogance or employing evangelical and paternalistic practices" (Smith, 1999). Although participatory research is the preferred approach for research with Aboriginal people, it does not come without its challenges. Challenges include community members' reluctance to participate in the research, skepticism towards the perceived benefits of the research, time constraints as participatory research is time consuming, communities having other priorities such as securing the basic necessities of life, and loss or lack of energy, interest, or trust from participants during the course of the research (Bennett, 2004).

Aboriginal ways of doing research are different from Western ways. Cultural protocols, values and behaviors are considered to be integral parts of the research design. This includes reporting back to the communities involved in the research and sharing knowledge on an ongoing basis, in a culturally appropriate way and in a language that they can understand. Ultimately, this simply comes down to conducting research in a respectful and ethical manner (Smith, 1999).

This research is therefore conducted in partnership with First Nations organizations: KORl - the Keewaytinook Okimakanak Research Institute and K-Net, the telecommunications services department of Keewaytinook Okimakanak (KO). KO is a tribal council of six First Nations in northwestern Ontario.

There are methodological implications resulting from these matters. Researchers must choose a methodology for gathering data that allows participants to be more deeply involved in the process. As stated by the research partners, the communities in the Sioux Lookout district prefer an inclusive and user-centered approach to gathering data. Their approach is centered on building partnerships with researchers in order to get results that fit everyone's needs, including users', Web site developers' and contributors', as well as researchers'. This chapter will therefore describe a user-centered method for gathering data that is inclusive in nature, where researchers form a partnership with the users.

Furthermore, as discussed in chapter 2, researchers have used the term "evaluation" to describe the method in which they are gathering data. As expressed by the First Nation partners in this research, the term "evaluation" can create fear for many Aboriginal people, stemming from past negative experiences of having their people evaluated by non-Aboriginal "experts". For that reason, the term "evaluation" will not be used in order to answer the concerns of the people of the Sioux Lookout district.

5.2 Research Model for Online Health Information

The results of a number of studies outlined in chapter two suggest that health-related websites should be customized to fit the particularities of the target audience and be culturally-relevant (Friedman & Hoffman-Goetz, 2007; Gilbert et al., 2005; Williams, Nicholas, Huntington, & McLean, 2002b; Williams, Nicholas, Huntington, & McLean, 2002b).

Considering the health problems in Aboriginal people and the issues associated with living in rural and remote locations, such as limited access to healthcare and the Internet, improved access to health information is essential. First Nations people believe that providing more information on health related topics in their

communities, reviving Aboriginal cultures and traditions and returning to Aboriginal medicines and healing practices would contribute to improving Aboriginal health (First Nations Centre - National Aboriginal Health Organization, 2003). The matters related to Aboriginal culture discussed in Chapter 3 highlight the complexity associated with the search for health information on a website in Aboriginal context. The diversity of Aboriginal cultures and the specific aspects of the diseases presented on the websites are susceptible to have an influence on the preferences of online health information on these sites. The research model described hereafter takes into account the link to user preferences of these various cultural aspects and living location particularities.

5.2.1 *The Influence of the Context*

The research model in figure 5.1 suggests that there are contextual influences on the preferences of online health information for users: Aboriginal health issues, access to healthcare, culture, living location, and Internet access are factors of influence that the literature review has highlighted.

First, major current health issues of the people of the Sioux Lookout district could possibly have an influence on what type of online information these people would prefer. For instance, as discussed earlier, diabetes is a major concern for the people of the district; consequently, they are inclined to want more elaborate information on this disease.

Second, the fact that the First Nations communities of the district are all rural locations may also have an influence on their preferences of health information. For example, when providing diet recommendations for a person with diabetes, it is important to consider that certain foods may be more difficult to obtain in rural locations, therefore, information on alternative foods to eat may be more relevant to them.

The limited access to healthcare due to the remoteness of communities can also be a factor influencing online health information preferences. For instance, if patients do not have the possibility of consulting a healthcare professional 24/7, then they may

need to access more detailed health information online. In addition, they may feel the need to consult with other patients or health professionals online, through online forums or chats.

Although we know that all communities in the district have access to broadband Internet, this does not mean that all residents have Internet access in their homes nor does it mean that the access is reliable. Therefore the location where they access the Internet could have an influence on their preferences. For instance, if a person is accessing the Internet in a public place, then a video might not be the best medium to get information on health, as the people around might be bothered by the audio from the video and the person looking at the information might want to keep the information private.

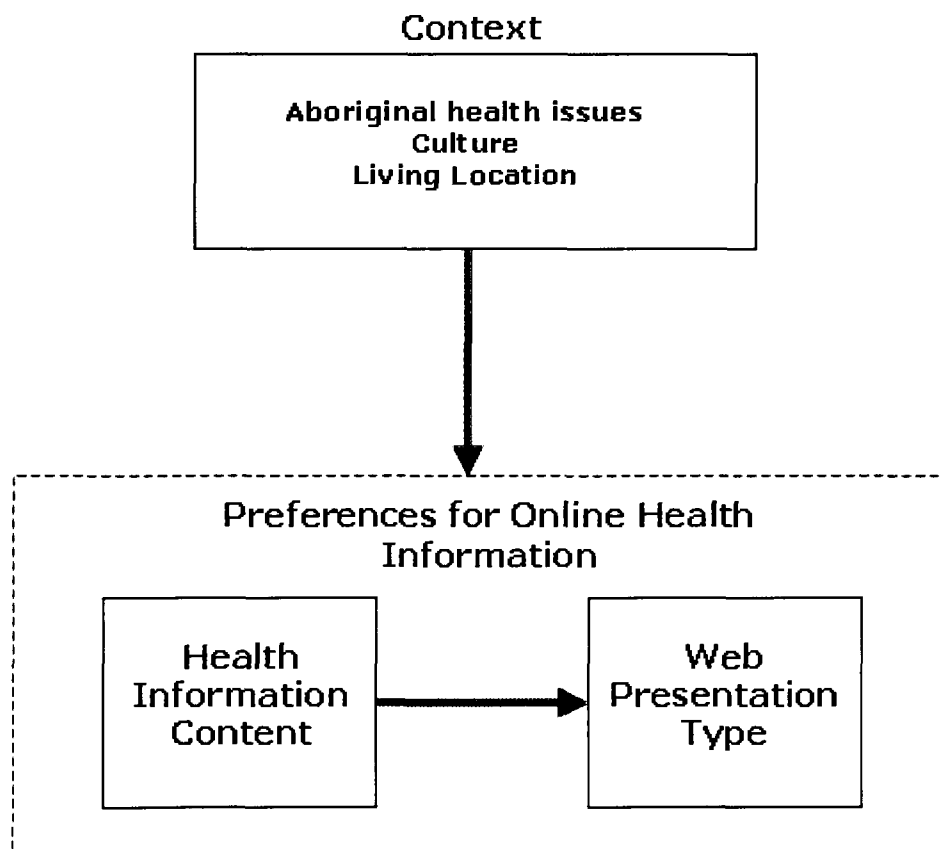


Figure 5.1: Model of Research for Online Health Information⁴

⁴ The health information content depicted in the model varies by disease and various aspects of each disease. Every disease aspect is a category of content.

Third, culture may have an influence on the preferences of online health information for users. For example, Aboriginal people may want to find information on holistic approaches to healing. Also, for information to be culturally-relevant, it may have to be presented in a certain way, such as by using culturally relevant images to accompany the text explanation of how to treat a specific disease, or providing anecdotal stories using cultural heroes and symbols that the users can relate to.

5.2.2 Health Information Content and Presentation

When exploring the preferences of online health information for users, two dimensions have to be considered: the preferences of the content and the preferences of the presentation types of that content.

Health information content differentiates itself by the disease that is being presented on the one hand and on the other hand by the various aspects of each disease. For a disease, every aspect of this disease represents a category of content. Examples of categories of content are information on symptoms management, information on disease prevention, information on the complications of a disease, and so forth.

The Web presentation types are defined as the different ways in which content can be presented to the user on a website. Examples of how information can be presented are forums, the language of presentation, and different media formats such as video, text and images.

The model suggests that the categories of content on a website will have an influence on what is the most appropriate way to present this information.

5.3 Empirical Models of Research

This research will explore the preferences of the Sioux Lookout district people of online information on Diabetes⁵ and COPD (Chronic Obstructive Pulmonary Disorder, which includes Emphysema and Chronic Bronchitis) and their presentation, as well as the influence of context on those preferences.

Diabetes was chosen for this study because it appears that a high rate of First Nations people from the Sioux Lookout district suffer from this chronic disease. As indicated in the tables 4.1, 4.2 and 4.3 (see Chapter 4), the First Nations communities of Lac Seul, Deer Lake and Sandy Lake had 17.0, 10.9, and 16.2 percent respectively of people suffering from diabetes in the 2001 Aboriginal Peoples Survey. COPD was also chosen for the same reason. Seventeen percent of adults in Lac Seul, 13 percent in Deer Lake, and 8.1 percent in Sandy Lake suffered from respiratory problems, which include COPD, in the 2001 Aboriginal Peoples Survey (Statistics Canada, 2004).

5.3.1 Categorization of Health Information Content

Concerning these two diseases, the first objective consists in determining the major aspects that characterize them. Consequently, three experts were consulted individually: Dr. Katherine Baldwin, MD, Dr. Valérie Gratton, MD, and Dr. Kristy Staples, MD, were asked the following question: what would be the key information that a person looking for information on a specific disease (i.e. Diabetes, COPD) should seek online? The answers given by the three experts were compiled into a list and categorized. The experts were then asked to review and validate the categories. The final categories identified for diabetes are the following:

- Definition of Diabetes, which includes the risk factors, the prevalence, the natural progression of the disease, and the symptoms.

⁵ Note: In this thesis, when speaking of diabetes, we are referring to type II diabetes as this is the type of diabetes that is prevalent in the Sioux Lookout district and in Aboriginal people.

- Lifestyle changes that the disease incurs, including changes in diet and exercise. Examples of what could be found on the website would be examples of accessible foods to eat, menus, exercise programs, etc.
- Monitoring, which includes monitoring blood sugar at home, caring for eyes and feet, and routine visits to a health care provider to monitor eyes, cholesterol, blood pressure and blood sugar.
- Medications, such as insulin and oral hypoglycemics.
- Complications, such as heart disease and stroke, eye complications, kidney disease, and nerve damage.

Only three content categories for diabetes information are retained for this study: definition of the disease, lifestyle changes and monitoring.

The final categories identified for COPD are the following:

- Definition of COPD, including a definition of chronic bronchitis and emphysema, the prevalence, the natural progression of the disease, and the symptoms.
- Medications, which mostly includes inhalers.
- Lifestyle changes, which includes smoking cessation.

Although it is important to identify the key disease aspects from a medical point of view, this study also looks at the content preferences of users to complete this information.

5.3.2 Categorization of Presentation Types

A systematic process of selection of the types of presentation was developed (described in section 5.5). This resulted in the following choices. Four presentation types will be looked at specifically for diabetes information: non-cartoon videos, cartoon videos, text-based web pages and online forums:

- **Non-Cartoon Videos:** videos with real life experts explaining facts about the disease;
- **Cartoon Videos:** videos where fictional cartoon characters are being interviewed about their specific experiences living with the disease;

- Text-based Web pages: A single Web page containing text, images and links to other Web pages
- Forums: Online user discussion forums on various topics relating to the disease.

Three presentations will be looked at specifically for COPD information: non-cartoon videos, text-based web pages, and online forums.

5.3.3 Empirical Models for Diabetes and COPD Websites

This research will explore the preferences of the Sioux Lookout district people for health information content on Diabetes and COPD and their presentation on health websites and how the context has an influence on these preferences. Figures 5.2 and 5.3 outline the different dimensions that will be retained from the research model for this study for Diabetes and COPD.

The influence of the various dimensions of context on the preferences of information are examined to the exception of health issues, as consulting people about their personal health issues is out of the scope of this research. Note that Diabetes and COPD were chosen as health information content to present not only because of the situation at the Sioux Lookout district, but also because of the prevalence of these diseases in Aboriginal people (Statistics Canada, 2004).

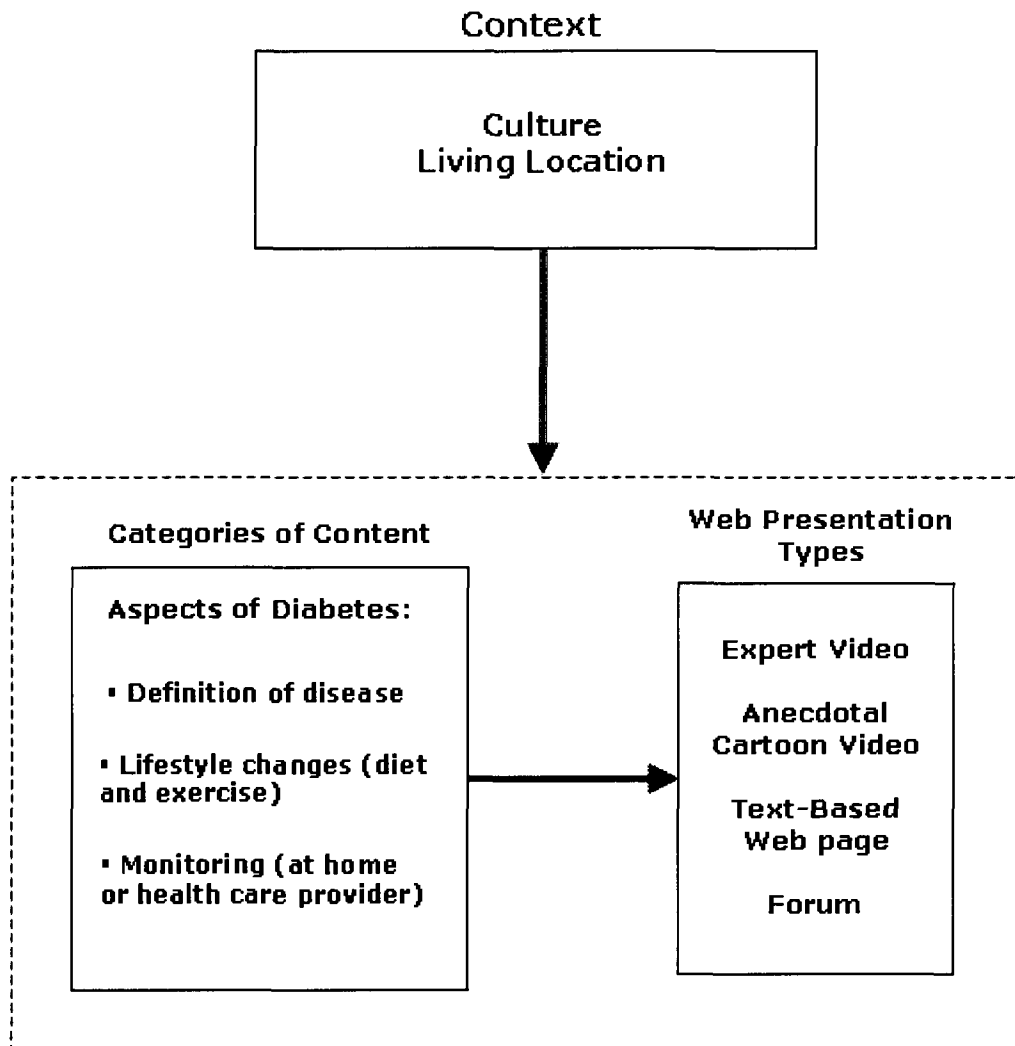


Figure 5.2: Empirical Model for Diabetes Websites

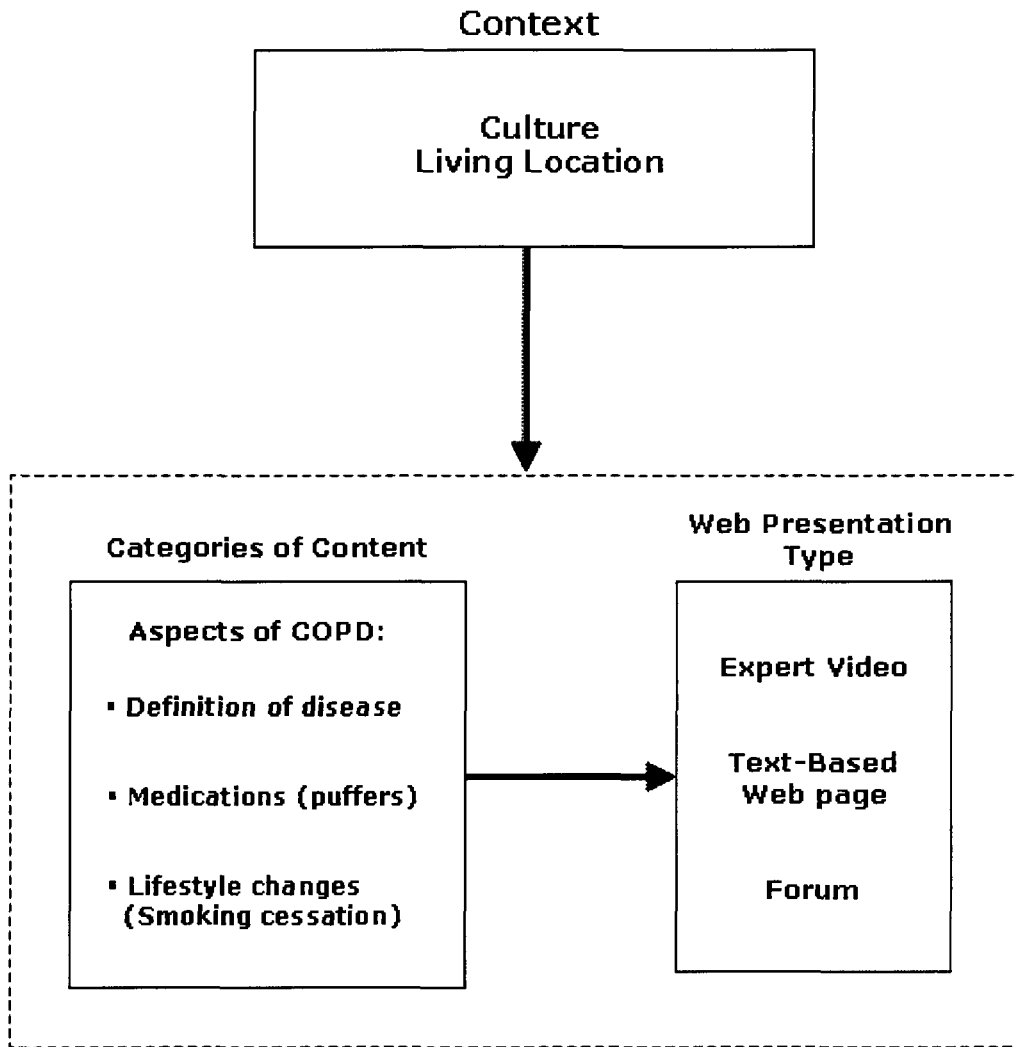


Figure 5.3: Empirical Model for Chronic Obstructive Pulmonary Disease (COPD) Websites

5.4 Research Hypotheses

From the empirical models described above are derived the following four hypotheses.

Ha₁: *Aboriginal people prefer one Web presentation type on health websites over other types regardless of the disease that is presented.*

This hypothesis tests whether or not the expressed preferences are the same regardless of the disease consulted.

Ha₂: *Aboriginal people's preferences of Web presentation types on health websites is invariable regardless of the disease aspect presented.*

This hypothesis tests the relations between Web presentation type preferences and disease aspect. Are the preferences affected by the disease aspect that is being presented?

Ha₃: *Living location factors have an influence on Aboriginal people's preferences of content and presentation type on health websites.*

This hypothesis test whether living location factors, such as the access to health care services, the access to Internet and other related factors are susceptible to influence the preferences for online health information.

Ha₄: *Aboriginal people would prefer health websites that contain elements related to their culture.*

This hypothesis tests the role that culture plays on the appreciation of health websites.

To estimate the extent to which these hypotheses are supported, various methodological tools were selected or developed (as Web presentations and questionnaires).

5.5 Selection of Web Presentation Types

Different types of online presentations for specific content categories have been chosen to show participants and have them compare and state their preferences. The different types of Web presentations outlined in the empirical model were chosen for each content category.

5.5.1 Selection Process

An extensive compilation of different websites on Diabetes and COPD was made to choose the best available presentations for each category of content.

The most representative websites of each content category for each presentation type have been retained. When websites appeared to be equally representative of the content category, the retained website was chosen based on three criteria: the focus on the content category, the credibility of the source of the presentation, and the length of the presentation. For video presentations, the quality and clarity of the audio and the video were also considered.

As such, priority was given to websites from professional associations, such as the Diabetes Association, and to the fact that they were confined to their content category of reference, that the length of the presentation was under five minutes (in the case of videos), and that the audio and video was of the best available quality.

The limited number of presentations available on the Web and the evident differences of quality facilitated the selection process⁶.

5.5.2 The Source of the Retained Web Presentations

A complete list of the Web pages showing different types of Web presentations for each content category is outlined in tables 5.1 and 5.2. A forum on various topics

⁶ No formal evaluation of the accuracy of the content (ex: panel of doctors) was considered as this was out of the scope of this research.

relating to diabetes and a forum on various topics relating to COPD were also presented to participants and are outlined in table 5.3.

Content categories for Diabetes	Type of presentation	URL
Definition of disease	Video (non-cartoon)	http://www.mdkiosk.com/Diabetes%20Type%20-topicview.php
	Video (cartoon, anecdotal story)	http://www.diabetes.org/all-about-diabetes/chan_eng/i2/i2dms.htm
	Text	http://www.nada.ca/diabetes/definitions.php
Lifestyle changes (diet, exercise, losing weight, etc.)	Text	http://www.diabetes.org/nutrition-and-recipes/nutrition/foodpyramid.jsp
	Video (cartoon, anecdotal story)	http://www.diabetes.org/all-about-diabetes/chan_eng/i21/i21dms.htm
	Video (non-cartoon)	http://diabetes.emedtv.com/diabetic-diet/diabetic-diet.html (click on "Diabetic Diet")
Monitoring	Video (cartoon, anecdotal story)	http://www.diabetes.org/all-about-diabetes/chan_eng/i5/i5dms.htm
	Text	http://www.diabetes.org/type-2-diabetes/blood-glucose-checks.jsp
	Video (non-cartoon)	http://www.mdkiosk.com/Diabetes%20Type%20-topicview.php (click on "monitoring blood sugar")

Table 5.1: Different types of Web presentations for Diabetes content categories

Content categories for COPD	Type of presentation	URL
Definition of disease	Text	http://www.lung.ca/diseases-maladies/copd-mpoc/what-quoi/index_e.php
	Video	http://www.youtube.com/watch?v=aktIMBQsXMo&amp;feature=related
Medications (puffers)	Video	http://www.youtube.com/watch?v=k77vqaUnd1Y&amp;feature=related
	Text	http://www.lung.ca/diseases-maladies/copd-mpoc/treatment-traitement/medications-medicaments_e.php
Smoking cessation	Video	http://www.youtube.com/watch?v=3aIeF5LjaDk
	Text	http://www.lung.ca/protect-protegez/tobacco-tabagisme/quitting-cesser/index_e.php

Table 5.2: Different types of Web presentations for COPD content categories

Forum on Diabetes	http://community.diabetes.org/n/pfx/forum.aspx?webtag=adatype2
Forum on COPD	http://copdforum.portalone.us/

Table 5.3: Web Forums for Diabetes and COPD

The three cartoon videos, two of the text-based web pages and the forum on Diabetes were taken from the American Diabetes Association website. The other text-based web page on Diabetes was taken from the Canadian National Aboriginal Diabetes Association. The cartoon videos, the text-based web pages and the forum were chosen from these two websites because of the authoritative role of the associations.

As the American Diabetes Association and the National Aboriginal Diabetes Association websites did not contain any non-cartoon videos, these had to be chosen from different websites. Two of non-cartoon videos on Diabetes were taken from the MDKiosk website and the other non-cartoon video on Diabetes was taken from the eMedTV website. The videos were chosen based on the relevance and focus to the content category, the length (not more than 5 mins), and the quality and clarity of the audio and the video. The videos chosen were judged by the researcher to be the best currently available videos on Diabetes.

The three text-based web pages on COPD were taken from the Canadian Lung Association website because of the authoritative role of the association. Online videos on COPD were limited. The COPD videos chosen were taken from YouTube and were judged to be the best currently available videos on COPD. Forums on COPD were also limited. The forum chosen was taken from the COPD Support Inc. website and was judged as the best currently available.

5.6 Questionnaires

Two questionnaires were developed to collect data from participants during the focus group interviews. Both questionnaires contained the same questions but one was

customized for the Diabetes groups and the other one was customized for the COPD groups. Questions were derived from the research model and the hypotheses in order to collect data that would test the hypotheses made. The two questionnaires are outlined in Appendix.

This research was conducted under the VideoCom project, which investigates the use of video communications and other Information and Communication Technologies (ICT) by and for remote and rural First Nation communities, in partnership with First Nations organizations. The VideoCom project is funded by the Social Sciences and Humanities Research Council (SSHRC).

The VideoCom research protocols were approved by the research ethics boards at the University of New Brunswick and the National Research Council. The approved research protocols include interviews, focus groups and surveys with First Nations community members. The specific protocols used for the various studies are approved by the First Nation research partner KORI - the Keewatinook Okimakanak Research Institute. KO approved the research protocol as well as the questionnaires used for this study.

From the review of the questionnaires by the First Nations partners, one question was criticized (question #16 in the Diabetes questionnaire and #13 in the COPD questionnaire in appendix). This question was therefore reviewed and modified according to the comments and suggestions made by the partners.

The questionnaires are structured into three phases. The first phase contains a set of questions for each content category that was presented to participants, asking participants to state their preferences for each and to rate the presentations based on different criteria. The second phase focuses on the factors that can influence the preferences of users with more general questions on content and presentation. Finally, the third phase consists of the demographic questions.

5.7 Focus Group Interviews

Users' preferences of online Diabetes and COPD content and presentation types were explored in depth through focus group discussions.

The focus groups took place remotely using videoconferencing technology thus allowing for the interviewer and the participants to see each other during the sessions despite the distance. Five focus groups were conducted in total. Two of the groups viewed Diabetes websites and 3 focus groups viewed COPD websites.

Every participant had a printed copy of the questionnaire on-hand during the focus group interviews. During the sessions, the interviewer began by providing background information on the research, providing some instructions regarding the focus group sessions and reading the consent for participating in the study.

The interviewer then presented the first set of presentations for the first content category. To prevent technical difficulties and loss of resolution due to the videoconference, participants were sent the list of links ahead of time for them to view the presentations on their own computer. If for whatever reasons participants could not view the presentation on their own computer, the interviewer also presented it on the videoconference screen.

Participants were then asked to individually answer some questions on the printed questionnaire regarding their preferences for the presentations that had just been presented. The interviewer then asked participants to share their responses and discuss their preferences with the rest of the group. This process was repeated for each set of presentations, one set for each content category. For the groups viewing Diabetes websites, one non-cartoon video, one text-based Web page, and one cartoon video was presented for each of the three content categories: Definition of Diabetes, Lifestyle Changes, and Monitoring. For the groups viewing COPD websites, one non-cartoon video and one text-based Web page was presented for each of the three content categories: Definition of COPD, Medications, and Smoking Cessation.

The interviewer then presented an online discussion forum on the disease in question (i.e. Diabetes or COPD) to the participants. Participants were then asked to complete filling-out the remainder of the printed questionnaire which contained one question regarding the preferences for online forums, other questions regarding the influences

of variables on the preferences, and some demographic questions. Three open-ended questions from the questionnaire were then asked for group discussions.

The whole focus group took approximately 2 hours and was completely video recorded. Transcripts of the video recordings were made for analysis. Following the interview, participants sent their filled-out questionnaires to the interviewer via fax. The received questionnaires were then transcribed for analysis. NVivo software was used to analyze the data from both the questionnaires and the video transcripts.

An advantage of the method used for this research is having the combination of the group discussion with individual responses from the participants in the questionnaires. This method allows the interviewer to record details that would otherwise be impossible to record by simply using a questionnaire. The videoconference lets the interviewer see the participants' facial expression and body language, reducing the chances that answers will be misinterpreted. Furthermore, the interviewer can probe for more information if the answer given by the participant is not clear or incomplete. In addition, if the answers given on the questionnaires are not clear, they can also be compared to the answers given during the focus group sessions to clarify.

5.8 Sampling

The recruitment of participants was conducted with the help of the K-Net partners. Each community in the Sioux Lookout district has a Community Telehealth Coordinator (CTC). The CTC's manage the telehealth operations in their home communities working with the Community Health Director and KO Telemedicine. The CTCs in the communities are responsible facilitating during videoconferences for telehealth sessions with residents of the community (KO Telemedicine, 2008a). Because of their experience using videoconference and their interest in health matters, it was agreed with the partners that the CTCs would be approached to participate in remote focus group interviews for this research using videoconference, as part of their job responsibilities.

Asking the CTCs from each community ensures that most of the communities of the district are represented in the research. A research partner from K-Net took care of contacting all potential CTCs to ask for their participation, scheduled the focus group sessions and coordinated the videoconference during the focus groups. CTCs were also asked to invite other members of their community to participate. The focus groups were divided by tribal council: Independent First Nations Alliance, Matawa⁷, Windigo, Keewaytinook Okimakanak (KO), and the CTC team leaders of the tribal councils. Thirty participants of both sexes were recruited based on the following six criteria. Participants must:

- Identify themselves as being of Aboriginal ethnicity
- Be at least 20 years old
- Live in the Sioux Lookout district
- Have experience using a computer and the Internet
- Be fluent or comfortable in the English language (speaking and reading)

Nineteen different communities from the Sioux Lookout district were represented in the sample. Fourteen participants were recruited to view Web pages on diabetes, while the other 16 participants viewed Web pages on COPD.

Consent for the interviews was given orally at the beginning of the focus groups. Participants were told that the process was voluntary and that they could withdraw from the research at any time without penalty and without having to provide an explanation.

5.9 Participant Demographics

A total of 30 Aboriginal people living in the Sioux Lookout District participated in the research, 14 viewed Diabetes websites and 16 viewed COPD websites. Out of these 30 participants, 5 participants were eliminated from the results because they left early during the interview and were therefore unable to see all the presentations and answer the questions on the questionnaire. All participants were given time to

⁷ Although the Matawa tribal council is not officially part of the Sioux Lookout district and is therefore not depicted on the map, it is geographically located in the region of the Sioux Lookout district. The tribal council is also officially member of the Sioux Lookout First Nations Health Authority (SLFNHA, 2008).

answer the questionnaire during the focus group interviews. Out of the 25 remaining participants, 22 returned their questionnaires: 10 Diabetes questionnaires and 12 COPD questionnaires were returned in total. Demographic data is only available for the participants that returned their questionnaires (n=22), therefore the oral responses of the 3 remaining participants during the focus group sessions were also eliminated.

5.9.1 Gender

As shown in figure 5.4, there were more female participants than male, with 14 (64%) female participants and 8 (36%) male participants.

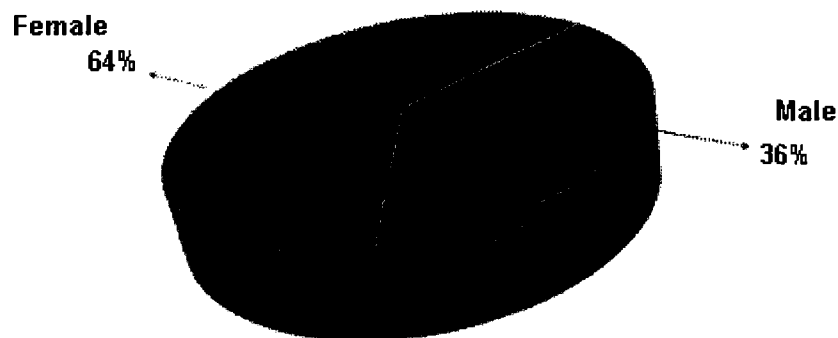


Figure 5.4: Gender

5.9.2 Age

Participants were between the ages of 20 and 59 years old, with 7 participants (32%) in the 20-29 age group, 8 participants (36%) in the 30-39 age group, 6 participants (27%) in the 40-49 age group, and 1 participant (5%) in the 50-59 age group. The age distribution of the sample is shown in figure 5.5.



Figure 5.5: Age

5.9.3 Culture

When asked if they considered themselves to be from an Aboriginal culture and to specify which one, 8 participants (35%) said to be from the Oji-Cree culture, 3 (13%) from the Ojibway culture, 1 (4%) from the Cree culture, 5 (22%) said they were from an Aboriginal culture but did not specify which one, 1 (4%) considered himself to be somewhat part of an Aboriginal culture and 4 (22%) were unassigned (figure 5.6). As described in Chapter 3, Aboriginal People in Canada are culturally diverse, however, despite the cultural heterogeneity of Aboriginal people, there are cultural characteristics that are unique to Aboriginal people and that unite all Aboriginal cultures together (INAC, 2006h).

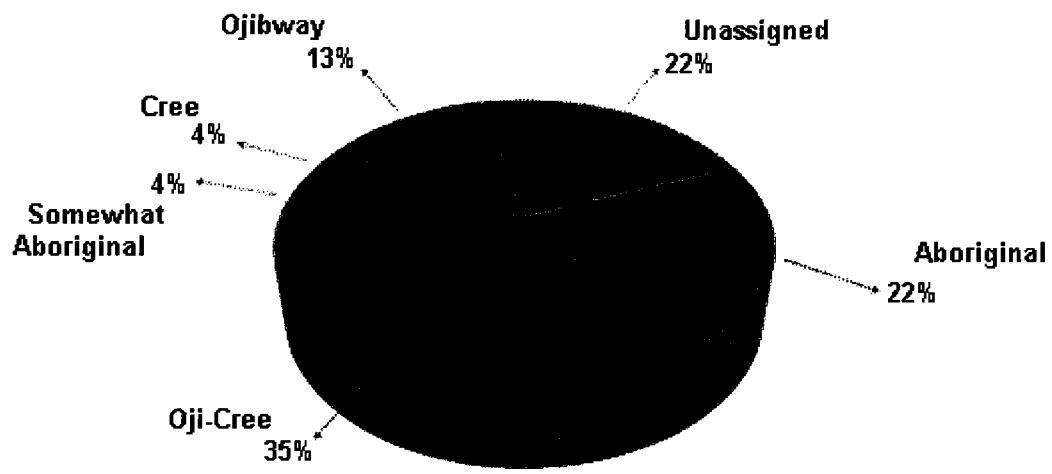


Figure 5.6: Aboriginal Cultures

5.9.4 Language

Most participants (86%) spoke an Aboriginal language either as their mother tongue or as a second language, while all of them spoke English and most of them read English fluently or well, with only 3 participants reading English moderately well.

Community	Mother Tongue	Second Language	Read English
Sioux Lookout	English	Not Applicable	fluently
Sioux Lookout	English	Not Applicable	fluently
Sioux Lookout	English	Not Applicable	well
Lac Seul	English	Ojibway	fluently
Sandy Lake	English	Oji-Cree	fluently
Slate Falls	Ojibway	English	fluently
Pikangikum	Ojibway	English	fluently
Mishkeegogomang	Ojibway	English	fluently
Pikangikum	Ojibway	English	well
Mishkeegogomang	Ojibway/English (bilingual)	English/Ojibway	well
North Spirit Lake	Oji-Cree	English	fluently
Sachigo Lake	Oji-Cree	English	fluently
Sachigo Lake	Oji-Cree	English	fluently
Big Trout Lake	Oji-Cree	English	fluently
Sandy Lake	Oji-Cree	English	fluently
Fort Hope	Oji-Cree	English	fluently
Deer Lake	Oji-Cree	English	moderately well
Keewaywin	Oji-Cree	English	moderately well
Sandy Lake	Oji-Cree	English	well
Wunnumin	Oji-Cree	English	well
Nibinamik	Oji-Cree	English	well
North Caribou Lake	Oji-Cree/English (bilingual)	English/Oji-Cree	fluently

Table 5.4: Communities and Languages

5.9.5 Education

Education levels of participants ranged from primary school to a bachelor's degree. However, most participant were either high school graduates (6), had done some high school (6) or had been to college (6). Only 1 participant said to have a bachelor's degree and only 1 participant's highest level of education was primary school. Two participants chose "other" as their level of education.

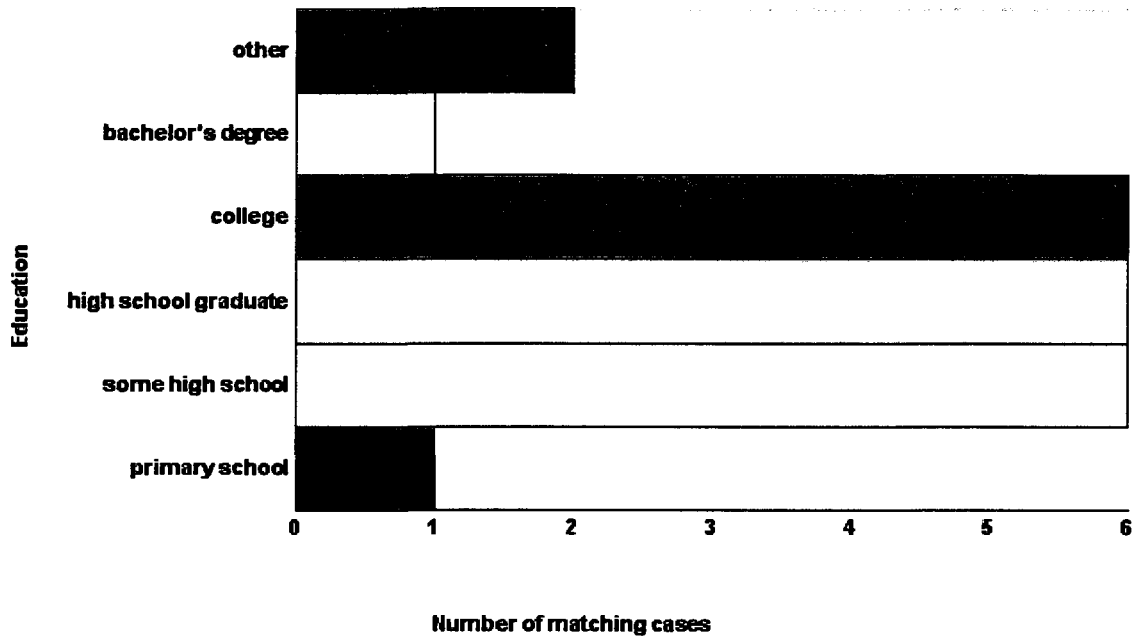


Figure 5.7: Education Level

5.9.6 Use of Internet

All 22 participants specified that they use the Internet at least once a day and said to have previously searched for health information online.

5.9.7 Community Telehealth Coordinators (CTC)

Nearly half of participants (59%) said to be Community Telehealth Coordinators (CTC). Of all CTCs, 11 have done the job for at least a year and up to 4 years, while only 2 have done the job for less than 1 year.

Chapter 6: Analysis of Preferences and Influences

This chapter presents a detailed analysis of the data collected during the focus group interviews. The analysis is divided into four sections. The first section provides an analysis of the data on the preferences of presentation types and attempts to verify hypotheses Ha_1 and Ha_2 .

The second section looks at the findings related to the living location, the level of access to healthcare and the conditions of access to the Internet and attempts to verify hypothesis Ha_3 .

The third section explores in detail a prevailing theme that surfaced in the analysis: the cultural sensitivity of websites. This section looks at verifying the fourth hypothesis: Ha_4 .

The fourth section provides a synopsis of the conclusions that can be drawn from the findings. A table summarizing the results is also presented.

6.1 Presentation Type Preferences

The analysis of the results in this section will attempt to verify the first two hypotheses (Ha_1 and Ha_2) regarding the preferences of presentation types:

Ha_1 : Aboriginal people prefer one type of Web presentation for content on health websites over other types regardless of the disease that is presented.

Ha_2 : Aboriginal people's preference of Web presentation for content on health websites varies depending on which disease aspect is presented.

The concept of Web presentation type refers to presentations made on the Web in the form of non-cartoon videos, cartoon videos, or text-based Web pages. Participants were asked to compare different presentation types and state their preference.

This section will also attempt to explain the reasons why one presentation was preferred over another by looking at the responses to an open-ended question and by examining the ratings given to each presentation type for each of three criteria: comprehensive, visually appealing and trustworthy. In addition, the influence of two demographic variables, age and education, on the preferences will be examined.

The preferences of participants for another presentation type, online discussion forums, will also be looked at separately from the other presentation types. Finally, suggestions from participants for different content and presentation types that they would like to see on health websites will be analyzed.

6.1.1 Presentation Preferences Overall for Diabetes Websites

During two focus group sessions, participants were shown three sets of Web presentations on Diabetes. Each set of presentations focused on one content category related to Diabetes. For example, the second set of presentations was on lifestyle changes for people with Diabetes. For each set, 1 cartoon video, 1 non-cartoon video and 1 text-based Web page was shown (figure 6.1) and each participant was asked to indicate which presentation they preferred. Therefore, each participant (n=10) was asked to express their preferences three times.

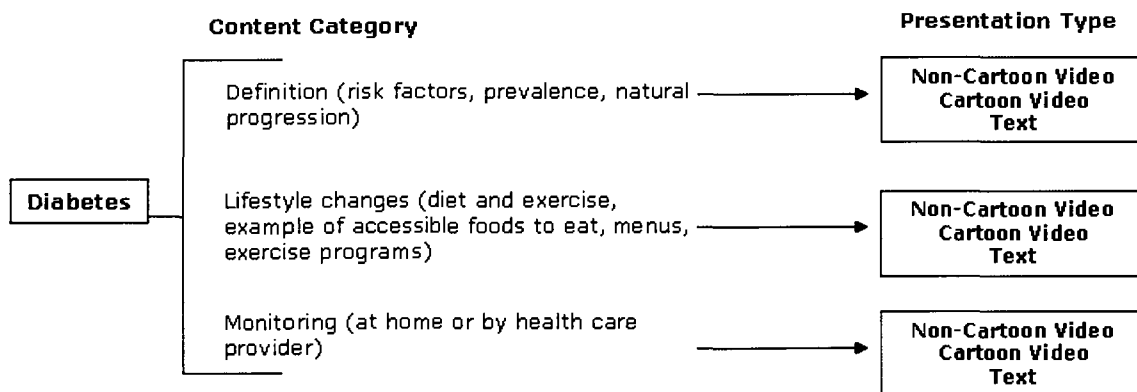


Figure 6.1: Diabetes Presentation Types by Content Category

The non-cartoon video presentation came up as a preference 11 times out of 30 possible answers (37% of answers). The cartoon video was preferred 6 times out of 30 (20% of answers). Both videos were equally preferred once (3% of answers). Text-based web pages were preferred 4 times (13% of answers). Video presentations and text-based presentations were equally preferred 8 times (27% of answers). When combining the results of the two types of video together (non-cartoon & cartoon videos), video presentation was therefore preferred 60% of the time over text-based web pages for Diabetes Web presentations. The distribution of answers is summarized in table 6.1.

<i>Preference for Diabetes Web Presentations</i>	<i>Frequency (out of 30)</i>
<i>Cartoon Video</i>	<i>6 (20%)</i>
<i>Non-Cartoon Video</i>	<i>11 (37%)</i>
<i>Text-Based</i>	<i>4 (13%)</i>
<i>Both Videos</i>	<i>1 (3%)</i>
<i>Both Videos and Text-based</i>	<i>8 (27%)</i>

Table 6.1: Preferences for Diabetes Web Presentations

6.1.2 Presentation Preferences Overall for COPD Websites

During three focus group sessions, participants were shown three sets of Web presentations on COPD. For each set, one video was shown and one text-based Web page was shown (figure 6.2). Participants were asked to state their preferences of Web presentation for each set. Participants (N=12) were therefore asked to state their preferences three times.

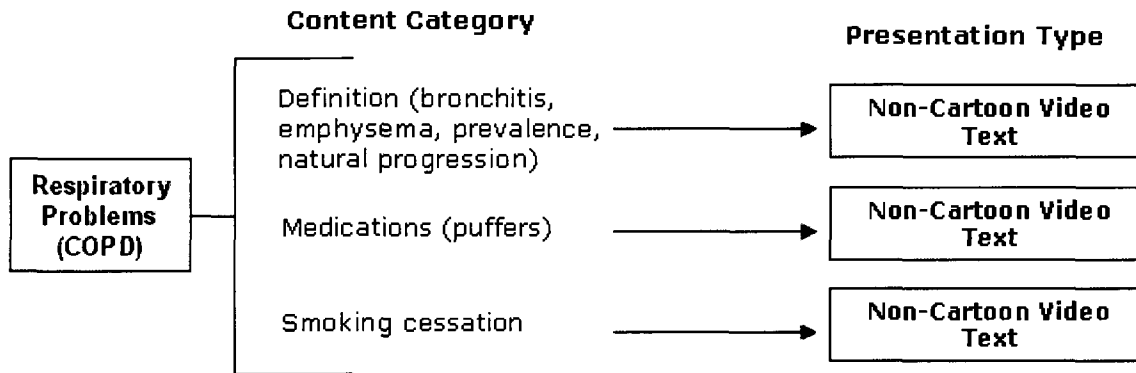


Figure 6.2: COPD Presentation Types by Content Category

For COPD Web presentations, the text-based Web page was more often chosen as a preference than the video, with video chosen 3 times (8% of answers) and text-based chosen 24 times (67% of answers). Both video and text-based Web page were equally preferred 9 times (25% of answers). Table 6.2 provides a summary of the results.

<i>Preference for COPD Web Presentations</i>	<i>Frequency (out of 36)</i>
<i>Video</i>	3 (8%)
<i>Text-Based</i>	24 (67%)
<i>Both Video and Text-based</i>	9 (25%)

Table 6.2: Preferences for COPD Web Presentations

6.1.3 Conclusion for Presentation Preferences by Disease

If the answers for both Diabetes and COPD Web presentations are considered together, text-based Web pages are preferred a little more than video overall, with video being preferred 32% of the time and text-based being preferred 42% of the time. Both video and text-based Web pages were equally preferred 26% of the time (table 6.9).

<i>Preference</i>	<i>Frequency (out of 66)</i>
<i>Text-Based</i>	28 (42%)
<i>Video</i>	21 (32%)
<i>Both Videos and Text-based</i>	17 (26%)

Table 6.9: Preferences for COPD and Diabetes Web Presentations

Even though text-based was preferred more often overall, the difference is minor. The difference in preferences is much more noticeable when comparing the answers between the group that viewed the COPD web presentations and the group that viewed the Diabetes Web presentations. Participants preferred text-based Web pages more often for COPD presentations while participants preferred video most often for Diabetes presentations.

The type of disease could therefore possibly have an influence on the preference for the presentation. For instance, the nature of the disease could make a video more appropriate to present information whereas text-based might be more appropriate for another disease. H_{a1} is therefore not supported.

For a more in depth explanation, we must look at the analysis by content category.

6.1.4 Presentation Preferences by Content Category for Diabetes Websites

It is interesting to look at whether or not the preferences vary depending on the content category being presented. For Diabetes websites, three different content categories were presented: 1) Definition of the disease, 2) Lifestyle changes (diet, exercise, losing weight, etc), and 3) Monitoring (blood glucose level). When comparing the results for the 3 content categories for Diabetes presentation, we observe that most participants preferred the videos over the text-based presentations in all three cases (tables 6.3, 6.4 and 6.5). Some liked both the video and text Web pages equally but few preferred the text-based Web page. This is consistent with the results for the overall presentation preferences.

<i>Preferences for Definition of Disease (Diabetes)</i>	<i>Frequency (n=10)</i>
<i>Video</i>	2
<i>Cartoon Video</i>	3
<i>Both Videos</i>	0
<i>Text-Based</i>	2
<i>Both Videos and Text-Based</i>	3

Table 6.3: Preferences of Web Presentations for Definition of Disease (Diabetes)

<i>Preferences for Lifestyle Changes (Diabetes)</i>	<i>Frequency (n=10)</i>
<i>Video</i>	2
<i>Cartoon Video</i>	3
<i>Both Videos</i>	0
<i>Text-Based</i>	1
<i>Both Videos and Text-Based</i>	4

Table 6.4: Preferences of Web Presentations for Lifestyle Changes (Diabetes)

<i>Preferences for Monitoring (Diabetes)</i>	<i>Frequency (n=10)</i>
<i>Video</i>	7
<i>Cartoon Video</i>	0
<i>Both Videos</i>	1
<i>Text-Based</i>	1
<i>Both Videos and Text-Based</i>	1

Table 6.5: Preferences of Web Presentations for Monitoring (Diabetes)

However, the biggest difference observed between the three content categories is in the preferences of Web presentations on “monitoring your blood sugar”. Eighty percent of participants preferred video over text-based for presentations on “monitoring your blood sugar” compared to 50% of participants for the definition of the disease and 50% of participants for lifestyle changes. Furthermore, for

presentation on “monitoring your blood sugar”, none of participants preferred the cartoon video out of the 2 types of videos.

The participants’ answers hint as to why the non-cartoon video was chosen more often for presentations on “monitoring your blood sugar”. Most participants appreciated the fact that the non-cartoon video gave a demonstration of how to monitor your blood glucose level. For example, one female participant from North Caribou Lake says: “I think people understand more when they see someone actually teaching them how to monitor their blood sugar, cause some of these people might not know how or they don’t think it’s really important, so seeing somebody and learning why it’s so important monitoring your blood sugar, like it’s good, so I like the second video too.” Therefore, video format is possibly preferable over text-based format when a demonstration is needed of how a patient can treat or monitor something related to their disease on their own without the help of a doctor or nurse.

6.1.5 Presentation Preferences by Content Category for COPD Websites

For COPD, three different content categories were also presented; 1) Definition of the disease, 2) Medications, and 3) Smoking Cessation. Most participants preferred text-based Web pages over the video for all three cases, which is consistent with the results for the overall presentation preferences, with 67% preferring text for the definition of the disease, 75% for the medications, and 58% for smoking cessation (tables 6.6, 6.7 and 6.8). A slight trend can be observed when comparing the preferences between each content category. No participants preferred the video for the medication content category. No other important differences can be observed between the three content categories.

Preferences for Definition of Disease (COPD)	Frequency (n=12)
<i>Video</i>	1
<i>Text-Based</i>	8
<i>Both Video and Text-Based</i>	3

Table 6.6: Preferences of Web Presentations for Definition of Disease (COPD)

<i>Preferences for Medications (COPD)</i>	<i>Frequency (n=12)</i>
<i>Video</i>	0
<i>Text-Based</i>	9
<i>Both Video and Text-Based</i>	3

Table 6.7: Preferences of Web Presentations for Medications (COPD)

<i>Preferences for Smoking Cessation (COPD)</i>	<i>Frequency (n=12)</i>
<i>Video</i>	2
<i>Text-Based</i>	7
<i>Both Video and Text-Based</i>	3

Table 6.8: Preferences of Web Presentations for Smoking Cessation (COPD)

6.1.6 Conclusions for Presentation Preferences by Content Category

For COPD presentations, slight differences were apparent in the results between content categories, and more important differences were apparent for Diabetes presentations. Therefore, it appears that the aspects of each disease must be considered when presenting the content.

These results indicate that the content category has an influence on the preference of the presentation type. Hypothesis H_{a2} is therefore not supported by the findings in this research. More research would be necessary to determine how each content category should be presented and if a general rule could apply across all diseases. For instance, as explained earlier, video might be more appropriate to present information where a demonstration is needed.

The type of disease and consequently the content categories have an influence on the preference of the presentation type. Hypotheses H_{a1} and H_{a2} are not supported by the findings in this research. Further research with a larger sample size and with other disease websites should be conducted to confirm these results.

6.1.7 Reasons for Web Presentation Preferences

After participants were asked to give their preference for the different Web presentations, participants were asked to provide the reasons why they preferred one presentation over another in the form of an open-ended question. Three reasons were identified for the preferences of non-cartoon video presentations (summarized in table 6.10), four reasons for the text-based preference (summarized in table 6.11), four reasons for the cartoon video (diabetes only, summarized in table 6.12), and two reasons for the participants that had no preference (summarized in table 6.13).

6.1.7.1 Reasons for Non-Cartoon Video Preference

Several participants preferred the video because of the visuals and graphics used to explain certain things about the disease. A total of 8 references were made to liking of graphics in the videos.

Others preferred the video because they found the content to be more complete. A total of 5 references were made to the preference of the video because of the content.

Two participants said to have chosen the video because some people can't read or others have more difficulty with the English language (table 6.10).\

Reasons for Non-Cartoon Video Preference	Number of References*	Example Citation
Visuals/Graphics	8	"I prefer the first video. The use of pictures to explain the functions helped me to understand more."
Content (more information)	5	"[I preferred the] 2 nd video, because it provides more info on monitoring your sugar".
Can't read/Difficulty with English language	2	"(Video) The reason I chose that is there are people who don't understand, or can't read."

* Some participants identified more than one reason in a single answer.

Table 6.10: Reasons for Non-Cartoon Video Preference

In summary, non-cartoon videos appeared to be useful for people that cannot read or have difficulty with the English language and to demonstrate and provide more information regarding the practical aspects of a disease.

6.1.7.2 Reasons for Text-Based Preference

Four reasons were identified for the text-based preference (table 6.11). Among the participants who preferred the text-based Web pages, most of them (17 references) said that the text-based Web pages had more complete information than the videos.

Other participants (8 references) liked the convenience of a text-based Web page. They appreciated the fact that they could reread the content if they didn't understand or navigate to more content to learn more.

One participant also mentioned to have liked the text-based Web page because of the use of graphics.

Another male participant from Sachigo Lake preferred the text-based Web pages over the videos because he did not want to worry about the possible technical difficulties associated with the audio.

Reasons for Text Preference	Number of References*	Example Citation
Content	17	"I prefer the text-based webpage because it has a lot more information, so it's pretty straight forward and easy to understand."
Convenience	8	"[the text-based Web page] was the best because I was able to read it then reread it if I need to understand better."
Graphics/Visuals	1	"Chronic Obstructive Pulmonary Disease Web Page, cause it shows pictures"
Technical difficulties	2	"[...] Sometimes there's uh, on the video there's audio problem and I can't pick up the, what's he talked about. So that's why I like the text-based Web page."

Table 6.11: Reasons for Text Preference

In brief, text-based appears to be a better form of presentation to offer information where users need to re-read and navigate to more content to understand better. It is also appreciated for its technical simplicity.

6.1.7.3 Reasons for Cartoon Video Preference

For the Diabetes presentations, some participants preferred the cartoon video for various reasons (table 6.12). Three participants found the cartoon to be more appealing and entertaining:

Others specified how the cartoon video would especially appeal to children, like one participant from North Caribou Lake who also notes that Diabetes also affects children in the North.

Some preferred the content of the cartoon video.

One person also appreciated the fact that the characters in the cartoon video spoke in the first person.

Reasons for Cartoon Preference	Number of References *	Example Citation
Appealing/Entertaining	3	"I liked the cartoon. It was entertaining, it kept my attention."
Attract different audiences (children)	2	"[The cartoon video] catches my eye and would be useful for young people even children. Diabetes in the north is also affecting the younger generation."
Content	2	"I preferred the cartoon character. It was able to show how a person lost weight and what she did to lose weight."
Spoke in the first person	1	"[I liked] the cartoon because the character spoke in a first-person point of view. The fact that she said 'I' and 'my' a lot."

* Some participants identified more than one reason in a single answer.

Table 6.12: Reasons for Cartoon Video Preference

The cartoon video appears to be the better form of presentation when people need to be motivated, to attract different audiences and for the education of children.

6.1.7.4 Reasons for No Preference

Participants that liked the videos and the text-based Web pages equally did so because they found that the two formats or the content of both were complementary (table 6.13). One woman from Slate Falls liked the text-based because it was informative and appreciated the video for its use of pictures. Another woman appreciated listening to someone explain in the video and then being able to read up on the subject herself on the text-based web page.

Some participants pointed out that every presentation offered different content and was therefore equally interesting.

Reasons for No Preference	Number of References	Example Citation
Complementary formats	11	<i>"I liked both again. Listening to the doctor and for what ever reason, maybe I don't understand anything, I prefer to use web page for clarification."</i>
Complementary content	6	<i>"Again, I liked all three. The last video gave # values per food and the website gives example servings and the cartoon gave different practical information that someone could relate to."</i>

Table 6.13: Reasons for No Preference

To conclude, the use of a combination of different presentation types can be useful to communicate different aspects of a disease. For instance, text allows the user to reread the content if they don't understand, and can therefore be used for more complex information, while video can be useful to explain certain disease aspects orally or to give demonstrations of practical aspects of a disease.

6.1.8 Comprehensive, Visually Appealing, and Trustworthy Criteria of Web Presentations

In order to learn more information about the reasons for their preferences, participants were asked to rate each Web presentation on a five-point Likert scale (from strongly disagree to strongly agree) for the following three criteria: comprehensive, visually appealing and trustworthy (figures 6.3 and 6.4).

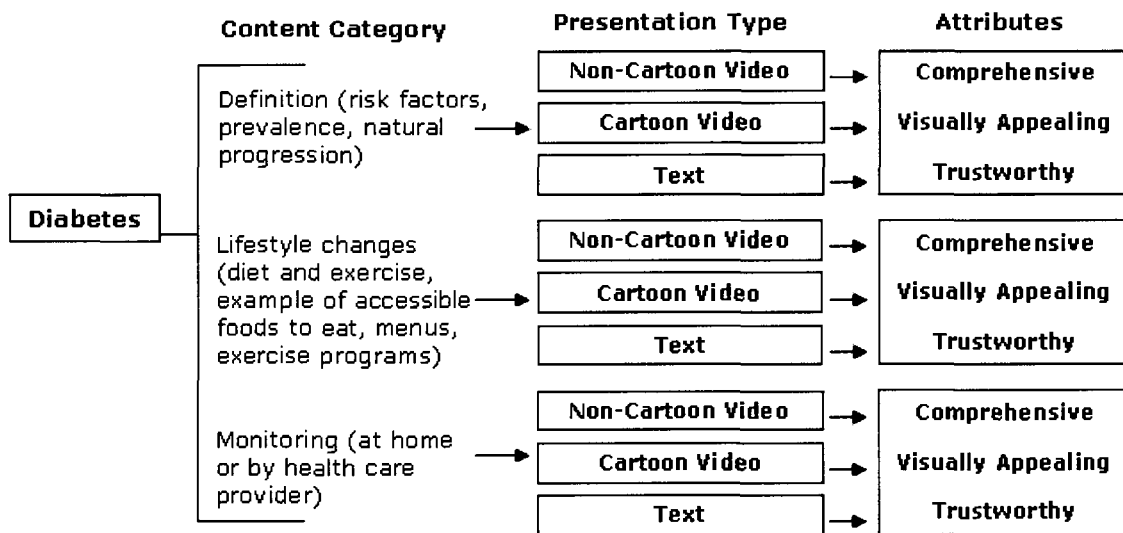


Figure 6.3: Criteria for Diabetes Web Presentation Types

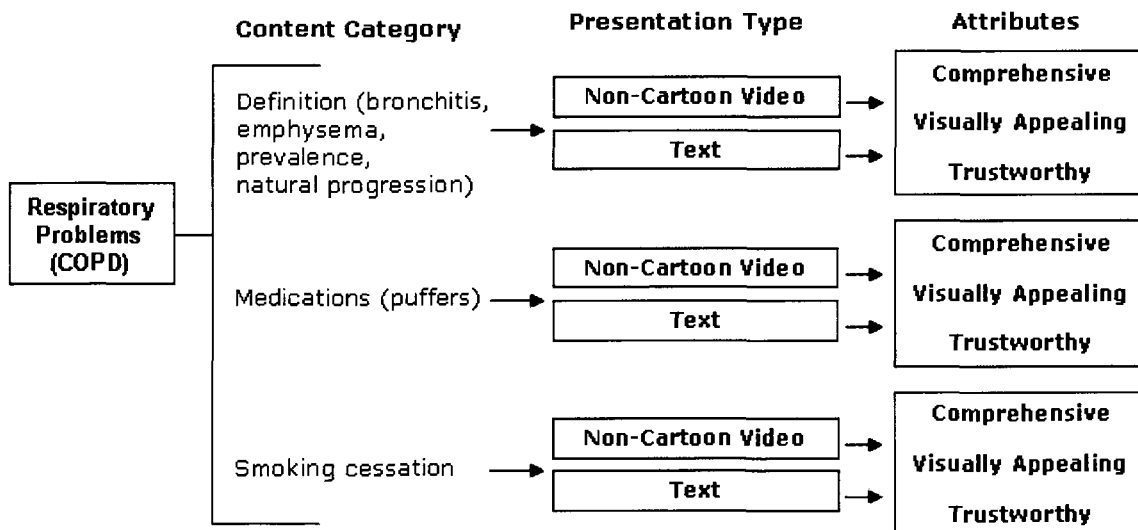


Figure 6.4: Criteria for COPD Web Presentation Types

Results were compiled and charted onto a graph for each criteria for both COPD and Diabetes websites, comparing responses for each Web presentation. All in all, most participants responded positively for all presentations, having the majority of responses (84%) in the “strongly agree” or “somewhat agree” points. However some trends can be observed that can help explain the reasons why participants preferred one presentation over another.

6.1.7.1 Criteria Ratings of Diabetes Web Presentations

Figures 6.5, 6.6 and 6.7 show the distribution of results for the Diabetes Web presentations. Although the majority of users preferred video for the Diabetes presentations, text-based was still rated higher for both the comprehensive and the trustworthy criteria. The fact the participants found the text-based Web pages more comprehensive can be explained by the reasons identified in their answers: text-based Web pages allowed users to navigate to more information if they didn't understand, making them more comprehensive than the videos. However, in the case of Diabetes Web sites, as supported by the answers to the open-ended question, the use of graphics in the videos appears to have been more important than the inability to navigate as users still preferred videos overall.

Explanations can be given after reviewing the answers to open-ended questions as to why participants found the text-based presentations to be more trustworthy for Diabetes websites. Participants spoke about how they would like to see people from their culture in the videos so that they could relate more to the characters (the culture theme is discussed in greater detail in section 6.3). Participants could possibly find it more difficult to relate and trust people that are not from their culture and that even have different accents making the videos less trustworthy than the text-based Web pages. In addition, since users said to have found the text-based Web pages to be more comprehensive, this could possibly have caused them to trust the source better.

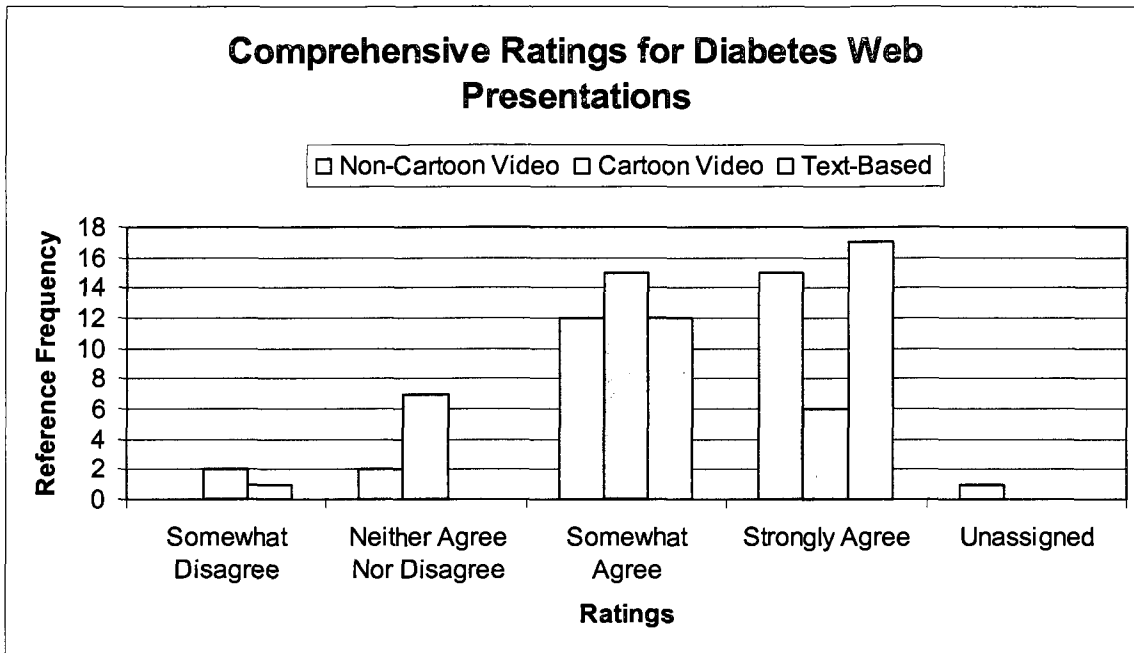


Figure 6.5: Comprehensive Ratings for Diabetes Web Presentations

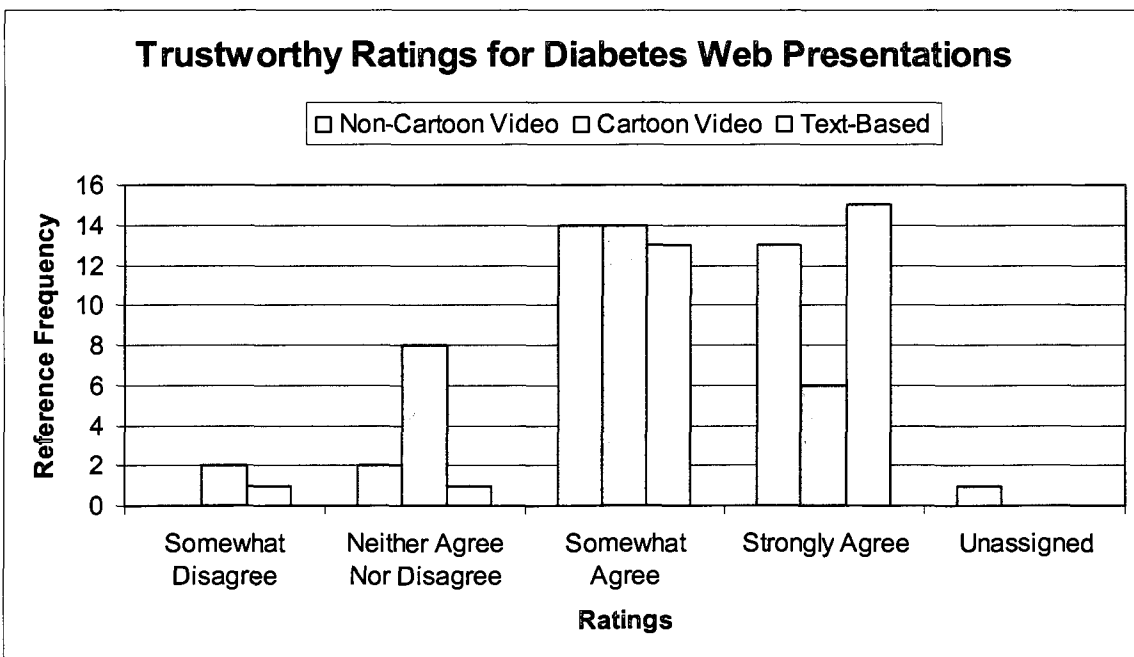


Figure 6.6: Trustworthy Ratings for Diabetes Web Presentations

The non-cartoon video rated much higher for the visually appealing criterion than the cartoon video and the text-based Web pages. This can be explained by the multiple

references made by participants in their answers to open-ended questions about how they liked the use of pictures and visual aids in the non-cartoon videos. Visual aids were lacking in the text-based Web pages, as well as in the cartoon videos.

The cartoon video has a better rating for the visually appealing criterion than with the comprehensive and the trustworthy criteria. Some participants spoke about how they liked the cartoons because they found them to be eye-catching and entertaining, keeping their attention, even though they didn't find them to be as comprehensive and trustworthy.

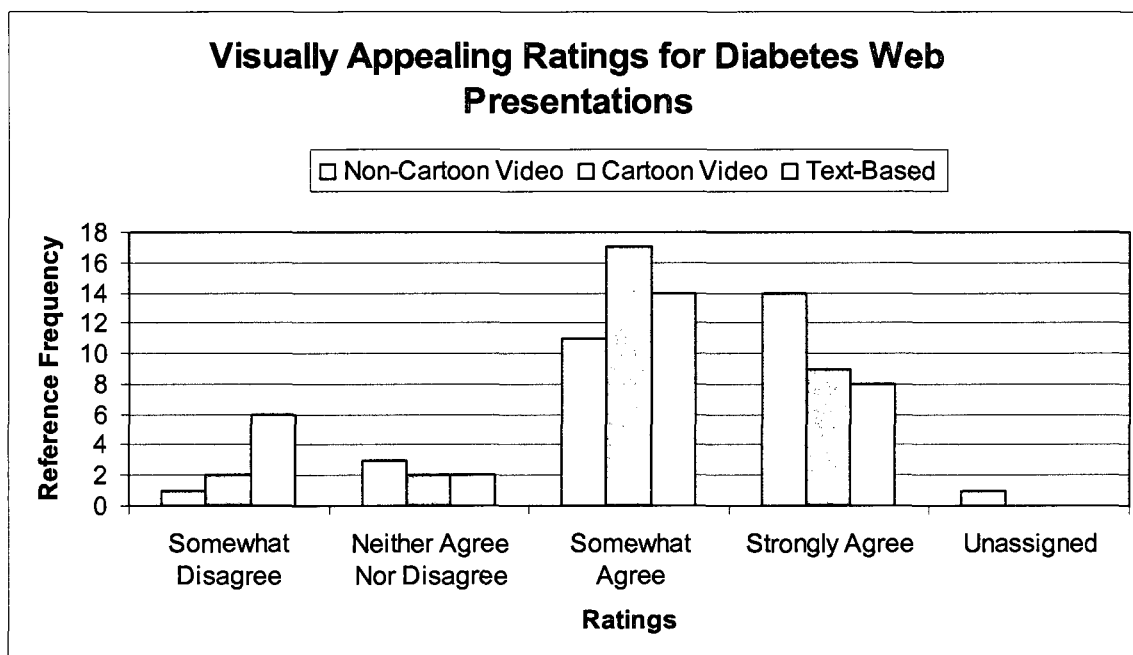


Figure 6.7: Visually Appealing Ratings for Diabetes Web Presentations

6.1.7.2 Criteria Ratings for COPD Web Presentations

Figures 6.8, 6.9 and 6.10 show the distribution of results for the COPD Web presentations. All three criteria were rated higher for the text-based web pages which is consistent with the earlier findings that the majority of participants preferred text-based web pages for COPD Web presentations. In general, regarding this disease, participants found the text-based Web pages to be more comprehensive, visually appealing and trustworthy than the videos.

Figure 6.8 shows the distribution of results for the comprehensive criterion. The majority of participants strongly agreed that the text-based Web page was comprehensive, while the responses were rated much less frequently as “strongly agree” for the video. The responses for the video were more distributed across the scale. The fact the participants found the text-based Web pages more comprehensive can be explained by the reasons identified in their answers. As outlined in the previous section, most users liked text-based Web pages because they had more content and it was easier to navigate around to get more information in order to understand the content better.

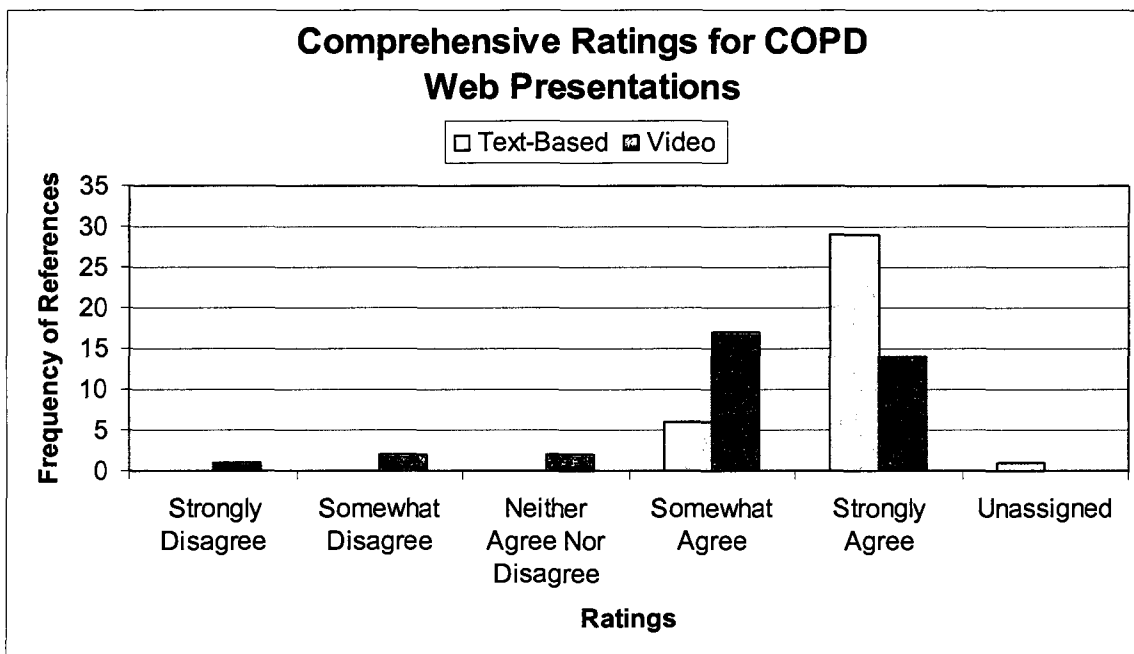


Figure 6.8: Comprehensive Ratings for COPD Web Presentations

Although more participants rated the text-based to be more visually appealing than the video, less difference can be observed than with the comprehensive criterion (figure 6.9). Both video and text-based were rated high for the visually appealing criterion. As explained earlier, several participants preferred videos because of the use of graphics, possibly explaining why the video would rate high for the visually appealing criterion event though text-based was preferred overall.

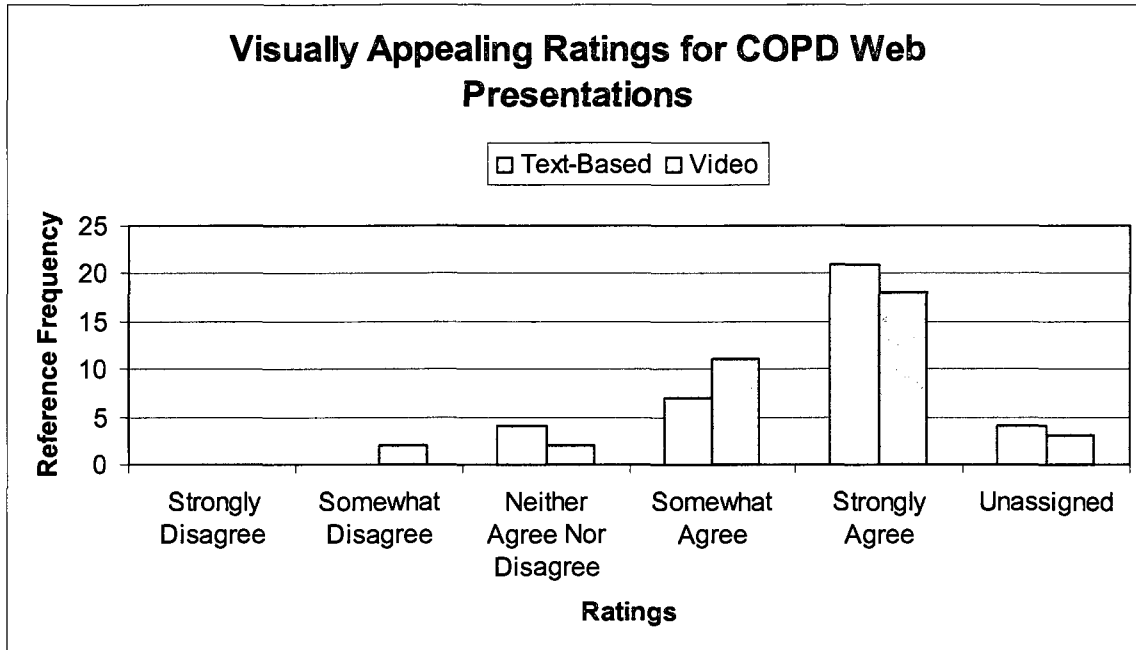


Figure 6.9: Visually Appealing Ratings for COPD Web Presentations

For the trustworthy criterion, a larger difference is apparent between the ratings for text-based and the rating for video (figure 6.10). Participants appeared to have found the text-based Web pages more trustworthy than the videos. The fact that participants found text-based Web pages to be easier to understand (as explained earlier) and that they gave a high rating for the trustworthy criterion, brings us to conclude that text-based is a presentation type susceptible to confer more confidence trust in a website than other types of presentations. As explained for diabetes presentations, a possible explanation for this could be that participants found it more difficult to relate to the speakers in the videos because they were not from their culture and consequently found it more difficult to trust the source.

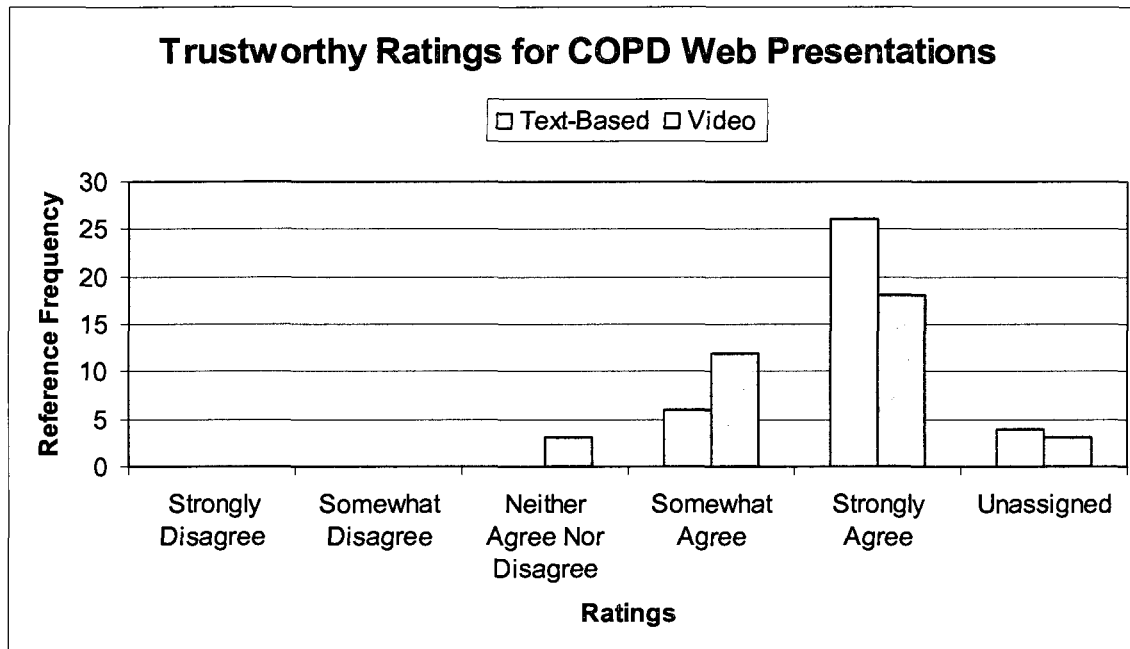


Figure 6.10: Trustworthy Ratings for COPD Web Presentations

6.1.9 Influence of Age on Presentation Preferences

As already noted, for COPD presentations, participants preferred text-based Web pages more often, and for Diabetes presentations, participants preferred video most often. Comparing the age groups of the people that viewed diabetes websites with the people that viewed COPD websites shows that the majority of participants (80%) in the Diabetes group are between the ages of 20 and 39, while the majority of participants (75%) in the COPD group are between the ages of 30 and 49 (figure 6.11). Therefore, the age difference between the two groups could possibly have an influence on the preferences of the participants.

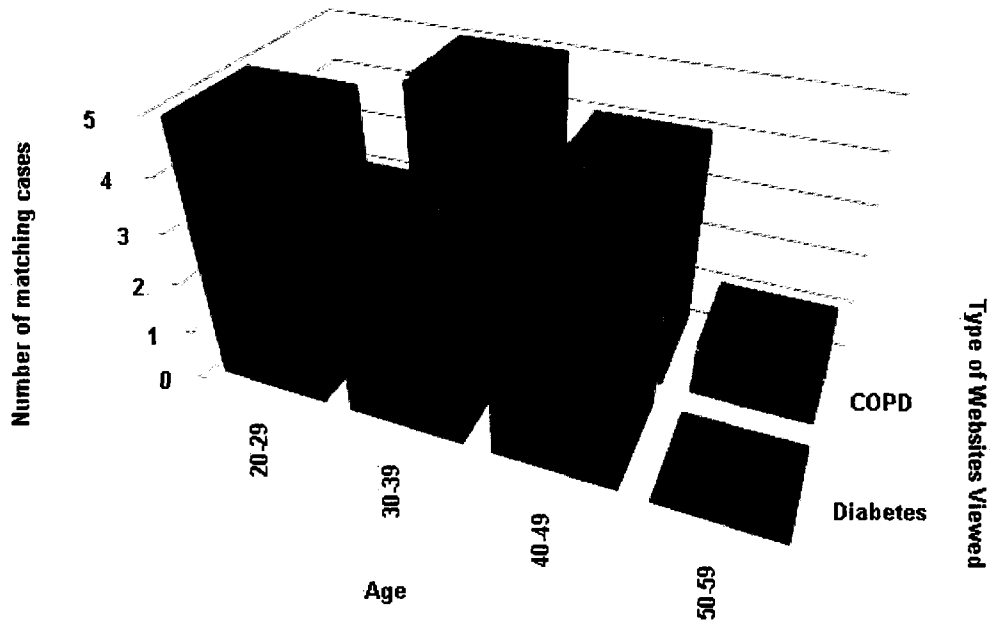


Figure 6.11: Age by Type of Websites Viewed

However, when crossing the age with the preferences, no important differences can be observed between the age groups for the preferences of Web presentations (table 6.14). For instance, in both age groups, text was a preference the majority of the time, with 48% of answers for the 30-49 group and 40% of answers for the 20-39 group. Text is preferred slightly more often than video in the 30-49 age group compared to the 20-39 age group, but the difference is minor. Therefore, age does not seem to have a major impact on the preferences of Web presentations.

	Age = 20-39	Age = 30-49
Text preference	18 (40%)	20 (48%)
Video preference	15 (33%)	13 (31%)
Video & Text Preference	12 (27%)	9 (21%)

Table 6.14: Preferences for Web Presentations by Age

6.1.10 Influence of Education on Presentation Preferences

When looking at the level of education between the Diabetes group and the COPD group, the COPD group has the majority of its participants that have college as their highest level of education, while the Diabetes group has the majority of its participants that have high school as their highest level of education (figure 6.12).

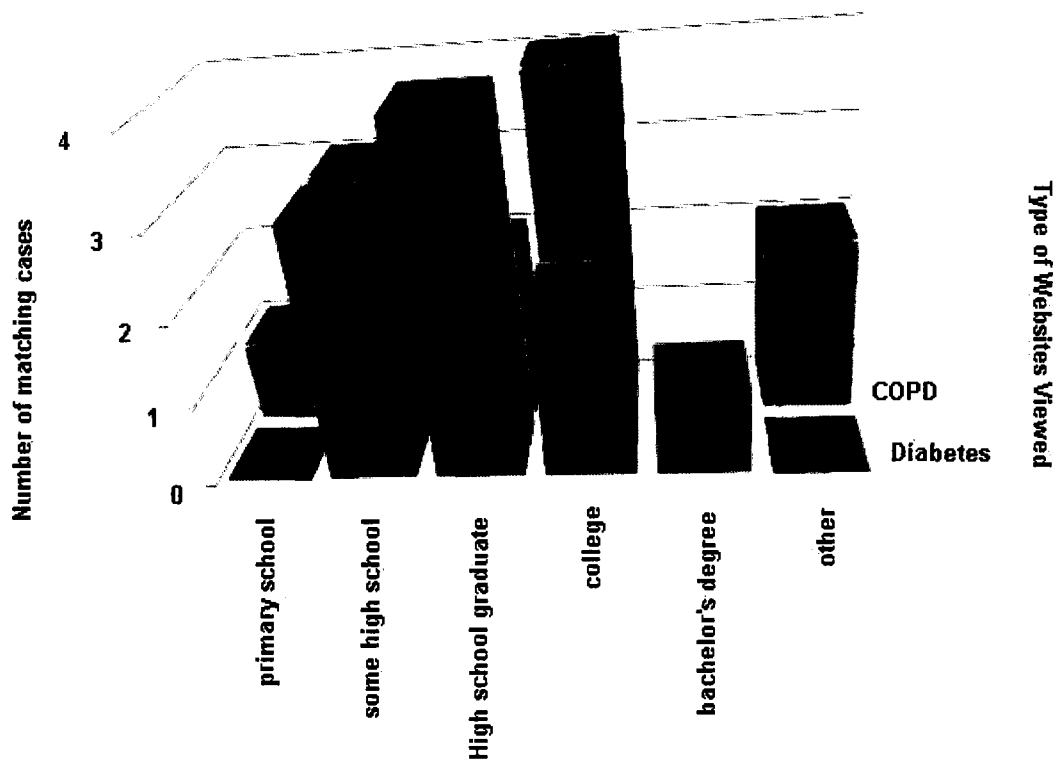


Figure 6.12: Education Level by Types of Websites Viewed

To examine if trends between groups with different education levels could possibly explain the fact that participants preferred text-based Web pages more often for COPD presentations than for Diabetes presentations, the education level is crossed with the preferences for Web presentations (table 6.15). It can be observed that a higher percentage of participants that have college as their highest level of education (67%) prefer text-based Web pages over video (22%) than the participants that have high school as their highest level of education (28% of answers for text and

39% for video). The people who have a college education are more likely to prefer text-based Web pages than the people who only have a high school education, which provides a partial explanation for the difference in preferences between the COPD group and the Diabetes group.

	high school graduate	college
Text preference	5 (28%)	12 (67%)
Video preference	7 (39%)	4 (22%)
Video & Text Preference	6 (33%)	2 (11%)

Table 6.15: Preferences of Web Presentations by Education Level

6.1.11 Online Discussion Forums

Participants were also shown an extra Web presentation type: an online discussion forum. Participants from the COPD group were shown a forum on COPD and participants from the Diabetes group were shown a forum on Diabetes. Participants were then asked if they would like to discuss with other Web users on an online forum such as the one that was presented to them if they were searching for information on that disease. Seventy-seven percent of participants said that they would like to participate in a forum. The majority of participants (68%) answered that they would appreciate the group dynamic of forums.

A discussion forum would allow them to share with other users, learn from other users, and give them a sense that they are not alone. A woman from Sioux Lookout explains that she may be able to find more meaningful information from people who have lived with the disease than from a doctor (table 6.16).

One person said that she would use a forum to find out more information on the topic so that she could promote it to the community. One person said that he might use a forum if he found the time and 1 person did not answer the question. The remaining 4 participants (18%) said that they wouldn't like to discuss with other users on an online forum. One man preferred to search for the information himself,

one female participant preferred to see the person she was talking to, and the other 2 participants preferred to consult a health professional such as a medical doctor or a dietician.

Themes for Online Discussion Forums	% of answers	Example Citation
Liked the Group Dynamic	68%	"Yes, it helps to know what other diabetics go thru and what steps they took to fix a problem they were going thru, kind of like a support system that you aren't alone." "Yes, because I would hopefully be able to find personal examples & experiences rather than medical talk."
Would Like To Promote to the Community	5%	"I would use the forum, maybe to find out what I don't know or to find how I can promote the topic to the community."
Might use it if had time	5%	"Maybe whenever I get a chance to do this"
Unassigned	5%	N/A
Did not like Forums	18%	"I prefer to actually see the person I am discussing topics with."

Table 6.16: Themes for Online Discussion Forums

In conclusion, a forum is an especially useful presentation type when users need to consult with other users, such as in cases where a disease requires support. For diabetes and COPD, users might require support from others for achieving lifestyle changes, like changes in diet and quitting smoking

6.1.12 Users' Suggestions for Different Web Presentations

Participants were asked to provide some suggestions on how the information that they had seen could be presented differently. Some participants (4) suggested how the content could be presented in a more culturally appropriate way. This will be discussed in section 6.3.

Four participants suggested different presentations that would help simulate the group dynamic which is so important in First Nations communities. Participants suggested videoconference or online discussion forums.

Six participants would like to see more visuals on the Websites. For example, one participant suggested: "Maybe pictures of what a person looks suffering from COPD on the video and even on the webpage could make or bring people to think about smoking" (table 6.17).

<i>Suggestions for different presentations</i>	<i>Number of References*</i>
<i>Culturally appropriate presentations</i>	4
<i>Simulation of group dynamic (videoconference, discussion forums, etc.)</i>	4
<i>More visuals/graphics</i>	6
<i>Anecdotal stories, personal quotes</i>	2
<i>Different presentations for different target audiences (i.e. children, adults, elders)</i>	1
<i>Combine all formats into a video</i>	1
<i>Simpler Language</i>	1
<i>No change</i>	3
<i>Not sure/unassigned</i>	7

*When asked what other type of content they would like to see on a health website, 7 participants provided suggestions for different presentations instead. The difference between the content and presentation may not have been clear for some users. Those answers were therefore grouped with the answers to this question. Therefore, the number of total references (29) is larger than the sample size.

Table 6.17: Suggestions for Different Presentations

Two of the participants suggested having people that have actually lived with the disease present their experiences, either through personal quotes or anecdotal stories. One person suggested that the information should be separated into 3 categories, in order to reach the different target audiences: children, adults and elders. One person suggested that the information be presented in simpler language, without medical jargon, for the average person. Another person suggested combining all formats into a video. Three people felt that the presentations that they

had seen were adequate and did not suggest any other presentations, and 7 participants did not answer the question.

These results show that other presentation types would be appreciated by the users than the ones that were shown. More research needs to be conducted regarding the preferences of other presentation types, such as text-based web pages containing graphics, presentations in the form of anecdotal stories or personal quotes, or presentations targeted to different age groups.

6.1.13 Content Preferences

Participants were also asked what other type of content they would like to see on a Diabetes or COPD website. Some participants (4 references) would like to see cultural content on the website. This theme is discussed in detail in section 6.3 of this chapter. Other participants gave additional suggestions of different types of content specifically related to the disease that could be added to the website to make it more complete (table 6.18).

<i>Suggestions for different types of content</i>	<i>Number of References*</i>
<i>Cultural content</i>	4
<i>More content specifically related to the disease (ex: complications of Diabetes)</i>	5
<i>Not sure/unassigned</i>	6

*When asked what other type of content they would like to see on a health website, 7 participants provided suggestions for different presentations. Those answers were grouped with the answers to the question of suggestions for different presentations. Therefore, the number of total references (15) is smaller than the sample size.

Table 6.18: Suggestions for Different Types of Content

The following is what participants would like to see in addition to the information that they saw during the interviews: information on sexual complications related to Diabetes (2 references), information to other complications related to Diabetes (depression, amputation, ketoacidosis – 1 reference), more information on smoking for COPD websites (1 reference) and information on medications for COPD and how to cope with COPD (1 reference).

6.2 Living Location, Access to Healthcare and Access to Internet

The analysis of the results in this section will attempt to test hypothesis H_{a3} :

H_{a3} : Living location factors will have an influence on Aboriginal people's preferences of content and presentation on health websites.

One theme that surfaced during the interviews was related to the living location of the people in the Sioux Lookout district. Most participants live in remote communities that are only accessible by air. This causes problems for access to healthcare and the Internet (as described in chapter 4).

The fact that these communities are in the North also means restricted access to certain foods such as fresh fruit and vegetables. Diet plays an important role in preventing certain diseases or complications associated with a disease, or in controlling the symptoms of certain diseases. Diabetes is one of those cases and content related to diet was therefore presented to participants.

Also, a consequence of the communities being geographically separated from one another is that they are more likely to have developed their own cultural beliefs and practices. All these factors could have an influence on the preferences for content and presentation on health-related websites.

6.2.1 Living Location

A number of participants (4 references) mentioned how some foods are not available in the North, or are too expensive; consequently suggestions of alternatives to these foods would be appreciated (table 6.19).

Some participants (2 references) specified how the living location would influence what type of cultural information they would like to see on the Websites. Because every community is remote, each has their own cultural practices and beliefs. This indicates that for content to be meaningful to all communities, a common

denominator of cultural elements would have to be identified to present on health websites in Aboriginal context.

Themes related to Living Location	Number of References	Example Citation
Availability/Cost of Food	4 (18%)	"with that one Web site where there was the ingredients, maybe, because food is so expensive up North, find ingredients that have like wildlife, like moose meat stew and whatever."
Different Cultural Beliefs	2 (9%)	"I don't know, I guess it would depend, every reserve is different. Every reserve has different beliefs. So I think I would say herbal medicines and spiritual."
Healthcare Access	2 (9%)	"The nurses/doctors are usually too busy [for us] to ask for health information."
Website Access Difficulties	16 (73%)	"Up North – Internet is too slow and takes longer to upload videos."

Table 6.19: Themes related to Living Location

Answers related to healthcare access and website access difficulties are discussed in the following two sections.

6.2.2 Access to Healthcare

When asked what type of healthcare access they had in their communities, 50% of participants answered that they did not have a medical doctor available at all times in their community. Of these 50%, 41% have access to a nurse and telemedicine, 5% have access to a nurse, a healer and telemedicine, and 5% have access to a nurse only. Not only do these communities have no hospitals or medical specialists, they do not even have constant access to any medical doctor. Some communities will get visits from a doctor on a regular basis, once a month or even once a week, but this still means that patients must wait days or even weeks before seeing a doctor. Furthermore, since all patients must see the doctor on the same day or within the

span of a few days, this means that the doctor may be very busy and may not have enough time to dedicate to each patient. These findings confirm what has already been stated in chapter four, that access to healthcare is limited for the communities of the Sioux Lookout district.

This lack of access to healthcare increases the need for patients to have alternative ways to get health information, the Internet being one of them. As already mentioned, all 22 participants said they had previously searched for health information online because of the lack of help from health professionals (table 6.19). When asked what difficulties she could encounter to access health-related websites, a woman from Sachigo Lake answered: "Sometimes when we look for information or resources that are close to home, [the resources are] not always available." This indicates that health websites are lacking in providing information on resources that are close to home for some people.

6.2.3 Access to Internet

Another challenge arising as a result of living in remote communities is the access to the Internet. As explained in chapter 4, all communities in the Sioux Lookout district now have Internet access. However, the cost can be very high and this does not mean that residents have Internet access in their homes, that the bandwidth is high enough for certain types of presentations, such as video, or that the connectivity is reliable. Sixty-eight percent of participants said they consult websites from home, therefore, the majority of participants have Internet access at home. Of the 32% remaining participants, 27% said they normally access the Internet from work and only 5% said they access it at a community center.

When asked what difficulties they could encounter to access health-related websites, several themes came up (table 6.20). Out of the 22 participants, 23% said that they could encounter bandwidth problems, 18% said that they could have problems with accessibility, such as not having a computer or not having Internet access, and 14% of participants spoke about how some people might not know how to use a computer, especially elders. Others (14%) spoke about how they might have

difficulty to find information that is culturally relevant or in plain language, as English is often the second language of First Nations people.

<i>Difficulties when Accessing Health-Related Websites</i>	<i>Number of References</i>	<i>Example Citation</i>
<i>Bandwidth</i>	5 (23%)	<i>"Up North – Internet is too slow and takes longer to upload videos."</i>
<i>No Internet/No computer</i>	4 (4%)	<i>"No computer, connectivity is major issue"</i>
<i>Computer literacy</i>	3 (14%)	<i>"Not a lot of elders know how to work the computers"</i>
<i>Accurate/Useful information</i>	3 (14%)	<i>"Not knowing what is right or good information."</i>
<i>Culturally relevant information/use of language</i>	3 (14%)	<i>"Some websites have these big words I've never heard of and makes it harder for me to understand."</i>
<i>Power failures</i>	1 (5%)	<i>"Power failures and slow internet service."</i>
<i>No difficulties</i>	1 (5%)	N/A
<i>Don't know/Unassigned</i>	5 (23%)	N/A

Table 6.20: Difficulties when Accessing Health-Related Websites

Another 14% were concerned with finding accurate or useful information. One person mentioned the risk of power failures. Only one person said he did not have any difficulties accessing health websites, however 23% of participants did not know or did not answer the question. All of the themes identified, except one, are related to the living location and how this can cause connectivity problems, computer literacy problems, and accessibility problems. The other theme, culturally relevant information, is more related to culture than to the living location and is discussed in the next section.

6.2.4 Conclusions for Influence of Living Location on Preferences

The results from this research show that the living location factors have an influence on Aboriginal people's preferences of content and presentation on health websites. These findings from a qualitative analysis indicate that hypothesis H_{a3} should be supported. Further research should be pursued to characterize this relation and precisely define the extent of its influence and its diverse impacts.

6.3 Cultural Sensitivity for Diabetes and COPD Websites

One prevailing theme identified in the answers was a preference for culturally appropriate content and presentation on Diabetes and COPD websites. The findings described in this section will attempt to verify the fourth hypothesis (H_{a4}):

H_{a4} : Aboriginal people would prefer health websites that contain elements related to their culture.

Out of 22 participants, only 2 mentioned that they were not into Aboriginal traditions. The remaining 20 participants would like to see some sort of cultural information or presentations on the Web. When asked what type of information related to Aboriginal traditions they would like to introduce in health websites, several sub-themes came up (table 6.21). We tackle these successively.

Cultural Themes	Number of References	Example Citation
Traditional Medicine/ Herbal Medicines	13	"[I'd like to see] traditional medicine. Um, for myself, I don't really know where to find it, how to prepare it, so that kind of information would be helpful."
Aboriginal Practices (spirituality, healing circles, smudging, fishing, canoeing, etc.)	9	"Active lifestyles – how we actually do exercises in our communities. i.e.: fishing, canoeing, walks in our environment; people collecting herbal meds; foods available in our communities."
Traditional Foods	7	"Myself I thought of traditional foods versus store-bought foods...I'd like to see more of that, [...] I grew up on reserve but I'd like to know how much nutrition...how nutritious is wild or traditional foods versus store-bought...and to uh, to teach the children how it was before and how it is now."
Cultural Symbols (language, syllabics, role models, etc.)	6	"We can have cartoon video done in our language and it would attract older people, those are the ones that have Type II Diabetes more. And most of them understand the native language here."
Aboriginal Health Issues	6	"More culturally appropriate for First Nations. I hate to say it but a lot of First Nation people have the disease and we need more information or be educated"

Table 6.21: Cultural Themes

6.3.1 Traditional and Herbal Medicine

Several references (13) were made to traditional and herbal medicines (table 6.21). One female participant, who would also like to see information on herbal medicines, specified how the traditional practices were different in each community: "Like maybe the kind of plants that we use, I don't know, like um, cause it's different in different areas, like in First Nations, some are very traditional, some are more Christian communities, so I guess it all depends". Some participants would appreciate information on the benefits of using traditional medicine. More

specifically, some participants specified that information on how traditional medicine could help with the healing of a disease, reducing symptoms or preventing complications would be useful. For example, this man from Pikangikum said: “[I would like to see information on] traditional medicine. [I] would like to know what would help to quit smoking, so would others I bet.” Aboriginal medicine could therefore be integrated into health websites to complement Western medicine but cultural diversities of Aboriginal people must be considered.

6.3.2 Traditional Aboriginal Practices

Another theme that came up was traditional Aboriginal practices. Nine references were made to different Aboriginal practices (table 6.21). One female participant from Slate Falls would like to know how a specific Aboriginal practice could be helpful. For example, she wonders: “Does smudging/pipe have an affect [on COPD]?” One man from Pikangikum stated that he would like find information on the specific ways of healing of his own community. Another female participant from Sandy Lake explained how people in the North have their own ways of exercising and eating in their communities and how this information should be found on the health websites (table 6.21)”.

Another participant spoke about how they would like the medicine wheel to be linked to the disease: “Maybe try to infiltrate the COPD in the wheel (ie: spirituality, mentally, aspects etc)”. Spirituality is another subject that came up as a component that participants would appreciate on the websites. Some participants explained the important practice of elder teachings in First Nations and how this should be reflected on the Websites: “I’d like to see more targeted groups, [...] elders especially, to target more of them, because they’re, they’re the backbone of the reserve...of all reserves. [...] Elders will basically, if they understand more about diabetes, they’ll pass it down to their children and so forth, like that.”

Several participants emphasized the importance of healing circles in their communities and suggested that this group dynamic could somewhat be presented online, like this man from North Spirit Lake proposed: “Healing circles, like a group chat or like video conference sessions with the different communities if that’s

possible". Another man stressed the significance of learning from others and sharing information with others: "Through my experience for a number of years of working at the CHR that's how I got to know my CHR workers, through the other people that I listen to, like I said, through face to face meetings, and somewhere in the community where we break into groups and select a person to speak. That way everybody get a chance to speak up. Especially when you have a large group. And those can calm a lot of people that have fears. Makes a lot of a difference, and that's how these new workers gets a lot of information from." Again, the diversity of Aboriginal cultures is reflected in the answers and this should be taken into account when incorporating information on cultural practices into health websites.

6.3.3 Cultural Symbols

Another theme identified was the use of cultural symbols, such as language, syllabics, and role models. One woman from Sandy Lake suggested that the language in the videos should be localized, to attract older people in the communities (table 6.21). Another female participant supported this comment and added that content should also be translated into syllabics: "[...] all the presentations should be translated into our native language, and written in syllabics."

One participant suggested that Aboriginal people should be seen on the websites: "I'd like to see more Aboriginal people as like role, like models for that site, like that if you are presenting it in the Northern communities. That would mean [they] could relate to it more." Another participant added that the environment that the people in the communities live in should be portrayed in the cartoon videos. The use of Aboriginal role models in the videos and other cultural symbols should therefore be included in health websites. Translation of content into Aboriginal languages should also be considered but a cost-benefit analysis would have to be conducted as the maintenance of multilingual sites can be costly.

6.3.4 Traditional Food

Traditional food was also identified as a theme among the answers, especially from those who had viewed Diabetes websites. Diet is an essential part of the management of Diabetes; therefore food came up as a subject quite often (7 references, table 6.21). Participants who spoke about food explained how it would be useful to get information on traditional foods and how they can be included in a healthy diet. Some participants mentioned how they would like to get their foods in traditional ways, such as by hunting, fishing or gathering herbs rather than buying it in the store; therefore, knowing what traditional foods can be used instead of store-bought foods in a healthy or diabetic diet would be valuable.

A woman from Sioux Lookout would like to find some information on what traditional foods are safe to eat when you are diabetic: "the information that I think would be really helpful is, especially from being around this area is a lot of people want to know what kind of traditional food they would like, or what is safe to use or eat, even like the herbal medicines, what is safe to use and what isn't. And a lot of people don't know that information. Especially being a diabetic, there's not really a lot of that out there. I thought that would be something to add to any website. Just as an alternative."

Some people were interested in getting information on the nutritional benefits of eating traditional foods versus store-bought foods (table 6.21). This is an important aspect to consider that is linked not only to cultural practices and beliefs but to the specific living conditions of remote communities.

6.3.5 Specific Aboriginal Health Issues

Another theme that surfaced was specific Aboriginal health issues. Some participants stated that Diabetes is a problem for a lot of First Nations people, including children and they would appreciate more information on the subject.

One woman would like to see more information on why Diabetes affects more First Nations. She believes that this type of information could help people understand the causes and consequently help prevent the disease: "Regional history of diabetes. Ie:

why are native people so susceptible to it? Changes of our way of life and eating habits? [...] I think if people know that it would help to understand and prevent diabetes.”

When asked what difficulties she could encounter when to access health-related websites, one woman pointed out: “I wouldn’t have problems accessing websites but I might have a problem with accessing culturally demographically appropriate information.” This statement suggests that health-related information needs to be tailored to the specific characteristics of Aboriginal people not only culturally but also to their specific health issues, in order to be relevant to them.

6.3.6 Who should be Presenting Information on a Health Website

To explore whether or not the preferences of participants for health websites could be affected by who is presenting the information, participants were asked to express their preference, from 1 to 3, of who should be presenting information on a health-related website from the following choices: a medical expert, a medical expert from your community, anyone from your community, a medical expert from any Aboriginal community, any Aboriginal person, or other. The results of #1 choices are depicted in figure 6.13.

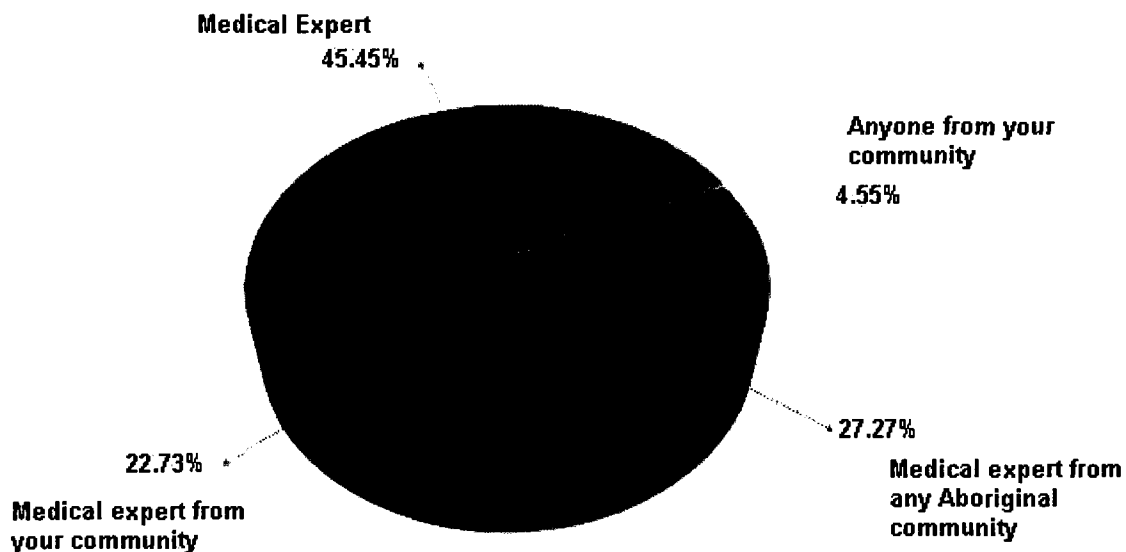


Figure 6.13: Who Should be Presenting Information on a Health Website

Almost half of participants ranked “a medical expert” as their number 1 choice of who should be presenting health information on websites. However more than half (55%) preferred to have someone from their own community or any Aboriginal community, with fifty percent preferring that this person be a medical expert and only 5% preferring anyone from their community. This indicates that primarily, participants would like the person presenting health information on a website to be a medical expert and secondly, participants prefer that this person be from their culture. If information is presented by someone from the user’s culture, then this user could possibly find the website to be more appealing or even more trustworthy. Or perhaps users could find that a person from their own culture is more suited to present content that is culturally relevant to them.

6.3.6.1 Crossing Results with Age

Answers to the question regarding who should be presenting information on health websites were crossed with age to determine whether or not this demographic variable could have an influence on the results.

When crossing the results with age, a slight trend can be observed (table 6.22). It appears that a smaller percentage of participants under the age of 40 were concerned with having someone from their culture presenting health information, with 47% of the participants under the age of 40 compared to 71% of the participants over the age of 40. Having a medical expert present the information appears to be more important to the younger generation than having someone from their culture.

who should be presenting health info	Age = 20-29	Age = 30-39	Age = 40-49	Age = 50-59
A medical expert from any Aboriginal community	1	2	3	0
Anyone from your community	0	1	0	0
A medical expert	4	4	2	0
A medical expert from your community	2	1	1	1

Table 6.22: Who should Present Health Information Crossed with Age

6.3.6.2 Crossing Results with Education

To determine whether education has an influence on the results, answers to the question regarding who should be presenting information on health websites were crossed with education. No trends can be observed (table 6.23), therefore education does not have an influence on the results.

who should be presenting health info	primary school	some high school	high school graduate	College	bachelor's degree	other
A medical expert from any Aboriginal community	0	2	1	1	1	1
Any Aboriginal person	0	0	0	0	0	0
Medical expert	1	3	2	4	0	0
Medical expert from your community	0	1	3	0	0	1

Table 6.23: Who should Present Health Information Crossed with Education

6.3.7 Consultation Process of Health Websites

Participants were also asked with who they would prefer to consult a website on health information between the following choices: in the presence of a healthcare professional, in the presence of a friend you trust, in the presence of a respected member of your community, individually, in a group or other. Table 6.24 summarizes the results.

<i>In the presence of who would you like to consult a website on health information</i>	<i>Number of References*</i>
<i>Individually</i>	<i>13 (59%)</i>
<i>In the presence of a healthcare professional</i>	<i>6 (27%)</i>
<i>In a group</i>	<i>4 (18%)</i>
<i>In the presence of a friend you trust</i>	<i>3 (14%)</i>
<i>Other</i>	<i>3 (14%)</i>
<i>In the presence of a respected member of your community</i>	<i>1 (5%)</i>

*Several participants provided more than one answer

Table 6.24: Consultation Process of Health Websites

The majority of participants (59%) prefer to consult a health website alone. However, the remaining 41% of participants prefer to be in the presence of someone else. Twenty-seven percent of participants prefer to be in the presence of a healthcare professional when consulting a health website. Considering the limited access to healthcare in the communities of the Sioux Lookout district, this could possibly pose a problem. One woman from Mishkeegogomang who had chosen both "individually" and "other" specified that she would first like to consult the website individually and then consult with a healthcare professional to get more information and to know what else she should bring back to the community.

Eighteen percent of participants prefer to be in a group when consulting a website on health information. Again, the concept of sharing with your community and learning from others is shown here. One woman from Mishkeegogomang who also chose "other" specified that she would possibly like to do this by videoconference. This indicates that this woman would like to share information with people outside of her community, possibly from other Aboriginal communities. Fourteen percent said to prefer to be in the presence of a friend they trust and only 5% said to prefer to be in the presence of a respected member of their community. One woman who chose "other" specified that she would like to consult a diabetes website in the presence of someone who has diabetes and is in control of the disease. This could indicate that this woman feels that a person who has gone through the experience of having the disease and who has succeeded in controlling it could offer the best guidance in finding the appropriate information.

6.3.7.1 Crossing Results with Age

When crossing the results with age, interesting trends can be observed. More participants in the 20-29 age group prefer to consult health websites in the presence of a healthcare professional than in the other age groups. Therefore, the younger generation might feel more comfortable consulting a health website with someone that has professional experience and training on the topic to be able to guide them throughout the process. In addition, no participants in the 20-29 age group would like to consult in groups. This indicates that the younger generation does not desire to be in a community environment when searching for health information online but

appreciates the presence of a healthcare professional. Furthermore, no participants above 30 would like to consult with a friend.

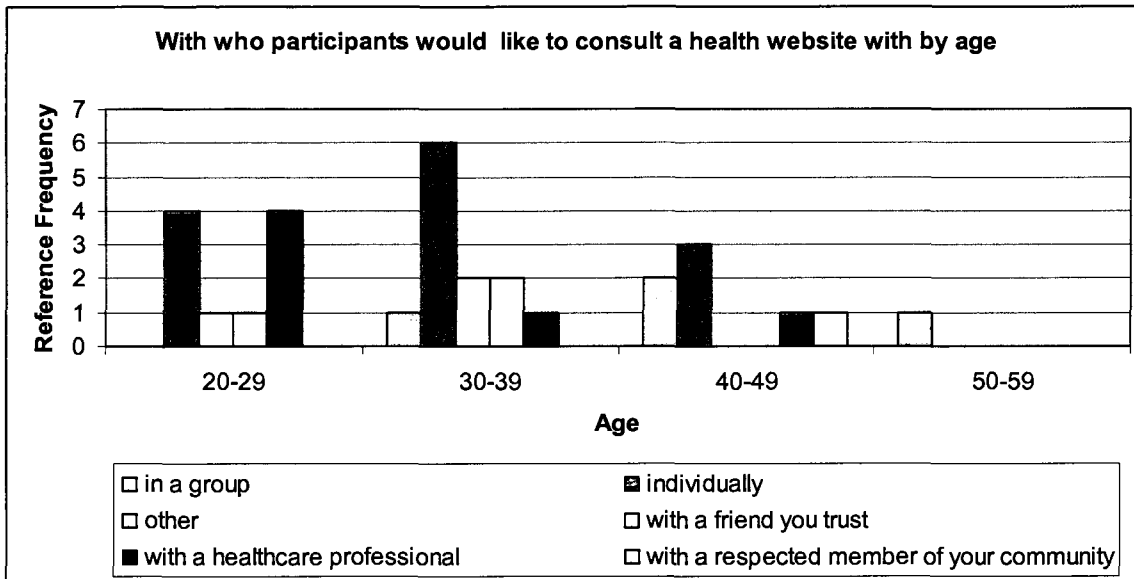


Figure 6.14: Crossing the Consultation Process of Health Websites with Age

6.3.7.2 Crossing Results with Education

When crossing the results with education, more trends can be observed. The majority (83%) of participants that have a college education prefer to consult a health website individually, while the responses of participants that have a high school education are much more distributed. Only 18% of participants with a high school education prefer to consult health websites individually, 27% prefer to consult with a healthcare professional and another 27% prefer to consult with a friend they trust. From this trend, it can therefore be said that the higher the education level of participants, the more likely they are to prefer to consult individually.

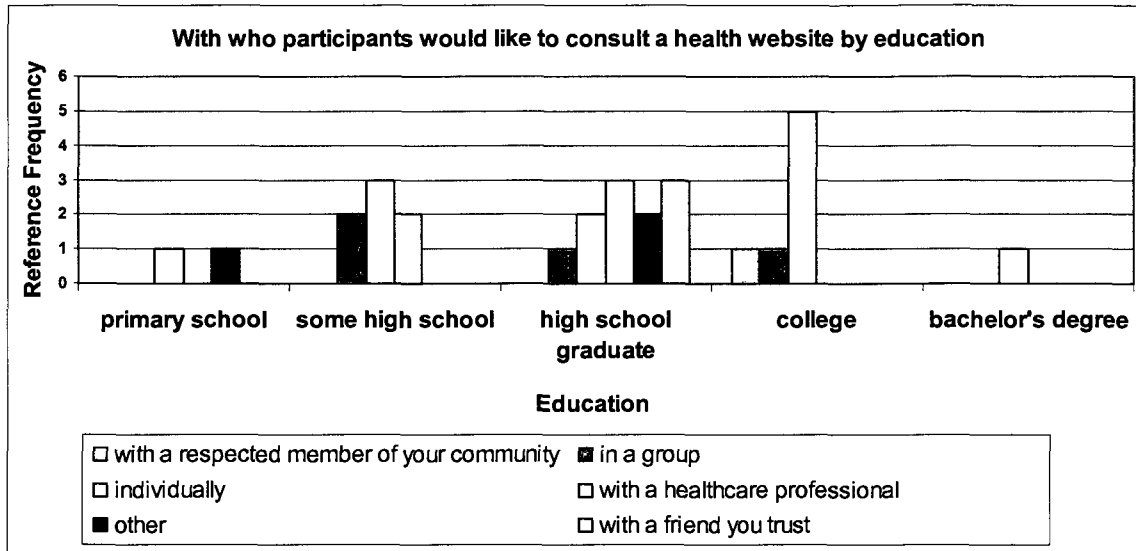


Figure 6.15: Crossing the Consultation Process of Health Websites with Education

6.3.8 Conclusions for Importance of Cultural Sensitivity on Health Websites

The findings from this research show that Aboriginal people would prefer health websites that contain elements related to their culture. This therefore supports hypothesis Ha₄.

6.4 Synopsis of Results

The research model (described in Chapter 5) proposes the hypotheses that there are contextual influences on the preferences of online health information for users: Aboriginal health issues, access to healthcare, culture, living location, and Internet access. Furthermore, the model shows that when exploring the preferences of online health information for users, two dimensions have to be considered: the preferences of the content and the preferences of the presentation of that content. The model suggests that the content category on a website will have an influence on what is the most appropriate way to present this information. Four hypotheses were derived from this model. This chapter has provided the detailed analysis of the data gathered during focus group sessions and how this can help support the hypotheses derived from the model.

This section provides a synopsis of those findings (table 6.25).

Question	Findings
Preferences of Web Presentations	
Preferences for Diabetes Web Presentations	<i>Video presentation was preferred the majority of the time.</i>
Preferences for COPD Web Presentations	<i>Text-based Web pages were preferred the majority of the time.</i>
Comparison of Preferences between Diabetes and COPD presentations	<i>The differences of preferences in the results between the COPD group and the Diabetes group could indicate that the type of disease and consequently the disease aspects could have an influence on the preference for the presentation (Ex: Video for demos, text for complex information, forums for support groups).</i>
Ratings of Web Presentations	
Ratings for Non-Cartoon Video (comprehensive, visually appealing, trustworthy)	<i>The non-cartoon video rated high for the visually appealing criterion.</i>
Ratings for Text-Based (comprehensive, visually appealing, trustworthy)	<i>In general, for COPD presentations, participants found the text-based Web pages to be more comprehensive, visually appealing and trustworthy than the videos. Although the majority of users preferred video for the Diabetes presentations, text-based was still rated higher for both the comprehensive and the trustworthy criteria.</i>
Ratings for Cartoon Video (comprehensive, visually appealing, trustworthy)	<i>The cartoon video had a better rating for the visually appealing criterion than with the comprehensive and the trustworthy criteria, which could be because some participants found the cartoons to be eye-catching and entertaining, even though they were not preferred overall compared to the non-cartoon video and the text-based Web pages.</i>
Reasons for Preferences of Content and Presentation	
Reasons for Non-Cartoon Video Preference	<i>Visuals/Graphics, Content (more/useful information), Easier to understand because can't read/difficulty with English language</i>
Reasons for Text-Based Preference	<i>Content (more/useful information), Convenience (can reread and navigate), Graphics/Visuals</i>
Reasons for Cartoon Video	<i>Appealing/Entertaining, Attract different audiences (children), Content (more/useful information), Characters spoke in the first person</i>

Reasons for no preference	<i>Complementary formats and content</i>
<i>Influence of Age and Education on Preferences</i>	
Crossing preferences with Age	<i>Age does not seem to have a major impact on the preferences of Web presentations.</i>
Crossing preferences with Education	<i>People who have a higher level of education may be more likely to prefer text-based Web pages than people with a lower level of education. Since the majority of participants from the COPD group have a higher level of education than the majority of participants in the Diabetes group, this could explain the difference in preferences between the COPD group and the Diabetes group.</i>
<i>Preferences for Online Discussion Forums</i>	
Preferences for Online Discussion Forums	<i>Seventy-seven percent of participants said that they would like to use an online forum to discuss with other users on the topics of COPD and Diabetes. Sixty-eight percent of them answered that they would appreciate the group dynamic of forums, allowing them to share and learn with others.</i>
<i>Suggestions for Different Types of Content and Presentations</i>	
Suggestions for Different Presentations	<i>Culturally appropriate presentations, simulation of group dynamic (videoconference, discussion forums), more visuals/graphics, anecdotal stories/personal quotes, different presentations for different target audiences (children, adults, elders), combining all formats into a video, simpler language</i>
Suggestions for Different Types of Content	<i>Cultural content, more content specifically related to the disease (ex: complications of Diabetes)</i>
<i>Living Location, Access to Healthcare and Access to Internet</i>	
Themes related to Living Location Identified in the Suggestions	<i>Alternative foods to eat because of unavailability/high cost of food, information customized for different Aboriginal cultures, limited healthcare access, website access difficulties</i>
Access to Healthcare	<i>Fifty percent of participants do not have a medical doctor available at all times in their community. Of these 50%, 41% have access to a nurse and telemedicine, 5% only have access to a nurse, and 5% have access to a nurse, a healer and telemedicine.</i>
Consultation Process of Health Websites	<i>The majority of participants (59%) prefer to consult a health website alone and 41% of participants prefer to be in the presence of someone else, with 27% preferring to be in the presence of a healthcare professional when consulting a health website. Considering the limited access to healthcare in the communities of the Sioux Lookout district, this could possibly pose a problem</i>

<i>Crossing Age with the preferences for consultation process of health websites</i>	<i>The younger generation would not like to consult a health website in a group but might feel more comfortable consulting a health website with someone that has professional experience and training on the topic to be able to guide them throughout the process.</i>
<i>Crossing Education with the preferences for consultation process of health websites</i>	<i>The higher the education level of participants, the more likely they are to prefer to consult a health website individually. Hypothetically, this could be because they feel comfortable with their own knowledge and do not feel the need to consult other people to confirm their findings.</i>
<i>Difficulties when Accessing Health-Related Websites</i>	<i>Low Bandwidth, no Internet/no computer, computer literacy, accurate/useful information, culturally relevant information/use of language, power failures</i>
<i>Cultural Sensitivity</i>	
<i>Cultural Themes Identified in the Suggestions</i>	<i>Traditional medicine/herbal medicines, Aboriginal practices (spirituality, healing circles, smudging, fishing, canoeing, etc.), traditional foods, cultural symbols (language, syllabics, role models, etc.), Aboriginal health issues</i>
<i>Preference for who should be presenting health information online</i>	<i>Half of all participants preferred to have a medical expert from their own community or any Aboriginal community present health information on a website, as opposed to any medical expert.</i>
<i>Crossing Age with preferences for who should present information on health websites</i>	<i>A smaller percentage of participants under the age of 40 were concerned with having someone from their culture presenting health information than participants over 40. Having a medical expert present the information appears to be more important to the younger generation than having someone from their culture.</i>
<i>Crossing Education with preferences for who should present information on health websites</i>	<i>No trends can be observed; therefore education does not have an influence on the preferences of who should present information on health websites.</i>

Table 6.25: Summary of Findings

The analyzed findings presented in this chapter are discussed in the conclusions of this thesis, which lead us to defining the principles that should govern the conception of health websites in Aboriginal context.

Chapter 7: Conclusion

The present chapter concludes this thesis. The first section summarizes the background on this study. The next section discusses the findings of this research, followed by recommendations of the principles of conception for health websites in Aboriginal context. The final two sections provide the limitations of this research and suggestions for future research.

7.1 Background Summary

This study has concentrated on the evaluation of the quality of health-related websites based on the relevance of content and presentation for a specific target audience, Aboriginal people. The First Nations in the Sioux Lookout district were chosen as a focus for this study because of their need for online health information. A user-centered approach was used to learn about the preferences of users for content and presentation types on health websites to help establish the principles that should be used for the conception of health websites that are relevant to Aboriginal people. Because of the prevalence of Diabetes and COPD in the Sioux Lookout region, websites containing information on those two diseases were chosen to present to participants.

As culture can have an influence on the preferences of users (Singh et al., 2006), we describe in detail what culture means for Aboriginal people in Canada and its important links to health. Aboriginal People in Canada are culturally diverse, however, despite this, there are cultural characteristics that are unique to Aboriginal people and that unite all Aboriginal cultures together (INAC, 2006h). Although each community is different, all Aboriginal people share a common way of life (Assembly of First Nations, 2002; Hill, 2003; INAC, 2006h).

This common way of life is reflected in the way they traditionally practice medicine: the physical, mental, spiritual, and emotional aspects of a person must be balanced in order to be healthy. Other cultural aspects that are apparent in Aboriginal cultures is their strong ties to the land, their profound spiritual beliefs, the importance of

language to ensure the survival of their culture and the fundamental concept of sharing with and learning from other family or community members (INAC, 2006i).

As Aboriginal people suffer a significantly lower health status than the general population (National Aboriginal Health Organization, 2008) some organizations and governmental bodies are creating programs to promote traditional medicine to help restore the health of Aboriginal people by bringing them back to their culture.

To further understand the background of the target audience, we describe the geography and demographics of the Sioux Lookout district, the health issues prevalent in the region, the level of Internet connectivity, and the availability of healthcare and health information of the region. Based on this background, we examine how these websites should be built in order to reach them and if cultural and living location factors should be taken into account when building these websites. This is conducted through a qualitative analysis of the data collected from videoconference focus group sessions using a combination of group discussions and printed questionnaires.

In the end, one of the key things to consider is that any health program should be developed to be fully inclusive of Aboriginal people and their diversities (National Aboriginal Health Organization, 2008). This includes having Aboriginal people part of the development process of websites that will be created to deliver health information to them. The next section discusses the findings of this research.

7.2 Discussion of Findings

The analysis of the data gathered during the focus group interviews has lead to findings that test whether the hypotheses derived from the research model are supported.

The first hypothesis relates to the preference of Web presentation types of users on health websites:

Ha₁: *Aboriginal people prefer one Web presentation type on health websites over other types regardless of the disease that is presented.*

The text-based Web presentation type was preferred the majority of the time for COPD while the video Web presentation type was preferred for Diabetes. This leads to believe that there exist differences in the preferences of Web presentation types between diseases. Hypothesis Ha_1 is therefore not supported by the findings in this research. The differences in preferences between diseases can be better explained when comparing the preferences of presentation types for its various disease aspects.

Ha₂: Aboriginal people's preferences of Web presentation types on health websites is invariable regardless of the disease aspect presented.

Presentation types appeared to be complementary to present the different aspects of a disease.

Videos have the advantage of being visual and thus rated highly for the visually appealing criterion. Findings show that practical aspects of a disease requiring a demonstration are better presented by video, such as when a demonstration is needed, which was clear in the case of the video showing how to monitor your blood glucose level.

Text-based Web pages have the convenience of allowing users to reread and navigate to more content and appeared to be more comprehensive and trustworthy than the videos. More complex information not requiring a demonstration are better presented textually, which appeared to be the case for information on the definition of the disease and medications.

The use of graphics and visual presentations emerged as a key element that should appear on health websites, in both videos and text-based web pages. These are especially helpful to accompany text or verbal explanations to make them more comprehensive to the user. Graphics can be used to help demonstrate practical aspects of a disease or clarify complex elements of a disease.

Furthermore, one key element to take into account for presentation types in Aboriginal context is that some people can't read or have more difficulty with the English language. In this case, the use of visual presentations such as video or

graphics would be more appropriate presentation types. An alternative would be to use simpler language with no medical jargon in text-based web pages.

Online discussion forums simulate the dynamic of support groups, allowing users to share with others and learn from the experiences of others. Patients that have a chronic disease that requires lifestyle changes such as diet and exercise changes for Diabetes or smoking cessation for COPD might require the help of a support group. In that case, a forum would be the most appropriate form of presentation. Another presentation type that was suggested to simulate the group dynamic is the use of online videoconferencing.

Cartoon videos on the other hand appeared to be a better presentation type when the purpose is to motivate, entertain or appeal to children, such as for diseases that touch children.

These results indicate that there are differences in the preferences when comparing the various disease aspects within a disease. Hypothesis Ha₂ is therefore not supported by the findings in this research.

The third hypothesis related to the influence of the living location on the preferences:

Ha₃: Living location factors have an influence on Aboriginal people's preferences of content and presentation type on health websites.

The Web accessibility problems related to the living location, such as low bandwidth and not having internet access do not seem to have a major influence on the preferences since references to such problems were not mentioned in the answers to the open-ended question regarding the reasons for preferring one presentation type over another⁸.

Another challenge related to the living location, the inaccessibility of certain foods in the North, has an influence on the preferences of content. Some foods such as fresh fruits and vegetables are not available or are very expensive in the North. These

⁸ Although accessibility problems do not appear to have an influence on the preferences, this does not mean that the problems are not present. More research is needed on this topic to remedy this problem in order for users to gain access to the information they need on health websites.

foods are necessary for a healthy diet and to prevent or manage certain diseases, therefore, having websites suggest that people up north eat these foods to stay healthy is a cause of frustration. When diet is an important aspect of a disease, suggestions for alternative foods to eat should be put on health websites in Aboriginal context because of the living location of many Aboriginal people.

The heterogeneity of Aboriginal cultures is also related to the living location. Even though some communities may say to be from the same First Nation, geographical distances between these influence their cultural beliefs and practices, which will in turn have an influence on the preferences of information and presentation on health-related Websites. The cultural diversity of Aboriginal people should therefore be reflected into health websites.

The limited access to healthcare confirmed the need for users to have other means to find health information, such as on health websites. Most users prefer to consult a health website alone. However, it was indicated in the preferences of several users that the presence of a healthcare professional when consulting a health website would be appreciated. Considering the limited access to healthcare in several Aboriginal communities, this could possibly pose a problem. Therefore, access to health resources in communities remains essential (as community nurse, videoconference, and medical doctor) even though health resources are provided online.

The results from this research show that the living location factors have an influence on Aboriginal people's preferences on health websites and therefore support hypothesis Ha_3 .

The fourth hypothesis related to the influence of culture on the preferences:

Ha₄: *Aboriginal people would prefer health websites that contain elements related to their culture.*

It was highlighted in the answers provided by the users that more culturally appropriate presentations were essential in Aboriginal context. Information on traditional and herbal medicine and information on different Aboriginal practices such

as healing circles or spirituality were identified as valuable information that should be found on health websites.

Information on the nutritional information of traditional foods and how these foods could help with a disease would be useful since several Aboriginal people still use traditional methods to obtain food such as hunting and fishing. The use of different cultural symbols, such as the local language on the websites or the use of Aboriginal people as role models in the videos, were also expressed in the preferences of users. Information about health issues that are prevalent in Aboriginal people would also be beneficial, including information on the history of such health issues.

Although users primarily preferred that the person presenting health information on a website be a medical expert, they also preferred that this person be from their culture. Efforts should therefore be made to actively involve Aboriginal people in the creation of any health website targeted to the people of this culture.

The findings show that Aboriginal people would prefer health websites that contain elements related to their culture, which supports hypothesis Ha₄.

Age and education are two demographic variables that appear to have an impact on the preferences of Web presentation types and content. People who have a higher level of education were more likely to prefer text-based Web pages and were more likely to prefer to consult a health website by themselves than people with a lower level of education. Since the majority of participants from the COPD group have a higher level of education than the majority of participants in the Diabetes group, this could explain why more people from the COPD group preferred text-based than people from the Diabetes group.

For the younger generation, having a medical expert present the information on health websites appears to be more important than having someone from their culture when comparing with the older generation. They also prefer to consult a health website with a health professional, to guide them throughout the process, and would not like to consult a health website in a group.

How can we interpret all these findings? What meaning can we assign them? What lessons should we draw?

Primarily, health websites in Aboriginal context should be built in line with the preferences of their target audience. Different presentation types and content are more appropriate for different populations and health websites should be modulated according to these target audiences. Examples of these target audiences are children, teenagers, elders, illiterates, people with different levels of educations, and so on. For instance, cartoon videos appeared to be more appropriate for children. The older generation on the other hand would prefer someone from their culture to present the information on a health website. Text-based Web pages are more suited for people with a higher level of education, while videos are useful for illiterates or people not comfortable with the language of presentation.

Secondly, the information on health websites should be categorized by disease aspects and presentations should be adapted based on these different categories. Findings show that certain presentation types are more appropriate based on the category of content. In addition, content categories should also be divided further into subcategories or sequences of disease aspects. For this thesis, content categories were established for Diabetes and COPD websites; however these categories should be divided into subcategories or sequences. For instance, one category identified for Diabetes was "Monitoring". As part of this content category, presentations on "Monitoring blood glucose levels" were shown. However, the "Monitoring" content category also contains other subcategories, including caring for eyes and feet, and routine visits to a health care provider to monitor eyes, cholesterol, blood pressure and blood sugar.

Although video was the most appropriate presentation type for "Monitoring blood glucose levels", other presentation types could be more fitting for other subcategories of "Monitoring". A meticulous categorization of information should be conducted for each disease and the most suitable presentation type should be chosen for each of those subcategories. The categorization of this information would require medical specialists, including medical doctors, nurses, healers, and health technicians. A study of the different behaviors associated with each disease aspect

sequences or subcategories would have to be done to adopt the most fitting presentation type.

Third, for each of the identified subcategories, the presentation types should be adapted to each target audience. For instance, even though text-based web pages are the most appropriate choice of presentation type for more complex information, such as medications, text-based would be useless for illiterates or people who have difficulty with the English language. In this case, a video with a combination of illustrations and people explaining and enacting certain concepts would be a better choice. The categories of content must be finely subdivided in order to identify to presentation type that corresponds to the preferences of the target audience.

Fourth, when building health websites, an awareness of the challenges associated with living in remote communities should be taken into account. Web accessibility issues must be considered. When providing information using presentation types that require high bandwidth, such as video, alternative presentation types, such as text-based should also be provided. The user living in remote communities may not have the necessary bandwidth to download videos. Likewise, graphics should be accompanied by alternative text that provides a description of what the image illustrates. When diet is an important aspect of a disease, suggestions of alternative foods to eat that include traditional foods and foods that are available up North should be given. The nutritional information of these foods compared to less accessible foods and information on how they can be helpful to stay healthy should be given.

Fifth, within each of the disease aspect subcategories identified and considering each target audience, a consideration of how certain desired cultural elements can be introduced into the presentation or content should be made. For instance, considering a video presentation of how to monitor your blood glucose level targeted at Aboriginal elders, people from their culture should be used in the video and the content should be translated into Aboriginal languages.

7.3 Principles of Conception for Health Websites

The findings of this research are useful to determine the principles that should govern the conception of health websites in Aboriginal context. The following recommendations have been developed based on these findings.

1. Target different audiences (children, elders, people with a high school education, etc.) and modulate presentation types and content according to the preferences of those audiences.
2. Categorize health information by various disease aspects and divide these categories into subcategories or sequences of these disease aspects with the help of medical specialists (nurses, medical doctors, healers, health technicians)
3. Choose the appropriate presentation types and content for each of the identified subcategories based on a careful study of these.
4. Adapt presentation types and content to fit both the subcategories and the target audiences' preferences.
5. Consider the challenges associated with the living location such as Web accessibility problems, limited access to healthcare, cultural diversity and limited access to certain foods and adjust presentation types and content accordingly.
6. Incorporate cultural elements (traditional and herbal medicine, Aboriginal role models, medicine wheel, spirituality, healing circles, smudging, translation of content⁹, etc) into each of the subcategories taking into account the target audience and the heterogeneity of Aboriginal culture.
7. Ensure graphics are widely used to accompany text or video to illustrate the explained concepts.
8. Build websites with the ability to navigate to more content.
9. Write content using simple language, free of medical jargon.
10. Include medical experts from an Aboriginal culture or any Aboriginal people in the conception of health websites.

⁹ Note that the implementation of websites in Aboriginal languages would be complex as several languages are spoken in the Sioux Lookout district.

7.4 Limitations of the Research

Some limitations were identified in this study. Conclusions and recommendations made about the preferences of online health information for the people of the Sioux Lookout district are based on a qualitative study with a sample of 22 participants. Therefore, the small sample size has been identified as a limitation of this study.

Because of limited resources, interviews, Web presentations and questionnaires could not be translated into the mother tongue of the participants, making this another limitation of the research. Even though the majority of participant said to be fluent in English, the mother tongue of several participants was an Aboriginal language (Ojibway or Oji-Cree) and English was their second language. Even though continuous monitoring was exercised in this regard, language barriers could cause misunderstandings and misinterpretations of content on the websites, interview questions, and the responses of the users by the interviewer which could create a bias in the results.

Furthermore, because the content could not be translated, only participants who said to be almost fluent in English, both speaking and reading could be recruited for this research. In a region where English is the second language of many, having only participants that are fluent in English may not be representative of the general population.

In addition, more than half of the participants recruited for the focus groups were Community Telehealth Coordinators (CTC). CTCs are professionals of the community that organize and coordinate videoconferences for telemedicine. The responses of the participants could be biased because of their experience working with telemedicine patients and professionals and their frequent exposure to health matters. Sampling could have been more representative of the general population.

Even though the majority of participants said to be from the Oji-Cree culture, participants' cultural background were still heterogeneous, with participants from the Ojibway culture, the Cree culture and others simply indicating that they were from the Aboriginal culture without being more specific. Furthermore, because all communities in the Sioux Lookout district are remote, cultural practices and beliefs

may vary from one community to another even if the people say to be from the same Nation. With such a small sample from the different cultures, results cannot be generalized to the whole population of the region as responses of participants could be influenced by their own cultural biases. A larger sample size of each community would have been necessary. Even more so, as the Aboriginal population in general is comprised of several different cultures, the results cannot be generalized to Aboriginal populations in other regions of Canada.

Although conducting all interviews remotely had several advantages, mostly cost and time savings, it could possibly have an impact on the dynamic of the focus group sessions. Even if the participants and the interviewer could see each other on the video conference screens, not being physically face-to-face in the same room may influence the mood of participants and atmosphere that you would get in a normal focus group setting. The feelings of closeness and privacy with the group might not be as strong.

Also, coordination between speakers during video conferences is much more difficult. As only the current speaker and the last person that had spoken could be seen on the screen at once, participants had to speak up and interrupt if they wanted to add something to the conversation instead of lifting their hand or giving another type of signal to indicate that they wanted to speak. Several participants may decide to speak all at once or some users may talk less because they are not sure when it is their turn to speak or they might be afraid to interrupt someone. Group discussions could possibly be less active in this case.

Furthermore, there is a loss of resolution when showing a computer screen through a videoconference screen. Even though the interviewer ensured that all participants had no trouble viewing the Web pages during the focus groups, the loss of clearness of the websites on the video conference screen could influence the preferences of the users and this is another limitation of this study. However, it is important to note that participants did have the liberty of viewing websites on their own computer, if they had access to one, during or after the interview.

Although consulting with users to get their opinions and preferences for content and presentation on health-related websites provides us with valuable information that can be useful to build websites targeted to this population, a combination of other

evaluation methods should be conducted to build a quality health website, including usability assessments, assessment of content quality by medical experts, performance evaluation, and so on. This study only covers one aspect of the quality of health website, which is the relevance of the material and presentation for the target audience, which is another limitation of this study.

While efforts were made to choose the best currently available Web presentations to show participants, a confirmation of the validity of the content in the presentations should be conducted by medical experts to ensure the best possible quality of the conveyed information.

7.5 Future Research

Several different topics for future research have come out of this qualitative research to expand and reinforce the findings of this study. A study with a larger sample that looks at the preferences of online information on health-related websites for the people of the Sioux Lookout district could help strengthen the findings of this research. To further reinforce these, research could be conducted using an experimental design based on varied predefined websites.

Similarly, future research should include larger samples of different Aboriginal nations in Canada to determine whether the results could be generalized to the whole Aboriginal population. This research only included participants from the Oji-Cree, Cree and Ojibway nations. Examples of other Aboriginal nations in Canada that could be included in future research include Inuit, Mamac and Algonquin. This would allow for the results to be compared between cultures to see if differences apply. In addition, the professional background of participants should be more diverse as this research had half of its participants that were professionals working in the health sector (Community Telehealth Coordinators). In future research with a larger sample, a good mixture of professionals and non-professionals from different backgrounds could be better representative of the general population.

Other types of quality evaluations could also be conducted such as usability assessments, looking at the quality of the content from a medical point of view, assessing the readability of the information on websites, conducting performance

evaluations, and so on. This provides a number of topics that could be the focus of many future studies.

The translation of content on health websites into different Aboriginal languages and writing the content into syllabics could be explored in future research. A cost-benefit analysis might be necessary in certain cases, as the initial cost of the translation and the maintenance of multilingual websites can be high.

Furthermore, although the participants in this study were asked to provide suggestions for other types of presentations that they would like to see, only videos, text-based web pages and forums were presented to participants to determine their preferences. Therefore, it could be interesting to look at the preferences of users for other types of presentations in future research, such as more interactive presentations like live chats with other users or health professionals or looking at the preferences of presentations adapted to wireless technologies.

Also, only two types of disease websites were looked at in this research: diabetes and COPD websites. Future research should look into determining the preferences of users for other types of disease websites. Results could then be compared to see if they vary from one disease to another. Likewise, other disease aspects should be presented to the users to determine their preferences in order to reinforce the findings that the disease aspect has an influence on the preferences.

In addition, future research should include the collaboration of health professionals to analyze whether or not the fact that a person has a disease or not could influence their preferences of health websites. Health professionals would also be useful in future studies that look at the division of disease aspects into refined subcategories and sequences.

Although the use of videoconferencing provides the participants with the sense that they are face-to-face with the interviewer and other focus group participants, future research should look at whether the results would vary if interviews were actually conducted in person. Collecting data on site could help establish trust with the participants and consequently gain a more representative sample of the population.

However, such research would be very costly and time consuming as the interviewer would have to travel to all remote communities to meet with participants.

We hope that this study will be a stepping stone for additional research in the future.

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Appendix

Questionnaire for Websites on Diabetes

Diabetes Websites

Introduction

Canadians are increasingly using the Internet to access health information. Due to the nature of health information it is crucial that users have access to accurate, reliable, relevant, and easily accessible health information. With the large amount of health information found on the Internet, it is becoming more important to ensure the quality of these health websites and that these websites communicate the information in a clear, comprehensive, and appealing manner.

We are inviting you to participate in this interview to help us better understand the preferences for various types of information on health-related Web sites.

Your participation is voluntary. You are consenting to participate in this project by completing this interview. You may withdraw from this research at any time without any penalty or providing any explanation.

This interview is confidential. Your name, other personal information, and your responses to this questionnaire will not be revealed outside the research team or reused for any purpose other than this research. This research project has been approved by the National Research Council (Government of Canada) ethics review board as part of the VideoCom project with partner Keewaytinook Okimakanak. This research will develop understanding about video and text information on health websites that will be useful for First Nation communities.

The interview will take approximately 2 hours. A video recording of this interview will be taken. This recording will only be used for creating transcripts and will later be erased.

For more information, contact:

Marie-France Gratton

University of Ottawa/National Research Council Canada

Email:

Fax:

Phase 1 – Set of Questions for Each Content Category

Content Category: Definition of the disease

Three different Web presentations for information on what is diabetes will be presented to you: 2 different videos and 1 text-based Web page. First, a video with a person explaining facts about the disease will be shown. [Play video, approx. 3 mins: <http://www.mdkiosk.com/Diabetes%20Type%202-topicview.php>, click on "Intro & Prevention"]

A video where a fictional cartoon character is being interviewed about his specific experience when he was first diagnosed with diabetes will be shown [Play video, approx. 3 mins: http://www.diabetes.org/all-about-diabetes/chan_eng/i2/i2dms.htm]

A text-based Web page with information on what is diabetes will be shown. You can read this Web page for 3 minutes. [Allow user to view Web page for 3 minutes: <http://www.nada.ca/diabetes/definitions.php>]

1. For information on what is diabetes, did you prefer the first video, the second video (cartoon) or the text-based Web page and for what reasons?

Reflecting on the different Web presentations you have just seen, please rate the following statements on the scales below:

2. In your opinion, **the first video** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

3. In your opinion, **the second video (cartoon)** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

4. In your opinion, the **text-based web page** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

Content Category: Lifestyle changes (diet, exercise, losing weight, etc.)

Three different Web presentations will be presented to you for information on lifestyle changes for people with diabetes, such as diet changes, exercise, and losing weight. First, a text-based Web page on a good diet for diabetic people will be shown. You can read this Web page for 3 minutes. [Allow user to view Web page for 3 minutes: <http://www.diabetes.org/nutrition-and-recipes/nutrition/foodpyramid.jsp>]

A video where a fictional cartoon character with diabetes who is being interviewed about her specific experience with losing weight will be shown. [Play video, approx. 3 mins: http://www.diabetes.org/all-about-diabetes/chan_eng/i21/i21dms.htm]

A video animation about the diet for people with diabetes will be shown. [Play video, approx. 3 mins: <http://diabetes.emedtv.com/diabetes-video/diabetic-diet.html> (scroll down and click on "Diabetic Diet")]

5. For information on lifestyle changes, did you prefer the text-based web page, the first video (cartoon) or the second video and for what reasons? _____

Reflecting on the different Web presentations you have just seen, please rate the following statements on the scales below:

6. In your opinion, the text-based web page was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

7. In your opinion, the first (cartoon) video was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

8. In your opinion, the second video was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

Content Category: Monitoring

Three different Web presentations for information on monitoring your diabetes, such as checking your blood sugar level will be presented to you. First, a video where fictional cartoon characters with diabetes are being interviewed about their experiences with monitoring their blood sugar will be shown. [Play video, approx. 3 mins: http://www.diabetes.org/all-about-diabetes/channel_eng/i5/i5dms.htm]

A text-based Web page on how to monitor your blood sugar will be shown. You can read this Web page for 3 minutes. [Allow user to view Web page for 3 minutes: <http://www.diabetes.org/type-2-diabetes/blood-glucose-checks.jsp>]

A video with a person explaining how to monitor your blood sugar will be shown. [Play video, approx. 3 mins: <http://www.mdkiosk.com/Diabetes%20Type%20-topicview.php> (click on "Blood Sugar Monitoring")]

9. For information on monitoring your blood sugar, did you prefer the first video (cartoon), the text-based web page, or the second video and for what reasons?

Reflecting on the different Web presentations you have just seen, please rate the following statements on the scales below:

10. In your opinion, the first video (cartoon) was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

11. In your opinion, the text-based web page was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

12. In your opinion, the second video was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
i. comprehensive					
ii. visually appealing					
iii. trustworthy					

Phase 2 – General Questions on Content and Presentation

An online discussion forum on diabetes will be presented to you [Show forum <http://community.diabetes.org/n/pfx/forum.aspx?webtag=adatype2>]

13. If you were searching for information on diabetes on the Web, would you like to discuss with other Web users on an online forum such as this one and for what reasons?

14. What other information would like to see on a diabetes website? _____

15. Please provide some suggestions on how the information that you have seen today could be presented differently.

16. In your opinion, who should be presenting this type of information on a health website? Please express your preference from 1 to 3 by placing the number in the appropriate box:

- a medical expert
- a medical expert from your community
- anyone from your community
- a medical expert from any Aboriginal community
- any Aboriginal person
- other, please specify _____

17. In terms of content on a diabetes website, what type of information related to Aboriginal traditions would you like to see? (for example, information on Aboriginal ways of healing, herbal medicines, spirituality, etc.)

18. Where do you normally go to consult a website?

- Home
- Community Center
- School
- Other, please specify _____

19. When consulting a website on health information, would you prefer to consult:

- In the presence of a healthcare professional
- In the presence of a friend you trust
- In the presence of a respected member of your community
- Individually
- In a group
- Other, please specify _____

20. What difficulties could you encounter to access health-related websites?

21. What type of healthcare access do you have in your community?

- nurse
- medical doctor
- healer
- telemedicine

other, please specify _____

Phase 3 – Demographic Questions

22. What is your mother tongue? _____

23. Do you speak any other language(s)? Which one(s)?

24. I read English:

Fluently

Well

Moderately well

With difficulty

25. Do you consider yourself to be from an Aboriginal culture? If yes, which one?/If no, what culture are you from?

26. Do you live in the Sioux Lookout district?

Yes

No

27. In which community do you live most of the time?

28. How long have you lived in this community?

29. What is your age category?

15 – 20

20 – 29

30 – 39

40 – 49

50 – 59

60 – 69

70 and
above

30. What is your highest level of education?

primary school

some high school

high school graduate

college

bachelor's degree

graduate degree

other, please
specify

31. Are you a Community Telemedicine Coordinator?

Yes. For how long? _____

No

32. How often do you use the Internet?

at least once a day

at least once a week

at least once a month

at least once a year

never

33. Have you ever looked for health information on the Internet? If no, why not/If yes, how often?

Questionnaire for Websites on COPD

COPD Websites

Introduction

Canadians are increasingly using the Internet to access health information. Due to the nature of health information it is crucial that users have access to accurate, reliable, relevant, and easily accessible health information. With the large amount of health information found on the Internet, it is becoming more important to ensure the quality of these health websites and that these websites communicate the information in a clear, comprehensive, and appealing manner.

We are inviting you to participate in this interview to help us better understand the preferences for various types of information on health-related Web sites.

Your participation is voluntary. You are consenting to participate in this project by completing this interview. You may withdraw from this research at any time without any penalty or providing any explanation.

This interview is confidential. Your name, other personal information, and your responses to this questionnaire will not be revealed outside the research team or reused for any purpose other than this research. This research project has been approved by the National Research Council (Government of Canada) ethics review board as part of the VideoCom project with partner Keewaytinook Okimakanak. This research will develop understanding about video and text information on health websites that will be useful for First Nation communities.

The interview will take approximately 2 hours. A video recording of this interview will be taken. This recording will only be used for creating transcripts and will later be erased.

For more information, contact:

Marie-France Gratton

University of Ottawa/National Research Council Canada

Email: :

Fax: |

Phase 1 – Set of Questions for Each Content Category

Content Category: Definition of the disease

Two different Web presentations will be presented to you, 1 video and 1 text-based Web page, for information on what is COPD, which is a long-term lung disease usually caused by smoking. First, a video with a person explaining what COPD is will be shown. [Play video, approx. 3 mins:

<http://www.youtube.com/watch?v=aktIMBQSMo&feature=related>]

A text-based Web page explaining COPD will be shown. You can read and browse this Web page for 3 minutes. [Allow user to view Web page for 3 minutes:

http://www.lung.ca/diseases-maladies/copd-mpoc/what-quoi/index_e.php]

1. For information on what is COPD, did you prefer the video or the text-based Web page and for what reasons?

Reflecting on the different Web presentations you have just seen, please rate the following statements on the scales below:

2. In your opinion, **the video** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
iv. comprehensive					
v. visually appealing					
vi. trustworthy					

3. In your opinion, the **text-based web page** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
iv. comprehensive					
v. visually appealing					
vi. trustworthy					

Content Category: Medications (puffers, etc.)

Two different Web presentations for information on the different medications or treatments for COPD will be presented to you. First, a text-based Web page on the different medications for managing COPD will be shown. You can read and browse this Web page for 3 minutes. [Allow user to view Web page for 3 minutes:

http://www.lung.ca/diseases-maladies/copd-mpoc/treatment-traitement/medications-medicaments_e.php]

A video with a person explaining the different possible treatments for managing COPD will be shown. [Play video, approx. 1 min:

<http://www.youtube.com/watch?v=k77vqaUnd1Y&feature=related>]

4. For information on COPD medications, did you prefer the text-based web page or the video and for what reasons?

Reflecting on the different Web presentations you have just seen, please rate the following statements on the scales below:

5. In your opinion, **the text-based web page** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
iv. comprehensive					
v. visually appealing					
vi. trustworthy					

6. In your opinion, **the video** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
iv. comprehensive					
v. visually appealing					
vi. trustworthy					

Content Category: Lifestyle Changes (Smoking Cessation)

Two different Web presentations for information on smoking cessation for people with COPD will be presented to you. A video with a person explaining why it's important to quit smoking will be shown. [Play video, approx. 3 mins:
<http://www.youtube.com/watch?v=3aIeF5LjaDk>]

A text-based Web page on smoking cessation will be shown. You can read and browse this Web page for 3 minutes. [Allow user to view Web page for 3 minutes:
http://www.lung.ca/protect-protegez/tobacco-tabagisme/quitting-cesser/index_e.php]

7. For information on smoking cessation, did you prefer the video or the text-based web page and for what reasons?

Reflecting on the different Web presentations you have just seen, please rate the following statements on the scales below:

8. In your opinion, **the video** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
iv. comprehensive					
v. visually appealing					
vi. trustworthy					

9. In your opinion, **the text-based web page** was:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
iv. comprehensive					
v. visually appealing					
vi. trustworthy					

Phase 2 – General Questions on Content and Presentation

An online forum on COPD will be presented to you [Show forum and let user browse for 1 min. <http://copdforum.portalone.us/>]

10. If you were searching for information on COPD on the Web, would you like to discuss with other Web users on an online forum such as this one and for what reasons?

11. What other information would like to see on a COPD website?

12. Please provide some suggestions on how the information that you have seen today could be presented differently.

13. In your opinion, who should be presenting this type of information on a health website? Please express your preference from 1 to 3 by placing the number in the appropriate box:

- a medical expert
- a medical expert from your community
- anyone from your community
- a medical expert from any Aboriginal community
- any Aboriginal person
- other, please specify _____

14. In terms of content on a COPD website, what type of information related to Aboriginal traditions would you like to see? (for example, information on Aboriginal ways of healing, herbal medicines, spirituality, etc.)

15. Where do you normally go to consult a website?

- Home
- Community Center
- School
- Other, please specify _____

16. When consulting a website on health information, would you prefer to consult:

- In the presence of a healthcare professional
- In the presence of a friend you trust
- In the presence of a respected member of your community
- Individually
- In a group
- Other, please specify _____

17. What difficulties could you encounter to access health-related websites?

18. What type of healthcare access do you have in your community?

- nurse
- medical doctor
- healer
- telemedicine
- other, please specify _____

Phase 3 – Demographic Questions

19. What is your mother tongue? _____

20. Do you speak any other language(s)? Which one(s)?

21. I read English:

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Fluently | Well | Moderately well | With difficulty |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

22. Do you consider yourself to be from an Aboriginal culture? If yes, which one?/If no, what culture are you from?

23. Do you live in the Sioux Lookout district?

- Yes
- No

24. In which community do you live most of the time?

25. How long have you lived in this community?

26. What is your age category?

- | | |
|----------------------------------|----------------------------------|
| <input type="checkbox"/> 15 – 20 | <input type="checkbox"/> 50 – 59 |
| <input type="checkbox"/> 20 – 29 | <input type="checkbox"/> 60 – 69 |

27. What is your highest level of education?

- | | |
|---|--|
| <input type="checkbox"/> Primary school | <input type="checkbox"/> bachelor's degree |
| <input type="checkbox"/> some high school | <input type="checkbox"/> graduate degree |
| <input type="checkbox"/> high school graduate | <input type="checkbox"/> other, please specify |
| <input type="checkbox"/> college | |

28. Are you a Community Telemedicine Coordinator?

- Yes. For how long? _____
- No

29. How often do you use the Internet?

- | | |
|---|--|
| <input type="checkbox"/> at least once a day | <input type="checkbox"/> at least once a month |
| <input type="checkbox"/> at least once a week | <input type="checkbox"/> at least once a year |
| | <input type="checkbox"/> never |

30. Have you ever looked for health information on the Internet? If no, why not/If yes, how often?
