A WIRED WAITING ROOM: INTERVENTIONS TO ENHANCE ACCESS TO ONLINE HEALTH INFORMATION

by

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ABSTRACT

The complexities of introducing Internet access to support health information seeking in a medical clinic waiting room have not been well documented in the literature. This is problematic because Canadian policy emphasizes the need to leverage technology (e.g., government-produced health information Web sites) to increase the health care system's effectiveness and efficiency. In my research regarding the introduction of an Internet terminal to the waiting room of a Vancouver medical clinic, I explored policy discourse and conducted fieldwork, including interviews and participant observation before and during the terminal's introduction. I argue interventions are required at government, community, and individual levels to enhance Internet access to health information. Necessary changes range from small modifications of interfaces to substantial support for end users in community locations. Coordinated efforts by multiple stakeholders are required to address the social and technical challenges of access.

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ACRONYMNS

BC	British Columbia
CAP	Community Access Program
CHC	Community Health Centre
CHI	Consumer Health Information
CMC	Computer Mediated Communication
CSCW	Computer Supported Cooperative Work
e-government	Electronic Government
HCI	Human-Computer Interaction
ICT	Information Communication Technology
IHAC	Information Highway Advisory Council
IS	Internet Session
KWIC	Key-Words-In-Context
MOH	Ministry of Health
MOHS	Ministry of Health Service(s)
PHAC	Public Health Agency of Canada
PII	Pre-Internet Interview
PIO	Pre-Internet Observation
SCOT	Social Construction of Technology
URL	Uniform Resource Locator

CHAPTER 1: INTRODUCTION

According to the trickle-down view, there may be inequalities of access and use during the early stages of a technology but it is assumed these disappear, or are at least much reduced, as the technology becomes more widely diffused (Thomas & Wyatt, 2000, p. 26).

1.1 Introducing Access

Since the mid 1990s, with the launch of the first graphical Web browser, individuals have been encouraged to enter the wired world of the Internet or information superhighway as consumers, citizens and patients. Undeniably, this has broadened the scope of how universal access to health services and information are conceptualized. However, inequalities to health information and health services persist. Factors such as socio-economic status, culture, language or ability may serve as barriers to health care or information. These factors must be identified and acknowledged if they are to be ovecome. Like Thomas and Wyatt (2000), I am reluctant to rely on a passive "trickle-down" (p. 26) diffusion of technology. The idea that active efforts are required to bypass inequalities of access to health information, figures prominently in the pages to follow. My thesis describes the findings from an action research project focussed on planning and introducing an Internet terminal to the waiting room of the Mid-Main Community Health Centre (CHC) on a trial basis. Constructing universal access to health information Web sites requires that both the social and technical aspects of access be addressed (Clement & Shade, 2000).

The Mid-Main CHC is an innovative, nonprofit primary health care centre that serves a particular urban community in Vancouver, Canada. The computer at Mid-Main was introduced in part to address the digital divide,[1] and to compensate for disadvantages faced by the patients who are not connected to the Internet at home to access health information. In my research I have explored policy discourse and conducted fieldwork including interviews and participant observation before and during

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[1] The *digital divide* is a term commonly used to refer to the gaps between the developed and developing world's access to the Internet. Additionally, a digital divide may occur within a country or a community based on socio-economic status, age, or any factors, which may inhibit access.

the introduction of the Internet terminal. During the Internet phase of the project, the homepage of the browser was rotated between two Web sites. These two Web sites were developed by government agencies, in efforts to support the health of Canadian citizens: the BC HealthGuide (maintained by the BC Ministry of Health Services (MOHS)), and the Canadian Health Network Web site developed by Health Canada, and subsequently supported by the recently formed Public Health Agency of Canada (PHAC). Through the research, the computer was made available to patrons for general health information seeking.

In this chapter I begin by describing previous research addressing computers for patient education. I situate my research in relation to ACTION for Health, a federally funded project which supported my work. Next, I introduce the notion of levels of analysis, my research questions and the social construction of technology as my theoretical framework. This chapter concludes by outlining the significance of the research and by outlining the content, methods and data sources of subsequent chapters.

1.2 Previous Research

The introduction of computers to medical clinic contexts is something that has been discussed in the literature. Wofford, Smith and Miller (2005) conducted a systematic review in the Medline and Cochrane databases and found that with multimedia computers in a medical office "there is the potential for improving the efficiency of the office through computer-assisted patient education...but better proof on the impact on clinical outcomes is warranted before this strategy is accepted into the office setting" (p. 148). This article helped focus the literature search by providing the controlled language terms of 'Patient Education' and 'Computer Systems' for the Medline database. This served as a launching point into related articles. Within the literature there is consensus that patient education could be made digital as a strategy to address time constraints faced by physicians (Sechrest & Henry, 1996; Wofford et al., 2005) and efficiency goals for high-needs patients (Glasgow, Toobert & Hampson, 1996). However, the clinical trials discussed by Wofford et al. addressed computer-based information for patients with discrete medical issues (i.e. depression, autism, and breast cancer). Such a precise focus on particular medical conditions is not consistent with the goal of making broad health information available to patients at Mid-Main or empowering individuals. Condition specific information also pre-supposes that when seeking health information, patients have already received a diagnosis.

Other studies have emphasized making an array of information available to patients. Budtz and Witt (2002) found that in their study of Danish patients that the "Internet is used not only as a general source of information but also in direct preparation for a visit to the GP" (p. 20). Tang and Newcomb (1998) found that patients need information "whenever questions arise" such as at home following an appointment (p. 569). The optimization of the location of the computer to access information differs across research studies. While access to computer based health information at the clinic is emphasized in some articles (Glasgow et al., 1996; Sechrest & Henry, 1996), in other articles, community access points for computers to retrieve health information are highlighted as significant locations (Milo, 1996; Nicholas et al., 2001; Wagner & Jimison, 2003). These differing trends in the literature suggest that planning for and implementing an Internet terminal in the waiting room at the Mid-Main Community Health Centre would be a unique undertaking with contextual considerations that are specific to a clinic location with a community orientation.

1.3 Situating the Research

The introduction of the Internet at Mid-Main was completed as part of a larger project called ACTION for Health,[2] funded by the Social Sciences and Humanities Research Council of Canada (grant # 512-2003-1017). ACTION for Health is headed by Principal Investigator, Dr. Ellen Balka who is my academic supervisor. Dr. Balka has identified that little effort has been directed towards investigating the effectiveness of implemented projects in the computerization of health care in relation to policy goals (Balka, 2005a). In order to address this knowledge gap, Dr. Balka has established research relationships with a variety of partners ranging from community organizations to government ministries who develop and maintain health information Web sites. To evaluate health information Web sites, partnerships with Mid-Main and the BC MOHS

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[2] The ACTION for Health project was funded by a $3 million grant issued by the Social Sciences and Humanities Research Council of Canada. The grant brings together Canadian and international collaborators who often partner with organizations to gain a better understanding of the use of technology in the health sector as it relates to lay users, health professionals, and associated legal and ethical issues. A variety of technologies including a wireless call system, electronic medical records, and health information Web sites have been investigated thus far. For further information please see the ACTION for Health Website: www.sfu.ca/act4hlth

were important. A research relationship also exists between ACTION for Health and PHAC.[3] As a result of these relationships, channels exist to communicate and apply research findings across various levels of decision-makers, involved in the design and use of health information Web sites. Many ACTION for Health projects emphasize, in the tradition of Suchman (1994), "that there is in fact no distinct boundary between technology design and use" (p. 24). Implementation and use in context are part of the design process.

1.4 Research Question and Levels of Analysis

Understanding that government, community organizations and citizens are involved in designing health information Web sites, I developed a broad research question to guide my inquiry. My question was: *what interventions are critical to enhance the usefulness of access to health information Web sites for patients in the Mid-Main waiting room?* This question encouraged me to look for the relevant levels of analysis where decision-making occurs about health information Web sites. The macro, meso and micro levels proved useful in conceptualizing potential locations for intervention through research.

Macro, meso and micro levels have been applied in a variety of research projects across disciplines. Chambers (2003) states that with "Micro/Macro Analysis" there has been a "recent tendency within the social sciences to resituate the local within the larger context of regional, national and even global events" (p. 400). In studies of technology, a multi-level approach is informed by the traditions established by Suchman's (1987) situated, or context specific actions. Within the larger field, Vaughan (1999) expresses that "science and technology studies has persuasively demonstrated how social context affects the production of...technical knowledge, revealing how both micro level interactions and macro level contingencies affect the interpretive work" (p. 913). Additionally, she suggests that "formal organizations are meso level social structures" which comprise another level that can be analyzed (p. 913).

In research specific to health and technology, Balka and Kahnamoui (2004) used the macro, meso, and micro model to conceptualize an ethnographic field study where a move in a hospital required the staff to become familiar with an entirely new set of

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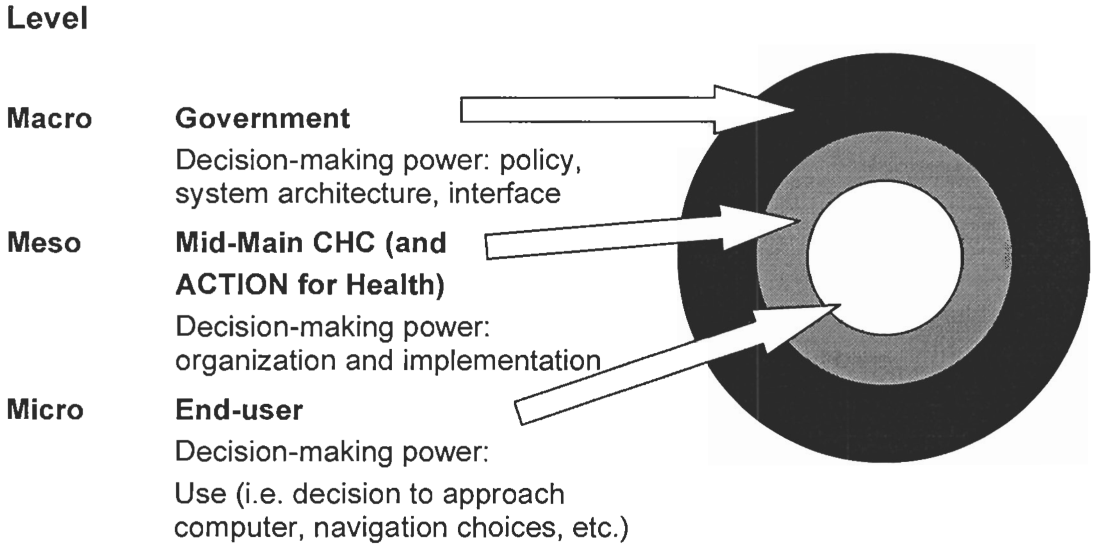
[3] As PHAC was formed following the start of ACTION for Health project, a research relationship has developed without a formal partnership.

technology. Drawing upon Gartner and Wagnar (1996), Balka and Kahnamoui point out that in relation to the move: individual work practice and interaction with technology occurs at the micro level; organizational issues are situated at the meso level and broader organizational relations partially comprise the macro level. In relation to my research problem, I found it helpful to map the actors onto a diagram of concentric circles representing the government, the Mid-Main and ACTION for Health Research partnership, and the patients for the macro, meso and micro levels as outlined in figure 1.1. The far left side of the diagram identifies the levels on which decisions are made. The text in the middle identifies the organizations or individuals involved and examples of their decision-making power.

Figure 1.1: Levels of Analysis



This diagram and model for research suggests that there are multiple levels of decision-making involved in the design, implementation, and use of health information Web sites. These levels span the formal and informal stages of design. These interlinked levels of analysis are also consistent with applied research traditions where “deliberate efforts to intervene and bring about change invariably place the populations subject to such efforts in a relationship with a larger sphere of influence” (Chambers, 2003, p. 400). Consequently, it seems essential that interventions to enhance the usefulness of access to health information over the Internet consider all locations where decision-making occurs. My emphasis on interventions drew me towards action research. This methodological choice is addressed at greater length in chapter 4.

1.5 Social Construction of Technology

To integrate the macro, meso, and micro levels of analysis, the social construction of technology (SCOT) served as a guiding theoretical framework for my thesis. SCOT is an approach that opens the black box of technology to examine both the successes and failures of design in a non-linear fashion (Pinch & Bijker, 1989). Pinch and Bijker find it problematic that in the past, the study of innovation has largely emphasized successful designs as linear progressions. They describe how social groups influence the design of technological artefacts because they collectively experience problems which require solutions. Pinch and Bijker also suggest that the final design of artefacts is not an inevitable outcome, but is socially constructed by multiple participant groups. They state that a wide variety of social groups may participate in design processes in this manner. They define social groups broadly as "institutions and organizations (such as the military or some specific industrial company), as well as organized or unorganized groups of individuals" (p. 30). Pinch and Bijker point out that social groups are not merely the actively engaged parties but also the opponents or non-users.

Pinch and Bijker's (1989) observations suggest that numerous groups would participate to develop health information Web sites. The finalized Web sites should reflect the interests of multiple groups or actors. Indeed, this is borne out when one explores health information Web sites. In the case of the Canadian Health Network and BC HealthGuide Web sites made available at a public Internet terminal in the waiting room, participants whose interests shaped the implementation of the computer in the waiting room included government, clinic administrators, end-users, and non-users. In identifying these particular social groups, I have also drawn upon feminist approaches to studying technology which consider users and context (i.e., Cowan, 1989; Franklin, 1999). While I am highly interested in the individual user experience of seeking health information online, I understand that this experience is constructed within organizations and systems of power. My investigation is consistent with recent attempts to understand the co-construction of users and technologies (Oudshoorn & Pinch, 2003). It is my intention to consider issues of design and power within various spheres of decision-making.

1.6 Overview of Thesis

I intend to share the struggles and successes that exist around the implementation of a basic computer, wired to the Internet, in a community waiting room. Each chapter of my thesis discusses access in relation to key concepts or a particular level of analysis. Chapter 2, Key Concepts, introduces *interventions, access,* and *usefulness* as topics in the literature that informed my research methods and approach to study the design and use of an Internet terminal. Subsequent chapters address the specific levels where decisions are made about access to government health information Web sites. Table 1.1 is intended to act as a quick reference, and provides an overview of the relationship between the methods, data, and fieldwork.

Table 1.1 Method and Data Overview by Chapter

Chapter	Framework	Method(s)	Data Source
Chapter 3: Constructing Access	Action Research and the Social Construction of Technology	Discourse Analysis	46 policy documents
Chapter 4: Implementing Access		Semi-structured interviews and participant observation	28 pre-Internet interviews and field notes from observations of 67 participants before the Internet was introduced
Chapter 5: Experiencing Access		Semi-structured interviews and participant observation[4]	25 Internet sessions, predominantly captured using motion screen capture and audio recording
Chapter 6: Supporting and Sustaining Access		As per chapter 5	As per chapter 5

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[4] In chapters 5 and 6 I will outline how I interacted with participants. As a researcher I also assisted and tutored participants in a capacity not captured by the term observation.

In chapter 3, Constructing Access, I explore macro level policy discourse surrounding the BC HealthGuide and Canadian Health Network. From this analysis the underlying values and objectives, which have informed the design of government produced Web sites are rendered clear. The themes of relevance located include: configuration, equity, self-care, and reform. Each of these themes will be discussed in relation to the architectural elements of the health information Web sites. In this manner, the interventions at the interface level conducted by government to promote policy objectives of health information access will be explored.

In chapter 4, Implementing Access, I will introduce the Mid-Main Community Health Centre as my research partner and outline the meso level context. As the location where an Internet terminal was introduced for participants to look up health information, Mid-Main was integrally involved in creating a community-based location for health information seeking. As a nonprofit Community Health Centre, Mid-Main prioritizes patient participation within their organization. In efforts to respect this aspect of the organization, interviewing and participant observation were conducted in advance of the Internet terminal under an action research framework, insights from those interviews were used to inform the implementation. From the analysis of the results, interventions such as the set-up and signage for the computer were generated to inform later stages of the research. Trends emerged about the preference for human centred care, and the desire for guidelines for acceptable use of the Internet terminal in the waiting room.

In chapter 5, Experiencing Access, my blend of ethnographic and human-computer interaction (HCI) methods will be discussed. These methods were employed within an action research framework. They were applied to the study of the Internet sessions at Mid-Main where participants chose to look up health information at the Internet terminal. The homepage was set to rotate between the Canadian Health Network and BC HealthGuide, sites chosen in part because of the relationships established through the ACTION for Health project. Motion screen capture software was used to record the screen activity that took place during patient's health information seeking sessions, and an audio track was also recorded to capture responses to interview questions or candidly spoken comments. The oral and video components of the Internet sessions were transcribed and coded to explore how participants experience access. Patterns emerged around the drivers which encourage use (i.e., previous participation) and what type of content is of interest to patrons. Additionally, issues around the "journey" (Rutten, Arora, Backos, Aziz & Rowland, 2005, p. 250) of seeking health information emerged. Many interventions were conducted to attempt to enhance usefulness and the experience of health information seeking in response to participants' opinions and statements.

In chapter 6, Supporting and Sustaining Access, I expand my discussion to consider how users are configured, and reflect about how these configurations come to bear on universal access to health information. Influenced by the importance of non-users' interests in design, I reflect critically on my role as an "outside agent," (Labonte & Laverack, 2001, p. 117), "warm expert" (Bakardjieva, 2005, p. 99), and "participant interventionist" (Karasti, 2001, p. 80). Across these roles, I assisted and tutored participants as they used the computer in the waiting room.

Action research and interventions have encouraged me to think of the considerations of the project for policy, practice, and future research. In chapter 7, I conclude by providing these insights. I review the findings and results from chapters 1 through 6. Additionally, I discuss the limitations of this research project and suggest future directions. In conclusion, I hope to illustrate how participants negotiate and share the tasks associated with designing and implementing an Internet terminal for health information in a community location.

1.7 Research Significance

Through the work reported here, I hope to share insights gained about the impact of policy on organizational and individual practice and vice versa. Although the Mid-Main Community Health Centre is just one location where Canadians have accessed online health information, I hope that by describing the complexities that emerged during the implementation of the Internet terminal, I will raise critical insights of relevance to citizens, clinics and government. From my research question, I believe I have implicitly articulated many of my goals and objectives to impact change. This research was conducted within an action research framework with an explicit intention of broadening how organizations and individual end-users are conceptualized as participants within the design process. As such, this program of research is in no way unbiased or objective. As an action researcher, my presence and my interactions with participants in the waiting room of the Mid-Main CHC have noticeably shaped the introduction of the

Internet terminal and the experience of research participants. The value of such research is that I have attempted to implement useful interventions in a community context. By actually trying things out, I hope to be able to provide some constructive suggestions that can be used to enhance access in the "real world of technology" (Franklin, 1999) and health care.

1.8 Chapter Summary

This chapter introduced the community based research initiative of implementing an Internet terminal in the Mid-Main Community Health Centre waiting room. This implementation differs from some previous research involving computers in clinics due to the action and intervention-oriented approach. Theoretically, the social construction of technology assisted to identify government, the Mid-Main CHC, and individual end-users as some of the relevant social groups which impact the constructions of access. In the next chapter, I will define the key concepts embedded in the research question which assisted me to launch into a multi-level analysis to identify interventions to enhance the usefulness of access to health information Web sites.

CHAPTER 2: KEY CONCEPTS

My research question "what interventions are critical to enhance the usefulness of access to health information Web sites for patients in the Mid-Main waiting room?" contains three key concepts: *intervention, access,* and *usefulness.* In attempting to enhance the experience of using government-produced health information Web sites in a community setting, these terms can be contextualized within larger traditions. Defining these terms will require literature from the diverse disciplines of communications, health services, public policy, and interactive design. In this chapter I will provide explanations and definitions of these terms to assist the reader in understanding how I have operationalized these three key concepts in the research described in the subsequent chapters. Because the terms intervention, access, and usefulness are embedded in my research question, the relevant literature surrounding them provides a launching point into the methods, results, and analysis of my thesis.

2.1 Interventions

Government-produced health information Web sites serve as an interesting starting point from which to explore how a term such as intervention can be defined from various disciplinary angles. In public policy, the term intervention is used to describe a general or targeted policy direction that may be based on economic priorities (Frommer & Rychetnik, 2003; Leeper & Zha, 2003), or particular social and contextual factors (Frommer & Rychetnik, 2003). From a public health perspective, an intervention is "intended to promote or protect health, or to prevent ill health; and most are planned and implemented with the primary intention of benefiting communities or populations rather than individuals although they often benefit individuals as well" (Frommer & Rychetnik, p. 61). In communications, an intervention can take any form of personal interaction or be a media-based strategy to attempt to impact change. A strategy such as an interactive Web site implies that an intervention is a technological translation of a real-world process which will act as a solution to a problem (Shedroff, 2001). Government-produced consumer health information (CHI) Web sites in Canada seem to blend aspects of intervention from each of these fields.

At the core of my inquiry lies the idea of the critical intervention in relation to community and end users' access to health information Web sites. I drew upon the principles of action research and participatory design to formulate the objective of locating multi-level opportunities for intervention. Action research will be described in greater depth in chapter 4. It typically supports social equity goals such as the elimination of discrimination against women, minorities, and disadvantaged groups. To be successful in this goal, Briston and Esper assert the research "must be tied to *specific* implementation practices" and should be designed to impact change (qtd. in Reinharz, 1992, p. 178).

Similar principles are embodied in the participatory design tradition, which originated in Scandinavia to provide workers (a group disadvantaged in comparison to management) with greater input into the design of technology and hence the quality of their working experiences (Bjerknes & Bratteteig, 1995). Participatory design has been somewhat influential in the creation of software and can thus be considered in relation to Web sites. However, potential gaps exist in the participatory design community's success in intervening on behalf of diverse users outside of the labour-management structure. In reference to software design, Nyce and Bader (2002) state:

> "Intervention"—is still something we know little or nothing about. In the design-and-development literature "intervention" is portrayed as something much like a scientific "solution" to a technical problem—a logical, disinterested proposal or procedure whose objectives serve everyone equally well. But interventions are not necessarily neutral or value free. Nor is it enough to acknowledge (as the [participatory design] PD literature does) that these interventions reflect power, structural, and ideological differences (p. 36).

My emphasis on multi-level interventions within my research design is an explicit attempt to acknowledge how multi-level changes are required to address the diverse issues associated with access to health information. I conceptualize the macro, meso, and micro levels as overlapping layers where as Foucault suggests, power flows through a network (Wilcocks, 2004). Digital divide factors and the overlapping social determinants of health[5] (such as socio-economic status and literacy) may make the power differences between the research participants, the clinic, and the government evident in the attempt to make information useful.

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[5] The social determinants of health refer to the factors which influence health beyond the medical system; some additional examples include housing status, education, etc..

2.2 Access

Access is the second major concept that is central to my research question. A broad definition of *access* may suggest that it is one's right or capacity to obtain information and services. However, the concept of access has a more specific historical and rhetorical significance in relation to Canadian health care and Internet connectivity programs. The *Canada Health Act* enshrines accessibility as one of the four essential criteria that provinces must meet if they are to receive federal funding for health service delivery (Canada, 1984, ch. 6, s. 7). Similarly, one of the federal government's cornerstone programs for connectivity was called the Community Access Program (CAP) (Rideout, 2003). CAP provided funding for rural areas and urban regions until 2000 and 2001 respectively so as to connect public locations such as libraries and schools to the Internet (Rideout, 2003). Industry Canada continues to consider CAP applications, however now the sites must be targeted to serve digital divide groups (Canada, 2006c). Based on these policy traditions of universal access, it is not surprising that access to the Internet and health services are areas where conceptual models have been developed to convey the elements required to enable citizens to access information and services. Models for these different types of access are not as disparate as one might imagine.

2.2.1 Internet Access

Internet access is a phrase likely understood by many Canadians to describe the connections required to reach the World Wide Web, or send and receive e-mail. Some government-supported Internet access programs have emphasized and prioritized the physical aspects of connecting, which are described by Warshauer (2003) as being based on "devices and conduits" (p. 31). *Devices* are items such as computers, while the term *conduits* refers to the aspects of access that require "connection to a supply line that provides something [i.e. electricity, bandwidth, etc.] on a regular basis" (p. 33). He continues to state that the "diffusion of devices is comparatively easy and quick, compared to the diffusion of conduits, content and practices" (p. 31). Warshauer offers a description of a model for access which includes both social and technical aspects to overcome the limitations of considering devices and conduits in isolation of other factors.

Specific to the Canadian context, academics and public sector participants have carried out a variety of research and commentary related to socio-technical access.

Some of this work has been chronicled in a bibliography (Nilsen, 1997) or in policy maps (Bodnar, Moll, & Shade, n.d.). One significant aspect of the research has been the development of access models. In 1996, Clement and Shade stated that "in order to more fully define what access to the information infrastructure encompasses, and to account for the intricate relationship between the social/technical architecture of the information infrastructure, a different model of access needs to be delineated" (Clement & Shade, 1996b, para. 24). As an initial solution, they provided the 7-layer Access Sandwich model (para. 24). Soon after, this layered model was adapted into a new visual metaphor, the Access Rainbow (Clement & Shade, 1996a, 2000).

Figure 2.1: Access Rainbow Model[6]

With the Access Rainbow model (Clement & Shade, 2000), the authors suggest the layers of universal access blend together like the colours of a rainbow. The element

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[6] This image is courtesy of Andrew Clement. It was last accessed July 28, 2006, from: http://www3.fis.utoronto.ca/research/iprp/publications/wp/wp10.html

arching over all others is governance, which refers to the rules and regulations associated with universal access and "how decisions are made concerning the development and operation of infrastructure" (Clement & Shade, p. 37). Next, "literacy/social facilitation" is required to promote the development of the skills and capacities required to leverage universal access opportunities (Clement & Shade, p. 37). "Service/access provision" is essential; it is offered through organizations that provide a physical location and point of connectivity (i.e., library, office) (Clement & Shade, p. 37). "Content/services" are the "actual information and communications services people find useful" (i.e., health information Web sites) (Clement & Shade, p. 37). Next, "software tools" (i.e., Web browsers) are the programs used to access information and services (Clement & Shade, p. 37). Similarly, "devices" such as a computer, mouse, and keyboard are what people actually operate to obtain universal access (Clement & Shade, p. 37). Finally "carriage" refers to the "facilities that store, serve or carry information" (i.e., telephone lines or cable) (Clement & Shade, p. 37). According to Clement and Shade, "the main constitutive element is the service/content layer in the middle, since this is where the actual utility is most direct. However, all the other layers are necessary in order to accomplish proper content/service access" (p. 35).

With the Rainbow Access model, Clement and Shade (2000) have attempted to describe the components required to construct universal access. Although it has been a decade since the Access Rainbow model was introduced, it is still relevant to the introduction of Internet technology in community contexts such as the Mid-Main Community Health Centre. Each band of the rainbow was addressed during the implementation of the Internet terminal at Mid-Main, yet following the steps to implement access is a persistent challenge for many community-based organizations with limited influence over some rainbow bands. Thus a broad array of elements and stakeholders remain essential to construct and support access.

2.2.2 Health Services Access

Health services access is a second area where models have been leveraged to describe access. Drawing upon health services access rather than health information access is of relevance, because as described in the next chapter, policy documents conflate health information with service access in certain ways. For example, some may believe that citizens' use of online health information can lessen the burden on important resources such as emergency room services (British Columbia, n.d.-b). In this manner, health information is being conceptualized as a health service replacement, or at minimum as an entry to the appropriate health services.

The Andersen Model (Andersen, 1968) has been a highly influential contribution to the literature on health services access (Goldsmith, 2006).[7] As described in an article outlining its adaptations over time, the Andersen Model was first introduced in the late 1960s as part of Ronald Andersen's doctoral dissertation (Andersen, 1995). In the 1960s, the Andersen Model originally suggested that "people's use of health services is a function of their predisposition to use services, factors which enable or impede use, and their need for care" (1995, p. 1).

In an interview response chronicling the development of the model, Andersen (2004) states:

> The model has evolved over the years from a focus on simple measures of access (e.g., whether or not people see a physician or are admitted to a hospital) to one stressing more whether access is effective (e.g., improves peoples' health) and efficient (can be effective and still contain costs). I have also concentrated more on access for vulnerable population groups (e.g., homeless persons and people with HIV). Some of my current interests are better understanding how community and organizational factors (as well as their own personal characteristics) influence access to care and why we observe ethnic differences in health and access to care ("An interview with Dr. Ron Andersen", para. 4).

Through the development of the model, it is evident there is increased emphasis on the politics of access for disadvantaged populations.

Andersen (1995) suggests a nuanced and "multi-dimensional" definition of access is necessary when considering the planning of health policy to promote access (p. 4). He sets out multiple components of access: 1) "potential access is simply defined as the presence of enabling resources [i.e., community infrastructure,]" 2) "realized access is the actual use of access"; and 3) "equitable and inequitable access are defined according to which predictors of realized access are dominant" (p. 4). By describing the Andersen Model from the 1960s to the present, I have attempted to present the language that makes evident the overlapping similarities between major examples of

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[7] Goldsmith (2006) compares citation rates for several versions of the Andersen model against others, including The Institute of Medicine's 1993 model and a model by Penchanksy and Thomas from 1981. Her finding is that the Andersen model is "the most cited access theory by far" (p. 19).

access models for the Internet and health services. At the end of his 1995 article, Andersen specifically states that "continuing directions of so-called 'health care reform'" make "studies of equity and efficient and effective access...relevant and important for the indefinite future" (p. 8). Thus Andersen has pointed towards the need for an integrated understanding of access. Chapter 3 will discuss how Web sites fit within health care reform and renewal initiatives.

2.2.3 An Integrated Understanding of Access

Comparisons of the Access Rainbow (Clement & Shade, 2000) and the Andersen Model (Andersen, 1995) reveal certain similarities between access models from the communication and health services disciplines. From these models, it is evident that physical and technical infrastructures are inadequate on their own to ensure access is realized. Across the Access Rainbow and Andersen Model it is evident a broad array of social factors impact access to Internet-based content and health services. Within the Canadian context, attempts have been made through policy to ensure both Internet and health services access are equitable. However, the realization of this goal is impeded by both digital divide factors and the social determinants of health.

Many digital divide factors and social determinants of health such as socio-economic status, education, literacy level, and culture overlap. For example, a factor such as low socio-economic status may inhibit both access to the Internet and access to health services. Although universality is idealized for both Internet connectivity and health care, both may oblige individual users to incur costs. For example, bus fare may be required to reach a library for Internet access or a health care provider's office for an appointment. Low income and living in a rural or remote location can dramatically compound the challenges of connectivity to health information or transportation to a health care provider, as well as compound the costs to be borne by the individual.

Perhaps the most important learning about access emerges when considering the challenges faced by a single hypothetical individual with a low income. To determine how something really works, models need to be applied to real-world problems and data sets. Researchers need to be prepared to revise their models and preconceived notions of how things work. Iterations are evident in both the Access Rainbow (Clement & Shade, 2000) and Andersen Model (Andersen, 1995). An iterative process of constructing access was applicable to the action research project of the implementation of the Internet terminal at Mid-Main, where I had considerable leeway in identifying problems with access and addressing them. This was especially true at the meso, or organization level where the Mid-Main Community Health Centre and ACTION for Health research partnership took place, and where I was able to collaborate with others to make decisions about implementing the Internet terminal in the waiting room. In this manner theoretical modes of access have assisted with this project.

2.3 Usefulness

The final key term in my research question is *usefulness*, which suggests that technology can be applied towards a practical purpose. Rideout and Reddick (2005) state: "technologies are primarily understood as intermediary tools that are beneficial when they can be used to provide access to resources which meet people's needs (e.g., ...health information [needs])" (p. 47). The usefulness of a technology can be considered in relation to social outcomes (which are relevant to the individual user), or in relation to task completion. For a health information Web site, social outcomes of relevance to the individual may include improved health or empowerment. If one considers health information seeking a task, discussions about e-government[8] and electronic transactions become relevant. The governments of Canada and British Columbia have placed a wide variety of information online for citizens. In some cases, online information replaces in-person information dissemination for citizens who are able to access the Internet. Health information on the Internet is therefore a component of both individual activity and the larger structures of government service and information delivery.

2.3.1 Individual and Social Outcomes

Presumably, people access health information online because they perceive it will be of benefit to them. For example, individuals may believe that online health information can help them to improve their health and make knowledgeable decisions about maintaining it, or that it can be used to assist family and friends. Such uses of health information Web sites have been promoted in policy discourse as self-care and

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[8] The term *e-government* describes electronic government. This abbreviation format will be followed for any other terms with an online component or electronic channel (e-commerce, e-service, etc.)

will be discussed in depth in the next chapter. The perceived usefulness of a technology may encourage use. However, throughout this work, this gap is highlighted between perceived usefulness and actual use of health information Web sites.

2.3.2 Tasks and Transactions

Since the 1990s, an increasing number of government services in Canada have been digitized to enable citizens to interact with the state.[9] Barney (2005) emphasizes that the Canadian government has attempted to "role-model" the effective use of information communication technologies (ICTs) (p. 110). Lenk (2002) suggests that electronic service delivery is a component of the modernization of government. He discusses how states interact with citizens over electronic channels through electronic transactions which are similar to e-commerce activities. The perceived usefulness of online health information delivery reflects ideals about achieving efficiency and cost savings in comparison to other information and service delivery channels. The issue of efficiency will be further explored in chapter 2.

However, Lenk (2002) provides us with an important cautionary perspective. He asserts that in areas such as health and personal care, "the Internet, at its present stage of development, can only be helpful in preparing the contact, e.g. through the better information for citizens and by facilitating contact and 'intake'" (p. 89). For full e-service or transactional service delivery, the consumer obtains information about products or services, makes contact to request a service, negotiates details of the service, and obtains a service contract (Lenk). Subsequently the service is implemented, and any required follow-up is completed (Lenk). Although many e-health services are being developed both in Canada and internationally, such a model would be problematic in the waiting room of the Mid-Main CHC. In health care, although information provision is a service, other forms of in-person care are still often required or preferred.

2.4 Chapter Summary

In this chapter I have provided insight into the key concepts in the literature that I have operationalized within my research design. The themes of interventions, access,

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[9] The Government On-Line initiative in Canada exemplifies this initiative. For further reading, see: Barney, D. (2005). *Communication technology.* Vancouver, British Columbia, Canada: UBC Press.

and usefulness provide the rationale for my selection of methods and approach. Intervention to enhance access was presented as a possibility at the policy, organizational, and individual end user levels of analysis. Chapters 3, 4, and 5 will each focus on one of these levels (macro, meso, or micro) as a site for intervention to enhance the usefulness of access. The initial key concepts were however only a starting point. Chapter 6 synthesizes the findings resulting from this research by drawing upon the additional concepts of support and sustainability.

CHAPTER 3: CONSTRUCTING ACCESS

Access has been most often considered in a political context. "Improved access" to care is an important goal of much of health policy...It may be well, then, to characterize health policy as the starting point for consideration of the access concept (Aday & Andersen, 1992, p. 545).

3.1 Policy as Intervention

In the previous chapters, governance was introduced as an element of universal access within the Access Rainbow model (Clement & Shade, 2000). Governance however, influences more that just the "development and operation of infrastructure" (Clement & Shade, 2000, p. 37). Policy decision-making also influences the development of content and services which are made available online to the general public through Web sites. The policies around government health information Web sites can be thought of as interventions, developed to affect broad populations.

The tradition of political economy scholarship provides a starting point for critical analysis of health information Web sites. Mosco (1996) states that political economy examines, "the social relations, particularly the power relations, that mutually constitute the production, distribution, and consumption of resources" (p. 25). Although political economy will not be discussed in depth, this tradition provides a rationale from the communication discipline for looking at policy as the "starting point" (Aday & Andersen, 1992, p. 545) for exploring access as a construct which is influenced by government power, within a network of other stakeholders. As government ministries have been highly involved in the creation of the Canadian Health Network and BC HealthGuide, their self-articulated understandings of their own goals and motivations are a location from which one can explore the design and development of health information Web sites.

This chapter will focus on the complexities of defining the broad policy objectives that are prioritized to promote the health of Canadians and British Columbians through access to health information Web sites. The Canadian Health Network and BC HealthGuide were selected for analysis because they were the major sites accessed during the Internet introduction at Mid-Main. Additionally, the agencies responsible for these two health Web sites have research relationships with the ACTION for Health project. In this chapter, I begin by describing two major policy directions that influenced the creation of health Web sites at the federal and provincial levels. In the second part of this chapter, I introduce the social construction of technology as a lens through which to understand the methods used to explore policy discourse related to Internet-based access to health information, as well as the results and analysis from the discourse analysis of 46 documents (see appendix 1) that have been pertinent to the development of the Canadian Health Network and BC HealthGuide. A wealth of relevant policy documents are available online such as press releases, Hansard transcripts, and reports about the federal and provincial governments' goals for the Canadian Health Network and BC HealthGuide.[10] These resources provide insight into the socially constructed expectations of government and the technological artefacts they produce in relation to health information access. The theme of access was explored through the themes of configuration (i.e. communication channels such a phone and Internet); equity (i.e., for women and Aboriginal people); renewal (i.e., primary health care reform); and self-care (i.e., at home) that were located in both discourse and site architecture. The chapter concludes with some examples which suggest that government-produced health information Web sites are not solely a top-down design directive controlled by government alone. Instead, policy just as technological design is a multi-directional phenomenon which is impacted by citizens and participant interests.

3.2 Major Policy Directions

3.2.1 Connectivity

Connecting Canadians to the Internet has been a policy objective since at least the mid-1990s. In 1994 following the Speech from the Throne, the Information Highway Advisory Council (IHAC) was formed under Industry Canada leadership (Information Highway Advisory Council & Industry Canada, 1995).[11] In 1995, IHAC released a report describing Canada's future connections to the Internet (Information Highway Advisory Council & Industry Canada). In the 1997 Speech from the Throne, the Connecting

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[10] Please refer to appendix 1 for clarification on which documents I reference as policy documents.

[11] This report is available on the Health Canada Web site rather than Industry Canada for unknown reasons.

Canadians strategy suggested a broad policy framework under which to develop health information Web sites (Gutstein, 1999). Gutstein indicates this strategy was intended to make Canadians leaders in Internet connectivity and use. He outlines the strategy as having six components. Firstly, community access points to the Internet needing to be established in schools, libraries and public locations. Secondly, electronic commerce was to be fostered and implemented. In the third area, Canadian-created content such as "post-secondary courses, major cultural collections, and health" were to be developed in Canada (p. 10). Fourth, government documents, information and services were to be translated into Web formats "providing seven-day, twenty-four-hour service to Canadians and leading the way for Canadian businesses and consumers to follow" (p. 10-11). The fifth area of development was to be the creation of Smart [wired] Communities. The sixth and final component of the strategy requires Canada to connect to the industrial world and garner foreign investment. Since Gutstein's *e.Con* was published in 1999, the federal government has made varying degrees of progress in implementing projects and programs in each of the six areas in relation to health.

Major investments have been made by federal and provincial governments to create online health information resources. At the federal level, these investments have been referred to as the health infostructure:

> The term "health infostructure" refers to the development and adoption of modern systems of information and communications technologies (ICTs) in the Canadian health care system which would allow the people of Canada (the general public, patients and caregivers, as well as health care providers, health managers, health policymakers and health researchers) to make informed decisions about their own health, the health of others, and Canada's health system (Canada, 2006a, para. 2).

Multi-million dollar budget allocations have been distributed to the health infostructure since 1997. In 1997, the year the Connecting Canadians strategy was unveiled, money was allocated to six programs, including the Advisory Council on Health Infostructure, the Canadian Health Network, the Centre for Surveillance Coordination (CSC), the First Nations and Inuit Health Information System, the Health Infostructure Support Program, and Health and the Information Highway Division (Canada, 2006b). In the 2004 budget, money was allocated to Canada Health Infoway Inc. (Canada, 2006b), a nonprofit corporation with a membership consisting of "14 Deputy Ministers of Health of the federal, provincial and territorial governments of Canada" (Canada Health Infoway, 2005, para. 1). Federal and provincial leaders have participated in the creation of the electronic health infostructure. Some federal investments in health infostructures have been paralleled at the provincial level, while other investments are expected to directly impact the citizens of individual provinces and territories.

3.2.2 Primary Health Care Renewal

A second major policy direction that has influenced the creation of government-produced health information Web sites is primary health care renewal or reform. Federally and provincially, the major tenets of primary health care renewal pivot around citizens' access to care. In British Columbia, the document *Primary Health Care Renewal in B.C.* articulates the tenets of primary health care renewal for patients:

- Improved access to a health professional they can call or see for urgent care 24-hours, seven days a week.
- Increased access to family practices for extended hours to meet patients' needs.
- Reduced repetition of medical testing and information.
- Improved health outcomes, especially for patients with chronic illnesses.
- Increased access to education on risk factors, disease management, and self-care to enhance health and wellness (British Columbia, 2004c, p. 1)

Both federally and provincially, primary health care includes both access to care and the integration of information and communication technology. At the federal level, primary health care renewal is described as promoting interdisciplinary teams, electronic health records, and telehealth (Canada, 2004b). Information is assumed to empower patients by enabling them to make responsible decisions about their health and use of scarce resources.[12]

3.3 Discourse Analysis of Policy Documents

As the connectivity strategy and primary health care reform policy illustrate, the shift of health care services to informational networks and communication channels has occurred within a very particular social and political context. Due to a variety of pressures and priorities in Canadian society, the government has supported these policy directions. However, both converging and competing values underlie connectivity strategy and primary health care reform initiatives. Moscowitz (1994) states there are explicit values in use "when policy decision-makers articulate the societal and cultural

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[12] See section 3.6, theme 4 self-care for further information.

norms that root and shape government action" (p. 96). There are also implicit values, which are so entrenched they require no explanation by policy makers (Moscowitz). A variety of values are assumed to have impacted the design of health information Web sites as programs under the broad policy directions of connectivity strategy and primary health care reform.

3.3.1 Values in Policy and Technology

We can attempt a determination of what broad social values may be incorporated in government-produced health information Web sites via a cursory review of the literature. Values such as efficiency and equity are two concepts which appear to be prominent in the debate. These ideas have been popularized for the public through lectures, books, articles, and public consultations. For example, through the Massey lectures Stein (2001) engaged the public in considering the impact of policy that is based upon the value of an efficient society. Perhaps to an even greater extent, the tenets of the *Canada Health Act* have been popularized as policy values in the public consciousness through widespread public awareness of the Romanow Commission on the Future of Health Care in Canada (2002) and its final report.

The Romanow Report (2002) *Building on Values: The Future of Health Care in Canada*, adamantly states that Canadians "support the core values on which our health care system is premised—equity, fairness and solidarity" (p. xvi). Romanow describes the five program criteria of the *Canada Health Act* which must be followed for provinces to receive funding from the federal government: "(a) public administration; (b) comprehensiveness; (c) universality; (d) portability; and (e) accessibility" (Canada, 1984, ch. 6, s. 7), which he suggests have become "iconic" values to Canadian citizens (p. xxiv). As described by Hankivsky (2004), values surrounding health care incorporate an "ethic of care" within social policy (p. 1-2).

Still, it remains difficult to describe how these abstract values become instrumentalized in the policy programs of health information Web sites. Feenberg (1999) states that "non-economic values intersect the economy in the technical code" (p. 97). Given my awareness of the overarching policy directions and strategies promoting the creation of health information Web sites, I determined that policy objectives could be better defined by reviewing policy documents to seek out descriptions of the values in policy discourse which influenced the technical code of the Web sites accessed at Mid-

Main. From this investigation it became clear that a parallel discourse and site architecture[13] analysis informed by the social construction of technology was an appropriate approach to take in analyzing the documents to obtain a more refined understanding of the rhetorical themes and values incorporated into the access and accessibility of health information Web sites.

3.4 Social Construction of Technology

As described in chapter 1, SCOT is an approach that explores the impact of participant interests, particularly users' interests in design. In the following section, a method will be outlined for conducting discourse analysis of policy documents and two health information Web sites. The SCOT influence can be seen in this method, because although both the federal and provincial governments are powerful institutions, they are also relevant social groups with interests related to the design of health information Web sites. SCOT has been criticized for failing to consider power relations (Oudshoorn & Pinch, 2003). However, I propose that because policy and governance so explicitly links to power in a macro, meso. and micro framework, it is an appropriate entry point through which to begin to explore how access to health information through the Web is socially shaped.

3.5 Method

Phillips and Hardy (2002) "define a discourse as an interrelated set of texts, and the practices of their production, dissemination, and reception that brings an object into being" (p. 3). In the case of the Canadian Health Network and BC HealthGuide, this includes both policy documents and the Web sites which are the resultant technological artefacts. The initial motivation for conducting discourse analysis of the Canadian Health Network and BC HealthGuide Web sites and related policy documents was to understand their purpose as defined by the government. Guiding questions at the start of this analysis included: why did the government decide to build health information Web sites? Who were the perceived end users? What were the Web sites intended to achieve for citizens and patients? How was architecture impacted by conceptualizations of

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[13] With the term site architecture I am referring to structural elements such as the navigation options.

access? These questions reflect my social-constructivist approach to understanding how participant interests are incorporated into both policy decision-making and design.

I located relevant documents in the public domain relating to the Canadian Health Network and BC HealthGuide program through government search engines and text links on the BC government's homepage and the Public Health Agency of Canada site. I began on the provincial site search engine by querying "BC HealthGuide", then sifted through the top 100 hits deemed by the system to be relevant. During this process, I discarded the majority of the links to actual pages of the BC HealthGuide Web site. Documents describing the purpose, design, or history of the BC HealthGuide were relevant to this analysis, but I considered relevant only limited quantities of the actual content of the site. I proceeded to repeat a similar retrieval and discard process to locate policy documents related to the Canadian Health Network. From these search strategies I obtained 46 documents (see appendix 1), which I categorized by format.

Table 3.1 Categorization of Policy Document

	Number of Documents		
Document Type	**Canadian Health Network**	**BC HealthGuide**	
• Hansard transcripts	4	2	
• Government committees	9	0	
• Reports	4	4	
• Press releases, public relations or marketing	8	4	
• Advisory board meeting minutes	9	0	
• Health Information Web sites	1	1	
TOTAL	**35**	**11**	**46**

Schwandt's (1994) writing about constructivist research methods influenced my next steps. He suggests:

> The constructivist or interpretivist believes that to understand this world of meaning one must interpret it. The inquirer must elucidate the process of meaning construction and clarify what and how meanings are embodied in the language and actions of social actors (p. 118).

This position encouraged me to seek to understand the interests of the actors involved in producing and maintaining the Canadian HealthGuide and BC HealthGuide resources by considering the major policy directions. In spring 2005, I conducted a pilot study using the BC HealthGuide policy documents. I hypothesized that the rhetoric surrounding the Web sites would be distinct for audiences of citizens, politicians, and health care practitioners and administrators. I believed the rhetoric in the public relations documents for citizens would be about empowerment, whereas cost savings would perhaps be emphasized in documents whose intended audience was administrators or politicians.

To begin to test this hypothesis I developed trees of coding categories which were informed by my policy knowledge and personal experience navigating health information Web sites. When I expanded the analysis to include the Canadian Health Network, coding categories were iteratively adjusted and adapted as they were applied within the NVivo 2.0 qualitative data analysis program. Table 3.2 outlines the schema that was applied in NVivo with 3 major codes and 18 nodes.

Table 3.2 Coding Tree for Rhetorical Themes Related to Access[14]

--------------------------Access--------------------------		
Equity (equit*)[15]	**Self-care**	**Reform**
• Rural, remote	• Prevent*	• Renewal
• Aboriginal, First Nation*	• Well*, promot*	• Primary health*
• Wom*n	• Deci*	• Innovat*
• Senior	• Home	
• Disab*	• Informat*	
• Francophone,	• Manag*	

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[14] Codes that were discarded from the thematic analysis are: needs, cross-cutting, Mid-Main and omitted (occurrences of KWIC words that were out of context). These themes may be relevant for other types of analyses. The category of cost became relevant in a discussion of configuration which was identified as a theme primarily by considering the Web site architectural elements.

[15] The '*' symbol denotes a wild card search to capture variations of similar terms.

<table>
<tr><th colspan="3">--------------------------Access--------------------------</th></tr>
<tr><th>Equity (equit*)[15]</th><th>Self-care</th><th>Reform</th></tr>
<tr><td>French, bilingual</td><td></td><td></td></tr>
<tr><td>• Translat*, language*</td><td></td><td></td></tr>
<tr><td>• Immigra* (immigrant, immigration),</td><td></td><td></td></tr>
<tr><td>• Cultur*</td><td></td><td></td></tr>
</table>

Under the overarching theme of access, the categories that emerged as important were equity, reform, and self-care. Passages and contextual instances of key words were coded throughout the texts. This methodological strategy was informed by "key-words-in-context (KWIC) lists" as described by Ryan and Bernard (2003, p. 269). However, unlike Ryan and Bernard suggest, the passages were not limited or restricted to a specific number of words so as to construct concordances of uniform length. While searching for KWIC, I also made extensive use of the asterisk symbol to conduct wild card searches for the stems of words. In parallel, while coding text passages, I identified architecture and interface elements that operationalize these constructions of access into the technological design of health information Web sites.[16] Upon reviewing my coding trees and Web site interface examples, I found they lead towards answering questions about access.

Table 3.3 Questions of Access

Equity (equit*)	Self-care	Reform
Who can or should access online health information?	What is the purpose of online health information access?	Why does access to health information exist?

These questions expand upon the broad questions which Clement and Shade pose about universal access in relation to two specific government Web sites: "1) Access for what purposes? 2) Access for whom? And 3) Access to what?" (Clement & Shade,

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[16] The health information Web sites were not coded in NVivo. Architectural elements (i.e. navigation structures) were commonly drawn from the Web sites. Some architectural elements such as drop down menus are not easy to capture in text only format within the context of the site and hence do not translate well for NVivo coding.

2000, p. 36). When I began writing this chapter, issues of configuration were also relevant. The term *configuration* was used to address passages and content which addressed "local configuration" (Suchman, 1994, p. 4) of the design of health information Web sites specific to the Canadian and British Columbia contexts. Some of this information had been coded under the category of cost, a category I considered discarding. Other examples of configuration were drawn from architectural elements.

3.6 Access in Policy and Architecture: Results and Analysis

As a product of iterative coding, the schema (see table 3.2) in conjunction with the actual Web sites, describe how two levels of government construct access. Numerous instances of the rhetorical themes arose in the BC HealthGuide and Canadian Health Network policy documents; however, no quantitative results of the analysis will be provided due to the complexity and overlapping instances of the rhetorical themes that make analysis of discrete thematic constructions of access problematic. Instead, the contextual patterns will be presented that demonstrate how the government constructs access through discourse and health information Web sites. Both the coded documents and site architectures demonstrate the government conceives of access quite broadly and in socio-technical terms. Below I describe the major themes to emerge from the coding and writing process.

Theme 1: Configuration

The history of the configuration of the Canadian Health Network and BC HealthGuide programs within a wider array of services emerged as fundamental pieces of information within the review of the Web sites and policy documents. It is significant to note that both the Canadian Health Network and BC HealthGuide have experienced some flux in terms of their architecture within broader health information programs. Consistent with the social construction of technology, their respective designs reflect the differing roles of the state and the province within health care delivery. The design cannot be considered stabilized as changes periodically occur; for example, a redesign of the BC HealthGuide occurred during this research.[17]

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[17] The examples presented in this chapter will focus on the current BC HealthGuide Web site. Chapters 5 and 6 will present information relevant to the old version of the site which was accessed by many research participants.

Historically the Canadian Health Network Web site emerged out of offline information services once provided by Health Canada. The origins of the Web site are described in the Standing Committee on Public Accounts *Eighth Report*:

> Following the 1994 Program Review, Health Canada (the Department) merged four clearing houses providing health information into one entity. In 1997, the Department decided that the clearing house (which had been using phones, faxes, and printed documents to disseminate information) would shift to a Web-based service to be known as the Canadian Health Network (CHN, the Network). Health Canada hired the same contractors who were running the clearing house to set up the Web-based initiative. The Department turned to Public Works and Government Services Canada (PWGSC) to assist in the contracting process. The final cost of creating the Web site amounted to over $25 million (Canada, n.d., para. 1).

A backgrounder about the Canadian Health Network envisions a "longer-term view...to provide multi-mode access (for example, 1-800, email, or fax back) to reflect the varied needs and preferences of Canadians" (Canada, 1999f, para. 4). However, today this type of multi-modal access does not exist for the Canadian Health Network. Instead, it serves as a portal, or meta web-based "network of networks" (Canada, 1999f).

However, the BC HealthGuide program has far surpassed the Canadian Health Network in multi-mode information delivery. The BC HealthGuide consists of four components[18] which facilitate access to information and services for the residents of the province. The program contains four channels: (1) a 24-hour BC NurseLine augmented by pharmacists after the business day; (2) a Web site; (3) one-page fact sheets called HealthFiles available online; and (4) a paper handbook (British Columbia, n.d.-b). As with the Canadian Health Network, the present configuration of the program has not always been consistently reflected in policy documents. For example, in the *Primary Health Care Compendium* maintained by the BC Ministry of Health Services, the fact sheets are omitted as a component of the program, and the compendium states the program has just three parts (British Columbia, n.d.-b). This omission perhaps reflects the shifting nature of government programs.

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[18] The online homepage of the BC HealthGuide displays these four components. My verbal description was based on observations made from the homepage www.bchealthguide.org which I last accessed on June 15, 2006.

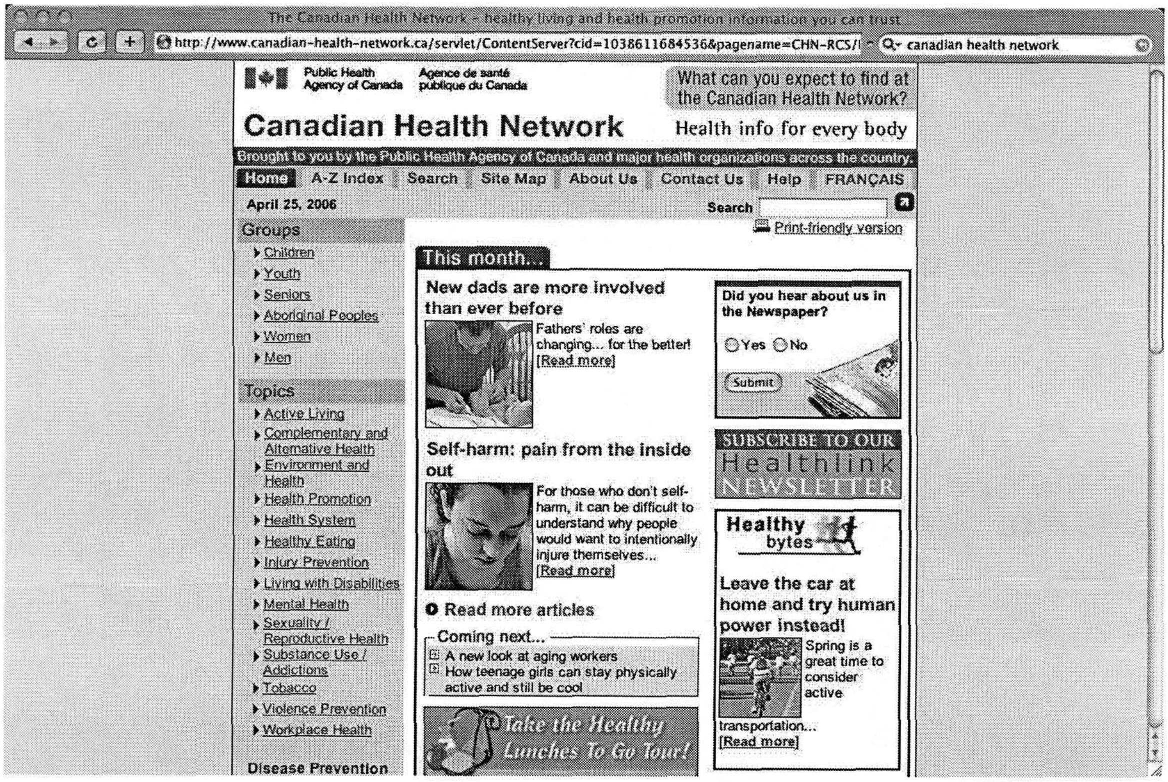

Figure 3.1: Homepage of the Canadian Health Network[19]

The Canadian Health Network – healthy living and health promotion information you can trust

http://www.canadian-health-network.ca/servlet/ContentServer?cid=1038611684536&pagename=CHN-RCS/

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Leave the car at home and try human power instead!

Spring is a great time to consider active transportation... [Read more]

The configuration of the two Web sites can also be examined in terms of site content and architecture (see table 3.4). The Canadian Health Network is a decentralized information portal. Much of the health information is created by partner organizations such as nonprofit health associations. The Canadian Health Network also links to provincial resources such as the BC HealthGuide. In contrast, the BC HealthGuide is a centralized information hub. Much of the content provided on the BC HealthGuide Web site has been licensed from Healthwise Inc., a nonprofit corporation that specializes in syndicating content for health information resources. What these different histories, conceptions and configurations of technology reveal is that the design process is not fixed, and that a stabilized design is not an inevitable outcome. Differences and similarities are outlined in table 3.4.

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[19] This image is courtesy of PHAC and the Canadian Health Network. This page is updated frequently and is available from: http://www.canadian-health-network.ca/servlet/ContentServer?cid=1038611684536&pagename=CHN-RCS/Page/HomePageTemplate&c=Page&lang=En

Table 3.4 Canadian Health Network and BC HealthGuide Comparison

	Canadian Health Network	**BC HealthGuide Online**
• **Program Configuration**	The Canadian Health Network (CHN) is **exclusively online** and replaces the older tradition of phone, fax, and mailed information available from Health Canada.	The BC HealthGuide is an integrated **online and offline** strategy including: a) print handbooks distributed to all BC residences in 2001 and via pharmacies in 2006; b) a 24 hour NurseLine; c) HealthFiles fact sheets; and d) the BC HealthGuide Online, which will be discussed in the remainder of this table.
• **Architecture Strategy**	Much of the content available through the CHN is from a **decentralized** networked architecture.	The BC HealthGuide Online uses a **centralized** architecture strategy
Users:		
• **User Categories**[20]	Children Youth Seniors Aboriginal Peoples Women Men	Family Children and Youth Health Women's Health Men's Health Senior's Health Aboriginal Health Multicultural Health
Content:		
• **Content Sources**	The CHN draws upon internal and external content. It has established community **partnerships**[21] including nonprofit organizations and provincial	The BC HealthGuide Online draws largely upon content provided from the American based nonprofit Healthwise Inc. and can be considered **syndicated**, although altered

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[20] As last accessed on June 15, 2006 these listed categories are direct quotes from the Web sites http://www.canadianhealthnetwork.org/servlet/ContentServer?cid=1038611684536&pagename=CHN-RCS/Page/HomePageTemplate&c=Page&lang=Enand http://www.bchealthguide.org/ ; see also figure 3.3 and 3.4

[21] See 'About Us' at http://www.canadian-health-network.ca/

	Canadian Health Network	**BC HealthGuide Online**
	and regional levels of government.[22]	for BC relevancy. Drug information is also licensed from Mediresource Inc.[23]
- **Major Health Content Categories**[24]	Active Living Complementary and Alternative Health Determinants of Health Environment and Health Health Promotion Health Systems Healthy Eating Injury Prevention Living with Disabilities Mental Health Sexuality / Reproductive Health Substance Use / Addictions Tobacco Violence Prevention Workplace Health...	Health Topics Medical Tests Medications Community Support
- **Languages**	English and French	English and limited content in the online BC HealthFiles in French, Farsi, Punjabi, and Cantonese
Navigation:		
- **Navigation Elements**	Text links, A-Z links, search engine, site map, pull-down menus	Text links, A-Z links, search engine, site map, pull-down menus
Operations		
Ministry Responsible	Public Health Agency of Canada (formerly Health Canada)	BC Ministry of Health

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[22] In addition to the information provided by the Public Health Agency of Canada, the Canadian Health Network links out to information from a broad array of experts, including universities, nonprofit organizations, and libraries.

[23] See http://www.bchealthguide.org/kbase/default.htm and http://www.bchealthguide.org/medications.asp to verify where the BC HealthGuide online is obtaining information from at the present date

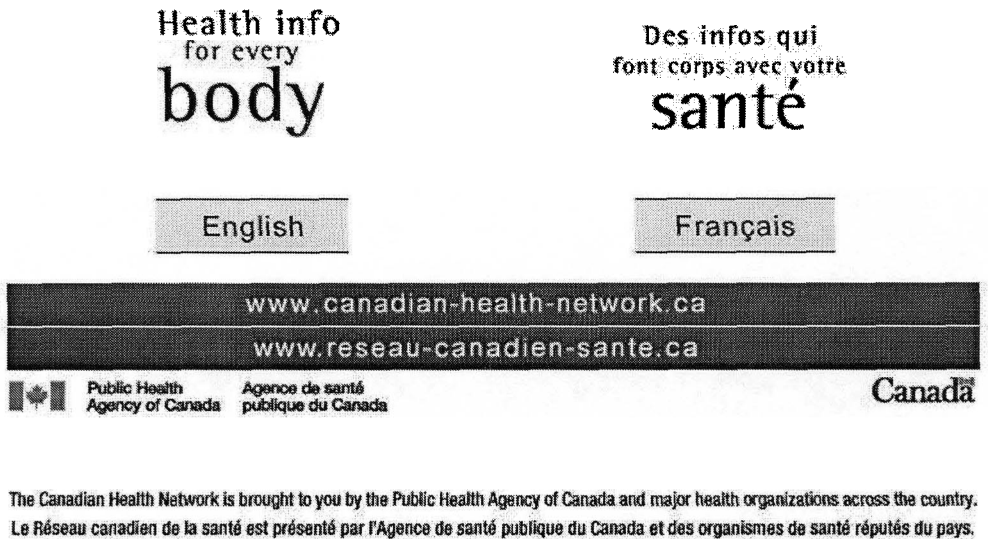
[24] See http://www.canadian-health-network.ca and www.bchealthguide.org/kbase/default.htm for navigation categories. These category labels are direct quotes from a broader array of options. The listed options were last accessed August 5, 2006.

The similarities and differences between the Canadian Health Network and BC HealthGuide over time are explored in greater depth in the subsequent sections.

Theme 2: Equity

As stated earlier, Romanow (2002) has identified equity as one of the foundational values of the Canadian health care system. Within the texts analyzed, both the Canadian Health Network and the BC HealthGuide attempt to fulfil this obligation by providing equitable access for diverse citizens and residents. Equitable provision of information for both French- and English-speaking Canadians appears to be one of the initial priorities of the Canadian Health Network At the federal level, the Hon. Allan Rock as Minister of Health stated in the House of Commons: "The [Canadian Health Network] services are available in English and in French everywhere in Canada" (Canada, 1999a, para. 10). Similarly a variety of other policy documents related to the Canadian Health Network make reference to the French, francophone, bilingual, or official languages access (Canada, 1999b, 2003b) provisions as an essential attribute of the resource. This emphasis is not surprising given the first screen of the Canadian Health Network and *Reseau Canadien Sante* enables the user to select between an English and French version of the site (see figure 3.2). It is notable that the universal resource locator (URL) for the site is also bilingual (see figure 3.2).

Figure 3.2: Canadian Health Network Language Selection Screen[25]



The Canadian Health Network is brought to you by the Public Health Agency of Canada and major health organizations across the country.
Le Réseau canadien de la santé est présenté par l'Agence de santé publique du Canada et des organismes de santé réputés du pays.

In addition to the Canadian Health Network's emphasis on bilingualism, other kinds of diversity are reflected in policy discourse and site architectures. In the case of the Canadian Health Network, partnerships to provide content for the Web site were fostered to "focus on population groups like seniors, children, youth and women" (Canada, 1999d, para. 10). The Canadian Health Network has also attempted to provide appropriate information for disabled (Canada, 1999c) and rural Canadians (Canada, 1999c). Similarly, the BC government has emphasized meeting the needs of diverse citizens and linguistic communities; therefore French (British Columbia, 2004b) and Aboriginal (British Columbia, 2003) versions of the BC HealthGuide handbook were released. Across the policy documents it is evident that several categories of citizens (i.e., French, Aboriginal, seniors, and women) are intended users of the health Web sites. The intention to provide information to these audiences is further reflected in the fact that many of these populations are listed as links on Web site menus (see figures 3.3 and 3.4).

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[25] This image is courtesy of PHAC and the Canadian Health Network. The image was last accessed June 15, 2006, at http://www.canadian-health-network.ca/

Figure 3.3: Canadian Health Network User Group Menu[26]

Figure 3.4: BC HealthGuide User Group Menu[27]

- **Family, Child & Youth Health**
- **Women's Health**
- **Men's Health**
- **Senior's Health**
- **Aboriginal Health**
- **Multicultural Health**

It is particularly interesting to note that both the Canadian Health Network and BC HealthGuide are making substantial efforts to reach out to diverse citizens who are disadvantaged when it comes to receiving medical care. The Canadian Health Network "identified as a priority the development and implementation of a strategy to better meet the health information needs of Canadians living outside of large urban centres and in under-serviced areas" (Canada, 2004a, para. 7). The BC HealthGuide program has provided a multilingual phone line to various cultural communities: "Translation services are...available upon request in 130 languages, including Cantonese, Mandarin, Punjabi, German, French, Tagalog, Spanish, Italian and Korean—the most widely spoken

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[26] This image is courtesy of PHAC and the Canadian Health Network. It was last accessed June 15, 2006, from: http://www.canadian-health-network.ca/servlet/ContentServer?cid=1038611684536&pagename=CHN-RCS/Page/HomePageTemplate&c=Page&lang=En

[27] I created this image myself based on the BC HealthGuide navigation options for user groups current as of June 15, 2006. The text links are direct quotes from the Web site within a larger menu. See: http://www.bchealthguide.org/ for the full menu of options.

languages in B.C. other than English" (British Columbia, 2004a, para. 2). Increasingly the BC HealthGuide is providing multilingual options online.

Unlike the Canadian Health Network, the BC HealthGuide is not bilingually accessible in French and English; however, through the "Multicultural" link, information is available on the overall BC HealthGuide program in a variety of languages, including French, Farsi, Cantonese, and Punjabi.[28] Additionally, limited quantities of information on health topics are available in Chinese, French, Punjabi, Spanish, and Vietnamese through the BC HealthFiles available online.[29] At the provincial level, there appears to be a trend towards broadening access and working towards equity through inclusion. The differences between the federal and provincial interfaces as they relate to language and equity may link to policy and law. The Canadian Constitution and *Canada Health Act* assign responsibility to the provinces for service delivery. For example, a 1997 Supreme Court of Canada ruling[30] effectively obliges the provinces to fund translation services for the deaf as needed to ensure equitable access to services in locations of care such as hospitals (Eldridge v. British Columbia (Attorney General), 1997). The *Eldridge v. British Columbia (Attorney General, 1997)* ruling stated:

> It is purely speculative to argue that the government, if required to provide interpreters for deaf persons, will also have to do so for other non-official language speakers, thereby increasing the expense of the program dramatically. The possibility that a...claim might be made by members of the latter group cannot justify the infringement of the constitutional rights of the deaf (para. 23).

Perhaps because of this speculative potential and the differing responsibilities of the federal and provincial government, British Columbia is providing increased multi-lingual accommodations online as a measure of promoting equitable access.

Theme 3: Renewal

Primary health care reform or renewal is a policy direction intended to update and improve access to the health care system. At the federal level, this change is

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[28] The multicultural information was located at http://www.bchealthguide.org/multicultural.stm; it was last accessed on June 15, 2006.

[29] The translated BC HealthFiles (which are available online but separate from the BC HealthGuide online component) were accessed on June 15, 2006, at http://www.bchealthguide.org/healthfiles/httoc.stm

[30] Information on the ruling is available online at http://www.lexum.umontreal.ca/csc-scc/en/pub/1997/vol3/html/1997scr3_0624.html

discussed in broad terms; for example, Minister Rock stated, "The CHN promises a new era in health information technology for the 21st century" (Canada, 1999c, para. 3). British Columbia has received large sums of money from the federal government to attempt to implement change. In 2002, the Hon. S. Hawkins stated that the province of British Columbia had $74 million from Health Canada's transition funds to spend over four years (British Columbia, 2002). From this funding, Hawkins said: "we hope to access and set up different kinds of models [of care]. We're looking at other options. We've got some primary care demonstration projects across the province, but we're looking at and open to different kinds of models..." (British Columbia, 2002, p. 1557). The funding from the federal government to British Columbia through the Health Transition Fund links information technology with changes to service models of health care. For example, Hawkins noted:

> In the intermediate to long term, we are looking again at primary care renewal and what kinds of ways we can provide for patients to access the system so it's not necessarily an emergency room or a doctor's office (British Columbia, 2002, p. 1557)

The BC HealthGuide program represents an alternative mode, which is actually and explicitly intended to divert patients from face-to-face care:

> The BC HealthGuide Program is an innovative self-care program that involves three integrated components: the BC HealthGuide Handbook, BC OnLine and the BC NurseLine.... Goals and objectives of the program are to increase consumer health education to help people make wise health decisions; to reduce pressures on emergency resources including physicians, Emergency Rooms and other acute care resources; and to reduce or re-allocate financial costs by promoting improved utilization of health care resources across British Columbia (British Columbia, n.d.-b, p. 70).

Clearly, the provincial government has an interest in preventing unnecessary trips to the emergency room. This example demonstrates how architecture and design can align with policy goals. Specific architectural elements that may help to change patterns of access to the health care system will be discussed in the next section.

Theme 4: Self-care[31]

Both federally and provincially, similar language has been used to describe the value of information to aid patients in making decisions about their health. Self-care acknowledges that patients are not passive recipients of information or services, but rather participants in their own care. For example:

> As a result of new communications technology, the federal government in conjunction with its partners has an opportunity to significantly increase the knowledge of Canadians regarding their health. 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. The Canadian Health Network (CHN) responds to these challenges (Canada, 1999e, para. 1).

In this direction, the "Canadian Health Network offers a range of health information, focussing initially on how to lead a healthier life and prevent disease, then branching into broader topic areas including self-care..." (Canada, 1999e, para. 3). Similarly, the BC HealthGuide program "is based on the Healthwise self-care program that supports citizens to make wise health decisions for themselves and their families" (British Columbia, n.d.-b, p. 70). According to the discourse, when information is available, patients can become empowered actors within the health care system by making informed decisions (British Columbia, 2004a, para. 2).

An applied outcome of making health information available online may be that patients decide to take care of themselves at home or preventively. A press release backgrounder states that between 2001 and 2004, "About 32 per cent [of callers to the BC NurseLine] were advised to use home treatment or seek non-urgent health services such as a follow-up visit with a doctor the next day" (British Columbia, 2004a, para. 8). Interface elements on the BC HealthGuide Web site and Canadian Health Network also support this possibility. For example, on a Canadian Health Network page, visitors are advised to take precautions such as getting a flu shot or washing their hands.

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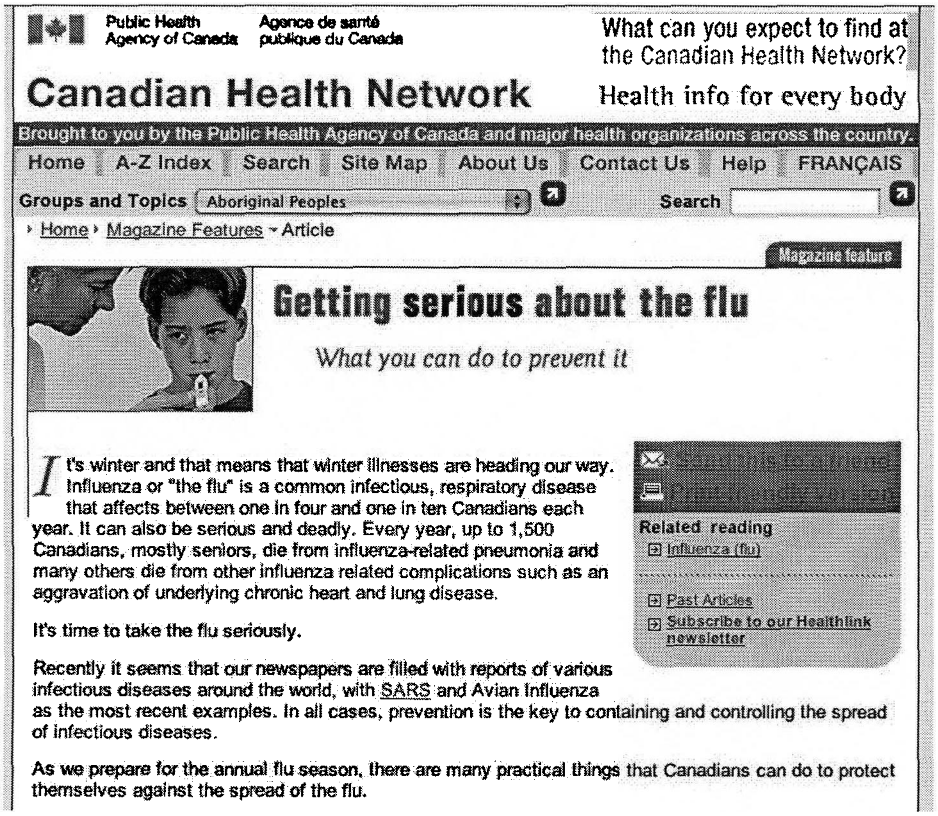
[31] *Self-care* is a term located in the policy discourse. Although presented in that context in a positive light, where government is primarily perceived to be attempting to achieve cost savings, it may be problematic or debatable as being in the public interest if services are decreased.

Figure 3.5: Canadian Health Network Flu Article[32]



Getting serious about the flu

What you can do to prevent it

It's winter and that means that winter illnesses are heading our way. Influenza or "the flu" is a common infectious, respiratory disease that affects between one in four and one in ten Canadians each year. It can also be serious and deadly. Every year, up to 1,500 Canadians, mostly seniors, die from influenza-related pneumonia and many others die from other influenza related complications such as an aggravation of underlying chronic heart and lung disease.

It's time to take the flu seriously.

Recently it seems that our newspapers are filled with reports of various infectious diseases around the world, with SARS and Avian Influenza as the most recent examples. In all cases, prevention is the key to containing and controlling the spread of infectious diseases.

As we prepare for the annual flu season, there are many practical things that Canadians can do to protect themselves against the spread of the flu.

On a similar page in the BC HealthGuide online, there is an additional emphasis on providing guidance about when to visit a health professional. Explicit guidelines on 'When to Call a Doctor' are on the provincial site to inform patients about when they need to access professional care instead of taking care of themselves at home.[33]

3.7 Discussion and Analysis

Having provided examples of access through the rhetorical themes of configuration, equity, reform, and self-care in the policy documents, I propose that together, they relate to issues of power which underlie the concept of access. In the quote that opened this chapter, Aday and Andersen (1992) stated: "access has been most often considered in a political context" (p. 545). The macro level policies and

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[32] This image is courtesy of PHAC and the Canadian Health Network. It was last accessed June 15, 2006, from: http://www.canadian-health-network.ca/servlet/ContentServer?cid=1065630278792&pagename=CHN-RCS%2FCHNResource%2FCHNResourcePageTemplate&c=CHNResource&lang=En

[33] The 'When To Call a Doctor' page for influenza was last accessed on June 15, 2006, at http://www.bchealthguide.org/kbase/topic/major/hw122012/whn2call.htm

decisions of government clearly constitute a political context. The Canadian Constitution and *Canada Health Act* demonstrate that to facilitate access to health services, power sharing occurs between the federal and the provincial governments. Through health information Web sites, a similar power sharing is illustrated via the "local configuration" (Suchman, 1994, p. 24) of Web sites for the nation and a province based on equity considerations (i.e., through language options which are appropriate for target users).

However, political contexts do not exist exclusively at the governmental level. Both the federal and provincial policy documents indicate a similarity in their attempts to include and empower citizens and the community. Linkages with community organizations and individual citizen-patients are essential to attempt to achieve change in the health care system. The goals of self-care, changing practice models, and primary health care reform rely highly on a broader participation. Identification of access as being constructed within a network of power at the macro level is significant for my overall research project. Considering the goal of executing multi-level interventions to make government health information Web sites useful for individuals in the waiting room of the Mid-Main Community Health Centre, it is significant the government is aware of community needs and priorities. Analysis of the policy and architecture of large-scale government health Web sites may seem abstract and removed from the context of working to introduce a computer to the waiting room of a community clinic, but fortunately, the gap between policy decision making and the Mid-Main Community Health Centre is not as large as it might be. Within one analyzed text, the Mid-Main Community Health Centre and their pharmacist were held up as an example of innovation, commitment, and tenacity in primary health care reform (Canada, 2003a, p. 1335). My supervisor, Dr. Ellen Balka, was cited in another text for attending and presenting at an Advisory Board meeting for the Canadian Health Network (Canada, 2004a, para. 6). These instances reflect the connections that exist between macro, meso, and micro levels where interventions for access can be executed, and people, ideas and suggestions can flow among these levels.

3.8 Chapter Summary

In this chapter, I have discussed policy as a form of intervention. I have focussed on connectivity and primary health care renewal as major interlinked policy directions that underlie the development Canada's health information highway. Subsequently, I provided an overview of the methods used to conduct discourse analysis of policy documents related to the Canadian Health Network and BC HealthGuide. A discussion about values underlying both technology and Canada's health system preceded a discussion of the research methods used in conducting discourse analysis of documents related to the emergence of Canada's health information infrastructure. An analysis of the policy documents led to the identification of four related themes: (configuration, equity, self-care, and reform) which were used as thematic categories. Analysis of the Web sites and policy documents suggested that configurations such as a meta or centralized network strategy are made in response to local considerations. Equity influences the development of content and navigation categories for perceived end users. Renewal relates to the Internet as a channel for information delivery. Finally, self-care relates to government's view that citizens need or want to take greater responsibility for their health. Taken together, one can see that health information networks reflect the sharing of power between government, clinics and citizen end users. Chapter 4, will examine the Mid-Main CHC as another location where decision-making power was implemented in relation to health information Web sites. With Mid-Main's ideal of including patients in decision-making, the sharing of power to implement universal access extends into the "service/access" element of the Access Rainbow (Clement & Shade, 2000, p. 37).

CHAPTER 4: IMPLEMENTING ACCESS

Formal organizations...have structures, goals, informal networks, processes, histories, cultures and a mix of professions that are uniquely their own. How do these characteristics of organizations affect the interpretive work of scientists and technical experts within them, as they construct facts and artefacts? (Vaughan, 1999, p. 914)

4.1 Planning, Reflection and Actions for Access

This chapter will explore the organizational context of the Mid-Main Community Health Centre (CHC) where an Internet access point was constructed. From the Access Rainbow perspective, a CHC can offer "service/access provision" (Clement & Shade, 2000, p. 48). Clement and Shade describe health information intermediaries, such as clinics, as "already experienced in providing information services, [and]...well positioned to host public access sites, [and] contribute to decision making around health info-structure development" (p. 48). The implementation of the Internet terminal in the waiting room of the Mid-Main CHC incorporated many of these elements. The action research framework of the project consisted of a series of iterative activities related to planning, reflection, and action that led to the introduction of the terminal. As an organization, the Mid-Main CHC is comprised of patients, volunteers, and staff with an interest in improving the health of individuals and the local community. Research-related activities that were carried out in advance of the introduction of the Internet terminal included planning meetings, interviews, and participant observation in the waiting room. This chapter will describe Mid-Main as an organization, situate the research methods in the literature, and present findings from the pre-Internet interviews and participant observation. This sets the context for discussion of the interventions taken to enhance the introduction of the Internet terminal.

4.2 Organizational Context

The organizational context of this research project was the Mid-Main Community Health Centre, located in Vancouver, British Columbia (see figure 4.1). According to Vaughan (1999) "formal organizations...have structures, goals, informal networks, processes, histories, cultures and a mix of professions that are uniquely their own" (p.

914). She continues: "these characteristics of organizations affect the interpretive work of scientists and technical experts within them, as they construct facts and artefacts" (p. 914). The Mid-Main Community Health Centre has unique characteristics that stem from how it offers primary health care services to patients under one roof. The clinic takes a team approach to primary health care and includes both a dental and medical practice. The medical clinic employs physicians, a primary care nurse clinician, a clinical pharmacist, and a chronic disease coordinator[34] (Mid-Main Community Health Centre, n.d.-d, para. 1-4). Traditional services, unusual in today's context, are available to Mid-Main patients. They include after hours care and house calls when necessary (para. 1).

Figure 4.1: The Mid-Main Community Health Centre[35]

Two specific priorities of the organization show a commitment to participation and social equity. The Mid-Main Website provides insight into the philosophy underlying the organization of care at the clinic:

- People who use our health services should help decide what our services will be and how they will be offered in the community. We will ensure that community input helps shape our vision and goals.

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[34] The job titles are those used by Mid-Main. Please see the cited Web site for more information.
[35] Photograph taken by the author.

- Social and economic factors can profoundly affect the health of the people we serve. We will coordinate our services with other agencies to provide optimum care for high needs and high risk clients (Mid-Main Community Health Centre, n.d.-c, para. 2).

These goals function to encourage community capacity building around health issues.

Labonte and Laverack (2001) define community capacity building in the health promotion literature as "a generic increase in community groups' abilities to define, assess, analyze and act on health (or any other) concerns of importance to their members" (p. 115). This definition suggests that within a community group such as the Mid-Main Community Health Centre, the patient base of community members are able to improve their health situation through participation. This type of participation centred approach was followed during the development of the ACTION for Health research project undertaken with Mid-Main staff. During the initial planning stages of the ACTION for Health project, clinic staff expressed an interest in placing an Internet terminal in the waiting room, as this was seen as a means through which patient's access to information could be improved (E. Balka, personal communication, May 30, 2006). Access to information could potentially support both personal empowerment and self-care.

Labonte and Laverack draw upon Hawe, King, Noort, Jordens, and Lloyd (2000) to link grassroots community capacity building to the powerful social groups and institutions involved in health promotion. Health infrastructure capacity can be thought of as the top-down interventions that have been executed from government ministries or the administrative structure of the clinic; however, because of Mid-Main's emphasis on participation by patients, there is also a bottom-up influence. The Canadian Alliance of Community Health Centres[36] states: "we believe citizens have a responsibility and a right to maintain, enhance and control their health. The role of health care providers is to help citizens exercise this responsibility and right" (Canadian Alliance of Community Health Centre Associations, n.d., para. 8). As a CHC, Mid-Main achieves this goal by including patients as members (Mid-Main Community Health Centre, n.d.-a) and offering opportunities for formal participation in decision-making such as on the Board of Directors (Mid-Main Community Health Centre, n.d.-b).

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[36] The Canadian Alliance of Community Health Centres is connected to the Mid-Main Community Health Centre via a Mid-Main representative who sits on the Board of Directors. This information on the board composition was located at http://www.cachca.ca/english/ and accessed on March 18, 2006.

4.3 Situating the Research in Larger Traditions: Health, Technology, and Action Research

Mid-Main's emphasis on patient participation and primary health care reform promote change within the health care system. Action research as a method aligns with these goals of altering the status quo. Action research, participatory action research, and participatory research are similar methodological terms (Institute of Health Promotion Research & B.C. Consortium for Health Promotion Research, 1995). They refer to activities undertaken which combine: "research (usually described as social investigation), education and action" (p. 3). Action research is widely agreed to work to impact change in society or address social problems (Dickson, 1997; Institute of Health Promotion Research & B.C. Consortium for Health Promotion Research, 1995; Oates, 2006; Reinharz, 1992). The introduction of an Internet terminal into the waiting room of the Mid-Main CHC is closely related to two areas of the literature which situate the initiative in the larger traditions of action research and applied scholarship. Firstly, action research is connected to design enhancements to technology through ethnography. Secondly, the history of action research can be linked to interventions to attempt to improve the health of individuals or communities. Subsequent sections of this chapter will provide an overview of action research in these areas to give a rationale for the methods undertaken at the Mid-Main clinic to introduce the Internet terminal.

4.3.1 Action Research and Technology

In technology design, one method that is closely linked with action research is ethnography. It can be used to assist in the design of computer technology and it has "been applied for some years now within the Computer Supported Cooperative Work (CSCW), the Human Computer Interaction (HCI) and the Participatory Design (PD) communities" (Simonsen & Kensing, 1998, p. 20). The question remains somewhat unclear whether such activities promote the hoped-for social change which is characteristic of action research. Oates (2006) cautions that action research is neither well accepted in the information systems field nor is there a substantial body of literature related to it and the Internet. However, a closer reading of Simonsen and Kensing's writing challenges Oates's findings. They critique how ethnographic methods have been situated: "in order for ethnography to have a direct impact on a design project, it may not be sufficient to produce critical 'after the fact' analyses" (Simonsen & Kensing, 1998, p.

21) . They also call for an enhancement of the "interventionist approach...in which the role of ethnographers and the role of designers are more blurred" (p. 21). Essentially, this call suggests that researchers need to make greater efforts to impact change through design and to make it both more visible and more immediate. The history of action research may show this visible impact which is being sought in the design field.

4.3.2 Historic and Future Links Between Action Research and Health

Kurt Lewin was a pioneer of action research in the 1940s and 1950s (Hart & Bond, 1995; Oates, 2006). As a psychologist, Lewin attempted to apply research efforts to address psychological and social issues. Lewin (1946) asserted, "research that produces nothing but books will not suffice" (p. 35). One of his questions: "what shall we do?" is indicative of his inclination to attempt to find practical solutions to problems (p. 35).

Similarly, in the 1950s and 1960s, the Tavistock Institute in London, England, worked to improve treatment for patients who endured psychological difficulties following World War II (Oates, 2006). A key element of this work was that improvements to care were generated through a process where scientists "planned, acted and reflected upon their interventions with the patients" to enhance their capacity to deliver appropriate care (p. 155). According to Oates, early action research undertaken at the Tavistock Institute demonstrated that research is not solely the domain of academics. Action research enabled lay people without special training to conduct research and impact change through their work activities. Hart and Bond (1995) suggest this model is particularly appropriate for the work of health professionals (p. 3). Through the tradition of Lewin and the Tavistock Institute, action research can be strongly linked to the health care field.

However, action research has not focussed merely on the activities of health care providers. Later, action research as a method was influenced by the work in education by Pablo Freire as he began to identify and address through dialogue, the issues faced by disadvantaged populations (Dickson, 1997, p. 18).[37] By the 1970s, action research explicitly attempted to address social issues such as health in relation to disadvantaged patient populations (Institute of Health Promotion Research & B.C. Consortium for

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[37] As described by Dickson (1997), Freire's work in Brazil around literacy and political awareness of peasants emphasized the importance of speaking with a community rather than for a community as an "expert." Freire's work can be examined in the book, *Pedagogy of the Oppressed.*

Health Promotion Research, 1995). It seemed inescapable that "researchers found the causes of [health] problems faced by people in their communities rooted in political oppression" and the social determinants of health such as poverty (Institute of Health Promotion Research & B.C. Consortium for Health Promotion Research, 1995, p. 9).

A variety of action research projects related to health have been undertaken in Western Canada to attempt to address health issues faced by specific populations with lower health status. For example, Dickson (1997) developed a participatory health assessment in cooperation with "grandmothers" of an Aboriginal community (p. 9). Reid (2004) worked with the Women Organizing Activities for Women group to study and act on the health issues facing low socio-economic status women in the Vancouver area. Dickson and Reid demonstrate that research can attempt to address social determinants of health. As the Mid-Main patient base is acknowledged to include "high needs and high risk clients" (Mid-Main Community Health Centre, n.d.-c), action research methods seem to be an appropriate method to attempt to build capacity around health.

4.4 Action Research Framework

Action research was the methodological framework under which research activities were conducted in cooperation with the Mid-Main CHC. This method was selected because it is consistent with Mid-Main's goal to promote patient participation and because of the opportunity to intervene in order to enhance the usefulness of online health information and support. Rather than being a detached observer, I attempted to provide help within a nonprofit organization by assisting with an issue of interest that was generated by the community organization.

Lewin (1946) has described action research as consisting of "a spiral of steps each of which is composed of a circle of planning, action, and fact-finding about the result of the action" (p. 38). According to Dickson (1997) there are four stages of participatory action research:

- orientation to a community
- dialogue and negotiation with groups of people to clarify community problems and to raise consciousness
- collective research
- collective action (p. 23).

The remainder of this chapter will discuss the research, reflection, and action cycle that relates to these four components (see figure 4.2). My orientation to the Mid-Main Community Health Centre occurred through meetings held with the executive team to plan the computer's introduction.[38] Additionally, my ACTION for Health colleagues shared their learning from previous research activities conducted in cooperation with Mid-Main, a partner in the ongoing ACTION for Health research, which helped orient me to both the clinic and ACTION for Health's framework for working with community partners.

As I embarked upon the research, I carried with me some assumptions that were informed by my knowledge of the literature and of online health information seeking. Firstly, I assumed Mid-Main patients would have heath information needs that could be met by the Internet, as high usage statistics for health information seeking in Canada are indicative of this trend. For example, in 2000, Statistics Canada cited that nearly half of Canadian Internet users look for health information online (Dryburgh, 2001, p. 8); presumably some people find the resultant information helpful. Secondly, I assumed that seeking health information online is complex and that patients likely used "suboptimal" search strategies, such as the Google search engine, to attempt to find relevant information, as found by Eysenbach and Kohler (2002, p. 573) in previous research. I believed that awareness of government-produced health information Web sites would be much lower than awareness of search engines. Thirdly, I assumed that individuals in the waiting room would be Mid-Main patients.

Under an action research framework, the iterative cycle of research, reflection, and action is reflected in pre-Internet interviews and participant observation which were carried out in advance of the introduction of the computer. Familiarity with the literature, dialogue, research, reflection, and action challenged my assumptions and informed the introduction of the computer.

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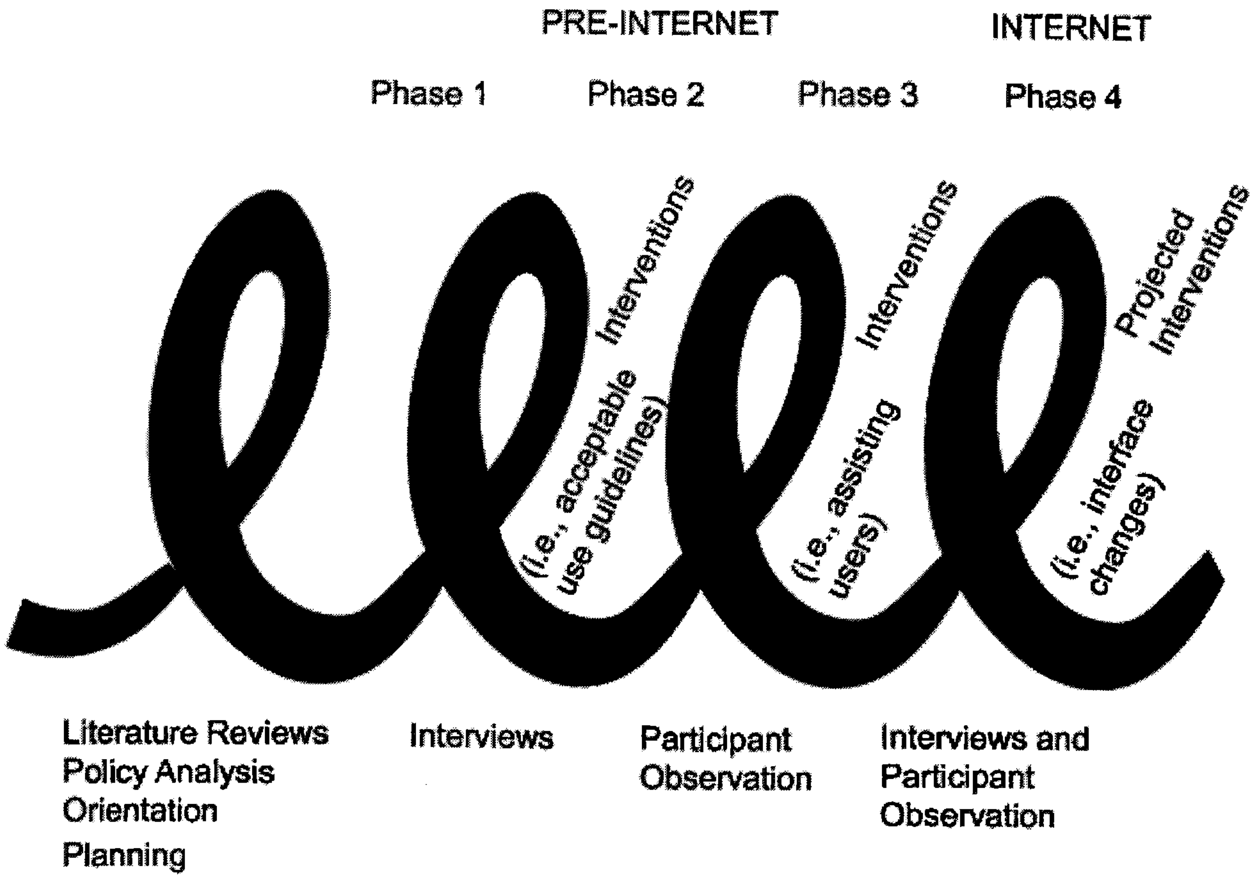
[38] Special thanks to Nina Boulus who was a great assistance during the introduction phase.

Figure 4.2: Action Research Cycles



4.5 Results and Analysis

4.5.1 Pre-Internet Interviews

To develop an understanding of the Mid-main patient community, their Internet usage, and resource awareness, I obtained informed consent and spoke with 28 individuals over the age of 18 in the waiting room of the Mid-Main clinic. Approximately 7 hours were spent in the field in mid-April 2005, during which this phase of the data collection occurred.

The participants included 21 women (75%) and 7 men (25%). The interview questions (see appendix 2) sought to gather information and ideas from the individuals (the intended end users of the Internet in the clinic) in advance of implementation. The interviews were an attempt to check my assumptions and to include an avenue for participation[39] in the decision-making process about the introduction of Internet technology in the waiting room. In creating the interview script, it was important to consider that power relations and descriptions of the quality of participation have traditionally been glossed over, even in participatory design (Balka, 2005b). In implementing an interview script in a clinic waiting room, some of the challenges I faced included:

- Patients waiting for an appointment may be feeling ill.
- The waiting room is a public space that can be noisy and crowded.
- Only limited privacy is possible in the waiting room.
- The time patients have available to speak with me as a researcher is limited.
- Interviews could end abruptly at any time when patients were called for their appointments.

Despite these factors and what many researchers may consider a poor interview setting, the interviews conducted in the waiting room prior to the introduction of the Internet terminal proved to be a rich source of information that aided in the planning and decision making related to the introduction of the Internet terminal. In contrast to the anticipated challenges, I found most individuals to be very receptive and willing to speak with me; many also expressed an eagerness to help the clinic by participating.

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[39] Participation in the design was mediated and not direct.

To analyze the data from the interviews, I began by fully transcribing each of the interviews. Subsequently, the interviews were coded manually for themes related to access and the introduction of the Internet terminal at Mid-Main clinic. Coding was later transferred to the NVivo software program version 2.0. Some of the codes were generated from the transcripts by locating *"'in vivo'* categories" which Richards (2005) explains as a phrase taken from grounded theory to label categories using participants' own words (p. 95). In NVivo I created 9 major codes and 22 nodes. By identifying patterns, this process yielded 5 high-level themes which will be discussed below (see also appendix 4).

Theme 1: Support for the Internet Terminal

Patients' support of an Internet terminal for health information was not presumed in advance of the interviews. Through the interviews, the following results were calculated:

Table 4.1 Patient-Participant Support of the Proposed Internet Terminal

Level of Support for the Internet Terminal	**Number and % of Participants**
Positive	13 (46%)
Neutral or Constructive[40]	8 (29%)
Negative	3 (11%)
Not Captured[41]	4 (14%)
Total (n)	28 (100%)

The interviews indicated a high level of support among patients and individuals in the waiting room for an Internet terminal. A number of participants were uncritical of Internet access in the waiting room as exemplified by the following comments: *"it's a fine idea"* (PII [Pre-Internet Interview] participant 4, personal communication, April 2005), *"It's neat, sure. Why not?"* (PII participant 8, personal communication, April 2005), *"I think it's a great idea"* (PII participant 9, personal communication, April 2005), and *"I think it's good"*

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[40] *Constructive* was a category used to code responses which indicated an intervention which would be required to make the Internet useful; as the response was neither positive nor negative, it was considered neutral.

[41] As discussed previously, some interviews ended abruptly as patients were called to their appointments.

(PII participant 20, personal communication, April 2005). However, other participants offered more tempered or constructive feedback under the neutral or constructive category. Some individuals were negative or disinterested in the computer. From the interview responses, a variety of themes and suggested interventions to attempt to improve the Internet introduction were generated.

Theme 2: Human-Centred Care:

The patient-centred approach in practice at the Mid-Main clinic and the trusted relationships patients have established with its health care professionals and staff was a major theme to emerge from the interview transcripts. Nearly all of the respondents indicated they view human health care professionals such as doctors and nurses as their most trusted sources of health information. PII participant 4 stated that to find trusted answers to health questions, she often comes to Mid-Main: *"I ask...[my doctor] and I ask [the pharmacist]"* (personal communication, April 2005). However, the balance between technology and human-centred care emerged as something negotiated by individual patients. One participant stated, *"I find it difficult to relate to a doctor. So I go to the Internet, and also to have a second opinion"* (PII participant 11, personal communication, April 2005). Yet overall, patients seem to value the professionals at the Mid-Main clinic as a trusted source of health information. Some patients there primarily see the Internet as a source for health information that augments other reputable sources of information: *"...the Internet it's more for broadening my information. If I have a serious inquiry, I'll come to the doctor"* (PII participant 13, personal communication, April 2005). Another patient adamantly reinforced the importance of the human relationship in care: *"if I come to the doctor's, I come to talk to a human being not to talk to an Internet screen. But, I don't think it would suck. I think a lot of people are really comfortable with that..."* (PII participant 10, personal communication, April 2005). Ultimately, processes involving human care appear to be favoured by Mid-Main patients, but there also still appears to be a supplementary role for technologically mediated health information.

Theme 3: Acceptable Use

The importance of defining acceptable use of the Internet in the waiting room emerged as another pertinent theme. Some patients expressed concern about individuals visiting inappropriate sites, while others assumed the clinic would restrict access to approved medical sites only. For example:

> ***PII participant 25:*** *You'd have to I guess set up your browser so that it would do only for certain things. You don't want them going to some porn sites or something like that or maybe limit to medical information, research...(*personal communication, April 2005).
>
> ***PII participant 27:*** *How would the centre monitor what people are using the Internet for as well, I wonder? I think it could be helpful with guidelines set out* (personal communication, April 2005).

In contrast, some patients proposed using the Internet at Mid-Main for non-health related activities or general Internet browsing:

> ***PII participant 9:*** *You can go there [the Mid-Main Internet terminal], and punch away, and whatever you want to look at you know, as long as it's you know nothing x-rated or anything like that...you can go online, check out some scores, schedules, sports, stuff like that. It could kill the time pretty good* (personal communication, April 2005).

Due to the range of comments and expectations surrounding the Internet in the waiting room, it seemed appropriate to develop "guidelines" as suggested by participant 27 in the form of an acceptable use policy. This intervention will be discussed in a later section.

Theme 4: Reputable Resources

During the interviews, I gauged patients' knowledge of reputable government health information programs. Many patients recognized the BC HealthGuide Handbook. For example, PII participant 27 remembered the positive experience of using the handbook for health information during an allergy attack. Awareness of other components of the BC HealthGuide program such as the handbook and NurseLine may lend credibility to the Web site. However, an obstacle to overcome in relation to the handbook is that all citizens of the province do not utilize the resource; some received it, but *"haven't looked through it"* (PII participant 18, personal communication, April 2005); only skimmed it (PII participant 1, personal communication, April 2005; PII participant 13 personal communication, April 2005); or *"threw it out"* (PII participant 14b, personal communication, April 2005; PII participant 24, personal communication, April 2005). This may in part explain why the existence of the BC HealthGuide Web site was unknown to most of the participants interviewed at Mid-Main. Through the intervention of site recommendations, it seemed likely that awareness and positive experiences surrounding use of a reputable Website can be built in the waiting room at Mid-Main clinic. For example, one participant stated: *"I don't know any [government sites]...like that Website you mentioned [BC HealthGuide and Canadian Health Network]. If I knew about it, I'd probably go there"* (PII participant 20, personal communication, April 2005). The lack of awareness of government-produced Web sites appears to send Mid-Main patients to search engines, with the most popular among them being Google, which was mentioned by 9 (36%) of the 28 interview respondents.

Theme 5: Computer Configuration

A final theme to emerge from the interviews concerned the physical configuration and setup of the Internet station in the Mid-Main waiting room. Two participants suggested configurations to maximize privacy, for example: *"make sure that it [the computer screen] was facing a wall"* (PII participant 10, personal communication, April 2005), or construct a *"kiosk area"* (PII participant 27, personal communication, April 2005). Another participant considered a printer to be an integral part of the Internet terminal setup. She stated: *"some people may just want to print out a lot of things out of the Internet. It's not going to be just for reading through the Internet page, Web page, it is going to be more like printing out"* (PII participant 3, personal communication, April 2005). The preferences of the patients for specific "local configurations" (Suchman, 1994, p. 4) of the Internet terminal at Mid-Main were taken into account through critical interventions.

Pre-Internet Interview Summary

The major themes from the pre-Internet interviews were support, human-centred care, acceptable use, reputable resources, and configuration. Having described the major themes to emerge from the interviews, I now turn to participant observation conducted in advance of the Internet terminal's introduction. Participant observations of waiting room activities was undertaken to gain insights about the natural activities occurring in the waiting room before the Internet was introduced. Following an overview of the insights gained, my critical reflections and the interventions associated with the introduction of the Internet terminal will be integrated with the analysis of the participant observation results.

4.5.2 Participant Observation

Participant observation is a research activity traditionally conducted by ethnographers. However, Atkinson and Hammersley (1992) explain that methods from anthropological ethnography have been appropriated by other disciplines "in applied fields such as education, health, and social policy" (p. 253). The expansion of ethnography to assist a technological implementation provides another pertinent example. In June 2005, I spent 14 hours in the waiting room of the Mid-Main Community Health Centre observing patients in advance of the introduction of the Internet terminal. These observations function as a baseline against which to compare the health information seeking activities undertaken by the patients with the computer. Pre-Internet observations were recorded about participants who provided informed consent; a tracking sheet that supported collection of information about appointment time, arrival time, departure time, and waiting room activities was maintained for each participant. Over the period of observation, 73 participants consented to be observed. Of these 55 participants (75%) were female, 15 participants (21%) were male, and the gender of three participants (4%) was not captured. The most significant findings in relation to the pre-Internet participant observations involved the reading activities of patients and the entry and exit patterns of patients from the waiting room.

Theme 1: Reading Activities

As with many medical waiting rooms, the Mid-Main Community Health Centre contains magazines and health handouts to help patients pass the time. The magazines are scattered on end tables beside chairs and couches. The health handouts include brochures and business cards; they are located in three main locations: in a large, acrylic brochure rack; in a small wire brochure rack; and on an end table. As recorded on June 21, 2005, there were 40 brochures in the plastic acrylic rack. These were produced by a variety of nonprofit and for-profit organizations and covered a wide variety of health topics, including medical conditions, tests, and nutrition. In the wire rack, there were 8 Med Action/PharmAction Guides which are sponsored by pharmaceutical companies and other organizations.[42] The business cards were somewhat different in that they provided information about how to access information. For example, the BC NurseLine's phone number (British Columbia, n.d.-a) and the URL for the BC Centre for Disease Control's sexually transmitted disease resource site (BC Centre for Disease Control, n.d.) were communicated via the business cards. In addition to the brochures, the Mid-Main waiting room also features a bulletin board upon which health information and resources are posted.

While I conducted participant observation, I recorded the reading activities of patients: 21 magazines were accessed by 21 (29%) individuals and 18 medical brochures were accessed by 8 (11%) individuals. Reading was a common activity undertaken by patients to pass the time in the waiting room. However, information related to health was less frequently accessed—and by fewer individuals—than popular magazines such as *O* (The Oprah Magazine), *Time*, and *Glamour*.

Among the participants who accessed health information through brochures, one female was very actively engaged in selecting brochures. During her time in the waiting room, she obtained seven brochures on: dementia (British Columbia Medical Association, 2005), prostate cancer (BC Cancer Agency, n.d.), and overweight children (British Columbia Medical Association, 2004); two postcards on meningitis (Vancouver Coastal Health & BC Centre for Disease Control, n.d.-a, n.d.-b); and two brochures with mammogram information from the BC Cancer Agency (BCCA) (pre-Internet observation [PIO] participant 56). The BCCA had a particularly strong presence of information in the waiting room as exemplified by multiple brochures (BC Cancer Agency, 2002a, 2002b, 2002c, 2003, n.d.). PIO participants 1, 8, and 56 each accessed information from the BCCA through brochures.

Another highly prominent information source for health information in the Mid-Main waiting room appeared to be the postcards on meningitis prepared by Vancouver Coastal Health and the BC Centre for Disease Control (Vancouver Coastal Health & BC Centre for Disease Control, n.d.-a; , n.d.-b). Using the catchy slogans, "Need to Get Poked? Hey Guys, the Meningitis Outbreak Isn't Over Yet!" and "If U Toke Get Poked: Hey Guys the Meningitis Outbreak Isn't Over Yet!", these postcards attracted attention.

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[42] For example, the brochure "The Cholesterol Test: Why you May Need it" (n.d.) included the following authorship information: "brought to you by Pfizer and Your Provincial Pharmacy Regulatory Authority."

PIO participants 56 and 61 examined both postcards. Additionally, the Mid-Main bulletin board featured a poster from the meningitis campaign. PIO participants 9 and 38 viewed the bulletin board. Participants appeared to be attracted by graphic design and visually appealing information.

Theme 2: Time and Patterns of Entry and Exit

A second significant issue to emerge out of observing individuals in the waiting room was time related. Entry and exit times from the waiting room were captured for 68 participants. The average time spent in the waiting room was 13.63 minutes. However, patients were not exclusively waiting before their appointments. PIO participant 1 came back after her appointment. PIO participants 19 and 32 left the waiting room for short periods of time and returned. PIO participants 34 and 58 had appointments with multiple practitioners and waited twice. PIO participant 36 left the waiting room to move her vehicle and then returned. Finally, PIO participant 54 waited in the room for three separate time periods. This participant observation made it clear the time individuals would have available to use the Mid-Main Internet terminal was likely to be extremely limited and prone to a variety of interruptions.

4.6 Reflections and Planned Interventions

Based on the information gained from the pre-Internet interviews and participant observation, interventions to enhance the usefulness of health information Web sites were generated for future stages of the research. Although these interventions were based on patients' comments, they at times also confirmed the appropriateness of my intended next steps within the research design. Interventions suggested by patients, such as privacy and the provision of a printer, were discussed and addressed in cooperation with the Mid-Main executive team. The interventions formulated through an action research process were twofold and addressed issues concerning how the Internet terminal in the waiting room would be configured and what my role as a researcher would be. The plans that emerged as a result of pre-Internet interviews and pre-Internet waiting room observations are addressed in the next section.

4.6.1 Configuration

- **An Acceptable Use Policy:** in response to patients' suggestions, and in cooperation with the Mid-Main clinic, an acceptable use policy for the Mid-Main computer was authored in advance of the computer's introduction. The document provided a guideline as to the maximum amount of time patients could spend on the Internet. Additionally, the document featured a "Do/Don't" list developed under the guidance of a Mid-Main executive team member. In advance of the Internet introduction, the acceptable use policy was printed out on bright yellow paper, laminated, and posted on the waiting room wall to notify patients of appropriate computer use in a friendly manner. Within the acceptable use policy, patients were notified that printing was not available. In the absence of a printer, a notepad and pen were provided by the research project to allow Internet session patients to take notes if desired.

- **Blocked Web sites:** in response to concerns about inappropriate use expressed in the interviews, I generated a list of inappropriate sites such as Web-based email and chat sites. The blocked sites were discussed with a Mid-Main team member. The inappropriate sites were input into a browser security configuration to prevent them from being accessed in the waiting room.

- **Privacy:** during the pre-Internet interviews, participants offered suggestions to maximize privacy. These suggestions were consistent with the research plan to orient the computer with the screen facing a wall to maximize privacy. This intervention was extremely easy to implement.

- **Reputable Resources:** the intention to rotate the homepage between the BC HealthGuide and Canadian Health Network Web sites within the research design during the Internet introduction was confirmed as appropriate and as being an opportunity to enhance awareness of reputable resources. It was also seen as an opportunity to guide health information seekers away from Google and other similar search engines.

4.6.2 Orientation of Researcher

The second level of interventions, which occurred following the pre-Internet interviews and participant observation, addressed my conceptions and misconceptions about the Mid-Main community and participants' needs. Shifts in my mindset occurred as a result of my orientation to the community. Upon critical reflection of my executed and intended activities as researcher, I determined I needed to consider:

- **A Broadened Conceptualization of Health Information:** careful examination of the waiting room, participant observation, and interviews brought to my attention the degree to which patients seek a wide array of information about wellness.

- **A Broadened Understanding of Potential End Users:** when beginning the pre-Internet interviews and participant observation, I wrongly assumed that individuals in the waiting room would be patients of the clinic. However, other individuals such as caregivers, family, and friends may accompany patients to the clinic. As such the Mid-Main Community Health Centre waiting room is truly a location where community members convene, and it became evident that not only the patients would seek health information. Rather, it seemed likely health information would be sought by a variety of others (family members, caregivers, etc.) who might serve as information intermediaries[43] to patients.

- **A Commitment to Human Support:** the intention to introduce the Internet terminal with the human support of the researcher was confirmed by waiting room visitors during pre-Internet interviews, as consistent with visitors' preferences for person-to-person interaction at the Mid-Main Community Health Centre. The pre-Internet interviews and participant observation provided me as a researcher with a greater understanding of the barriers some Mid-Main patients face in relation to the Internet and written health information (i.e., PII participant 26 who indicated she is dyslexic) which may make this type of human support essential for a computer in the waiting room.

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[43] An information intermediary is a person who relays relevant information to an individual. These intermediaries may assist with selecting and interpreting relevant information.

These insights, which subsequently were incorporated into interventions, demonstrate how I as a researcher participated in a cycle of dialogue, reflection, and action in cooperation with patients and the Mid-Main administration through interviewing and participant observation within an action research framework.

4.7 Chapter Summary

As demonstrated by the pre-Internet interviews and participant observation at the Mid-Main Community Health Centre, cycles of dialogue, reflection, and action can be used to inform interventions. This process demonstrates that action research and patient participation can contribute to the social construction of an infrastructure to access information within a community organization. Interventions aimed at improving delivery of health information to waiting room patrons can be informed by a variety of influences. The literature, orientation to a community context, and interaction and observation can help inform action research practitioners and contribute to the design of interventions aimed at making technology more useful.

The interventions that have been described within this chapter, such as the acceptable use policy and orientation of the computer, are perhaps the most successful of the research project in terms of visibility. From the research partnership between the Mid-Main and Community Health Centre and ACTION for Health, the possibility opened to integrate the individual or micro level of participation[44] in meso level decision-making. This aspect of the research reflects a second level of power sharing and dispersion. As suggested in chapter 3, multi-level involvement is essential; the Mid-Main clinic and action research process facilitates involvement. A change like the introduction of Internet access within a community location required the consideration of both macro and micro issues. At the macro level, Web content remains to be provided by the government as a provider of information through the "content/services" band of the Access Rainbow (Clement & Shade, 2000, p. 37). Exploration of the micro level issues and stories of individual experiences of access will continue in the next chapter, which provides an overview of the implementation of the Internet terminal in the waiting room.

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[44] This participation was representative, not direct. As researcher, I mediated the participation of patients and visitors to the waiting room.

CHAPTER 5: EXPERIENCING ACCESS

Most technological experiences - including digital and, especially, online experiences - have paled in comparison to real-world experiences and have been relatively unsuccessful as a result. What these solutions require...is an understanding by their developers of what makes a good experience; then to translate these principles...into the desired media without the technology dictating the form of experience (Shedroff, 2001, p. 3).

5.1 Researching User Experience

With community and executive backing for the plan to introduce an Internet terminal, the next theoretical and methodological challenge became studying the micro level user experience of Mid-Main patrons as they accessed government-produced health information Web sites. User experience can refer to the function that has been engineered into a technological resource such as a Web site. However, Shedroff's (2001) idea of replicating positive, real-world experiences into digital ones seems to be a highly ambitious project for health information Web sites. The traditional process in which a patient receives health care information from an offline resource or human health care provider can be a very complex interaction that is unlikely to be replaced entirely by technology.

In the previous chapter, the importance of human involvement in health care was articulated by Mid-Main patrons. Similarly, in *The Enigma of Health*, Gadamer (1996) asserts the significance of the relationship between practitioner and patient. He states, "the dialogue between doctor and patient ....[is] part of the treatment itself and...something which remains important throughout the entire process of making a recovery" (p. 128). At the Mid-Main clinic, the focus on providing a range of health care services under a single roof means that strong relationships exist between patients and their physicians, as well as with other trusted care providers such as the pharmacist and the clinical nurse specialist. The introduction of the Internet in the waiting room was intended to augment the availability of health information, not to replace the patient and practitioner relationships that already exist. In this manner, the user experience aspect of this study is somewhat unique.

This chapter will provide a case example of how I carried out contextually situated user experience research. This chapter will explore individual experiences of access which begin to describe how users interact with the "content/services", "software" and "devices" from the Access Rainbow model (Clement & Shade, 2000, p. 37). I begin this chapter by outlining how my methodological choices melded aspects of human-computer (HCI) interaction and ethnography. My use of tools from the HCI tradition in qualitative research enabled me to gather unique information. With permission, recordings of the on-screen activity and an audio track of Internet sessions were recorded as Mid-Main patrons used the Internet to look up health information. This allowed me to gain an understanding about the *drivers* which motivate patrons to use the Internet terminal as well as an understanding of the actual *use* of the Internet within the context of patrons' lives and a community setting.[45] This chapter will focus on these micro level considerations which prioritize the individual's interests.

5.2 Situating the Research in Larger Traditions: Ethnography and Human-Computer Interaction

Within an action research framework, ethnography and HCI greatly informed my methodological approach for studying the user experience of patrons' access to health information Web sites at Mid-Main. As discussed in the previous chapter, ethnography and participant observation are closely associated with the tradition in anthropology where the researcher enters into another culture to observe the 'other.' In the field of computer-mediated communication (CMC), and in early studies of the Internet, the "other" has often been a disembodied online persona (Markham, 2005). Turkle (1995) identified that in multi-user domains, participants may have multiple identities that are different than the real-world self. However, such an analysis requires and encourages the recognition of the real-world end users, their identities, and increasingly the contexts where they use technology. Although an offline identity such as that of an ill patient can be obscured in an online environment, the "true" self may also inform and contribute to online activities. Markham suggests there is great value in studying the "other-in context" with Internet research (p. 795) and hence in considering the individual user.

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[45] My ACTION for Health colleagues Guenther Kruger and Bev Holmes have previously coded data using *drivers* and *use* as codes in publications under review. Please see http://www.sfu.ca/act4hlth/ for publication references.

The approach advocated by Markham was consistent with the intention to understand Mid-Main patrons as real people in the waiting room.

The idea to conduct research about Mid-Main patrons' access of health information is situated within larger traditions of ethnography. Within Canadian and international scholarship, there have been a variety of ethnographic studies undertaken in attempts to understand end users in a particular context: internationally, nationally, or locally. There has also been a repeated emphasis on understanding the use of the Internet within "everyday life" through ethnography. A variety of authors use this phrase or a similar variation in book and chapter titles (i.e., Bakardjieva, 2005; Clement, Aspinall, Viseu & Kennedy, 2004; Miller & Slater, 2000; Wellman & Haythornthwaite, 2002). These titles reflect a trend of situating users within the contexts in which they employ technology, rather than attempting to understand behaviours in laboratory settings. For Bakardjieva the Internet in daily life includes Internet use in Canadian households and the domestic context. Clement et al. have used ethnography to explore Internet usage in a Toronto neighbourhood. Miller and Slater examined how people in the country of Trinidad and the diaspora use the Internet in ordinary life. Similarly, Balka and Peterson (2002) have studied Internet usage at the Vancouver Public Library. There remain significant research opportunities to understand how patients, citizens, and consumers access health information in public locations such as the Mid-Main Community Health Centre as a new aspect of ordinary life.

The opportunity to observe and study end users in real-world contexts has been lost in some applied research initiatives; however, my work with Mid-Main provided one. Human-computer interaction (HCI) and usability studies[46] sometimes place the user in an artificial environment away from natural contexts of use. HCI is defined as "a discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them" (Hewett et al., 1996, p. 5). In the past, some HCI studies have gathered data measuring efficiency or productivity such as the number of keystrokes or timing of mouse clicks made by users, often in laboratory settings (Hewett et al., 1996). HCI has evolved to include testing that employs usability methodologies to assess the end users' "ease of use" (Shackel & Richardson, 1991, p. 24) of a Web site. In many settings,

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[46] Jacob Nielsen is considered a usability expert whose Web site www.useit.com chronicles progressions in the field. Additionally he has authored and co-authored a variety of books on the topic. See: Nielsen, J. (2000). *Designing web usability.* Indianapolis, IN: New Riders.

usability testing involves presenting users with tasks or scenarios that they should attempt to complete using the Web site under evaluation. Users are also often asked to "think out loud" while testing sites (Nielsen, 1994, para. 12). This type of testing can occur in a usability testing laboratory where equipment such as video cameras and capturing devices record activities such as eye position or mouse clicks.

Despite laboratory-based traditions, the portability of laptop computers and Internet session-capture technology is enabling research to move outside of the laboratory. 'Guerrilla' or 'discount' usability (Nielsen, 1994) tools are now increasingly available to researchers. The combination of the data capturing technology of HCI and usability studies with the traditions of ethnography can potentially enhance the ability of the researcher to understand the user experience of health information seeking in a community context such as the Mid-Main clinic. The "laboratory" can thus become a location in the real world. In the next section, I will outline what HCI and usability technologies I borrowed to carry out participant observation and interviews under an action research framework at the Mid-Main Community Health Centre.

5.3 Method for Studying User Experience at Mid-Main

Taken from usability studies, Internet session capture software was a major asset to the research at Mid-Main. Software such as Camtasia Studio records a movie of the on-screen activity with the option of additional audio and video tracks of the end user. Yet as per the earlier stages of this study, despite the use of a technological tool, action research remained the guiding framework for the research design. Participant observation and interviews *in situ* as patrons accessed the Mid-Main Internet terminal were selected as the means, with the expectation being of gathering data about the patrons' experiences of interacting with the interfaces and content of the rotated homepages of the BC HealthGuide and Canadian Health Network. Camtasia software was selected to help record for later analysis very detailed records of Internet sessions and *in situ* interviews with patients while they were using the Internet terminal.

From this approach to studying user experience, I initially believed there were three potential arenas for intervention. Firstly at the individual level, information could be gained to enable participants to become more knowledgeable and potentially more empowered patients. Secondly, at the organizational level, programs or services could be developed based on a better understanding of patient health information seeking.

Thirdly, at the macro policy and program level, the ACTION for Health project provided a potential avenue for the communication of findings to the civil servants involved in maintaining the BC HealthGuide and Canadian Health Network Web sites. In such a manner, changes reflecting the needs of the Mid-Main Internet terminal held the potential to impact decision making related to the Web sites' structure, content, context, and impact.

By considering multi-level actions for change, I foresaw that the impact of usability tools (such as Internet session capture technology) could be broadened. Typically, usability intervenes only at the interface level. Usability studies respond to the issues where multiple users experience problems. However, this potential can be expanded to a broader array of issues than are traditionally assessed. For example, an increased understanding of the experience of health information seekers in a community clinic may eventually lead to new programs to support community organizations providing Internet access.

5.3.1 Recruitment and Participant Observation

To recruit participants, I was physically present and prominent when the Internet was placed in the waiting room. Data collection occurred over a 100 hour period between July and September 2005. While present in the waiting room, I wore a yellow T-shirt with the logo. "Researcher in the Waiting Room" (see figure 5.1). Additionally, posters informed patrons that they could use the Internet to look up health information. When someone approached the computer and looked ready to use it, I explained the project and invited him or her to participate with informed consent. With permission, I turned on Camtasia Studio to record an Internet session digital video file that captured natural search activity, including the user's interactions with the screen. A synchronized audio track of candid comments and interview responses was also captured.

Figure 5.1: T-shirt Logo "Researcher in the Waiting Room"[47]

5.3.2 Interviewing

With recruited participants, the interviews carried out were semi-structured. The questions (see appendix 2) were intended to reveal information about patrons' experience of seeking health information online. These questions were developed using the pre-Internet interview protocol as a starting point. The protocol was revised substantially to attempt to capture the frustrations and difficulties of users seeking health information. Additionally, a number of questions were added to determine how users evaluate and use Internet-based health information. Initially, I intended to have a phase of uninterrupted Internet search activity where participants did not respond to interview questions. However, very early in the Internet implementation phase of the fieldwork, participants requested assistance from me, which made it impossible to simply observe. Additionally, usage of the Internet terminal was lower than I anticipated, which encouraged me to attempt to interview every health information seeker at the computer. In addition to the interviews, some participants also spoke candidly about their experiences with technology and health. The audio track of the Internet sessions captured a variety of questions, concerns, and interests of the individual participants that yielded content falling outside my pre-scripted interview topics.

5.3.3 Equipment for Studying User Experience

I utilized a variety of equipment to carry out participant observation and interviews with Mid-Main patrons (see table 5.1). In some cases, the equipment choices directly reflected the constraints of researching in the Mid-Main waiting room that I

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[47] Image created by the author.

identified in relation to physical space and public setting. Privacy, space, and portability were key considerations. For example, a data key was necessary to store Internet sessions externally due to privacy considerations. To address space constraints, a flat screen monitor and computer cart were selected to minimize the footprint of the Internet terminal in the waiting room. Additionally, the cart was mobile. A hospital bedside table on wheels was converted into a computer cart by removing the drawer and attaching a keyboard tray underneath the tabletop (see figure 5.2). This portable solution was pursued in response to concerns that leaving the Internet terminal in the waiting room in the absence of research staff would increase the workload for the clinic's front desk staff. As the attending researcher, I needed to take it out and put it away frequently.

Table 5.1 Research Equipment Used at Mid-Main

Computer and Peripherals	Furniture	Software
• Dell Computer	• Computer Cart	• Camtasia Version 7.0
• 15-Inch Flat Screen Monitor	• Chassis Stand	• Web Browser[48]
• Mouse	• Keyboard Tray	
• Keyboard	• Cable Lock	
• Data Key		
• Microphone		

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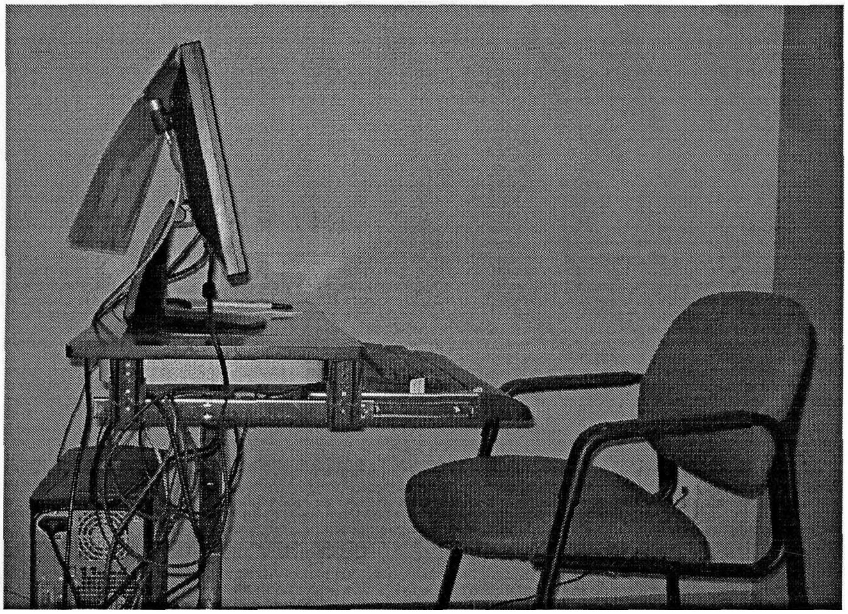
[48] The security settings of the browser were used to block inappropriate content.

Figure 5.2: Internet Terminal at Mid-Main[49]



5.4 Results and Analysis

In total, 22 participants consented to be included in the research project as they conducted natural search activities for health information in the waiting room (see appendix 5 for a participant description table). From these participants, 25 sessions were recorded, as 3 participants completed two sessions. The majority of the sessions were recorded using the Camtasia software program. Three participants declined being recorded in a session: one participant was a beginner user and refused, one participant did not actually navigate online as her arm was in a sling, and one participant declined for her second session. However, each of these participants allowed note taking about their sessions.

To compile the results and analyse the data from Camtasia, data resulting from all the Internet sessions were transcribed. Firstly, all verbal comments were transcribed.[50] Secondly, embedded into the transcriptions, a timeline was created outlining the sequence of events. End user activities such as selecting a link on a particular page were noted. All data was then imported into NVivo software and coded for themes (see appendix 6). Six high level themes were developed for NVivo coding:

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[49] Photograph taken by the author.

[50] The audio track on two sessions did not function as the microphone cord was likely unplugged accidentally. The audio components in other sessions include interview responses, candid comments, and ambient noise.

driver, barrier, use, context, power and *learn.* Power and learn were discarded due to a lack of pattern development. The themes of drivers and use will be discussed in this chapter. Barriers and context, which incorporated the role of the researcher, will be discussed in chapter 6. In addition, a table describing research participants and their notable characteristics and experiences was created and accessed in conjunction to NVivo (see appendix 5 for partial table). The results section of this chapter will begin by describing the characteristics of the Mid-Main Internet information seekers. Subsequently, I will explore the drivers that underlie use of the Internet for health information seeking.

Of the participants who consented to participate in the study in the waiting room of the Mid-Main Community Health Centre:

- 14 participants (64%) were female, 8 (36%) were male
- 19 participants (86%) were Mid-Main patients with appointments, 3 (14%) were accompanying others to appointments
- 15 participants (68%) indicated they spoke English most often at home, 3 participants (14%) indicated they spoke English and another non-official language (German, Polish and Spanish), 2 participants (9%) indicated they spoke English most often at home, but that their native language was taken away or oppressed (i.e., due to residential schools and the systematic oppression of Aboriginal languages), 1 participant (4.5%) indicated they spoke English but they are French and English bilingual, 1 participant (4.5%) indicated they spoke French and English[51]
- the average age of participants was 44.5

I attempted to gather self-reported information about the cultural and ethnic backgrounds of the participants; however, much of this information (collected at the end of the sessions) was lost due to a software glitch that functioned to shorten the audio track of the Internet sessions, thus causing a data loss. Incomplete information was also

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[51] The language diversity of the computer users at the Mid-Main terminal does not appear to be entirely reflective of the Mid-Main patient population. Using the PCensus program at the SFU library, I mapped a polygon against the streets boundaries from which Mid-Man accepts new patients. The program features a command which extracts 2001 Census Canada data for the selected area. From this search it was determined that 27% of individuals in the Mid-Main area speak a non-official language at home, the top five being Chinese, Punjabi, Vietnamese, Pilipino, and Hindi. None of these languages were mentioned by participants. Some patrons who speak these languages may have self-excluded themselves from using the Internet and participating in the research due to language barriers. See appendix 3 for further details.

gathered about other locations where participants used the Internet. Findings from data collected via participant observation, screen capture of user sessions, and audio capture of user comments while using the terminal are addressed below.

Theme 1: Drivers

Having described the research participants, drivers were considered to be the motivating factors or influences which encouraged Mid-Main patrons to approach and make use of the Internet terminal. As a researcher, one of my base assumptions was that Mid-Main patients have health information needs which drive them to approach the Internet. As revealed from the Internet sessions, other drivers included: symptoms, desire to be prepared for an appointment, or participation in previous stages of the research. Although patients may have information needs, it appears that for some participants other factors also provided compelling reasons to approach an Internet terminal in a public location.

Health Information Needs

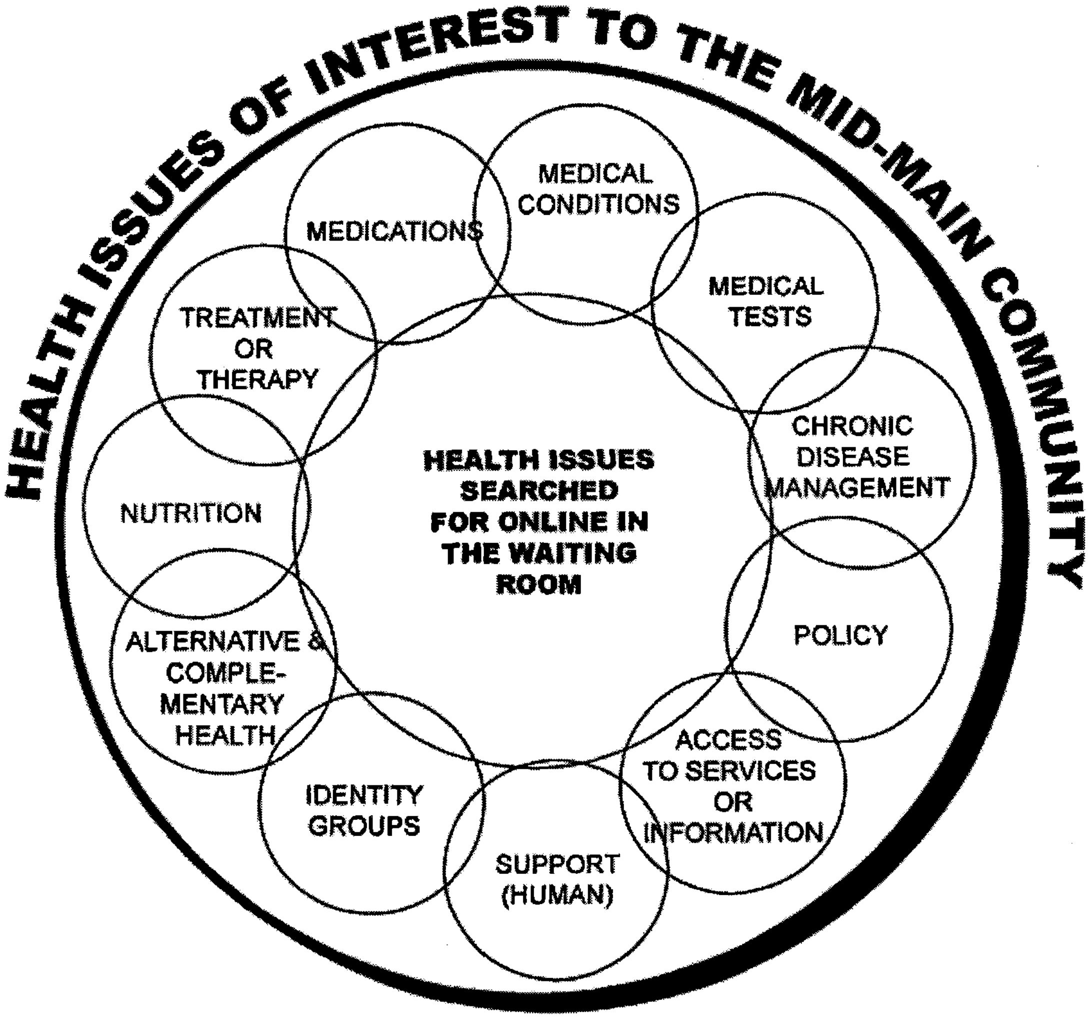
Health information needs are an entrenched but ambiguous concept in the literature. In relation to the network society, Castells (2000) states that experience "is constructed around the endless search for the fulfilment of human needs and desires" (p. 7). Castells's ideas suggest that health-related needs and desires are the initial step that could motivate individuals to go online to try to fulfil their need. From a nursing perspective, after completing a literature review Timmins (2005) states that a health information need is not a "gap or deficit in knowledge" on the part of the patient; rather "information needs refer…to the items that individuals want to be told about" (p. 181). Timmins points out that quite frequently, patients pose questions to health care practitioners to address their information needs (p. 181). Timmins findings that there are patterns in information needs, but they can also be "individual and subjective" (p. 174), is highly applicable to Internet information seeking. The health information needs of Mid-Main patrons who accessed the Internet terminal in the waiting room will be described first for aggregate trends. For example, in relation to cancer patients, Rutten Arora, Backos, Aziz, and Rowland (2005) have suggested much work remains to be done to chronicle the information needs of patients throughout their illness "journey" (p. 250).

Rutten et al.'s concept of chronicling information needs can be extended to times of good health or within times of illness in everyday life.

Trends in Information Needs

The health information needs of Mid-Main patrons who accessed the Internet terminal were grouped into categories developed out of the comments made by research participants and/or their navigation activities while seeking information online. These categories (see appendix 6) were intended to capture the major purpose of each individual's online information seeking. However, users often had overlapping needs and accessed multiple types of information; thus, often multiple categories were counted for individual participants. The most commonly accessed type of information concerned medical conditions. Of the 22 participants, 13 participants (59%) accessed information specific to a medical condition. Medications, access to services or information, and identity groups, such as women were also popular categories, which were respectively accessed by 6 participants (27%), 5 participants (23%), and 4 participants (18%). The categories of health associations, support, and alternative or complementary health were moderately popular with three participants (14%) who accessed each of these topics. Two or fewer participants (9%) accessed the categories of policy, medical tests, nutrition, and other. Often a single participant accessed multiple categories of information. Figure 5.3 represents the overlapping queries and navigation patterns.

Figure 5.3: Health Issues of Interest to Mid-Main Patrons



In table 5.2, I have drilled down in the medical conditions category to convey what conditions patients sought information about. This information was coded in a table, then transferred to NVivo (see appendix 6). The medical conditions of interest were identified by locating at least one of the following: verbal comments, navigation activities or search engine queries indicating interest in a particular medical condition. Multiple interests for a single participant were included. Mental health and cancer were the conditions for which there was the most patron interest amongst those who participated in this study. Under the mental health category, information was accessed or interest was expressed in information about depression, or more broadly, mental health. Under the cancer category the information sought was gendered as patrons sought information about uterine cancer, endometrial cancer, and ovarian cancer respectively.

Table 5.2 Medical Information Needs at Mid-Main

Medical Condition*	**Number of Sessions Accessing**
Mental Health	3
Cancer	3
Allergies/Hives	2
Vertigo	2
Cardiovascular Disease and Stroke	1
Head injuries	1
Arthritis	1
Acne	1
Gallstones	1
Meniere's Disease	1
Gastroesophageal Reflux Disease	1
Total	**17**[52]

Although Mid-Main patrons sought information on categories that can be aggregated to show patterns, a data table is somewhat lacking in descriptive detail and does not adequately convey the richness of the patrons' health information needs. The depth of these needs relates both to the contexts of their own lives and the Mid-Main waiting room as an environment. The experience or the "journey" (Rutten et al., 2005, p. 174) of fulfilling information needs at an individual level is still absent in this chapter and warrants further attention. The subsequent sections and chapter 6 will attempt to correct this.

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[52] This number is greater than the 14 participants who looked up this category of health information because in some cases, multiple topics were accessed by a single participant.

Approach of the Computer

Assuming that a health information need exists, a first step for some Mid-Main patrons to access health information was to approach the computer. This step could be easily forgotten as a part of the journey if Internet technology is viewed as natural or the obvious solution to a health information problem. However, Hine's (1998) approach to using ethnography to understand the Internet provides a rationale for treating the approach to the computer as strange. In relation to her own activities, she states, "I am using ethnography...to render the use of the Internet as problematic: rather than being inherently sensible, the Internet acquires its sensibility in use" (para. 19). Observations from the field of the patrons' approach to the computer in the waiting room indicated that use of the computer for health information is not entirely normalized; for some, the very presence of the computer was new and conversation-worthy.

A very limited number of Mid-Main patrons were observed to approach the computer directly upon entering the waiting room (IS participant 1 and IS participant 10). This type of direct and confident approach seemed to indicate a high level of familiarity with the Internet and a desire to look up information immediately to fulfil a health information need. In contrast, a number of the research participants engaged in small talk with me before approaching the computer (IS participant 6; IS participant 7; IS participant 11; IS participant 12; IS participant 14; IS participant 15). Being readily identifiable in my researcher T-shirt, a typical icebreaker conversation addressed the subject matter of the research project. However, unique conversations also occurred; for example, IS participant 14 had a strong reaction related to the politics of the placement of a terminal in the waiting room. An excerpt from our conversation follows which situates the computer as a politicized addition to the waiting room:

> ***Me:*** *When you saw the computer screen, you said right away, "I hope this doesn't have to do with the cutbacks."*
>
> ***IS participant 14:*** *Oh, I thought it was a government program, trying to think of more ways to cut services for the public, for the consumers. Umm like what they're doing with the BC Health [NurseLine] 'call up this number' 1-800 or whatever 604. 'There will be a nurse at the other end of the line' [sarcasm] and it's just all...ummm...I didn't like that approach* (personal communication, summer 2005).

This passage indicates why it is important in research to still consider the Internet as being strange and not assume it will be seen as neutral, benign, or even welcome by patrons. However, despite some negative impressions of the terminal, other factors such as an interest in better understanding symptoms, the availability of the Internet terminal in the waiting room, and participation in earlier stages of the research made the computer approachable for many participants.

Symptoms

The immediate impact of symptoms can act as a driver to encourage people to use the Internet to look up health information. IS participant 18 stated they look for health information online *"whenever certain symptoms arise"* (personal communication, summer 2005). IS participant 20 used the computer to look for a free dental clinic *"because I'm in a lot of pain. My gums hurt. But you know, I'm on social assistance, so you know they don't cover my dental"* (personal communication, summer 2005). Symptoms such as pain that cause immediate discomfort are likely to trigger use of the Internet if it is available, accessible, and perceived to offer helpful information. In the case of IS participant 20, locating a dental clinic was a challenge due to socio-economic barriers and life circumstances.

Preparation

Increasingly patients may feel a responsibility to be prepared for their appointments. Due to the jargon, specialized vocabulary, and variety of treatment options, patients may believe in a need to educate themselves before interacting with a medical professional. One comment in this regard was made by a participant: "*Yeah that was kind of why I was using it [the Internet]. Just to refresh my vocabulary before I go in there.*" The person later stated, *"...I've read this before, I just want to make sure that she knows that I know what I'm asking about"* (IS participant 8, personal communication, summer 2005). Though this need to prepare was not frequently echoed verbally as a motivation for approaching the computer, similar themes re-emerge in the use section of this chapter.

Participation

A final factor that seemed to encourage an approach to the Internet terminal in the waiting room was involvement and participation in the research activities that preceded the introduction of the Internet terminal. A number of research participants indicated they had seen me in the waiting room before or participated in previous stages of the research (IS participant 1, IS participant 16, IS participant 19, and IS participant 22). IS participant 16 directly attributed her approach towards the Internet terminal to participation:

> ***IS participant 16:*** *Umm… I happened to be sitting here waiting for an appointment…well maybe it was you and some of the people you work with were sitting here talking about how to set this up.*
>
> ***Me:*** *Oh, okay.*
>
> ***IS participant 16:*** *and I was sitting here listening and you asked me some questions.*
>
> ***Me:*** *Ohm.*
>
> ***IS participant 16:*** *so I was sitting here and I was yakking with you when you set it up and I went oh there it is.*
>
> ***Me:*** *Okay, I remember now!*
>
> ***IS participant 16:*** *I was like oh there it is; I wonder what you guys decided to do.*
>
> ***Me:*** *That totally jogs my memory to the day when we were…*
>
> ***IS participant 16:*** *Yeah.*
>
> ***Me:*** *…envisioning the design.*
>
> ***IS participant 16:*** *Yeah, yeah (*personal communication, summer 2005).

This repeated involvement, activity and interest in the Internet terminal demonstrates the power of the "honey pot effect" or "sociable 'buzz'" (Brignull & Rogers, 2003, p. 4). Brignull and Rogers acknowledge Greenberg and Churchill et al., who note that it can be challenging to entice users to interact with a public display. However, they also identify that a honey pot effect, or a "sociable 'buzz'" (p. 4), can be constructed when potential users perceive the screen as offering interesting or worthwhile information, especially when others are involved. Interest appears to stem in part from participation and involvement in the implementation process. Participants included individuals who felt encouragement or curiosity stemming from previous conversations and involvement. In the next section, I will discuss the actual process of seeking and using health information.

Theme 2: Use

As stated earlier, the description of health information needs of patrons, in the absence of the context of their lives and location of the computer, provides only limited insights about actual use. In contrast, actual cases of use of the Internet terminal by Mid-Main patrons provide a means through which user experience can be described. Internet use can refer to the process in which information is applied for a practical outcome. As outlined in chapter 2, policy documents suggest that many potential policy outcomes can stem from the use of online health information. The themes in the policy documents that were found to link to access were configuration, equity, reform, and self-care. Within the context of the short sessions in the waiting room, these goals for use of the Internet as a means of enhancing access will be discussed and overlaid with the informational needs of participants.

Access to Services, Information, and Configuration

From a patient or patron perspective, access to services and information may occur through various channels. At the policy level, the configuration of the delivery channel for health information and services is something that is planned and executed. Patrons may express preferences for particular channels. As stated previously, IS participant 14 was concerned the BC Health NurseLine and Internet terminal were being put in place so that the government could achieve cost savings at the expense of needed service delivery. Scepticism, or at best a lack of awareness of government-produced health information online, was also expressed by IS participant 16:

> ***Me:*** *Do you use the Internet often to look up health information?*
>
> ***IS participant 16:*** *No never.*
>
> ***Me:*** *Never?*
>
> ***IS participant 16:*** *Never. I use that little book that the NDP government sent many years ago. The BC HealthGuide.*
>
> ***Me:*** *Okay. The BC HealthGuide.*

> ***IS participant 16:*** *Yeah. I think that's what it's called.*
>
> ***Me:*** *Yeah and you're actually on the online...you started off at the online version of that today.*
>
> ***IS participant 16:*** *Okay....*
>
> ***Me:*** *Did you know that there was a Web site as well...?*
>
> ***IS participant 16:*** *No. No* (personal communication, summer 2005).

It is notable that two participants viewed the online health information delivery in relation to the political happenings of *"cutbacks"* (IS participant 14) and the New Democratic Party's term in power (IS participant 16). Thus the configuration of the channels for health information delivery were effectively seen by two participants as linked to political power. These factors can impact the attractiveness of an information source and whether its information is of interest for patrons seeking health information.

Identity Groups and Equity

The socially constructed categories of individuals who are conceptualized to benefit from enhanced access to health information through online channels connect to the concept of equity. Four research participants accessed information that was pertinent to identity groups[53] such as the disabled, Aboriginal people, men, or women (IS participant 9, IS participant 11, IS participant 12, IS participant 15). Presumably, equitable access to information is intended to assist populations with lesser access to information to address their health information needs (i.e., Aboriginal people), or a greater perceived need for health information (i.e., disabled people).

IS participant 15 represented a number of these identity categories as a French-speaking and female member of the population with arthritis. French-speaking Canadians may encounter challenges in accessing health information due to the predominance of the English language on the Internet. As both traditional family caretakers and the dominant consumers of online health information (Fox & Fallows, 2003), women commonly seek health information. Finally, arthritis itself can cause

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[53] As described in chapter 2, identity groups and categories exist to guide users through navigation within health information Web sites. However, identity politics are extremely complex as will be illustrated through examples on the next page.

physical challenges with fine motor control and create a barrier to using a computer.[54] With some affiliation to each of these identities, IS participant 15 looked for health information through the Mid-Main Internet terminal. She selected the French language option and the "women" link on the Canadian Health Network site. She then stated:

> ***IS participant 15:*** *C'est pas complet. It's not complete. You understand? So...*
>
> ***Me:*** *That's disappointing.*
>
> ***IS participant 15:*** *Uhh...yeah, C'est pas complet. [Pause] Is that the Web site to....Because you know I went through here [perhaps the pull-down menu]...and I wanted to see about arthritis because I have arthritis.*
>
> ***Me:*** *Okay.*
>
> ***IS participant 15:*** *And I can't find it....It's just.*
>
> ***Me:*** *Yeah, it's not one of the choices.*
>
> ***IS participant 15:*** *Yeah...C'est pas complet* (personal communication, summer 2005).[55]

As a woman with arthritis, participant 15 did not find the content presented reflected her identity or her specific needs.

IS participant 11 experienced a somewhat similar frustration. As a participant who expressed that her language had been taken away in residential schools, she found the content which loaded upon her selecting the "Aboriginal Peoples" link on the Canadian Health Network and then a navigation selection for "healing practices" to be problematic:

> ***IS participant 11:*** *No bu[t]..no but they're going domestic they're going violence. But they're not saying where the violence stems from. Like violence the violence has come from residential schools...and alcoholism...like addictions. Before, when the missionaries came, it umm that was a loss of our language, our culture, artefacts, and dance, and*

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[54] The comment about arthritis and fine motor control is a general statement, not an observation of IS participant 15.

[55] Special thanks to Anne McCulloch, my ACTION for Health colleague, for assisting me with French translation and spelling.

> *ceremonial artefacts and regalia...*(personal communication, summer 2005).

The experience of IS participant 11 reflects a very serious question about appropriate representation. Within Canada's legacy of the oppression of Aboriginal people and culture, representations constructed through the presentation of information can be problematic for end users. Although IS participant 11 eventually found information of interest to her, she had an initial strong and negative reaction to some of the content presented within the Aboriginal people section. As demonstrated by the experiences of both IS participant 11 and 15, what is present and what is lacking on a Website is of significance. The experience of seeking health information can be slowed by categories which are not reflective of the individual self. Use can also be inhibited by interface design if the categories do not reflect the users' expectations or sense of self.

Chronic Disease Management and Renewal

In another session, the Internet terminal was accessed by IS participant 22 who identified himself as diabetic. His use of the Internet related to chronic disease management and primary health care renewal. The participant indicated that he was using the computer to register his One Touch blood glucose monitoring system. Use of the Internet terminal to register a device to manage a chronic disease such as diabetes is directly connected to primary health care changes, because as described in chapter 2, the *Primary Health Care Renewal in B.C.* document describes how the reforms are intended to promote "improved health outcomes, especially for patients with chronic illnesses" (British Columbia, 2004c, p. 1). Self-monitoring and increased tracking or surveillance of patients with chronic disease conditions is an element of primary health care reform. Chronic disease management in British Columbia attempts to assist "individuals [to] maintain independence and keep as healthy as possible through prevention, early detection, and management of chronic conditions, such as congestive heart failure, asthma, diabetes, and other debilitating illnesses" (British Columbia, 2005, para. 1).

The details available about IS participant 22's online activities are somewhat limited, as I elected to take notes rather than record the Internet session due to my concern that personal information such as name, contact information, and medical information could be revealed through an online registration process. Still, this particular session indicates the Internet could prove useful for patients requiring access for chronic disease management activities related to their medical conditions. Devices such as blood glucose monitoring equipment may necessitate that patients seek out Internet access.

Medications and Self-care

During the Internet sessions 6 participants looked up information about medications (IS participant 1, IS participant 3, IS participant 4, IS participant 5, IS participant 12, and IS participant 15). This search activity directly relates to self-care because participants appear to be using the information to inform their decisions about medications. In the BC HealthGuide handbook, the Healthwise Self-Care checklist encourages patients to "observe the problem[,]" "learn more about it," "make an action plan," and "evaluate your progress" in a series of four steps (Kemper, 2005, p. 1). The handbook encourages patients to bring a copy of the completed checklist to their medical appointments (Kemper). Although physical copies of the checklist were not provided, participants accessing the Internet terminal were at different stages within this checklist process.

With Internet-based information, one participant was able to identify a risk related to a medication in the past. IS participant 15 showed a considerable interest in understanding the effects of a medication on her overall health. An excerpt from our conversation follows:

> ***IS participant 15:*** *Well, I know that there's a, there's ahh...ahh...one treatment for arthritis I got the information that it is not really that good.*
>
> ***Me:*** *Oh okay.*
>
> ***IS participant 15:*** *Then I stopped. And I even talked to my doctor. I told her I can't take this medicine because I went through the Internet and she said well if you don't try it, you can't know. And I said no, I'm not going to try if it gives me liver disease or you know or other disease. You understand?*
>
> ***Me:*** *Okay. You found out about side effects?*
>
> ***IS participant 15****:* *Yeah, side effects.*
>
> ***Me:*** *Things like that on the Internet.*

> ***IS participant 15:*** *Okay. That makes me know more, much more, about this treatment and even much more...my specialist told me it's monitored if I give you this...if you take it ...start taking it you will be monitored ...but what can she [do]...I mean if it's too late? If I have a problem with my liver...I have no problem [with my liver]. I have pain in my joints. I thank God I have no other problem. But if I take this...* (personal communication, summer 2005).

With the information regarding the possible risk to her liver, IS participant 15 made a decision not to take a particular medication.

Another participant attempted to use the computer to learn about anti-depressants while in the waiting room and mentioned a side effect he was currently experiencing:

> ***IS participant 4:*** *I'm deciding whether...to find out [if] the last one [an anti-depressant] the one I'm coming off of is...which I'm told it's really dangerous to come off of [laughs]. Or the one [anti-depressant] that I'm going on to which I don't know too much about. So, mmmm...coin toss! Oh how about the one that be positive and go with the one that I'm coming on to – so the new one.*
>
> ***Me:*** *Ok.*
>
> ***IS participant 4:*** *...which is mmm Celexa...*
>
> ***IS participant 4:*** *One of the side effects is one of the things I'm trying to get rid of. [Laughs]. That's not good. [Laughs] But I'm sure the doctor has read into that. Ah sleepy...drow[voice become quiet and whispery] headaches – hmm - that could explain my headaches oh...*(personal communication, summer 2005).

In this case, the participant appeared to be at the evaluation stage of the self-care checklist. He believed a medication was causing a side effect which he hoped would be addressed by a medication change.

The process of patients completing self-care activities in relation to medications reveals they place varying degrees of trust in their physicians and medical professionals. Not all participants trust the doctor's judgement in relation to prescribing practices. Participants may have an interest in doing research to consider their own situation and the best course of action. When decisions are being made, self-care activities may require patients to advocate for their position in consultation with their physician.

5.5 Chapter Summary

This chapter began by introducing contextually situated user experience research as a method in which micro level considerations of interest to the individual may emerge. HCI and usability provide a tradition of intervening at the interface level. Qualitative research aimed at influencing change can be undertaken in order to impact change around policy and organizational issues. The next chapter, Sustaining and Supporting Access (chapter 6), continues to explore user experiences. It will provide case examples of users who were assisted and tutored when using the Internet terminal in the Mid-Main waiting room. The NVivo codes of barriers and context (including the role of the researcher) will also be addressed. Embarking on such an exploration is integral, because unaddressed issues of literacy, particularly computer literacy remain a concern.

In various ways, design processes at the macro and meso levels revolve around idealized views of end users. These idealized visions come to bear on an individual's experience of seeking health information. By idealizing end users to have certain competencies in policy, interface design, and technological implementation, problems and frustrations emerge for individuals. The "co-construction of users and technologies" has been discussed within technology studies and related fields (Oudshoorn & Pinch, 2003, p. 16). This co-construction will continue to be explored in the next chapter where my role as researcher and the difficulties of use are discussed. Special emphasis will be placed on my interactions with patrons who required tutoring and assistance to make use of the Internet terminal. If issues of configuration, equity, reform, and self-care reflect policy values federally and provincially, then the experience of individuals who experience difficulties with technology should be explored as a test of the rhetoric in practice. In the next chapter, I demonstrate how an analysis of individual experience can be used to help identify the pitfalls and potential of online health information for a broad spectrum of Canadians, and I consider how access can be supported and sustained in a community context.

CHAPTER 6: SUPPORTING AND SUSTAINING ACCESS

The warm expert mediates between the technological universal and the concrete situation, needs and background of the novice user with whom he is in a close personal relationship (Bakardjieva, 2005, p. 99).

6.1 Supporting Users

Oudshoorn and Pinch (2003) state that "configuring the user" occurs to "conceptualize the successes and failures of technologies mainly in terms of the extent to which designers adequately anticipate users' skills and behaviour" (p. 15). When design is broadened to include the context of use, successful design may require technology support for end users. User support can therefore be considered an aspect of effective access design. In the Access Rainbow, user support includes "literacy/social facilitation" to foster skill development (Clement & Shade, 2000, p. 36). The importance of support came to the forefront when some end users at the Mid-Main Community Health Centre lacked the competencies and skills which were treated as given within policy documents and technology design. The support needs of patrons in the waiting room have potential implications to the organization.

This chapter will begin by exploring the idea of failed design. Internet access has not been available at the Mid-Main CHC for patrons since the end of the fieldwork phase of this project; however, this itself is not necessarily a failure, as the amount of work involved with supporting patrons was a factor. This will be described by drawing upon the experiences of patrons who faced challenges in using the Internet terminal in the Mid-Main waiting room. I will provide a description of the support offered to participants in the form of assistance and tutoring. I will also discuss my role as researcher and draw upon specific concepts from the literature including: the "outside agent" (Labonte & Laverack, 2001, p. 117), "warm expert" (Bakardjieva, 2005, p. 99), and "participant interventionist" (Karasti, 2001, p. 80) to reflect upon my role in sustaining access through support activities. Examples of participants who required assistance or tutoring to use the computer will be integrated to illustrate the various roles. To conclude this chapter, I will discuss and analyze sustainability considerations for policy.

6.2 Failed Design?

It may seem inevitable that a number of end users experienced challenges when using the Internet terminal in the waiting room. Despite this reality, examining the interventions required to successfully introduce a new technology remains somewhat of an uphill battle in science and technology studies. Social constructivism has encouraged researchers to open the black box of technology. Pinch and Bijker's (1989) well known analysis of failed 'speed' bicycle attributes exemplifies this process. Similarly, Latour (1996) wrote about the failure of an automated French transport system called Aramis, "a combination of private cars and public transportation" (p. 2). In Latour's description, the death of the Aramis transportation system cannot be attributed to any particular group involved in the technological design or funding of the project (p. 3-4). Still, before the failure or death of a technology, there may be an effort to promote the sustainability of a design.

I am emphasizing the issue of failed technology design at this point because some might view the Internet terminal at the Mid-Main Community Health Centre as a failure as it has not been available since the fieldwork phase ended in September 2005. The computer was introduced with human support at a time when several other technological changes—many of which staff found challenging—were also introduced. When as a result of the implementation of the Internet terminal in the waiting room, it became clear that many users required substantial human assistance in order to use it, a decision was made to discontinue its use at the end of the research period to avoid burdening the front-desk clinic staff with added responsibilities associated with attending to patrons at the terminal. Once it was clear how much assistance some patients needed to use the terminal, clinic staff were concerned that transferring this support work from the researcher to a Mid-Main staff member could interrupt the staff member's regular duties. For example, problems could arise if a medical office assistant who usually works behind a reception desk were assigned to attend to Internet users' questions or concerns. Coming out from behind the desk and into the waiting room would make it impossible for the person to greet incoming patients at the desk. Thus, identifying the potential implications of the Internet terminal on staff was an essential component of the design and implementation. Although the computer is no longer available, it could be argued that a design failure would have been to continue implementation in a manner that adversely affected the clinic staff or did not provide required support for patients and patrons of the clinic. To illustrate the intensity of work which may be required to support the Internet terminal, in this chapter I will describe the caring interventions which I conducted as a researcher to attempt to enhance the usefulness of the terminal to patrons.

6.3 Caring Interventions

Caring intervention is a term I developed to describe my activities as a researcher when I intervened with and attempted to assist end users who were experiencing difficulties with the technology of health information Web sites. To formulate this term to describe my activities, I drew upon the traditions of feminist critiques of work such as Waring's (1988) analysis of unpaid caretaking work. Hankivsky (2004) furthers this inquiry and poses a probing question about the policy implications of caring work. She asks, "What are the consequences of the human need for care in social policy?" (pp. 1-2). Waring's legacy and Hankivsky's question are highly relevant when considering the types of work that may be rendered invisible by economics and policy.

The caring interventions associated with technological support are a form of work that could remain invisible, unrecognized, and absent from social policy and programs involving technology if they are not explicitly discussed. For example, Rideout (2003) has identified that the cost of community access programs never factored in the "volunteer labour that has been provided to teach Canadians how electronic communication links can be used for both individual and community development" (p. 198).

6.4 Independent, Assisted and Tutored Users

Of the patrons who accessed the Internet terminal in the waiting room, differing levels of support were requested or required. From the 22 participants:

- 12 patrons (54%) were independent users of the computer
- 7 patrons (32%) were assisted
- 3 patrons (14%) were tutored

Independent users were considered those who searched independently, did not appear to run into difficulty, and did not pose questions or request the assistance of the researcher. In comparison, some patrons who were categorized as assisted requested my direct assistance. For example:

> ***IS participant 20:*** *I couldn't find the information I wanted. Like I get why people have toothaches and what are the basic things that you should do to have good teeth. But I can't find whether there is you know like a place? Is there any way you can help me out?* (personal communication, summer, 2005)

Other patrons were assisted when they were observed to be experiencing frustration or difficulty and I felt I could aid them. For example, I told IS participant 17: *"Oh. Here's an idea. In the top links services, products, about us, Weblinks, press search. Search might help"* (personal communication, summer 2005). In contrast to assisted users who required only occasional assistance, tutored computer users were considered those who required ongoing support to use the mouse and complete tasks such as scrolling and selecting links. The coding category of barriers in NVivo overlapped with the examples of challenges of use located by considering the various support levels.

6.5 Supporting Access through Multiple Roles

As a researcher who assisted and tutored users, I fulfilled multiple roles at different times to assist Mid-Main patrons as they accessed the Internet. Although I have framed my activities as caring interventions, previous literature can be drawn upon to explain the quality and objectives of these activities. The roles of the "outside agent" (Labonte & Laverack, 2001, p. 117), "warm expert" (Bakardjieva, 2005, p. 99), and "participant interventionist" (Karasti, 2001, p. 80) each function to define some elements of my role as researcher. These situated identities will be discussed to serve as the scaffolding for a more nuanced discussion of the caring interventions that occurred in the Mid-Main waiting room.

6.5.1 An Outside Agent

Labonte and Laverack (2001) suggest that in health promotion, building community capacity may require an "outside agent" (p. 117). They define an outside agent as "an important link between communities and external resources. Their role is especially important near the beginning of a new program, when the process of building new community momentum maybe triggered and nurtured" (p. 123). The dual aspects of triggering and nurturing were extremely relevant to the Mid-Main context.

As I was wearing a yellow T-shirt with the "Researcher in the Waiting Room" logo, I was readily identifiable as an outsider. I was surprised at times how my presence also encouraged patrons to ask questions to make links to useful information. My familiarity with the Canadian Health Network and BC HealthGuide influenced my opinion about where appropriate information was located and assisted me in linking patrons to the appropriate resources.

Triggering and Linking: "Is there any way to get that information?"

While she was on the Canadian Health Network Website, IS participant 10 was seeking specific information about a medical test which she was finding difficult to locate:

> ***IS participant 10:*** *What I'm wanting is specific information, because I already kind of know some of this information [on what allergies are]....There is supposedly a blood test that can be done for allergies and I'm not sure if it can be done in Canada....*
>
> ***Me:*** *Okay.*
>
> ***IS participant 10:*** *So is there any way to get that information at all?*
>
> ***Me:*** *And there is nothing on the page that you're at that's triggering it?*
>
> ***Me:*** *One other thing I can suggest is to go to the BC HealthGuide Website.*
>
> ***IS participant 10:*** *Okay....*
>
> ***Me:*** *And I'm suggesting that because I do know that they have a section on tests.*
>
> ***IS participant 10:*** *Oh really? Excellent. Ok cool.* (personal communication, 2005)

When no navigation actions were readily triggering the desired information on the Canadian Health Network, I suggested this user move over to the BC HealthGuide Web site which included content about medical tests.

Nurturing

Nurturing, the second component of Labonte and Laverack's definition of the outside agent, explains the motivations behind my recommendation to change Web sites. Although the BC HealthGuide can be accessed through the Canadian Health Network search engine, browsing using the "medical tests" menu seemed to be the most direct option. After approximately nine minutes of Internet use, IS participant 10 located the name of the allergy test and the information about it that she was seeking. Retrieval of such information is reflective of a success that occurred in part because it was nurtured through support. The nurturing aspect of the outside agent links closely to the next role I assumed as a researcher, which is discussed below.

6.5.2 A Warm Expert[56]

During the pre-Internet interviews at Mid-Main, many patients expressed a preference for "warm" human contact rather than "cold" technology when accessing health information. As described earlier, pre-Internet participant 10 stated an explicit and emphatic preference, *"if I come to the doctor's, I come to talk to a human being not to talk to an Internet screen"* (personal communication, April 2005). In the case of the introduction of the Internet terminal in the Mid-Main waiting room, it was not an either/or scenario, as warm assistance for the computer was available. In her study of home Internet use, Bakardjieva (2005) has coined the term *warm expert* to describe the human role in assisting novices to use technology, particularly in domestic contexts and everyday life (p. 99). She defines the warm expert as:

> An Internet/computer technology expert in the professional sense or simply in a relative sense compared with the less knowledgeable other. The two characteristic features of the warm expert are that he or she possesses knowledge and skills gained in the System world of technology and can operate in this world but, at the same time, is immediately accessible in the user's lifeworld as a fellow man/woman. The warm expert mediates between the technological universal and the concrete situation, needs and background of the novice user with whom he is in a close personal relationship (p. 99).

As a researcher in the waiting room, over an extended period of time I assumed the role of warm expert in many different ways. During my fieldwork in the waiting room, patrons

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[56] I would like to acknowledge the participants and discussion at the ACTION for Health Theme 1 Science and Technology Studies workshop in November 2005 for suggesting that I draw upon Bakardjieva to reflect on my role as researcher.

were directed through the signage to seek me out if they had any technical difficulties with the computer. Having studied multimedia at the post-secondary level and having a high level of computer literacy, I possessed the technical expertise to be a warm expert. Spending extensive periods of time in the waiting room also made me a familiar face to some of the participants.

Assisting: "How do you spell...?"

Offering spelling help emerged as a form of assistance to patrons on the very first day of fieldwork. For example, one participant asked for my warm assistance during his session to provide the correct spelling for the medical condition for which he was seeking information:

> ***IS participant 1:*** *How do you spell "allergies", do you know?*
>
> ***Me:*** *Allergies?*
>
> ***IS participant 1**: Yeah.*
>
> ***Me:*** *Yeah no problem? "A-L-L-E-R-G-Y" or "I-E-S" for "allergies".*
>
> ***IS participant 1:*** *Okay, cool. Thanks.*
>
> ***Me:*** *You're welcome* (personal communication, summer 2005).

Accessing a computerized dictionary was a potential option. However, the preference for "warm" assistance set the tone for support that I offered regarding the spelling of search queries.

In one example, I attempted to subtly offer warm assistance regarding spelling. In describing a medication about which he was seeking information, one participant and I engaged in a discussion. He was a beginner computer user and needed help navigating:

> ***IS participant 4:*** *...mmm Celexa*
>
> ***Me:*** *Okay. So does that start with the letter "C" do you think?*
>
> ***IS participant 4:*** *"S".*

> ***Me:*** *"S".'*
>
> ***IS participant 4:*** *It's "S".*
>
> ***Me:*** *Okay.*
>
> ***IS participant 4:*** *It's "S". S-E-L-I...*
>
> ***Me:*** *So then you want to find the "S" and click that. Yep (*personal communication, summer 2005).

As a researcher, I was aware the human factors of the name of the drug Celexa have been a source of much confusion as well as an important issue regarding patient safety. For example, in the United States, over 100 medical errors have been attributed to the confusion between Celebrex, Cerebyx, and Celexa (Institute of Medicine, 2000). However, as I am not a medical professional, I did not feel it was my place to correct the participant's spelling or assume to know precisely about which drug he was seeking information.

During the session he continued to struggle with the spelling and even to visualize the box:

> ***IS participant 4:*** *Hey-yah. Ok Sel..Sel...Selixa - Salexa - Sa.. [articulates different pronunciations likely to sound out the spelling]*
>
> ***IS participant 4:*** *I'm trying to picture the box right now in front of myself.*
>
> ***IS participant 4:*** *Selexa, Serotona, maybe serotonin maybe. Selective serotonin. Ok so these are the categories. Maybe if I push it back up again?* (personal communication, summer 2005).

My hunch that he was looking for Celexa spelled with a "C" proved to be correct later in the session, as eventually, navigation through text links brought the participant to "Celexa" spelled with a "C". As indicated by the medical errors, knowing the correct spelling of a pharmaceutical drug can be difficult even for medical experts. Therefore, there are many opportunities to offer warm assistance with spelling.

Tutoring: "Do you know how to scroll?"

Other forms of warm expert assistance were more intensive and can be categorized as computer tutoring. In addition to being uncertain of the spelling of

Celexa, IS participant 4 was a beginner computer user. He experienced challenges in operating the mouse and navigating on the screen:

> ***IS participant 4:*** *These things [cursors] hop all over the place.*
>
> ***Me:*** *Yeah, it's hard work getting it to the right place.*
>
> ***IS participant 4:*** *It's like a pong game I had on the TV. Ah-ouch gees, gees. I'll click fast while it's there.*
>
> ***IS participant 4:*** *So, so…*
>
> ***Me:*** *So…and do you know how to scroll?*
>
> ***IS participant 4:*** *Umm. No.*
>
> ***Me:*** *No – okay, scrolling just means making it go down so you can see what you can't see right now.*
>
> ***IS participant 4:*** *Umhuh.*
>
> ***Me:*** *So you can try and grab that grey bar there over on the right and try to pull it. [Pause]. So if you click on it with, if you put the arrow there. Yep.*
>
> ***IS participant 4:*** *[Makes a noise something like] there.*
>
> ***Me:*** *And press the button…and then try to move your hand and pull it down. [Pause] Yeah, there you go!*
>
> ***IS participant 4:*** *Hey-yah…*(personal communication, summer 2005).

The steps required to use the computer were not obvious or automatic for IS participant 4. Although he had played a video game on the television before, he needed to learn the intricacies of using the mouse to interact with a graphical user interface. As such, my verbal instructions in response to his interactions with the screen were an attempt to help him to learn about the system world in a friendly and encouraging manner.

Similar step-by-step instructions were required by participants to log in to the BC HealthGuide site. Until September 2005, the BC HealthGuide Web site featured an interface design element that was directly comparable to a deadbolt on the front door of a house. When you have the key, a door is easy to open. However, without the key, trying to enter a locked building can be an extremely frustrating experience. In the case of the BC HealthGuide, the lock took the form of a text entry field that required users to enter their BC or Yukon postal code and click the login button to enter the site. The login field requires end users to have mastered both the mouse and keyboard and to have familiarity with interface conventions. To illustrate the number of tasks associated with the login, please consider the intricacy of the required steps as revealed from my interactions with IS participant 11, who described herself as *"computer illiterate:"*

> ***IS participant 11:*** *How do I change the page here?*
>
> ***Me:*** *Yeah, no problem.*
>
> ***IS participant 11:*** *How do you change it like?*
>
> ***Me:*** *Okay so the basic way you get around using this computer is you can use the mouse which is over there.*
>
> ***IS participant 11:*** *I know what the mouse is.*
>
> ***Me:*** *Ok…yep. So to enter [the Website] you put the cursor which is the arrow into the box here.*
>
> ***IS participant 11:*** *[Sighs] Okay, there.*
>
> ***Me:*** *Can you move it right [into the cell]…*
>
> ***IS participant 11:*** *Where?*
>
> ***Me:*** *In there [the text entry field] and press [the left mouse button] the…yep…and for here you have to type in your postal code to enter* (personal communication, summer 2005*).*

Later in the session this participant experienced further difficulties with the process of typing the postal code. She was sufficiently frustrated by the login process to consider giving up her search: *"Stop, so I'll just stop. My appointment should be here pretty soon so we'll just…maybe I'm never supposed to be here on this computer. I don't know but I can't even see the letter 'V'."* (personal communication, summer 2005). The login process was sufficiently complicated that a participant considered quitting. However, despite the frustration, she spent just under 52 minutes at the computer during a two-part session.

Due to this participant's difficulties with the postal code login, I readily identified that other users with differing levels of computer competencies also experienced problems logging in. Within Internet session 11, a list of previously entered values (i.e., other participants' postal codes and incorrect entries) appeared, when the mouse rolled over the field. Two participants had attempted to use the login box as a search engine. Another participant experienced difficulties with the login because he was 'just visiting' British Columbia while being a permanent resident of another province (IS participant 12). He decided to use a local postal code to gain entry to the site. Extrapolating from these experiences, other members of society, such as the homeless or new residents who lack a permanent address, may face exclusion from the information resources contained behind the login field. Varying levels of assistance and tutoring may be required to help individuals learn an interface to access health information.

6.5.3 A Participant Interventionist

The descriptions of the outside agent and warm expert roles strongly link my activities to caring interventions in a community setting and the everyday life of patrons. However, I do not wish to convey that my presence was universally perceived as altruistic. Seeking health information can be conceptualized as a form of work to be conducted by responsible citizens and patients. As described in chapter 2, self-care by citizens is at times conceptualized as a way to reduce pressures on emergency rooms and physicians (British Columbia, n.d.-b). In this manner, certain work previously completed as paid employment by medical professionals is being transferred onto the shoulders of citizens as self-care. This work may either be perceived as a burden or be of voluntary interest to citizens.

In considering health information as citizens' or patients' work, I found influential Karasti's (2001) description of her role as a participant interventionist in researching the redesign of a teleradiology system. She described her role in the following terms:

> Turning into a participant interventionist introduced and intertwined an explicit technology focus and change thinking into the fieldworker role. It required an explicit articulation and making visible of the ongoing transition in the work communities and a definite interest in exploring the technological change from within the actual work practice (p. 85).

In her fieldwork, Karasti observed the work practice of radiologists to incorporate understanding of work practice in system design. Karasti's emphasis on studying the transition and technological change are of relevance to my activities in the Mid-Main waiting room.

Although I believe many of my research activities are demonstrative of caring interventions to enhance the usefulness of technology, I am also aware that my presence in the waiting room could be construed as supporting the transitional shift towards more obligatory self-care work by patients. As a researcher, I do not presume that conducting self-care information seeking work is of interest to all Mid-Main patrons or Canadian citizens. However, as there was no obligation for Mid-Main patrons to seek health information, this issue did not cause me a major dilemma in the field. As 22 participants approached the computer voluntarily, grassroots individual interest in the computer aligned with policy aims regarding self-care by patients. Nonetheless I wish to acknowledge that one of my functions as a researcher in the field was to assist non-users to become part of the user category, a role which is somewhat problematic to me. I believe the use of the Internet for health information should remain a choice regardless of the impact on resources (i.e., follow-up or emergency room visits).

6.5.4 Summary of Researcher's Roles

My multiple roles as a researcher demonstrate the multi-faceted nature of carrying out caring interventions associated with the introduction of an Internet terminal. These activities are summarized in table 6.1:

Table 6.1 Researcher's Role in Carrying Out Caring Interventions

	Outside Agent	**Warm Expert**	**Participant Interventionist**
Main Function(s) in the literature	• Linking • Triggering • Nurturing	• Acting as a technology expert • Being available	• Influencing system redesign in response to work practice
My Research Activities	• Suggesting sites	• Assisting • Tutoring	• Migrating users to the Internet

These three roles are integrally linked to issues of sustainability of Internet access. Discussion and analysis of sustainability in relation to my roles as researcher will be carried out in the next section.

6.6 Discussion and Analysis: Sustainability

According to the Rainbow Access model introduced in chapter 2, a variety of socio-technical elements are required to build universal access (Clement & Shade, 1996b, 2000). The rainbow elements of universal access are a starting point to consider how to make access sustainable over time. Harrison and Zappen (2005) have argued that within a social constructivist framework, sustainability of technology is demonstrated when "a system is re-enacted on a routine basis by their users" (p. 146). From a Canadian perspective, a challenge in sustainability for connectivity programs is due to gaps surrounding a rainbow element which Clement and Shade label "literacy/social facilitation" (2000, p. 36). This important element has not always been re-enacted in the Canadian context due to the termination of funding programs, a lack of staff for programs, and volunteer burnout (Rideout & Reddick, 2005).

Based on an array of research on the digital divide, CAP and Community Learning Network programs in Canada, Rideout and Reddick (2005) argue that we need to define "sustainability in terms of supporting community organizations that provide social development and related content and services to the public, with support for core services, content development as well as technical access and networking" (p. 45). Rideout and Reddick look to government to fund both physical connectivity and human support when necessary to address social inequalities. They state, "funding should be used for technical services, the development and maintenance of core operations (staff, volunteers, overheads) and content services that can be accessed using communication technologies" (p. 45). Similar to the macro, meso, and micro levels of analysis of this project, Rideout and Reddick (2005) suggest that sustainability requires initiatives at multiple levels. In the case of the Internet terminal at Mid-Main, sustainability would likely require: an ongoing commitment to use the terminal by patrons, organizational support from the Mid-Main Community Health Centre, and resources supported at a policy level. The resources from at the policy level could include appropriate content for use in a medical waiting room and financial support for the Mid-Main CHC to provide physical access and support to end users. This form of sustainability is "layered and inclusive" and suggests that "'top down' help from government...can be exploited in the 'bottom up' community development process" (Simpson, 2005, p. 108). It is my assertion that the work required to support and sustain a computer in a community context needs to be better recognized in program design that is undertaken to support connectivity policy and primary health care reform. These types of policy initiatives require a genuine community driven interest in technology in order to succeed.

6.7 Chapter Summary

As identified through my interactions with the patrons in the Mid-Main waiting room, support is an essential element to enhance the usefulness of Internet access. The outside agent, warm expert and participant interventionist roles each contribute to patron support in different ways. The intensive level of support that can be involved in making access useful has inhibited the continuation of an unattended Internet terminal at the Mid-Main CHC. Previous research has identified that a lack of ongoing funding, lack of staff, and burnout of volunteers make it a challenge to sustain community Internet access in Canada. The current unavailability of Internet access at the Mid-Main CHC is not unusual in this regard. The macro, meso, and micro levels are integrally involved in the support and sustainability of Internet technology. In the next chapter, I will summarize the previous chapters and provide final thoughts.

CHAPTER 7: CONCLUSION

7.1 Overview

Thus far, I have illustrated that interventions at the macro policy level (chapter 3), meso organizational level (chapter 4), and micro individual level (chapter 5) can impact the success of technology in a community context. I have explored this issue by analyzing policy documents and conducting interviews and participant observation before and during the Internet introduction. Additionally, I have explored the issue of human support and my role as researcher during the implementation of an Internet terminal at Mid-Main (chapter 6). The issue of human support spans the macro, meso, and micro levels. Drawing from the earlier chapters, I will now review their major elements, then provide some considerations which suggest future directions for policy, practice and further research as well as discuss the limitations of my work. To conclude, I will provide final thoughts on implementing Internet access in community locations.

7.2 Review of Thesis

In earlier chapters, I discussed a variety of interventions to enhance access to health information through the Mid-Main Internet terminal. In chapter 1, I began by introducing the online health information in the Canadian Health Network and BC HealthGuide Web sites as an example of an e-government program being pursued by the federal and provincial levels of government. My research question encouraged me to explore the issue from the macro policy, meso organizational, and micro end user levels. The social construction of technology (SCOT) was introduced as a theory used to integrate the levels of analysis by considering various participant interests within the design and implementation of health information Web sites. From feminist critiques of SCOT, I determined that examining decision making and power relations were of great importance.

In chapter 2, I discussed three key concepts from the literature: interventions, access, and usefulness. These concepts were embedded in my research question and served to influence the methods I selected and my analysis of data. Next, in chapter 3, I introduced the connectivity strategy and primary health care reform as policy trends which have informed the design of health information Web sites by government. I shared the results of discourse analysis conducted on 46 policy documents to demonstrate how governmental interests have contributed to the construction of access and health information Web sites. The themes of configuration, equity, reform, and self–care were located in the discourse and through the interfaces of Web sites.

In chapter 4, I described the process to implement Internet access in the Mid-Main CHC waiting room. Mid-Main's emphasis on participation by community members was incorporated into pre-Internet research stages, including interviews and participant observation. From these research activities, it was determined that the plan to introduce the Internet terminal had patient backing. Additionally, human-centred care, appropriate use guidelines, recommended resources, and privacy are of high importance to Mid-Main community members. Based on these findings, interventions were designed and executed during the implementation phase.

In chapter 5, the results of participants' Internet access experience were shared. The drivers and use of the Internet emerged as areas of interest. Mid-Main patrons sought to use the Internet due to factors such as their health information needs, including medical conditions. Additionally, approaching the computer appeared to be triggered by particular factors such as the onset of symptoms and the patrons' participation in previous stages of the research. Use of the Internet terminal was mapped against the policy themes of configuration, equity, self-care, and reform from chapter 2. From the bottom up, individual participants appear to have some objectives in using health information Web sites that either closely align with policy or critique its application.

In chapter 6, I integrated the macro, meso, and micro levels by focussing on support issues. The alignment of individual participants' use of health information Web sites and policy goals is neither direct nor without tension. As a researcher I conducted multiple types of caring interventions to assist and tutor end users who experienced problems or barriers with the Web sites. Provision of the human resources to conduct caring interventions at community access points is an integral component in technology programs to acknowledge and attempt to dismantle digital divide barriers. Support is a major component of sustainability in community contexts and one that needs greater recognition. In this final chapter I will present considerations that may be applicable to policy, practice, or research when designing technologies for implementation in a community context. Sustainability is an ongoing issue of concern in promoting universal access to health information.

7.3 Considerations for Policy, Practice, and Research

The implementation of the Internet at Mid-Main points towards policy considerations at the macro, meso, and micro level which may enhance the sustainability of Internet access to health information Web sites in the future. I have compiled this list in part to address my research question: *what interventions are critical to enhance the usefulness of health information Web sites for patients in the Mid-Main waiting room?* Although the Internet terminal is not currently available to patients and patrons in the Mid-Main waiting room, it could potentially be reintroduced in the future or repeated elsewhere. Issues of interest for researchers, policy decision makers, patrons, and community organizations involved in programs similar to the one at Mid-Main may be:

- To consider each of the locations where decision-making occurs around health information Web sites and access (macro, meso, and micro).
- To design access in such a way that it supports user needs in diverse community contexts.
- To explore how to configure technology for end users as individuals, not aggregates.
- To factor in human support requirements as an essential component of design.
- To make decision-making and design processes transparent whenever possible.
- To explore the grassroots needs of citizens as health information seekers and to balance them with organizational and policy goals.
- To incorporate and advocate for processes which more directly involve citizens in design.

7.4 Limitations and Scope of Research

In developing these considerations, I have reflected upon the limitations of my research. A central problem with most research, including my own, is what is included and what is excluded as evidence to support a position. Within the scope of this project, decisions were made at each level of analysis which may be critiqued for a “lack of impartiality” (Baskerville & Wood-Harper, 2002, p. 140) as per other action research in information systems studies. At the macro level of analysis, it may be viewed as a weakness or bias that policy documents were reviewed rather than interviewing or observing designers or politicians. At the meso level, additional members of the Mid-Main organization could have been included in the research planning. At the micro level, a wider diversity of end users and patrons or non-users could have been included. In the preceding pages, I have attempted to make the research process and the participatory elements as transparent as possible to define the parameters of the inquiry. I acknowledge that increasing the scope for participation at each level may have enhanced the project. The scope of the project however, also relates to context.

The issues that action research "is context-bound and not context free" is a second potential limitation of this study (Baskerville & Wood-Harper, 2002, p. 140). The project could have been broadened to include additional Web sites and community contexts where the Internet is used for health information seeking. From a broader study, I may have gained the ability to generalize the findings. By considering the multiple levels of policy, organizations, and individuals, I have merely been able to scratch the surface of what is required for the successful and sustainable implementation of Internet technology in a community context.

My research was only somewhat successful at executing and identifying the interventions necessary for making health information seeking over the Internet an enhanced experience for Mid-Main patients and patrons. My central research question was answered and addressed to some extent. A number of interventions such as acceptable use guidelines, the computer's configuration for privacy, the accessibility of reputable resources, opportunities for participation, and the warm expert assistance and tutoring seemed to enhance the introduction. However, presumably different and other interventions would have also been appropriate. For example, I could have written grant applications to promote a more sustainable Internet access point. It is therefore a limitation that the setup that was developed through the research was not sustainable following my withdrawal from the field. However, from this short-term trial introduction, many lessons were learned which may be of interest to other clinics, to Mid-Main, or to government Web site teams.

7.5 Final Thoughts

Through analysis of the construction, implementation, experience, support, and sustainability of access, I have chronicled the story of a local attempt to introduce technology to enhance the accessibility of health information at one location. This story is one that is strongly rooted in the context of the Mid-Main Community Health Centre, so it is unlikely that identical events would unfold elsewhere. However, at other locations it seems inevitable that factors such as policy, interface design, organizations, and individuals will be in play, and may constrain access to Internet-based health information. Each of these factors could continue to construct challenges and inhibit the implementation of a sustainable public access terminal for Web-based health information.

Franklin (1999) suggests an optimistic strategy which I propose points towards appropriate future research about health information Web sites. On technology, she states that studies should be conducted in a context where things work well (p. 131). From the success stories, she suggests that we can learn about "processes and institutions that work well—at times in spite of, rather than because of, the system in which they are situated" (p. 131). It is the lessons learned from challenges and positive experiences of implementing the Internet terminal at the Mid-Main Community Health Centre that are significant from the research project. Although the Internet terminal is not currently available, some of the findings about appropriate design interventions for a community access location can be carried forward.

APPENDICES

Appendix 1: Policy Documents[57]

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Appendix 2: Semi-structured Interview Questions

a) Pre-Internet

- Are you 18 or older?
- When is your appointment time?
- Which doctor are you seeing?
- If you have a question about your health, how do you find out the answer?
- What three sources do you trust most for health information?
- In general, would you say your health is: [Scale: select one] excellent, very good, good, fair, or poor?
- Do you use the Internet? Where from?
- In a typical month do you use the Internet to search for medical or health related information?
- The Mid-Main Clinic plans to install a computer with Internet accessing the waiting room for patients to use in the upcoming months. What do you think about this idea?
- Would you use the computer in the waiting room? How so?
- Are you aware of the BC HealthGuide Handbook, a book that was mailed to all BC households in the summer of 2001 by the Ministry of Health?
- Have you used the BC HealthGuide Handbook in the last 6 months?
- Are you aware that there is a BC HealthGuide Website?
- Have you used the BC HealthGuide Website in the last 6 months?
- Are you aware that there is a Canada Health Network Website?
- Have you used the Canadian Health Network Website in the last 6 months?
- People living in Canada come from many different cultural and racial backgrounds. How would you describe your background?
- What language do you speak most often at home?
- To learn about your health, where would you like to be?
- If you needed to look for health information and decided to go online, how would you search for health information?

b) Internet Sessions

- When is your appointment today?
- What physician/practitioner are you seeing?

- If you have a question about your health, how do you usually find out the answer?
- What three sources do you trust for health information?
- In general would you say your health is [Select one] excellent, very good, good, fair or poor?
- Do you use the Internet? Why or why not? Where from?
- What types of things do you do using the Internet?
- In a typical month do you use the Internet to search for medical or health related information?

- Can you 'talk out loud' as you explore the site to tell me about the choices you make?
- What is confusing about this website?
- What do you like about this website?
- What would you like to change about this website?
- Did you make mistakes, or feel frustrated while using the website?
- Why did you decide to go there?

- Have you found the information you are looking for?
- Can you find [insert a content or navigation element] on this website?
- Do you understand the information you found?
- Is the information you found reliable?
- How do you know it is reliable?

- What do you plan to do with the information you found?
- Do you need to do further research?
- Where will you get more information?
- Will you discuss the information with a physician or nurse?
- Can you make a decision to improve your health or wellness based on information you found on the Internet today?
- Has the Internet helped you to make a decision about your health previously? How so?
- Are there changes required to make health information websites better suit your needs? What are they?

- People from Canada come from many cultural and racial backgrounds. How would you describe your background?

- What language do you speak most often at home?
- Are there any barriers or circumstances that make it difficult for you to use the Internet?
- How old are you?
- What is your postal code?

Appendix 3: PCensus Data

2001 Census
Home Language
2001 Census Traced Polygon

Total Population by Home Language	**97,456**	**% base**
Dominant Official Language	English	100%
Top 5 Non-official Languages	Chinese	55%
	Punjabi	19%
	Vietnamese	9%
	Tagalog (Pilipino)	5%
	Hindi	2%

Appendix 4: Pre-Internet Coding

Help
- Intermediary

Opinion (of terminal) -> Support for the Internet Terminal
- Positive
- Negative
- Neutral/Constructive

Rules -> Acceptable Use
- Guidelines
- Misuse

Skills
- Beginner
- Competent

Search -> Reputable Resources
- Google
- Offline
- General
- Government
- Reputable Organizations

Where
- Home
- Library
- Other
- Now here (Mid-Main)

Configuration

Barriers

Health Information (Sources)
- Doctor or Professional -> Human-Centred Care
- Mixed (Miscellaneous)
- Doctor, Professional and Internet
- Internet and books
- Books

Appendix 5: Internet Sessions Participant Description Table

Internet Session Participant Number	Sex	Age	Language Spoken Most Often at Home	Level of Computer Support	Number of Internet Sessions
1	M	32	English	Assisted	1
2	M	43	English	Independent	1
3	F	42	English	Independent	1
4	M	43	English	Tutored	1
5	M	42	English	Independent	1
6	F	46	English	Independent	1
7	F	72	English and German	Tutored	1
8	M	27	English	Independent	1
9	F	28	English	Independent	2
10	F	36	English	Assisted	1
11	F	45	English (but language taken away due to residential schools)	Tutored	2
12	M	56	English	Independent	1
13	F	72	English and some Spanish	Assisted	1
14	F	50	English (but language impacted by residential schools)	Assisted	1
15	F	47	French and English	Independent	1
16	F	51	English	Assisted	1
17	F	46	English	Assisted	1
18	F	27	English	Independent	1
19	M	59	English (but French-English bilingual)	Independent	1
20	F	31	English	Assisted	2

Internet Session Participant Number	**Sex**	**Age**	**Language Spoken Most Often at Home**	**Level of Computer Support**	**Number of Internet Sessions**
21	F	38	English and Polish	Independent	1
22	M	46	English	Independent	1

Appendix 6: Internet Session Coding

a) NVivo Codes

Driver

- Health Information Need
- Participation
- Symptoms/Concerns
- Availability/Accessibility
- Knowledge/Preparation
- Politics
  - Anti-driver
- Media Information
- Medical Conditions
  - Cancer
  - Mental Health
  - Allergies
  - Vertigo
  - CarioStr (Cardiovascular and Stroke)
  - Head Injuries
  - Arthritis
  - Gallstones
  - Menieres
  - Gastroreflux
  - Acne

Barrier

- Physical
- Attitude/Preference
- Skill
  - Fine Motor
  - Scrolling
  - Configuration
  - Keyboard
- Interface
  - Postal Code
  - Categories
  - Search Engine
  - Spelling
  - Drop Down
  - For Profit
- Computer Accessibility

Use

- Help
  - Interface
  - Spelling Terminology
  - Configuration
  - Website Choice

- Time Issue
- Success
- Empower
    - Discuss
    - Decide
    - Question Authority
- Categories
- Self-care
- Search Google
- Visuals
- Trust and Privacy
    - Evaluate
    - Reliability

Context
- Role of Researcher

Power

Learn
- Noise
- Configuration
- Help
- Public
    - Help
    - Inquiries
    - Conversations

b) Table Codes

Health Information Needs

- Medical Conditions
- Medications
- Access to services or information
- Identity groups
- Advocacy, patient or nonprofit groups
- Support (human)
- Alternative or complementary health
- Treatment or therapy
- Policy
- Test
- Nutrition
- Chronic Disease Management
- Other
- Unknown

Approach/Motivation

- Direct
- Conversation

- Previous Participant
- Symptoms
- Preparation
- Unknown

Skill/Level of Assistance

- Independent
- Assisted
- Tutored

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