

**INFORMED CHOICE?
ENGLISH- AND FRENCH-SPEAKERS' USE OF
THE CANADIAN HEALTH NETWORK**

by

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ABSTRACT

Few studies of the ways patients and consumers seek health information have investigated use of web portals or differences in French- and English-speakers' understanding and use of web-based health information. Interviews were conducted with French- and English-speaking Canadian Health Network (CHN) users to understand how this web portal fit in their practices of information seeking and use. Interviewees accessed the CHN, among other websites and non-internet resources to expand their understanding of health issues, participate more actively in their health care and support other people's understanding of health. French-speakers faced additional constraints to understanding health information as they crossed linguistic, cultural and jurisdictional boundaries on the web. This study also investigated the policy assumptions underlying the CHN through discourse analysis and a focus group with portal managers. It found the policy discourse assumed the CHN would improve access to health information and personal responsibility for health and health care decision-making.

Keywords: health information; internet; information seeking; use; health promotion; 'informed patient'

Subject Terms: internet – social aspects; health promotion; patient education; literacy; health policy Canada

I dedicate this work to my parents and grandparents.

Their love, support and inspiration is unending.

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ACRONYMS

CHN	Canadian Health Network
CNA	Canadian Nurses Association
EE	Preferred language is English and interview conducted in English
FE	Preferred language is French but interview conducted in English
FF	Preferred language is French and interview conducted in French
F/P/T	Federal/Provincial/Territorial
GOL	Government On-Line
ICTs	Information and Communication Technologies
IHAC	Information Highway Advisory Council
MP	Member of Parliament
PHAC	Public Health Agency of Canada
SCOT	Social Construction of Technology
STS	Science and Technology Studies

CHAPTER 1: INTRODUCTION

1.1 The Internet and Health Information Use

When health is understood as a social construction, it becomes what people, through interacting with each other, define as health (Blaxter, 2004). The physician who asks the patient about her health in the German language says, 'what are you lacking?' When we are healthy, we do not notice our body and answer 'I am fine.' In contrast, when we are unwell, we become aware of our bodies, we turn inward and we notice something that was previously there is gone (Gadamer, 1996). This introspection is one of the ways we perceive and experience the physical body. It occurs through social interaction, in different ways across languages and cultures. Gadamer (1996) argues it is impossible to treat the body with medicine alone, as we must also possess knowledge concerning the whole being. Those who are optimistic about the internet's¹ promise for communicating health information might consider the internet user to be at the intersection of bodily understanding and a wealth of evidential and experiential health knowledge, and thus well-positioned to ascribe meaning to their health.

Assumptions about the internet's potential with respect to the communication of health information abound. In the Canadian context of health reform, the internet is framed as an efficient, cost-effective way of providing citizens with health information so "health-informed individuals will participate, alongside their health care providers, in a process of shared decision-making" (Wathen & Harris, 2007, p. 640). Rather than taking for granted this reflexive use of health information obtained on the internet, this thesis first examines the assumed potential of a government health web portal,² as articulated in the Canadian health policy discourse. It then explores whether this potential is realized in actual use of the technology by talking with people about how they engage

¹ While the technical difference between the internet and the world wide web is recognized, the internet, the web, web-based and on-line are used interchangeably throughout this thesis, as they are in everyday speech, when referring to the world wide web.

² A web portal is "an internet site providing a directory of links to other sites" (Oxford English Dictionary, n.d., para. 1). It is set up as a single point of access to information on the web (Wikipedia, 2007c).

with the internet to understand health and how they use any knowledge they develop through their engagement with this technology. The participants were both English- and French-speakers, and I was alert to differences between these two languages and cultures.

My interest in this topic originates from my background writing about science and health for newspapers and radio, and an experience in a social context where health promotion through radio seemed likely to influence people's behaviours and health. After the mid-day meal in a Ugandan village, many, if not all of the women sat on the shaded steps of the buildings and listened to a radio drama about spousal abuse and monogamy in the local language. Every few minutes, they erupted in laughter. It seemed as though radio was the effective form of mediated communication in the area, but I remained curious about whether mass media messages about health – a topic that is scientifically complex, highly personal and important to both individuals and communities – are incorporated into people's lives, and if they are, how. These questions are also interesting in the Canadian context, where the internet has become central to the lives of many Canadians and improving health system efficiencies by placing responsibility for health on the individual seems to take priority over addressing the social determinants of health. Given the complexity of matters of the body and the simplistic manner in which the mass media often presents health, I was interested in exploring how people of Canada's two major linguistic groups use the internet to understand health and in what ways they use on-line health information in their everyday lives.

1.2 The Canadian Health Network

1.2.1 Technology

A government health web portal and the specific technology under study in this thesis is the Canadian Health Network (CHN) website – a national, bilingual health promotion program of the Public Health Agency of Canada (PHAC).³ The CHN Division, which manages the CHN website, is part of the Centre for Health Promotion located in the Health Promotion and Chronic Disease Prevention Branch of PHAC (Public Health

³ The CHN was situated within Health Canada when it was launched in 1999. The CHN moved to the PHAC when this agency was formed in 2004 (EKOS Research Associates, 2006).

Agency of Canada, 2006). The CHN's mission is to promote healthy choices by communicating trustworthy information about health promotion and disease and injury prevention through a network of expert organizations (Public Health Agency of Canada, n.d. a). The CHN works with 22 health organizations across Canada, which it calls affiliates. Examples of affiliates include the Canadian Cancer Society, Alberta Centre for Active Living and the Canadian Centre for Occupational Health and Safety. The affiliates build and maintain a collection of more than 17,000 Canadian web resources by working with a network of more than 1,200 contributors who provide the content for the website (EKOS Research Associates, 2006).

Figure 1.1 The Canadian Health Network Homepage⁴



A CHN user can read feature articles on the homepage or receive these articles in newsletter format through a biweekly e-mail. On the right-hand side of the homepage

⁴ This image is reproduced with permission from the Canadian Health Network. The webpage is updated frequently and is available from: <http://www.canadian-health-network.ca>

is a list of six groups, 14 topics and five diseases. Clicking on any of these links leads to a page with what the CHN considers relevant information, links to the affiliate responsible for the subject, links to selections of key Canadian and international resources, and a link to frequently asked questions and three search tools. A “guided search” automatically returns a list of links to websites within the network, and a “quick search” suggests a list of search topics. Users can also enter a keyword to search the entire CHN website.

1.2.2 Research Partnership

It was possible to study the CHN because of an established research partnership between the CHN Division and ACTION for Health⁵ – a federally funded project that supported my thesis work. The Principal Investigator, Dr. Ellen Balka, presented material about the research program at the June 23, 2004 meeting of the CHN’s advisory board, and indicated her project would examine where the CHN fits into individual health information seeking behaviours (n.d. d). ACTION for Health’s study of the CHN was included in the CHN’s evaluation matrix in connection with the strategic direction to strengthen the CHN’s focus on health promotion and the following evaluation issue: “What is the level of awareness of the CHN website among the Canadian public and health professionals?” (EKOS Research Associates, 2006, p. 4). Collaborating with an organization in the non-academic community is an aspect of the action research approach, which aims to bridge the gap between theory, research and practice, and generates research about a social system while trying to change it. Those in the position to effect change participate in defining the research problem, and the researcher is granted access to the area of investigation (Holter & Schwartz-Barcott, 1993). While this study of the CHN website is unlikely to change federal policy, it may lead to incremental change by contributing to how the CHN Division understands actual use of the CHN website. Chapters 2 and 3 discuss in more detail the CHN Division’s involvement in this study.

⁵ The Social Sciences and Humanities Research Council of Canada funded the ACTION for Health project through grant #512-2003-1017. The grant brings together Canadian and international researchers to study the use of technology in the health sector, often in partnership with organizations. For more information, please visit the ACTION for Health website: www.sfu.ca/act4hlth

1.3 A Case Study of the Canadian Health Network

While a case is sometimes considered a choice of what to study (Stake, 2000), it is also a methodology for exploring a system bounded in setting or context through detailed, in-depth data collection involving multiple sources of information (Creswell, 2007). This is an intrinsic⁶ case study of the CHN – the Canadian government’s key internet-based health information program for the general public (Health Canada, 2006a; Health Canada, 1999a), a program on which the Canadian government had spent approximately \$55 million prior to 2006 (EKOS Research Associates, 2006; Office of the Auditor General, 2002). It is also intrinsic because it aims to better understand the basic assumptions underlying the CHN website from the perspective of federal policy-makers and the CHN Division, as well as people’s actual use of this program (Stake, 2000).

This case study will investigate the following research questions: What are the basic assumptions underlying the construction of the CHN website? and How do they fit with the actual use of this website? Although these research questions do not specifically address linguistic and cultural diversity, a focus on differences and similarities between French- and English-speaking CHN users helped frame the research reported here. However, because it was difficult to make comparisons within a small sample of interview participants, and commonalities between the experiences of French- and English-speaking interview participants were evident as data collection progressed, an explicit focus on linguistic differences and cultural diversity was not retained as a research question. An analysis of the sources in Table 1.1 will form the basis for answering the above-mentioned research questions and interpreting the meaning of the case (Creswell, 2007).

⁶ An intrinsic case study is one of three types of case studies – intrinsic, instrumental and collective – described by Creswell (2007), Stake (2000) and Yin (2003). An intrinsic case study is undertaken because, out of interest, the researcher wants a better understanding of a specific case “in all its particularity and ordinariness” (Stake, 2000, p. 437).

Table 1.1 Case Study Data Sources

Source	Perspective	Presentation of Findings
Policy documents from the internet and the CHN Division	Federal policy-makers and the CHN Division	Chapter 2
Focus group	The CHN Division	Chapter 2
Minutes of meetings and e-mails exchanged between ACTION for Health and the CHN Division	The CHN Division	Chapter 2
Semi-structured telephone interviews	CHN users	Chapters 4 and 5
Follow-up e-mails	CHN users	Chapters 4 and 5
Health websites mentioned in the interviews	CHN users	Chapters 4 and 5

Triangulation was achieved by seeking multiple perspectives, as articulated in policy documents and by the CHN Division and CHN users, in relation to the research questions (Richards & Morse, 2007). The policy document analysis, focus group and documents produced through the research partnership between the CHN Division and ACTION for Health are appropriate for investigating the following sub-question: What are the basic assumptions underlying the construction of the CHN website? Semi-structured telephone interviews, follow-up e-mails from interview participants and the health websites they mentioned visiting are appropriate sources for investigating the second sub-question: How do the supports and constraints at play when CHN users make sense of health information come to bear on their use of this information? Combining the findings from investigating both sub-questions will allow for the comparison of the basic policy assumptions underlying the CHN website and actual use of this website.

1.4 Social Construction of Technology

Within Science and Technology Studies (STS), the social construction of technology (SCOT) approach guides this study of the basic assumptions underlying the construction of the CHN website and its actual use. The SCOT approach was developed through case studies of technologies, and opens the black box of technology to examine its multidirectional development (Bijker & Pinch, 1989). Rather than seeing

the CHN website as a complete and successful technology, the SCOT approach views the CHN website as one in a range of possible variations of an artifact that presents problems and solutions to various social groups who attach meaning to this artifact (Bijker & Pinch, 1989). This study considers three heterogeneous relevant social groups: federal policy-makers, the CHN Division and CHN users, with alertness to variations in the meanings they associate with the CHN website. CHN users are not presumed to necessarily use the CHN website as its designers expected, or even at all. There is no one possible, or best way of designing the CHN website, and the current design is but a stage in the artifact's development. The CHN website is one among many health information websites, the internet one among many technologically mediated and non-mediated sources of health information.

1.5 Previous Research in E-Health

E-Health is defined in many ways. A map of the emergence and scope of e-health listed 36 definitions and concluded the field could be characterized by the global definition suggested by Eysenbach and Eng: "e-health is the use of emerging information and communication technology, especially the internet, to improve or enable health and health care" (Pagliari et al., 2005, para. 38). The literature of e-health is extensive, much of it relating to patient and consumer health information on the internet (e.g. Eysenbach & Kohler, 2002; Flicker, Goldberg, & Read, 2004). In this emerging field, scholars from a variety of disciplines have addressed multiple areas of inquiry, including the "digital divide" (e.g. Brodie & Flournoy, 2000; Cotten & Gupta, 2004; Pandey, Hart, & Tiwary, 2003; Skinner, Biscope, & Poland, 2003) and information quality and credibility (e.g. Bates, Romina, Ahmed, & Hopson, 2006; Eysenbach, Powell, Kuss, & Sa, 2002; Peterson, Aslani, & Williams, 2003). This thesis focuses on one aspect of e-health – the 'informed patient' or the 'reflexive consumer' – a topic that draws on several interdisciplinary fields, including medical sociology, health informatics and communication. Scholars of science and technology studies (STS) have also explored this topic, and STS orients the frame of inquiry for this thesis. A challenge of this research has been to reach depth when the topic of study crosses a breadth of disciplines. It is beyond the scope of this thesis to undertake a full review of these multiple fields of inquiry, but chapters 4, 5 and 6 will discuss salient contributions from each.

1.6 Limitations of Previous Research

A focus on the topic of the 'informed patient' or the 'reflexive consumer' is a way of conceptualizing health information use. As Henwood, Wyatt, Hart and Smith (2003) point out, these concepts can be taken to mean individuals assume some responsibility for expanding their medical knowledge towards assessing for themselves the risks and benefits of different courses of action related to their health. Researchers have identified a diversity of ways patients or consumers use health information, not all of which take place in the context of the medical encounter. These uses include understanding a health issue (Hart, Henwood, & Wyatt, 2004; Morahan-Martin, 2004; Wathen & Harris, 2007; Ziebland, 2004), making decisions regarding health care (Morahan-Martin, 2004; Wathen & Harris, 2007), preventing disease (Quintana, Feightner, Wathen, Sangster, & Marshall, 2001), preparing for interactions with health professionals (Wathen & Harris, 2007; Ziebland, 2004). Researchers who have begun to investigate people's use of web-based health information both in the context of the medical encounter and in daily life emphasize the need to identify the many different ways and stages at which this information is used and the meaning the internet has for patients (Hart et al., 2004; Ziebland, 2004). Henwood and colleagues' (2003) study of the 'informed patient' in the context of the patient-practitioner relationship is a valuable contribution to understanding the constraints to the emergence of the 'informed patient' and could be applied in further study of both constraints and supports in the broader context of daily life uses of web-based health information.

Bessell et al. (2002) reviewed studies that evaluated the effectiveness of web-based educational programs for consumers as interventions aimed at specific health issues, however researchers have not studied health information portals intended for the general public in a similar manner. Wyatt, Henwood, Hart, & Smith (2005) call for more research "to understand the different human-machine configurations which may (or may not) help both novice and more experienced users make sense of an ever-increasing volume of information" (p. 214). Interestingly, a research project in France is developing a catalogue and index of French-speaking medical websites (CISMeF) to facilitate the access of health professionals, medical students, patients and the general public to relevant, high-quality web-based health information. Researchers suggest they take into account the diversity of end-users (Soualmia & Darmoni, 2005), an approach which is usefully applied to the study of other health information portals.

The influence of cultural and linguistic diversity on internet use among ethnic groups and Francophones is a matter of concern in Canada. Despite efforts by the federal government to maintain bilingual content on its websites, French-speaking Canadians have tended to use the internet less than English-speaking Canadians (Hirji, 2004). Researchers have begun to study the health information needs of immigrants to Canada (Poureslami, Rootman, & Balka, 2007; Zanchetta, 2006), however the specific needs of Canada's Francophone population are under-studied. Morahan-Martin (2004) conducted a review of research to understand cross-cultural differences in how health information on the internet is retrieved, evaluated and used in the United States, France, Germany and Japan, but no similar English-language study was conducted focusing on differences among French- and English-speaking Canadians.

1.7 Empowerment

The term empowerment often appears in the discourses of health care reform, health promotion and the CHN, and in discussions of the 'informed patient.' While it is beyond the scope of this thesis to explore the concept of empowerment in depth, a brief overview will help to contextualize the analysis of policy documents related to the CHN (Chapter 2) and the experiences of the CHN users who participated in this study (chapters 4 and 5).

Empowerment is not easily defined or measured. In the most general sense, "empowerment refers to the ability of people to gain understanding and control over personal, social, economic and political forces in order to take action to improve their life situations" (Israel et al. in Judd, Frankish, & Moulton, 2001, p. 367). This definition, however, emphasizes individual agency and control over structural factors. In the field of health promotion, people are understood to require the support of social structures to empower themselves.

Behind this concept is the notion of people building their own sense of personal strength through determining their own destinies, and having the personal and material resources to do so in a supportive environment (Raeburn & Rootman, 1998, p. 11).

This statement alludes to the idea that empowerment is a process that occurs among people within communities. Viewed as a social action process, empowerment promotes the participation of people, organizations and communities towards the goals of

increased individual and community control, political efficacy and improved quality of life (Wallerstein, 1992). This brief overview of only a few of the many perspectives of empowerment serves only to emphasize that a technology, unto itself, cannot empower people. Technology and its users exist in complex, situation-dependent contexts influenced by inter-connected individual and social factors.

1.8 Understanding Use through Seeking and Sense-Making

Underlying this thesis is sensitivity to the difference between studying a technology's impact on its users and studying how users incorporate technology into their lives. Dervin's sense-making model helped focus the study not on how people use the internet for health information, but rather on how people use the health information they find on the internet to make sense of their worlds (Dervin, 2003). In her critique of the transmission model of communication, Dervin understands information seeking and use as communicative practices in a complex process of meaning creation that occurs in varied situations across space and time (Dervin, 1999). Dervin's sense-making methodology informed some of the theoretical propositions leading the interview portion of the case study (Chapter 3), as well as the structure of considering the processes through which interview participants sought and made sense of health information (Chapter 4) before considering how they used this information in their daily lives.

1.9 Thesis Overview

The upcoming chapter presents the basic assumptions underlying the design of the CHN website through discourse analysis of policy documents related to the CHN. Chapter 3 explains the methodology for conducting interviews with CHN users, which were undertaken in order to understand actual use of the CHN website. The following two chapters present the findings and analysis of the interviews with CHN users. Chapter 4 focuses on the process of seeking and making sense of web-based health information and Chapter 5 addresses how the CHN users interviewed used health information obtained on the internet. Chapter 6 discusses interview participants' health information use in light of the constraints and supports they experienced in making sense of web-based health information. The concluding chapter presents a review of the thesis that links the actual use of the CHN website to the basic assumptions underlying its design.

1.10 Research Significance

The significance of this work lies in the insight it offers to policy-makers and the research community regarding the complexities of how the Canadian public use the federal government's main health information web portal in the context of their information seeking and their day-to-day lives. This work contributes to the growing body of research exploring the many different ways people use health information they obtain from the internet and the meaning it holds for them. It focuses not only on the constraints they face but also on the supports they draw on, so the CHN Division might recognize shortcomings and build upon successes with a broadened awareness of actual use of the CHN website across the country. This research begins to explore differences and commonalities in how English- and French-speakers use the internet for health information so majority language-speakers might become more alert to linguistic diversity and culture. Finally, for me this research was an opportunity to begin to explore with an insightful, forthcoming group of people how science is understood when it touches our lives.

1.11 Chapter Summary

This chapter begins the thesis by presenting an overview of the topic and technology of study, the methodological and theoretical approaches framing the inquiry, the limitations of past research and the key concept of empowerment.

This thesis is an intrinsic case study of the Canadian Health Network government web portal that investigates the topic of health information use through discourse analysis of policy documents related to the CHN, a focus group with the CHN Division and interviews with CHN users. These sources will lend insight into the basic assumptions underlying the construction and design of the technology under study – the CHN website – and actual use of this technology. The social construction of technology approach frames this inquiry into the multiple meanings attached to the CHN website during its ongoing, non-linear development.

Previous research about e-health that addresses patient and consumer health information on the internet calls for further study of the many different ways web-based health information is used, the supports and constraints influencing this process, the role

of cultural and linguistic diversity on internet use for health information among French-speakers, and the use of web portals for health information.

The next chapter presents an analysis of the policy discourse related to the CHN, which was undertaken both as a means of contextualizing the study and of examining the policy goals related to the CHN.

CHAPTER 2: HEALTH INFORMATION USE IN THE DISCOURSE OF THE CANADIAN HEALTH NETWORK

Finally, I'd just like to mention that we're working on empowering the public. It will be launched soon by the minister in a very public way, but it's actually been up and running. We have an extensive series of partners in the development of something we call the Canadian Health Network.

*—Mr. Ian Potter, Assistant Deputy Minister,
Health Promotion and Programs Branch, Health Canada
(Standing Committee on Health, 1999a, para. 239)*

2.1 Introduction

When the aim of the CHN is summarised casually in these brief sentences, it is to empower the public, but the concept of empowerment provides little insight into what the CHN website gives the public power to do. A more detailed examination of the policy discourse of the CHN can shed light on how federal policy-makers and the CHN Division expected Canadians to use health information obtained on the CHN website. The social construction of technology and discourse analysis provide the theoretical and methodological framework for exploring the basic assumptions underlying the design of the CHN website, as they were articulated in relevant policy documents. This chapter will describe the methodology for the discourse analysis and a focus group conducted with the CHN Division, and will present and discuss the findings. To contextualize the case study, this chapter will first present a brief historical policy context of the CHN (Creswell, 2007).

2.2 The Canadian Health Network's Historical Policy Context

Considering the CHN website from a social construction of technology (SCOT) perspective involves taking a backwards look at the artifact's path of development to understand the different problems and solutions that lead to different interpretations and designs (Bijker & Pinch, 1989). This chapter begins by situating the CHN website within its macro-political context, an aspect SCOT has been criticized for failing to consider

with depth (Klein & Kleinman, 2002; Pinch, 1996). As Barney (2005) suggests, “technological outcomes are not wholly determined by design. All technological instruments and practices are situated in complex social, political, and economic environments that strongly condition their possible elaborations in human practice” (p. 19). The historical policy context of the CHN can be divided into three aspects – health policy, internet policy and e-health policy. A brief overview of each is presented below and will inform the discussion of the discourse analysis findings.

2.2.1 Health

The health policy environment in which the CHN developed is concerned with growing health system costs due to increased use of technology and pharmaceuticals, an ageing population, and the shift from acute to chronic disease as the major source of health issues. “The focus of concern changes from cure to care when major population health problems are chronic conditions, usually multiple chronic conditions, that develop over a long period of time” (Dean & Kickbusch, 1995, pp. 35-37). Despite increasing demands for health care services, the primary objective of Canadian health care policy, set out in the *Canada Health Act* in 1984, remains unchanged – “to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers” (Department of Justice, 1984, section 3). The federal government’s role in health includes setting and administering national principles for the system and providing financial support to the provinces and territories, which administer and deliver most of Canada’s health care services. However, the delivery of public health programs does fall within the federal government’s scope of responsibility (Health Canada, 2006b).

In these days of widespread fiscal conservatism, based on the rhetoric of ‘fiscal crisis’, it should be no surprise that population health appears to have gained considerable currency at all levels of government in Canada. Unintended as it may be, population health provides powerful justification for major cutbacks in health care, the Canadian version of health care ‘reform’ (Robertson, 1998, p. 163).

But as Robertson goes on to point out, removing resources from health care can further penalize those whose health is compromised by structural inequalities. A health promotion approach based on the social determinants of health requires government reallocation of resources to address underlying structural inequalities (Robertson, 1998).

2.2.2 Internet

Claims regarding the necessary connection between the internet and particular policy outcomes are commonplace in government discussions about the potential of information and communication technologies (ICTs). Just as the Government On-Line (GOL) initiative “began with a vision to change the nature of the government's relationship with its citizens by using technology” (Government of Canada, 2006), the CHN was credited with “harnessing the power of the internet to provide Canadians with a vast array of practical, high-quality information about health” (Health Canada, 2000, p. 15). Government seems to expect the essential characteristics of the internet to determine the practical outcomes of implementing this technology (Barney, 2005).

In Government On-Line 2006, the Canadian government reported it had successfully become the world's most connected country to its citizens, a goal it initially articulated in the 1999 Speech from the Throne (Government of Canada, 2006). The initiative aimed to make all government services available via the internet to improve efficiency, reduce costs, develop quality control and manage privacy and security concerns while making services accessible, convenient and responsive for users. Portals and gateways were developed to group services and information by subject or intended audience (e.g. aboriginal peoples, seniors, persons with disabilities) (Barney, 2005). The CHN is therefore consistent with the Canadian government's strategy of developing web-based portals to facilitate public access to services.

The Canadian policy strategy for the development of a national digital communication infrastructure was charged to an institution established by Industry Canada in 1994 – the Information Highway Advisory Council (IHAC). Barney suggests IHAC was clear that the development of ICTs was an industrial project that relied on market forces, except where they failed to meet public interest objectives such as universal access (Barney, 2005). IHAC considered computer and internet literacy “a necessary precondition for success in the emerging knowledge society and economy” and looked to the public education system, continuing adult education and commercial training programs to meet this need (Barney, 2005, p. 49). Internet access and related literacy training remained the responsibility of government, which was otherwise to act as a model user of a market-driven technology (Barney, 2005).

2.2.3 E-Health

The letter addressed to the Minister of Health at the beginning of the Advisory Council on Health Infostructure's final report (1999) indicated the council expected "the Canada Health Infoway will become the key information and communications foundation for our health care system in the 21st century" (para. 3). Though it evolved into Canada Health Infoway Inc., a partnership between Canada's 14 deputy ministers of health and public sector partners that aims to implement an interoperable electronic health record, Canada Health Infoway initially set the vision for initiatives that deployed information and communication technology to "help to empower Canadians with better health information and new opportunities" (Advisory Council on Health Infostructure, 1999, p. 3). An aspect of this vision was the recognition of health information as an essential public good that should be readily available and accessible to all Canadians as part of the publicly funded health system. According to the advisory council, "this information should include whatever might help Canadians facing decisions about their own health or trying to hold the system accountable" (Advisory Council on Health Infostructure, 1999, p. 7). Technology was seen as a means of transforming many aspects of the health system, and web-based health information in particular was to empower the public to make informed choices about their health and health care.

2.3 Methodology

The methodology for the portion of the case study that examines the discourse of the CHN describes and discusses discourse analysis and the collection of data through the research partnership between the CHN Division and ACTION for Health, as well as the process of selecting texts and conducting the analysis.

2.3.1 Discourse Analysis

Phillips and Hardy (2002) define discourse as "an interrelated set of texts, and the practices of production, dissemination, and reception, that brings an object into being" (p.3). Discourse analysis explores the relationship between discourse and social reality, which is produced and made real through discourses (Phillips & Hardy, 2002). In this study, discourse analysis was conducted to understand the current iteration of the CHN website by investigating changes in the basic assumptions underlying its design since its launch in 1999. The policy discourse of the CHN does not provide the detail

necessary to trace the major design changes to the artifact according to the SCOT approach, though it does allow for the identification of the basic assumptions embedded within the final design. Through discourse analysis, I set out to answer the following research question: What are the basic assumptions underlying the construction of the CHN website? I hypothesized that federal policy-makers and the CHN Division presupposed Canadians would use the CHN website to make informed choices regarding health and health care. I also expected federal policy-makers and the CHN Division to acknowledge challenges faced by disadvantaged Canadians, and to have implemented strategies to address these challenges. Even with such strategies, I expected the CHN website would most likely support healthy lifestyle choices among a select group of Canadians for whom the internet is accessible, health promotion information is a priority, and making informed choices based on on-line health information is possible.

Towards the end of understanding the basic assumptions underlying the CHN website's design from the perspective of the CHN Division, I also conducted a focus group with employees of the CHN Division to understand current organizational-level goals, priorities and challenges. I expected to observe differences in the policy discourse surrounding the CHN, as articulated by the CHN Division and federal policy-makers, for two reasons. Documents are historical once published and different social groups can interpret a technological artifact differently (Bijker & Pinch, 1989); and the outcomes of computerization are understood differently at the macro and meso levels of structuring (Taylor, Groleau, Heaton, & Van Every-Taylor, 2001).

2.3.2 Research Partnership with the Canadian Health Network

The researcher-instigated discourse of the focus group with the CHN Division is not part of the discourse that constructs the CHN website, but it plays a useful role in understanding the social context of the policy documents (Phillips & Hardy, 2002), as do the minutes of meetings and e-mails exchanged between the CHN Division and ACTION for Health investigators. The ACTION for Health project's research partnership with the CHN allowed for access to perspectives of CHN Division staff. I conducted a focus group with four self-selected employees of the CHN Division on November 9, 2006 at the CHN's office in Ottawa that lasted about 40 minutes. The focus group questions are included in Appendix A. Four meetings took place between the CHN Division and

ACTION for Health between December 16, 2005 and November 9, 2006. The e-mails under consideration were exchanged from June 2, 2006 to February 2, 2007. The focus group and most of my other interactions with the CHN Division occurred before I conducted the discourse analysis. They served as preliminary research to identify specific issues in the policy discourse of importance (Morgan, 1997) to the CHN's future development.

2.3.3 Selection of Texts

Between January 19 and 22, 2007, I located 103 publicly available documents related to the CHN.

Table 2.1 Summary of Policy Documents Reviewed

Document Type	Number of Documents
Reports	21
Articles and promotional documents	7
News releases	15
Hansard transcripts	11
Parliamentary committees	14
Proceedings of non-CHN meetings and hearings	2
CHN advisory board summary proceedings	11
CHN webpages	22
TOTAL	103

Appendix B contains a complete list of the policy documents located and reviewed in this analysis. I located them through a focused internet search, beginning with a search in Google's "pages from Canada" for the documents mentioned in the CHN advisory board proceedings. I then searched the Public Health Agency of Canada (PHAC), Health Canada and Parliament of Canada websites for "Canadian Health Network." I discarded any documents that only mentioned the CHN, reproduced the brief, standard overview paragraph about the CHN or presented CHN content. I also discarded documents by CHN affiliate organizations, provincial governments and any

other organizations or individuals because my focus was on the perspectives of federal policy-makers and the CHN Division. Among my final steps was to request the documents mentioned in the advisory board proceedings from my contacts at the CHN, which led to an advance copy of the CHN's 2006 evaluation report, the CHN's four key priorities for 2001 to 2003 and assurance that the CHN's mission, vision and values have remained the same since 2001. I finished my focused search with a hand search for annually published documents, which my previous on-line searches had returned for only select years. I limited my search to English-language documents because the parliamentary record is published equally in both official languages and government publications on the internet are available in both official languages (Department of Justice, 1982). I accept and analyse the English-language discourse but acknowledge subtle differences may exist in the French-language discourse, subtleties I would be unable to detect with my French-language abilities.

2.3.4 Analytic Strategy

As Phillips and Hardy (2002) wrote, “the aim of discourse analysis is to identify (some of) the multiple meanings assigned to text” through interpretation and by generating categories based on how language is used (p. 74). Towards the end of understanding the basic assumptions underlying the design of the CHN website, I based my analysis on the following guiding questions: Who were the perceived users? What are the users intended to do with information from the CHN website? Did these expectations change over time? What problems arose during the development process? How were these problems addressed? Did the CHN change over time? These questions reflect my social constructivist approach to understanding policy development and technological design.

I began by identifying the voice of the document and its context of production, dissemination and reception (Phillips & Hardy, 2002). I then used the find tool in Microsoft Word, Adobe Acrobat or the Mozilla Firefox web browser to locate mentions of “Canadian Health Network” within the documents. I read the surrounding text to answer the questions guiding my analysis and coded these answers according to emergent themes (Phillips & Hardy, 2002). I considered the focus group transcript, meeting minutes and e-mails according to the same analytic strategy, though separately from the

policy documents because they are not part of the policy discourse that constructs the CHN.

2.4 Findings and Analysis

The term empowerment is sprinkled throughout the policy discourse related to the CHN and is often ill defined. For example, the Advisory Council on Health Infostructure (1999) referred to empowerment in this way: “the Canada Health Infoway should empower the public to make informed choices about their own health, their health care and about health policy” (p. 2-1). In a news release leading up to the launch of the CHN, Health Canada stated:

Today the focus of governing is on partnership, citizen engagement and empowerment. Governments are no longer expected to make decisions for their citizens. Rather, they are expected to create and support the infrastructure citizens need to make their own informed decisions (Health Canada, 1999c, para. 1).

In a budget document, Health Canada was to “work to improve health and health care through public empowerment, consumer participation and better communication with Canadians” (Health Canada, 1999a, p. 50). Since empowerment appears frequently but is seldom accompanied by a definition, it seemed prudent to look within the policy discourse to uncover some of the implicit meanings of the term empowerment.

Three themes related to the notion of empowerment emerged through focused reading of the policy documents – individual responsibility for health, diversity of users and access to information. I will consider the evolution of each theme in three phases to show how the policy discourse of the CHN changed over time. Key events in the CHN’s history and the release of key reports distinguish the phases. The first phase began in 1998, when the CHN was created and the Advisory Council on Health Info-structure released its interim report, and ended in 2001, when the Federal/Provincial/Territorial (F/P/T) Advisory Committee on Health Infostructure released its *Tactical Plan for a pan-Canadian Health Infostructure*. The second phase began in 2002, the year of the release of an Auditor General’s report focusing on the mismanagement of contracts related to the CHN. The third phase began in 2004, when the CHN moved from Health Canada to the PHAC, and ended on January 22, 2007, when I finished collecting the policy documents for this study. In the second and third phases, the CHN’s advisory

board proceedings provide insight into the policy discourse within the CHN. In the third phase, the focus group, meetings and e-mails with the CHN Division were also considered.

2.4.1 Individual Responsibility for Health

In 2004, a webpage entitled “What can you expect to find at the Canadian Health Network?” was added to the CHN website in response to an area for improvement identified in 2002 that called for a clearer explanation of the purpose of the CHN (Public Health Agency of Canada, 2005). The website now states CHN users can expect to find health promotion and disease and injury prevention information to help them make healthy choices (Public Health Agency of Canada, n.d. e), but articulated in the policy discourse of the early years of the CHN’s development were expectations for the Canadian government’s flagship web-based health information service that fell well beyond its mandate.

The news release from the launch of the CHN in 1999 stated what the federal government initially intended Canadians to do with the website. “The information resources are intended to help people lead healthier lives by providing them with trustworthy information on how to take care of themselves and others and help prevent illness and disease” (Health Canada, 1999b, para. 6). In the first phase of the CHN’s development, the website was said to provide Canadians with information on self-care and the performance of the health system (Health Canada, 1999a). These uses of the CHN website are consistent with those identified by the Advisory Council on Health Infostructure, which considered the CHN “one mechanism for providing Canadians with access to reliable health information” (Advisory Council on Health Infostructure, 1999, p. 2-6).

The Canada Health Infoway should empower the general public by: a) providing reliable health information useful to Canadians as patients, informal caregivers and citizens; b) ensuring equitable access to health information; and c) offering opportunities for individuals and communities to hold dialogue on health care, engage in self-care and mutual aid, hold the system accountable, participate in health policy debates and provide input into health policy” (Advisory Council on Health Infostructure, 1999, p. 1-4).

The advisory council's strategic framework is based on the premise that Canadians want to take more responsibility for their health and want a more accountable health system (Advisory Council on Health Infostructure, 1999, p. 1-4). The report also states the public can use the information to manage specific health conditions, review the pros and cons of various treatment options and contribute insights in their communications with health professionals, where "the professional becomes more a coach, a consultant or a facilitator than final authority" (Advisory Council on Health Infostructure, 1999, p. 2-3). A similarly expanded role for the CHN also appeared in verbal discourse. For example, during presentations about Health Canada's activities to the Standing Committee on Health, an assistant deputy minister said the following regarding the CHN: "With all this information and in consultation with your physician, it is then possible to make a much more enlightened decision on the required treatment" (Standing Committee on Health, 2001, para. 50). In the 1999 budget debate, a Liberal Member of Parliament described the CHN as a tool "to address issues related to the ever increasing demands on our health care system" (House of Commons, 1999, para. 537). Health Canada launched the CHN as a health promotion and disease prevention website, but the language "to take care of themselves" is perhaps the window that opened expectations for the CHN to include supporting self-care and individual decision-making regarding health care in the first phase of the CHN's development (Health Canada, 1999b, para. 6).

The second phase began with the release of two key reports on health care in Canada, the first by the Senate Standing Committee on Social Affairs, Science and Technology chaired by Senator Michael Kirby and the second by the Commission on the Future of Health Care lead by Commissioner Roy Romanow. Both reports called for the expansion of the CHN to include information related to self-care. The interim report from Senator Kirby's committee stated "programs which enable individuals to be responsible for their own health must be given high priority" and recommended building on the success of the CHN to "give Canadians access to comprehensive and trusted health-related information that could support self-care decision making" (Standing Senate Committee on Social Affairs, Science and Technology, 2002b, para. 19). The committee defined an internet-based health information network as "a system that empowers individuals to make informed choices about their own health and well-being, their health care and about health policy" (para. 81), and detailed several types of information that could be communicated to the public via the internet, including information about health

promotion, disease prevention, treatment options, drugs, illness management, public health issues, the determinants of health, and health and health care policies (Standing Senate Committee on Social Affairs, Science and Technology, 2002a). The Romanow Commission also favoured building the CHN into a comprehensive health information website by linking to other electronic sources and building an electronic health information evidence base through the Canadian Institute of Health Research (Commission on the Future of Health Care in Canada, 2002). These reports suggested Canadians should make decisions about their health care based on health information they obtained on the CHN.

The Kirby and Romanow reports emphasized the CHN's potential, but with the release of the Auditor General's report that found government contracting rules and regulations were not followed when more than \$25 million was spent on the CHN (Office of the Auditor General, 2002, p. 3), the discourse shifted to emphasizing the value of the website to Canadians. When then Health Minister Anne McLellan appeared before the Standing Committee on Health, she said,

The substance of the network itself is absolutely key. It gets, I think, five million hits a month or something, which makes it the third most-used health data bank or website in the country, after Yahoo and our own Department of Health website. In fact it's gaining adherents every month. It speaks to this tremendous desire on the part of the public for good, reliable information as it relates to their health care, new developments, new discoveries, new this, new that – all this sort of thing (Standing Committee on Health, 2002, para. 230).

Liberal MP Reg Alcock also emphasized the value of the website in committee:

As someone who spends a fair bit of time looking at these sites around the world...you can go into any good search engine and type in any kind of disease and get an absolute range of possible solutions with all sorts of wonky advice. We desperately need what that network provides, that is, branded, reliable information. You can get information that you can actually use in the management of your own personal health. I would be very concerned if anything happened to diminish the department's support for that (Standing Committee on Health, 2002, 219).

When appearing before the Standing Committee on Public Accounts, Scott Broughton, an Assistant Deputy Minister with the Department of Health said,

In principle, we believe in the value of this initiative, and in practice it's working for Canadians...Canadians need not surf the Internet to find the

health information they need. With the Canadian Health Network they will not be sold anything. They can search in confidence and with privacy. They are not bombarded with Internet advertising and they can be assured about the accuracy of what they find (Standing Committee on Public Accounts, 2002, para. 337).

The discourse focused on the value Canadians received for the \$25 million spent on a website, and the CHN was purported to provide Canadians with a comprehensive, credible health information resource.

In 2004, the CHN was transferred to the newly created PHAC and the purpose of the CHN was clarified and refocused on the provision of health promotion and disease and injury prevention information (Public Health Agency of Canada, 2005).

The Canadian Health Network works to educate and influence behavioural changes at the individual and community levels and provides consumers with the information they need, and how to use it, to better manage their health and/or to assist them in avoiding escalation of a health issue where it can be prevented or minimized. This is a key aspect of the Canadian Health Network in supporting the health continuum (Government of Canada, 2007, para. 137).

The CHN's focus on health promotion was reiterated in its 2004-2006 strategic directions, even though the advisory board discussed the possibility of expanding the CHN's scope to include disease and treatment information at its June and November 2003 meetings (Public Health Agency of Canada, n.d. d). In the focus group with employees of the CHN Division, an interest in exploring whether the CHN should expand its website to include information related to health care was expressed. It was articulated that a current priority of the CHN Division was to achieve a balance on the website between the health promotion and disease and injury prevention information government mandates the CHN to provide, and disease- or condition-specific treatment information the CHN's surveys have found its users want.

I think that we're constrained in that we don't get into disease treatment information or into medications, that sort of thing. I don't think we could consider ourselves a comprehensive resource, but a good general consumer support tool that people can use to supplement their information and help to make the decisions. I don't know that we could ever say exclusively that we could be a one-stop shop for Canadian decision-making on health but it's certainly important and credible support towards making better decisions about their health (focus group with the CHN Division).

After clarifying its mandate, the CHN began to consider the possibility of expanding the type of information provided through the CHN towards supporting earlier expectations for the website and user needs.

2.4.2 A Diversity of Users

Over the years, the policy discourse predominantly described CHN users in the broadest of terms – Canadians. CHN users were also often referred to as individuals, people, consumers, patients, the general public and laypeople, and as early as 1998, health professionals were identified as an audience of the CHN (Advisory Council on Health Info-structure, 1998). In the first phase of the CHN's development, the discourse at the federal level focused on the diverse needs of Canadians as potential CHN users, but in the subsequent two phases, it was largely silent on the issue. The diversity of the CHN's potential users was more prominent in the focus group with the CHN Division, in which participants spoke of the progressive expansion of the website's reach.

The early federal discourse emphasized the heterogeneity of those who might use on-line health information. The Advisory Council on Health Infostructure (1999) pointed out "there is no such thing as a "general public" when it comes to health information needs. Information must be tailored to individual users or specific groups of users and to people's differing needs for information over time" (p. 2-4). It emphasized website content must match the needs and capacities of the public, which change with individual and family circumstances and depend on culture, language, level of education, income and disability, health concerns, cognitive abilities and access to and ability to use information technology (Advisory Council on Health Infostructure, 1999, p. 2-4). The federal policy discourse also acknowledged the CHN was more likely to reach certain segments of the Canadian population. As the F/P/T Advisory Committee on Health Infostructure (2000) stated, "an important user group of the health system – the uneducated, the poor and children, are not seen as high users of the service and require other avenues to obtain information" (p. 23). The flexibility of a website was seen as a means to reach a diversity of users through the CHN, but the very fact that it was a website meant the CHN could not reach all Canadians.

From 2002 to 2007, the issue of diversity had largely disappeared from the federal policy discourse, but within the organization-level discourse of the CHN, diversity became more prominent. Better responding to the diverse needs of Canadians was

among the four strategic directions for 2004 to 2006, whereas the strategic priority related to diversity for 2001 to 2003 focused on strengthening the Francophone component of the CHN (EKOS Research Associates, 2006). The CHN has several strategies for connecting with a diversity of Canadians. It provides links to information specifically intended for five population groups – children, youth, seniors, aboriginal people, women and men (Public Health Agency of Canada, n.d. b). Though the CHN markets to women between the ages of 35 and 54 with children at home and women aged 25 to 34, it also markets to health professionals and allied health workers (meeting minutes, December 16, 2005). This third target audience was expected to expand the reach of the website resources to people with literacy and access issues and who desire personal contact (Public Health Agency of Canada, n.d. d). The CHN advisory board proceedings identify two key strategies for meeting the needs of its diverse audience – an aboriginal strategy and rural, remote and northern strategy (Public Health Agency of Canada, n.d. d). The CHN Division explained the website resources are enhanced to reach out to these target groups who may not receive services elsewhere. Using the technology of a website, the CHN is attempting to reach more Canadians by marketing to those who are likely to find the information useful and share it with others, and making the content more relevant for those who might not otherwise use the information.

2.4.3 Access to Information

The discourse of access related to the CHN focuses primarily on the CHN's contribution to improving the accessibility of health information, though the inability of some Canadians to access the internet was acknowledged in the first phase of the CHN's development. The Advisory Council on Health Infostructure (1999) recommended providing health information through "multiple modes of access" including not only the internet but also "phones, faxing traditional hard copy and direct contact with sensitive, knowledgeable staff" (p. 2-8). Senator Kirby's committee indicated government should also pursue public awareness campaigns to reach those Canadians without computers (Standing Senate Committee on Social Affairs, Science and Technology, 2002b). The CHN planned to supplement the website with other modes for people without internet access (Public Health Agency of Canada, 2002; Standing Committee on Health, 1999b), but after 2002, this approach disappeared from the discourse, likely because not-for-profit health organizations and provincial governments

were providing telephone health information services (Pascal, 2001), though despite the F/P/T Advisory Committee on Health Infostructure's (2001) recommendation of an integrated approach to the provision of health information that would link the CHN to provincial and territorial self-care and telecare services. The CHN instead developed as a distinct entity, integrated with other health information websites rather than other types of government health services.

Throughout its development, the CHN was intended to provide Canadians with easy access to high-quality, accurate, trustworthy health information. As an assistant deputy minister said to the Standing Committee on Health (1999c),

We wanted to become involved in ensuring that when people come through the Health Canada site and ask for information they can at least be assured that some sources are judged by us as being reliable and people have access...It's not that we'll vouch for everything, but at least we can tell them that this site is a reliable source, but that one we don't know about (para. 394).

The main barrier to access considered in the policy discourse was not the internet itself, but rather finding information on the internet. Some of the challenges of on-line health information identified in the policy texts were the onerous task of finding information in the vast amounts available (Health Canada, 1999b), finding unbiased information (Standing Senate Committee on Social Affairs, Science and Technology, 2001), and finding information that is presented in an accessible manner (Standing Senate Committee on Social Affairs, Science and Technology, 2006). To improve access to health information, the CHN has worked to improve the quality of the resources on its website by enhancing the collection of information and quality assurance policies and practices (Public Health Agency of Canada, n.d. d). As the CHN Division explained in the focus group, the CHN aims to make on-line health information more accessible to Canadians by identifying credible resources and protecting the health information of not-for-profit organizations from commercial interests. The CHN therefore intends to make on-line health information more accessible to those with access to the internet.

2.5 Discussion

The complexity of the term self-care likely contributed to some of the inconsistencies in the purpose of the CHN articulated in the policy discourse. According to Dean and Kickbusch (1995), the concepts of self-care and health promotion both

represent a shift from reliance on medical care to recognizing the structural, social and behavioural determinants of health maintenance and protection. Individual self-care decisions include whether to do nothing, actively promote health, self-treat, seek care from another or follow advice. However, in the context of the demystification of professional health services, better educated populations with greater expectations, limitations of high-tech medicine and rising health care costs, the aspects of self-care related to individual response to illness received more attention than the health promotion and disease prevention aspects (Dean & Kickbusch, 1995). The goal of the CHN is clearly stated on its website – “to help Canadians find the information they’re looking for on how to stay healthy and prevent disease” (Public Health Agency of Canada, n.d. a, para. 1). The disclaimer instructs users to contact a qualified health professional if they have a medical problem. It states the website is intended for educational and informational purposes only, not for crisis situations, medical diagnoses or treatment information (Public Health Agency of Canada, n.d. c). Throughout its development, the focus of the CHN has been narrow, despite much broader expectations in its surrounding policy discourse.

Maintaining a narrow focus on health promotion was likely attractive to the federal government because it presents fewer issues related to liability, federal-provincial jurisdiction, professional responsibility and accountability. Also, in the wake of the Information Highway Advisory Council (1995), which put information and communication technology in the hands of the marketplace rather than government, it is not surprising the federal government chose to limit the scope of the CHN to health promotion. Even the creation of a government-funded web-based health promotion program is inconsistent with public policy that prioritizes market forces over the democratic public interest (Barney, 2005). The federal government initially assumed responsibility for coordinating the non-profit affiliate organizations of the CHN with the intention of handing the program over to them, but it was brought into Health Canada because of the mismanagement of asset purchases and contracts (Office of the Auditor General of Canada, 2002). A tension seems to exist between the desire of the federal government to minimize its involvement in the CHN and the investment required on the part of the government to leverage a website to promote individual responsibility for health and relieve some of the pressure of rising health care costs.

The policy discourse of the CHN acknowledges there is no typical CHN user and health promotion information will never reach all Canadians through a website. Despite attempts by the CHN to make its content relevant to disadvantaged Canadians and reach Canadians with literacy and access issues through health professionals as information intermediaries, the CHN is largely a resource for the privileged. In the latest evaluation of the CHN, 62 per cent of CHN users surveyed were university educated and half of respondents reported an annual household income of \$60,000 or more (EKOS Research Associates, 2006, pp. 32-33). For those Canadians with the capacity to use a website to make lifestyle changes towards improving their health, the CHN makes high-quality information more easily accessible to them, while those Canadians with other health information needs or who do not use the internet to access health information receive no benefit from the CHN. The CHN privileges those Canadians whose health information needs match those anticipated by the CHN.

2.6 Chapter Summary

This chapter presented a discourse analysis of 103 policy documents to explore the basic assumptions underlying the construction of the CHN website. The assumptions of the CHN Division were considered through analysis of a focus group with employees of the CHN Division, and minutes of meetings and e-mails exchanged between the CHN Division and ACTION for Health. A brief overview of health, internet and e-health policy was first presented to situate the policy discourse and the technology in the context in which they emerged. This backwards look at the assumptions underlying the construction of the CHN website, during its ongoing process of development, arose from a social constructivist approach to the study of technology.

Federal policy-makers assumed CHN users would engage in self-care, take more responsibility for their health, manage their conditions, weigh treatment options and participate in health care decision-making with health professionals. These uses of the CHN website fell beyond its mandate to provide health promotion and disease and injury prevention information. Policy-makers assumed the Canadian public needed a web portal to provide access to reliable health information. Federal policy-makers and the CHN Division never assumed the CHN website would reach all Canadians. The CHN Division assumed health professionals and links to information intended for specific populations would extend the website's reach to a more diverse audience. Federal

policy-makers assumed the CHN website would improve the accessibility of health information, and the CHN Division assumed improving the quality of resources on the CHN website would improve access to health information.

This chapter explored what federal policy-makers and the CHN Division assumed Canadians would do with information they obtained on the CHN website. The following chapters will explore the ways in which a sample of CHN users found, understood and used on-line health information.

CHAPTER 3: TALKING WITH CANADIAN HEALTH NETWORK USERS

Chapter Overview

In this chapter, I present the research design for in-depth telephone interviews with CHN users. I will explain my purpose for conducting the interviews, the theoretical framework underlying this purpose and the analytic approach that guided the data collection process. Points of particular interest within this chapter are the rationale for accessing respondents through a partnership with the CHN, for conducting interviews over the telephone, for conducting interviews rather than observations when studying people's practices, and for conducting half the interviews in the second language of the interviewer or interviewee.

3.1 Purpose

The interviews were conducted to explore how people who use the internet and the CHN website to seek health information make sense of the information they find and put it to use in their professional and personal lives. The aim was to gain a better understanding of the supports internet users draw on and the constraints they experience when making sense of health information. The research focuses on differences between how Anglophones and Francophones use the internet for health information seeking and sense-making. The research question for the interview portion of the case study was: How do the supports and constraints at play when CHN users make sense of health information come to bear on their use of this information?

3.2 Theoretical Framework

The previous chapter explored the policy discourse of the CHN to understand the assumptions underlying the construction of the CHN website. Interviews were conducted to understand actual use of the CHN website. This focus on users' experiences with a technology arose from the social construction of technology (SCOT) approach, according to which users and non-users experience different problems and

solutions with respect to technology (Bijker & Pinch, 1989). I interviewed CHN users to explore the experiences of people whose use of the technology was most likely to align to the policy assumptions underlying the construction of the CHN website. Woolgar (2002) cautions against focusing on the effects, outcomes or impacts of technologies because these terms imply a separation of the technology from the contexts that constitute it. He argues theories of the internet's impact ought to be informed by "close scrutiny of the widely varying actual experiences of the design and use (and misuse) of the technologies on the ground" (Woolgar, 2002, p. 4). He suggests researchers investigate to whom new technologies are making a significant difference and in what ways, as well as experiences of actually making the technology work (Woolgar, 2002). I did not consider the CHN users interviewed representative of the Canadian population, the broader population of CHN users or on-line health information-seekers in general. Instead, I considered them ideal users because, in possessing the basic skills necessary to conduct searches and an interest in health topics that motivated them to search for health information and participate in this study, they were in a position to use the technology and make it work for them. As I carried out this study, I found it helpful to think of the unhappy-looking pregnant woman I once saw smoking a cigarette at a SkyTrain station in Vancouver. She was the person the CHN most needed to reach, but I am certain she was not among the participants in this study. I expected interviewees would be on the advantaged side of the digital divide – well-educated, relatively young and with convenient access to the internet – and was interested in the constraints these people faced and the supports they drew on when they accessed the CHN website and health information websites in general.

3.3 Analytic Strategy

A case study generally presents a detailed description of the case and its setting, and the analytic themes or issues that emerged from the study, upon which the researcher bases interpretation or generalizations about the case (Creswell, 2007; Stake, 2000). While case studies can be used to develop theory (Berg, 2007), they are also valuable for refining existing theory and suggesting complexities for further investigation (Stake, 2000). The interview portion of this case study set out to answer six questions:

1. How did users seek the health information? (e.g. internet, books, radio, friends, health professionals, etc.)
2. Why did they seek it in these ways?
3. How did they make sense of health information?
4. Why did they make sense of it in these ways?
5. How did they use the health information?
6. Why did they use it in these ways?

Yin (2003) specifically recommends the analytic strategy of following the theoretical propositions leading the case study. Dervin's sense-making methodology and previous social shaping of technology studies about health information seeking behaviour guided the development of the following theoretical propositions:

- The reasons CHN users sought health information arose from their lived realities and did not necessarily conform to system-level goals for on-line health information (Dervin, 1999; Wathen & Harris, 2006). Users may challenge expert information rather than accept and follow (Dervin, 1999).
- CHN users seek health information from multiple sources and various websites and media (Henwood, 2003; Wyatt, 2005).
- CHN users employ multiple, dynamic, situation- or context-dependent strategies to seek, make sense of and use health information (Dervin, 1999; Wathen & Harris, 2006).
- Constraints and supports, including intermediaries (Wyatt, 2005) and computer, information and health literacy, influence sense-making and information use (Henwood, 2003; Wathen & Harris, 2006).
- Information may be useful, useless or harmful (Dervin, 1999).

After the methodology for data collection and analysis is described and the findings from the interview portion of the case study are presented and analyzed, the theoretical propositions will be discussed in light of the interviewees' experiences and the policy goals for the CHN.

3.4 Methodology

The methodology for the interview portion of the case study describes and discusses participant recruitment through the CHN, the sampling process and resulting sample, data collection through telephone interviews, and the challenges of cross-cultural interviewing.

3.4.1 Participant Recruitment

Interview participants were recruited through an established research partnership between the ACTION for Health project and the CHN Division, which allowed access to

people who had visited the CHN website. Respondents to a survey posted on the CHN website from August to October of 2005 were asked whether they were willing to participate in further research to help with the continual improvement of the website to better meet the needs of consumers. During the survey period, visitors to the CHN website and subscribers to the CHN e-mail newsletter would have likely been aware of the survey because it was publicised through a banner on the main page of the CHN website and the CHN e-mail newsletter (EKOS Research Associates, 2006). Web survey respondents subsequently self-selected to become interview participants in this ACTION for Health study. As Klein and Kleinman (2002) point out, some groups may be prevented from participating in the design process of a technology due to power differences rooted in the structures of social life. The voices of Canadians who lacked the time, interest or perhaps language ability to participate in an interview, as well as those who do not access the internet or research health information, had no possibility of influencing the design process through this study. However, it would have been difficult to access CHN users in any other manner, and users are the best source for information about the patterns and goals associated with their use of a technology.

Of the 1,317 respondents to the web survey, about 800 provided their name and e-mail address for further research.⁷ In October 2006, the CHN Division contacted the approximately 800 respondents again via e-mail to invite them to participate in a qualitative study about the ways the public and health professionals find and use health information on the internet. The CHN Division then provided ACTION for Health the names, e-mail addresses and telephone numbers of 125 respondents divided into two strata – 18 respondents whose preferred language was French and 107 respondents whose preferred language was English (e-mail communication, October 19, 2006). The fact that only 27 per cent of web survey respondents indicated their mother tongue was French likely contributed to the small number of potential interview participants whose preferred language was French (EKOS Research Associates, 2006, p. 32). I requested the demographic information collected through the web survey for this subset of respondents so I could select a stratified random sample according to sex, age, level of education and occupation (health professional or not) (Berg, 2007). I wanted to avoid interviewing only members of the lay public from the CHN website's largest user-group,

⁷ The CHN Division estimated 800 web survey respondents had provided their contact information for further research. The exact number was unavailable.

university-educated women (EKOS Research Associates, 2006), or only retirees with the time to participate. The CHN Division did not transfer this demographic information to ACTION for Health because the Public Opinion Research and Evaluation Division of the Public Health Agency of Canada advised that linking responses to names would breach respondents' privacy (e-mail communication, October 11, 2006). I received a list of the 125 potential interview participants stratified by preferred language because the CHN Division asked for this information when it contacted the approximately 800 web survey respondents via e-mail to ask them whether they were still willing to participate in further research.

Recruiting participants through the CHN was advantageous because it provided access to the perspectives of people who had visited the CHN website from across Canada and from both official linguistic groups. This method of participant recruitment also required the research partner to invest employee resources in organizing the study, which may have increased buy-in on the CHN's part.

3.4.2 Sample

A stratified random sample of English- and French-speakers was selected because the CHN Division indicated it was interested in gaining a better understanding of differences between how Anglophones and Francophones use the website (meeting minutes, March 20, 2006). The web survey had found Francophones were more apt to recommend content on the CHN website to others, whereas Anglophones were more likely to recommend links found through the CHN website (EKOS Research Associates, 2006, p. 24). This stratified sample was also chosen because of the Canadian government's constitutional obligation to provide services to Canadians in both official languages (Department of Justice, 1982) and the lack of literature exploring Francophones' use of web-based health information. Though I am not bilingual, I expected my ability in the French language was strong enough to offer those whose preferred language was French the opportunity to participate in this research. Prior to conducting the interviews, I took an advanced French conversation course through continuing studies at the University of British Columbia to refresh my memory and to practice because I rarely encounter an opportunity to speak my second language in day-to-day life in Vancouver.

I randomized each stratum using Microsoft Excel and began contacting potential participants on October 20, 2006, starting from the top of each list and working my way down, contacting four to six potential participants at a time. The first 15 English-speakers in the list and all 18 French-speakers were sent an e-mail with information about the study and an invitation to participate. I telephoned each potential participant within a week of sending the e-mail to answer any questions and to schedule an interview. I set a goal of interviewing about 20 people, a number I thought was manageable in light of the timeline I had set out for completing this thesis and providing a summary of findings to the research partner, the CHN Division (Lofland & Lofland, 1995). After making an effort to interview everyone I contacted by e-mail, 25 people were enlisted in the study – 13 whose preferred language was English and 12 French. I began the interviews on October 26, 2006 and completed the last interview on January 31, 2007.

Table 3.1 Summary of Interview Participant Selection

Preferred Language	Potential Interview Participants	Interview Participants Contacted	Interviews Declined	Non-responses	Interviews Conducted
English	107	15	1	1	13
French	18	18	3	3	12
Total	125	33	4	4	25

Establishing legitimacy and convincing potential interviewees to participate did not present challenges because of my connection with a large research project, the involvement of the CHN Division and the participants' prior participation in the web survey. The response rate among the English-speakers was high – one declined an interview because she was writing exams, and no response was received from a potential participant who provided only an e-mail address to the CHN Division. Ongoing attempts to contact three of the French-speakers by telephone were unsuccessful and three declined participation. Hectic end-of-year schedules, the time gap between the web survey and the follow-up interviews, and my limited fluency in French may have deterred these six potential participants. If they did not trust that I would understand

them in French and they did not feel their skills were strong enough to participate in English, they likely declined the interview.

Given that participants were invited to participate in the study on three separate occasions and the sample size shrunk from approximately 800 to 125 through the recruitment process, participants in this study can be said to be self-selected. The recruitment process and stratifying the sample only by preferred language lead to a sample of, for the most part, well-educated women with home internet access and a keen interest in health. Considering I was interested in exploring the health information seeking experiences of those who have visited the CHN website, it is acceptable that this study's sample was consistent with the typical CHN users, who are predominantly female, highly educated and report higher than average household incomes (EKOS Research Associates, 2006). Based on name and voice, I assumed 22 interview participants were female and three male. In hindsight, I should have asked about gender during the demographics portion of the interview. Gender was not a focus of this study, and I chose only to collect demographic information related to the research focus.

All of the interview participants had home internet access, and 12 also had internet access at work. One participant's province of residence was suppressed for protecting anonymity, as it was more important to the focus of the study to consider the participant's occupation. Among the Francophones, 10 lived in Quebec and two in Ottawa, therefore they were not linguistic minorities. Though only seven interview participants identified themselves as health professionals (five Anglophones and two Francophones), 22 interviewees searched for health information for other people, as well as for themselves. Searching for others was a common practice among health professionals and lay participants alike. Table 3.2 and the bar graphs that follow summarize the demographic information collected from interview participants.

Table 3.2 Telephone Interview Participant Description Chart

Participant	Preferred Language	Language of Interview	Health Professional?	Highest Level of Education	Place of Internet Access	Province	Age	Sex
1	English	English	no	undergraduate	home	B.C.	74	male
2	English	English	nurse practitioner	Master's	work, home	Alberta	35	female
3	French	English	no	College	home	Quebec	44	female
4	English	English	no	undergraduate	home	Ontario	56	female
5	English	English	no	undergraduate	work, home	Nova Scotia	52	male
6	French	French	no	College	home, work	Quebec	25	female
7	French	French	no	College	home	Quebec	54	female
8	English	English	no	Master's	home, work	B.C.	58	female
9	French	French	no	High school	home	Quebec	47	female
10	English	English	parish nurse	Master's	work, home	Ontario	55	female
11	French	French	no	Master's	home, work	Quebec	28	female
12	French	French	no	high school	home	Quebec	53	female
13	French	French	ultrasound technician	College	home	Quebec	36	female
14	French	English	no	undergraduate	home	Quebec	32	female
15	English	English	no	College	home, work	Ontario	45	female
16	French	English	no	Master's	home	Ontario	65	female
17	English	English	nurse	College	home	Ontario	49	female
18	French	English	no	undergraduate	home	Quebec	51	male
19	English	English	no	Master's	home, work	Alberta	37	female
20	English	English	no	undergraduate	home	New Brunswick	38	female
21	English	English	nurse	undergraduate	work, home	B.C.	38	female
22	English	English	no	Master's	work, home	Ontario	36	female
23	French	French	nurse	College	home	Quebec	39	female
24	English	English	occupational health nurse	undergraduate	work, home	Suppressed	48	female
25	French	English	no	Master's	work, home	Ontario	65	female

Figure 3.1 Highest Level of Education of Interview Participants

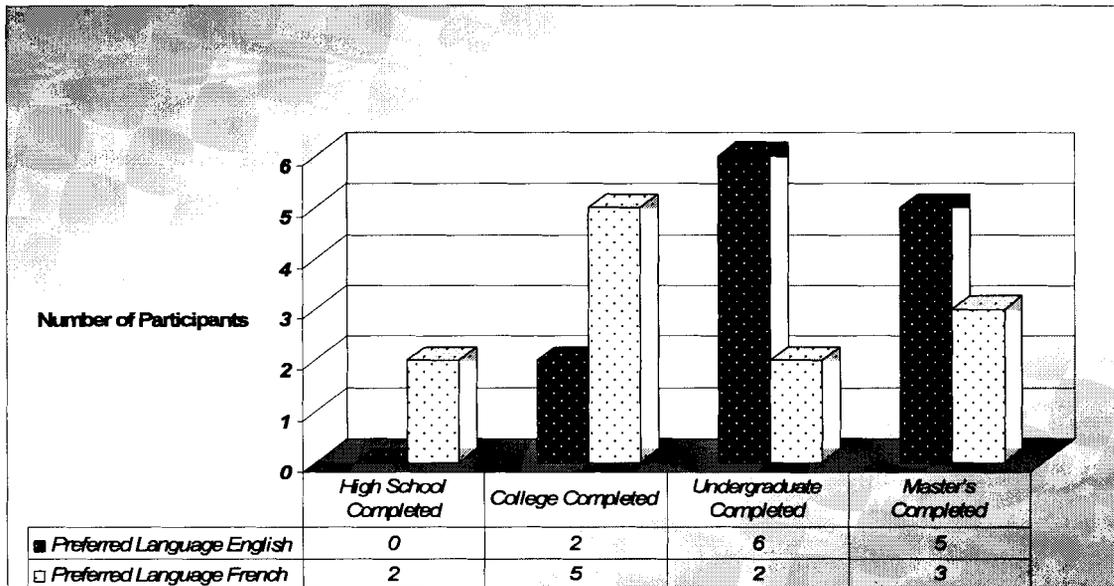


Figure 3.2 Age of Interview Participants

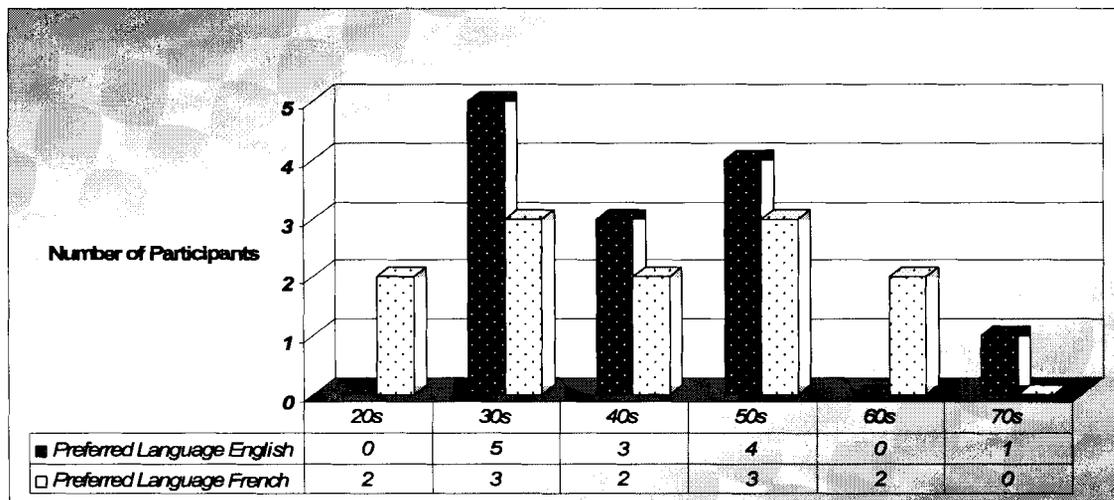
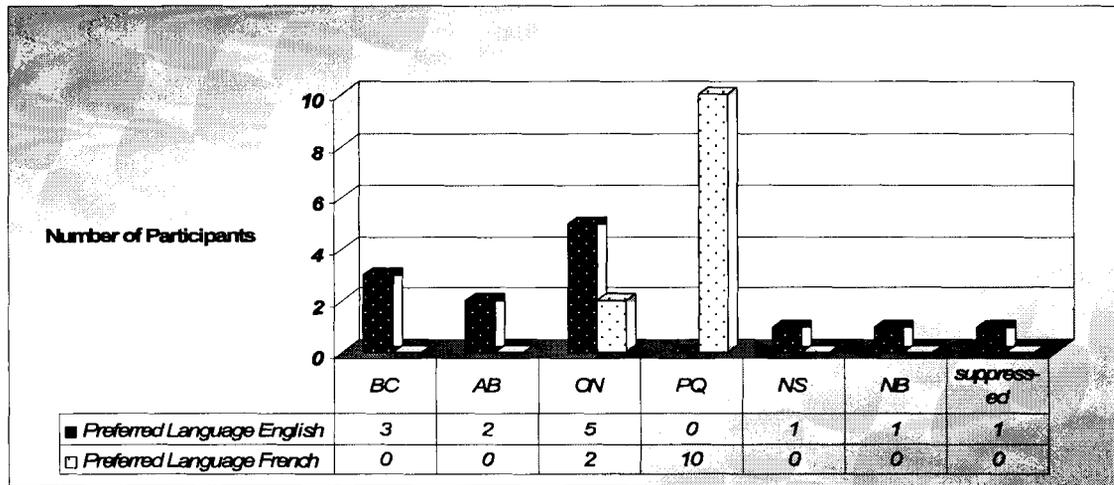


Figure 3.3 Province of Residence of Interview Participants



3.4.3 Data Collection

Though the in-person interview is advantageous because it allows the interviewer and interviewee to respond to each other's non-verbal cues, the telephone interview was the only viable method to reach a sample population in geographically diverse locations (Berg, 2007). This data collection method also offered other benefits. The telephone provided participants with "instant anonymity" that likely helped them to speak candidly and about personal health issues (Berg, 2007, p. 110), though it prevented the interviewer from interacting face-to-face with the interviewee in a comfortable, intimate setting (Douglas, 1985) and achieving intimate familiarity with the social contexts of the actions under study (Lofland & Lofland, 1995). The latter was not a drawback in this case because the activities of seeking, understanding and using health information take place in multiple contexts over time. Telephone interviews, as opposed to participant observation, offered the advantage of allowing participants to reflect back on and describe their past behaviours (Dillman, 1978). It was also advantageous that I could not see the interview participant as they spoke about their personal health problems because I could not make judgements based on appearance. For example, I understand web-based information about diet and exercise is not enough to motivate P18FE⁸ to manage his eating habits because he told me this over the telephone.

⁸ Throughout this thesis, I will refer to interview participants by number, preferred language and language of their interview. For example, P18FE was the 18th participant interviewed. His preferred language was French and his interview was conducted in English.

Whether he was lean or heavy is less meaningful than how he described his experience. The interviewer was situated at Simon Fraser University in the shared workspace of the Assessment of Technology in Context Design Lab or in a private office in the School of Communication, and the interviewees were at their homes or workplaces.

Semi-standardized telephone interviews allowed the interviewer to explore several specific, predetermined topics with the freedom to probe on topics of particular relevance to the interviewee (Berg, 2007). Probing questions were also used to elicit more detailed responses when the interviewees discussed topics of particular relevance to the study, particularly language and culture (Berg, 2007). The interview questions were developed based on the interests of the researcher, the ACTION for Health project's Theme I research focus on consumption and interpretation of health information (ACTION for Health, 2006), the interview protocols of prior Theme I projects, and the interests of the research partner, the CHN Division, as communicated through meetings and e-mail communications. The questions focused on attitudes, beliefs and behaviours in three categories: sources of health information, the process of seeking and understanding health information and health information use. Age, city or town of residence, level of education and whether they considered themselves a health professional were the only attributes considered relevant to the study and, therefore, the only attributes collected from all participants. The interview guide was pre-tested on two other researchers, a person likely similar to the people to be studied and the first three study participants, and it was reviewed by the CHN Division and ACTION for Health's principal investigator. The interview questions were revised throughout the pre-testing phase based on feedback and the researcher's observations. Beyond the clarification of wording and the deletion of questions unrelated to the research focus, the major changes were the addition of questions regarding the advantages and disadvantages of the internet compared with other sources, how the quality of information obtained through the CHN compared with other websites, and how health professionals support the health information-seeking of patients or clients. The final list of telephone interview questions is included in Appendix C.

The interviews lasted between 25 and 60 minutes. With the participants' permission, all interviews except the first were audio recorded and fully transcribed. The recording equipment failed during the first interview, but anticipating this malfunction, I kept detailed notes. Immediately after conducting each interview, I wrote out my

immediate impressions of the interviewee's responses and the interview experience. Follow-up e-mails containing one to four questions were sent to 24 participants to allow both the interviewer and interviewee to reflect on the conversation and clarify or add to the responses provided. I expected some interview participants might feel more comfortable expressing their thoughts in writing. P12FF in particular opened up in her follow-up e-mail and provided details that helped me understand how she used health information she obtained on the CHN website differently than any other participant. No follow-up e-mail was sent to P25FE out of respect for the time she contributed to the study. She mentioned on several occasions when scheduling and conducting the interview that she was overworked and overwhelmed by the amount of e-mail she receives.

As Fontana and Frey (2003) point out, an interview is an interaction and a relation, the knowledge generated is a product of this social dynamic as much as it is accurate accounts and replies. These authors suggest the respondent's behaviour (including embellishments, socially desirable responses, omissions, faulty memory), the sequence or wording of the questions, and the interviewer's characteristics and techniques influence the responses collected through structured interviewing. I acknowledge that the interview is "negotiated text," a discourse between speakers in which the meanings of questions and responses are contextually grounded and jointly constructed by interviewer and respondent (Mishler, 1986, pp. 33-34). In an attempt to improve my understanding of interview participants' processes and experiences of finding, making sense of and using on-line health information, I set out to establish a rapport with interview participants by posing open-ended questions and encouraging them to elaborate on their responses and to share additional thoughts. While I am confident the participants felt they had the opportunity to express themselves, at least by the end of the interview once rapport was established, the interviewees' answers remain decontextualized from their "essential sociocultural grounds of meaning" (Mishler, 1986, p. 23). Issues of language and culture between the interviewer and some interviewees exacerbated this disconnect and further complicated the construction of mutual understanding.

3.4.4 Cross-Cultural Interviewing

By including Francophones in this study, I conducted half of the interviews either in my second language or in a non-native language of the interviewee. I did this because I wanted to offer all potential interviewees the opportunity to participate in their preferred language, and the alternative was unsatisfactory to me. As a graduate of the French immersion program in Alberta and someone who continued to develop my French through post-secondary education and life experiences, excluding Francophones from this study because I am not fluent seemed to me a failure of Canadian bilingualism policy. From a methodological perspective, communicating in the language of the interviewee helps ensure the intentions of the questions were clearly understood (Berg, 2007).

In interviewing members of groups other than our own, then, we are in somewhat the same position as anthropologists who must learn a primitive language, with the important difference that, as Icheiser has put it, we often do not understand that we do not understand and are thus likely to make errors in interpreting what is said to us (Becker & Geer in Berg, 2007, p. 102).

Though communicating in non-native languages introduced cultural challenges to the construction of mutual understanding, both the interviewer and interviewee were acutely aware of these challenges and worked to compensate for them through careful speech and listening.

The CHN Division asked potential participants to specify their preferred language for an interview. One person indicated that she preferred either French or English, so I contacted her in English. I translated the study information, informed consent documents and interview guide into French and then a Québécoise graduate student at SFU edited them, so I could begin to build the trust of potential interviewees upon first contact. Of the 11 interviews whose preferred language was French, four began speaking English after I initiated a conversation with them in French on the telephone or offered to speak English for the interview. I expect these participants decided they were stronger in their second language than I and I would understand them better if they spoke in English.

Those participants interviewed in French were patient, at times even encouraging, and appeared to make a genuine effort to express themselves clearly by speaking slowly, rephrasing their responses and avoiding idioms I most likely would not

understand. They took on more responsibility for making themselves understood because they were in the advantaged position in the exchange. P11FF told me in her follow-up e-mail that she appreciated that I conducted the interview in French, even though it did not seem as though it was my first language. Though it is easy to misinterpret data generated in different cultural contexts and to misunderstand the deeper assumptions on which the responses are based (Broadfoot, 2000), as Fontana and Frey (2003) wrote, “to learn about people we must treat them as people, and they will work with us to help us create accounts of their lives” (p. 99).

3.5 Analytic Technique

The narratives interview participants constructed to communicate the multiple meanings they attached to their experiences seeking, making sense of and using health information websites (Silverman, 2003) were analysed based on the six questions and the theoretical propositions leading the case study. Overall, strategies for analysing case study findings have not been well defined (Yin, 2003). Among the authors who discuss case study research, Yin (2003) is the most specific when he outlines five analytic techniques, but none were appropriate for the case study at hand because they focus on causality. Creswell (2007) recommends focusing on a few key themes to understand its complexity rather than for generalization. The qualitative research software NVivo 7 was used to organize the interview transcripts and e-mail responses. The coding process was iterative, beginning with reading through the transcripts, returning to the literature and then re-reading the transcripts again. Some themes emerged from the data and others were developed based on the literature. Appendix D contains a list of the codes, which were used in data analysis and also assisted with data retrieval for interpretation, the development of analytic categories and the presentation of narrative description (Stake, 2000).

3.6 Chapter Summary

This chapter discussed the research design for in-depth interviews with CHN users. The purpose of the interviews was to explore the constraints and supports at play as users found, made sense of and used health information from the CHN and other websites in their personal and professional lives, a research question that fit both my interests and those of the CHN Division. The approach of considering users’

experiences with health information websites arose from studies of the social shaping of technology. I was interested in understanding the meaning of this technology for a social group on the favoured side of the digital divide, whose social relations were most likely to support its use for that purpose. The analytic strategy of the interview portion of the case study was to query the data to explore theoretical propositions.

Participants were recruited for the study through ACTION for Health's research partnership with the CHN Division. Although the interviewees self-selected, this method of recruitment allowed for access to a sample of CHN users from across Canada and from both official linguistic groups. I conducted 25 telephone interviews, and though I am not fluent, I found that my second language ability was strong enough to include Francophones in the study, as planned. Telephone interviews can present particular methodological challenges, but this data collection method was chosen because it provided access to perspectives from across the country and an opportunity to reflect back on past experiences. Follow-up questions were sent to interview participants after the interviews to allow both the interviewer and interviewees to reflect back on and add to the conversation.

In sum, although cross-cultural interviewing complicated this study, both the interviewee and interviewer participated in constructing meaning during the interview – an interaction where culture and context were crucial to mutual understanding and which lead to a cooperative approach to mutual understanding.

The two upcoming chapters present the findings and analysis of these interviews and follow-up e-mail communications.

CHAPTER 4: SEARCHING FOR UNDERSTANDING

“Health literacy is thought to include the ability to find, understand and communicate health information and the ability to assess it” (Rootman & Ronson, 2005, p. S63). This definition neglects the dimension of health literacy that focuses on the ability to use health information (Nutbeam, 1998b), however it emphasizes the relationship between health literacy and general literacy, as well as computer, cultural, media and scientific literacy (Rootman & Ronson, 2005). How participants found, understood, communicated and assessed health information is the focus of the first four questions of the interview portion of the case study and the subject of this chapter. Part One will explore how interview participants sought health information and why they sought it in these ways. Part Two of this chapter will explore how interview participants made sense of health information and why they made sense of it in these ways. Information landscapes, or the sources and environments in which information is accessed and used, are the focus of Part One. Some of the social determinants of health arose as constraints and supports to the sense-making process and will be considered in Part Two. “Literacies” are among the supports and constraints at play in interview participants’ information landscapes and in the processes they used as they made sense of health information.

4.1 Part One: Information Landscapes

OK, I'll tell them all in no particular order. [Laugh] Books, the internet, my own family and friends. And here in Quebec we have something called Info-Santé as well.

-P14FE

The internet was a key information source for the CHN users interviewed, but they also reported using other sources, including books, newspapers, magazines, pamphlets, provincial telephone health information services, physicians, nurses, pharmacists, friends and family members. Previous studies have also found people consult multiple sources for health information (Hart et al., 2004; Wathen & Harris, 2007). Henwood et al. (2003) found general practitioners were the most important

source, and other human sources such as family members, friends and pharmacists were mentioned by study participants before media including the internet. These findings are consistent with studies of health information seekers who used the internet in public libraries in Vancouver, British Columbia (ACTION for Health, 2005) and in England (Harris, 2007). The interview participants in this study likely relied on the internet more than was found in the above-mentioned studies because they were recruited through the internet, and the internet was easily accessible to them. They all had internet access at home or both at work and at home, whereas 67.9 per cent of Canadians aged 18 or older accessed the internet from any location in 2005, 60.9 per cent accessed the internet from home and 26.3 per cent accessed the internet at work (Statistics Canada, 2006).⁹ Henwood et al. (2003) refer to the key information sources and media someone uses to access health information as an information landscape. These and other researchers who study people's health information seeking practices from a science and technology studies (STS) perspective do not assume the internet necessarily empowers its users but instead investigate how the internet fits into people's information landscapes (Henwood, Wyatt, Hart, & Smith, 2002; Wyatt et al., 2005).

In the field of library and information science, an information landscape is described as the environment in which information is accessed and used. It includes the place, resources and human supports available to the information-seeker (Cheng, 2001). From an STS perspective again, examining the context of internet use and non-use can help to shed light on the factors that shape the practices of health information seeking (Henwood et al., 2002). Among those interview participants in this study who sought health information for personal purposes, the environment or context in which they accessed health information included the perceived severity of their health issue and the accessibility of resources. For those who searched professionally, it included the accessibility of resources and their job requirements. The upcoming section will discuss why interview participants who searched for health information in their personal and professional lives said they did or did not use the internet. It will also discuss how the search strategies of interview participants influenced their information landscapes, as well as why they did or did not access the CHN website.

⁹ The percentage of Canadians who access the internet from any location counts an individual only once. The other two percentages are not mutually exclusive. For example, an individual included in the percentage who access the internet at home might also be included in the percentage who access the internet at work.

4.1.1 Personal Searches – Why (Not) the Internet?

All but two interview participants (P2EE, P21EE) spoke of seeking health information for personal purposes. Two factors – the perceived severity of the health issue they faced and the accessibility of various sources – typically influenced the source they used for personal health information. These analytic categories emerged from the interview data, in which participants spoke of the role of the internet in their health information seeking practices, specifying the sources they turned to in particular situations.

4.1.1.1 Severity of the Health Issue

It depends on the seriousness I suppose. If it was serious, I would call my physician right away and go in. If it's just something I'm sort of wondering about, then I'd probably ask somebody else what they thought, having experience with it. And I might look it up on-line, type in symptoms and things, and see what came up.

–P15EE

The urgency and severity of the health issue faced influenced the resource accessed by those interviewees who searched for health information for personal purposes. A pregnant woman and two mothers who quickly needed to figure out what to do in response to an urgent health issue reported calling the provincial telephone health information service (P11FF, P14FE, P15EE). P14FE called Info-Santé when her baby caught his first cold and she needed to decide whether it was safer for him to sleep in his crib or his parents' bed, but she goes to the internet when she faces a non-emergency. When P15EE's son double-dosed, she wanted to determine whether he needed to see a physician. She went to the internet first but soon realized her question could not be answered generically. She then called Telehealth Ontario, and based on her son's size and the medication, a pharmacist advised her he did not need medical care. In these instances, interview participants found the information they needed through human supports – specifically health professionals – accessible to them in their information landscapes because their context required an immediate, individualized resource.

When serious health issues arose, interview participants said they saw a physician (P1EE, P11EE, P15EE, P20EE, P25FE). Some recalled going to the internet before their appointment because they felt that by informing themselves about the health

issue, they could improve the quality of care and information they received from their physician. One participant said she went to the internet before going to the physician to figure out how to describe the pain in her shoulder succinctly in a short appointment (P20EE) and another to prepare to ask questions and make suggestions to his physician (P1EE). P25FE spoke of researching cancer treatment options so at her husband's next appointment, she could question his physician about the chosen treatment so she would get better information from the physician, understand more about the treatment and feel more secure. This information seeking approach demonstrates health literacy in that these interview participants found and understood health information from the internet and communicated it to their physician with the aim of better understanding their serious health issues, with the support of their physicians.

Interview participants facing minor health issues did not always mention seeing a physician, but those who did said they searched the internet after the appointment to clarify the physician's explanation or advice, particularly when the physician prescribed a medication (P1EE, P6FF, P16FE) or used unfamiliar terminology (P6FF, P14EF, P23FF). Participants also said they went to the internet or other resources when they felt their physician did not provide them with enough information about their health issue (P3FE, P14FE, P18FE). For example, a new mother said she looked in her baby books after her physician diagnosed a minor health issue in her son and told her not to worry, they would keep an eye on it. She wanted to understand the condition and different treatments (P14FE). "I have a lot of books on health for babies. So my first reflex would be to go to a book if I have one on that subject," said P14FE. One participant showed self-reliance when she spoke of diagnosing her daughter's pinkeye based on internet health information, seeing a physician for a prescription and discussing different treatments and contagion with a pharmacist (P22EE). P6FF said she went directly to the internet when a common health issue, such as a cold, arose. P19EE also showed self-reliance when she spoke of wanting to try a remedy recommended by her friend and looking on the internet, but she said she did not find the practical information about dosages and side-effects she would need to try it herself and planned to ask her physician about it at her next appointment. The internet was an often-called-upon resource among these interview participants who wanted to assume some responsibility for their health issues.

Among those participants in this study who reported searching for health information for personal purposes, most went to the internet to look up newly emerged health issues. Some participants also mentioned reading about chronic conditions and wellness on the internet. These findings are consistent with those of the Pew Internet and American Life Project, which found the most popular health topics of on-line searches are a specific disease or medical problem, a certain medical treatment or procedure, diet, nutrition, vitamins or nutritional supplements, exercise or fitness, and prescription or over-the-counter drugs (Fox, 2006, p. 4). Wellness topics searched by interview participants included diet, exercise, vitamins, supplements, public health (flu and chicken pox vaccines and pandemic flu preparedness), prevention (aging, stroke, diabetes, hypertension, osteoporosis, environmental causes of ill health) and mental health (stress, fatigue, depression, social isolation and adult learning). Interview participants also brought up the internet as a resource for satisfying curiosities (P7FF, P11FF), answering unimportant questions (P12FF) and finding general information (P4EE, P19EE).

Previous studies of health information seeking have found this practice is influenced by contextual factors that interplay with a person's self-reliance and health literacy, and the support of other people in professional and non-professional roles (Henwood et al., 2003; Wathen & Harris, 2007). Women in rural Canada reported visiting the hospital emergency department when an acute health problem arose, whereas they would often consult the internet in response to a chronic or nagging health problem. Whether they made contact with a health professional or engaged in self-care – or their degree of self-reliance – was influenced by the lack of locally available health services, other aspects of rural living, and their ability to cope with the volume and complexity of health information available (Wathen & Harris, 2007). For women in England who wanted to know about hormone replacement therapy, physicians remained an important source of health information. The resource they accessed was influenced by their willingness or reluctance to take on more responsibility for their health, their level of information and computer literacy, and the response of their health professional to an 'informed patient' (Henwood et al., 2003). Participants in this study often articulated a willingness to take responsibility for their health but continued to rely on physicians and other professional resources in information landscapes that included health issues of varying degrees of perceived severity, individual health literacy abilities and information needs arising from interactions with health professionals.

4.1.1.2 Accessibility

As Wyatt et al. (2005) suggest, “access involves much more than being in the vicinity of the right type of equipment: it also includes the gendered and generational social relations which form the context in which people’s daily interactions or non-interactions with the internet take place” (p. 213). In this study, the interconnected contextual factors of place, profession, generation and connectivity influenced whether interview participants accessed health information via the internet.

Place sometimes influenced the health information source accessed. Some interview participants reported relying heavily on an internet connection constantly accessible right in the living room (P3FE) or on the office computer (P22EE), and P9FF said her home internet connection was her major source of health information because her physical mobility was limited. Others mentioned referring to books they had at home (P8EE, P10EE, P11FF, P14FE, P16FE, P17EE, P23FF, P25FF), keeping an eye open for articles of interest in magazines (P3FE, P11FF, P14FE) and picking up pamphlets of interest at the community health centre or physician’s office (P9FF, P18FE). Place and profession influenced the health information sources of other interview participants. P23FF said she asked personal questions to nurses and physicians at work, and others had books (P10EE, P17EE) and periodicals (P10EE) at home because of their occupation. P25FE said she received health news through an internet bot¹⁰ on her work computer, but referred to her books when a minor health issue came up in her household because she would rather not return to the computer after a long day at work. P10EE also mentioned accessing the internet at work but referring to textbooks and her extensive paper filing system of articles at home because of a dial-up internet connection and much competition within her household for the phone and internet. For these women, the technology was made accessible to them in the workplace but was a less important information sources in their roles as mothers and wives (Wyatt et al., 2005).

In some contexts, participants chose not to use the internet, typically because they were inexperienced internet users while at the same time other sources were

¹⁰ An internet bot, or a web robot, is a software application that runs automated tasks over the internet, including the retrieval, analysis and filing of information from web servers (Wikipedia, 2007a). P25FE may have been referring to an RSS feed, which is a software program that checks whether content on user-specified websites was updated, retrieves new content and presents it to the user (Wikipedia, 2007b). Her point was technology that allowed her to view health news from multiple websites at once was available to her at work.

conveniently available. As P16FE put it, “I prefer reading something in the written form rather than on internet. Internet, and I’m only 65, but internet for me is not something I’ve mastered.” She also mentioned talking to people with expertise, such as nurse friends, pharmacists and librarians. A 55-year-old, who said she was getting better at using the internet to find health information but is not yet excellent, phoned the drug company instead of going to the internet when a health issue arose. “I don’t see why I wouldn’t though. It would be a resource for me. I just haven’t” (P10EE). A 54-year-old, who described her on-line health information seeking ability as a seven out of 10, recounted often finding the information she needed on routine health issues in a medical dictionary she received when she was a teenager (P7FF). Particularly among older interview participants, if a resource other than the internet was conveniently available and yielded helpful information, they consulted that resource. Slow or unreliable computers or internet connections limited some interview participants’ access to web-based health information, though the internet remained one of their sources (P4EE, P9FF, P17EE). As Wyatt, Thomas, & Terranova (2002) suggest, whether people stop using the internet can depend on how much time and money they have invested in hardware and software and learning to use the internet, as well as the availability of alternative means of accessing equivalent information and how far the user is embedded in social circles that value and promote internet use. It is important to note, however, the factors influencing people’s use of the internet are not always under their control. For example, P4EE said high-speed internet was unavailable in the rural area where she lived.

4.1.2 Professional Searches – Why (Not) the Internet?

Among the CHN users interviewed, seven participants or 28 per cent identified themselves as health professionals. One health professional said she was an ultrasound technician, and the other six said they were nurses working in a variety of roles. In the nursing literature, the internet is considered by some a resource for nurses’ continuing education, clinical decision-making and patient education (Cobb, 2004; Nicoll, 2002; Secco et al., 2006). As professional knowledge expands and the health care system changes, the roles of nurses also change and continuing education is essential (Griscti & Jacono, 2006). In this study, interview participants who reported searching for health information for professional purposes did so for two reasons – continuing professional education for themselves or other professionals, and patient or client

education. They identified their job requirements and the accessibility of the internet as the primary factors affecting the resources they used.

4.1.2.1 Job Requirements

Job requirements, connected with level of education, influenced how interview participants used the internet in their work as health care professionals. A nurse working in health promotion policy and programming for a regional health authority (P21EE), a nurse practitioner (P2EE) and an occupational health nurse who was also president of a professional association (P24EE), all of whom held at least a bachelor's degree, said they used the internet for continuing professional education. They relied heavily on the internet, but also mentioned consulting other sources, such as colleagues, textbooks, medical magazines (P2EE), the librarians at work (P21EE) and professional contacts (P24EE). A hospital nurse (P23FF), an ultrasound technician (P13FF) and a nurse who used the internet for insurance billing (P17EE) were college-trained and reported occasionally using the internet for continuing professional education or patient or client education. A parish nurse (P10EE) and the nurse practitioner (P2EE), both of whom held a Master's degree, said they used health information from the internet for patient or client education.

My colleagues, both medical and nursing consider disseminating health information both via internet sources and paper based part of their jobs. They also help to guide families to sources. This is often done in collaboration with myself and others who are aware of reputable sources. As a result of discussions about valuable patient resources, we have a number of websites listed in the computer in our parent quiet room/resource room (P2EE, e-mail communication).

This comment suggests that for health professionals to use health information on the internet in patient education, the support of other health professionals with advanced information literacy is often required. P23FF offered another example of when a collaborative approach to evaluating the quality of web-based resources legitimated their use in patient education. She said though she would never recommend websites to patients, one of her colleagues once found an excellent document on personality disorders, so they printed it and distributed it to patients, their families and the other nurses. P17EE said she would only share health information from the internet with patients with a physician's permission. "Basically unless it's the physician recommending something, it's not appropriate to direct someone to alternative

treatments, whatever, that kind of thing. You have to look it up for your own knowledge kind of thing” (P17EE). Nurses’ perceptions of their role educating patients through web-based resources were influenced by their job responsibilities and educational background.

Discussions in the nursing literature regarding the changing role of nurses as patient educators, at a time when patients search for health information on the internet, call on nurses to teach patients how to find and evaluate on-line health information (Jenkins, 2004; Nicoll, 2002; Timmons, 2001). Amongst those interviewed as part of the project reported here, only nurses with Master’s level education assumed this role, which suggests it requires a high level of information literacy, though time and differences between the jobs of Master’s- and baccalaureate-level nurses may also play a role. As Timmons (2001) suggests, teaching patients to find and evaluate web-based health information requires nurses to develop their own research, evaluation and communication skills. Other studies suggest nurses also need to develop their knowledge about using computers and the internet (Atack, 2003; Canadian Nurses Association, 2006b; Cobb, 2004). While a baccalaureate degree is now required for entry to nursing practice (Canadian Nurses Association, 2006a), only 2.4 per cent of Registered Nurses employed in nursing in Canada in 2005 held a Master’s degree in nursing, 31.5 per cent held a baccalaureate degree and 66 per cent held a diploma (Canadian Nurses Association, 2006c, pp. 2-3). Though the average age of a nurse employed in Canada was 44.7 years in 2005, it is likely the young nurses with advanced education entering practice will have the abilities necessary to use the internet in patient education.

4.1.2.2 Accessibility

The Canadian Nurses Association’s (CNA) e-nursing strategy aims to integrate information and communication technologies into nursing practice and the CNA developed the Canadian Nurses Portal as a gateway to a collection of resources and services on the internet to support ongoing professional development of nurses (Canadian Nurses Association, 2006b). However, in this study, those interview participants who worked in hospitals said they did not have internet access on-the-job (P13FF, P23FF, P24). An occupational health nurse working as a part-time consultant in an emergency department said she recalled a time when a patient had a condition she

had never heard of and she wanted more information, so she took her lunch break and went to the medical library.

I access [the internet] at home and I access it at work. I am unable to access it at my other job, which is the hospital in the ER. And that is very frustrating and very, very, um, like I used to work off-shore on a gas rig off Sable Island and I could access the internet. But because, you know, some physicians and paramedics couldn't help themselves but looking at porn, they stopped it all (P24).

She said nurses often need additional information, whether they look it up themselves or ask someone, and they should have the opportunity to look up information while practicing. As CNA (2006a) pointed out, for the internet to be accessible to nurses, administrators must consider it a priority and an important contribution to evidence-based practice, but even still, nurses' work may not be flexible enough to schedule time for computer use.

4.1.3 On-line Search Strategy

J'ai déjà quelques sites de santé que je connais. Je regarde ceux là. Je prends connaissance parce que je cherche dans les sites que je connais déjà. Pour la recherche plus approfondi, je peux aller sur Google, taper le là. Soit la maladie, soit, Google. Il y a MSN, ils y ont Copernic, il y a 13 moteurs de recherche. Appartir de là, j'en fait une recherche.

-P9FF

This interview participant is typical in that she used both general search engines and websites she knew to find health information. Interestingly, she went to websites she knew for basic health information but reached more depth through multiple search engines. The CHN users interviewed who relied only on general search engines were either strong internet users (P3FE, P15EE) or less skilled internet users who spoke of Google taking them places (P4EE, P17EE). Those interview participants who primarily visited websites they knew did so because it saved time (P5EE) and yielded reliable information (P10EE, P23FF) with little searching (P12FF). They described their internet skills as limited. While the CHN users interviewed indicated they faced challenges when searching the web, their abilities were advanced compared with the participants in Eysenbach and Kohler's 2002 study, most of whom used search engines, two tried to

guess a web address and none started their searches at medical portals or the websites of medical societies or libraries.

While the information-seeking approach of interview participants related largely to internet experience, their choice of search engines and websites was somewhat influenced by their language and culture. Most interview participants used Google, with the exception of P24EE, who used Ask.com instead of Google, and P2EE, who used both Ask.com and Google. Some Francophone interview participants used multiple search engines (P7FF, P9FF), as well as a wider variety that included Copernic (P3FE, P9FF), MSN (P9FF), Toile de Québec and Canoe.ca (P7FF, P18FE). These search engines either are Quebec-based or provide content in French. Surprisingly few Quebec-based websites were mentioned by the Francophone interview participants. The websites they did mention were Passeport Santé (a consumer website on the use of complementary and alternative medicine with traditional medicine) (P13FF, P25FE), Service Vie and Canal Vie (on-line health and lifestyle magazines) (P13FF), websites of the Quebec health department (P14FE, P16FE, P23FF) and the Quebec menopause centre (P16FE). Doctissimo.fr (P7FF, P13FF, P23FF) and e-santé.fr (P23FF) were the only French websites mentioned. Otherwise, the Francophones recalled using Canadian or American websites, often in English. The Anglophones recounted using a wide variety of Canadian and American websites. The only websites mentioned by more than one Anglophone interview participant were the Mayo Clinic (P1EE, P8EE), Pubmed/Medline (P8EE, P19EE) and the Centre for Disease Control (P5EE, P24EE). Similarly popular among Anglophones and Francophones were e-mail newsletters other than the CHN's (P1EE, P10EE, P11FF, P16FE) and Google Alerts (P1EE, P3FE, P16FE), but on-line bulletin boards or discussion groups were more popular among the Anglophones (P6FF, P8EE, P10EE, P15EE, P24EE), though predominantly unpopular among the interview participants.

4.1.4 Why (Not) the Canadian Health Network?

The CHN was not the first choice of websites or the only website most interview participants visited. With the exception of P12FF, who visited only the CHN to learn about her father's symptoms of mental illness, the interview participants used general search engines or visited more than one website they knew, sometimes including the

CHN, when a health-related question arose. Figures 4.1 and 4.2 summarize how interview participants accessed and used the CHN website.

Figure 4.1 Access to the Canadian Health Network Website

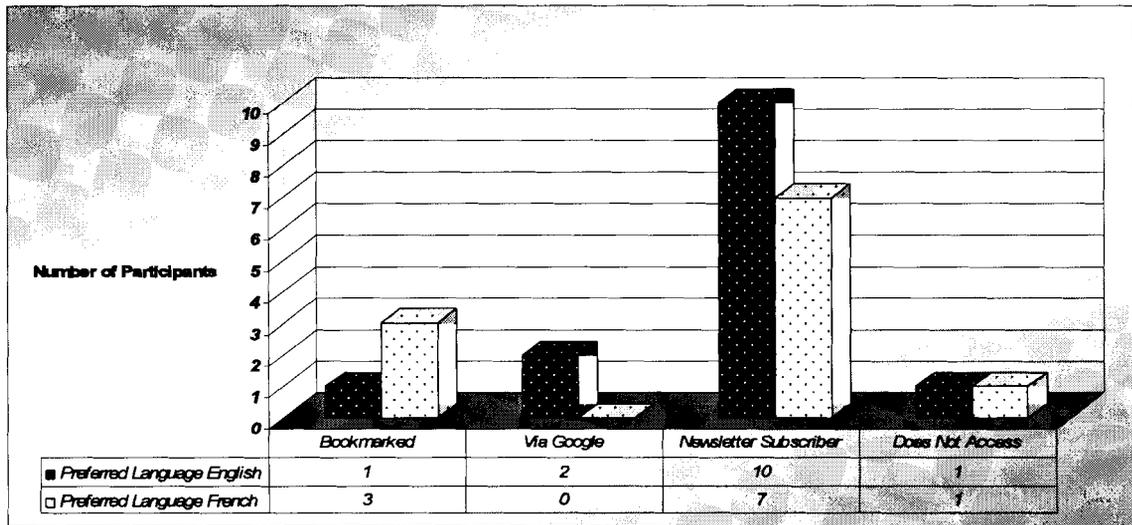
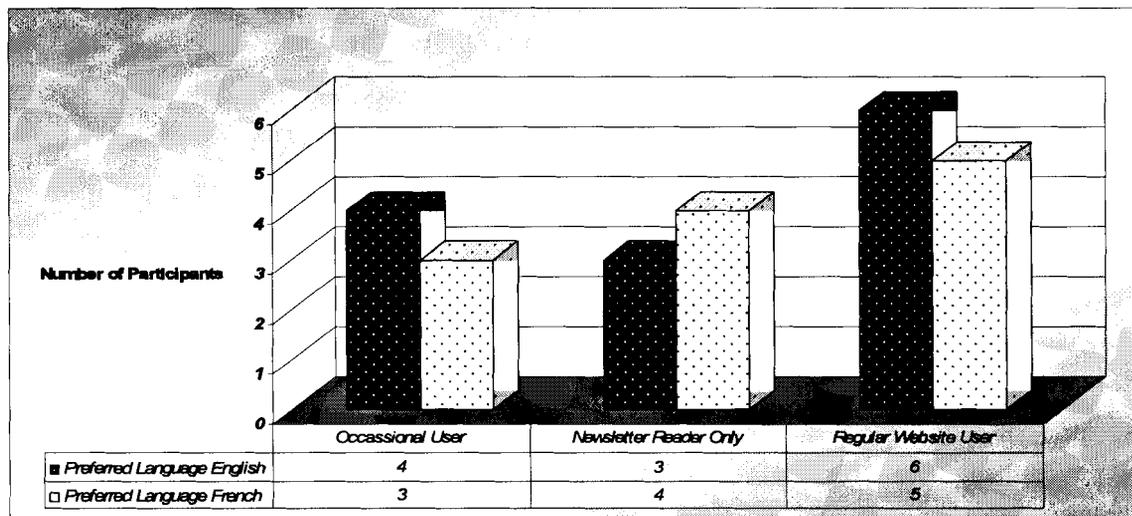


Figure 4.2 Use of the Canadian Health Network Website



The behavioural model of information seeking on the web of Choo, Detlor and Turnbull (2000) is useful for understanding when interview participants used the CHN. According to this model, information seekers visit portals when they need information on

a general area of interest or their specific need has yet to reveal itself. This type of browsing leads to “serendipitous discovery.” Though information seekers who know what they are looking for may monitor the CHN or use its search tool, Choo et al.’s (2000) study found those who could formulate simple queries went directly to known websites or used search engines most frequently, while those who could specify targets in detail used search engines most frequently.

Consistent with Choo et al.’s (2000) model, the CHN users interviewed who said they found the CHN too basic were conducting extensive searches on specific topics of personal or professional importance (P2EE, P3FE, P6FF, P8EE, P10EE, P16FE). Some interview participants said they did not find the CHN relevant. P1EE and P11FF found the newsletter topics were not of interest, P2EE needed paediatric-focused information, P7FF found her medical dictionary more helpful for the routine health issues she needs to look up, and P16FE did not think a website is an effective way of relating to people older than age 40. Only two participants mentioned finding the website difficult to navigate, specifically the menu choices were not helpful in finding information (P17EE) or it took time to find the desired information through the pathways (P24EE). Some participants facing these constraints looked elsewhere for health information (P1EE, P2EE, P3FE, P7FF, P11FF, P17EE), while others continued to use the CHN in combination with other sources (P6FF, P8EE, P10EE, P16FE, P24EE). Comparing the information between websites was also a strategy used by many interview participants to locate additional information and determine its credibility. Despite describing the CHN as trustworthy, accurate, interesting, user-friendly and up-to-date, and appreciating that the CHN is Canadian, bilingual and covers a breadth of issues, most interview participants chose to also visit other websites as part of their information seeking behaviour.

4.2 Part Two: Sense-Making

[The internet is] not interactive. In the sense that you have information but sometimes, you know, it gives you some questions. More questions on something. And you don't have the..., you know, you don't have anybody on your side to tell you if that kind of information can relate to you or say that...it can be true but only in those circumstances. So you have to be careful.

–P18FE

The sense-making aspect of the definition of health literacy considered in this chapter includes the ability to understand and assess health information. To explore how interview participants made sense of health information and why they made sense of it in the ways they did, both individual and societal factors require consideration. As Rootman and Ronson (2005) suggest, health and learning are so closely interconnected that the socio-cultural determinants of health also determine literacy. The Public Health Agency of Canada (2003) currently identifies the following key determinants of health: income and social status, social support networks, education and literacy, employment/working conditions, social environments, physical environments, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, gender and culture. Four social determinants of health emerged through the interviews as influencing participants' ability to understand and assess health information – education, culture, language and social support networks. Language is not among the Public Health Agency of Canada's social determinants of health, but the US Institute of Medicine's Committee on Health Literacy included language among the conditions that affect individual ability to participate fully in a health-literate society (Nielsen-Bohlman, Panzer, & Kindig, 2004), and wrote, "health literacy must be understood and addressed in the context of culture and language" (p. 10). This section explores the constraints and supports at play when CHN users made sense of health information, as they relate health literacy and the above-mentioned social determinants of health.

4.2.1 Education

Rather than considering only the highest level of formal education attained by interview participants to explore the relationship between education and health literacy, I also considered lay and professional knowledge about health. I set out to explore

whether health professionals would experience fewer challenges in understanding health information they obtained on the internet, given their formal training and background knowledge. Unlike Bessell et al. (2002), I did not exclude health professionals from this study because I presumed they have the skills and training that enable them to interpret the quality of health information in a manner different from the public. I expected lay participants would develop background knowledge through experience, informal learning and the study of particular topics of interest that may help them make sense of on-line health information. My thinking was influenced by the sociology of health and illness, which explores the particularity of reflexively constituted lay knowledge developed through a process of 'bricolage' rather than formal training (Busby, Williams, & Rogers, 1997).

The health professionals interviewed acknowledged their formal training helped them understand on-line health information, but they also faced constraints in the sense-making process. The nurse practitioner interviewed found her extensive knowledge of health helpful. She said, "considering the sources that I'm looking at, absolutely. I don't tend to look at public sources often. It's normally medical sources. So I expect the information to be at a certain level" (P2EE). She was among the health professionals who said they found it challenging to come up with the right keywords for a relevant, focused search of credible sources (P2EE, P10EE, P21EE, P24EE). Other health professionals encountered health information that was difficult to understand or confusing (P17EE, P21EE). As a nurse explained,

I think it depends on the audience too of who it's written for. If it's written for a layperson versus a health professional. And even the type of health professional. You know, sometimes it can be far more than what you need and it's not in, sort of easy language to understand. And I feel quite fortunate because I'm, you know, in the business, so I think you sort of have a better understanding of some of the health literature out there (P21EE).

Her background knowledge aided the sense-making process, but health care is a field of disciplines and specialties, therefore the limits of one's knowledge necessarily constrains both lay people and health professionals.

Lay participants interviewed also considered their knowledge of health a support to sense-making (P1EE, P3FE, P8EE, P11FF, P14FE, P15EE, P24), though some seemed to consider it natural or a given (P4EE, P13FF, P16FE). "Yes, I do. It's, it may

not be conscious, but I'm sure I do" (P20EE). "C'est une sujet qui m'a beaucoup attirée. Donc, si je peux prendre des connaissances une petite par ci une petite peu par là, mais c'est sûr qu'il accumule aux long des années" (P7FF). Whether it was apparent or latent, lay and professional knowledge of health did support the sense-making of many interview participants. Limited health knowledge was a constraint for some lay participants. P6FF said she had difficulty knowing what keywords to enter into search engines to retrieve a manageable number of relevant results, P8EE said she did not know how to spell the condition she was searching but the search engine caught her mistake, and P6FF said she needed the brand name rather than the generic name provided by her physician to look up information on a medication. Other lay participants recalled retrieving websites that were too medically advanced for them to easily understand (P7FF, P8EE, P12FF, P14FE, P15EE, P20EE).

When lay participants shared other examples of instances when they could not find the information they were looking for on the internet, it was unclear whether the constraining factor was their knowledge of health or their skill in using the internet. For example, P6FF could not find any information on the reasons a particular illness develops and P19EE could not find the practical advice she needed to try a remedy. What Norman and Skinner (2006) call the composite skill of eHealth literacy "requires that people are able to work with technology, critically think about issues of media and science, and navigate through a vast array of information tools and sources to acquire the information necessary to make decisions" (para. 1). It was often difficult to isolate which component of eHealth literacy was constraining for interview participants. Ability to find the information they wanted might depend on the keywords they chose – searching for "plantar fasciitis" would likely yield more relevant results than "foot hurts" (P8EE) – which would depend on their health knowledge, or in this case, support received from a massage therapist who provided the terminology. However, the ability to find the information they wanted might also depend on selecting relevant websites and the proper operators for searching in different interfaces, as well as the critical thinking skills to judge what information is relevant and reliable.

Health literacy could be developed through the education system (Rootman, 2004), and some interview participants, both lay and professional, credited their education with providing them with the skills to find and understand on-line health information (P1EE, P2EE, P4EE, P5EE, P24EE). Though difficulties reading basic

health-related information are typically associated with low literacy (Rootman, 2004), those interview participants with graduate degrees reported difficulties finding precisely the information they wanted. For example, they found information that was too technical or too simplistic (P8EE), faced the constraint of limited internet skills (P16FE), concluded the information was unavailable (P19EE) or produced search results with too many irrelevant hits (P22EE, P25FE). Lay participants (P5EE, 6FF, P8EE, P11FF, P15EE, P21EE, 25FE) and some health professionals (P2EE, P10EE, P13FF) were overwhelmed by the amount of health information available on the internet. Only two participants (P2EE, P21EE) mentioned refining their keywords to narrow their search. The other participants relied on their judgement as they went through the list of hits looking for the most helpful or reliable websites. Quantitative studies reporting on-line health information seekers are more highly educated than those who seek health information through non-internet sources (Cotten & Gupta, 2004) or that once people gain access to the internet, its use is similar across education levels (Brodie & Flournoy, 2000) do not shed light on the constraints faced even when those people with formal health education and advanced degrees make sense of web-based health information.

4.2.2 Culture

The ideas, meanings and values of the Francophone community can differ from those of the dominant culture, therefore health literacy within this cultural group was identified as a priority for literacy and health research in Canada (Rootman & Ronson, 2005). The Francophone interview participants in this study accessed health information websites developed in other cultures, which constrained their sense-making process by requiring them to assess whether the information was relevant in their context and then to adapt the information to their context. As the US Institute of Medicine pointed out, “culture provides a context through which meaning is gained from information, and provides a context through which people come to understand their health status and comprehend options for diagnosis and treatments” (Nielsen-Bohlman et al., 2004, p. 109).

Francophone interview participants mentioned visiting Canadian websites and websites based in the province of Quebec, as well as French and American websites. None of the interview participants indicated they preferred Quebec-based websites, but many preferred Canadian websites to European websites because they found it

challenging to determine whether information originating in Europe was relevant to their situation. Interview participants who reported searching for information on mental health topics mentioned this constraint in particular because they found the French approach to mental health different from the North American approach (P3FE, P18FE). Similarly, some Anglophone interview participants faced challenges making sense of health information from the United States because of different standards of practice (P22EE) and measurement units for heart, haemoglobin, blood work and cholesterol (P10EE). P14FE found it difficult to use home remedies from European websites because they use different weights and measures, and found information on alternative approaches to health was more readily available on European websites because Europeans are more accepting of these approaches than is typical in Canada. P23FF and P16FE remarked that different medications and supplements are available in Europe than in Canada. Though several Francophones had no concerns about using European health information (P6FE, P9FF, P13FF, P25FE), making sense of health information obtained on websites originating in other cultures required a higher level of health literacy because interview participants needed to assess the cultural perspective of the website and then consider it from their own cultural perspective.

Anglophone and Francophone interview participants both considered websites with information based on medical research or clinical practice reputable. With the exception of P19EE, who mentioned searching for information about a home remedy, only Francophones spoke of searching for information related to complementary and alternative medicine (P13FF, P14FE, P16FE, P25FE). This difference may be influenced by the availability of information on the use of alternative and complementary medicine in conjunction with traditional medicine through the Quebec-based internet health portal PasseportSanté.net funded by la Fondation Lucie et André Chagnon (PasseportSanté.net). Two Francophone participants mentioned this portal (P13FF, P25FE). The CHN web survey found Francophones were more apt to recommend content on the CHN website to others, whereas Anglophones were more likely to recommend links found through the CHN website (EKOS Research Associates, 2006). Portals such as PasseportSanté.net and the CHN may play a more important role in the information landscapes and sense-making processes of Francophone participants in light of the smaller web-presence of French-language health information.

4.2.3 Language

For non-native English-speakers, literacy issues are compounded by language and specialized medical vocabulary (Nielsen-Bohlman et al., 2004). Most of the Francophone interview participants reported visiting both French- and English-language websites, with the exception of a few interviewees whose English-language ability was limited (P11FF, P12FF, P23FF). Some of those who were not reading in their mother tongue found the information difficult to understand (P13FF), particularly when they encountered medical terminology (P7FF, P11FF, P20EE). Other language-related challenges arose due to differences in how Canadians and Europeans speak the French language. P7FF said she avoided European websites because they contain terminology inappropriate for North America, and P16FE found the Parisian French used on most websites “misleading.” P14FE and P16FE said they mostly visited English-language websites because they found less health information available in French, and P11FF thought Francophones lack reliable, complete, interesting, well-publicized health information websites. Contradictorily, P13FF and P25FE found there are enough health-related websites on the internet in French.

In Statistics Canada’s 2000 General Social Survey, nearly 40 per cent of Francophone respondents felt there was not enough French-language content on the internet, whereas this issue was negligible among the Anglophones (Statistics Canada, 2001, para. 25). Estimates of the number of websites in various languages vary, though the internet is predominantly English. One website estimates 68 per cent of websites are in English and three per cent are in French (Global Reach, 2004, para. 42), while another estimates 56.4 per cent are in English and 5.6 per cent are in French (netz-tipp.de, 2002, para. 1). Clearly, those who consult French-language websites are drawing from a much smaller pool than those who consult English-language websites, though this may not influence whether they use the internet in their first language. A UNESCO study that questioned the assumption English dominates the internet found that in only a minority of groups in a minority of situations did non-native English speakers use the internet in English rather than in their national language (Wright, 2006). The smaller number of French-language websites may support the sense-making process for Francophones, given the challenges presented by the overwhelming amount of health information available on the internet in English.

Differences in impressions of the availability of French-language websites among this study's interview participants likely relate to awareness. The interviewees who thought there were enough mentioned established French-language health information portals, *PasseportSanté.net* (P13FF, P25FE) and *Doctissimo.fr* (P13FF), whereas P11FF, P14FE and P16FE did not refer to these tools. Similarly, none of the interview participants referred to CISMef (catalogue and index of French-language medical sites). This might be considered the French version of Medline and MedlinePlus, which only two Anglophone participants mentioned using (P8EE, P19EE). CISMef was designed at Rouen University Hospital in France to help health professionals, medical students and the public find the information they are looking for "among the tons of documents available on-line" by correcting and refining their queries (Soualmia & Darmoni, 2005). While such tools exist, they are consistently underutilised, likely because users are unaware of their presence on the internet or visit multiple websites as part of their information seeking behaviours.

4.2.4 Social Support Networks

As the quotation that opened this section suggests, internet use can be an isolated and isolating activity. P18FE explained that information found on the internet can raise questions, and it can be difficult to figure out what information is personally relevant when there is no one there to ask. P16FE conveys a similar idea differently.

You're on internet and you're in your room, it seems that the, uh, the information is just so close to you, while most of the time it's something that belongs to another country, or it's not, uh, you know. There's a question of, I don't know if I express myself sufficiently, clearly enough, but it's just like if, you have the impression that the information is right there, but then, uh, it's more, it's much more complex than that (P16FE).

She prefers talking with people who have expertise over spending time on her computer, which is not surprising in light of a previous study that found women health information seekers in rural Ontario consult with a collection of formal and informal sources who provide not only information but also time for discussion and caring interaction (Wathen & Harris, 2006). Wyatt et al. (2005) found that health information seekers rely heavily on "warm experts" or intermediaries not only for their technical competence, but also for their help with making sense of complex medical knowledge. Chapter 5 will discuss how

the CHN users interviewed in this study use of web-based health information in their own role as intermediaries.

Though some interview participants recounted no instances of receiving help from other people to make sense of on-line health information (P4EE, P9FF, P13FF, P20EE), most spoke of interacting with their social support networks in some way during this process. Several participants said they posed questions arising from on-line health information to physicians (P3FE, P6FF, P7FF, P11FF, P13FF, P15EE, P20EE) and pharmacists (P6FF, P16FE), while some had friends or family members with health care training to consult. P6FF said she asked her sister and her sister's partner, both of whom were nurses, for more details related to what she found on the internet, P10EE said she e-mailed a health-related question to her sister, a nutritionist, and P16FE said she posed questions to her nurse friends. Some of the health professionals interviewed said they sometimes asked colleagues about personal health issues (P23FF), locating a specific piece of information (P24EE) and accessing resources (P2EE). Other interview participants mentioned that family, friends or colleagues recommended websites to them (P8EE, P10EE, P14FE, P17EE, P23FF). Interview participants hardly used librarians. One participant contacted a librarian to research the authors of articles she found on the internet to determine their reputability (P16FE) and a health professional asked her organization's librarians to conduct literature searches for her (P21EE). Interview participants drew on the human resources immediately available to them, and their sense-making process rarely occurred in isolation.

Seeking support via the internet was not popular among interview participants, unless they felt the person providing the support held expertise. Many indicated they did not consider personal experiences documented on the internet reputable (P6FF, P14FE, P18FE, P20EE, P21EE). P15EE said when she faced difficulties understanding on-line health information about learning disabilities, she posted a question to an on-line bulletin board for the parents of children the same age as hers. She said she found it helpful to read information from someone who had experienced the situation and could explain information in lay terms. Some interview participants mentioned consulting their professional contacts via e-mail or a listserv to locate health information and answer health-related questions (P10EE, P24EE, P25FE). While P1EE and P17EE said they sometimes read on-line discussion groups, none of the other interview participants did. P14FE's firm "I do not chat on the internet" is representative of the general feeling that

the practice was unfamiliar or unaccepted by interview participants. P25FE said she might be more inclined to participate if a community of physicians brought expertise to the discussion so it would be more focused and less opinionated. Drawing on Bakardjieva's (2003) typology of different forms of on-line involvement, most interview participants held a rationalist ideal of internet use in which they turned to the internet for timely, accurate, reliable information, or approached on-line discussions as rational interaction in which information and ideas were exchanged.

4.3 Chapter Summary

This chapter explored the supports and constraints that influenced how interview participants searched for health information and made sense of the information they found. In Part One, this chapter considered why interviewees conducting searches for personal and professional purposes did or did not use the internet in general and the CHN website in particular. It also considered why interview participants adopted the on-line search strategies they did. Part Two of this chapter considered four individual and social factors that influenced the sense-making processes of interview participants – education, culture, language and social support networks. Different types of “literacies,” including computer, cultural, media and scientific literacy, came into play during the information seeking and sense-making processes of interview participants. Chapter 4 contributes to a more nuanced understanding of the health information seeking and sense-making process than was articulated in the policy discourse related to the CHN, as discussed in Chapter 2.

Part One of Chapter 4 found the CHN users interviewed did not rely on the internet exclusively as a source of health information, but rather consulted a wide variety of people, media and health care services, often to support their use of another source. The source consulted was influenced by the interview participant's context, which included the accessibility of resources and either their job responsibilities or the perceived severity of the health issue they faced. If the health issue was urgent, serious or even minor, interviewees typically consulted their physician, often in conjunction with the internet. They only used the internet, without consulting any other sources, for information related to wellness, chronic conditions and inconsequential questions. Issues related to accessibility, including place, connectivity and profession influenced the resource used, and language, culture, internet experience, level of education and

information literacy also played a role. Figure 4.3 summarizes these relationships graphically. It provides a model demonstrating the relationships that emerged from interviews with participants (shaded shapes), as well as relationships that are likely to exist, based on this research, but were not specifically identified by interview participants (unfilled shapes). Though the interview participants were aware of the CHN, in only one instance was it the only website consulted. They typically used general search engines and websites they knew provided health information, their on-line search strategy influenced by internet experience, language and culture.

In Part Two, some of the social determinants of health, namely education, culture and social support networks, as well as language, emerged as influencing participants' ability to understand and assess web-based health information. While lay and professional knowledge of health contributed to interviewees' ability to make sense of health information obtained on the internet, the critical thinking skills developed through advanced education also played an important role in the sense-making process. The Francophone interview participants often accessed health information websites developed in other cultures, which constrained their sense-making process by requiring them to assess whether the information was relevant in their context and then to adapt it to their context. Many Francophone participants accessed health information in English, while underutilizing the French-language health information resources available on the internet. Social support networks were important to the sense-making process of most interview participants, networks that typically existed in their non-virtual lives.

The next chapter presents the analysis of how interview participants used the health information they obtained on the internet and understood that information through their sense-making processes.

CHAPTER 5: USING KNOWLEDGE

The US Institute of Medicine Committee on Health Literacy used the following definition of health literacy, developed in 2000 for the National Library of Medicine: “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman et al., 2004, p. 32). By emphasizing the connection between finding and understanding health information and making use of it, this definition adds another dimension to health literacy beyond what was discussed in Chapter 4. As was discussed in Chapter 2, the intended overarching policy outcome of on-line health information was an empowered public that made informed choices about their health and health care (Advisory Council on Health Infostructure, 1999). This chapter explores the last two questions to which I sought answers in the interview portion of the case study – how interview participants used the health information they found and why they used it in the ways they did. The distinct approaches to health information use in the literature on health care and health promotion, as well as interview participants’ descriptions of how they used health information obtained on the internet, contributed to the development of three categories of use – health care decision-making, supporting others and what the CHN calls “healthy choices” (Public Health Agency of Canada, n.d. a). Lastly, this chapter will explore interview participants’ use of the CHN website in light of the ways in which they used health information on websites in general.

5.1 Health Care Decision-Making

Wolf, Chan, Harris, Sheridan, Braddock, Kaplan, Krist, O’Connor, & Tunis (2005) suggest the roles and expectations of patients and health care providers have changed in the internet era. Whereas the paternalistic physician with exclusive purview over medical knowledge once chose the best treatment for patients, ideally, the patient now engages actively in decision-making. These authors account for this shift in treatment paradigms in part due to increased patient autonomy, broader access to information, expanding clinical options, ascendancy of chronic illness, complex trade-offs and greater accommodation of personal values. Patients, however, may not want this

new role, may face cognitive and emotional challenges, or may not have the knowledge required to engage in their roles as treatment partners. Clinicians, on the other hand, may not be ready to partner with patients, in part because the health care system was not designed to support informed patient decision-making (Woolf et al., 2005). Given these complex interrelated factors, patients may not necessarily inform themselves about their health issues or use their knowledge to become actively involved in health care decision-making. Previous studies of how people use on-line health information have identified other constraints to the emergence of the 'informed patient' (e.g. Hart et al., 2004; Henwood et al., 2003) and other ways besides decision-making for patients to participate actively in their health care (e.g. Barbot, 2006; Eggly et al., 2006). In this study, interview participants used on-line health information for three purposes related to their health care – understanding, peace of mind, active engagement with their physician and informed decisions to access health services. Though interview participants actively informed themselves about their health issues, they rarely engaged in the role of treatment partner with their physician.

5.1.1 Understanding and Peace-of-Mind

Well, it was just more informative than anything. It really didn't, it didn't change anything or anything like that. It was more just more information. I'm just one of those types that the more information I have, the happier I am [laugh].

-P20EE

This participant's attitude towards on-line health information was echoed by other interviewees who viewed it as a means to expand their understanding or to put their mind at ease, rather than to make informed decisions regarding their health care or to engage more actively with their physician. However, the health information appeared to have more significance for the other interview participants who used on-line health information for understanding or peace-of-mind. P3FE spoke of giving herself the whole picture of her health issue, and P13FF said she alleviated some of her mother's worry, as well as her own, by researching her mother's condition between the visual examination and the biopsy. P9FF mentioned feeling less afraid of health issues, and P14FE said that she understood her baby's physical and behavioural reactions better after on-line searching, making her a more confident mother. P16FE found out how drugs would impact her body to prepare for side-effects, P6FE found out about the

medical testing she was undergoing, and P7FF informed herself about fibromyalgia, a condition affecting people she knew. In using health information obtained on the internet to become more knowledgeable or to feel more secure, these interview participants escaped the disempowerment inherent in ill-health but did not empower themselves to make informed decisions.

Numerous studies found health information obtained on the internet was helpful in understanding health problems, among other effects (e.g. Morahan-Martin, 2004, Peterson et al., 2003; Wathen & Harris, 2007). Using on-line health information for developing knowledge is often discussed in the context of chronic conditions. The Pew Internet and American Life project reported 39 per cent of its survey respondents said on-line health information changed the way they cope with a chronic condition or manage pain (Fox, 2006, p. iii). Becoming informed is a way for patients to participate actively in their health care. In Hibbard, Stockard, Mahoney, & Tusler's (2004) conception of the activated patient and consumer with a chronic disease, the first stage is believing they have an important role to play in managing their care, whereas the subsequent stages are knowing how to manage the condition and having the skills and behavioural repertoire to do it. According to this conception of the activated patient, taking the initiative to alleviate concern and understand the condition through independent research is a prerequisite of informed decision-making. By gathering the information, patients also reduce the need for someone else to provide this information to them, so in this way, they played an active role as it relates to their health.

Empowerment, summarized in Chapter 1, is difficult to define and measure. In a study of men with prostate cancer, Broom (2005) explored whether the internet reduces feelings of powerlessness, helplessness, hopelessness, loss of a sense of control over one's life and dependency. He found the internet did empower some respondents by giving them a sense of purpose and control, which had a profound affect on their ability to deal with the illness. Ziebland (2004) found another sample of cancer patients talked about using the internet to develop expertise and present a type of competence and social fitness. Consistent with the interview participants described above, on-line health information was useful for improving understanding and building a sense of control, though it is not empowerment defined in terms of making informed decisions.

5.1.2 Active Engagement with a Physician

Other interviewees used on-line health information to participate actively in their appointment with a physician. P1EE said he used the information to ask questions and make suggestions, and P9FF mentioned directing her physician towards a solution to a problem she was experiencing with her eyes. These interview participants valued medical expertise but wanted to ensure their physician made the most appropriate decision, while others wanted to glean the best information possible from their physician. P20EE recalled researching shoulder pain so she could better explain it to her physician in her short appointment, and said she kept in mind some of the suggestions she read for alleviating pain, in case they corresponded with her physician's advice. P25FE spoke of researching cancer treatment options on the internet, but rather than attempting to influence her husband's care, she recalled using the information to question his physician so she would understand the chosen treatment better and feel more secure (P25FE). These interview participants were able to remove themselves from a position of disempowerment in the medical encounter, but they did not empower themselves to make informed decisions regarding their health care.

Researchers studying people's use of on-line health information have focused extensively on its role in the patient-physician relationship (e.g. Anderson, Rainey, & Eysenbach, 2003; Broom, 2005; Hart et al., 2004). Other researchers (Henwood et al., 2003; Kivits, 2006) have focused specifically on the emergence of the 'informed patient', "who is said to be empowered through information acquisition and the associated decline of the asymmetrical physician-patient relationship" (Kivits, 2004, p. 511). According to some studies, an 'informed patient' need not necessarily take on responsibility for decision-making. Question asking in medical encounters was considered an indicator of active participation (Eggle et al., 2006). Street, Gordon, Ward, Krupat, & Kravitz (2005) suggest patients who actively participate in medical consultations provide their physicians with valuable information for diagnosis and treatment, tend to receive more information and support, and are generally more committed to treatment plans and more satisfied with the care they receive. By using on-line health information to ask questions and make suggestions, interviewees participated actively in their medical appointments as 'informed patients' without making decisions regarding their health care.

Barbot (2006) suggests on-line health information is used to question the legitimacy of medical decisions, however, consistent with the findings of this study, other researchers found patients who looked up their health issues on the internet continued to trust their physicians. Henwood et al. (2003) found respondents made a distinction between informing themselves and disclosing to their physicians what they learned through the internet, the boundary between the expert health professional and the patient remaining robust. For Kivits (2004), the importance of being informed about one's own health is not solely for personal management, but rather "the reflexive project of the informed self" connected to the contemporary imperative of the information society (p. 525).

The objective of gathering information about a health condition or ailment is undertaken neither to assert specific medical knowledge nor to challenge professionals. By becoming more knowledgeable, the objective of information seekers is to expand and make meaningful their everyday health experience, within and outside the medical interaction (Kivits, 2004, p. 521).

This study found on-line health information often complemented physician expertise and supported the patient-physician interaction. In effect, interview participants were getting a second opinion on the internet, which is not necessarily a challenge to physician's recommendation but rather a confirmation of the physician's diagnosis.

5.1.3 Informed Decisions

Only two interview participants spoke of making an informed decision related to their own health care after consulting their physician and conducting research on the internet. P1EE said he decided not to take the medication his physician prescribed because he thought the problem was less severe than his physician did. P22EE recalled choosing not to have her children vaccinated for chicken pox, despite her physician's advice, because she did not find enough medical evidence to support the vaccination through her research. The only other health care-related decisions interview participants reported making independently of their physician were whether to access health care services. P12FF spoke of choosing to arrange a mental health examination for her father after researching his symptoms on the internet. P22EE said she used on-line health information to determine her daughter had pinkeye, and then took her to her general practitioner for a prescription and talked to a pharmacist about treatment and

contagion. P15EE, however, was unable to decide whether to take her son to a physician using the internet. Her son had double-dosed, and the information she found on the internet was not specific to his size and the medication he took, so she called Telehealth Ontario and talked with a pharmacist. In none of these instances did interview participants avoid engaging with a health professional, though had they determined their health issue was minor based on on-line health information, they may have chosen not to access health services.

Attfield, Adamns, & Blandford (2006) found that establishing whether a consultation was necessary was a motivation for seeking health information from telephone health information services, knowledgeable peers or the internet. A rationale behind assessing the need for medical care was to avoid wasting health system resources and personal time on minor problems that do not require treatment (Attfield et al., 2006). As discussed in Chapter 2, the CHN did not intend its users to make decisions regarding whether to access health services based on its website. Rather, the CHN intended its website for educational and informational purposes (Public Health Agency of Canada, n.d. c). While people can trust their bodies when they feel ill and seek health care when they feel it is necessary, as Attfield et al. (2006) argue, interpreting physical symptoms requires general knowledge of the relationship between symptoms and conditions. "An informal diagnosis is frequently a necessary part of correctly recognizing that help is required" (Attfield et al., 2006, p. 174). In this sense, researching symptoms via the internet can either quell worry or, with timely care, act as a preventative measure by keeping them from escalating into a more serious condition.

5.2 Supporting Others

There's at least three days a week where I'm with elderly people and trying to understand, first of all, the information they receive from their physician. Because they don't understand, they're too shy to have the physician repeat himself. Or too shy to show him that they don't understand what he's saying. And I find this is one of the major problem in helping the elderly. So uh, I find most of my task is trying to understand, to help them, first of all help them understand why they received that new medication, help them to find the questions they should have asked the physician concerning that medication, you know. I'm just a link, if you like, between the physicians, mostly between the physicians and the patient, and the elderly person.

-P16FE

This interview participant reported conducting research about the medications prescribed to the elderly people she accompanies to their physician and communicating to them the information she finds because they are unable to locate the information themselves. Returning again to the definition of health literacy considered in Chapter 4, a key aspect is the ability to communicate health information (Rootman & Ronson, 2005). Many interview participants, both lay and professional, recounted instances when they acted as an intermediary to find and assess health information for someone else and communicate it to them. In Chapter 4, I discussed how the interview participants as health information seekers spoke of drawing on “warm experts” or intermediaries for their technical competence and for help with making sense of complex medical knowledge (Wyatt et al., 2005). Interview participants also recalled using on-line health information in their own role as intermediaries. They spoke of supporting others by recommending specific websites and helping them understand the relevance of the information. Only three among the 25 interviewees did not speak of acting as a formal or informal health information intermediary in some capacity for someone else (P7FF, P8EE, P18FE). Given that only seven interview participants identified themselves as health professionals, 15 were acting as health information intermediaries with no formal health training. Three of the 15 lay health information intermediaries acted in this capacity as part of their paid work (P4EE, P5EE, P22EE).

5.2.1 Patient or Client Education

Several health professional and lay interview participants appeared to engage in patient or client education by recommending particular websites and communicating health information obtained on the internet in other formats. A parish nurse spoke of guiding people by preparing handouts with references including websites (P10EE). A nurse practitioner said she printed parent handouts from websites and had posted a list of recommended websites on the computer in the parent quiet/resource room (P2EE). P22EE said she provided information from websites via mail or e-mail in response to questions from members of the public in her work with a health organization.

Other interview participants said they used on-line health information on the job as background for facilitating other people’s understanding of health issues. In her work in rural development, P4EE said she shares information with different groups of people in different ways ranging from picture boards to wikis, depending on the level of general

literacy and computer literacy.¹¹ The parish nurse mentioned using internet health information in oral presentations and maintained paper files of information on health topics in case someone requested information (P10EE). As a physical education teacher, P5EE said he “walks the walk” by choosing healthy behaviours. “I talk about other choices to make, with athleticism, etcetera and proper fuel, etcetera. So, but, you know, having a can of Coke in my hand would certainly raise the odd eyebrow” (P5EE).

As was discussed in Chapter 2, this manner of using on-line health information was anticipated by the CHN, which targets health professionals in particular with the expectation they can facilitate people’s access to web resources. The Community Intermediaries Research Project of the University of New Brunswick emphasized the role of community organizations as providers of government information and services (Rideout et al., 2006). Wathen and Harris (2006) suggest public libraries and public health services should be explored as venues to provide information and health literacy skills. The findings of this study support their suggestion, though the range of professionals who support health information seeking and communicate health information appears to extend beyond the library and public health centres to other institutions including churches, schools, health organizations, hospitals and rural development organizations.

5.2.2 Continuing Professional Education

In providing information resources from the internet to colleagues, interview participants seemed to contribute to the continuing professional development of others. P10EE, the parish nurse, mentioned printing an article and handing it to her pastor so he would take time to read it. The nurse practitioner said she prints articles and distributes them among her nursing staff (P2EE). As a consultant in programming and policy for a regional health authority, P21EE described herself as a knowledge broker who conducts research, determines what is appropriate for practice and sends it to nurses in the field. She said many if not most of her staff used the internet as part of their work, and she supports them by recommending useful websites for themselves or their clients (P21EE, e-mail communication). P24EE, president of a professional organization, said she e-mailed resources to colleagues when they requested information or when she expected

¹¹ A wiki is a website that allows visitors to add, remove and edit content. It is a collaborative technology for organizing content on websites (Wikipedia, 2007d).

they would find a particular website or article interesting for their practice. The health professionals who reported using on-line health information as resources in their practice by maintaining paper files of articles on health topics for future reference (P10EE), learning from others about parent teaching rather than reinventing the wheel (P2EE) and looking up information for self-knowledge (P17EE) support others indirectly through their own continuing professional education.

While the CHN anticipated health professionals who used the CHN website would share information with patients, clients and students, it did not anticipate they would use the information in professional development (EKOS Research Associates, 2006). This did occur among the interview participants. The nurse practitioner recalled distributing to her nursing staff articles relevant to nursing and health and lifestyle issues, and P24EE mentioned she sent an article from the CHN about mixing green tea with medications to the occupational health nurses' organization she leads. While a website such as UpToDate (www.uptodate.com) provides clinical information to health professionals, and the internet is used in professional development in nursing (e.g. Atack, 2003; Cobb, 2004; Griscti & Jacono, 2006), the transfer of web-based health information between health professionals is not typically explored in studies of on-line health information use.

5.2.3 Lay Intermediaries

In their personal lives, interview participants facilitated access to on-line health information for family and friends. Several participants spoke of sending articles or website links (P3FE, P9FF, P11FF, P12FF, P13FF, P19EE) and looking up information on behalf of friends and family (P13FF, P14FE, P17EE, P20EE, P23FF, P25FE). One interviewee provided this type of support through an on-line community. P3FE reported maintaining a website with links to other relevant websites for fellow parents of children with mental health issues. However, most interview participants supported people within their non-virtual support networks.

I'm a bit selective on what I tell [my mother]. [laugh] She worries a lot. So knowing that sometimes information on there can be, I mean it can be inaccurate in general, or to the specific circumstances. I tend to just sort of give her the broad generalities and tell her where I found it, and if she wants to look it up, then she can (P20EE).

This interview participant supported her mother by locating relevant websites and communicating the information to her with interpretation. P1EE, on the other hand, did not recommend websites to a friend but instead verbally shared the information he found through his own research. When a friend who was recently diagnosed with a condition asked him how serious it sounded, he shared his thoughts, told him the hopeful signs and answered his friend's questions. Previous studies of on-line health information use among laypeople do not typically mention supporting the information seeking of others, and have generally focused on the independent nature of health information seeking on the internet (Morahan-Martin, 2004). As was discussed in Chapter 4, family and friends are often part of a person's information landscape.

5.3 Healthy Choices

*C'est aussi de la prévention un petit peu, comme la grippe aviaire.
Ça serait intéressant de savoir un peu qu'est qui peut se passer là.
Ça aussi je regarde aussi un peu plus générale, même si ça ne
touche pas encore, mais pour prévenir un peu là.*

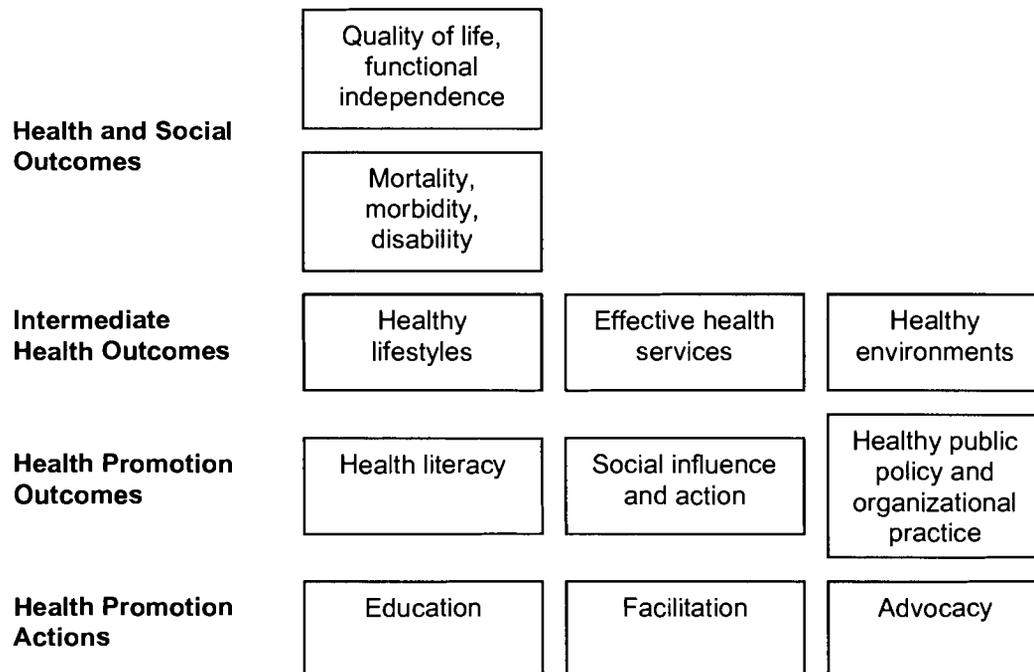
–P6FF

This interview participant sought information out of interest in what was happening in other places and how to prevent illness if avian influenza were to arrive in her community. Though she did not report taking action based on the information in this instance, she was among six interview participants who mentioned they incorporated health information from the internet into their lives. Given that interview participants were recruited through the CHN, surprisingly few mentioned instances when they fulfilled the CHN's mission to "promote healthy choices" or its vision that individuals and communities would "make informed health decisions that improve their quality of life" (Public Health Agency of Canada, n.d. a) based on health promotion and disease and injury prevention information obtained on the internet. Some interview participants recalled using the information in exercise routines (P10EE, P16FE, P22EE), meal planning (P10EE, P22EE), and vitamin and supplement usage (P10EE, P16FE). P6FF and P14FE said they used the information to prevent illness in their families, while others spoke of using it to protect their own health related to cholesterol (P16FE, P23FF), blood pressure, diabetes, heart disease and other conditions related to ageing (P16FE). P10EE mentioned using on-line pandemic preparedness plans to stock her home, and

P16FE said she made her home safer. These types of healthy choices are consistent with the CHN's mission.

Instances of using on-line health information for health promotion and disease and injury prevention to make informed health decisions likely arose infrequently in the interviews for three reasons: the nature of health promotion, social determinants of health and problems with the study design. The Ottawa Charter defines health promotion as “the process of enabling people to increase control over, and to improve, their health” (World Health Organization, 1986, p. 1). Valued outcomes include empowerment and changes to the social determinants of health because they improve the capability of individuals to take action (Nutbeam, 1998a). In Nutbeam’s outcome model for health promotion (1998a, p. 30), reproduced below in Figure 5.1, the most immediate target outcomes of health promotion interventions are modifications to the personal, social and structural factors that are a means to improve people’s control, thereby changing the social determinants of health (intermediate health outcomes). This highlights the distance and complexity separating the consumption of on-line health information as a health promotion action and any resulting health and social outcomes.

Figure 5.1 An Outcome Model for Health Promotion¹²



In seeking health information, interview participants engaged in all three of the health promotion actions in Nutbeam’s model. He defined education as the creation of opportunities for learning. Facilitation includes the formation of partnerships between individuals, and advocacy is undertaken on behalf of individuals and communities (Nutbeam, 1998a). Interview participants learned through their health information seeking and facilitated the learning of others through their intermediary roles, and parents advocated on behalf of children. For the most part, the outcomes of the health promotion actions undertaken by interview participants, in both the realms of healthy choices and health care decision-making, fell into the health literacy and effective health services categories of Nutbeam’s model. Examples falling into the categories of healthy lifestyles did arise in the interviews, though fewer than expected from this sample of CHN users.

The second reason interview participants rarely mentioned instances of informed choice relates specifically to the social determinants of health. As the Public Health Agency of Canada (2003) explains the social determinants of health, “at every stage of

¹² This model is reproduced with permission from Don Nutbeam.

life, health is determined by complex interactions between social and economic factors, the physical environment and individual behaviour. These factors are referred to as 'determinants of health.'" Among the social determinants of health are social support networks, health services, employment/working conditions and social environments.

AM: Do you find that you're able to use the information you find on the internet for the purpose you had in mind when you started looking or started reading?

P18FE: Most times no. It's a question of motivation, to change things in your life, in your lifestyle, it's not easy. And if you don't have any social environment to motivate you or you don't see a physician often. So, uh, it somehow isn't easy to change. Give you information that can, you know, make you, uh,...to something, but to change yourself, like to change your, uh, uh, eating habits, it's not easy, you know. Information can help, but it cannot do all the work, you know.

P18FE is a 51-year-old man who retired from his job with the federal government last year because of his health problems. He is bipolar and diabetic. He does not have a strong social network, and without help from anyone, he searches the internet for organizations and groups in his neighbourhood "to have some social health." Despite his ability to find and understand on-line health information, these personal, social and structural factors influence his ability to make healthy choices.

The third reason relates to the study design. In the follow-up e-mails, I asked some interviewees whether the health information they found on the internet had impact or consequences for them or their families. This question yielded insightful answers, and posing it to all interview participants may have lead to more instances of health decisions. Those who responded that the information had consequences provided examples of when they used it to protect or improve their health (P6FF, P10EE, P16FE, P22EE), with the exception of P12FF who felt the reassurance or diversion of on-line health information was a positive consequence. P14FE said she was empowered by the information.

I would say that internet info definitely helps me to prevent illnesses or better understand my baby's reactions (either physical or behavioural) and you know what they say...information is power! Basically I would say I am a much more confident and less stressed out mom thanks to all the information that I receive through web newsletters and various baby web sites (P14FE, e-mail communication).

Even though P23FF put into practice advice from the internet or shared it with her family, she only credited the internet with improving her knowledge, whereas P7FF did not consider her learning or satisfied curiosities a consequence. In light of structural factors and the gap between information consumption and use in a health promotion model, interview participants may have required more prompting to identify instances when they made healthy choices, though it is interesting that few made the connection between the information and its application.

5.4 Using the Canadian Health Network

C'est automatiquement, oui. Mais c'est just en mettant le courriel dans le fond. À part de ça, je vais pas beaucoup sur leur site là. C'est juste pour regarder les liens qu'ils m'envoient qui m'intéresse là. Je vais voir un petit peu, puis c'est tout. Oui.

–P11FF

When this interview participant automatically received the CHN's e-mail newsletter, she read what interested her but never went to the CHN website to seek additional health information. Other interviewees also found the newsletter interesting but made no mention of basing health decisions on what they read there (P2EE, P5EE, P8EE, P9FF, P11FF, P13FF, P15EE, P18FE, P20EE, P23FF, P25FE). As P2EE explained, "it almost seems kind of like a medical newspaper. It's topical, um, it's easy to understand. It would not be one of my first sources of information necessarily. It kind of, like I said, it kind of reminds me of a newspaper, but a specialized newspaper for the public." Some participants said they did not find the CHN website useful because the information was not of interest (P1EE, P7FF), too basic (P3FE, P6FF, P8EE, P16FE, P25FE) or difficult to find on the website (P17EE), while a few interviewees provided examples of when they found CHN content useful. P20EE said it re-enforced healthy behaviours such as exercise and behaviours to avoid such as smoking, P8EE said it offered great articles about mental health and stress at work, and P19EE mentioned it brought to mind healthy practices such as encouraging children to wear sunglasses. The few instances when participants may have made health decisions based on information from the CHN website, compared with their emphasis on the information's value in terms of interest, suggests the CHN was not achieving its mission to promote healthy choices. However, health promotion is an activity directed towards enabling people to take action rather than constituting an outcome in its own right (Nutbeam,

1998a). Therefore, those interview participants who read the CHN webpages and shared them with other people engaged in the health promotion processes and used the CHN towards the end its architects intended.

As was discussed in the “supporting others” section of this chapter, interview participants often shared health information they obtained on the internet with other people, and in some cases, this information came from the CHN. In addition to the examples previously described, the high school teacher said he recommended the CHN to students as a resource for class projects (P5EE) and P9FF said she shared information from the CHN’s newsletter with her children. The parish nurse explained that she posted CHN information on the bulletin board she updates monthly and used it in presentations and handouts (P10EE), and P21EE said she found the CHN website helpful when researching healthy schools for policy and programming at a regional health authority.

The line between decisions regarding one’s own health care, as discussed earlier in this chapter, and decisions that help a person stay healthy and prevent disease is not always clear. As was discussed in Chapter 2, the CHN encourages its users to contact a health professional if they have a medical problem (Public Health Agency of Canada, n.d. c) and does not provide information regarding treatment options. One interview participant, however, was able to find the information she needed on the CHN to decide whether to seek medical care for her father, likely because mental health is one of the 14 topics the CHN covers. In researching her father’s symptoms of mental illness on the CHN and sharing the information with her family so they could assess whether to arrange a medical examination, P12FF recounted making a decision based on CHN information that falls beyond the scope of the website. P12FF wrote that she wanted to make an informed decision because the consequence of her action was significant – after arranging her father’s mental health examination, he wanted her dead, he stopped speaking to her and everything changed for her. P12FF’s circumstance illustrates the health information needs of Canadians are complex and can intersect with issues of health care or extend far beyond the narrow scope of health promotion and disease and injury prevention.

5.5 Chapter Summary

In this chapter, I introduced three categories of health information use – health care decision-making, supporting others and healthy choices – and discussed how, in each category, interview participants often found on-line health information useful but in the majority of instances did not make decisions regarding their health and health care based on the knowledge they gained.

While some interview participants recalled using health information to engage more actively with their physician, in most instances their priority was to understand the health issue better and to alleviate concern, rather than to participate in decisions regarding their health care. Though most interview participants did not empower themselves to make informed decisions using health information obtained on the internet, they took steps away from the disempowerment inherent in ill health and the medical encounter.

Interview participants used on-line health information in their roles as professional and lay intermediaries by recommending websites they considered reputable and helping others to understand health issues. The role of information intermediaries from the perspective of those who use the internet for the purpose of helping others seek and understand health information requires future study.

Few interview participants reported making informed choices based on health promotion and disease prevention information because of the distance that typically separates the consumption and use of such information, which also make it challenging for individuals to recognize and recall when they used what they learned through their research. The social determinants of health, including social support networks and education and literacy, also make it challenging to make lifestyle changes. While reading CHN information out of interest and passing it on to other people fits within the health promotion model, it is difficult to assess whether these activities would lead to behavioural changes. Health promotion programs are notoriously difficult to evaluate because of the long time-lag between action and outcome, and the technical challenges of isolating cause and effect in complex, 'real-life' situations (Nutbeam, 1998b, p. 358).

The next chapter discusses interview participants' use of health information obtained on the internet in light of their information-seeking behaviours and the supports and constraints at play in the sense-making process, as presented in Chapter 4.

CHAPTER 6: DISCUSSION

The final interpretive phase of a case study reports the learned meaning of the case (Creswell, 2007). When I presented the methodology for interviewing CHN users in Chapter 3, I introduced the theoretical propositions that served as a foundation for this case study. These theoretical propositions will guide the discussion, which aims to interpret the meaning of the case towards the end of refining existing theory and suggesting complexities for further investigation. I will discuss the experiences of the CHN users interviewed in relation to the theoretical propositions and in light of the policy assumptions and context of the CHN, which I previously discussed in Chapter 2. Some key themes threaded through the case study – language and culture, the role of health professionals in the public’s use of on-line health information and “literacies.” These themes will figure prominently in this discussion of how the supports and constraints at play when interview participants made sense of health information came to bear on their use of this information.

6.1 Driven to Understand

The first theoretical proposition leading the case study was that CHN users sought health information for reasons arising from their lived realities, and these did not necessarily conform to system-level goals for on-line health information (Dervin, 1999; Wathen & Harris, 2006). Also, users may challenge expert information rather than accept and follow (Dervin, 1999). The CHN users interviewed did seek health information for reasons arising from their lived realities, and while these reasons were sometimes consistent with the goals for the CHN, in other instances, they extended beyond its intended scope. Interview participants rarely challenged their physician’s expertise, and they all accepted the medical approach, including the few who also search for information about alternative approaches to health or made decisions regarding their health care contrary to their doctor’s advice. The lived realities of interview participants often included the health information needs of those around them.

The CHN users interviewed did speak of reading the type of health promotion and disease and injury prevention information provided by the CHN out of general interest or an interest in protecting or improving their health. In addition, health issues arose in their lives or the lives of their family or friends that lead them to search for health information. Caring for a sick child, undergoing diagnostic testing or receiving a prescription arose in interview participants' lives, just as wanting to prevent osteoporosis or cope with depression did. As was discussed in Chapter 2, federal policy-makers and the CHN Division have recognized the Canadian public's need for information related to emerging health issues, in addition to health promotion and disease and injury prevention information, but they have not addressed this need through the CHN website. Previous studies that discuss the use of web-based health information typically focus on people living in particular circumstances, including patients experiencing cancer (Ziebland, 2004) and menopause or erectile dysfunction (Hart et al., 2004), or women living in rural communities (Wathen & Harris, 2007). This study contributes insight into the diverse health information needs of members of the Canadian public through clear distinction between searching for health information, the use of health information for specific health issues, and for health promotion.

The CHN users interviewed predominantly used the internet, in connection with other sources, to expand their understanding of health care and health promotion, to help others understand these topics, and to participate more actively in their health care and protecting their health. Consistent with these uses of on-line health information, for the most part, interview participants did not challenge medical expertise but instead supplemented it. The CHN users interviewed conceptualized health narrowly, compared to participants in a recent study of the health information needs of rural Canadians, who also sought alternative or natural approaches to treatment and wellness (Wathen & Harris, 2007). Both studies, however, found Canadians want to understand health topics ranging from childbearing and parenting, to nutrition and exercise, to treatments and diagnoses.

6.2 Varied Landscapes

The second theoretical proposition was CHN users seek health information from multiple sources and various websites and media (Henwood et al., 2003; Wyatt et al., 2005), and this accurately describes interview participants' health information seeking

behaviours. The practice of consulting more than one resource for health information appeared to support the sense-making process of interview participants. For example, interviewees spoke of clarifying a physician's explanation by going to the internet or books, looking up medical terminology from websites in a medical dictionary, and asking questions of a physician or pharmacist based on health information from a website. Interview participants also mentioned visiting multiple websites to find reputable sources that presented relevant information at a level of complexity they needed and understood. Conceptualizing the internet as a resource that, in conjunction with other sources and supports, can help people understand health topics is different from the perspective offered by Henwood and colleagues (2003), whose study focused on factors constraining the emergence of the 'informed patient,' however both approaches question the assumption that the internet necessarily empowers health information consumers.

The interconnectedness of the processes of searching for and making sense of health information through multiple sources seems on the surface a counter argument for a government web portal such as the CHN, that provides a single point of access to specific information, however, it can also serve to support the need for the CHN. CHN users interviewed said government was a trusted source of health information and, similar to participants in previous studies (Broom, 2006; Eysenbach & Kohler, 2002; Wathen & Harris, 2006), they faced challenges determining the reliability of websites. The CHN users also said they found the CHN interesting and useful, among the other resources they accessed, for some types of information. Some participants who offered suggestions for improving the CHN emphasized the need to expand the website and raise its profile. P8EE recommended addressing the lack of in-depth knowledge on the CHN by building layers of detail within the website, starting with high-level summaries and then drilling down from there, ending with links to the medical literature. P18FE suggested building connections between related health topics for users, for example, on a page about depression include health promotion information on the benefits of walking such as endorphins and links to local walking clubs. Some participants remarked how little the CHN is publicized (P18FE, P11FF, P20EE), and P11FF suggested the broadcast of a television show that presents the various features of the CHN. It was telling that some participants could not remember the CHN's name or seemed to refer to the CHN, the Public Health Agency of Canada and Health Canada interchangeably (P8EE, P12FF, P14FE, P24EE). As was argued at the Canadian Radio-television and Telecommunications Commission hearings on new media (Canadian Radio-television

and Telecommunications Commission, 1998), promoting the creation of highly visible, inclusive, attractive and useful public portals is likely more effective than regulating large commercial, monopolistic portals. A similar argument applies to the CHN. If the CHN website were advertised more extensively and it were to provide a more diverse range of content, and Canadians were to find the health information they needed there, the CHN website might begin to figure more prominently in the health information landscapes of Canadians than it did for participants in this study, and therefore play a larger role in supporting their information seeking and sense-making processes.

Expanding the CHN website's scope, however, is not a substitute for building the "literacies" of Canadians. Even if health information seekers found more through the CHN, the findings of this study suggest they are still likely to consult other websites as part of their information and sense-making processes. Consistent with the findings of studies that focused on the internet in general, a tool such as the CHN does not replace the support of health professionals or members of people's personal networks in understanding health issues (Wathen & Harris, 2007; Wyatt et al., 2005). Neither does the CHN eliminate the need to improve the literacy and health of Canadians through a combination of health communication, education and training, and community, educational, organizational and policy development (Rootman & Ronson, 2005).

6.3 The Complexity of Context

The third theoretical proposition was that CHN users employ multiple, dynamic, situation- or context-dependent strategies to seek, make sense of and use health information (Dervin, 1999; Wathen & Harris, 2006). Three main situation- or context-dependent factors influenced how interview participants sought, understood and used health information – the health issue they faced, the place where they accessed health information and the social determinants of health.

It is not surprising the nature of the health issue influenced how interview participants sought health information, given participants in Wathen and Harris' 2006 study reported that a nagging or chronic problem lead to an internet search, whereas an urgent health situation called for a visit to the hospital emergency department or general practitioner. Interestingly though, none of the CHN users interviewed mentioned visiting the hospital, perhaps because they did not consider health crises as information-seeking or they accessed telephone health information services and walk-in clinics instead. This

difference between these two studies also emphasizes the importance of place. The CHN users lived in a mixture of urban and rural areas, whereas Wathen and Harris studied women living in rural Ontario, who faced shortages in health services.

Place, in terms of household and workplace, also influenced the information seeking of the CHN users interviewed. Internet connectivity, computer functionality and social relations within the home encouraged some interview participants to access the internet at work, while the job responsibilities of other interview participants influenced whether they had internet access at work. As Wyatt et al. (2005) suggest,

Access is not simply a matter of kit and connections; nor is it only about providing people with the education and skills necessary to use the equipment. Access involves feeling comfortable with the technology and not being afraid of it. It also involves living in a household where the sexual division of labour enables women to get involved with the machine (p. 208)

This study of CHN users began to investigate similar issues in the context of the workplace by considering the use of web-based health information by professionals working in health-related fields. Observations about collaboration among health professionals with varying levels of education and information literacy to facilitate internet use among patients and health professionals require further study. The next section will explore the social determinants of health as constraints and supports to making sense of health information and using it.

6.4 Constraints and Supports

The fourth theoretical proposition leading the case study concerned how constraints and supports, including intermediaries (Wyatt et al., 2005) and computer, information and health literacy, influence sense-making and information use (Henwood et al., 2003; Wathen & Harris, 2006). While intermediaries and these “literacies” did play a role for the participants of this study, the influencing factors were more extensive and interconnected than anticipated. It was helpful to consider the foreseen constraints in the context of the social determinants of health, specifically education, culture and social support networks, and in relation to language, to explore their complexity.

Interview participants’ prior professional or lay knowledge of health supported the sense-making process, as did advanced education, however even highly educated interview participants and those with formal health training faced challenges finding and

making sense of web-based health information. Some of these constraining factors were similar to those identified in prior studies. Examples are the overwhelming volume of information available on the internet (Wathen & Harris, 2006) and the need for personal resources, including basic reading and numeric skills, information literacy and health literacy to find and interpret web-based health information (Wathen & Harris, 2007). This study, however, emphasizes that the skills, “literacies” and prior knowledge required are not necessarily basic or easily applied in the context of on-line health information seeking.

Health information websites originating in Europe or the United States constrained the sense-making process of some interview participants by requiring them to assess the websites’ relevance in the Canadian context and consider the health information from their own cultural perspective. Different cultural approaches, as well as practical considerations such as the United States’ system of measurement, presented challenges to using health information from other countries. This finding again emphasizes the advanced health literacy often required to make sense of on-line health information, particularly for French-speaking Canadians who may have different views of health (Rootman & Ronson, 2005) and may not realize they are accessing health information from another country. Eysenbach & Kohler (2002) found health information seekers sometimes ended up in websites based in other countries without realizing it and the information there was not necessarily applicable in their context. When discussing physician responses to unsolicited e-mail requests for medical advice, Eysenbach & Diepgen (1998) wrote:

Physicians who give medical advice have to take into account different, ethical, cultural, or economic backgrounds of patients, as well as variations in health care settings and delivery systems, which might preclude the availability of certain therapeutic or diagnostic procedures (p. 1335).

On-line health information-seekers must consider these differences as well. The CHN links to some Canadian resources on the internet, as does Google’s “pages from Canada,” however only one interview participant mentioned using the latter tool and all but one interview participant also visited websites other than the CHN, which again speaks to the importance of continuing to develop the health literacy abilities of Canadians.

Francophone interview participants who accessed health information in English faced the constraint of understanding medical terminology in a language other than their mother tongue. Some of those who sought health information in a second language were constrained by the availability of French-language websites, despite the availability of established French-language health web portals, tools similarly underutilized by French- and English-speaking interview participants. The challenge of retrieving relevant information in the mass of health information available on the internet is not unique to English-speakers – French researchers have identified this challenge as well (Soualmia & Darmoni, 2005). This study begins to reveal some of the challenges experienced by French-speaking Canadians who seek health information on the internet, an area of inquiry unexplored thus far in the English-language literature.

When interview participants encountered information on the internet that was difficult to understand or confusing, they often consulted another person with expertise developed through formal health care training. Previous studies have found a similar need for support from social networks within information-seekers' lived contexts (Wathen & Harris, 2007; Wathen & Harris, 2006; Wyatt et al., 2005), however the value information-seekers placed on interpersonal sources with health care expertise was not uniform across these studies. This study of CHN users suggests complexities to the role of the health professional as an information intermediary. The health professionals interviewed experienced some of the same constraints as the lay people did, though the health professionals did have access to additional supportive resources through their work. The intermediary role from the perspective of the health professional therefore requires further investigation, which should include a focus on their informational needs.

6.5 The Question of Impact

The final theoretical proposition was that information may be useful, useless or harmful (Dervin, 1999). This study suggests certain complexities to these three possibilities, particularly given the factors influencing information consumption and use raised in the preceding discussion. The study also suggests complexities in necessarily connecting information obtained on the internet to specific outcomes, since a person might use health information for another purpose at another time than they had initially intended.

The health information seeking described by the CHN users interviewed was never useless because it served to develop their overall health literacy, which may support the process of health information seeking, sense-making and use in some way in other situations. The interview participants who read health information, including the CHN newsletter out of interest were not engaging in a useless activity but increasing their knowledge, or learning (Ellis in Choo et al., 2000). The two CHN users interviewed who did make health care decisions based on information from the internet and their physician were both knowledgeable lay people, therefore increasing knowledge may also support information use. Dutta-Bergman (2004) suggests information gathering on the internet is an active process and therefore a viable mechanism for informing what he calls “health conscious individuals” about different preventions and treatments (pp. 285-286), “health conscious” meaning positive attitudes towards measures, such as exercise and healthy eating (p. 275). The CHN users interviewed demonstrated a positive attitude towards health promotion and health care information through their participation in the study and recounted their previous experiences seeking health information, and therefore would likely use the information they gathered on the internet when it becomes relevant in their lives.

Given the findings and analysis presented in Chapter 5, health information obtained on the internet was useful to the interview participants. Some acted on the information by engaging with a physician, by making a health care decision or a healthy choice, or by supporting another person’s information seeking and sense-making process, while others used it for understanding or peace-of-mind. An unexpected use of on-line health information arising from this study was the sharing of web-based health information between health professionals. This finding suggests internet use in the context of health is a collaborative learning project among people with varied knowledge, experience and ability. Not only do people with expertise support those with weak internet skills or a low level of literacy, internet users appear to guide each other through the web and use the technology to share information with each other.

The issue of harm in relation to web-based health information is complex. Perspectives on harm may vary, as may perspectives on the patients’ role in communicating their symptoms and values to physicians. A 2001 survey asked United States physicians what they saw as the effect on health outcomes of the patient bringing health information from the internet to a visit. Seventy-five per cent of physicians

believed that the information had made no difference to the patient's health outcome, 21 per cent believed it had improved the health outcome and four per cent believed it had been deleterious (Murray et al., 2003). However, in this study of CHN users, two interview participants mentioned an occasion when they made decisions based on health information obtained on the internet that contradicted their physician's advice, and others said they thought the information they brought to the appointment from the internet improved the care they received from their physician. It is not known whether any harm came to the interview participants who made their own health care decisions or whether they will experience negative consequences resulting from these decisions in the future. In a letter to the editor of the British Medical Journal, Eysenbach (2002) describes a project undertaken by his research unit to collect cases of adverse events related to the internet in a database.

Cases include misdiagnosis or wrong treatments due to on-line prescription of drugs or medical consulting over the internet; the discontinuation of lifesaving treatments because patients have misinterpreted internet information; the addictive potential of the internet; and the potential of the internet to encourage suicide (para. 6).

However, the patient perspective on harm also requires consideration. Some patients may choose not to follow their physician's advice because of religious beliefs or other values. Patients may also perceive the physician's diagnosis or lack of diagnosis as harmful, particularly when they know something is wrong with their body and care deeply about resolving the problem. For example, according to the Canadian Hemochromatosis Society, until recently physicians were taught this condition was extremely rare, so symptoms were attributed to other causes, early symptoms went unnoticed and individuals went undiagnosed until irreversible damage has occurred (Canadian Hemochromatosis Society). This suggests harm can come to both to those who do and do not assume some responsibility for understanding their health issues.

6.6 Chapter Summary

In this chapter, I discussed the findings of interviews conducted with CHN users presented in chapters 4 and 5 in relation to each of the five theoretical propositions leading the case study and the policy assumptions and context of the CHN, as discussed in Chapter 2.

Most of the case study findings were consistent with the theoretical propositions, however complexities unexplored in previous studies did arise. The lived realities of interview participants did drive their searches for health information, an activity they pursued to expand their understanding of the health issues that touched their lives rather than to question medical expertise. The CHN users interviewed consulted multiple websites and sources for health information, a practice that supported the sense-making process. Complex, context-related factors influenced whether interview participants sought health information on the internet and how they understood and used this information. Considering the supports and constraints to interview participants' use of web-based health information from the perspective of the social determinants of health helped to explore their interconnectedness and complexities. It was argued that none of the health information seeking of interview participants was useless, however the dispersed nature of health information seeking activities and use of the health information obtained makes it difficult to identify instances when health information is useful or harmful.

The concluding chapter presents an overview of this thesis, discusses the limitations of the study and offers suggestions for further research.

CHAPTER 7: CONCLUSION

This thesis has explored the complexities of the ways 25 people from across Canada who had visited the CHN website used the internet to understand health and put the knowledge they gained to use in their lives. This chapter will review the key elements of the thesis, discuss the limitations of the research and suggest areas for future research that build on the case study undertaken in this thesis.

7.1 Review of Thesis

The intent of this study was to investigate the basic assumptions underlying the construction of the CHN website and consider how they fit with people's actual use of the website. After introducing the technology of the CHN website, I explained that the study was undertaken within an action research approach. The CHN Division was involved in defining the research problem, which also allowed access to study participants and the opportunity to present the study findings to the organization that manages the technology. Focusing this case study on a government health web portal and differences between French- and English-speaking Canadians' experiences finding, understanding and using web-based health information arose through the research partnership with the CHN Division and a review of e-health literature related to consumer and patient use of web-based health information. The social construction of technology approach guided this investigation of the various meanings federal policy-makers, the CHN Division and CHN users have attached to the CHN website during its ongoing process of development.

I investigated the basic assumptions underlying the construction of the CHN website through a discourse analysis of federal policy documents related to CHN and a focus group with the CHN Division (Chapter 2). The mandate of the CHN focused narrowly on promoting healthy choices by communicating health promotion and disease and injury prevention information. The federal policy discourse also assumed the CHN website could also support self-care and individual health care decision-making, and Canadians, in consultation with a health professional, want to take more responsibility

for their health. The federal policy discourse and the CHN Division assumed the CHN website would contribute to improving the accessibility of on-line health information by providing Canadians with easy access to high-quality, accurate, trustworthy health information.

In Chapter 3, I presented the methodology for interviewing CHN users to understand actual use of the CHN website. More specifically, the aim was to gain a better understanding of the supports that English- and French-speaking internet users draw on and the constraints they experience when making sense of health information from the internet and putting it to use in their professional and personal lives. I argued the telephone interviews were the only viable method of reaching a sample population in geographically diverse locations. It allowed participants to reflect back on and describe their past behaviours in seeking, understanding and using health information in multiple contexts over time. Interviewing people of a different language, culture and geographic location than my own complicated the construction of mutual understanding, however the interviewees and I were acutely aware of the challenges and worked to compensate for them through careful speech and listening.

The information landscapes of the CHN users interviewed, as well as the supports and constraints at play as they made sense of health information obtained on the internet were presented in Chapter 4. As Dervin's sense-making model (1999) suggests, it was not easy to distinguish among the processes of seeking, understanding and using information. I had anticipated I would be able to discuss specifically how the supports and constraints at play in making sense of health information came to bear on the interviewees' use of the information. Instead, I found that interrelated factors influenced health information seeking, sense-making and use in a single, complex process. I will therefore review the key elements of each of these three stages in turn and highlight the connections between them where possible.

Interview participants consulted a wide variety of people, media and health care services, often to support their use of another resource and their understanding of the information. The source interview participants accessed to seek health information was influenced by the factor in their lives that prompted their search and how they intended to use the information, as well as other contextual factors including the accessibility of sources at home and at work, and job responsibilities.

The interview participants who searched for health information for personal purposes drew on the support of health professionals when an urgent health issue required an immediate, individualized resource. Communicating health information obtained on the internet to physicians as a way of understanding serious health issues required health literacy. Web-based health information was used to clarify or supplement information obtained through interactions with health professionals regarding minor health issues.

Nurses with varying levels of education were interviewed. Their job responsibilities and educational background influenced perceptions of their role as patient educator using web-based health information. Only nurses with Master's level education assumed the role of patient educator, which suggests a high level of information literacy is required to fill this role. Other than the nurse practitioner (P2EE), those interview participants who worked in hospitals said they did not have internet access on the job. This constrained their use of web-base health information in their work, though some used the internet at home for work-related purposes.

The sense-making process was influenced by a combination of lay and professional knowledge of health, information literacy and education, as well as the web presence of health information from other cultures and in other languages, and the availability of support from people with expertise.

Lay and professional knowledge of health was a support to interview participants, though even those with formal health education and advanced degrees faced constraints when making sense of web-based health information. It was sometimes challenging to distinguish whether the constraining factor was their knowledge of health or their skill in using the internet.

Interview participants accessed health information websites developed in other countries and cultures, which required a high level of health literacy to assess the cultural perspective of the website and then consider it from their own cultural perspective. Most of the Francophone interview participants reported visiting both French- and English-language websites, sometimes in response to a perceived shortage of French-language websites. Reading in a second language, particularly when the text included medical terminology, challenged some interview participants. They rarely used portals designed to support access to health information websites, likely because they

were unaware of their presence on the internet or they visited multiple websites as part of their information seeking behaviours.

Most interview participants spoke of interacting with their social support networks in some way during the sense-making process. Seeking support via the internet was unpopular among interview participants unless they felt the person providing the support held expertise. Drawing on Bakardjieva's (2003) typology of different forms of on-line involvement, most interview participants held a rationalist ideal of internet use in which they turned to the internet for timely, accurate, reliable information, or approached on-line discussions as rational interaction in which information and ideas were exchanged.

The CHN users interviewed not only used health information obtained on the internet to protect their health, but also to manage their health care and to support other people's understanding of health-related issues. Though interview participants actively informed themselves about their health issues, they rarely engaged in the role of treatment partner with their physician. They did take the initiative to alleviate concern and understand their health issues through independent research on the internet. By using on-line health information to ask questions and make suggestions, interviewees participated actively in their medical appointments as 'informed patients' without making decisions regarding their health care.

Many interview participants, both lay and professional, recounted instances when they acted as an intermediary to find and assess health information for someone else and communicate it to them. Health professionals and lay interview participants working in churches, schools, health organizations, hospitals and rural development organizations engaged in patient or client education by recommending particular websites and communicating health information obtained on the internet in other formats. By providing information resources from the internet to colleagues, participants contributed to the continuing professional development of others, and in their personal lives, facilitated the access to on-line health information of family and friends.

The CHN was not the first choice of websites or the only website most interview participants visited. When a health-related question arose, most used general search engines or visited more than one website they knew, sometimes including the CHN. Despite describing the CHN as trustworthy, accurate, interesting, user-friendly and up-to-date, and appreciating that the CHN is Canadian, bilingual and covers a breadth of

issues, most interview participants chose to also visit other websites as part of their information seeking behaviour.

Among the 25 interview participants, six mentioned making informed choices based on health promotion information from the CHN website. Other participants fulfilled the goals of health promotion by reading the CHN website and passing information found there to others. Instances of “informed choice” likely arose infrequently because of personal, structural and social factors and the gap between information consumption and use in health promotion. The interview participants’ focus on the CHN’s value in terms of interest rather than in terms of usefulness suggests the CHN was not achieving its mission. However, reading the CHN website and sharing the information with other people is engaging in the health promotion processes and using the CHN website towards the end its architects intended.

I will now review how the interviewees’ actual use of the CHN website fits with the policy assumptions underlying its construction. The CHN users interviewed sought health information for reasons arising from their lived realities, and while these reasons were sometimes consistent with the policy assumptions of the CHN, in other instances they extended beyond its intended scope. Just as the need for information to help them protect their health arose in their lives, so too did the need for information regarding the specific health issues they faced. As the policy discourse assumed, the CHN users interviewed wanted to take more responsibility for their health, in consultation with a health professional. They did not want to manage their own health care. The CHN website did not contribute to the accessibility of on-line health information for the CHN users interviewed, as the policy discourse assumed. It facilitated access to a collection of health promotion resources, and CHN users continued to search the internet for health information.

7.2 Limitations of the Study

I interviewed 25 people in this study, 12 of whom had indicated their preferred language was French and 13, English. Only seven of the 25 identified themselves as health professionals. While this study explored differences in how English- and French-speaking CHN users, as well as laypeople and health professionals, retrieved, evaluated and used web-based health information, these comparisons were difficult to make because few interview participants fell into each demographic category. This study only

scratched the surface of investigating cultural and linguistic difference, and lay and professional knowledge of health, as it relates to use of web-based health information. However, it was worthwhile to begin to investigate these complexities, since they raised interesting issues for further investigation, which I will discuss in the upcoming section.

I had expected telephone interviews would allow participants to reflect back on and describe their past behaviours, and I asked interview participants to speak about specific examples that occurred recently in their lives. Their statements sometimes gave me the impression they were speaking about something they had experienced “only in a cognitive (as opposed to a physical) sense” (Dillman, 1978, p. 83). I expect this occurred, in part, because many of the interview participants had a professional interest in the provision of health information via the internet and shared their beliefs on the matter rather than their own experiences. I also observed some confusion in the interview transcripts regarding whether the interview was about health information seeking in general, use of the internet for health information or the CHN website only. Taking more time at the beginning of each interview to review the explanation of the study I distributed via e-mail and to gain more insight into why participants were interested in the study and how prominently health information seeking fit into their lives likely would have contributed to the collection of richer data.

In the interest of maintaining the relationships I developed with interview participants and managing the data collected, I chose to ask demographic questions that related closely to the research focus only. During the research process, I realized the analysis would benefit from situating each interview participant in a larger socio-cultural context that, in an interview, I could only discover through demographic questions. In discussions of cultural and linguistic diversity, knowing whether someone was among Canada’s aboriginal peoples or an immigrant to Canada, whether they spoke other languages or even whether they were Canadian, may have shed light on further complexities of their health information seeking experiences. On the other hand, interview participants were forthcoming with the factors they perceived to influence their experiences, for example, P9FF indicated her mobility was limited. I was primarily interested in how interviewees described their experiences and wanted to avoid making judgements and assumptions based on demographic questions, however, the details collected through these questions would have contributed to a more nuanced understanding of the group of people I interviewed.

Conducting this study through a partnership with the CHN Division provides the opportunity to communicate the findings to those in a position to effect change (Holter & Schwartz-Barcott, 1993). It remains uncertain whether the findings will lead to changes in policy or technology design. A challenge of academic research is the long period between commitments made and delivery of findings, analysis and recommendations. More than three years will have elapsed between when ACTION for Health's principal investigator presented to the CHN's advisory board and when I deliver a report based on this study to the CHN Division. The executive director of the CHN who participated in defining the research problem for this study filled her position in acting capacity and no longer works for the CHN Division. In the focus group, when I asked the CHN Division why it collaborated with ACTION for Health and someone laughed, "Because it's free!" I realized the CHN Division's institutional memory is short. However, the CHN Division did rearticulate its interest in the study findings in the focus group.

At least anecdotally, [this study] is an interesting avenue of pursuit for us. I mean I feel it reinforces some of the...assumptions that we already have about our audience and whether or not our service is meeting the needs. But it would be equally beneficial to know if there's something we're really missing, and you know, let us know (focus group with the CHN Division).

7.3 Suggestions for Further Research

As previously mentioned as a study limitation, this research served only to begin raising issues of cultural and linguistic diversity related to use of web-based health information. In the Canadian context, future research should continue to investigate French- and English-speaking information seekers' awareness of the country and cultural origin of the health information websites they consult, as well as the constraints they face in interpreting and adapting health information from other countries and cultures for their own use. Differences in how French- and English-speakers use portals and search engines also require further investigation to adapt such tools to user needs.

Through its focus on the various ways people use web-based health information, this study began to explore the role of a health information intermediary from the intermediary's perspective. Many interview participants searched for health information for the purpose of facilitating someone else's access to on-line health information or their understanding of health issues. Previous studies have discussed the intermediary role from the perspective of those who rely on intermediaries (Wathen & Harris, 2007; Wathen & Harris, 2006; Wyatt et al., 2005). No study has explored the experiences of

those who seek and communicate health information to others. This warrants consideration both among lay intermediaries and among health professionals who engage in patient education or support the professional development of other health professionals using the internet. Considering the role of the internet in the health professionals' workplace, in both hospitals and community care settings, is likely to shed light on contextual, hierarchical, generational and gendered factors that influence internet use.

Given many interview participants used the internet to build their understanding of health issues relevant to their lives and in light of Hibbard et al.'s (2004) suggestion that understanding a condition through independent research is a prerequisite of informed decision-making, a longitudinal study of the development of health literacy and related decision-making is required. Such a study would need to differentiate among the influence of internet ability, information literacy and health knowledge on understanding and decision-making in order to identify ways of supporting informed health decision-making based on health information obtained on the internet.

7.4 Final Thoughts

Here in lies my own deepest hope, or perhaps I should say, dream: that form the shared inheritance which is gradually being built up for us from all the different human cultures across the globe we might eventually learn how to recognize our needs and address our difficulties through becoming explicitly conscious of them (p. 78).

Hans Gadamer (1996)

I began this thesis by reflecting, as Gadamer (1996) did, on some of the ways people understand health, such as social interaction, awareness of the body, news media and the internet. I also began sceptical about whether people incorporate health information communicated through mass media and the internet into their lives. Though this study found unfulfilled policy assumptions related to the potential of the internet and identified challenges to understanding and using web-based health information, I was continuously inspired by the people I interviewed, who, above all else, simply wanted to expand their knowledge of health. Like Gadamer, I am hopeful that with the support of people and technologies, we can build our understanding, across cultures, towards better human health.

APPENDICES

Appendix A: Focus Group Questions

Introduction

Thank you very much for your willingness to, as a group, answer some questions about the CHN's current goals, activities and approach to developing the website, and your views on partnering with a university research project.

I would first like to confirm with you that you received the information sheet for participants, the informed consent form and the participant feedback form I sent to you via e-mail. [If not, allow them time to read the documents] If you didn't bring them with you, I have copies here.

I would like to highlight two points about these materials.

Firstly, I am asking for your consent to use three types of information as research materials: what you provide in this focus group today, what you have provided to me in prior meetings and e-mails, and what you will provide to me in future meetings and e-mails. I reviewed my notes from our three teleconferences and all our e-mails. The information from our teleconferences I would like to use relates to what the CHN would like to find out through this research study. The information from our e-mails relates to the process within the CHN of setting up the research study. I can provide more detail or examples, if needed.

The second point is regarding anonymity. Research ethics requires that the investigator offer study participants anonymity, but in this case it isn't possible because people outside this room are aware of your participation in this research partnership and will most likely be able to identify your comments in any documents produced as a result of this study. Though I can't offer anonymity, I can offer you the choice of how you are identified in these documents. You could remain unidentified (e.g. CHN employee #1) or be identified by name and position or by position only. On the consent form, there is space for you to indicate your choice. You may wish to discuss this as a group and let me know which option you choose. [Allow time for discussion]

Do you have any questions or concerns?

Please review and sign the informed consent form and return it to me.

Are we ready to proceed with the focus group?

Let's begin.

Questions

I am interested in finding out more about your current priorities for the CHN and the challenges you face in meeting your goals at the operational level, as you run the network. I am also interested in gaining a better understanding of how the CHN has developed since its launch in 1999. I'll start by asking you:

1. What priorities are currently guiding the development of the CHN?
2. Have these priorities change since the CHN's launch? How so? What has influenced these priorities?
3. How has the implementation of the CHN matched or differed from the original goals?
4. Who do you see as your audience? Has this changed over time, and if so, how?
5. How did the CHN choose what topic areas and population groups to focus on? Have these changed? How or why not?
6. In the interviews we are conducting with Canadians, we are trying to find out more about the differences in health information seeking behaviours of French- and English-speaking Canadians. What challenges have you faced in providing resources in both English and French? What are your strategies for building a bilingual website?
7. We are particularly interested in how Canadians from both linguistic groups use the health information they find on the internet. How do you see information consumption fitting in with health?
8. What do you see as the CHN's role in the provision of health promotion content to Canadians? Has this changed?
9. Could you explain the quality assurance process to me using a recent example of how it was operationalized with an organization and its website? OR How does the CHN decide what information to include or link to? Has this changed over the years?
10. How involved is the CHN with working with organizations to develop content for their websites?
11. What do you see as the value-added of the CHN? Has this changed over time? If so, how?
12. I have found a number of documents on the Health Canada and Public Health Agency of Canada websites that discuss the CHN [bring list], but I would like to ask you whether you could provide me with any important documents containing previous evaluations and history that I may not have been able to find on-line.
13. As you know, your partnership with ACTION for Health pre-dates my involvement with the project. Could you tell me about why you decided to engage in this research partnership? What for you is the value of a research partnership?
14. As a student, it is a unique opportunity to conduct my research in partnership with a group of people directly involved in with the issues I am studying, and I want to be sure the documents I produce are helpful to you. In a perfect world, what would be the ideal outcome of our research partnership?
15. Is there anything else anyone would like to add?

That's all then. Thank you very much for sharing your thoughts with me.

Appendix B: Policy Documents Reviewed

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Appendix C: Telephone Interview Questions

Introduction

Thank you for your interest in participating in a follow-up interview after completing the Canadian Health Network's on-line survey. I would first like to confirm with you that you received the information I sent to you via e-mail regarding the ACTION for Health project and the research I am conducting. [If yes] Do you have any questions? [After answering any questions] In the interview, I will ask you some questions about your experiences looking for health information and how you used the information you found. If there are any questions you don't feel comfortable answering, please let me know. You can choose to skip a question or withdraw from the study at any time. The questions are only intended to guide our discussion, so please feel free to elaborate and share additional thoughts. The information you provide will be kept in confidence. I estimate the interview will take about 30 minutes. I would like to tape record our conversation to be sure I capture your thoughts accurately. Do I have your permission to do so? Do have any other questions? [After answering any questions] Do I have your consent to proceed with the interview? [If yes] Let's begin.

1. When you have a health-related question, what sources of information do you turn to? [Probe for on-line and offline]
 - a) Do you normally start looking for information at the same place, or does it depend on the topic? Where do you begin?
 - b) How do you decide which source to consult in which situation? [on-line and offline]
 - c) What websites do you visit?
 - d) Are you loyal to particular websites?
 - e) Do you read or participate in discussions of health-related topics on the internet? [If yes] What kinds?
 - f) What do you see as the advantages of the internet compared with other sources of information? What do you see as the disadvantages?
 - g) Do you access health information in [French/English] on the internet?
 - h) Where do you access the internet? Do you have internet access at home?
 - i) [If unclear so far] Are you a health professional? [If yes] What type?

2. Please think back to the most recent occasions when you went to the internet for health information.
 - a) Did you look for information for yourself or for someone else? [If someone else] For whom?
 - b) [Lay only] Did you look for information before or after seeing a health professional?
 - c) What were the purposes of the information? For example, was it for general understanding, prevention or self-diagnosis, treatment or management of a condition?
 - d) How did you go about finding what you were looking for? Could you please describe your search process?
 - e) Did you experience any difficulties finding what you were looking for? [If yes] What kind? How did you address these difficulties?
 - f) How well do you feel you know how to use the internet to find health-related information?

- g) [Lay only] Did you get advice from a friend, family member, health professional, librarian or anyone else about where to look?
 - h) [Health professionals only] Did you get advice from a colleague, librarian or anyone else about where to look?
3. [Health professionals only – this section] When you have searched for health information on the internet, what have been your thoughts on the usefulness of the information for your patients/clients?
 - a) Do you share health information from the internet with your patients/clients or recommend websites to them?
 - b) [If they share health information with patients] How do you determine what health information on the internet is appropriate for your patients/clients?
 - b) How do you determine whether the level of literacy required to make use of the information is appropriate for your patient/client?
 - c) How do you ensure the information works for the patient/client?
 4. [Lay only – this section] When you searched for health information, did you encounter any information that was difficult to understand or confusing?
 - a) [If yes] What made it difficult to understand or confusing?
 - b) How did you address this?
 - c) Did anyone help you? [If yes] Who?
 - d) Did your prior knowledge about health help you understand the information? [If yes] How?
 - e) How knowledgeable do you feel about health in general? About your topics of interest in particular? From where did you gain this knowledge?
 5. How did you tell high-quality health information from low-quality health information on the internet?
 - a) How confident are you that you found reliable information? What makes the information authoritative?
 - b) Do you use the Canadian Health Network? [If yes] How did you come to use the CHN? How helpful is it? How do you use the website? [searches vs. reading articles] [If no] Why not?
 - c) [Health professional only] Do you recommend the CHN to your patients? Why / why not?
 - d) How did the quality of the health information you found on the Canadian Health Network compare with what you found on other websites?
 - e) Have you used the Canadian Health Network's checklist for how to find the most trustworthy health information websites? [If yes] How helpful is the checklist? *[Still posted on the CHN]*
 6. How were you planning to use the information you found?
 - a) Were you able to use it for this purpose? [If no] What stood in your way? [If no] How did you use it?
 - b) In the end, did you find what you were looking for?
 - c) Did the information you found leave you with any questions? [If yes] What questions? Were these questions ever answered? [If yes] How?
 - d) Were you left wanting more information or more detailed information? [If yes] What more did you want?

- e) [If they shared it with a friend, family member, client or patient] What was your experience sharing health information with [insert person]? Was the person you shared the information with unable to access the information on their own?
- f) [If layperson looked before seeing a health professional] Did you share health information from the internet with [stated health professional]? [If yes] What was your experience like? [If no] Why not?
- g) Can you think of any other examples of difficulties you encountered with on-line health information? [If yes] What were they? How did you resolve them?

7. Is there anything else you would like to add?

Before we finish, I would like to ask you a few demographic questions, if I may.

8. How old are you?

9. What is the highest level of education you attained?

10. [If no reference to gender was made in the interview] And you're male/female?

11. Where do you live? (city/town and province)

Thank you for your participation in this study. Please feel free to contact me by e-mail or telephone if you have anything more to add or you would like to ask any questions about the study. May I contact you again by e-mail for clarification or with additional question or two after I review our conversation?

Appendix D: NVivo Coding for Interviews and Follow-up E-Mails

Driver

- New health concern/symptom
 - Severe
 - Nagging
- Chronic condition
 - Severe
 - Nagging
- Wellness
 - Diet
 - Exercise
 - Public health
- General understanding
- Shared decision-making
 - Reluctance
 - Indifference
 - Willingness
- Self-reliance/care
 - Reluctance
 - Indifference
 - Willingness
- Personal responsibility
 - Reluctance
 - Indifference
 - Willingness
- Profession
 - Continuing professional education
 - Communicating with patient/client/student
- Personal relations
 - Caretaking
 - Intermediation
- Social inclusion/fitness
- Medical knowledge
 - Acceptance
 - Scepticism
- Lay knowledge
 - Acceptance
 - Scepticism

Source

- Internet
 - CHN
 - Interactivity
- Other media
- People

Computer literacy (user skill and ability with computers)

- Constraints
 - Intermediary
 - User skill/ability
 - Technological (access, newsletters, feeds, alerts, search engines, links, website layout)
- Supports
 - Intermediary
 - User skill/ability
 - Technological

Information literacy (user skill and ability with information – critical thinking, judgement)

- Constraints
 - Intermediary
 - Outdated
 - Volume
 - Language
 - Local
 - Foreign
 - Time
 - Uncritical of quality, trustworthiness
 - Basic
 - Credible
- Supports
 - Intermediary
 - Currency
 - Language
 - Local
 - Foreign
 - Time
 - Judging quality, trustworthiness
 - Detail
 - Non-credible

Health literacy (ability to find, understand, communicate and assess health information)

- Constraints
 - Intermediary
 - Complexity
 - Irrelevance
 - Lay information
 - Expert information
 - Lay knowledge
 - Expert knowledge
- Supports
 - Intermediary
 - Relevance
 - Lay information
 - Expert information
 - Lay knowledge
 - Expert knowledge

Language/culture

Power

- Empowerment
- Disempowerment

Place

- Internet use
 - Home
 - Work
- Foreign
- Local

Use

- Shared decision-making
 - Reluctance
 - Indifference
 - Willingness
- Self-reliance/care
 - Reluctance
 - Indifference
 - Willingness
- Personal responsibility
 - Reluctance
 - Indifference
 - Willingness
- Profession
 - Continuing professional education
 - Communicating with patient/client/student
- Personal relations
 - Caretaking
 - Intermediation
- Social inclusion/fitness
- Medical knowledge
 - Acceptance
 - Scepticism
- Lay knowledge
 - Acceptance
 - Scepticism
- General knowledge

Result

- Positive
- Neutral, none
- Negative

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