

Design and Development of a Personal Health Record System for Prostate Cancer
Patients

by

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MD, Tehran University of Medical Sciences, 1995

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of the Requirements for the Degree of

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Supervisory Committee

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Abstract

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There is a growing demand to involve patients in their own healthcare. Personal Health Records are among the most promising tools for this purpose. However, these tools need to meet patients' needs and interests in order to be fully adopted and successfully used.

This study takes a user centered design approach to design and develop a personal health record for prostate cancer patients by involving them in two main activities of a user centered design: requirements gathering and evaluation. The first phase of the study uses content analysis to analyze interviews with patients and elicit their needs and concerns.

Results of this phase showed that patient's information needs are different depending on the stage of the disease. Before starting treatment, patients are more interested in information about different methods of treatment and their potential side effects.

However, after treatment, patients mostly need information about the management of treatment complications and the long term follow ups of their disease. Results also showed that the Internet is the most common information source for patients to find information. However, patients expressed concerns regarding the credibility and reliability of information they found on the Internet. The majority of patients also showed interest in accessing their medical records. However, some patients were concerned about the understandability of the information. Also, there was some concern regarding electronic access to medical records and security of personal data. The findings from

phase one are used in phase two to modify a preliminary prototype of the system. In phase three, the modified prototype is evaluated by undergoing usability testing. Overall, the results of usability testing showed that the system was generally useful and easy to use. However, a number of issues were identified that could be resolved in the next iteration of its design and development.

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Dedication

I lovingly dedicate this thesis to

my wife, Rosita,

who supported me each step of the way.

Thank you for all your understanding and patience.

CHAPTER 1: Introduction

Personal Health Records (PHRs) are quite new to health IT and as compared to other areas, little research has been done to date on them (Kaelber, Jha, Johnston, Middleton, & Bates, 2008). However, PHRs are believed to have an enormous potential to change healthcare especially with regard to chronic diseases (Sittig, 2002). Increasing healthcare costs, the growing demand for care, and demands for higher quality of care are among important challenges that healthcare systems around the world are facing. Western countries, in particular those with an aging population, are experiencing a higher incidence of chronic diseases in the population. Among the most important solutions to these healthcare management challenges is the concept of engaging individuals in their own healthcare (Kaelber & Pan, 2008; Pagliari, Detmer, & Singleton, 2007). In a patient-centered care model, with the focus of care shifted to patients instead of healthcare providers, patients play a more active role in the management of their own health. The whole concept of patient self-management is based on the premise that by equipping patients/individuals with access to their health information, accompanied by educational resources, self-monitoring/management tools, and communication channels with caregivers, patients can make informed decisions, avoid unnecessary visits and treatments, paperwork is not duplicated, unnecessary tests can be avoided, and chronic diseases can be managed more effectively. All of these benefits not only have the potential to save healthcare dollars, but also may improve the quality of healthcare and patient satisfaction.

Personal Health Records (PHRs) may be able to help patients self-manage their health by harnessing the power of information technology. Moreover, healthcare consumers are

now demanding tools like PHRs. In a recent survey, two thirds of the public were interested in accessing their own personal health information electronically (*Markles Foundation, 2003*). This willingness has led to an increase in the adoption of PHRs. PHR adoption has more than doubled in only two years (*California Healthcare Foundation, 2010*). The same survey also found that more than half of adults are interested in using online applications to track health-related conditions.

However, the current adoption of PHRs among patients is still low (i.e. around 7 percent) (*California Healthcare Foundation, 2010*). Some believe that a PHR's success depends on adoption by patients (Kaelber et al., 2008). While a variety of patient-related factors including privacy concerns, internet access, and computer and health literacy are involved, low adoption of PHRs may be a result of failure in system design which has led to systems that have limited value to patients and therefore are not adopted by them (Kahn et al., 2009).

One important way to tackle this problem is to involve patients in different phases of PHR engineering including design, development, implementation and evaluation (Pagliari et al., 2007). By engaging patients in the design process, particularly in the requirements gathering phase, the system can be designed and developed based on patients' needs and may lead to a more useful PHR (Dabbs et al., 2009). A user-centered design approach involves the users from the early stages of system design and development by eliciting their requirements and evaluating the developed prototypes in an iterative manner. The purpose is to ensure that the final product meets users' needs and preferences and is easy to use. This may lead to a better adoption since low PHR adoption may be related to problems of PHRs to meet patients' needs (Kahn et al., 2009).

The study described in this thesis presents a user centered design approach to the design and development of a PHR for prostate cancer patients.

CHAPTER 2: Review of the Literature

The purpose of this chapter is to review the literature addressing PHRs and the importance of involving users in design and development of these systems. The literature review encompasses the relevant literature addressing the differing aspects of PHRs including the need for them, their various types, potential functionalities, benefits, and the barriers to adopting them. Also, the potential role of PHRs to help manage chronic diseases and chronic type cancers such as prostate cancer will be reviewed. The chapter then focuses on the literature addressing issues related to the design of health information systems that are targeted toward consumers and the approaches that tackle these issues.

2.1 What Are PHRs?

There is no uniform definition of a PHR in the literature and in the industry. One definition that is more widely accepted and used is the Markle Foundation's definition.

Markle Foundation defines a PHR as (*The Markle Foundation*, 2003):

“An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.”

The above definition is relatively broad, yet it does not cover all the features of a PHR. It is believed that access to personal health information on its own cannot improve the quality of care nor can it empower patients and help them make informed decisions unless they have access to some tools and services to interact with the system and get support for their decisions (Detmer, Bloomrosen, Raymond, & Tang, 2008; Tang, Ash,

Bates, Overhage, & Sands, 2006). Access to relevant information, secure communication between patients and caregivers, appointment scheduling, and prescription renewal, are some examples of these tools/services that can be integrated into PHRs in order to make them more *useful*. For this reason, some experts think that the term “Personal Health Record” is not descriptive enough and can limit innovation and usage of these systems. Personal Health Record Systems (PHRS) and Personal Health Platforms (PHP) have been suggested as more appropriate terms (Moore, 2009a; Moore, 2009b).

Other terms that in fact are not much different from PHRs in terms of their purpose and function are “Patient Portals” and “Patient Accessible Electronic Health Records (PAEHR)”. Patient Portals cannot be considered as an independent entity. Instead, they are a form of PHR delivery. In other words, as it is discussed later in this chapter, PHRs can have various architectures. One form could be an Internet-based portal. These portals usually provide patients with services/tools in addition to access to health records. Patient Accessible Electronic Medical Records are Electronic Health Records equipped with extra functionalities that enable patients to access their information (usually through the Internet). As a matter of fact, PHRs, Patient Portals, and PAEMRs are similar as they are used by patients. While Patient Portals focus on the underlying technology that delivers a set of services/tools to the patient/individual, PAEMRs make the provider/EMR perspective more prominent. Among these, “Personal Health Records (Systems)” seem more appropriate as they focus on the individual patient or healthcare consumer.

For the purpose of this study, it is important that we define the Electronic Medical Record (EMR) and the Electronic Health Record (EHR). The author will also describe the

relationship between PHRs and these systems. The Healthcare Information and Management Systems Society (HIMSS) defines the EMR as (Garets & Davis, 2005):

“An application environment composed of the clinical data repository, clinical decision support, controlled medical vocabulary, order entry, computerized provider order entry, pharmacy, and clinical documentation applications. This environment supports the patients’ electronic medical record across inpatient and outpatient environments, and is used by healthcare practitioners to document, monitor, and manage healthcare delivery within a care delivery organization (CDO). The data in the EMR is the legal record of what happened to the patient during their encounter at the CDO and is owned by the CDO.”

In other words, EMRs can be defined as the patient’s medical information that is limited to a particular facility such as a hospital or a physician’s office. The HIMSS definition of EHR is (Garets & Davis, 2005):

“The Electronic Health Record (EHR) is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports. The EHR automates and streamlines the clinician's workflow. The EHR has the ability to generate a complete record of a clinical patient encounter - as well as supporting other care-related activities directly or indirectly via interface - including evidence-based decision support, quality management, and outcomes reporting.”

The EHR aggregates patient's data from multiple EMRs across a health system (e.g. a health authority), or multiple health systems (e.g. provincial EHR), or even all the systems existing in a country (a national EHR). The purpose of the EHR is to create a single, central, longitudinal record for each individual that can be accessed across different facilities and healthcare systems. However, it is important to note that the EHR is not totally patient-centric and may not cover *the entire* patient's health information. For instance, the EHR may not include input from patients. Also, if the patient has an encounter outside a particular health system that the EHR covers, then the EHR will not cover that information.

The PHR has the potential to pull its data from EHR and provide patients with extra features such as patient ability to add data and interact with the system (e.g. sending messages to clinicians, ability to schedule appointments, etc). For example, Google and Cleveland Clinic conducted a pilot program to test the ability of Google's PHR platform called Google Health to exchange data with Cleveland Clinic's EMR (Rodriguez, Casper, & Brennan, 2007). Google Health provided the connection to health information systems in a variety of healthcare organizations (Google health: Personal health services, 2010). Google Health was discontinued in Jan 2012 due to a low adoption rate among consumers (An update on Google health, 2011).

2.2 Types of PHRs

From an IT architecture point of view, PHRs can be divided into three types (Tang, Ash, Bates, Overhage, & Sands, 2006).

2.2.1 Stand-alone PHR

This is the simplest form of a PHR that does not connect with any other systems. The data is usually entered manually by the patient (Tang et al., 2006). This type of PHR can be in the form of USB devices, CDs, smart cards, desktop applications, or even web-based applications that can be accessed through the Internet. Although this model of PHRs gives patients complete control over their data and the PHR seems more secure as it has no connection to other systems, such PHRs often lack reliability and usefulness and are not considered a preferred model (Tang et al., 2006). Some physicians may question the accuracy and completeness of self-reported/patient-entered information (Detmer, Bloomrosen, Raymond, & Tang, 2008). Stand-alone PHRs can only be considered computerized versions of paper-based health records that some people keep.

2.2.2 Tethered PHRs

In this model, the PHR is a view to the providers' health information system that allows patients to access their personal health information. The type of health information that patients can view depends on the policies of the healthcare provider organization and may contain parts of the medical history, laboratory results, prescriptions, and other health related information. In addition to access to personal health information, these types of PHRs may also offer other functionalities such as secure messaging between the patient and caregivers, prescription refills, appointment scheduling, or even adding data by the patient (Tang et al., 2006). Added functionalities are mainly targeted towards increased system efficiency, lowered costs, decreased clinicians' workload, and increased patients' satisfaction while improving the quality of patient care. However, in this model, patients usually have limited control over their information. The biggest advantage of this

type of PHR is that it is integrated into the provider information system and the provider usually maintains the application and the information. Therefore, no data is transferred or copied into any external repository. Instead, the PHR only creates a view of the existing information in the health information system (EMR or EHR). This integration can make these PHRs more secure and potentially rich in their functionality. In addition to this, patients can feel secure that their information is backed up regularly, and is not lost (as in the case of abnormal situations such as hardware damage or even disasters) (Tang et al., 2006). However, interoperability is an issue with this type of PHR and data transfer limits when patients decide to change their healthcare provider.

Tethered PHRs may be developed by differing parties. They can be developed by EMR vendors. For example, MyChart is a web-based PHR developed by the well-known vendor of ambulatory care information systems, Epic Systems (Halamka, Mandl, & Tang, 2008). Any healthcare provider who uses the Epic Systems EMR can easily provide its patients with access to their own information using MyChart. Sometimes hospitals develop their own PHR. PatientSite (www.patientsite.org) is one example of a hospital-based PHR developed by Beth Israel Deaconess Medical Centre (Halamka et al., 2008). A more advanced model of a tethered PHR was developed by a Health Information Exchange (HIE) network. This type of PHR has the potential to integrate more data sources from a network of healthcare providers and leverage sharing of information between different facilities (Dixon, Miller, & Overhage, 2009). Kaiser Permanente's "My Health Manager" is one such example.

2.2.3 Interconnected PHRs

In this model, the PHR is an independent application which has the ability to connect to and exchange information with a variety of information resources and act as a hub for information sharing (Halamka et al., 2008). Data can be populated from a variety of sources including providers' information systems (e.g. EHRs), insurance companies, and also by the patients themselves. This type of PHR can provide consumers as well as healthcare providers with a more complete view of health information (Detmer et al., 2008). This model seems to hold the promise of having a lifelong longitudinal health record for an individual. Patients, caregivers, insurers, employers, and other possible parties are all equal contributors and stakeholders. However, the ownership and control of the information completely remain with the individual. By putting the individual/patient/consumer at the center, this model seems to be closest to the patient-centric concept of a PHR. These characteristics of a PHR are especially useful in a scattered healthcare environment such as what is seen in the United States where different parts of a patients' information are maintained in different information systems. Since these types of PHRs need to exchange data with different systems, interoperability is a big challenge. Examples of this type of PHR are Google Health, Microsoft's HealthVault, and Dossia. Dossia was developed by top US employers such as AT&T, Walmart, and others to serve their employees with a personally controlled PHR system (Steinbrook, 2008). A Canadian example of this type of PHRs could be TELUS Health Space which is powered by Microsoft HealthVault (TELUS licenses Microsoft HealthVault to launch TELUS health space, Canada's first consumer e-health platform, 2009).

In addition to the above mentioned types of PHR models, another model that can be hypothetically considered is a National PHR. In this model, a single system such as a national portal provides access to personal health information and related tools. Some may argue that this model is not different from the tethered model, but since it is more than a PHR tethered to a single system or a network of systems and usually requires a national or at least jurisdictional approach, it can be considered an independent type of PHR. This model may have the advantages of both tethered and interconnected models but requires a national health *infostructure* (information infrastructure) to operate. In addition, a high level of EMR adoption is necessary for the infostructure to be rich in information. One advantage of this type of PHR is that it does not have to have a communication interface with different systems as this communication can be implemented at the level of the health infostructure and the PHR only needs to connect to a single consolidated entity. Having an adoption rate of nearly 100 percent among primary care physicians, Denmark provides its citizens with such access in the form of a national portal (<http://www.sundhed.dk>). Some UK citizens also benefit from a similar health portal called HealthSpace (<https://healthspace.nhs.uk>). Considering the fact the Canada's healthcare system is to some extent similar to the UK and Denmark in terms of being a public sector organization governed by the government, and the fact that Canada Health Infoway is pursuing an e-health strategy toward "One Patient One Record" system, a national or at least a provincial PHR seems to be a promising model for Canada.

2.3 PHRs Potential Functionalities

The basic functionality of a PHR is to provide access to personal health information. However, this does not mean that patients will have access to all of their information or can control the way the information will be accessed and shared. This is especially true in the case of tethered PHRs where the provider decides about the access and governance of personal health information. Yet, as the author of this thesis mentioned before, access to information is not enough. There should be other tools and services integrated into a PHR to enable patients to interact with a system and healthcare providers to harness the true power of information technology (Detmer et al., 2008; Tang et al., 2006). These tools/services can be categorized into four different categories: 1) Provider-patient interaction, 2) Decision support, 3) Disease/Health management and 4) Social networking.

2.3.1 Provider-patient Interaction

Perhaps this is the most useful category which has a great potential in terms of bringing convenience to patients and saving time and money for a caregiver. Most tethered PHRs use these features. Some of the major functionalities in this category are:

Communication with caregivers: Patient surveys suggest that about 75 percent of Americans report they would communicate electronically with their doctor if given the means to do so (Halamka et al., 2008). With this functionality, patients can send secure email-based messages to their doctor asking confidential questions or report on post-visit information without having to present physically to the doctor's office. A recent study (Zhou, Kanter, Wang, & Garrido, 2010) showed that the use of patient-physician

communication was associated with a statistically significant improvement in effectiveness of care.

Appointment scheduling: Patients schedule appointment on the Internet which saves office staff a lot of time (Kaelber et al., 2008).

Prescription refills: Instead of going to a pharmacy every time to refill a prescription, patients can order refills online. This feature is especially convenient for elderly patients and/or patients with chronic diseases who have to refill their prescriptions frequently.

Pre-appointment questionnaires: Having to answer the same questions before each visit is tedious for patients. On the other hand, nurses and receptionists have to spend a lot of time before each visit to gather basic information from patients. An online questionnaire filled by the patient before the appointment can be a very useful tool integrated into a PHR. Moreover, by pushing the existing basic information to the requesting facility system, the patient is not even required to fill out a form each time at a physician visit (Kaelber et al., 2008).

Patient data input: This function enables patients to add information to their health record. This is different from patient-provider communication as the data is added to patient's health record in a pre-formatted fashion. This function is mostly used in interconnected PHRs (Detmer et al., 2008).

2.3.2 Decision Support

PHRs have the potential to truly empower patients and help them to make informed decisions. There are three types of decision support tools that can be integrated into PHRs:

Educational material: People are using the web as a source for health-related information more than ever. According to a new survey (*California Healthcare Foundation*), 67 percent of adults searched online for information about a disease or medical problem. PHRs can provide users with relevant patient-oriented information based on their health status. This personalization of patient education is especially helpful for patients with limited computer and/or Internet competency who may not be able to find relevant information easily. Educational material can be highly customized to make PHRs more useful (Tang et al., 2006).

Reminders and alerts: Automatic reminders can remind patients to refill their prescriptions, attend appointments, or take their medications. Alerts can prevent patient safety events such as drug interactions. Reminders and alerts may improve the quality of care by helping patients to make decisions about their self-management. These notifications can be sent as emails or text messages to cell phones.

Business directories: Access to healthcare related business information (e.g. doctors, hospitals, and pharmacies) combined with consumer and third-party ratings of healthcare facilities and clinicians enables patients to make informed decisions about where to seek care.

2.3.3 Disease/Health Management

Among the most important potential benefits of PHRs is enabling patients to become involved in their healthcare by equipping them with health management tools (Kaelber & Pan, 2008; Pagliari et al., 2007). This is especially important in patients with chronic diseases (Kaelber et al., 2008). By creating graphs and generating warnings based on abnormal trends, these tools can enable patients to monitor their home test results (e.g.

blood glucose test for diabetic patients), symptoms (e.g. pain), diet, and exercise history. The required data can be captured from home test devices such as those used for blood glucose tests entered by patients. To make the capturing of information easier, some PHR vendors are working with medical device manufacturers on instruments that can upload test results to the PHR. For instance, a variety of health and fitness devices (e.g. heart rate monitors, glucometers, blood pressure monitors, etc.) can connect with Microsoft Healthvault (Devices that connect with HealthVault.2010).

2.3.4 Social Networking

Social networking tools such as discussion forums, blogs, and support groups can be used within the context of PHRs to create a communication channel between patients and between patients and caregivers. By using tools like forums, social networking portals, and support groups, patients can share their information and experiences with each other. Patients with similar conditions can highly benefit from this type of networking. Sharing the information can leverage informed decision making among patients (Eysenbach, 2008).

2.4 Benefits of PHRs

There is little disagreement that PHRs are potentially beneficial to patients (Pagliari et al., 2007). Also, there are estimates that show PHRs are beneficial to health systems as well (Kaelber & Pan, 2008).

2.4.1 Benefits to Patients

Improved quality of care: Access to personal health information accompanied with targeted educational resources can give patients a deeper understanding of their

conditions. This can empower them to make more informed decisions and become more involved in their own healthcare which in turns can result in a higher quality of care (Pagliari et al., 2007). In addition, disease management tools will result in better care for patients with chronic conditions (Tang et al., 2006). Also, patients' ability to enter data into PHRs can improve the quality of care as it may result in a more detailed data for clinicians to review as well as support clinician decision making. If the data could be shared, there is a potential that patients may receive more coordinated care.

Improved safety and accuracy: Having access to their health records, patients can verify that their information is complete and accurate. This can reduce the probability of adverse drug interactions or reactions (Pagliari et al., 2007).

Convenience and time saving: Functionalities like appointment scheduling and prescription refill are not only much more convenient, but also save a patient's time.

2.4.2 Benefits to the Health System

Reducing healthcare costs: It seems that one of the biggest challenges of healthcare in the future is increasing costs. Total health expenditure in Canada was estimated at \$161.0 billion in 2007, \$173.6 billion in 2008 and \$183.1 billion in 2009 (Canadian Institute of Health Information, 2009). At the provincial level, total health expenditure as a percent of provincial GDP ranged from 8.2% to 16.7% in 2009 (Canadian Institute of Health Information, 2009). Among the territories, the ratio of health expenditure to GDP reached as high as 25.8% for Nunavut in 2009. PHRs have the potential to reduce healthcare costs by engaging patients in their healthcare through improved lifestyle, decreased utilization of health services, better disease management, improved care coordination, and improved adherence to care (Kaelber et al., 2008). PHRs may also save healthcare dollars by

eliminating unnecessary duplication of tests and services. Saving Clinicians' time by substituting office visits with online consultation as well as decreasing the time being spent gathering patient medical history may also reduce the costs (Detmer et al., 2008). Furthermore, increased quality and safety of care arising from PHR use can result in fewer interventions and contribute to a reduction in the cost of healthcare (Bronson & O'Meara, 1986). A study in the U.S. has already shown that an 80% adoption of PHRs by consumers could result in a net value between 13 to 29 billion USD (Kaelber et al., 2008). The savings resulting from adopting PHRs in Canada could reach \$1.5 billion (Deloitte, 2009).

Increasing the efficiency and reducing the burden for healthcare staff: It has been estimated that online appointment scheduling, pre-appointment questionnaires and prescription refills through a PHR can significantly reduce the time spent by nurses and medical clerks on each patient (Kaelber et al., 2008). Asynchronous, electronic communication via a PHR and between patients and healthcare providers can free clinicians from the limitations of telephone and face-to-face communication or improve the efficiency of such personal contacts (Tang et al., 2006). PHR-mediated communication tools enable communication at the convenience of the patient and provider and automatically include patient-provider email in the record (Detmer et al., 2008).

2.5 Barriers to Adoption and Use of PHRs

Challenges to the development, adoption and use of PHRs can be divided into three different categories: 1) patient/consumer related challenges, 2) provider/organizational challenges, and 3) technical challenges.

2.5.1 Patient/Consumer Related Challenges

Although PHRs have the potential to improve the quality and safety of care through empowering patients, this will not take place unless patients actually use them. Despite a significant increase in use of PHRs during the last two years, the current adoption of PHRs among patients is still low (i.e. around 7 percent) (California Healthcare Foundation, 2010).

Computer competency, Internet access, and health literacy are important barriers to PHRs adoption (Kahn, Aulakh, & Bosworth, 2009). Access to computers and the Internet may act as an obstacle to PHR adoption (Kahn et al., 2009; Urowitz et al., 2008). However, increasing access to the Internet through mobile phones can be considered an opportunity since use of mobile phones needs less computer competency, and access to the Internet is much easier through these devices (Kahn et al., 2009).

Health literacy is another factor that plays a role in consumer adoption of PHRs (Kahn et al., 2009). The Canadian Public Health Association defines health literacy as (Canadian Public Health Association, 2010) “*skills to enable access, understanding and use of information for health*”. A study of information technology use and literacy found that nearly one out of two U.S. adults has difficulty understanding the information necessary to make basic health decisions (Nielsen-Bohlman, Panzer, & Kindig, 2004). In Canada, according to the Canadian Council on Learning, the majority of adults (60%) do not have the necessary skills to manage their health adequately (Canadian Council on Learning, 2007).

A major concern amongst patients is security and privacy. According to a recent survey (California Healthcare Foundation, 2010), 75 percent of respondents who do not use PHRs reported that they are concerned about the privacy of their personal health

information. However, less than half of PHR users are concerned about the privacy issues (California Healthcare Foundation, 2010). Consumers' privacy concerns have led to a need to address other challenges such as authentication methods, audit measures, etc.

2.5.2 Provider/Organizational Challenges

Challenges to PHR adoption and use are not limited to patients. Factors related to healthcare providers have also had a role in this regard. Some physicians may be reluctant to use PHRs due to concerns about whether adoption of PHRs will result in additional work (Halamka et al., 2008). In addition, it is not clear how physicians' online services through PHRs are going to be reimbursed (Halamka et al., 2008). Provider reluctance to use PHRs may come from concerns about new processes and increased responsibilities associated with interacting with patients and using new health information technologies (Detmer et al., 2008). There is no clear consensus about the type of information that patients can have access to (Lang, 2009). For instance, there is much debate about sharing some highly sensitive information such as sexually transmitted diseases, HIV, and substance abuse treatment. Some physicians are also concerned about patients' access to clinical notes since they think that these notes contain their personal thoughts and are not meant to be shared with patients (Halamka et al., 2008). Another major challenge to PHR adoption is the low rate of EMR adoption (Lang, 2009). By 2011, only 55% of office-based physicians in US had adopted an EMR (Jamoom et al., 2012). Especially with interconnected PHRs, most of the PHRs' information is supposed to be populated from EMRs. If EMRs are not widely adopted, and most of the information is not in a digitally transferable format, then there is nothing to be populated in a PHR. In fact, some experts even argue that PHRs will not be useful

until EMRs are widely in use (Moore, 2009). As for national PHRs, a national infostructure or at least local EHRs with a high rate of EMR adoption are prerequisites for a successful PHR.

2.5.3 Technical Challenges

It seems that the most important and challenging technical issue about PHRs is interoperability. Interoperability refers to the ability of systems to *talk* to each other and exchange data using a set of standards (Detmer et al., 2008). Lack of standards for interoperability and data portability is a key barrier to the integration and exchange of structured data between PHRs and other health information systems (Detmer, et al., 2008). A PHR cannot be information rich unless it is connected to other information systems to pull data. Even if there is no debate about the appropriate architecture of a PHR, interoperability is still the main issue. Tethered and interconnected models both need to be interoperable. Even national PHRs will need to be interoperable in an international scope. As a matter of fact, the interoperability challenge is the product of some other issues. Different medical terminology and information exchange standards and even different versions of a single standard make interoperability harder to achieve. Also, incompatibility between different systems and databases is another barrier to integrated records, although it will diminish with the adoption of consistent technology and data standards (Pagliari et al., 2007).

Authentication is another challenge with its roots in privacy concerns. Lack of a unique identifier in countries like US and Canada make it difficult to uniquely identify a patient. Accurate identification of the user is critical to maintaining the integrity of the health record and its privacy protection (Halamka et al., 2008).

There are also some challenges regarding the physical data. If the information is imported (i.e. copied) from the EHR into the PHR, how frequently does the import occur? How can two records be synchronized? What happens if the main record changes, but it is not synchronized, and the patient needs to access the information in the mean time? (Lang, 2009). Another technical challenge which can result in a low adoption is usability. Low PHR adoption may be due to failure in designing systems that meet users' needs and that are easy to use (Kahn et al., 2009). Systems with low usability have limited value to the end user and would result in a low rate of adoption.

2.6 PHRs and Chronic Diseases

Patient engagement in chronic disease management can result in more adherence (Pagliari et al., 2007) and eventually higher quality care. PHRs enable patients to track their disease in tandem with their care givers resulting in earlier intervention in case of need (Tang et al., 2006). A recent survey (California Healthcare Foundation, 2010) showed that patients with chronic diseases are more likely to experience positive effects of having their information accessible online. It has been argued that patients with chronic diseases (including cancer patients) can play an important role in the adoption of PHRs (Leonard, Casselman, & Wiljer, 2008). A recent study (Zhou et al., 2010) showed that using a communication channel between patients and physicians within a two-month period was associated with a statistically significant improvement in effectiveness of care.

PHRs can also decrease the potentially high costs of chronic disease (Tang et al., 2006). For instance, online communication between caregivers and patients with chronic

conditions will eventually decrease healthcare costs due to improved treatment monitoring and more efficient use of time (Detmer et al., 2008).

2.7 Prostate Cancer

The prostate is a gland of the size of a walnut located in front of the rectum and just below the bladder. It is part of a man's reproductive system. The prostate gland secretes a milky fluid (i.e. semen) that carries sperm. The urethra runs through the centre of the prostate, from the bladder to the penis, letting urine flow out of the body. The anatomical position of the prostate results in prostate disorders that are associated with urinary symptoms (Tanagho & McAninch, 2008).

Prostate cancer is a result of uncontrolled growth of prostate cells. Prostate Cancer grows slowly and may not cause symptoms until it is in an advanced stage. However, once prostate cancer begins to grow more rapidly or it spreads outside the prostate, it is dangerous. Prostate cancer has been related to genetic factors and diet and its incidence increases with age (Tanagho & McAninch, 2008).

Prostate cancer is the most common cancer and the second leading cause of death among North American men (Tanagho & McAninch, 2008). In Canada, an estimated 25,500 men will be diagnosed with prostate cancer and 4,400 will die of it per year (*Canadian cancer statistics*.2009). The mortality rate among prostate cancer patients have been declining since mid-1990. However, because of reductions in death due to cardiovascular disease and the aging of men, prostate cancer will continue to be a major healthcare problem (Chan et al., 2004).

As a result of screening and early detection, the majority of patients are diagnosed with localized prostate cancer. These patients have different treatment choices. One option is

“active surveillance” or “watchful waiting” in which the patient is monitored for disease progression without undergoing any kind of treatment. The other option is active treatment which may include surgery (prostatectomy), or radiation therapy (brachytherapy, external beam radiation) or hormone therapy (Lin, Aaronson, Knight, Carroll, & Dudley, 2009). Currently, the optimal method of treatment is highly controversial and makes treatment decision making very challenging to patients and their physicians (Wong et al., 2000). This controversy, along with a variety of possible side effects that each treatment method might have, makes the decision making phase a highly important phase for prostate cancer patients that require education and counselling. Therefore, the education of prostate cancer patients can be considered a fundamental need in decision making and in the follow-up process.

On the other hand, the desire of prostate cancer patients for information about the disease and treatment issues at different points of their illness is well documented (Feldman-stewart, Brundage, Nickel, & Mackillop, 2001; Templeton & Coates, 2003; Wong et al., 2000). However, the information needs of these patients are different at various points in their disease (Echlin & Rees, 2002). For example, in one study (Echlin & Rees, 2002) the following observation was documented:

One of the study participants, who had undergone surgery for prostate cancer, stressed that the information needs of patients differed before and after surgery. He stated that early after his diagnosis, treatment of the cancer was of paramount importance. However, later on, he required information about the side effects of his treatment. Although this information had been provided during his treatment consultations, he had failed to process this information.

These variations, related to disease stage, may apply to desired features/functionalities and tools as well. While tools like nomograms are very useful in the decision making phase, they may not be necessary for patients who have received their treatment. However, some information such as Prostate Specific Antigen (PSA) is essential for all prostate cancer patients regardless of their illness stage. Prostate cancer patients show a desire for access to their health records too (Pai & Lau, 2005). Moreover, they often desire shared decision making between the patient and doctor and to be an active participant in their healthcare (Wong et al., 2000). During and after treatment, these patients need follow-up to monitor any adverse effects of treatment, to detect recurrences or the progression of disease, and to address psychosocial problems. Information needs, desire for access to health records and educational material demand that there may be patient engagement in healthcare, and follow-up necessities, along with chronic behaviours associated with the management of the disease, make the PHR a perfect fit for the kind of patient-centered care that prostate cancer patients need.

2.8 Involving Patients in PHR Design and Development

Users are involved in system design in different ways. One typical approach is to consult users about their needs and desires during requirements gathering and to test early prototypes using usability testing (Abrams, Maloney-Krichmar, & Preece, 2004). The users' involvement is more likely to be beneficial if incorporated earlier in system design and development as modifications in the early stages of system development are less costly than even minor changes in the final product (Rodriguez et al., 2007).

In addition, evaluation of the product during the development phase and refinement of the system based on users' feedback will result in a system that is easier to use (Pagliari et

al., 2007). Patients' needs and wants are not limited to the content and type of information included in a PHR. They also include the way the information is delivered, the type of features/functionality to be included in the PHR, and even minor specifications in user interface design such as fonts and colours (Rodriguez et al., 2007). Another form of involving users in the design and development process is to use *participatory design* approach which originated in Scandinavia and have gained popularity in recent years. The level of involvement of users in the design process is so high as if they are co-designers. In participatory design, users participate in design meetings and represent their own needs and priorities (Abrams et al., 2004).

CHAPTER 3: Study Purpose and Research Questions

Despite recommendations that patients be involved in the design and development of consumer health information systems including PHRs, currently PHRs are not typically developed with a user-centered design approach (Rodriguez et al., 2007). Given the fact that patients are the major users of PHRs and harnessing the value of PHRs depends on widespread adoption by patients, it is very important to engage patients throughout the design and development process to ensure that the final product meets their needs and is usable enough to be adopted by them. This has been particularly recommended for patients with chronic diseases (Leonard et al., 2008). Moreover, the patient-centered nature of PHRs makes them great candidates for a user-centered design approach.

The main purpose of this study is to determine the information needs and desired functionalities of PHRs for prostate cancer patients in different phases of their care and to design, develop, and test an early prototype of a PHR system based on these requirements. The study will target specific categories of prostate cancer patients, namely those who are deciding on primary treatment for localized prostate cancer (PC), and those who have completed or are receiving treatment. In this regard, the research questions are:

1. What are the information needs and concerns of PC patients in these specific phases of care (i.e. in decision making phase, and during treatment/follow-up)?
2. What are desired functions that PC patients would like in their PHRs in these specific phases of care (i.e. in the decision making phase and during treatment/follow-up)?
3. Can information about PC patients' information needs be used to improve the design and implementation of a prototype PHR for PC patients?

It should be mentioned that the type of information that a patient might need is not limited to educational content. Patients' may wish to obtain more information about their health record, navigation through the healthcare system, resources, related news, and other patients' stories. They may even desire to find information about research related to their condition such as clinical trials in which they might be interested in participating . PHR data has been used to match patients with clinical trials (Allison, 2009; Atkinson et al., 2007). Patients' information needs may also affect the functionalities implemented in a PHR. For instance, especially in the case of chronic diseases, other patients' experience may be a source of information (Halamka et al., 2008). Therefore, a PHR may need to support some type of peer to peer communication, such as discussion forums or chat rooms. Selection of the most appropriate tool depends on available resources such as budget, technical capabilities of the developers, cost-effectiveness based on the complexity of the tool, and the number of users.

CHAPTER 4: Conceptual Framework

4.1 User-centered Design

User-centered design (UCD), also known as human-centered design, is a design approach that involves end-users in the overall development of a system to ensure that the final product meets users' needs and preferences and is easy to use (Abrams et al., 2004). User-centered design is not a replacement for software development methods. User-centered design can be used as a framework that ensures that user requirements are taken into consideration in the system design process and the final product will be a usable system. According to ISO 13407 (ISO 13407: Human centred design processes for interactive systems.2010), user-centered approaches include four design activities that need to be started in the early phases of a project. These are to:

- Understand and specify the context of use
- Specify the user and organizational requirements
- Produce design solutions
- Evaluate designs against requirements

The iterative nature of these activities is illustrated in Figure 4.1. The process involves iterating until the objectives are satisfied.

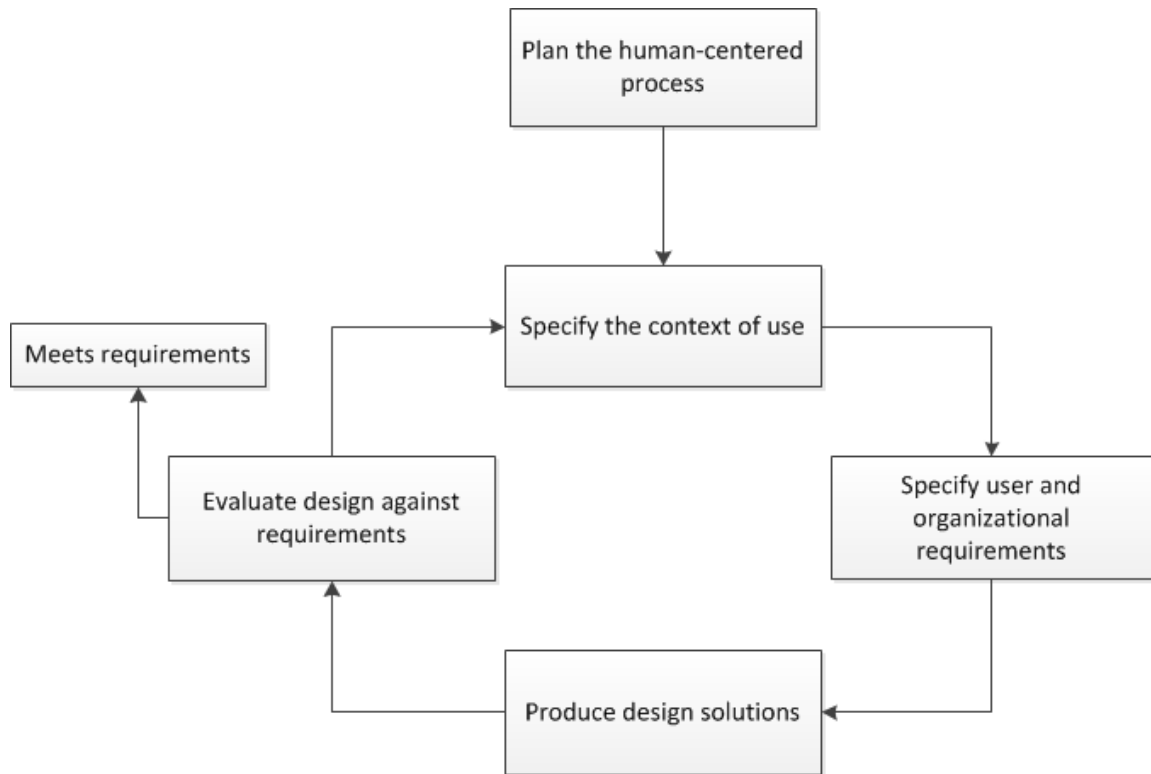


Figure 4.1: User-centered Design Activities (From ISO 13407)

Two important activities that clearly include user involvement are requirements gathering and evaluation. There are a variety of methods that can be used for each of the activities in the user-centered design. However, some of these methods are more commonly used in the industry compared to others (Mao, Vredenburg, Smith, & Carey, 2005). It seems that cost-benefit trade-offs play an important role in adoption of the user-centered design methods. For example, while methods such as field studies are considered highly important, they are infrequently used due to cost issues (Mao et al., 2005). On the other hand, heuristic evaluations are widely used because of their simplicity and low cost (Mao et al., 2005). As a method for requirements gathering, user interviews are considered highly valuable (Mao et al., 2005). The one-to-one nature of the interview provides the opportunity to address the informant's individual concerns. Moreover, mistakes and misunderstandings can be quickly identified and resolved (Interviews.2010).

As for the evaluation activity in a user-centered approach, usability testing is not only considered important by experts, but also frequently practiced (Mao et al., 2005).

Usability testing refers to a method of usability evaluation which involves subjects who are *representative* of the general population of users to perform *representative* tasks while their interaction with the information system is being recorded for later analysis (Kushniruk & Patel, 2004).

This study will use a user-centered approach toward the design and development of the personal health record. As a method of information gathering from potential users of the PHR, interviews will be used to elicit users' informational needs and desired requirements. Also, the designed system will be evaluated using usability testing methods to see if the system is aligned with users' needs gathered during the requirements gathering phase.

CHAPTER 5: Methods

This study used a qualitative research approach to explore requirements for designing and developing a PHR. Semi-structured interviews and questionnaires were used to ask open-ended and close-ended questions from prostate cancer patients about their information needs and concerns regarding their disease. A qualitative approach was also used to analyse the results of usability testing of a prototype PHR.

5.1 Participants

In quantitative research, samples need to be representative of the population under the study and of sufficient size to ensure generalizability of the results (Jackson & Verberg, 2007). In qualitative research the sample is not based on the statistical probability of selection, instead informants who have knowledge of a particular area are asked to participate (Coyne, 1997). Qualitative studies do not need large sample sizes and randomization because their goal is not to generalize the results of the study but rather to acquire an in-depth description of a phenomenon (Jackson & Verberg, 2007). This study will use a purposeful sample. According to Patton (Patton, 1990):

“The logic and power of purposeful sampling lies in selecting information-rich subjects for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose for the research”.

Another important concept related to sampling and sample size in qualitative research is saturation. Saturation refers to a situation in which participants' descriptions of the topic

under the study become repetitive and do not add anything new to the information that has already been gathered. Instead, new descriptions only confirm what has already been found from previous informants' input. When saturation is reached, it means that the data collection is completed (Jackson & Verberg, 2007). Therefore, in qualitative research, the sample size is not usually determined in advance. Instead, the recruitment of participants will continue until saturation is reached. The number of participants in a study to reach saturation depends on multiple factors (Morse, 2000). For instance, the broader the scope of the study, the more input data will be required to reach saturation. Similarly, if the topic being studied is clear and the interviews can easily capture enough information from participants then fewer interviewees are required (Morse, 2000). Qualitative studies do not need large numbers of samples. In fact, it has been argued that saturation may occur after twelve interviews with basic themes being present in the first six interviews (Guest, Bunce, & Johnson, 2006).

There were two groups of participants in this study: 1) Decision making group and 2) Post-decision making group. The first group included patients who had not started their treatment yet. Those patients were in the process of making a decision about their method of treatment. The second group consisted of patients who were receiving treatment or who were being followed-up after they had been treated.

Participant recruitment occurred at The Prostate Centre (TPC). A nurse staff at TPC explained the purpose of the study to the participants to help them understand the context. The participants then were asked if they were interested in participating in the study. They were asked to read and sign a consent form (see Appendix 6: Informed Consent (Phase 1)).

A total of 19 participants were recruited for the interview phase of the study (phase 1); 8 for the decision making and 11 for the post-decision making.

For the usability testing phase (phase 3), a sample of 4 participants were selected from 19 participants who participated in the interview phase (based on availability). The participants in both phases were selected based on a purposeful convenience sampling approach. Therefore, the following inclusion and exclusion criteria was used:

Inclusion Criteria (all of the following):

- Adult Male
- Histological diagnosis of adenocarcinoma of the prostate gland
- Has visited the TPC or been contacted by TPC
- Fluent in written and spoken English language
- Able to provide informed signed consent (Appendix 6: Informed Consent (Phase 1))
- Any of the following:
 - Has not started definitive treatment for localized prostate cancer
 - Is receiving some type of treatment
 - Is under follow-up; i.e. has completed a course of some type of treatment and is followed by a healthcare provider (e.g. by regular measurement of PSA level)

5.2 Materials and Setting

The study took place in The Prostate Centre (TPC) in Victoria, BC. The Prostate Centre is a community-based health organization that serves men with prostate cancer by focusing on offering up-to-date information and educational material, patient navigation

through the healthcare system, counselling, survivorship, and a follow-up program. Many prostate cancer patients are referred to TPC after they are initially diagnosed with prostate cancer. As previously mentioned, there are many different treatment options for prostate cancer; therefore, patient education and counselling play an important role in decision making process. Consequently, one of the key roles of TPC is to help meet the health information needs of patients. However, information tends to be generalized and not patient-specific, usually in the form of pamphlets, videos, etc. In addition, TPC provides assistance with follow-up care after patients have completed treatment for their cancer and have been discharged back to the community by a health organization like BC Cancer Agency (BCCA). One limitation with this follow-up service is the lack of availability of up-to-date patient records at TPC from BCCA, urologist, or family doctor's offices. Also, some prostate cancer patients who receive hormone therapy do not adhere properly to the treatment schedule and improved adherence and compliance is highly desirable. A PHR may be a potential tool to enable TPC to better follow those patients.

The first PHR prototype was developed before starting the interviews. That prototype was a web-based application developed using Microsoft Active Server Pages (ASP) technology. The backend database was SQL server 2008. The system contains three types of users: 1) Patients, 2) Caregivers, and 3) External users. Caregivers are in fact TPC staff who help patients with counselling and follow-up issues. External users are users that are invited by patients to view their information. These can be family members or even a patient's family doctor. All types of users have to log into the system before they can use it. Usernames and passwords, along with other basic information required for

administration of the system, are managed via a secure password-protected administration section. The first prototype included features such as access to relevant articles, communication between patients and caregivers, and tools for monitoring important factors such as Prostate Specific Antigen (PSA) levels. Figure 5.1 shows a mockup of the main page of the prototype where patients can see important information such as alerts and reminders as well as a summary of Lab Tests and Treatments. Also, some patient-tailored news is displayed. Displaying important information such as alerts on the main page makes it available to the patient as soon as the patient logs into the PHR. Figure 5.2 shows a screen shot of one of the pages of the first prototype where patients can track their PSA levels. The graph format helps the patient to better understand PSA changes.

The screenshot shows the homepage of the Prostate Centre Personal Health Record (PHR) first prototype. The page is titled "The Prostate Centre Personal Health Record" and includes a navigation menu, alerts/reminders, a care plan table, and news boxes.

Main Menu:

- Home
- My Profile
- Tools
- Communications (1)
- Appointments (1)
- Educational Material
- Research
- Diary
- Public Diaries
- My External Viewers

ALERTS/Reminder:

- Your PSA level shows an increasing trend. Please browse to [My PSA Levels](#) section for more information.
- You have UNREAD communications. Please browse to [Communications](#) section to view your communications.
- You have UPCOMING appointments. Please browse to [Appointments](#) section to view your upcoming appointments.

Your Care Plan at a Glance for Follow Up after Prostate Brachytherapy

	June 09	Dec 09	June 10	Dec 10	June 11	Dec 11	June 12	De
Treatments	Brachytherapy	Hormone Therapy	Hormone Therapy	Hormone Therapy	Hormone Therapy	Hormone Therapy	Hormone Therapy	Ho
Lab Tests	PSA (0.91) Testosterone	PSA (0.51) Testosterone	PSA (0.93) Testosterone	PSA Testosterone	PSA Testosterone	PSA Testosterone	PSA Testosterone	PS
Questionnaires	IPSS SHIM	IPSS SHIM	IPSS SHIM	IPSS SHIM	IPSS SHIM	IPSS SHIM	IPSS SHIM	IP
Doctor Visits		Dr. Pai		Dr. Pai		Dr. Pai		Dr

Prostate Cancer News:

- Click on each headline to see more details.
- 26 Jul 2010: Can ring finger predict prostate cancer?
- 26 Jul 2010: Oxford BioMedica's TroVax^A Gets FDA Approval For Phase II Study In Prostate Cancer

Figure 5.1: Screen shot of the homepage of the PHR first prototype showing alerts/reminders, care plan at a glance, and news boxes



Figure 5.2: Screen shot of the PHR first prototype showing PSA monitoring tool

The prototype PHR contained some added functionalities to a typical PHR functionality (i.e. access to medical record). Those added functionalities included a patient-nurse communication tool, a section for patients to record their diary, and relevant news to name a few.

Two survey questionnaires were used to gather information about computer/Internet/cell phone usage (appendix 1) and the demographic information (appendix 2) of the participants. The computer/Internet/cell phone survey questionnaire is adapted from a previous study conducted in BC Cancer Agency (Pai & Lau, 2005). The demographic information was later used to describe the sample under study. Also, an interview guide (appendix 3) was used to guide the interviews. The interview guide was the same for all interviewees and had only a few extra questions for interviewing the post-decision group.

The interview guide was developed based on the existing knowledge about the information needs of prostate cancer patients and potential functionalities of PHRs. A free open source voice recorder software, Audacity, was used to record the interviews. The software was installed on a laptop. A microphone was attached to the laptop to capture the participants' verbalizations. For the usability testing, Hypercam screen recording software was used to capture the screen and think aloud verbalizations during user interaction with the system.

5.3 Procedure

The study was conducted in three phases. In phase 1, participants were interviewed about their information needs and desired functions to be implemented into the system. In phase 2, the preliminary prototype was modified based on the results of phase 1. Phase 3 consisted of the usability testing of the modified prototype.

5.3.1 Phase 1

Phase 1 included one-hour interview sessions with participants in The Prostate Centre. At the beginning of each session, after an initial greeting, a brief overview of the study was provided to the patient and the parts of the interview session were explained. Each interview session had three parts. In the first part, the participant was asked to complete a computer/Internet/cell phone survey questionnaire (Appendix 1). The computer/Internet/cell phone questionnaire served two goals. First, it was a way to find out if individuals used a computer and the Internet at all. Second, it gathered some data about the level of computer literacy and use of computer, Internet and cell phone technology by the participants. These data could be used to see whether more computer literate participants could provide more useful feedback in interview or usability testing

phases. In the second part, one-on-one semi-structured interviews with participants were conducted using an interview guide (Appendix 3). The interviews were audio-recorded for further analysis. Following the interview, participants were asked to complete a demographic questionnaire as the third part of the session. The information from demographic questionnaire was later used to identify the demographic distribution of participants and whether demographic factors make any difference in terms of information needs.

5.3.2 Phase 2

The audio recorded interviews from Phase 1 were transcribed and analyzed using content analysis (as described in the Analysis section below) in order to identify the information needs of participants in the decision making group and the post-decision making group. Based on user information needs, modifications to the first prototype were made.

5.3.3 Phase 3

Phase 3 included usability testing of the modified prototype. The usability testing session was 30 minutes in length and was followed by a brief interview with a few questions. At the beginning of each testing session, the purpose of usability testing and the concept of think aloud technique was explained to participants in lay language. Each participant then was asked to complete a number of tasks (Appendix 4: Usability testing tasks (Phase 3)). The screen as well as participant's think aloud was recorded using the software Hypercam. After finishing tasks, a short interview was conducted using a questionnaire (Appendix 5: Post Usability Testing Interview (Phase 3)) to gather some complementary information.

5.3.4 Confidentiality

A two-digit number was assigned to each participant. All paper records (computer/Internet/cell phone and demographic forms) had this number on them instead of the participant's real name. All digital files were named by a combination of this number and the present date. Also, all unique and identifying data were stripped from the transcripts.

5.4 Data Analysis

5.4.1 Phase 1 (Interviews)

Content analysis was used to explore the informational needs and desired functionalities of prostate cancer patients. Content analysis was initially a quantitative approach with categorized data being analyzed using quantitative statistics (Morgan, 1993). But, a qualitative approach to content analysis has become more popular recently (Kondracki, Wellman, & Amundson, 2002). Qualitative content analysis is among the research methods used to analyze text data. Compared to other qualitative research methods such as grounded theory, whose main goal is to develop a theory (Jackson & Verberg, 2007), or ethnography, which aims to collect data about human behaviour at a cultural level (Jackson & Verberg, 2007), content analysis is focused on finding themes and ideas arising from the data (Hsieh & Shannon, 2005). Text data might have been acquired from different sources including open-ended surveys, transcripts of interviews, focus groups, or print media such as articles and books (Kondracki et al., 2002). Hsieh and Shannon (2005) define qualitative content analysis as:

“A research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns”.

Categories are the core concept in content analysis. A category is a group of content that shares a commonality (Krippendorff, 2012). Based on the way categories are developed and the text that is coded into them, three different approaches to qualitative content analysis have been identified by researchers (Hsieh & Shannon, 2005). In *conventional* content analysis, there is a lack of existing literature findings or theory about a phenomenon. In this approach, researchers avoid using predetermined categories. Instead, categories and their names emerge from the data. The advantage of the conventional approach to the content analysis is that interviewees are not biased with predetermined categories (Hsieh & Shannon, 2005). In *directed* content analysis, on the other hand, prior research or theory about a phenomenon exists and the goal of content analysis is to validate the existing evidence or extend the theory (Hsieh & Shannon, 2005). In this approach, an initial categorization exists based on prior research or existing theory and data will be coded into these predetermined categories. While the main advantage of a directed approach to content analysis is that existing findings and/or theory can be supported and extended, an inherent bias is associated with this approach (Hsieh & Shannon, 2005). In a *summative* approach to content analysis, certain words or content will be identified and counted in the text. Although at first glance summative approaches seem quantitative in nature, summative approaches may go beyond numbers and find relationships between different items and underlying meaning of content (Hsieh & Shannon, 2005).

A directed approach to content analysis was taken toward coding the interview data from the first phase of this study. A pre-determined set of categories was developed based on what was available in the literature in regards to personal health records functionalities and prostate cancer patients' information needs. Those categories were also reflected in the interview guide.

Audio-recorded interviews were then transcribed verbatim into Microsoft Word®.

Transcribed interviews were analyzed using a directed content analysis approach. The predetermined coding schema that was used as a preliminary basis for potential categories is in Table 6.5. All transcripts from the interviews were examined for themes and ideas using this predetermined coding scheme

In a directed approach to content analysis, coding of the data can be done in two ways depending on the researcher's goal (Hsieh & Shannon, 2005). If the objective is to identify and categorize all instances of a particular phenomenon, then while reading all of the transcripts, the researcher highlights all parts of the text that on first impression appeared to fall into a particular category. As the next step, the researcher codes all the highlighted parts using the predetermined coding schema. Parts of the transcript that could not be categorized using the present schema are given a new code. In the second coding method, the researcher will code the script as he reads it. Data that cannot be coded will be analyzed later to determine whether they represent a new category or a subcategory of an existing code. This strategy usually is used when the researcher believes that the predetermined coding schema will not prevent him from identification of themes embedded in the script (Hsieh & Shannon, 2005).

This study used the second strategy for coding of the transcribed interviews as the categories seemed very clear at the level of main categories based on the researcher experience and common sense. However, the categorized data was analyzed further to determine emerging themes.

5.4.2 Phase 3 (Usability Testing)

There are a variety of approaches that can be used to analyze data collected in usability testing (video and audio). These approaches can range from informal reviews of the data to formal methods of analysis using precise coding schemes (Kushniruk & Patel, 2004; Kushniruk & Borycki, 2006). In this study, the video file along with participant's think aloud of usability testing sessions were informally reviewed.

CHAPTER 6: Study Findings

The following study findings are reported in this chapter:

- Results of interviews with patients (phase 1)
- Modifications to the prototype (phase 2)
- Results of usability testing (phase 3)

6.1 Phase 1: Interviews

6.1.1 Introduction

This section reports on the results of interviews with patients. First, the characteristics of the participants including demographic characteristics, computer and internet literacy, and the type of treatment the patients received are reported on. Then navigation of prostate cancer patients throughout the healthcare system is described. The last two sections of the findings report on results derived from the analysis of the interviews. These results are presented as Coded Categories and Emergent Themes.

6.1.2 Characteristics of Participants

6.1.2.1 Demographics

Nineteen patients participated in the study; 8 (42%) in decision making group and 11(58%) in post-decision making group. Participants were between 51 and 88 years of age with an average age of 66.8 years. The average age was 71.1 and 63.7 years in the decision making and post-decision making group respectively. Fourteen (74%) participants were married and 5 (26%) had other marital statuses (separated/divorced, single, widowed). Slightly more than half (53%) had a university degree with the rest of participants having high school diploma or college education.

The average number of years since diagnosis was 1.13 in the decision making group and 4.35 in the post-decision making group. One patient in the post-decision making group had been diagnosed for 22 years. The average in the post-decision group excluding this patient was 2.5 years.

Table 6.1 shows participants' demographic characteristics in more detail.

Table 6.1: Demographic characteristics of participants

Characteristics	Decision Making Group (8)	Post-Decision Making (11)	Total (19)
	Frequency (%)	Frequency (%)	Frequency (%)
Age			
50-59	0 (0)	4 (36)	4 (21)
60-69	4 (44)	4 (36)	8 (42)
=> 70	4 (56)	3 (28)	7 (37)
Marital Status			
Married	5 (63)	9 (82)	14 (74)
Other	3 (37)	2 (18)	5 (26)
Retired	8 (100)	5 (45)	13 (68)
Education			
University Degree	3 (38)	7 (64)	10 (53)
Other	5 (62)	4 (36)	9 (47)
Years from Diagnosis			
< 1 Y	5 (63)	3 (33)	8 (44)
1-3 Y	2 (25)	3 (33)	5 (28)
3-10 Y	1 (12)	3 (33)	4 (22)
> 10 Y	0 (0)	1 (1)	1 (6) *

* Years from diagnosis was unknown for one patient in the post-decision making group

6.1.2.2 Computer/Internet Literacy

A questionnaire was given to the patients in order to gather information about the level of computer and internet literacy. This questionnaire was administered to find how and how frequently participants use a computer and the Internet and other related devices such as cell phones.

Fourteen (74%) participants mentioned that they used computer for more than 5 hours per week with about half of the participants (48%) using the computer and the Internet more than 10 hours per week. All participants had a computer and internet connection at home. The most common use of the Internet among participants was email (100%) followed by finding information (95%) and word processing (84%). Less than 50% of participants used the Internet for purposes such as Social Networking, Online Banking, and Calendar & Reminders. Table 6.2 provides more detailed information about computer and internet use of participants.

Table 6.2: Computer and Internet use among participants

Characteristics	Frequency (%)
Computer use per week	
< 1 h	1 (5)
1-5 h	4 (21)
5-10 h	5 (26)
> 10 h	9 (48)
Internet use per week	
< 1 h	2 (10)
1-5 h	4 (21)
5-10 h	4 (21)
> 10 h	9 (48)
Computer at home	19 (100)
Internet access at home	19 (100)
Type of connection	
Dial-up	0 (0)
ADSL	2 (11)
Broadband	13 (68)

Characteristics	Frequency (%)
	Don't Know 4 (21)
Internet uses	
	Email 19 (100)
	Finding Information 18 (95)
	Word Processing 16 (84)
	Picture Archiving 13 (68)
	Travel 12 (63)
	Online Banking 9 (48)
	Social Networking 8 (42)
	Online Shopping 8 (42)
	Calendar & Reminders 7 (37)
	Entertainment 7 (37)
	Graphics 6 (32)

Participants were also asked about their cell phone use. Only 12 (63%) participants mentioned having a cell phone and not all of them used their cell phone on a daily basis (67%). Only 50% of participants with a cell phone had internet connection on their cell phone and only one-fourth used their phone to send and receive text messages. Table 6.3 shows more detail about the participants' cell phone use.

Table 6.3: Cell phone use of participants

Characteristics	Frequency (%)
Have cell phone	12(63)
Use cell phone daily	8 of 12 (67)
Always carry cell phone	9 of 12 (75)
Text messaging	3 of 12 (25)
Internet on cell phone	5 of 12 (50)

6.1.2.3 Type of Treatment

As mentioned before, 11 out of 19 patients belonged to the post-decision making group.

These patients had already received treatment for their prostate cancer. Table 6.4

summarizes the type of treatments that these patients have received.

Table 6.4: Frequency of treatment methods

Type of Treatment	Frequency
Surgery	5
Brachytherapy	2
Radiation	1
Hormone Therapy	2
Surgery/Radiation/Hormone Therapy*	1
Total	11

* The patient had received surgery, radiation, and hormone therapy over 21 years

6.1.3 Navigation of Prostate Cancer Patient through Healthcare System

The diagnosis of prostate cancer usually starts with an observation of an elevated screening Prostate Specific Antigen (PSA) level or abnormal prostate examination during a routine primary care visit. The patient is then referred by a family physician to a

urologist for consultation. The diagnosis of prostate cancer will ultimately be confirmed by trans-rectal ultrasound guided biopsies showing cancer cells in the prostate gland tissue. Upon confirmation of a diagnosis, the urologist explains different aspects of the disease and treatment options to the patient. As discussed in chapter 1, educating patients and providing them with as much information as possible plays an important role in this key decision making process. On Vancouver Island, many patients are referred to the Prostate Centre in Victoria where they are provided with more educational material and counselling that can help them make a more informed decision. Patients are referred to oncologists at the BC Cancer Agency – Vancouver Island Centre to discuss non-surgical treatment options. Upon making a decision, depending on the method of treatment, patients will be treated and followed up by different healthcare providers. Patients undergoing surgery will be treated and followed up by an urologist. On the other hand, patients who choose non-surgical treatments such as radiation therapy will usually be managed by an oncologist. Patients treated with radiation therapy are often discharged back to the community physicians for subsequent follow-up care. PSA is a very important tumor marker that helps determine the presence of cancer after treatment (Tanagho & McAninch, 2008). Both surgical and non-surgical patients will have regular PSA tests that can be done in private laboratories such as LifeLabs, in the hospital outpatient blood test area or at BC Cancer Agency.

6.1.4 Coded Categories

As mentioned in Chapter 4, transcribed interviews were analyzed using a directed approach to content analysis. This approach required a pre-determined set of categories to be used for coding the interview transcripts. Table 6.5 shows the categories that were

used as the coding scheme. The coding scheme consists of categories and sub-categories depending on the granularity of the category. Some categories such as “Decision Making” have no sub-categories. On the other hand, categories such as “Information Needs” and “Access to Medical Records” have more sub-categories as they are directly related to research questions and have more questions related to them. The coding scheme also includes a description of when the code is used to code a part of interview transcripts. The coding scheme also contains some example quotes from participants. Interview transcripts were manually analyzed and coded by the author using the pre-determined coding scheme shown in Table 6.5.

Table 6.5: Pre-determined categories

Category	Subcategory	Coded when the participant referred to ...	Example Quote
DECISION MAKING		Reasons and processes that led to participant’s treatment decision (post-treatment patients)	<i>I chose the brachytherapy because it was the least invasive.</i>
NAVIGATION		Navigation through the healthcare system; transition between different parties i.e. Family Physician, Urologist, BC Cancer Agency, Oncologist, TPC, ...	<i>I had my bone scan and a chest x-ray within a couple of weeks after my diagnosis and it was just the steps that they told me would be taking place up until my surgery. I had a preadmission in the hospital. They showed me where I would be going and all of that kind of stuff.</i>
INFORMATION NEEDS		Information needed at the time of interview	

Category	Subcategory	Coded when the participant referred to ...	Example Quote
	TYPE OF INFORMATION	The subject of information e.g. treatment complications, survival rate of different methods, diets, vitamins, ...	<i>It would have been nice for me to have a kit before I go into surgery, organized alphabetically, this is day 1, day 2, expect this, after two weeks expect this.</i>
	SOURCE(S) OF INFORMATION	Different sources of information e.g. doctor, support group, ...	<i>Well, internet and also personal interviews with individuals who have either undertaken the treatment or are going to undertake the treatment</i>
	INTERNET	Using the Internet as a source to information	<i>I went on the internet at the same time and really started to do research.</i>
	PERSONALIZED	Whether he is interested in general information about PC or just information tailored to his particular situation	<i>I would say you want to sort of bifurcate or trifurcate after treatment, so I do not have to look at a bunch of stuff that is related to someone who has had surgery.</i>
TPC SERVICES		Patient's opinion about TPC services and whether it could have provided services that has not already provided	<i>Actually I found The Prostate Centre extremely helpful.</i>
ACCESS TO MEDICAL RECORDS		Desire to get access to personal medical records	
	TYPE OF INFORMATION	Type of information he would like to get access to e.g. laboratory results, physician notes, ...	<i>Notes would be useful because I could review what we were doing and what the doctor thought, you know, how things are going and that sort of thing.</i>
	FREQUENCY	How frequently he will check his medical records	<i>Probably after a visit I would look and may be review, but probably not more than, well I have these visits now every 6 months, so not very often.</i>

Category	Subcategory	Coded when the participant referred to ...	Example Quote
	PREFERRED METHOD OF ACCESS	The rout access to medical records, e.g. hard copy, online, ...	<i>I would like to have online, secure capability.</i>
	CONCERNS	Concerns he might have regarding access to his health records, e.g. privacy issues, difficulty in understanding the information, ...	<i>I worry about that information being, no matter the safeguards electronically, that information then becomes one more way, which can be hacked and found.</i>
COMMUNICATION WITH HEALTHCARE PROVIDER			
	METHOD OF COMMUNICATION	Method used to communicate to healthcare provider in case he has a question	<i>For diagnostic information I'm not keen on an email. That's a bit too impersonal for me. You know, I've got to be right there. I've got to shake someone's hand.</i>
	EMAIL	Whether he uses email as a communication method	<i>I would have liked to have felt I could have sent an email to either the urologist or the oncologist at some time and just ask them a quick question rather than making an appointment and on and on.</i>
	FREQUENCY	Whether he thinks if patients should be in regular contact with their healthcare provider	<i>Certainly before the operation I would say yes because there are a lot of questions and a lot of anxiety.</i>
SELF MONITORING			
		Tracking PSA levels as well as other health information	<i>Well, for the PSA obviously to make sure there's not a rise ... To monitor it, and the same with my cholesterol levels</i>
P2P COMMUNICATION & SUPPORT			

Category	Subcategory	Coded when the participant referred to ...	Example Quote
	TPC SUPPORT GROUP	Attending/Not attending TPC support group	<i>I have a really good circle of friends and we also attend a church in town with another large circle of friends and acquaintances there and I certainly have never felt alone.</i>
	SHARING SELF EXPERIENCE	Willingness to share his experience with other patients and if he already does so	<i>I just dropped by, a couple weeks ago, just to say hello basically and say, "Look. If you need me to talk with anyone at my age to go forward before the operation or if he's trying to decide, I can at least give him my opinion.</i>
	ONLINE METHODS	Online methods of communication such as forums, discussion boards, chat lines, social networking, ...	<i>The fact is many people, especially with something like prostate cancer, are reluctant to speak about it in any depth; however, when they've got a computer screen in front of them I think that would be a much less anxious venue for them.</i>

6.1.4.1 Decision Making

Participants in the post decision making group were asked about their process of decision making and the factors that influenced their decisions on the method of treatment.

Typically, after some discussions with the urologist, in most cases patients were encouraged to visit the Prostate Centre to receive more information that would help them with their decision. The Prostate Centre provides patients with educational material in different formats such as pamphlets, books, and videos. Also, patients had the chance to meet with prostate cancer survivors that are volunteers at the Prostate Centre. In addition,

a nurse with experience in cancer care was available to answer patients' questions and help them in the process of decision making. In most cases, patients did a lot of reading using different sources of information. Almost all patients searched the Internet for information. Some patients studied research results related to different treatment methods in detail.

Patients talked about factors that influenced their decision making. Long term survival and success rate played a role in decision making for some patients in post decision making group. Age was another factor for two other patients choosing surgery as their method of treatment (one patient was 47 and the other was 50 at the time of diagnosis).

The following quote indicates the role of age in decision making:

I felt at my age, which is just 50, I thought it gave me my best chance of eliminating the disease and living as close to a normal life again afterwards as I could. (Subject 13B, Line 7)

Three patients mentioned factors such as less invasiveness, better and faster recovery, less hospitalization, and the impact of the treatment method on their work as important factors influencing their decision making. The importance of less hospitalization for work reasons is expressed in the following quote:

I chose the brachytherapy because it was the least invasive. I work for myself, so if I had a surgery, it would have been 12 to 16 weeks that I would have been deactivated, couldn't work, whereas with brachytherapy, I could have gone back to work the next week and I did. (Subject 14B, Line 15)

Patients' personalities also has an impact on their decision. One patient didn't choose active surveillance simply because he didn't like the uncertainty accompanying this method. The following quote refers to this issue:

The discussion was that I could wait and see if it got any worse. To me, that would be a big dark cloud hanging over my head. I have cancer. I need to get rid of it. (Subject 27B, Line 86)

For one patient, the relationship with the healthcare provider was a factor in deciding the method of treatment as the following quote refers to:

I liked the confidence that the oncologist had in his method, and we just clicked, so by the end of the meeting I knew that was the road I was going to take. (Subject 17B, Line 28)

Yet, despite all the information that was provided to patients, patients still looked for their own information. Two patients mentioned that decision making was hard for them as there were too many options and they required more coaching as the following quote shows:

I think in some ways it would be better to have a much more, shall we say positive recommendation from the doctor. At the moment you're given too many options. You're given the information, but quite often when people first got prostate cancer, they're sort of, "Oh, is this going to be a death

sentence?” It’s very hard to get your head around a lot of, “Is option A, B, C, D or E the one for me?” (Subject 25B, Line 64)

Factors influencing patient decision can be summarized in the following table:

Table 6.6: Factors influencing decision making

Factors	n
Long Term Prognosis/Chance of Success	3
Age	2
Less Hospitalization/Faster Back to Work	2
Less Invasiveness/Better Recovery	1
Patient Personality	1
Relationship with healthcare provider	1
TOTAL	10

6.1.4.2 Navigation through the Healthcare System

Navigation through the healthcare system mainly referred to the transition of patients between different parties such as the family physician, urologist, oncologist, BC Cancer Agency, etc. Participants were asked if they had any concerns or experienced any problems related to their navigation through the healthcare system and if they knew which healthcare provider or service to contact and how to contact them if they had questions. Thirteen out of 14 patients (93%) mentioned that they experienced a smooth and timely process of moving through healthcare system and all the steps of their journey were clear to them. It seems that the current procedures in place are well established and patients are well aware of their transition process.

6.1.4.3 Information Needs

Participants were asked about their information needs at the very stage of their disease they were at the time of interview. They also were asked about resources they use to gather information including the Internet. Also, participants were asked whether they prefer to be provided with only the information specifically related to their condition or general information about prostate cancer as well.

6.1.4.3.1 Type of Information

Participants indicated a total of 41 different items that they considered information needs. Information items noted by interviewees ranged from items related to the decision making phase of the disease such as the pros and cons of different methods of treatment to items related to the follow-up phase after treatment. These items were categorized into 16 separate topics. Post-treatment participants talked about their information needs during decision making and the earlier stages of their disease as well as their needs at the time of the interview. Participants identified topics of interest that included:

- **What to expect before, during and after various procedures such as biopsy, surgery and catheter insertion/removal** (mentioned 4 times). This type of information was mentioned exclusively by participants in the post-treatment group. The following quote by one participant illustrates this:

It would have been nice for me to have a kit before I go into surgery, organized alphabetically, this is day 1, day 2, expect this, after two weeks expect this, like a little kit that you carry with you. That would be a great idea for anybody that goes through a prostatectomy because it is major surgery.

(Subject 20B, Line 444)

- **Side effects of various methods of treatment and how to manage them e.g. sexual dysfunction, incontinence, etc.** (mentioned 4 times). All 4 participants who mentioned this type of information were among the post-treatment group.
- **Other patients' stories** (mentioned 4 times). This type of information was mentioned by both pre and post-treatment patients. Pre-treatment patients' interest in other patients' experiences was mostly about the advantages and disadvantages of different treatment methods from a patient's point of view, whereas post-treatment patients were mainly looking for advice about long term follow-up and how other patients manage post-treatment phase. The following quotes illustrate the above mentioned:

I haven't talked to anyone that's ever had this brachytherapy either, you know. Just the information I read. If a person would describe how this ended up and whatnot and whether he was happy with it or whether afterwards he felt, "No, I should have done something else." That would be what I would like to see in there. (Subject 24A, Line 135)

Every now and then you would see a little something on the side where it said John, 55 years old tells his story; he is 1 year postop and what is going on in his life. That is the kind of stuff that I would click on just to read about his story. Once you have read all of the facts and figures written by the doctors, it all becomes rather a blur, but you do want to read about how ordinary guys are doing. (Subject 13B, Line 155)

- **Factors or substances that may have any effect on prostate cancer** (mentioned 4 times). Patients in both pre and post-treatment groups mentioned an interest in information about the role of diet, vitamins, exercise, life style, climate, age, tight clothing (e.g. wearing jeans) and even substances like marijuana on prostate cancer.
- **General information about different methods of treatment** (mentioned 3 times). This category included information about advantages/disadvantages, outcomes and complications of various methods of treatment.
- **New methods of treatment** (mentioned 3 times). Interviewees showed interest in information about newer methods of prostate cancer treatment such as cryosurgery or injecting substances into the tumor.
- **Research results** (mentioned 3 times).
- **Prognosis of various treatment methods** (mentioned 3 times).
- **Long term follow up after treatment** (mentioned 3 times). This topic was explicitly mentioned by patients in the post-treatment group. These patients had questions such as “How long to follow up after treatment?”, “How long to track PSA?”, and “What does a PSA spike mean?” This need is expressed in the following quotes:

What can I expect down the road, like how long am I going to have, you know, say I had a bladder problem or burning or the various things, how long can I expect this to last? How long can I realistically expect to be taking, like Lupron for instance? (Subject 21B, Line 166)

The only thing we are doing right now is taking blood, and so I guess what I would like to know is a little bit of information about, how long do we watch these numbers move along. If we see them not going down, I mean there have been lots of people who have gone through this, what is the sort of typical scenario and should you pay much attention to those numbers before the end of 2 years or not? (Subject 12B, Line 118)

He [the doctor] said it's going to spike, but I should have asked him for more of a definition of what that meant. Is it going to spike to 3 or 0.2 or what? You know, and how fast and for how long? (Subject 17B, Line 392)

- **General information about prostate cancer** (mentioned 2 times). Two patients explicitly noted that they needed information about Gleason Score. One patient indicated the issue in the following quote:

My urologist just kept saying, "You've got this. You've got a Gleason score of 16 and we'll take this away and that" and I go away and think, "Okay." Well, that's fine, but he's talking to me like I know what a Gleason score is. Well, I don't. (Subject 21B, Line 139)

- Participants also mentioned information needs that were grouped under **recurrence, alternative methods of treatment, information about healthcare provider** (each mentioned 2 times) and **Information for younger patients and limitations of various treatment methods** (each mentioned once).

Table 6.7 shows the overall frequency of topics mentioned by both groups of patients.

Table 6.7: Overall frequency of topics mentioned as information needs

Topic	Number of subjects
What to expect before, during and after various procedures	4
Other patients' stories	4
Factors/substances that may affect prostate cancer	4
Side effects of various treatment methods and how to manage them	4
Information about different methods of treatment	3
New methods of treatment	3
Research results	3
Prognosis of various treatment methods	3
Long term follow-up after treatment	3
General information (Gleason score)	2
Recurrence	2
Alternative methods of treatment	2
Information about the healthcare provider	2
Information for younger patients	1
Age limitations of various treatment methods	1

Table 6.8 shows the frequency of topics by patient group and relevance to the phase of disease. As the table shows, topics are categorized based on their relevance to the phase of prostate cancer (pre-treatment vs. post-treatment). While topics like "Information

about different methods of treatment” and “Side effects of various treatment methods and how to manage them” were easy to categorize as topics related to pre-treatment and post-treatment phases respectively, some topics such as “Other patients’ stories” and “Prognosis of various treatment methods” could belong to both phases. The table shows that none of the topics mentioned by pre-treatment patients was categorized as post-treatment; something that was expected. However, in looking at the pre-treatment topics, the researcher observed that patients in the post-treatment group mentioned some pre-treatment topics such as “What to expect before, during and after various procedures” that were not mentioned by pre-treatment group. This could be the result of more experience as a prostate cancer patient and a retrospective view of the pre-treatment phase.

Table 6.8: Frequency of mentioned topics by patient category and phase of disease

Phase	Pre-Treatment	Pre/Post-Treatment	Post-Treatment																																		
Patient																																					
Pre-Treatment	<table border="1"> <thead> <tr> <th>TOPIC</th> <th>#</th> </tr> </thead> <tbody> <tr> <td>Information about different methods of treatment</td> <td>2</td> </tr> <tr> <td>New methods of treatment</td> <td>2</td> </tr> <tr> <td>Alternative methods of treatment</td> <td>1</td> </tr> <tr> <td>Age limitations of various treatment methods</td> <td>1</td> </tr> </tbody> </table>	TOPIC	#	Information about different methods of treatment	2	New methods of treatment	2	Alternative methods of treatment	1	Age limitations of various treatment methods	1	<table border="1"> <thead> <tr> <th>TOPIC</th> <th>#</th> </tr> </thead> <tbody> <tr> <td>Other patients’ stories</td> <td>2</td> </tr> <tr> <td>Factors/substances that may affect prostate cancer</td> <td>2</td> </tr> <tr> <td>Research results</td> <td>2</td> </tr> <tr> <td>Prognosis of various treatment methods</td> <td>1</td> </tr> </tbody> </table>	TOPIC	#	Other patients’ stories	2	Factors/substances that may affect prostate cancer	2	Research results	2	Prognosis of various treatment methods	1															
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Post-Treatment	<table border="1"> <thead> <tr> <th>TOPIC</th> <th>#</th> </tr> </thead> <tbody> <tr> <td>What to expect before, during and after various procedures</td> <td>4</td> </tr> <tr> <td>General information</td> <td>2</td> </tr> <tr> <td>Information about the healthcare provider</td> <td>2</td> </tr> <tr> <td>Information about different methods of treatment</td> <td>1</td> </tr> <tr> <td>Information for younger patients</td> <td>1</td> </tr> <tr> <td>New Methods of treatment</td> <td>1</td> </tr> <tr> <td>Alternative methods of treatment</td> <td>1</td> </tr> </tbody> </table>	TOPIC	#	What to expect before, during and after various procedures	4	General information	2	Information about the healthcare provider	2	Information about different methods of treatment	1	Information for younger patients	1	New Methods of treatment	1	Alternative methods of treatment	1	<table border="1"> <thead> <tr> <th>TOPIC</th> <th>#</th> </tr> </thead> <tbody> <tr> <td>Prognosis of various treatment methods</td> <td>2</td> </tr> <tr> <td>Other patients’ stories</td> <td>2</td> </tr> <tr> <td>Factors/substances that may affect prostate cancer</td> <td>2</td> </tr> <tr> <td>Research results</td> <td>1</td> </tr> </tbody> </table>	TOPIC	#	Prognosis of various treatment methods	2	Other patients’ stories	2	Factors/substances that may affect prostate cancer	2	Research results	1	<table border="1"> <thead> <tr> <th>TOPIC</th> <th>#</th> </tr> </thead> <tbody> <tr> <td>Side effects of various treatment methods and how to manage them</td> <td>4</td> </tr> <tr> <td>Long term follow-up after treatment</td> <td>3</td> </tr> <tr> <td>Recurrence</td> <td>2</td> </tr> </tbody> </table>	TOPIC	#	Side effects of various treatment methods and how to manage them	4	Long term follow-up after treatment	3	Recurrence	2
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Recurrence	2																																				

In summary, while there was some information that was helpful for both groups of patients (i.e. pre and post-treatment) information needs differed. Pre-treatment patients' information needs were mostly focused on treatment options whereas post-treatment patients needed information about long term issues such as managing treatment's side effects and what involves in the follow-up after treatment for prostate cancer. Also, it seems that the extent and variety of information needs decreases as the patient move from the pre-treatment to the post-treatment stage.

6.1.4.3.2 Source of Information

Participants were asked about how they got the information they needed and which method they preferred to get their needed information. Information sources mentioned by participants were categorized into six different entities. The Internet was clearly the most frequent source of information for interviewed patients with 10 patients referring to it as a source of information. The second most frequent source of information was the doctor including the family physician, urologist, and oncologist. Another source of information was other PC patients. Six patients mentioned that one of their ways to find information is to ask other patients through various channels. Participants met other patients in different settings including face to face, online, in the community (e.g. church), and in the support groups. Other sources of information included informational package from the BC Cancer Agency (BCCA) cancer clinic, educational sessions of TPC support group, and educational material provided by TPC. Table 6.9 summarizes different sources of information by patient groups.

Table 6.9: Sources of Information

Source of Information	Pre	Post	TOTAL
Internet	5	5	10
Doctor	4	3	7
Other Patients	2	4	6
BCCA package	2	1	3
TPC Support Group (educational sessions)	1	2	3
TPC (educational material)	1	1	2

6.1.4.3.3 Internet

In a separate question, participants were asked whether they had searched the Internet for information and if they had found what they were looking for. This question was asked regardless of their answer to the previous question and whether they identified the Internet as a source of information or not. They were also asked whether they visited any websites related to prostate cancer on a regular basis. Seventeen out of 19 patients (89.4%) answered that they searched the Internet for information. Thirteen out of 17 patients (76.4%) stated that they found what they were searching for. Only 2 out of 19 patients mentioned that they regularly visited some website with prostate cancer related information. Both patients were diagnosed recently. One patient was in the decision making group and was under active surveillance since he was diagnosed 10 month ago. The other patient had undergone surgery and was diagnosed 2 months before the interview.

6.1.4.3.4 Personalized Presentation of Information

It seems that patients' preferences in terms of the information to be presented to them in a personalized way depends on where they are in the prostate cancer journey. Patients who were recently diagnosed need more general information that covers a wide range of information. A wide range of educational material helps these patients to gain a better understanding of prostate cancer in general as well as available treatment options. On the other hand, general information may not be very useful to patients who have been diagnosed for a longer period of time and are in the treatment or follow up phase. These patients are more focused on their treatment and its potential complications and follow up issues. These patients prefer the information to be presented to them in a personalized way so they do not have to spend time to retrieve the information that is specifically relevant to their situation. The following quotes illustrate patients' preferences in terms of a personalized content presentation:

I think it depends on where you are in the chain of things. If you've just been diagnosed, then I think it's sort of best to find out about the disease in general. (Subject 25B, Line 143)

I would say you want to sort of bifurcate or trifurcate after treatment, so I do not have to look at a bunch of stuff that is related to someone who has had surgery, there may be more information relevant to those who have had surgery that is not so relevant to those who have had brachytherapy, maybe. (Subject 12B, Line 231)

However, even patients who prefer personalized information want to have access to more general information in case they need to refer to it. Therefore, access to the content should not be limited for any group of patients. Instead, presentation of the information should be done in such a way so that the more relevant information will be presented first and if the patients require more information they can browse to relevant sections.

6.1.4.4 The Prostate Centre Services

Most of the patients who were interviewed for this study received some services from The Prostate Centre (TPC) in the form of educational material, counseling, email newsletters and support group meetings. As mentioned before, TPC is one of the important resources that patients use in the decision making phase. All patients who used TPC services cherished them. No patient thought that he could have had received services more than that TPC had already provided to him. One patient expressed his satisfaction with TPC services in the following quote:

I'm very pleased that my urologist recommended that I come here. I'm very pleased that I met the people and they gave me information. I was welcomed to come back. This was probably the fourth or fifth time I've been here. I think they're excellent. I don't know if they could provide very much more. It seems pretty complete to me. (Subject 27B, Line 202)

One patient even considered TPC as his point of contact when he needed a referral or advice. The following quote expresses that:

I would contact the Prostate Centre immediately and just ask their opinion because they got tremendous amount of experience and information and so many men coming in and histories. From there I would follow their advice. (Subject 19B, Line 258)

TPC members' knowledge and experience also helped some patients from a psychological perspective as one patient stated:

Actually I found The Prostate Centre extremely helpful. It gave me something that a lot of other people initially couldn't give me and that was hope. (Subject 20B, Line 47)

6.1.4.5 Access to Medical Records

Participants showed a strong demand for access to their medical record. All but two participants expressed a desire to have access to at least part of their medical record. One patient that was not interested in having access was not sure if he could understand the information and expressed his concern in the following quote:

In an untrained professional looking at your medical records, it may just cause you more anxiety and worry than anything. (Subject 13B, Line 233)

The other patient who didn't think that he needed access to his medical information explained his reason in the following quote:

I don't know if I need it. It's just more paper. (Subject 23A, Line 262)

When he was asked what if it was on the computer he replied that he did not think that it should be on the computer for security reasons.

Participants had different reason for their interest in having access to their medical records. While for some participants, it was a right to have such an access, some others believed that it would help them to stay on top of their health situation and be involved in their care. One participant thought that the medical record enables patients to access having all their medical information in one place. The following quotes express such reasons:

As a matter of fact, I just had the conversation just this afternoon with a retired nurse. Why is this chart not mine? Why does it belong to somebody else? This is my information. I wouldn't want somebody else to have it and I understand the need for privacy, but it's mine. This is me. It's not my doctor's, it's mine. (Subject 18B, Line 196)

I want access to my information because I want to know what's happening, so that I can do something about it. I don't have to wait until my doctor calls me or doesn't call me. More often than not they don't call you. That's why I want to know I'm on top of it and if I have an enquiry I can get onto him right away. (Subject 26A, Line 230)

It is important for me to be managing my health. I feel I have a responsibility; therefore, I need to be informed. (Subject 11A, Line 248)

In the event I need a second opinion or third opinion then I have it right in front of me. I don't have to make an attempt or waste time because I know things do take time getting information. (Subject 20B, Line 222)

Participants were asked about the type of information they would like to see if they had access to their medical records, e.g. laboratory results, doctor's notes, pathology results. Five out of 17 patients who were generally positive about access to their medical records expressed interest in access to all of their information regardless of the type of information. All participants mentioned laboratory results as being important information to have available. Laboratory results that were mentioned by patients mostly pertained to PSA levels but included other laboratory tests as well. Physician notes were the second most frequently mentioned type of information to be accessed in the medical record. As one patient has expressed in the following quote, the physician note can help the patient to get a general picture of his situation. As well, the physician note is a source of information that can be referred to if a patient cannot remember the information.

Notes would be useful because I could review what we were doing and what the doctor thought, you know, how things are going and that sort of thing. He says that but then I could look at it again. (Subject 14B, Line 128)

Participants generally didn't show much interest in more complex information such as pathology results as they were not sure if they could understand it. Rather, patients were more in favor of concise information that could give them a general picture of their situation as the following quote shows:

There's really no point in me having charts and diagrams that I can't decipher that only an oncologist can look at and say, "I don't understand what this means." I need information that will tell me in a snapshot what my prognosis is, what my treatments have been, a record of everything, my PSA scores and so forth. (Subject 20B, Line 230)

When asked how frequently patients thought they would check their medical record information had they had access, 16 out of 19 patients mentioned every 6 month or just before or after each visit or when there was a change in their situation.

Use of a secure website was the most desirable method to access medical record (13 out of 16 patients mentioned this as their desired method). One patient mentioned "*least costly for the system and most efficient for him*" (Subject 20B, Line 245) and two patients were in favour of a hard copy; one due to visual limitations and the other due to security concerns.

Eleven out of 19 patients expressed concerns regarding access to medical record. The most frequent concern (mentioned by six patients) was whether they would be able to understand the information. One patient, as mentioned above, indicated that he did not want access because of this concern. The following quote from one patient shows this concern:

You know, it is a matter of understanding what you are getting and I am not sure we are all skilled to understand the information, even if the information is available. (Subject 11A, Line 228)

The other source of concern, especially with electronic access, was security. Participants were concerned about security as well as the privacy of the electronically available records as following quote indicates:

I worry about that information being, no matter the safeguards electronically, that information then becomes one more way, which can be hacked and found. That is a real reservation I have. (Subject 19B, Line 158)

As the following quote shows, one patient thought his medical record should not be on the computer at all and he would not have problem not having access to it:

I don't think my personal whatever should be on the computer because I worry about hackers getting in and that could create problems if we were filing for insurance or a bank loan or you're not a good risk because it says here you've had cancer surgery. (Subject 23A, Line 274)

Two patients showed concerns about having access to physician notes in particular. They were concerned about physician notes being negatively impacted if they knew that the patient had access to it. The following quotes express this concern:

Here is the worry I would have, if the physician knows that I am going to be reading his notes, is he going to make the same notes as he would if he knows that I am not reading them? (Subject 12B, Line 319)

The only thing I don't want to do is query what the doctor is going to put down on paper so that he becomes liable for something. If that's the case, I

don't want my medical records. Keep it. I want him to be comfortable with that information going out. (Subject 15A, Line 423)

In summary, the majority of patients expressed a desire to have access to parts of their medical record such as laboratory results and physician notes. Most of the patients were in favour of secure Internet-based access to the records as opposed to paper based medical records. However, some concerns were raised in this regard including concerns about the ability to understand the information and security of electronic access to medical records. If incorporated to the proposed PHR, access to medical records does not seem to be a frequently used feature as most patients will use it immediately before or after a visit when new PSA results are available or when there is a change in their status.

6.1.4.6 Communication with Healthcare Provider

Participants were asked about their method of communication with their healthcare provider (in case they had a question). The majority of patients mentioned that they either made an appointment and saw their doctor in person (63%) or called their doctor (32%). Some patients made an appointment as they preferred face to face encounter over methods such as phone calls or email as the following quote shows:

For diagnostic information I'm not keen on an email. That's a bit too impersonal for me. You know, I've got to be right there. I've got to shake someone's hand. (Subject 20B, Line 268)

However, sometimes patients had to make an appointment even though they preferred to use other method as that was the only option available. The following quote expresses this matter:

Well, the doctor doesn't really answer a phone call. I mean, somebody answers the phone call and they'll say, "Oh well, you've got to make an appointment to come in." Sometimes you need that but maybe for a simple question you shouldn't necessarily need to go in to see him face to face.
(Subject 27B, Line 252)

Twelve out of 19 patients (74%) never sent an email to their healthcare provider mostly because they didn't have their doctor's email or never thought that could be an option. However, some participants showed interest in communicating via email as illustrated by the following quote:

I would have liked to have felt I could have sent an email to either the urologist or the oncologist at some time and just ask them a quick question rather than making an appointment and on and on. (Subject 21B, Line 54)

As a written medium, email can also serve as a documentation vehicle helping patients to keep a history of their communication with their healthcare provider later and enabling them to refer back to it (the email) if need be. The following quote illustrate this:

I think when you're going through something like this there's a lot of information and you don't always remember everything that you've been

told. It would kind of be nice to have a fallback like some information about what was actually said, so I could review this information. (Subject 21B, Line 57)

Most of the patients who mentioned emailing questions to their doctor, referred to a particular doctor who provided his email to patients through his staff and encouraged them to email him questions. It usually took the physician 2-3 days to reply with a phone call. These patients found communication by email timely and convenient.

But despite the above mentioned interest in email, many patients were not sure if email could be an effective or practical way of communicating considering how busy doctors are. They were mostly concerned that if patients use email as a communication tool, doctors might become overwhelmed with the number of emails that were sent to them and might not be able to answer them all as illustrated below:

If I am 1 of 500 emails that he gets for the day, he may or may not have the time to look at my email or any email for that matter. So, obviously I am concerned that he is not overwhelmed with a million emails a day. (Subject 13B, Line 266)

Even if a physician manages to answer the patient's questions, it might not happen in a timely due to time constraints such as those illustrated in the following quote:

I do not know how that would work and your expectations of getting a reply, I mean if you have to wait a month for a reply because the physician is busy. You would need a lot of resources to do that, I think. (Subject 11A, Line 299)

Patients were also asked whether they think prostate cancer patients should be in regular contact with their healthcare provider. Most patients thought that patient provider contact should be based on patient needs and mainly depends on what phase of the disease the patient is in. Patients who are in the decision making phase of their disease or need more to see their doctor more frequently are the ones that should have more regular contact.

The following quotes express those opinions:

Certainly before the operation I would say yes because there are a lot of questions and a lot of anxiety. (Subject 19B, Line 225)

I would say yes but some people need it every three months, which of course it will get to be, you know, when they're being watched very carefully; when they're not being watched carefully, once a year. (Subject 25B, Line 245)

Many participants expressed concerns regarding the pressure that regular contact could put on healthcare providers given the busy nature of their job. The following quote expresses this concern:

If nothing's going on, then I'm sure there's other people that are, you know, in line because doctors have only got so much time, but if everybody was to be in direct contact with the doctor all the time that would plug the system. (Subject 20B, Line 278)

Well, they're pretty busy people and I don't know whether you'd want to bother them anymore than you have to. (Subject 23A, Line 315)

Despite the fact that making an appointment or even a phone call to a doctor is relatively costly for the healthcare system, there is a lack of other possible communication methods that are less expensive. Also, patients can use other resources such as nurses who have experience in the prostate cancer area to ask their questions. This will not only decrease the pressure on doctors, but also can be less costly to the system. The following quote displays this:

I think that is something that is definitely lacking is some kind of avenue of easily, inexpensively getting questions answered and it's very difficult to have a phone conversation with your doctor. I mean, it's understandable how busy, given the busyness, so I think most people, if they have questions, make an appointment, which is the most expensive way to get the answer. So, if there was an avenue, a nurse practitioner or nurse or something like that.

(Subject 18B, Line 255)

6.1.4.7 Self-Monitoring

Participants were asked whether they track their PSA levels or any other health related information. The majority of participants (15 out of 19) mentioned that they track their PSA level after each test. Many of those patients also had a written history of their numbers. Two patients even mentioned that they had created graphs based on their PSA numbers using tools such as Microsoft Excel or manually. However, tracking did not necessarily mean that they kept the results. Some patients only had the numbers written down or just asked about the number right after the test and didn't bother to keep a hard copy of laboratory results.

Patients accessed their laboratory results in different ways. Some received a hard copy from the laboratory. Others obtained them from their doctor's office. A number of patients accessed their results online using LifeLabs online e-health service. The number of these patients will probably increase in the future as a few patients said that they had heard of such a service and will use it in the future.

6.1.4.8 Peer-to-Peer Communication and Support

6.1.4.8.1 TPC Support Group

The Prostate Centre has monthly support group meetings. The support group meetings have taken place since the early 1990s. These meetings provide patients with up-to-date information through presentations by medical professionals. Support group meetings are also a venue for patients to share their experiences and support each other emotionally.

This can be particularly helpful for those who are newly diagnosed.

Only 6 out of 19 interviewed patients were attending support group meetings on a regular basis, and all of them thought that the meetings were useful. Patients who didn't attend the meetings mentioned different reasons. Some patients didn't feel they needed to attend a support group as they already had people around them and felt supported emotionally as expressed in the following quote:

I have a really good circle of friends and we also attend a church in town with another large circle of friends and acquaintances there and I certainly have never felt alone. (Subject 13B, Line 328)

Availability of other sources of information such as the Internet could be one reason for patients not attending a support group as one participant expressed in the following quote:

The men that I saw were all generally in their 60s and 70s and not very computer literate or knowing how to use a computer. So, in that situation, I would probably say, yes that is why they were at the support groups, because they probably had questions and they did not know where to find the answer. Maybe that is why I feel I do not need the support groups as much, because I can research my own questions. (Subject 13B, Line 369)

Some thought that they simply don't feel the need to attend a support group. Some other participants were willing to attend but couldn't for various reasons such as being located outside Victoria, being out of town most of the time, or difficulty with driving or going out in the evenings when meetings were held. The following quotes are referring to some of these reasons:

You know at the moment, I think my answer would be no to that because I am comfortable with the information that I am getting. (Subject 11A, Line 386)

It's usually in the evening and I don't go out at night because I just don't like to be out by myself at night. I don't like driving my car at night. So, I don't go. If it was in the afternoon, I would probably go. (Subject 22B, Line 227)

One participant who was an organizer for the support group guessed that only about 10 to 15 percent of prostate cancer patients in the area attend support group meetings. One reason could be the reservation men have in terms of talking about their health problems and especially prostate cancer. The following refers to this:

Well that's the old story. Men don't, you know, men don't like to talk about their health. (Subject 18B, Line 329)

The same participant thought that the number of attendees had decreased in the last few years due to various factors such as availability of information from other sources like the Internet and lack of time due to a busier life style.

6.1.4.8.2 Sharing Experience with Other Patients

Most participants were positive about sharing their experiences with others. Some even actively offered their help to others as it is mentioned in the following quote:

I just dropped by, a couple weeks ago, just to say hello basically and say, "Look. If you need me to talk with anyone at my age to go forward before the operation or if he's trying to decide, I can at least give him my opinion. (Subject 19B, Line 67)

As was mentioned in the Information Needs section, other patients' stories were one type of information mentioned by participants. It is not only a source of information but could help other patients to deal with the disease more easily. One patient explained how his story helped another patient who read it:

He read it and it calmed him. He said, "Before I read your article, I was anxious and everything else but you told your story and how you went about it. Thanks very much for doing that." (Subject 26A, Line 120)

However, as another subject emphasized in the following quote, some patients are not comfortable to talk about their experiences:

It's not something I think men tend to talk about. (Subject 23A, Line 390)

6.1.4.8.3 Online Methods of Peer-to-Peer communication

Online communication tools such as discussion boards and social networking tools have advantages such as convenience. These tools can be an alternative or a complementary method of communication to support group meetings for patients who live outside Victoria or cannot attend meetings for various reasons. Also, considering men might not be comfortable with sharing their experiences with prostate cancer in face to face settings, online tools can play a useful role in this regard. The following quote highlights some of advantages of online communication tools such as discussion boards:

First and foremost the convenience and it's all about communication. The fact is many people, especially with something like prostate cancer, are reluctant to speak about it in any depth; however, when they've got a computer screen in front of them I think that would be a much less anxious venue for them. (Subject 19B, Line 316)

I don't think it would be necessary but that's easy for me to say because I'm right in the city of Victoria and can attend the monthly meetings. I guess if I were somewhere outside of Victoria, that kind of interaction with individuals would be missing and there's where a social network might be useful.

(Subject 29A, Line 254)

However, some concerns were expressed about the content provided by non-professionals as well as potential privacy issues as was expressed by a participant in the following quote:

I guess one of the issues I have a bit of concern about is that on the Internet anybody can post anything. It may not be right. You know, maybe it's an opinion rather than a fact, so how reliable is it? How accurate is it? (Subject 27B, Line 346)

In most cases, when the term “social networking” was used in the interview, interviewees thought of Facebook and in some cases Twitter and the reaction was not very positive as they were concerned about privacy. However, when it was explained to them that social networking does not necessarily equal Facebook or Twitter and could be in the form of discussion board, chat rooms or other communication channels, and can be focused on a particular subject such as prostate cancer, they expressed more interest. The majority of participants did not have any preferences in terms of remaining anonymous when using online communication tools.

6.1.5 Emergent Themes

During the analysis of interview transcriptions, a number of themes were identified that could not be categorized under any of the coded categories.

Table 6.10 summarizes these emergent themes.

Table 6.10: Emergent Themes

Theme	Coded when the subject referred to ...	Example Quote
INFORMATION GAP	Not being provided with enough information	<i>I knew I was going to have a catheter. I did not realize how uncomfortable the catheter was going to be.</i>
TRUSTING INFORMATION ON THE INTERNET	Difficulty trusting the information found on the Internet	<i>I will find sites in there that almost are opposite to that, even though I'm trying to look for more credible sites.</i>
DIFFICULTY IN RETAINING INFORMATION	Not remembering all the information that has been communicated to him	<i>I think when you're going through something like this there's a lot of information and you don't always remember everything that you've been told.</i>
SELF INVOLVEMENT	Desire to be involved in his care	<i>I want access to my information because I want to know what's happening, so that I can do something about it.</i>
LACK OF INTEREST IN INFORMATION	Loss of interest in information	<i>I am not interested in that and that is partly why I am not that interested in knowing what the numbers are.</i>

6.1.5.1 Information Gaps

Despite the wealth of information on prostate cancer available through various channels, some patients experienced a gap in the information they would have liked to receive.

Several patients mentioned phrases along the lines of "... *could have been explained more ...*" to express they didn't have enough information about their situation at some point of time.

The following quotes show how information prior to procedures such as biopsy or catheterization can be incomplete:

I will tell you one thing that was surprising when it happened, and this was pre biopsy, I think I got a little hand out about what to expect and there were some things that happened that I would say they should be a little more aggressively stated. (Subject 12B, Line 92)

I knew I was going to have a catheter. I did not realize how uncomfortable the catheter was going to be. (Subject 27B, Line 430)

Sometimes the information gap is a result of insufficient communication with the patient resulting in uncertainty for the patient. The following quote illustrates this:

As I say, quote un-quote, “You’re PSA is fantastic and I want to see you in six to seven months.” You know, and that was it really. So, I don’t feel like I know how fantastic I am. Maybe he should have said, “Here are the results of your PSA. As you can see, it looks good and because of that and how I responded to the treatment,” however I responded to the treatment, I don’t know. Has the tumor shrunk or disappeared, you know; I do not know what actually happened to the tumor. All I know is the PSA results are good. I’ve been told I’m fine and he probably doesn’t need to see me for six to seven months. “Come back and we’ll have a chat in six to seven months.” So, that’s as much as I know. I think I would like a little bit more information. (Subject 21B, Line 350)

6.1.5.2 Trusting the Information on the Internet

As was mentioned earlier, the Internet was one of the main sources of information, particularly during the decision making phase. However, the vast amount of information available on the Internet could be overwhelming for some patients. In addition, the information from different online sources can be conflicting or even false. Patients did not always trust information on the Internet. This could be especially challenging for patients during the decision making phase of their illness. The following quotes show this mistrust:

In that case, to be honest with you because, you know one of three thousand sites doesn't do a lot for me. I will find sites in there that almost are opposite to that, even though I'm trying to look for more credible sites. There still can be misinformation in there. (Subject 15A, Line 300)

Well, what I found is some of the drugs, the treatments that I've looked at I've found through oncologists at the Cancer Agency have indicated to me is that they only work 30% of the time. The information off the Internet is completely false. I'd assume they work 100% of the time ... The bottom line is being careful out there. Be careful. Particularly if you're using that information to make a decision for radiation or surgery as it was in my case. (Subject 20B, Lines 159 & 174)

Another source of mistrust of information on the Internet content that is user generated. Eight participants believed that despite the potential usefulness of reading about other patients' experiences, this kind of information cannot always be considered a reliable

source of information and should be interpreted cautiously. The following quotes show this concern:

They can be dangerous because if you take everything verbatim because there are people, most of them may not be educated or well-educated and maybe they don't express themselves well or maybe they take things as gospel, so you've got to sort of read between the lines and sort of get a feeling for it rather than just say, "Oh, that's – there it is." (Subject 17B, Line 579)

Participants stated the source of online information was a factor in their efforts to determine whether the information could be trusted or not. If the content belong to a recognized organization or person whom the reader was familiar with, the information was more likely to be relied on. The following quotes express this:

Well, I think if you knew when you got information here, whatever you're compiling, and we knew that it came not from the States and that it was legitimately from the Cancer Ward here and it was connected with the names of the doctors involved, so you have a sense you're getting the best information that's available. (Subject 23A, Line 214)

6.1.5.3 Difficulty in Retaining Information

Prostate cancer patients, especially in the decision making phase of their disease, are exposed to a lot of information during their visits to doctors as well as other healthcare professionals. This amount of information, particularly when it is communicated mainly

verbally, makes it hard for patients to remember all the details that have been discussed. Factors such as anxiety or the inability to process information as it is communicated make it even harder for patients to retain the information. The following quotes illustrate this issue:

I think when you're going through something like this, there's a lot of information, and you don't always remember everything that you've been told. (Subject 21B, Line 57)

I think the big thing is when you see any doctor, there's always an element of anxiety. If they're going through something, at least for myself, and I get caught up in something that he said and I'm thinking about it, he or she is already going onto item 7 and I'm still stuck on item 5. (Subject 23A, Line 103)

Having a record of what has been communicated during the visit helps patients to be able to refer to it later. A written record of communicated information also enables patients to better understand the information that was provided as they can read it on their own time and at their own pace. The following quotes show this need:

Sometimes when you get a phone call, and if you're distracted or whatever, you don't necessarily absorb everything that's been told to you. So, perhaps I learn better from the written word. I can look at it at my leisure. I can question it. It means more to me if I've got a written record. (Subject 27B, Line 219)

The consult results are quite enlightening in some ways because whether you heard some things at the consult or not, I don't know, but sometimes when you read them you wonder if you were actually in the room with them.

(Subject 25B, Line 202)

One patient had the opportunity to have another person accompanying him when he visited his doctor. The accompanying person, particularly if familiar with medical terminology, could help the patient to better understand the information and to recall it later. The following patient, whose wife was a nurse, expressed this in the following quote:

Whenever I was going to have a separate meeting, like when I came to see [the nurse] the first time here at the cancer unit, my wife came just to overhear, so that when I got home, I would say (I made a few notes), did she say this, did I understand this? She said, "Oh no. This means this." (Subject 23A, Line 128)

6.1.5.4 Self-Involvement

Some participants showed a high interest in being involved in different aspects of their health. They were interested in having access to their medical information as a tool that enables them to play an active role in their health management. The following quote shows how enthusiastic some patients are to be directly involved with all details of their care:

I want access to my information because I want to know what's happening, so that I can do something about it. I don't have to wait until my doctor calls me or doesn't call me. More often than not they don't call you. That's why I want to know I'm on top of it and if I have an enquiry I can get onto him right away. I don't wait for him to do it. He's there as my guide, my coach. I'm responsible for my health, not him. He's only there as a technician, more or less type thing. I don't go to him expecting him to make me healthy. (Subject 26A, Line 230)

6.1.5.5 Lack of Interest in the Information

Despite the initial interest in information that prostate cancer patients show (especially in the early stages of their disease), some lose that interest over time. These patients, who were in the post treatment group, were not seeking any new information and were not even interested in following their PSA levels. These patients may have felt that following their condition all the time would not only make no difference in terms of the outcomes, but also prevent them from redirecting their attention to other matters of importance to them. The following quote expresses this opinion:

First of all, there is nothing we can do about it. We can talk about it, but there is nothing we can do about it. It is just going to proceed as it proceeds and so the more you have events that you are thinking about it, it is not doing anything but bringing attention back to this thing that you have no control over. I am not interested in that and that is partly why I am not that interested in knowing what the numbers are. (Subject 12B, Line 389)

6.2 Phase 2: Modifying the Prototype

The first version of the PHR prototype that was introduced earlier in the Methods chapter was modified based on the results derived from the interviews. The modification included redesign of an existing section of articles as well as adding a new functionality called Patient Connect. This chapter describes these modifications in more details.

6.2.1 Articles Section

Results from the interviews showed that prostate cancer patients needed different types of information depending on the stage of disease they were in. For instance, while topics such as information about different methods of treatment are most needed by patients in the decision making phase, post-treatment patients are more interested in information regarding recurrence or long term follow up after treatment (Table 6.8). On the other hand, the overwhelming amount of information available on the Internet makes it hard for patients to distinguish between reliable content and low quality information. This could result in some information gaps and distrust in information (as was mentioned by participants).

A PHR that is designed based on patient needs can tackle these issues by compiling relevant information from credible sources and presenting that information to patients in a useful way. Patients who trust that PHR can use it as a “one-stop-shop” for all their information needs and save time and effort while being confident that they are getting information they can rely on.

The Articles section of the first version of the PHR prototype simply listed some prostate cancer related articles (Figure 6.1). All patients regardless of their phase of disease

viewed the same list of articles in the same order as there was no process in place to relate patients or articles to a particular disease phase.



Figure 6.1: Articles section in the first version of prototype

To facilitate access to relevant information, the prototype was modified in such a way so that patients were able to see a selection of articles that are directly related to their phase of disease in the first page of PHR after they log in (Figure 6.2). Also, while the all articles in the “Articles” page are still accessible to all patients regardless of their phase of disease, more relevant articles are always displayed on top, followed by articles marked as “General” and articles related to other phases of disease at the end of the page (Figure 6.3).

The Prostate Centre
Personal Health Record

Welcome **James Black** () | [Change Password](#) | [Logout](#)
Your Care Plan: *Follow up - Surgery*

Main Menu

- [Home](#)
- [My Profile](#)
- [My PSA](#)
- [My Appointments](#)
- [My Diary](#)
- [Articles](#)
- [Patient Connect](#)
- [Communications](#)

Information related to your care plan

Treatment Side Effects
Many men understand that when prostate cancer is caught early, it can be treated effectively, and the primary treatment options for localized disease are all excellent choices. However, many men also have significant concerns about the side effects of these treatments. [\[Read More\]](#)
*Source: **Prostate Cancer Foundation***
Related Care Plans: Treatment Decision Making, Follow up - Surgery, Follow up - EBRT, Follow up - Brachytherapy,

Erectile Dysfunction
Regardless of whether the nerves were spared during surgery or whether the most precise dose planning was used during radiation therapy, nearly all men will experience some erectile dysfunction for the first few months after treatment. [\[Read More\]](#)
*Source: **Prostate Cancer Foundation***
Related Care Plans: On Treatment - Radiation Therapy, Follow up - Surgery, Follow up - EBRT,

Figure 6.2: Presenting articles on the homepage of modified prototype

The Prostate Centre
Welcome **James Black** () | [Change Password](#) | [Logout](#)
Your Care Plan: *Follow up - Surgery*

Personal Health Record

Main Menu

- ▶ [Home](#)
- ▶ [My Profile](#)
- ▶ [My PSA](#)
- ▶ [My Appointments](#)
- ▶ [My Diary](#)
- ▶ [Articles](#)
- ▶ [Patient Connect](#)
- ▶ [Communications](#)

Articles

Erectile Dysfunction

Regardless of whether the nerves were spared during surgery or whether the most precise dose planning was used during radiation therapy, nearly all men will experience some erectile dysfunction for the first few months after treatment. [\[Read More\]](#)

Source: Prostate Cancer Foundation

Related Care Plans: On Treatment - Radiation Therapy, Follow up - Surgery, Follow up - EBRT,

Treatment Side Effects

Many men understand that when prostate cancer is caught early, it can be treated effectively, and the primary treatment options for localized disease are all excellent choices. However, many men also have significant concerns about the side effects of these treatments. [\[Read More\]](#)

Source: Prostate Cancer Foundation

Related Care Plans: Treatment Decision Making, Follow up - Surgery, Follow up - EBRT, Follow up - Brachytherapy,

10 Myths and misconceptions about prostate cancer

With the identification of more than 25 types of prostate cancer by PCF-funded scientists in the past 24 months, and the fact that it remains one of the least talked about cancers, it's no wonder there remains a great deal of confusion surrounding this disease. [\[Read More\]](#)

Source: Prostate Cancer Foundation

Related Care Plans: General: General

Brachytherapy following External Beam Radiation Therapy

The use of radioactive seed implantation after external beam radiation therapy has five-year disease-free rates around 50%. [\[Read More\]](#)

Source: Prostate Cancer Foundation

Related Care Plans: Follow up - EBRT,

Side effects of hormone therapy

Testosterone is the primary male hormone, and plays an important role in establishing and maintaining the typical male characteristics, such as body hair growth, muscle mass, sexual desire, and erectile function, and

Figure 6.3: Presenting articles on the articles page of modified prototype

To enable the prototype to identify articles that are related to a patient's phase of disease, a new entity called Care Plan was added to the system to represent phases of patient case such as "Treatment Decision Making", "On Treatment – Hormone Therapy" or "Follow up - Surgery". A complete list of available Care Plans is included:

- Treatment Decision Making
- On Treatment - Hormone Therapy
- On Treatment - Chemotherapy
- On Treatment - Radiation Therapy

- Follow up - Surgery
- Follow up - EBRT
- Follow up - Brachytherapy
- Follow up - Chemotherapy
- Follow up - Hormone Therapy
- On Active Surveillance
- Watchful Waiting
- Palliative - Pain and Symptom Management
- Palliative - Psychosocial Care
- Follow-up - Clinical Study or Trial

The next step in the modification involved making changes to the prototype administration section so that Care Plan could be associated with patients and articles. Care Plan was then used to relate articles to patients; e.g. articles that are associated with the Care Plan “Follow up – Surgery” would be displayed on the first page as well as on top of the list on the Articles page for patients who have “Follow up – Surgery” as their Care Plan. Therefore, patients will potentially be able to find relevant information more easily and faster. Note that articles can be related to more than one care plan. Also, a brief excerpt from each article as well as information about the source of the articles were added under each article’s title so that it is clear to the patient what the article is about and what the source of the information is (Figure 6.2 and Figure 6.3).

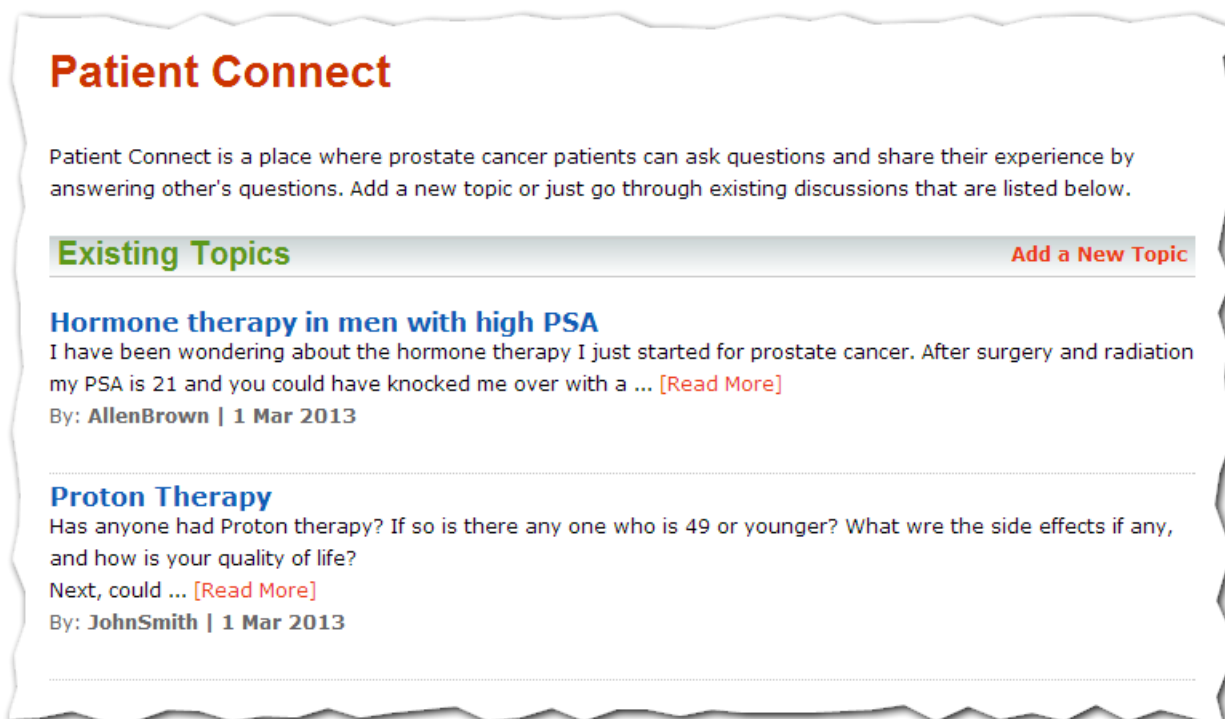
6.2.2 Patient Connect

Participants showed a strong desire to know about other patients’ stories as well as share their own stories. “Other Patient Stories” was one of the frequent topics mentioned by

patients as being an information need (Table 6.7 and Table 6.8). Participants were enthusiastic about sharing their own stories with other patients.

The existing prototype didn't provide any functionality for patients to have a two-way communication channel to share their stories with each other. The closest functionality that patients could use to share their story was to make their diary or at least selected diary posts public so that other patients could read them. However, public diary was simply a read-only media. There was no way for the reader to engage in a conversation (e.g. to comment) with the writer or other readers. A better communication avenue requires that the PHR be a more sophisticated tool that allows patients to ask questions or answer other patients' questions or simply to start a discussion with other patients. Other patients should be able to participate in the discussion. The ability to start and continue a discussion between multiple parties is a functionality that many online discussion boards provide.

Modifications to the PHR prototype led to the development of new functionality that was named "Patient Connect". "Patient Connect" is a simple discussion board tool that enables users to start a discussion and participate in other discussions. When patients navigate to Patient Connect home page, they can view the existing discussion topics with the most recent discussions displayed at the top (Figure 6.4). Patients can start a new discussion by adding a new topic. On each topics page, patients are able to write their opinion or answer a question and post the information to the topic (Figure 6.5).



Patient Connect

Patient Connect is a place where prostate cancer patients can ask questions and share their experience by answering other's questions. Add a new topic or just go through existing discussions that are listed below.

Existing Topics [Add a New Topic](#)

Hormone therapy in men with high PSA

I have been wondering about the hormone therapy I just started for prostate cancer. After surgery and radiation my PSA is 21 and you could have knocked me over with a ... [\[Read More\]](#)

By: **AllenBrown** | 1 Mar 2013

Proton Therapy

Has anyone had Proton therapy? If so is there any one who is 49 or younger? What wre the side effects if any, and how is your quality of life?

Next, could ... [\[Read More\]](#)

By: **JohnSmith** | 1 Mar 2013

Figure 6.4: Patient Connect home page

The screenshot shows a forum page with a white background and a dark grey border. At the top, the title "Patient Connect" is in red, and "Proton Therapy" is in green. Below this, there are two posts. The first post is by John Smith, dated 1 Mar 2013, with a dark grey header. The text of the post asks about proton therapy side effects and robotic surgery. The second post is by James Black, also dated 1 Mar 2013, with a dark grey header. The text of the post shares his experience with catheters and leakage. Below the posts is a blue "Reply" header, a large white text input area, and a "Post" button at the bottom.

Patient Connect

Proton Therapy

John Smith 1 Mar 2013

Has anyone had Proton therapy? If so is there any one who is 49 or younger? What wre the side effects if any, and how is your quality of life?

Next, could people please tell me more about Robotic, Da Vinci surgery. Has anyone not experienced prolonged incontinence or sexual dysfunction?

James Black 1 Mar 2013

Hi John,

I started getting stiff with the cath still in, wow is that uncomfortable. Morning wood the other day. 10 weeks since surgery, down to one pad per day less than a half ounce leakage per day. I'm a mech. running, lifting, all kinds of stuff. looking forward to going pad free on my off days soon. According to my brothers whom had the regular open gut surgery slight leakage with certain types of heavy lifting, still happens after two years

Reply

Post

Figure 6.5: Patient Connect topic page

In summary, changes to the existing prototype involved the modification of the “Articles” section and the creation of the “Patient Connect” tool. These changes were based on a

number of the most important issues and information needs that were mentioned by participants.

6.3 Phase 3: Usability Testing

As mentioned in CHAPTER 4: Conceptual Framework, this study used a user-centered approach toward the design and development of the PHR. Evaluation of the designed prototype is an important part of the iterative user-centered design approach. Usability Testing was used to evaluate the designed PHR prototype.

Four patients from the original 19 patients participated in the usability testing of modified prototype. At the beginning of each testing session, the purpose of the usability testing and the concept of “thinking aloud” was explained to participants in lay language. Each subject then was asked to complete a number of tasks that were selected by the researcher. The researcher selected tasks that he believed that were most potentially used tasks as well as tasks that were selected to evaluate modifications to the prototype. A summary description of the above mentioned tasks included:

1. Login
2. Use “Patient Connect” tool.
3. Find information about treatment options
4. Find information about PSA levels
5. Look for upcoming appointments
6. Logout

The complete details of the above mentioned tasks are included in Appendix 4: Usability testing tasks (Phase 3).

The computer screens as well as the participants' think aloud verbalizations were recorded using Hypercam. The recordings and verbalizations were then transcribed and analyzed by the researcher for potential usability problems. Potential problems were then identified in the video segments and transcripts.

As outlined in the methods section, a short interview was conducted using a questionnaire (Appendix 5: Post Usability Testing Interview (Phase 3)) to gather some complementary information. This data was also transcribed and analyzed using content analysis by the researcher.

In the next section of this study, the researcher will outline the usability problems that were identified in the analysis.

6.3.1 Wording and Presentation of Links

Four out of 6 tasks (Appendix 4: Usability testing tasks (Phase 3)) required users to use the left menu to navigate to a related section of the website before they could complete the task. Generally, the placement of the main navigation menu on the left side of the page was liked by all the participants, and none of the participants had difficulty looking for the links. However, while none of the participants had any problems with navigating to sections related to tasks "Use Patient Connect tool", "Find information about PSA levels", and "Look for upcoming appointments", 3 out of 4 participants had difficulty with finding the appropriate link to click on to complete the task "Find information about treatment options". Only one subject clicked on the "Articles" link right away. The following observation from the video recording is an example of how users couldn't find the appropriate link:

When asked to complete the task “Find information about treatment options”, the user hovered the mouse over all options on the left menu without clicking on any of them, and then finally clicked on the Homepage link. The user did not identify “Articles” as a potential helpful link. (Subject 1, 5:20[m:ss])

The user guessed that Cancer Treatment Options might be found under Articles link on the left menu. The user paused on the “Articles” link but did not click on it and said “I don’t know where to go from here”. (Subject 2, 5:52[m:ss])

One explanation for this problem could be the wording of the link (i.e. “Articles”). For other tasks, there were items on the left menu that could be easily identified since they used the same wording as the destination section. For the task “Use Patient Connect tool”, there was a “Patient Connect” link on the left menu. Participants were able to identify and click on that link right away. The tasks “Find information about PSA levels” and “Look for upcoming appointments” were quickly related to “My PSA” and “My Appointments” links respectively. However, the task “Find information about treatment options” did not necessarily imply that the information could be found under “Articles” link.

Another potential problem with links was “Add a New Topic” link in Patient Connect. In the task “Use Patient Connect tool”, participants were asked to use “Patient Connect” section of the website to share their experience with other patients or ask a question.

While all participants easily identified the appropriate link on the left menu and navigated

to the Patient Connect section, 3 out of 4 participants were unable to use the “Patient Connect” section to add a new topic or reply to one of the existing topics. It might be due to participants being unfamiliar with how online discussion boards and forums work.

6.3.2 Lack of Search Functionality

Another potential shortcoming in terms of navigation was lack of search functionality. The PHR prototype had no tools to enable patients to do a free text search on the content of the PHR. Search functionality could help users find information in case the main menu was not descriptive enough. The following statements were made by a participant that was trying to complete the task “Find information about treatment options”:

First of all, I thought it might be in this section [left menu]. It doesn't seem to be. Now I am looking for a search box; and I don't see one. So, ... Now I am reduced to clicking through things which doesn't seem right at all. (Subject 3, 2:40[m:ss])

I wouldn't normally go trying through every item on the left hand side menu. Either it's a heading or a search box. (Subject 3, 3:20[m:ss])

6.3.3 User Interface (UI) Problems

All of the participants in the usability testing users either complained about the small font size on the website or in the post-testing interview. The font size used for the prototype was 12. The following observation illustrates this problem:

When trying to read the PSA levels in the table, user took off his glasses and got very close (5-10 cm) to the monitor to read. “It is too small that I even cannot read with my computer glasses”. (Subject 3, 7:48[m:ss])

6.3.4 Post Usability Test Interviews

In the post usability test interview, 3 out of 4 participants said that they performed the requested tasks easily. When participants were asked about how they found using the prototype as compared to other websites that they had used before, participants were generally positive. One participant (Subject 4) characterized the prototype as “*Straight forward; not complicated*” and another participant (Subject 3) said that except for the problem with finding treatment options “*everything was easy to find*”. The following quote shows one participant’s opinion when comparing the prototype with other systems that he had been used:

It is like other systems. I have used eHealth from LifeLabs and it is similar.

This is usable. (Subject 1)

Participants answered the question of whether they will use such a system or not positively.

In summary, small font size was a major user interface problem that was mentioned by all participants. Another important problem was the wording of the navigation and action links as 3 out of 4 participants were unable to complete a task due to this problem. Table 6.11 summarizes the most commonly found usability issues.

Table 6.11: Frequency of usability issues

Usability Issue	Frequency
Wording of main navigation links	3
Wording and visibility of an action link (Add New Topic)	3
Lack of search functionality	1
Small font	4

CHAPTER 7: Discussion & Conclusion

This chapter provides an overview of the findings from the study and how they fit into the existing literature. The research questions and how they are answered by the study findings are discussed. Also, the implications for designing similar systems for prostate cancer patients and for system design in healthcare, as well as study limitations, are discussed.

7.1 Highlights of the Findings

7.1.1 Information Needs

The information needs of prostate cancer patients change as they go through different stages of their disease (Echlin & Rees, 2002). A systematic review of a number of studies in this area (Echlin & Rees, 2002) has shown that before treatment, patients are mainly interested in treatment choices and the likelihood of a cure, whereas after treatment, side effects arising from the treatment and how to monitor for the recurrence of the disease is an information need for patients. The current study found similar results. Findings from this study showed that patients who were in the decision making phase of their disease generally needed more general information about prostate cancer. Specifically, these patients were more interested in different methods of treatment and the potential side effects and complications associated with these treatments. On the other hand, the type of information needed after treatment was mainly along the lines of side effects of the treatment and long term follow up of prostate cancer. As is shown in Table 6.7 and Table 6.8, the type of information each individual patient demands may vary. As patients move on to the treatment and follow-up phases of their disease, they become more interested in

information that is closely related to their method of treatment and its potential side effects and complications. For instance, a patient undergoing radiation therapy might not be interested in information about complications of surgery.

7.1.2 Other Patients as Sources of Information and Peer-to-Peer Communication

Other patients are another source of information (Rozmovits & Ziebland, 2004). Both groups of participants showed a high interest in other patients' stories and experiences. However, some patients were reluctant to rely on information provided by non-professionals. Participants were not only interested in other patient's stories, but also willing to share their own experiences with others. Despite the usefulness of TPC support group, the attendance rate for the support group seemed to be low and decreased in recent years due to a number of reasons, including general reluctance of men to talk about their health and an increased availability of information on the Internet. Online methods of communicating with others such as discussion boards, chat rooms and other social networking tools seemed to be convenient and cost effective methods for conducting peer to peer communication. However, asynchronous tools such as discussion boards seem to be more a convenient method for communication between patients as these tools do not require both parties to be present at the same time. Also, due to patients' concerns regarding the credibility of content generated by other patients, patient to patient communication channels might be more reliable if they are moderated by a healthcare professional such as a nurse. A moderated asynchronous communication tool could be a very useful adjunct to a PHR. Patients can use these tools to connect with each other and share their experiences without being limited to any particular time or place. Such tools

can be useful for patients living outside Victoria who may not be able to travel to attend support groups.

7.1.3 Communication with Healthcare Provider

Participants showed an interest in using electronic communication methods such as e-mail to communicate with their healthcare provider. However, the majority of participants never sent an email to their healthcare provider mostly because they didn't have their doctor's email or never thought that they could email their physician. Not having the provider's email address and privacy concerns have been identified as barriers to sending emails to providers (Ye, Rust, Fry-Johnson, & Strothers, 2010). However, a new barrier that was identified in the current research was patients' concerns regarding the effectiveness of email as a method for communicating information between a patient and a doctor. Participants mentioned that given the busy nature of a doctor's job, the doctor might become overwhelmed if they receive a large number of emails from patients on a daily basis. Physicians might not even be able to reply and even if he or she manages to reply, they might be late in replying. Participants believed that added work of doctors emailing patients would be a burden to physicians. However, other healthcare providers such as nurses were considered alternative sources of information.

7.1.4 Trusting the Information on the Internet

The Internet is one of the most popular sources of information for patients. However, patients expressed a mistrust of some information provided by a large number of websites on the Internet. Patients believed this information was sometimes false. Patients generally prefer information from websites affiliated to credible sources such as universities or well-known clinics (Rozmovits & Ziebland, 2004). If the content was provided by an

organization or healthcare professional that patients know and trust, such as TPC or doctors from the BC Cancer Agency, the information is more likely to be trusted by patients.

7.1.5 Usability Testing

Participants found the designed prototype generally easy to use and straightforward. However, a few issues including small font size were identified following a usability analysis. The results of usability testing can be taken into consideration in the next iteration of the system design and development.

7.2 How Research Questions Were Answered

This section shows how findings can answer the research questions of this study. Chapter 3 of this thesis listed research questions as:

1. **Information needs and concerns:** What are the information needs and concerns of PC patients in these specific phases of care (i.e. in decision making phase, and during treatment/follow-up)?
2. **Desired Functions:** What are desired functions that PC patients would like in their PHRs in these specific phases of care (i.e. in the decision making phase and during treatment/follow-up)?
3. **Use of information needs in PHR design and implementation:** Can information about PC patients' information needs and concerns be used to improve the design and implementation of a prototype PHR for PC patients?

7.2.1 Information needs and Concerns

Despite the variability of desired information topics among individual patients, this study identified the types of information that are commonly needed by each group of patients

(i.e. patients in decision making and post-decision making phases). The researcher also found some types of information needs that were common across patients groups.

Patients in decision making phase of their disease were mostly interested in information about available methods of treatment and advantages and risks of each treatment method.

Patients in the post-decision making phase of their disease were more focused on information regarding side effects of treatment methods and what involved in the follow up after they received their treatment. Patients also showed a strong desire to access their personal medical information for various reasons. Patients wanted to access their laboratory results and PSA levels in particular. Patients were interested in tracking their PSA levels using a PHR. Another type of information that patients were interested in obtaining was information from other prostate cancer patients. Many patients found that other patients' stories were a valuable source of information. In summary, the information needs of prostate cancer patients in both groups can be grouped into three main areas:

1. Knowledge based information: This area cover a general set of information that is common for both groups of patients. It also includes information tailored to each group of patients.
2. Medical record information: The minimum needed information in this area is laboratory results including PSA levels. This information is needed by the post-decision making group.
3. Other patients' stories: This area is desired by both groups of patients. However, it is particularly useful for patients in decision making phase of their disease.

This study also answered the question about the type of concerns that prostate cancer patients might have. Some patients in decision making group found it hard to make a

decision about their preferred method of treatment. For those patients, information alone was not enough, and they required more coaching from a healthcare provider to be able to decide. Patients also were not always sure if they could fully trust the information they found on the Internet. Patients were more interested in websites that were affiliated with more credible sources of information such as well-known clinics or healthcare providers. Also, there was concern about information originating from other patients. Some patients were concerned that other patients might provide information based on their own perceptions that may not necessarily be valid. When it came to medical record information, the two main concerns were the ability of a patient to understand the information and the security of the information. Some patients even thought their medical information should never be placed on the web (even on a “secure website”) due to vulnerable nature of the web from a security perspective.

Potential patients’ concerns have been summarized below:

1. Concern regarding the ability to make a decision due to availability of various treatment methods. This concern mostly applies to the decision making group.
2. Ability to understand the information contained in the medical record
3. Security concerns if personal health information is available electronically (e.g. online)
4. Trusting information related to prostate cancer available on the Internet
5. Trusting information related to prostate cancer provided by other patients

7.2.2 Desired Functions

A minimum set of desired functionalities for a PHR geared toward prostate cancer patients were identified in this study. The findings showed that a PHR designed for prostate cancer patients needs to provide access to at least laboratory results (including PSA) and provide tools to enable patients to follow their PSA levels. Even if access to a

medical record is not possible for patients, a patient may still want to follow their PSA levels. Therefore, it would be beneficial to patients if a PHR provides a tool to enable patients to enter and maintain their PSA levels. Such a tool helps patients to keep information about their PSA levels in one place to follow it. The ability to visualize PSA level changes in the form of graphs is another function of a PHR that helps patients to better understand changes in their PSA levels over time. This functionality mostly applies to patients in the post-decision making phase.

Also, a peer-to-peer communication tool was desired by the majority of participants. Patients expressed a high interest in other patients' stories. Patients also demonstrated a willingness to share their own experiences. A discussion board functionality built into a PHR helps patients to communicate and share prostate cancer related information. This functionality could help patients in decision making phase of their disease to decide on their desired method of treatment and patients in post-decision making phase to share information that might help them manage possible treatment side effects.

7.2.3 Use of Information Needs in PHR Design and Implementation

The researcher used the findings from Phase 1 of this study (i.e. information needs and concerns) to improve the design of the first prototype. The first improvement was achieved by adding "Care Plan" to the design. By redesigning the "Articles" section, the PHR prototype was able to filter articles for patients based on their phase of disease. This is an example of how gathering requirements from end users can be used to improve the design of a system. The second improvement was adding the "Patient Connect" functionality. Participants showed a strong interest in other patients' stories as well as sharing their own knowledge. "Patient Connect" enabled the modified prototype to fulfill

that need. However, due to patients' concerns about the reliability of the content originating from other patients, a PHR with such functionality is better to be implemented in a setting where a care provider (e.g. a nurse) is available to moderate discussions and prevent circulation of misleading information. The concerns expressed by patients in this study could also be used to improve the design and implementation of a PHR. Patients showed a strong desire to access their medical information. The prototype PHR should be able to receive patient medical information from an electronic medical record system. This could be implemented through the integration of the two systems (i.e. the PHR and the electronic medical record) by designing data exchange capabilities between the two systems. However, a PHR also needs to address the security concerns of patients by incorporating security measures in terms of authentication of users and storing personal health information. This could impact the implementation of a PHR even at a physical level in terms of where the servers storing the data are physically located. The user interface design and usability of the system could also be improved by addressing the issues identified during usability testing. For instance, addressing issues such as small font size can improve the usability of the prototype PHR.

The above examples show that gathering information about patient needs and concerns not only helps to design the initial prototype, but also can be used to improve the prototype, especially if an iterative approach is taken.

7.3 Implications for Designing E-Health Applications for Prostate Cancer Patients

The majority of cancer patients use the internet as a source of information to make clinical decisions (Castleton et al., 2011). The results of this study showed that a PHR

rich in information could be an important vehicle for addressing patient information needs. However, the information should come from a credible source known to patients in order to earn a patient's trust. The PHR should be from a trusted body such as TPC. Including the source of information (i.e. reference) for the content (e.g. articles) provided in a PHR may result in the provided content to be more trustworthy for patients.

Research has shown that support groups play an important role in helping cancer patients to cope with their situation (Cella & Yellen, 1993). However, prostate cancer patients are uncomfortable in seeking advice or sharing their experiences in face-to-face meetings (Broom, 2005). A significant number of patients do not attend TPC support group for various reasons including reluctance to talk about their problems. An online communication method (e.g. a discussion forum) integrated into a PHR can provide an alternative to face-to-face support groups. A PHR would help patients share their experiences using methods other than face-to-face approaches. However, in order to prevent circulation of false information among patients, these communication channels can be moderated by a healthcare professional such as a nurse.

Although information desired by patients in each group of this study had similarities, there were variations at the individual level. The researcher found that information needs change over time as patients move through the phases of their disease. A PHR geared toward prostate cancer patients can take advantage of tools that can capture emerging information needs so that appropriate content can be added over time. This can be done by providing tools that enable patients to suggest new content or by identifying new topics indirectly from a "Question & Answer" section or a discussion board. Also, providing context sensitive content that is tailored to individual patients' needs may

increase the chance of acceptance by patients. The prototype developed in this study used care plans to personalize content delivery to some extent. However, more personalization can be achieved using tools that can capture user preferences.

Although participants of this study showed a great desire to have access to their medical records, there were concerns among participants regarding the security of their information. PHRs providing access to patients' medical records need to address the security concerns of patients; e.g. by implementing sophisticated authentication and security protocols.

In summary, e-health applications for prostate cancer patients need to provide a wide range of information from credible sources. Providing a moderated communication channel for patients to share their experiences could be another potential functionality. Also, implementing functionality to capture emerging information needs helps e-health applications to provide new content to patients. The content type and method of delivery can be personalized using different approaches. Access to medical records information is well desired by patients but security concerns need to be addressed.

7.4 Implications for System Design in Consumer E-Health Applications

Low adoption of PHRs by patients may be due to failure of system design to take users' needs into account (Kahn, et al., 2009). By engaging patients in the design process, particularly in the requirements gathering phase, a PHR could be designed based on a patient's needs, and the end result could be a more useful PHR (De, et al., 2009). The findings from this study can be used to inform the design and development of consumer e-health applications by engaging users in the early stages of design; i.e. requirements gathering. Understanding the requirements in the early stages of system design can

prevent waste of resources due to developing features that might not align with user needs. For instance, the author believed that an appointment reminder could be a useful tool for prostate cancer patients who have regular PSA checks, but patients didn't show much interest in such a tool according to the study results. Another general implication for system design in e-health could be iterative design and prototyping. By taking an iterative approach, developers of such systems can use users' feedback and refine their design before they invest too many resources in software development. Usability testing can be a very useful tool in this regard.

7.5 Implications for Future Research

PHRs are in their early stages of development, and there are a number of areas that need further research where this technology is concerned. There are many studies about the information needs of prostate cancer patients. However, there is little research about how e-health applications including PHRs can use patient information and preferences to present information that is tailored to an individual patient. In the case of PHRs, use of medical record information for context sensitive content delivery seems to be a potential new area of research. This study found that only slightly more than half of participants used their cell phone on a daily basis. Of those participants who used their cell phone on a daily basis only half were connected to the internet using their phone. However, research has shown that use of mobile devices to access health information is on the rise (Fox & Duggan, 2012). A potential area for future research could be the design and development of e-health applications in general and PHRs in particular for mobile platforms such as smart phones and tablets.

7.6 Study Limitations

Qualitative research requires participants who can provide in-depth insight into the research topic (Jackson & Verberg, 2007). However, in this study, participants were recruited based on availability. This limitation might have an impact on the value of information gathered from participants.

Research has found that spouses play an important role in the management of their partners' prostate cancer (Harden et al., 2002). Moreover, wives have a great desire for information and even seek information on behalf of their husbands (Lavery & Clarke, 1999). Therefore, partners are among the potential users of a PHR designed for prostate cancer patients, especially when it comes to seeking information. Partners, however, were not considered to be study participants. This potential group of users was not included in the requirements gathering process. This may have influenced the quality of the results.

7.7 Conclusion

This study took a user centered design approach toward eliciting prostate cancer patients' information needs and concerns. The study also evaluated a preliminary prototype of a PHR in order to improve the design and development of the final PHR. Findings from the study showed that generally, the information needs of prostate cancer patients who are in the early stages of their disease and are making a decision about their method of treatment are to some extent different from those patients who have already undergone treatment. While patients in the decision making phase of their disease mainly needed information about available treatments and their associated side effects and complications as well as the rate of success, patients in the post-decision making phase of their disease group were more interested in information regarding the management of treatment side

effects and long term follow ups. There were also types of information that were desired by both groups of patients (i.e. decision making and post-decision making groups). However, at the individual level, there was a high variability in the type of information needed. The PHR can use tools to capture the required information at the user level in order to make a good coverage from a content perspective. Also, the PHR can use personal patient needs and other information such as the phase of disease so that content can be tailored to each individual patient. Other patients' experiences were also identified as desirable pieces of information for patients to read about. A functionality to facilitate communication between patients was identified as a desired tool to help patients share their information. However, some patients expressed concerns about the credibility of information originating from other patients. To address this concern, communication via a PHR can be moderated by a healthcare professional such as a nurse to prevent misleading information from being published and used by other patients. Patients also showed a high interest in accessing their medical record and in particular laboratory results including PSA levels. PSA levels need to be monitored by the patients and their doctors after they have received treatment in order to monitor the state of disease and a possible recurrence. The overall result of usability testing was quite satisfactory as participants found the prototype generally useful and easy to use. However, a number of issues were identified that can be resolved in the next iteration of the PHR design and development. The study method can be used to design and develop patient centric PHRs using a user centered iterative approach.

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Appendix

Appendix 1: Computer, Internet, Cell phone survey

Patient Number:

Date:

1. **On average, how often do you use a *computer* per week?**
 - I don't use a computer
 - Less than one hour
 - 1-5 hours
 - 5-10 hours
 - More than 10 hours
2. **On average, how often do you use the *Internet* per week?**
 - I don't use Internet
 - Less than one hour
 - 1-5 hours
 - 5-10 hours
 - More than 10 hours
3. **Do you use other online tools such as calendars, reminders, news readers, etc?**
 - Yes
 - No
4. **Do you have a computer at home?**
 - Yes
 - No
5. **Do you have an Internet access at home?**
 - Yes
 - No
6. **What type of access is that?**

- Dial-up
- ADSL
- Broadband
- Don't know

7. Please check all of the following tasks that you use computer/Internet for:

- Email
- Social networking (e.g. Facebook, Discussion boards, ...)
- On-line banking
- Word processing
- Calendars, reminders
- Graphics
- Picture archiving
- Entertainment (Video, Games, Music, ...)
- On-line shopping
- Travel (e.g. making travel or hotel reservations)
- Finding information (including information about prostate cancer, news, ...)

8. Do you have a cell phone?

- Yes
- No

9. Do you use your cell phone on a daily basis?

- Yes
- No

10. Do you always carry your cell phone with you?

- Yes
- No

11. Do you use text messaging on your cell phone?

- Yes
- No

12. Do you connect to the Internet by your cell phone?

- Yes

No

Note: If the answer to questions 1 and/or 2 is the first option then the score is 0.

Appendix 2: Demographic Survey

Patient Number:

Date:

1. **What is your age? -----**
2. **What is your current marital status?**
 - Single
 - Married
 - Common Law
 - Separated/Divorced
 - Widowed
3. **Are you retired?**
 - Yes
 - No
4. **If you are currently working, what is your occupation? If you are retired, what was your previous occupation?**

5. **What is the highest level of education you have completed?**
 - Less than high school
 - High school diploma
 - College degree

- University degree
- Other (please specify) -----

6. Please check all of the following treatments you have received for your prostate cancer?

- I have not received any treatment yet
- External beam radiation therapy
- Prostate brachytherapy (also known as seed implant)
- Radical prostatectomy (surgery to remove prostate gland)
- Hormone therapy
- Chemotherapy
- Complementary/Alternative therapies
- Other (please list): -----

Appendix 3: Interview Guide

Patient Number:

Date:

Thank you for taking time to participate in this study. I am going to ask you to share your experience with your prostate cancer and the care you have received for it so far. The purpose is to determine your informational needs and desired functionalities to be implemented in a web-based personal health record that is going to be designed and developed for prostate cancer patients. Personal health records are web-based systems that provide patients with access to relevant information about their conditions (including their medical health record). The interview will be audio recorded. If you feel uncomfortable with any question, you can choose not to answer that question. If for any reason you feel unable to continue the interview, please let me know and we can arrange another time and place to complete the interview. You may also choose to end the interview at any time.

Your general experience with prostate cancer and the care you received

- How long have you been diagnosed with prostate cancer?
- What type of care have you received for prostate cancer so far?
- What treatments have you received for prostate cancer so far?
- Why did you decide to choose this treatment?

Navigation

- Do you have any concerns or did you experience any problems when your care was transferred from one provider to another (e.g. between GP and urologist and BC Cancer Agency)?
- Was it clear to you the process and steps for dealing and treating your cancer?
What was missing or not clear?

Access to Medical services or Healthcare Providers

- Did you know which healthcare provider or service (e.g. physiotherapy, psychologist, social worker, specialist physician, nurse, etc.) to contact and how best to contact them when you had a question or problem?

Information needs

- What kind of information do you think you need about your condition?
- What kind of information would help you make decisions about your care (e.g. deciding on treatment for your PC)?
- How do you get the information you need? How would you prefer to get the information?
- Have you ever searched the Internet for information regarding prostate cancer (PC)?
- Did you find the information you were looking for?
- Do you use any website related to PC on a regular basis?

- What kind of information would you like to be presented to you in the PHR?
(articles, news, videos, ...) (re-state PHR)
- Would you prefer to view only information related to your personal situation or all the information about PC?
- What other services or information could The Prostate Centre offer you that they haven't provided so far?

Medical Record access

The following questions are about your "desire" to have access to your medical record. Please be advised that access to personal medical information may not be granted to you in the context of this study as under the current Freedom of Information and Privacy laws, people cannot independently access their health records from clinics, doctor's offices, hospitals etc without a formal application process.

- Would you like to have access to your medical record (e.g. blood tests, pathology, doctor notes, radiology reports or images, etc.)? Why?
- What kind of information would you like to have access to if you had access to your health record?
- How frequently do you think you will check you information if you had access to your health record?
- How would you like to access or receive your medical records (e.g. phone call, by mail, email, using a PHR, using a website, on your mobile phone)?

Communications

- What method do you use to communicate with your care provider if you had a question? (In person, telephone, electronically, ...) Why?
- Have you ever sent an email to your doctor?
- How long did it take to get a reply?

- Did you feel a need for elaboration?
- Did you find it an effective method of communication?
- Did you find it a convenient method of communication?
- Do you think that PC patients should be in regular contact with a care provider?

Self monitoring

- Do you track your PSA levels or other blood tests (please specify)? Why?
- How do obtain the results?
- Where/How do you keep the laboratory results?
- What would you do if the level were not normal?
- What other items do you have to track regularly? (weight, blood pressure, ...)
- Generally, what do you record about your disease?

Peer-to-peer communication & support

- Do you attend any support group?
- Do you find it useful?
- Do you talk to other PC patients regularly?
- Do you share your experiences with other PC patients? How? (face to face, etc)
- What do you think of online discussion boards and social networking websites?
- Do you think they are useful for prostate cancer patients to share their experiences?
- Do you prefer to remain anonymous if you were using online communications such as discussion boards?

Medical Research

- Did you receive timely information on research studies that you might be interested in participating in?
- What kind of information about prostate cancer research or studies would you want to receive, and how would you want to receive it?

Treatment related needs (Post-decision Making group only)

- Have you forgotten and missed any treatments or appointments (e.g. hormone therapy injection, blood test, doctor's appointment)?
- Would you like a reminder for appointments or treatment?
- Did you have clear instructions on how to receive your treatment?
- Did you have enough information on treatment side effects, possible complications and expected outcome?
- Did you have problems with access to medications or requesting medications?

Follow-up care needs (Post-decision Making group only)

- Do you have any concerns about your follow-up care after treatment?
- What are your needs during follow-ups?
- Do you have enough information about side effects or complications after treatment?

Other Possible PHR Tools

- Can you think of any other tools or functions for a PHR?

Appendix 4: Usability testing tasks (Phase 3)

Please complete the following tasks while verbalizing your thoughts. If you think you cannot complete any task, skip it.

1. Use the following username and password to log into the website.
 - Username: john
 - Password: aa
2. Use “Patient Connect” section of the website to share your experience with other patients or ask a question.
3. Find some information about prostate cancer treatment options.
4. Find out how your PSA levels were during the year 2007.
5. Find out if you have any upcoming appointments. Describe the purpose, time, and place of the upcoming appointment (if any).
6. Logout

Appendix 5: Post Usability Testing Interview (Phase 3)

1. Do you feel that you successfully completed all the requested tasks?
2. Did you perform the requested tasks easily?
3. How did you find using the system in relation with other websites that you have used before?
4. How did you find the user interface? (i.e. font face, font size, colours, page layout,etc.)
5. Did you find useful information?
6. Was the information relevant to your particular situation?
7. How do you think about different types of representations? (for example different ways of showing PSA results)
8. If you are given access, would you use the system?

Appendix 6: Informed Consent (Phase 1)

Design and Development of a Personal Health Record for Prostate Cancer Patients

You are invited to participate in phase 1 of a study entitled “*Design and Development of a Personal Health Record for Prostate Cancer Patients*” that is being conducted by Avesta Razavi.

Avesta Razavi is a graduate student in the school of Health Information Science at the University of Victoria, and you may contact him if you have further questions by email (arazavi@uvic.ca) or phone (778-668-2006).

As a graduate student, I am required to conduct research as part of the requirements for a master’s degree in health information science. It is being conducted under the supervision of Dr. Andre Kushniruk. You may contact my supervisor at (250) 472-5132.

Purpose and Objectives

The purpose of this phase of study is to seek informational needs and desired functionalities/features of prostate cancer patients to be used in the design and development of a web-based personal health record. The resulting system will be implemented in The Prostate Center of Victoria, BC, community-based health organization that serves men with prostate cancer by focusing on offering up-to-date information and educational material, patient navigation through the healthcare system, counselling, survivorship, and providing assistance with follow-up care

Importance of this Research

Research of this type is important because it involves patients in the design process of the PHR by surveying their needs early in the design and development process of the system. Engaging users in the development of a PHR will result in a system that is based on users’ needs and has more chance to be adopted and used by its potential users.

Participants Selection

You are being asked to participate in this study because you are someone who has had a diagnosis of prostate cancer and are either beginning, currently involved in, or has finished your course of treatment, and you have been referred to The Prostate Center.

What is involved?

If you agree to voluntarily participate in the phase 1 of this research, your participation will include filling a 2 page form regarding computer/Internet/cell phone use, a brief one page demographic form, and participating in a one-on-one interview with the investigator. The interview will take up to an hour. The interview will be conducted in The Prostate Center and will be audio recorded. The audio file will be transcribed verbatim for further analysis. The transcription will be done by a transcriptionist who has signed a confidentiality agreement for the purpose of this project.

This study will also include testing the designed system in a phase 3. You may be invited to take part in that phase too. Your participation will include using the developed web-based personal health record by performing pre-determined tasks. You'll be asked to think aloud (verbalize all your thoughts) while working with the system. Your think aloud will be recorded and transcribed for further analysis. The computer screen will be recorded as well.

You will be provided with a separate informed consent form if you are invited to take part in phase 3.

Risks

The only known risk is the inconvenience of travel and the time spent in the Phase 1 interview and/or Phase 3 testing.

Compensation

The Prostate Centre will compensate the travel expenses for participants traveling from outside Victoria. This compensation includes 0.51\$/Km. **Benefits**

The potential benefits of your participation in this research to you include contributing information to assist with the design of personal health record systems for prostate cancer patients that may be used in the future to benefit your healthcare and information needs.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study, your data will not be used.

Anonymity

In terms of protecting your anonymity, a two digit number will be assigned to you at the beginning of the study. All forms filled by you as well as the audio file and its transcription will be coded using that number. Your name will not appear on the forms or

on the digital file names. Your identity will not be revealed if the results of this study is published or presented.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected. Only the researchers will have access to the information obtained from you. Your name will not be used in the study report or any other publication.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the form of a master's thesis. The results will be presented in the oral examination before the board of examiners.

Disposal of Data

Data from this study will be disposed of upon completion of the thesis defence. All digital files will be permanently deleted and paper documents will be shredded.

Contacts

Individuals that may be contacted regarding this study include Avesta Razavi (investigator) and Dr. Andre Kushniruk (advisor).

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca) or by contacting the Vancouver Island Research Ethics Office at (250) 370-8620.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

_____ (Participant to provide initials)

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix 7: Informed Consent (Phase 3)

Design and Development of a Personal Health Record for Prostate Cancer Patients

You are invited to participate in phase 3 of a study entitled “*Design and Development of a Personal Health Record for Prostate Cancer Patients*” that is being conducted by Avesta Razavi.

Avesta Razavi is a graduate student in the school of Health Information Science at the University of Victoria, and you may contact him if you have further questions by email (arazavi@uvic.ca) or phone (778-668-2006).

As a graduate student, I am required to conduct research as part of the requirements for a master’s degree in health information science. It is being conducted under the supervision of Dr. Andre Kushniruk. You may contact my supervisor at (250) 472-5132.

Purpose and Objectives

The purpose of this phase of the study is to test the developed web-based personal health record in order to determine the level of its usefulness and user-friendliness. The resulting system will be implemented in The Prostate Center of Victoria, BC, community-based health organization that serves men with prostate cancer by focusing on offering up-to-date information and educational material, patient navigation through the healthcare system, counselling, survivorship, and providing assistance with follow-up care

Importance of this Research

Research of this type is important because it involves patients in the design process of the PHR by surveying their needs early in the design and development process of the system. Engaging users in the development of a PHR will result in a system that is based on users’ needs and has a better chance to be adopted and used by its potential users.

Participants Selection

You are being asked to participate in this study because you have participated in the phase 1 of this study (interview). Your selection for phase 3 of the study was based on convenience and your expressed interest.

What is involved?

You have already participated in the phase 1 of this study which included a one-on-one interview. If you agree to voluntarily participate in this phase of research (phase 3), your participation will include using the developed web-based personal health record by performing pre-determined tasks. This session will take up to half an hour. You'll be asked to think aloud (verbalize all your thoughts) while working with the system. Your think aloud will be recorded and transcribed for further analysis. The computer screen will be recorded as well. The transcription will be done by a transcriptionist who has signed a confidentiality agreement for the purpose of this project.

Risks

The only known risk is the inconvenience of travel and the time spent in the Phase 3 testing.

Compensation

The Prostate Centre will compensate the travel expenses for participants travelling from outside Victoria. This compensation includes 0.51\$/Km.

Benefits

The potential benefits of your participation in this research to you include contributing information to assist with the design of personal health record systems for prostate cancer patients that may be used in the future to benefit your healthcare and information needs.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study, your data will not be used.

Anonymity

In terms of protecting your anonymity, a two digit number will be assigned to you at the beginning of the study. All forms filled by you as well as the audio file and its transcription will be coded using that number. Your name will not appear on the forms or on the digital file names. Your identity will not be revealed if the results of this study is published or presented.

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Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

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Signature

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