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Designing a Service Framework for Electronic Personal Health Records: A Patient-Centred Approach

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ABSTRACT

With the increase in the prevalence of diabetes and the resultant greater demand for diabetes services, and with fewer resources to pay for them, diabetes has become a multi-billion dollar economic burden the world over. Electronic personal health records (ePHRs) have been positioned as transformational agents that facilitate productive interactions between patients and their healthcare providers, and support self-management of chronic diseases such as diabetes. In keeping with a patient-centred model of care, healthcare services such as ePHRs that incorporate patients' preferences and level of activation are being sought to increase and sustain patients' utility of these services. This study examines patients' preferences for the attributes of an ePHR service that supports diabetes self-management. It also explores factors that might influence their preferences.

Conjoint analysis, one of the most widely used approaches to predict consumer preferences was chosen for this study. Specifically, adaptive choice-based conjoint analysis was used to identify the attributes of a winning ePHR service framework. Using Sawtooth Software's suite of interviewing products, a web-based survey was developed comprising six ePHR service attributes. Hierarchical Bayes estimations were used to quantify patient preferences while latent class analysis was used to segment the sample. Additional statistical analyses were conducted to identify any significant relationships between patient characteristics and their preferences.

A stratified sample of 150 patients with Type 1 diabetes, Type 2 diabetes, and Prediabetes were unwavering in their preference for an internet-based ePHR service supplied by a physician or specialist. They also preferred to exchange their health information with their physician or nurse, once a month, at no cost. Monthly service fees were considered the most important ePHR service attribute. These results were applied in market simulations and sensitivity analyses to uncover the more complex effects of the ePHR attributes on the overall utility of the service. Exchanging health information every two to three months as opposed to once a month, and offering an ePHR service in the form of a monitoring device as opposed to an internet-based application, may be viable options. Selling an ePHR service directly to patients via a commercial supplier had a negative impact on the utility of the service. This research also shows that it would be prudent to take patients' ages and perceived health status into consideration when developing and marketing an ePHR service. Surprisingly, patients' level of activation for self-management did not appear to play a major role in influencing their preferences for the attributes of the ePHR service framework identified in the study.

Keywords: electronic personal health records, PHR, ePHR, patient preferences, patient activation level, adaptive choice based conjoint analysis (ACBC), diabetes, self-management, chronic care

INTRODUCTION

Today, primary care in Ontario is transitioning from an acute model of care to a more integrated and supportive chronic disease prevention and management framework based on Wagner's Chronic Care Model (CCM). The aim of such a model is to transform patient care from acute and reactive to proactive, planned, and population-based (Coleman, Austin, Brach et al., 2009). Integrating patients into the disease management process is an essential component of the CCM, and calls for an activated, proactive patient. Health information technologies are being developed to support the CCM to optimize not only the delivery of care, but the patient experience, their quality of care, and their health outcomes. Electronic personal health records (ePHRs), in particular, are being positioned to help organize patients' health information, as well as support the behaviour changes necessary for self-management of their chronic conditions at home.

Diabetes, one of the more prevalent chronic diseases, is associated with high medical costs and lost productivity that result in an economic burden estimated to be in the billions of dollars in both Canada and the United States (Dall, Zheng, Chen et al., 2010). Due to these sobering statistics and the fact that diabetes has been the focus of provincial healthcare strategies and primary care quality improvement initiatives, diabetes was the chronic disease chosen for this ePHR study. It is within the context of diabetes that this study seeks to inform the design of an ePHR service framework that supports patients' chronic disease self-management. The objectives of this study were to 1) gain a better understanding of patients' preferences for the combinations of features and functions that make up an ePHR that supports diabetes self-management and to 2) determine the relationships, if any, between various patient demographics, including their level of activation for self-management, and their preferences for these ePHR features and functions.

Methodologies from the field of marketing research, with their depth of understanding and expertise in consumer behaviours, were chosen for this study. Conjoint analysis, one of the most widely used and extensively studied approaches to predict consumer preferences (Cunningham, Deal, Rimas et al., 2008) was applied. Specifically, adaptive choice-based conjoint (ACBC) analysis was used to elicit and quantify patient preferences for the features and functions of an ePHR that supports diabetes self-management.

This paper proceeds as follows. First, the background for the study is presented, followed by the methods section which describes the steps used to design and implement an online ACBC survey for patients with diabetes. Results of the study are then presented together with discussion and interpretations, followed by conclusions, study limitations, contributions to theory and practice, and suggestions for future research.

BACKGROUND

The Burden of Chronic Disease

Chronic diseases are responsible for 59% of all deaths and 46% percent of the global financial burden of disease and this growing burden threatens the sustainability of healthcare systems worldwide (Coleman, Austin, Brach et al., 2009). In Canada, nearly two in five adults have at least one of seven common chronic conditions including: arthritis, cancer, chronic obstructive pulmonary disease (COPD), diabetes, heart disease, high blood pressure, and mood disorders, such as depression. The prevalence of chronic diseases in Canada is projected to increase by 15% (Russell, Dahrouge, Hogg et al., 2009). Chronic conditions are more prevalent as people age, and having multiple chronic conditions, which is common, tends to make people's health problems more complex (Health Council of Canada, 2010). Primary health care, with its adoption of the Chronic Care Model, is beginning to make the shift from the single-disease focus of the past, to an approach that better handles the complexity of chronic disease prevention and management.

The Chronic Care Model

The Chronic Care Model (CCM) is now accepted worldwide as a blueprint for healthcare transformation, especially in the primary care community. It consists of six essential elements of a health care system that facilitate high-quality care, including: community resources and policies, health system organization of care, self-management support for patients, delivery system design, decision support systems that enhance adherence to evidence-based guidelines, and clinical information systems. In combination, these six elements have the potential to improve health outcomes by enhancing the interactions between patients, their families, and their healthcare providers (Hung, Rundall, Tallia et al., 2007).

Central to this model are activated patients who take a proactive role in managing their health on a day-to-day basis. Emphasis is placed on self-management of chronic disease, which for patients means having the skills and opportunity to be effective participants in their own health care. More actively involved patients who have good self-management skills can recognize when they have a problem and have the confidence to take appropriate action, which tends to result in better outcomes whether measured by satisfaction or by clinical parameters (Whittle, Conigliaro and Good, 2007 and HCC, 2010).

Diabetes

Diabetes Mellitus is the chronic disease of interest in this study. Referred to simply as diabetes, it is a group of metabolic diseases associated with abnormally high levels of glucose in the blood. This is due the body's inability to produce and/or properly use insulin; the body's regulator of energy and glucose metabolism. The underlying causes of diabetes differ by type, but they include genetics, environmental factors, history of gestational diabetes, excess weight, and a sedentary lifestyle (Dall, Zheng, Chen et al., 2010). Diabetes can lead to serious complications such as heart attacks, stroke, kidney disease, eye disease and premature death; however, controlling the disease can lower the risk of these complications (Public Health Agency of Canada, 2008).

Diabetes affects an estimated 285 million people worldwide. This total is expected to rise to 438 million within 20 years (International Diabetes Federation, 2010). In Canada, the projected increase of diagnosed diabetes will bring the number to 2.4 million by 2016 (Lavis & Boyko, 2009). The medical costs for people with diabetes are two to three times higher than for those without the disease. In 2005, the Canadian federal, provincial and territorial governments spent an estimated $5.6 billion to treat people with diabetes and its related complications (Lavis & Boyko, 2009).

Patients with three types of diabetes were recruited for this study, including those with Type 1 diabetes (T1D), Type 2 diabetes (T2D) and prediabetes. T1D occurs when the beta cells of the pancreas are destroyed by the immune system and can no longer produce insulin. T1D usually develops in childhood or adolescence and an external supply of insulin is necessary for the body to function. There is no known way to prevent T1D. T2D occurs when the body does not make enough insulin and/or does not respond well to the insulin it does make. People are usually diagnosed with T2D after the age of 40, although it is now also being seen in younger adults, adolescents, and children. Prediabetes (also called borderline diabetes) is a practical and now much-used term that refers to specific glucose impairments. When glucose levels are elevated but still below the threshold for a diabetes diagnosis, the risk of developing diabetes and its complications is high. Not all people with prediabetes will progress to diabetes and many who are diagnosed with prediabetes may revert to normal glycemic levels (Canadian Diabetes Association (CDA), 2008).

Successful diabetes management involves monitoring a number of different glucose levels. Two of the glucose tests referred to in this study include blood glucose monitoring by patients in their homes, and Hemoglobin A1c (HbA1c) testing which is usually performed in a clinic or laboratory. Home monitoring provides a snapshot of how well a patient is doing at that moment in time, while HbA1c tests measure a patient's average blood glucose levels maintained over a three month period. The HbA1c measure has been proven to be a much more accurate indicator of diabetes management (CDA, 2008).

Patient Preferences and Activation for Self-Management

To optimize their health, patients with diabetes are advised to adopt and maintain the central tasks of diabetes self-management including: practicing healthy lifestyle behaviours related to nutrition and exercise, taking medications as prescribed, self-monitoring blood glucose, and seeking medical care as appropriate. Until there is a cure for diabetes, these behaviours and activities must be sustained for a lifetime (Schechter and Walker, 2002).

Even though it is recognized that patients' opinions about their roles in diabetes management is an essential aspect of diabetes care, in practice, patients are not routinely asked about their opinions and preferences regarding their diabetes education and advised lifestyle changes (Wu, Chang and Courtney, 2008). Aligning programs and interventions with patients' preferences could improve their effectiveness by improving adoption of, satisfaction with, and adherence to clinical treatments and healthcare programs. Understanding patients' preferences is also vital to the optimal design and evaluation of healthcare interventions such as ePHRs, and ultimately may

result in licensing, reimbursement and policy decisions that better reflect the preferences of stakeholders, especially patients (Bridges, 2009).

Patient activation is the least well-developed element of the CCM (Hibbard, Mahoney, Stock et al., 2007) and although there is strong agreement that patients need to be more engaged and proactive about their care and their health, there is much less agreement about how to best achieve this (Hibbard, 2009). Not all patients benefit from self-management interventions, for instance, patients who are able to maintain their HbA1c measures close to 7% may already have well-developed self-management strategies and knowledge and may be able to manage their diabetes with minimal intervention by their healthcare providers. Therefore, it may be of value to assess diabetes knowledge and skill levels prior to introducing interventions that have as their goal to "up-skill" patients with diabetes (Costa, Fitzgerald, Jones et al., 2009). Patient activation measurements could be used to identify patients who are less likely to be compliant, and who need more help to follow recommendations and self-management strategies (Remmers, Hibbard, Mosen et al., 2009). Tailoring disease specific programs and interventions to augment patient activation can improve the quality of care patients receive, improve patient-provider communication (Alegria, Sribney, Perez et al., 2009), improve self-management skills (Fowles, Terry, Hibbard et al., 2009), save time and resources, and result in better health outcomes (Remmers, Hibbard, Mosen et al., 2009). The Patient Activation Measure™ (PAM) developed by Judith Hibbard and licensed by Insignia Health, was applied in this study to determine each patient's level of activation for self-management.

Conjoint Analysis

Conjoint analysis is a stated-preference interviewing method that is grounded in consumer theories and disciplines such as psychology, economics, decision sciences and marketing. It is used in the field of market research to quantify consumer preferences for various attributes of products and services and can be used to help with product design, line extensions, pricing research and market segmentation etc. Conjoint studies are increasingly being used in healthcare and medicine as a means to understand how patients and other stakeholders perceive and value different aspects of their health and healthcare interventions. Conjoint analysis has been applied successfully to the measurement of patient preferences for the attributes of a model of patient-centred care in hospitals (Cunningham, Deal, Rimas, et al., 2008). It has also been applied to a diverse range of healthcare applications from cancer treatments, HIV testing and treatment, dermatology services, asthma medications, genetic counselling, weight-loss programs, insulin therapy in Type 2 diabetes, diabetes prevention programs, colorectal cancer screening, to treatments for Alzheimer's disease (Bridges, Hauber, Marshall et al., 2008).

The underlying theory of conjoint analysis is that consumers view products as composed of various attributes and levels. In a conjoint study a product or service is decomposed into its constituent parts. Respondents in a conjoint study place a certain utility or value on each of the product attributes. They express their preferences for products by responding to changes in the product's underlying attribute levels. By observing how respondents evaluate products in this way, the impact or utility that each attribute level has on the overall product preference can be estimated. Once preferences for the various attribute levels are derived, simulations can be performed to predict how consumers might respond to any potential combinations of levels that

define a product or service. Adaptive choice-based conjoint (ACBC) methodology, applied in this study, is one of many ways of conducting conjoint analysis.

ACBC is a customized interactive survey experience conducted over the web. Typically, an ACBC module is incorporated into a longer web-based questionnaire containing standard survey questions. The ACBC module "learns" from previous responses in order to make choice options presented to survey respondents as relevant as possible. This adaptive feature gives the respondents a unique sense that their preferences are being considered as they "build" a product of their liking. Research shows that an ACBC study is perceived as more engaging and relevant to respondents, although it tends to take longer to complete than traditional choice-based conjoint studies (Sawtooth Software Inc., 2010). This ACBC feature is computer-dependant which makes a paper-and-pencil form of the survey obsolete.

A central task in the design of an ACBC study is the identification of a product or service in terms of its components, called attributes and levels. The main attributes are used to characterize, or potentially characterize, an overall product or service. The associated levels encompass a range of options that may be desirable to people even if hypothetical or not feasible given current technologies or state of the industry. In this study, the attributes of an ePHR service that supports diabetes self-management were identified.

The Concept of an ePHR Service

An electronic personal health record has been positioned as a tool that will enable patients to play a more active role in their self-management activities (Detmer, Bloomrosen, Raymond et al., 2008). Currently, however, there is no uniform definition of ePHRs. This is due to the fact that their form, meaning, scope and nature of content etc., continues to evolve as technology evolves and as a chronic disease progresses (NCVHS, 2010 and Steele & Lo, 2006). In general, an ePHR can be described as a "set of computer-based tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it" (Steele & Lo, 2006). ePHRs support the CCM by strengthening the partnership between healthcare providers and patients by providing access to needed information and decision support tools so that healthcare decisions and procedures can respect patients' needs and preferences. They also help improve the documentation of communication with patients and other healthcare providers, and support patients' home monitoring efforts (Demiris, Afrin, Speedie et al., 2008 and NCVHS, 2010).

Because of the diversity in ePHR design, function, and benefits, the attributes used to describe an ePHR in this study were based on the needs of patients for frequent communication and care coordination when managing their diabetes. The concept of an ePHR as a coordinated, patient-centred, timely and efficient, evidence-based and safe service was drawn from the extended CCM model developed by the MacColl Institute (Improving Chronic Illness Care, 2010). This model is illustrated in Figure 1. Copyright (1996-2010) to display this model was provided by the MacColl Institute. The Improving Chronic Illness Care program is supported by The Robert Wood Johnson Foundation, with direction and technical assistance provided by Group Health's MacColl Institute for Healthcare Innovation. Attributes of an ePHR service that enable patients to gather and share measurements and observations with their care providers were identified.

These included the self-management activities patients engage in to manage and control their diabetes, who they would like to share their health information with, how often, using what medium, supplied by who, and at what cost.

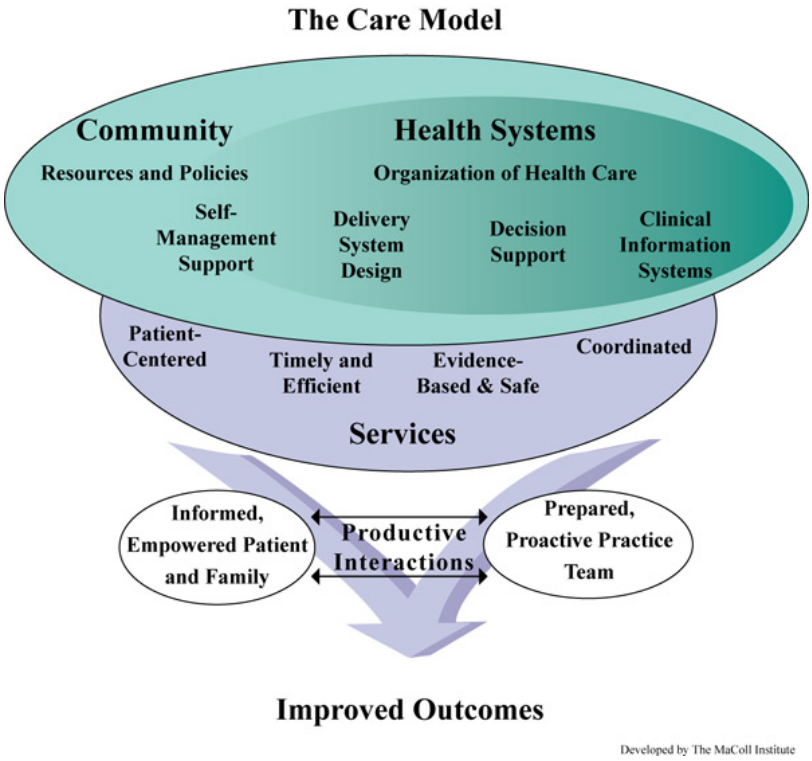

Figure 1 - Extended Chronic Care Model developed by the MacColl Institute

The results of this study are intended to inform the design of an ePHR service framework that supports chronic disease self-management. This information is required by the developers of information and communication technology (ICT) service models, whether the ICT service is based on subscription fees, on demand, pay as you go, pay per event or transaction, etc. At the same time, this information is also required by the developers of ePHR business models, whether the ePHR business model is utility-based, or based on software as a service, a platform, or web-based. Consensus is that any ePHR service must be flexible, customizable and adaptable. The Methods section that follows describes the steps taken to design and implement an adaptive choice-based conjoint survey that is just that – flexible, customizable and adaptable, not unlike the ePHR service framework it is intended to inform.

METHODS

Designing an ACBC Study

The process to create and field an ACBC study typically consists of four main steps: 1) understanding the product or service; 2) designing the conjoint study; 3) fielding the survey; and 4) analyzing the conjoint and non-conjoint data. Sawtooth Software's (SSI) Web v 7.0.2 suite of internet-based survey products were used to create a web-based survey consisting of an ACBC module together with traditional structured survey questions. Each step, as it was applied in this study, is described below.

Step 1: Understanding the Product or Service

The purpose of Step 1 is to understand a product or service so that it can be deconstructed into meaningful attributes and levels. A literature review and qualitative research methods such as interviews and focus groups are usually conducted to complete this investigation. A scoping review of the literature and other industry-related publications was conducted to gain an understanding of an ePHR as a communication tool and service that supports diabetes self-management. Six ePHR attributes were chosen to reflect this, including Self-Management Tasks, Exchange Partner, Frequency of Exchange, Exchange Medium, ePHR Service Provider and Monthly Service Fee. The development of each attribute's associated levels is discussed below.

Self-Management Tasks

The needs of patients and the strategies they use for managing diabetes are diverse. There are however some common self-management activities that are effective in controlling diabetes and reducing further complications. The results and observations from engaging in these activities can be recorded and monitored by patients and shared electronically in an ePHR.

The Association of American Diabetes Educators (AADE) believes that measurable behaviour change is the desired outcome of diabetes education and that behaviour change can most effectively be achieved using the AADE7™ Self-Care Behaviors framework. The seven self-care behaviours identified in this framework include healthy eating, being active, monitoring blood glucose, taking medication, problem solving, reducing risks and healthy coping. These overarching behaviours fall into two major categories: self-management behaviours and disease-specific self-management behaviours. Table 1 displays the activities recommended for diabetes self-management, as specified by the AADE.

Self-Management Behaviours	**Disease Specific Self-Management Behaviours for Diabetes**
• Engage in regular exercise. • Follow a low fat diet. • Read food labels for content. • Manage stress in a healthy way. • Know recommended weight. • Able to maintain recommended weight. • Ask about medication side effects when taking a new prescription. • Read about side effects when taking new prescription medication.	• Test glucose at least three times a week. • Check feet for cracks and calluses. • Keep a written diary of glucose levels. • Take diabetes medications as recommended.

Table 1 – Diabetes Self-Management Behaviours

The levels identified for the Self-Management Task attribute were abstracted from the AADE7™ Self-Care Behaviors framework and included self-monitoring of blood glucose, together with the main activities that influence glucose levels including managing diet, physical activity, and medications.

Exchange Partners

The majority of adults with diabetes seek their care from primary care providers (Crosson, Heisler, Subramanian et al., 2010). In accordance with the CCM, primary care office visits are becoming more multidisciplinary (Corser and Xu, 2009) and patients therefore have an opportunity to engage a variety of different people in their care. In Ontario, most diabetes care is provided by family physicians (Lavis & Boyko, 2009), yet nurses may be especially suited to implementing and delivering supportive diabetes self-management initiatives in typical office settings (Corser and Xu, 2009). Due to their relationship and proximity within a primary care office, these two healthcare professionals were grouped together as a level within the Exchange Partner attribute.

Piette (2007) found that the services involving Interactive Behavior Change Technology (IBCT) to support diabetes self-management resulted in more targeted disease-specific communication between patients and their caregivers. Caregivers in this context included family, significant others and/or friends. He also suggested that these technologies may enable access to greater support for day-to-day self-care and may provide caregivers with the tools they need to be more effective.

As well, disease management approaches that incorporate peer support may be a promising way to provide the self-management support required by patients with diabetes (Brownson, 2009 and Piette, 2007). Trained peers who are successfully managing their own diabetes, and who provide patient-to-patient support, can play a unique role that complements clinical care. Family members and peers were grouped together as another level within the Exchange Partner attribute. Together they represent the non-professional care providers patients might like to exchange their personal health information with.

Pharmacists were also included as potential ePHR Exchange Partners. They are currently being integrated into primary care teams to implement e-Prescribing systems and to create objective adherence reports that will improve the quality of diabetes medication adherence and counselling (Piette, 2007). In primary care, Specialists, Diabetes Educators and Social Workers are also found within a patient's circle of care and were therefore included within the Exchange Partner attribute.

Frequency of Exchange

Typically, the exchange of information through an ePHR involves some form of secure email or messaging between the patient and provider. Yet, despite increasing attention in the literature, few studies have comprehensively examined the frequency of physician-patient email use or the factors associated with this function (Brooks & Menachemi, 2006).Guidelines for physician-patient electronic communication have been established in both Canada and the U.S. and suggest

that physicians establish a turnaround time for electronic messages in order to manage patient expectations (CMA, 2005 and AMA, 2010). Few physicians make use of these guidelines let alone establish communication frequency intervals. Although specific intervals of use were not reported in the literature, frequent use of electronic secure messaging was found to be associated with better glycemic control and increased outpatient healthcare utilization (Harris, Haneuse, Martin, et al., 2009). Because of the lack of specific exchange frequency guidelines for technologies like secure messaging, other areas of patient care that involve frequent intervals of contact between patient and provider were sought to inform the levels of the Frequency of Exchange attribute.

In traditional care patient revisit intervals range from 1 month to over 1 year with the most common recommended intervals being 2, 3, or 6 months (Welch, 1999). In practice, and in accordance with the Canadian Diabetes Association (CDA) Guidelines (2008), patients are encouraged to attend and physicians are incented to conduct office visits every 3-6 months at which time patients' HbA1c blood glucose measurements are taken. Blood pressure is measured at every visit and patients are screened annually for complications of diabetes.

Frequency of exchange intervals might also be influenced by patient self-management of blood glucose (SMBG) habits. The CDA (2008) suggests that the "SMBG should be determined individually, based on the type of diabetes, the treatment prescribed, the need for information about blood glucose levels and the individual's capacity to use the information from testing to modify behaviours or adjust medication." For people with T1D, SMBG is an essential component of daily diabetes management and performing three self-tests per day was associated with a statistically and clinically significant reduction in HbA1c levels. The benefits and optimal frequency of SMBG in T2D are less clear than for T1D and current evidence is contradictory. Frequent testing of blood glucose in patients who are recently diagnosed, regardless of treatment, and for those with T2D using insulin, is thought to be an integral component of care. The CDA recommends testing once a day for those with T2D.

Using a combination of the revisit intervals mentioned above, the CDA diabetes care guidelines for physicians, and the SMBG guidelines for patients with diabetes, the Frequency of Exchange attribute was defined with the following levels: Daily, Weekly, Once a month, Every 2 to 3 months, Every 6 months, and Once a year.

Exchange Medium

A number of different technologies and tools have been developed to support patient self-management and care collaboration. The following technologies were incorporated as levels within the Exchange Medium attribute. ePHRs consisting of internet-based tools have been developed by companies like Google, Microsoft, WebMD, and health insurance plans (Tang & Lee, 2009). Stand-alone PHR applications that do not connect with any other system include mediums that store information on ''smart cards,'' USB drives, and CDs. (Tang, Ash, Bates et al., 2006). Remote monitoring technologies and devices that transmit clinical data from patients' homes to providers' offices, along with mobile technologies such as cell phones and Blackberries (devices currently at the heart of the mHealth movement) are considered communication mediums in this study. Kiosks, private booths strategically placed in clinics and pharmacies, for

example, are another means of facilitating health information exchange (Bensley, Mercer, Brusk et al., 2004). Printed copy was also included as a communication medium, since not all stand-alone ePHRs are portable. Taking a copy of monitoring results to a medical appointment enhances patient-provider communication and suggests that the patient is using a computer-based PHR.

ePHR Service Provider

Patients may create their own ePHR using commercially available applications developed by third-party vendors such Google, Microsoft, and WebMD (Tang, Ash, Bates et al., 2006). ePHRs are also currently supplied or sponsored by employers (e.g. Dossia, which is sponsored by Wal-Mart, BP and AT&T among others), and insurance companies (e.g. Shared Health Clinical Health Record™, which is sponsored by BlueCross) (Sunyaev, 2010). Some ePHRs are offered to patients by their healthcare providers (e.g. mydoctor.ca) as well, some ePHR services are being developed by patient advocacy groups and non-profit organizations like the Heart and Stroke Foundation of Canada. Government agencies such as eHealth Ontario, as well as hospitals are beginning to integrate their services into the community. Each of these service providers was added as a level to the ePHR Service Provider attribute.

Monthly Service Fees

Patients have shown an interest in paying between $2 and $25 per month for ePHRs in general and for a number of different ePHRs features including medical record storage and viewing, making appointment requests, accessing physicians through email, refilling medications, using blood glucose calculators, and for e-reminders (Accenture, 2007; Adler, 2006; Archer & Fevrier-Thomas, 2010, Deloitte, 2007; Bryce, 2007; El Emam, 2010). Yet, Karagiannis (2009), Bryce (2008), and Archer & Fevrier-Thomas (2010) report that patients tend to be opposed to paying anything for access to their health information. Based on this research the following range of monthly fees was associated with the Monthly Service Fee attribute: $0, $5, $10, $15, $20, and $25. This attribute has an *a priori* preference order, which means that a free ePHR service would be most desirable to most people. Because of this and as recommended by Sawtooth Software, the monthly service fee attribute was dropped from the Build Your Own section of the survey (this is described in the next section below). It was however incorporated in the screening and choice task sections of the ACBC survey (also described below).

Interviews

As well as identifying ePHR attribute levels through a review of literature, interviews were conducted with four healthcare providers to ensure that the medical terms and the concepts of diabetes self-management included in the survey were comprehensive and clear. Interviewees included a Diabetes Nurse Educator/ Site Leader of the Halton Diabetes Program, Burlington ON; a Chronic Disease Prevention and Management (CDPM) Practice Facilitator who created a paper-based PHR for patients of the Hamilton Family Health Team; the Manager of the Hamilton Family Health Team Nutrition Program; and a family physician and innovator of ePHRs for diabetes patients. Concepts that arose from the interviews included the prohibitive costs of diabetes supplies for patients, self-management concepts used in diabetes education

classes, and the complexity of diabetes care due to comorbidities. These concepts were incorporated into both the conjoint and non-conjoint survey questions.

Step 2: Designing the study

Key Attributes and Levels

The culmination of Step 1 led to the identification of six key attributes for an ePHR service for diabetes self-management along with their corresponding levels. Table 2 lists the attributes and levels used in the ACBC section of the online survey. In accordance with conjoint study guidelines, an attempt was made to balance the number of levels across all the attributes. Each of the attributes was composed of six levels except the ePHR Service Provider attribute. Seven levels were identified as being important for this attribute.

ePHR Attributes	Levels (Options)
Self-Management Tasks	• Diet & Physical Activity • Manage Medications • Monitor Blood Glucose • Monitor Blood Glucose + Diet & Physical Activity • Monitor Blood Glucose + Manage Medications • All options
Exchange Partners	• Physician or Nurse • Pharmacist • Diabetes Educator • Social Worker or Mental Health Counsellor • Specialist • Family member or Peer
Frequency of Exchange	• Daily • Weekly • Once a month • Every 2 or 3 months • Every 6 months • Once a year
Exchange Medium	• Mobile health application (using a cell phone, Blackberry etc.) • USB Flash Drive (memory stick) • Monitoring devices (using a glucometer, pedometer etc.) • Internet-based application (portal or website) • Kiosk (touch screen application in a clinic) • Printed copy

ePHR Service Provider	• Healthcare provider (e.g. physician or specialist) • Health Insurer (e.g. Blue Cross, Sunlife) • Commercial Supplier (e.g. Microsoft, Telus) • Government (e.g. Health Canada or Provincial Ministry of Health) • Employer • Canadian Diabetes Association • Hospital
Monthly Service Fee	• $0 • $5 • $10 • $15 • $20 • $25

Table 2 - ePHR Key Attributes and Corresponding Levels

Design Settings

The ACBC survey design settings were also determined in this step. Table 3 presents the design settings used in this study. These settings were pre-defined in the Sawtooth Software Web module as a guide and were not altered for this study. (Note: BYO = Build Your Own, this term is explained in the next section)

ACBC Design Settings	
Number of Screening Tasks:	8
Number of Concepts per Screening Task:	4
Minimum Attributes to Vary from BYO Selections:	1
Maximum Attributes to Vary from BYO Selections:	2
BYO-Product Modification Strategy:	Mixed Approach
Number of Must Haves:	2
Number of Unacceptables:	3
Maximum Number of Product Concepts Brought into Choice Tournament:	18
Number of Concepts per Choice Task:	3
Number of Calibration Concepts:	0

Table 3 - ACBC Survey Design Settings Used in the Study

Interview Flow

The ACBC portion of the survey consisted of 3 main sections: the build-your own (BYO) configurator, the screening section and the choice tournament.

The BYO configurator section introduced patients to the ePHR concept (Appendix A) and then to the ePHR attributes and levels (which were called "options" for clarity). Patients were asked to "build" their ideal ePHR service profile by choosing one option from each ePHR attribute. The BYO configurator screen used in the survey is presented in Appendix B.

The screening section of the survey was used to create ePHR service profiles that are similar to the BYO profiles built in the configurator section. Patients were asked to indicate whether or not the profiles displayed were acceptable or not. They were not asked to make final choices but were asked to indicate whether they would consider each one a possibility or not. *Must-Have* and *Unacceptable* questions were also included in the design of this section. These questions were based on choice patterns (previous answers). Patients were asked whether certain options must be included in their ideal ePHR solution. Identifying non-compensatory decision criteria like this helps create a more relevant patient experience and an evolving set of choice tasks, unique to the individual patient. Appendix C contains a sample of the screening questions used in the survey.

In the choice tournament section, patients were shown a series of ePHR profiles that included the surviving ePHR attributes and levels (those marked as possibilities in the screening task). Choice tasks were displayed in sets of three ePHR profiles at a time. Patients were asked to choose a "winner" among the three ePHRs displayed. An example of a choice task screen used in the survey is displayed in Appendix D.

Non-Conjoint Survey Design

Non-conjoint data was also gathered from the survey including traditional demographic data as well as perceived health status, patients' use of personal health records (paper or electronic), blood glucose monitoring habits, difficulty paying for diabetes supplies, and patient level of activation for self-management. Some of the scales used were drawn from established diabetes survey instruments. For instance, the perceived health status scale came from the Stanford University Patient Education Research Center (2010). The blood glucose monitoring questions came from the Diabetes Care Profile developed by Michigan Diabetes Research and Training Center (2010), and a research license was granted by Insignia Health for use of the 13-question Patient Activation Measure™.

Patient Activation

Research suggests that patient activation, a key component of the CCM, may be considered a moderator of how often and in what way patients access their ePHRs (Roblin, 2009). The Patient Activation Measure™ (PAM) developed by Judith Hibbard and colleagues assesses a patient's knowledge, skill, and confidence for self-management. Licensed and marketed by Insignia Health, it consists of a 10 or 13 question survey that asks people about their beliefs, knowledge, skills and confidence for engaging in a wide range of health behaviours. Evidence suggests that

there are four levels that people go through in the process of becoming fully competent managers of their own health (Hibbard et al. 2009). The PAM™ segments patients into one of four progressively higher activation levels. These stages of activation may provide insight into design strategies for ePHR services that support patient self-management. Appendix E contains a copy of the PAM™ questions used in the online survey. The different levels of activation together with samples of their related survey questions are documented in Table 4 below.

PAM Level 1
People do not yet grasp that they must play an active role in their own health, they may still believe that they can be a passive recipient of care. Example questions include: "When all is said and done, I am the person who is responsible for managing my health condition'' and ''Taking an active role in my own health care is the most important factor in determining my health and ability to function.''
PAM Level 2
People may lack the basic facts or have not connected the facts into a larger understanding about their health or recommended health regimens. Example questions include: "I know the different medical treatment options available for my health condition'' and ''I know what each of my prescribed medications does.''
PAM Level 3
People have the key facts and are beginning to take action but may lack confidence and skill to support new behaviours. Example questions include: ''I know how to prevent further problems with my health condition'' and ''I have been able to maintain the lifestyle changes for my health that I have made.''
PAM Level 4
People have adopted new behaviours but may not be able to maintain them in times of stress or health crises. Example questions include: ''I am confident I can figure out solutions when new situations or problems arise with my health condition'' and ''I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.''

Table 4 - Patient Activation Levels (descriptions and related questions)

Step 3: Fielding the pilot study and the final ACBC survey

Pilot Study

Using a McMaster University server located in the DeGroote School of Business (DSB), a pilot test was run with 25 locally recruited participants. Twenty patients with diabetes tested the survey and were compensated with a $25 drug store gift card. A software support person from Sawtooth Software, three PhD students and a Masters student from the McMaster University Information Systems Department, also tested the survey. Pilot study feedback was valuable and as a result the survey was enhanced for clarity and ease of use by rewording some of the instructional text and incorporating tool tips for quick reference to term definitions. The feedback also reflected the nature and functioning of a typical conjoint study including comments about

the greater length of time needed to complete the survey, the need for breaks in the text using graphics, and suggestions for the proper handling of the monthly service fee attribute.

Main Survey

The main survey was also fielded on a McMaster DSB server. Research Now (Toronto office), a commercial market research firm, was hired to facilitate the survey and recruit a stratified sample of 150 Canadian patients with diabetes. The study was restricted to adults (> 18 years old), living in Canada who had been diagnosed with either Prediabetes, Type 1 diabetes, or Type 2 diabetes. The sample quota was set at 50 patients for each type of diabetes.

Step 4: Analyzing conjoint and non-conjoint data

Sawtooth Software offers user friendly modules to conduct a number of analyses on the choice data generated from the survey, including, hierarchical Bayes (HB) estimations, importance measures, latent class analyses, market simulations and sensitivity analyses. A number of different statistical tests of variance were also conducted between the attributes, their levels and the sample demographic and non-conjoint data (covariates).

Hierarchical Bayes (HB) estimations were conducted in the SSI Web module to generate individual part-worth utilities for each ePHR level. Utility refers to patients' preferences for an overall ePHR concept, while the components of utility associated with each ePHR attribute level are called part-worth utilities.

Importance measures were used to characterize the relative importance of each ePHR attribute. These are study-specific, ratio-scaled scores that reflect the maximum impact, or the amount of difference, each attribute or level might have on the total utility of a specific ePHR design consisting of a combination of attributes. Each patient's part-worth utilities were used to calculate the importance scores.

Latent class analysis was used to identify segments of patients with similar preferences. This was accomplished by running the patients' SSI Web choice data through the Sawtooth Software Latent Class module (version 4.0.8). Using weighted averages, each patient's probability of belonging to a segment was determined. Custom segmentation using the covariates and Sawtooth Software Market Research Tools (SMRT) version 4.20 was also conducted.

Statistical tests of variance, using the General Linear Model approach in SPSS (PASW Statistic 18), were conducted on the ePHR attributes, levels and covariates (the latent class Segments, Type of Diabetes, Use of PHRs, PAM Level, Health Status and Age). These covariates were cross tabulated and analyses of variance (ANOVA) and multivariate tests of equality (MANOVAs) were conducted. All significant differences were identified, interpreted and summarized.

The Sawtooth Software *Market Simulator* (SMRT) was used to transform the raw conjoint utility data into shares of preference for different ePHR attributes. Sometimes average part-worth utilities do not tell the whole story and only by conducting market simulations and sensitivity

analyses can more complex effects of the attributes on the overall product be discovered. Shares of preference, which are more easily interpreted than part-worth utilities, were computed in the market simulations and sensitivity analyses. *Simulations* were run on the winning ePHR concept, as well as on three ePHRs constructed from products currently available to patients in the marketplace. Capturing any idiosyncratic preferences that might occur at the individual or group levels was the goal of the simulations. *Sensitivity analyses* were conducted to show how much an ePHR's overall share of preference can be improved or made worse by changing its attribute levels one at a time, while holding all other attributes constant.

The aim of the Results and Discussion Section that follows is to present the quantitative results as well as place them within the context of the ePHR field to date.

RESULTS and DISCUSSION

The final version of the online survey was fielded in May and June 2010. Of 153 completed surveys, three were considered unusable. In accordance with the PAM™ guidelines, two patients were disqualified because they appeared to be disinterested in the survey; they answered "Not Applicable" to more than five of the 13 PAM™ questions. A third survey record was deemed unusable by Sawtooth Software support staff. It was missing conjoint data that could not be retrieved. This was attributed to a software problem. A total of 150 completed surveys were therefore available for analysis.

Two main types of data were captured from the online survey: non-conjoint data and the conjoint (ACBC) data. The non-conjoint data (or covariates), which characterizes the total sample, included patient demographics as well as patients' perceived health status, difficulty paying for diabetes supplies, personal health record keeping habits, blood glucose monitoring habits, patient activation level for self-management and free-text comments about ePHRs. The ACBC data gathered, called choice data, was used to calculate individual part-worth utilities for all of the ePHR attributes and levels and to generate latent class segments of the sample. In the section below the study results are summarized and compared to the results of a timely and relevant study published in April 2010 by the California Healthcare Foundation (CHF) called the "National Survey of Consumers and Health IT."

Non-Conjoint Data Analyses

Demographics

Appendix F summarizes the characteristics of the sample. Most of the patients who responded live in Ontario (46%). The rest live in Alberta (10.7%), British Columbia (10.7%), and Quebec (9.3%) with smaller representation from the remaining provinces and territories. Females accounted for 52.7% of the sample while males comprised 47.3%. This demographic does not match the Canadian population who have diabetes in which 45% are female and 55% are male (Statistics Canada, 2009).

The majority of the sample was in the 50-69 age range (56.7 %) followed by those in the 30-49 age range (30%). This is in alignment with the Canadian population where 46% of people with diabetes are in the 65+ age range. Over 70% of the sample has some college or university education or more, in line with the Canadian population of internet users (Statistics Canada, 2009).

Fifty-five percent (55%) of the sample reported using PHRs either in paper or digital form. We can safely assume that the majority of the PHRs are in paper form, since only seven percent of adults in the United States are currently using an electronic PHR (CHF, 2010).

A priori segmentation of the sample by Type of Diabetes resulted in 49 patients with prediabetes, 48 patients with T1D, and 53 patients with T2D. Sixty-seven percent (67%) of the total sample have endured diabetes for up to 10 years. Eighty-two percent (82%) of the sample reported that they test their blood glucose. Of those that test blood glucose, 22% have prediabetes, 37% have

T1D, and 41 % have T2D. And of those that test, 96% have a device to do the testing. This suggests that the sample is very familiar with blood glucose monitoring devices, the data produced, and the associated costs of supplies for the devices. Sixty percent (60%) of the sample agree or strongly agree that paying for their diabetes treatments and supplies is difficult, thus we can assume that a fee-based ePHR will be met with some resistance.

Patient Activation Level

The PAM 13-measure instrument was used to assess patients' knowledge, skills and confidence for self-management. The ordinal question scores were converted into a 1-100 interval scale. The cut-off points for the four levels of activation, as supplied by Insignia Health, indicate that the higher the PAM score the greater the level of activation. The mean level of patient activation for the sample was 69.9. This equates to patient activation Level 4. It is suggested that people with Level 4 activation for self-management have adopted new behaviours required to keep their conditions in check, but may not be able to maintain these behaviours in times of stress or health crises (Insignia, 2009). Just over 80% of the sample were either in Level 3 (22.7%) or Level 4 (58%). Table 5 presents a distribution of patient activation levels for the sample by type of diabetes. Patients with T2D were found well distributed across Level 1 (63.9%), Level 2 (38.9%) and Level 3 (47.1%). The majority of patients at Level 4 (39%) had T1D. This makes sense considering people with T1D have been dealing with diabetes since their youth and therefore are more skilled and knowledgeable about managing their diabetes. No significant differences were found between type of diabetes and PAM level at the 5% level of risk.

Patient Activation Level	Total (n=150)	% of Total	Prediabetes (n=49)	% Prediabetes in each Level	T1 (n= 48)	% T1 in each Level	T2 (n=53)	% T2 in each Level
Level 1	11	7.3%	3	27.3%	1	9.1%	7	63.6%
Level 2	18	12.0%	6	33.3%	5	27.8%	7	38.9%
Level 3	34	22.7%	10	29.4%	8	23.5%	16	47.1%
Level 4	87	58.0%	30	34.5%	34	39.1%	23	26.4%

Table 5 - Level of Patient Activation for Sample by Type of Diabetes

Multimorbidities

When patients have more than one chronic condition (multimorbidity) it is challenging for them to deal with the volume of information necessary to manage all of their conditions. Multimorbid conditions may impair patients' functioning and may pose significant barriers to lifestyle changes and medication adherence, making standard diabetes self-care goals difficult to reach. These conditions compete for patients' time, energy, and financial resources (Piette, 2008). ePHRs can assist these patients by providing diabetes self-care information in smaller, targeted, and timely doses (Piette 2008). Interestingly, PHR users with two or more chronic conditions were most likely to say their PHR led them to do something to improve their health (CHF, 2010).

To further characterize the sample, patients were asked to indicate any or all other chronic diseases or conditions they have to deal with on a regular basis. As shown in Appendix F (demographics chart), high cholesterol and high blood pressure were the most frequently reported conditions. Stroke, cancer, heart disease and lung disease were much less reported. The other conditions reported by the sample included arthritis, depression, osteoporosis, and fibromyalgia, to name a few. A complete list of multimorbidities reported by the sample is presented in Appendix G. One of our survey patients commented, "I would want to see it manage all conditions, not just diabetes. Sometimes treatments for one ailment are not good for another ailment. All facts must be known to make good decisions." This illustrates the complexity brought about by multimorbidities.

Patient Comments

At the end of the survey patients were given an opportunity to enter unstructured comments about ePHRs. All free text comments, categorized by the themes that emerged, are presented in Appendix H. Most comments related to ePHRs in general, followed by self-management issues, costs of ePHRs, the benefits of sharing of health information and the frequency of sharing, as well privacy and security concerns, survey design comments and a comment about technology. These comments are incorporated into the presentation of the statistical analyses below and in the conclusions.

Conjoint Data Analyses

Before discussing the conjoint results, it is important to reiterate the difference between ePHR attributes and levels. *Attribute* refers to the six features that were used to define the ePHR service (Self-Management Tasks, Exchange Partner, Frequency of Exchange, Exchange Medium, ePHR Service Provider, and Monthly Service Fee). *Levels* represent specific options within an attribute. For example, the Frequency of Exchange attribute has "Weekly" as one of its six levels.

Importances of ePHR Attributes

After conducting the ACBC study, quantitative measures of preference for attributes and levels were computed. The measures that focus on the attributes are referred to as *importances*. Importances express the range between the most preferred and least preferred level of each attribute. This reflects the impact a particular attribute can have on the overall utility of or preference for an ePHR service concept. Table 6 presents the relative importances for each ePHR attribute. As expected, the Monthly Service Fee attribute had the most effect (26.26%) on the utility or appeal of the overall ePHR concept, as defined in this study. Interestingly, the Self-Management Task attribute had the least effect on the utility of the ePHR. This means that in the context of an ePHR service framework, the activities associated with diabetes self-management appear to be less important to the sample than other components of an ePHR service.

ePHR Attributes	Relative Importance (%)
Self-Management Tasks	8.89
Exchange Partner	13.96
Frequency of Exchange	16.72
Exchange Medium	16.73
ePHR Service Provider	17.44
Monthly Service Fee	26.26

Table 6 - Relative Importances of each ePHR Attribute

Part-Worth Utilities of ePHR Levels

The preference measures that focus on the ePHR levels are referred to as *part-worth utilities*. Part-worth utilities are simply numerical representations that express the value patients place on each level within an attribute. In this study, part-worth utilities were arbitrarily scaled to sum to 0 within each attribute (zero-centered differential). Because of this arbitrary scaling, the part-worth utility score of a level has no meaning by itself. Also, because a level receives a negative part-worth utility score does not mean that the level was unacceptable to the sample. In fact, the level may be acceptable to all patients. Appendix I displays the part-worth utilities for all levels numerically. Figure 2 below displays the part-worth utilities of each level graphically.

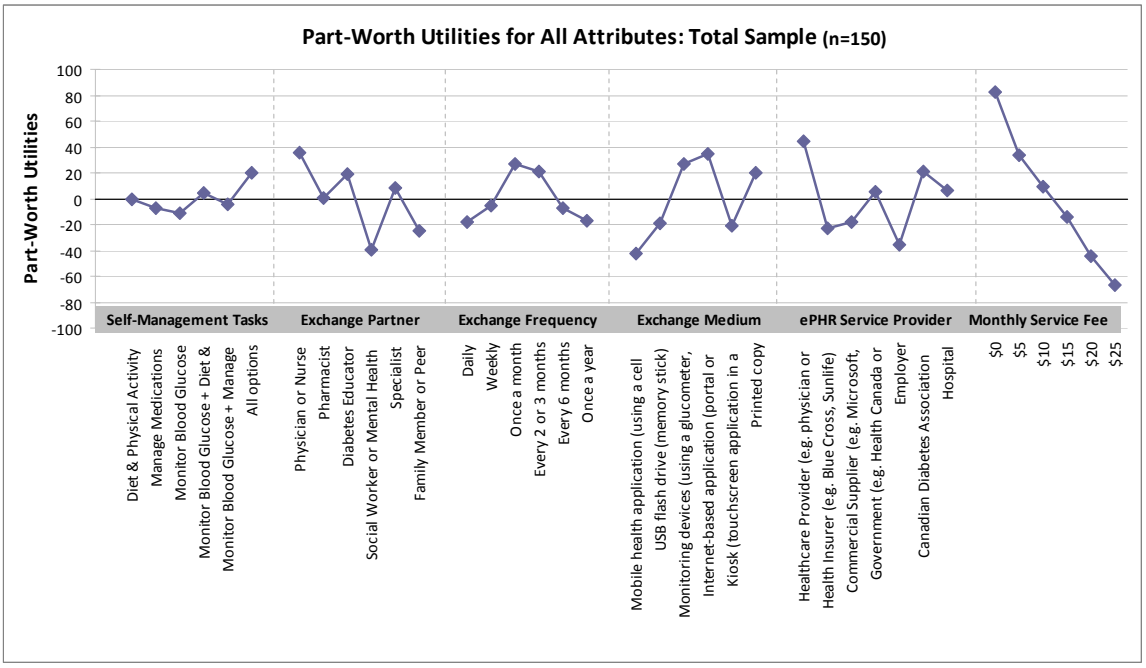

Figure 2 - Sample part-worth utilities for all ePHR attribute levels

It is important to note that when comparing part-worth utilities across attributes, **only the differences between levels can be compared.** For example, the difference between $0 and $5 (48.79 utiles) in the Monthly Service Fee attribute, is greater and therefore more important than the difference between Canadian Diabetes Association and Hospital (14.62 utiles) in the ePHR Service Provider attribute.

Winning ePHR Concept

The winning ePHR concept was derived from the part-worth utilities calculated for each of the ePHR levels. The levels that make up the winning ePHR concept have the highest part-worth utility scores; the higher the utility score the more desirable the level within that attribute. Table 7 presents the levels that make up the winning ePHR concept. Remember, don't compare part-worth utility scores across attributes.

ePHR Attributes	Relative Importance (%)	Winning Levels	Winning Level Part-Worth Utilities
Self-Management Tasks	8.89	All options	19.83
Exchange Partner	13.96	Physician or Nurse	36.04
Frequency of Exchange	16.72	Once a month	27.23
Exchange Medium	16.73	Internet-based application (portal or website)	34.60
ePHR Service Provider	17.44	Healthcare Provider (physician or specialist)	20.27
Monthly Service Fee	26.26	$0	44.37

Table 7 - The Winning ePHR Concept (n=150)

Segmentation by Latent Class Analysis

Latent class analysis was used to segment the sample according to patterns of preferences based on part-worth utilities for ePHR levels. A 2-group solution had higher probabilities of membership for almost all of its respondents, therefore it was chosen for analysis over a 3-group solution. The demographic characteristics of each segment are presented in Appendix J. The average part-worth utilities of Segment 1 (n=80) and Segment 2 (n=70) were identified using Sawtooth Software's market simulation module (SMRT). According to the relative importance scores, the overall Exchange Medium attribute was considered most important by Segment 1 (18.87%), whereas the overall Monthly Service Fee attribute was considered most important by Segment 2 (34.97%). The overall Monthly Service Fee attribute was found to be significantly related to Segments (F=19.424, p=0.000). Significant differences appeared at all Monthly Service Fee levels except the $10 level: $0 (F=133.42, p=0.00), $5 (Brown-Forsythe=32.81, p=0.00), $15 (Brown-Forsythe=32.60, p=0.00), $20 (Brown-Forsythe=131.36, p=0.00), and $25 (Brown-Forsythe=64.44, p=0.00). Segment 2 was observed to be more sensitive to monthly service fees.

For comparison purposes, Appendix K displays the part-worth utilities for both Segments and the overall study sample. Of note, Segment 2 preferred to exchange their health information every 2-3 months (pwu=22.45) while Segment 1 preferred an exchange frequency of once a month (pwu=31.44). Overall, the preferences of Segment 1 closely matched those of the total sample. Although some differences were observed between Segments, they were not persistent across all attributes and not enough to define two distinct groups within the sample.

Segmentation by Covariates

A number of non-conjoint variables (covariates), either alone or in aggregate, were also used to segment the sample. Type of Diabetes (Prediabetes, T1D, T2D), Gender, Patient Activation Level (PAM Level), and Health Status were merged into SMRT. Custom segments were created for each covariate and their average part-worth utilities were identified and compared. Overall, the shapes of the utility curves for Type of Diabetes and Gender were very similar to that of the total sample. This means that the winning ePHR concept was preferred by patients with any of the three types of diabetes and by males and females alike.

PAM Levels and Health Status were also used to segment the sample. Differences were observed in the Frequency of Exchange attribute. Figure 3 illustrates the variations starting to reveal themselves in the Frequency of Exchange attribute, in this case between the four PAM Levels. Patients at Level 2 activation for self-management tend to lack the confidence and understanding of their health or recommended health regimen. These patients preferred to exchange their health information 2-3 times per month (pwu=27.69) as opposed to the overall sample preference of once a month (pwu=27.23).

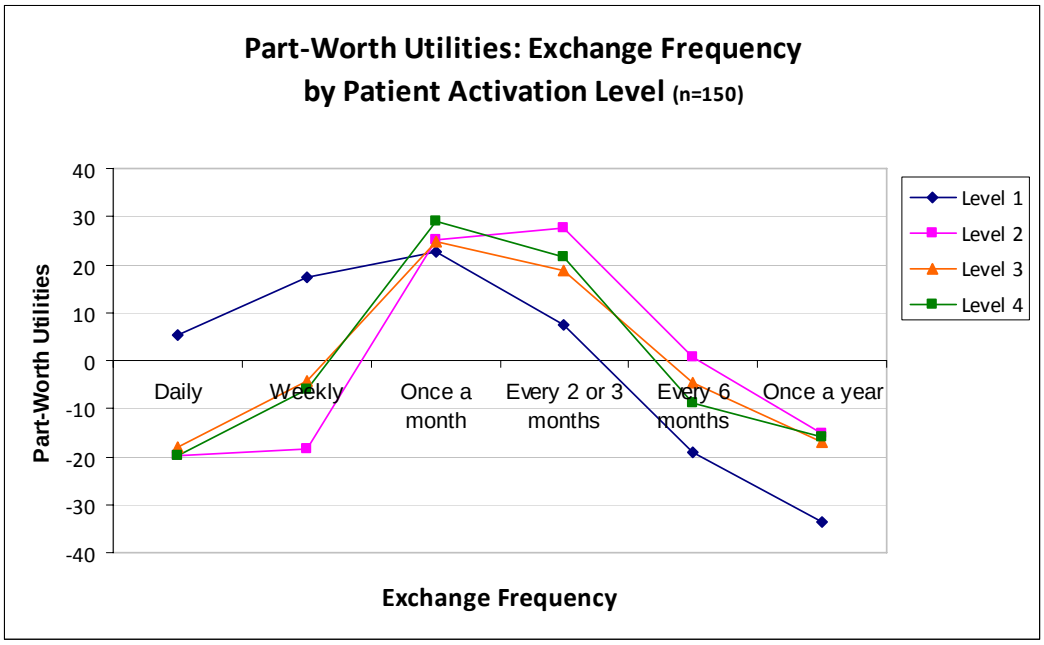

Figure 3 - Part-worth utilities for Frequency of Exchange by Patient Activation Levels

Figure 4 illustrates the Frequency of Exchange preferences by the five categories of Health Status. Patients who reported poor health preferred to exchange their health information less frequently, every 2-3 months (pwu=28.55). Patients who reported excellent health preferred the more frequent exchange of once a month. These results contradict some recent findings for frequency of in-office visits. Banerjee, Ziegenfuss, & Shah (2010) found that people who are healthy are likely to visit the doctor less often relative to those who self-identify as being in fair to poor health.

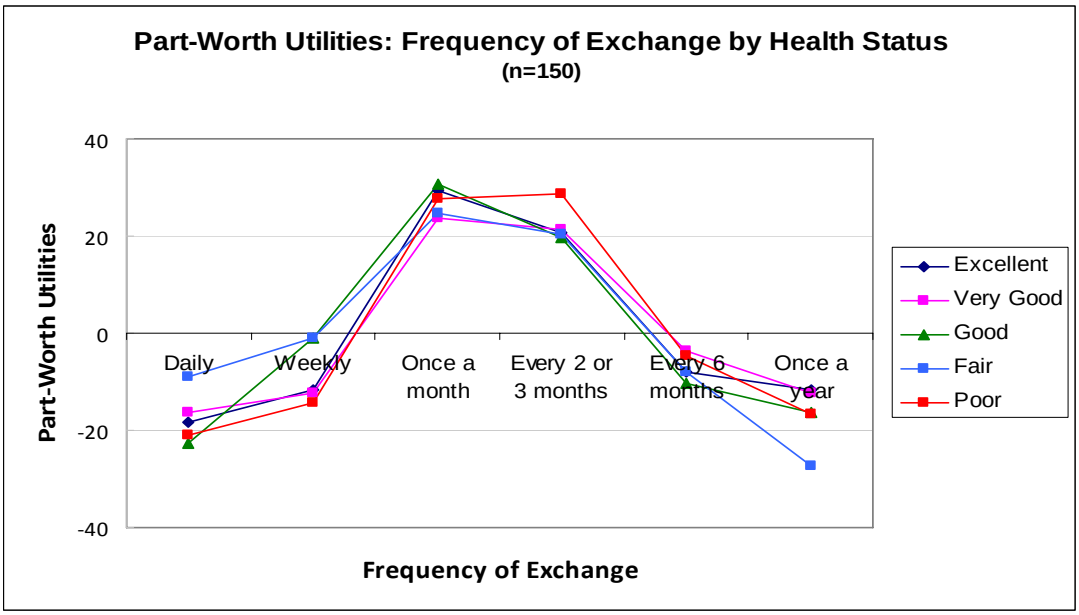

Figure 4 - Part-worth utilities for Frequency of Exchange by Health Status

The Exchange Medium attribute also showed some variation of preference by patients who reported excellent health. These patients preferred to use monitoring devices for health information exchange opposed to internet-based applications, as preferred by the overall sample and patients reporting other levels of health status. Figure 5 illustrates this Exchange Medium differences based on Health Status.

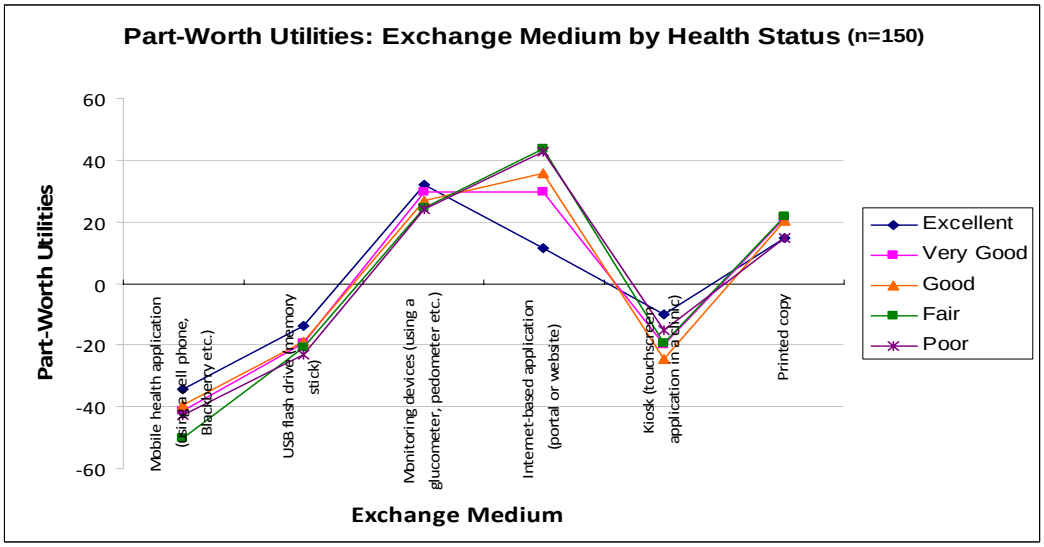

Figure 5 - Part-worth utilities for Exchange Medium by Health Status

Segmentation Summary

Attempts to segment the sample thus far revealed little variation of patient preferences for the attribute levels of the winning ePHR concept. Only slight variation was observed in Segment 2, for those with Level 2 patient activation, and among those with excellent and poor perceived

health status. The attributes affected were Frequency of Exchange and Exchange Medium. This minimal variation of preferences is notable and was also a motivator to drill deeper into the patients' preference data using statistical analyses of variance, the results of which are reported next.

Statistical Tests of Variance

The General Linear Model approach was used to further the investigation into the variations in patient preferences for ePHR attributes and levels. The Type of Diabetes, Age, Health Status, PAM Level, Segment and PHR Use covariates were cross tabulated, the results of which are presented in Appendix L. Because of the small sample, some of the categories contained fewer than 20 respondents, often considered to be the minimum per category for ANOVA and t-tests. Consequently, several of the covariates were recoded into two or three categories. The covariate names were changed depending on the number of categories represented in each variable after cross tabulation was performed. Type of Diabetes, Segment and PHR Use names remained the same. Age became Age2, Health Status became Health3, and PAM Level changed to PAM3. Multivariate tests of variance (MANOVAs) were conducted on the ePHR attributes by these covariates using the Wilk's Lambda test. "Tests Between Subject Effects" were conducted to check the covariates for variance within the individual levels. Levene's test was used to check the homogeneity of variance of the different levels. If the variance equality hypothesis was rejected the Brown-Forsythe test was used to test the equality of the means. Between group ANOVA tests were run on the covariates that showed equality of variance and Post Hoc testing was conducted using the Dunnett T3 test. In addition, independent sample t-tests were run on those covariates that had only two categories. The results are summarized below in the context of significant effects of covariates observed on preferences for levels within the six ePHR attributes. Appendix M summarizes all the significant effects observed.

Self-Management Tasks

Interestingly, a number of our survey patients commented about diabetes self-management with a focus on the human characteristics required for self-management such as self-discipline, the need to form habits around monitoring blood glucose, and the need to be committed, responsible and accountable for one's health, as opposed to the outcomes of self-management activities generated from monitoring blood glucose, for example. This certainly reflects another dimension of self-management support required by patients with diabetes. Results of tests on the Self-Management activities are discussed below.

All Options

In a recent study published by the California Healthcare Foundation (CHF) more than half the adults surveyed were interested in one or more types of online health related applications that involved tracking information about their chronic diseases, diet, calories and exercise, mood, and receiving reminders about when to take medications (CHF, 2010). This coincides with our overall sample that preferred that All Options within the Self-Management Tasks attribute be included in an ePHR for diabetes self-management.

At this level, significant differences were found within Health3 (ANOVA F=3.687, p=0.027). Patients reporting Good and Fair/Poor health were significantly different (difference between means = -7.76, p=0.045) but no differences were found between those reporting Excellent/Very Good and Good or Fair/Poor health.

When the part-worth utilities of the All Options level were compared, we found that patients who reported Good health considered the All Options level less appealing (pwu=17.93) than those with Fair or Poor health (pwu=26.07 and pwu=23.95, respectively). This is counter to what was reflected by the total sample, where overall, 74% of the patients reported Good or better health yet overall they preferred All Options (pwu=19.93).

Monitor Blood Glucose + Diet & Physical Activity

The overall Self-Management Task attribute was significantly related to Type of Diabetes (F=2.292, p=0.014) and to patients' Use of PHRs either in digital or paper form (F=2.727, p=0.022). Both appear to be due to differences at the Monitor Blood Glucose + Diet & Physical Activity level.

For this level, significant differences were observed by patients' Use of PHRs whether in digital or paper form (ANOVA F=4.934, p=0.028) and by Age2 (the 18-49 and 50 – 89 age ranges) (ANOVA F=4.323, p=0.040), as well as by Type of Diabetes (ANOVA F=5.712, p=0.004). Furthermore, Prediabetes and T1D were significantly different (difference between means = -10.60, p=0.008) but no differences were found between Prediabetes and T2D, nor between T1D and T2D.

Differences are expected between patients with prediabetes and T1D due to the differing natures of their condition. People with T1D may not be as engaged in diet and physical activity since their disease is insulin dependent and other self-management tasks may take priority. Patients with prediabetes may be more engaged in diet and physical activity opposed to medication management, knowing the effect they have on lowering their glucose levels and thus reducing the risk of acquiring diabetes. No differences between T2D and T1D, and T2D and Prediabetes may be expected, since depending on the severity of their condition, the symptoms and treatments of those with T2D may be quite similar to the other two types.

Exchange Partner

According to the patients in our study, the idea of sharing health information appeared to be important for the support it offers, for taking the place of an office visit, and for sharing of successes when goals are met. They also mentioned that sharing information with a variety of healthcare professionals was of interest but sharing with employers and insurance companies was not. These last observations were quantified in the ePHR Service Provider section where the Employer and Insurer levels were both found to be significantly related to Age2, Health3, Use of PHRs and Segments.

Overall, the most preferred Exchange Partner was a Physician/Nurse (pwu=36.04). Social Worker/Mental Health Counsellor (MHC) was the least preferred Exchange Partner (pwu=-

39.13). The overall Exchange Partner attribute was significantly related to Segment (F=5.020, p=0.000) only. This appeared to be due to the Social Worker/MHC level in which significant differences between the two Segments were observed (Brown-Forsythe=36.287, p=0.000). Significant differences were also observed between Segments at the Specialist level (Brown-Forsythe=3.970, p=0.048), and by Type of Diabetes at the Family Member/Peer level (F=3.272, p=0.041).

Although tracking mood and developing coping skills were not options within the ePHR Self-Management Tasks attribute, social workers and mental health counsellors were included as possible exchange partners. These professionals are currently being integrated into primary care teams to help patients manage the emotional and mental health aspects of chronic disease, especially depression. Having a Social Worker/MHC as an ePHR Exchange Partner was the sample's least desired Exchange Partner (pwu= -39.13). This is in alignment with the California study where only 23% of adults were "very" or "somewhat interested" in tracking their mood. Had a coping skills activity been added to the list of self-management tasks in our survey, it can be assumed that the overall appeal for the level would be low. These results reflect the stigma that is still attached to mental health issues today.

Frequency of Exchange

The frequency of sharing health information was commented on by some of the patients in the context of being newly diagnosed with the desire for daily or weekly contact, as well as in the context of HbA1c blood testing frequency which is conducted in a laboratory or clinic, typically every three months. One patient mentioned the necessity of taking measures of blood glucose frequently enough so that patterns that might require attention, can be revealed.

The overall Frequency of Exchange attribute was not shown to be significantly related to any of the covariates. Significant differences were, however, found between Type of Diabetes at the Daily level (F=3.708, p=0.029).

At the Daily level Prediabetes and T2D were significantly different (difference between means= -11.20, p=0.043). Those with Prediabetes were more adverse to a daily exchange frequency than those with T2D (pwu= -21.39 and pwu= -10.19, respectively). No differences were found between Prediabetes and T1D or between T1D and T2D.

At the Once a Year level, significant differences were also observed in Type of Diabetes (F=4.095, p=0.019). Prediabetes and T2 diabetes were significantly different (difference between means=15.55, p=0.008) but no differences were found between Prediabetes and T1D nor between T1D and T2D. Those with Prediabetes were less adverse to a yearly exchange frequency than those with T2D (pwu= -9.36 and pwu= -24.92, respectively)..

Statistically, there doesn't appear to be much variation at the Frequency of Exchange level. The patient comments, however, reflect the diversity of stakeholder needs that might influence the frequency of health information exchange. The needs of a newly diagnosed patient requiring frequent exchange for the support it offers when trying to adjust to a new lifestyle, differ from the needs of a healthcare provider, who by adhering to evidence-based guidelines and incentive

schedules, require patients to visit the office for a diabetes check-up and have blood work done every three months. The needs of the patient at home are also different, as they try to control their condition with frequent at-home blood glucose testing. Is the overall preferred Frequency of Exchange level of Once a Month (pwu=27.23) a nice compromise?

Exchange Medium

According to the California Healthcare Foundation (CHF, 2010) survey more than half of the adults surveyed were interested in using online (internet-based) applications to track health-related factors, and almost half were interested in using medical devices that can be connected to the internet (CHF, 2010). Our results were similar. The idea of an ePHR as a device is not new. ePHR developers are likely aware of the ISO 13485 standard that certifies software as a medical device. Many ePHR systems have already received this certification. In our study, although we assumed a stand-alone blood glucose monitoring device, it appears adding a computer or internet connection would increase the value of the device.

The two most appealing mediums for exchanging health information were Internet-based applications (pwu=34.60) and Monitoring Devices (pwu=27.27). The overall Exchange Medium attribute was significantly related to Age2 (F=2.455, p=0.037) and Health3 (F=1.985, p=0.035). This appears to be due to differences at *all* levels of Exchange Medium. Significant differences between the Age2 means were observed at the Internet applications level (F=4.948, p=0.028) and at the Monitoring Devices level (F=4.186, p=0.043). Age2 was also related to Mobile applications (F=9.261, p=0.003), USB (memory sticks) (F=10.161, p=0.002), and Printed Copy (F=5.509, p=0.020). Figure 6 illustrates the direction of each of these significant age relationships.

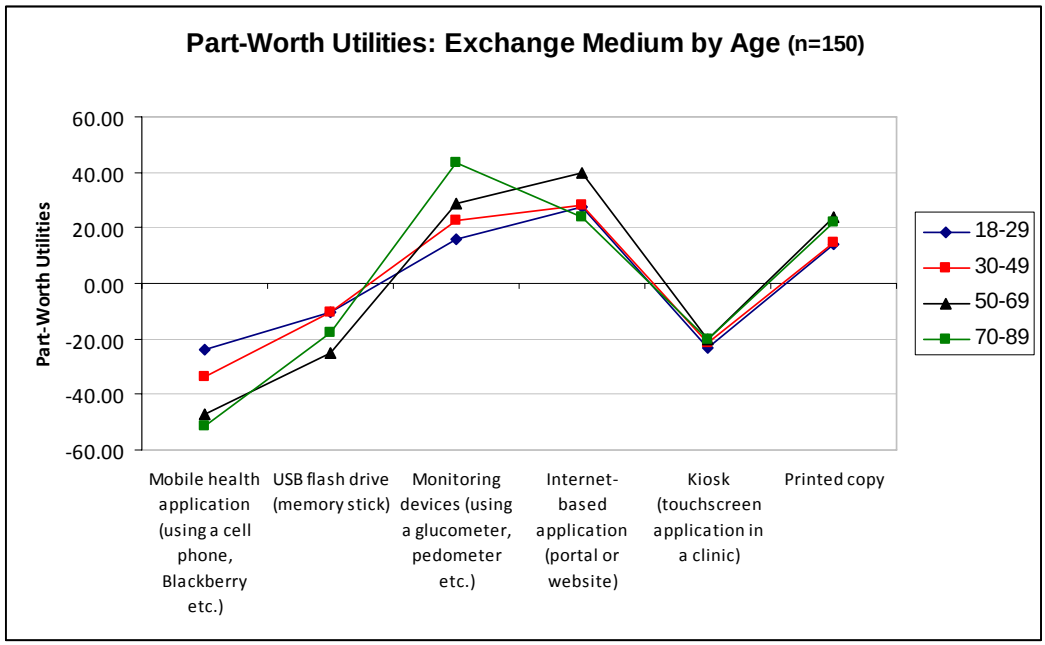

Figure 6 - Part-worth utilities for Exchange Medium by Age range

Significant variation was found at the Internet application level within Health3 (ANOVA F=4.935, p=0.008). Those with Excellent/Very Good health and Fair/Poor health were significantly different (difference between means = -17.23, p=0.005) but no differences were found between Excellent/Very Good and Good, nor Good and Fair/Poor. This concurs with the variation observed in part-worth utility scores for the different health levels. Those with Excellent health showed the least preference for Internet-based applications (pwu=11.46) compared to all other categories of health, especially those with poor health (pwu=45.52).

The overall sample reported that a Mobile health application was the least appealing Exchange Medium (pwu= -42.09). Although only one patient commented about the ePHR Exchange Medium attribute, stating that they didn't have a cell phone or Blackberry, this negative utility of mobile technology reflects the CHF (2010) finding that only two percent of adults surveyed used a health-related application on a cell phone. Digging deeper into the age ranges, we found that Age2 was the only covariate that was significantly related to the Mobile health application level (F=9.261, p=0.003). Looking at the part-worth utilities of mobile applications for the different age ranges, those < 49 years of age showed less aversion for mobile applications than those over 50 years old. Figure 6 above illustrates this distribution.

ePHR Service Provider

Currently, ePHR users in the United States are likely to have an ePHR supplied by their health insurer (56%), followed by their doctor or health care provider (26%) (CHF, 2010). This has not been the case in Canada. However, Sun Life Financial recently announced that they are offering its members an ePHR-like password protected online health navigation and information service to enhance its online wellness centre. In the California survey, when non-ePHR users where asked who they are most interested in having an ePHR sponsored by, 58% said their healthcare

providers (this included Hospitals) (CHF, 2010). In our study, the ePHR service provider of choice was also a Healthcare Provider (doctor or specialist) with a part-worth utility of 44.37.

The overall ePHR Service Provider attribute was significantly related to Health3 (F=3.435, p=0.000), Segment (F=4.321, p=0.001), and Age2 (F=2.661, p=0.018). This appears to be due to differences at all levels except Healthcare Provider (doctor or specialist), although no significant differences were related within any covariates were found at the Healthcare Provider level.

Significant differences were, however, observed at the Government level by patients' use of PHRs whether in digital or paper form (F=4.049, p=0.046). Those who do not use PHRs found this level more acceptable than those who use PHRs (pwu=1.61 and pwu=10.30, respectively). The Canadian Diabetes Association (CDA) level was significantly related to Age2 (F=5.876, p=0.017). Patients >49 years old found the CDA more acceptable as service provider than those less than 49 years.

At the Employer level mean differences were found within Age2 (F=9.893, p=0.002), PHR Use (F=4.183, p=0.043), and Segment (Brown-Forsythe=143.121, p=0.001). Those >49 years old, Segment 1 (pwu=-45.01) and those who do not use PHRs (pwu=-41.20) were most adverse to having an employer provide an ePHR service.

At the Insurer level mean differences were found within Segment (Brown-Forsythe=143.185, p=0.001) and Health3 (F=3.608, p=0.030). Furthermore, those with Excellent/VeryGood and Good health were significantly different (difference between means =10.01, p=0.034) but no differences were found between Excellent/VeryGood and Fair/Poor, nor between Good and Fair/Poor. Those in Segment 2 and those reporting Good health showed most aversion to an ePHR supplied by an Insurer (pwu= -32.20 and pwu=-28.60, respectively).

Significant differences were also found at the Commercial Supplier level within Health3 (F=4.936, p=0.008). Furthermore, those with Excellent/Very Good and Fair/Poor health were significantly different (difference between means =-12.53, p=0.008), but no differences were found between Excellent/VeryGood and Good, nor between Good and Fair/Poor. Patients reporting Excellent health showed most aversion for an ePHR supplied by a commercial vendor (pwu=-28.81).

Sharing information with a variety of healthcare professionals was appealing to many of our survey patients but sharing with employers and insurance companies was certainly not, and as mentioned above, Employer and Insurer sponsored ePHRs were found to be significantly related to patient age, health status, and their use of PHRs (either paper or digital). These findings are in line with current research. Health insurers and employers who are developing ePHRs are challenged to overcome consumers' general distrust of them because of their ability to access and act on patient-entered data (Grossman, Zayas-Cabán and Kemper, 2009; Witry, Doucette, and Daly, 2010 and Burkhard, Schooley, and Dawson, 2010). These same researchers, also found that privacy and security of patient data was of great concern when considering ePHRs sponsored by health insurers and employers. Only three of our survey patients commented that privacy and security, and access to information within an ePHR was of concern. Although not specifically asked in the survey, it is evident that privacy and security was not forefront in the

minds of most the survey patients. Although "two-thirds of the public remain concerned about the privacy and security of their health information…the majority of those who are using a PHR are not very worried about the privacy of the information contained in their PHR" and most ePHR users say "we should not let privacy concerns stop us from learning how health IT can improve health care" (CHF, 2010). It appears that if the value of using an ePHR is great enough, concern over privacy and security of health information may be reduced.

Monthly Service Fee

The study of ePHR service fees is complex and currently no cost models for PHRs exist (Shah, Kaebler, Vincent et al., 2008) and there is a lack of empirical evidence in healthcare and informatics literature to quantify the PHR value proposition (Detmer et al., 2008). Many of the perceived benefits of ePHRs accrue to patients, but it is not clear that they are willing to pay or subsidize the cost of these systems (Detmer et al., 2008). A recent study found that higher-income individuals are more likely to have used a PHR (CHF, 2010) and other surveys in the literature consistently show substantial numbers of consumers indicating their willingness to pay for integrated PHRs, yet this has not been demonstrated in practice (Detmer et al., 2008).

The Monthly Service Fee attribute was the most important attribute overall for the total sample (importance=26.26%) and factors such as Segments, Age and Health Status were found to be significantly related to the attribute.

Specifically, the overall Monthly Service Fee attribute was significantly different between Segments (F=19.424, p=0.000) and Segment 2 showed the most sensitivity to service fees. The $10 level had no relationship to the overall attribute yet significant differences were observed between Segments at:

- $0 (F=133.416, p=0.000),
- $5 (Brown-Forsythe=32.812, p=0.000),
- $15 (Brown-Forsythe=38.596, p=0.000),
- $20 (Brown-Forsythe=131.357, p=0.000), and
- $25 (Brown-Forsythe=64.438, p=0.000).

At the $5 level, significant differences were also observed within Age2 (ANOVA F=3.969, p=0.048), and Health3 (ANOVA F=4.612, p=0.011). Furthermore, at $5, Excellent/Very Good and Good, and Good and Fair/Poor were significantly different (difference between means = 11.71, p=0.036 and difference between means -11.66, p=0.033, respectively), but no differences were found between Excellent/VeryGood and Fair/Poor. Patients reporting Good health, and those in the over 49 year old group, were most adverse to a $5 service fee.

Although we didn't gather income data, 60% of our patients did indicate that they agreed, or strongly agreed, that paying for diabetes supplies was difficult. Adding a fee-based self-management ePHR service to the list of diabetes supplies a patient requires would probably elicit a similar response. Once the debate over frequency of testing blood glucose is resolved, and if that frequency is greatly reduced, money spent on glucometer test strips might possibly become available for ePHR services. Comments from the survey indicated that the cost of an ePHR

system was a concern to those with disabilities and for those on fixed incomes and budgets. One patient noted that paying for information that we should already have access to, for example laboratory data, was unacceptable.

Summary of Variances

Overall, few significant differences within the covariates were found across all attributes. Appendix M presents all the significant relationships observed by ePHR attribute level. Age, Health Status, and Type of Diabetes showed significant relationships with some of the attributes but meaningful interpretations cannot be made. It is only when market simulations and sensitivity tests are conducted on ePHR scenarios that the more complex relationships of the attributes on the overall ePHR service are revealed. It is then that the significant relationships between attributes and Age, Health Status and Type of Diabetes can be applied.

Market Simulations and Sensitivity Analyses

Market simulations are used to discover the more complex effects of attributes on the overall ePHR concept. Sawtooth Software's market simulator (SMRT) was used to transform patients' conjoint utility data to shares of preference. Shares of preference predict patients' interests in products that are run through the market simulator. Shares are expressed as percentages summing to 100% across competing product alternatives and they reflect effects of interactions between the attributes of a product. First, Randomized First Choice simulations were conducted on the winning ePHR to learn about the influence of the attributes on overall ePHR concept. This involved varying the attribute levels in different combinations and running each new scenario through the simulator. The winning ePHR attribute levels were used as the base case. Next, Randomized First Choice simulations and sensitivity analyses were run on three ePHR concepts constructed from products that are currently available to patients in the marketplace. NoMoreClipBoard (NMC), mydoctor.ca, and the Bayer Contour® USB blood glucose monitoring system, were chosen for these tests. The results of the simulations and sensitivity tests are presented next.

Market Simulations on the Winning ePHR Concept

A number of market simulations were run using the winning ePHR attribute levels as the base case. Appendix N summarizes the effects of substituting the winning attribute levels with other levels on the shares of preference for the modified product. The ePHR products that return shares that come closest to the shares of the winning concept indicate to ePHR developers what components of the ePHR need to be worked on to maintain higher shares.

One of the most notable findings from this set of simulations was observed when the Frequency of Exchange attribute was changed from the preferred Once a month (shares=53.97%) to Every 2 or 3 months (shares=46.03%). Although little statistical variation within the Frequency of Exchange attribute was found, it appears that the effects of these two levels on the overall product are noteworthy. It seems that either frequency (Once a month or Every 2 or 3 months) could be offered as part of an ePHR service without affecting the ePHR's shares too dramatically. Of course, this is due to the fact that the part-worth utility for Once a month is

27.23 and for Every 2 or 3 months is just slightly lower at 20.77. An ePHR with exchange services every three months may enhance the adoption of the service considering that in Ontario, three month visit intervals have already been established in accordance with diabetes care guidelines and related physician incentives are already in place.

Simulations run on the Exchange Medium attribute were also notable. When the preferred Internet-based application (pwu=34.60) was changed to a Monitoring device (pwu=27.27), shares of preference of the total sample dropped from 56.10% to 43.90%. As well, in the statistical analyses and mentioned previously, the two age groups (18-49 and 50-89) showed significant differences at both the Internet-based application level and the Monitoring Device level. Those 50-69 years old found the Internet-based application most acceptable (pwu=40.04) whereas those 70-89 years old found the Monitoring Device option most acceptable (pwu=43.32). Consumers' age appears to be an important consideration when developing exchange medium strategies for ePHRs.

Simulations were also run on Exchange Medium in relation to the two segments. The part-worth utility for Segment 1 was 34.08 for Internet-based application, and 30.52 for a Monitoring Device. For Segment 2, the part-worth utility was 35.19 for the Internet and 23.55 for a Monitoring Device. Consequently, we should expect that much less share of preference would be lost among Segment 1 patients when changing from the Internet to a Monitoring Device than among Segment 2 patients. In fact, this was born out through the simulations where the share of preference dropped from 53.24% to 46.76% for Segment 1 and from 59.36% to 40.64% for Segment 2.

Not surprisingly, when the Monthly Service Fee was changed from the preferred $0 to $5 the shares of preference of a fee-based ePHR service were reduced from 79.32% to 20.68%. As well, age, health status and segment were found to be significantly related to the $5 service fee. Patients in the over 49 year old group, those reporting Good health, and those in Segment 1 were most adverse to a $5 service fee. Taking age and health status into consideration when setting ePHR service fees would be prudent. While $0 would be the preferred price for almost everything that one would buy, it is clearly unrealistic for a product of value. It is instructive to note that if money must be charged for an ePHR, moving from $0 to $5 precipitates a drop in pwu from 82.43 to 33.64. But, moving from $5 to $10 is accompanied by a more modest drop from 33.64 to 9.25. It is very important to pay very close attention to these kinks in the price utility curve when designing pricing strategies for products.

Within the ePHR Service Provider attribute, when the Healthcare Provider was changed to Commercial Supplier, the share of preference of an ePHR service supplied by a commercial vendor dropped drastically to 10.51%. This finding would certainly be of concern to any ePHR vendor. The failure of the commercial Revolution Health ePHR service in February 2010, may be a "case" in point. Reporting on the failure, a news article published by the American Medical Association stated that "successful personal health records have to be well-integrated with or designed by existing hospital and physician systems, making it harder for a third-party system, such as the defunct Revolution Health service, to gain traction" (AMA, 2010). Interestingly, within the Commercial Supplier level, significant differences within the perceived health status were found. Specifically, patients with Excellent/Very Good and Fair/Poor health were

significantly different. Patients reporting Excellent health had the most aversion to an ePHR service supplied by a commercial vendor. Figure 7 shows the part-worth utilities for Commercial Supplier by Health Status.

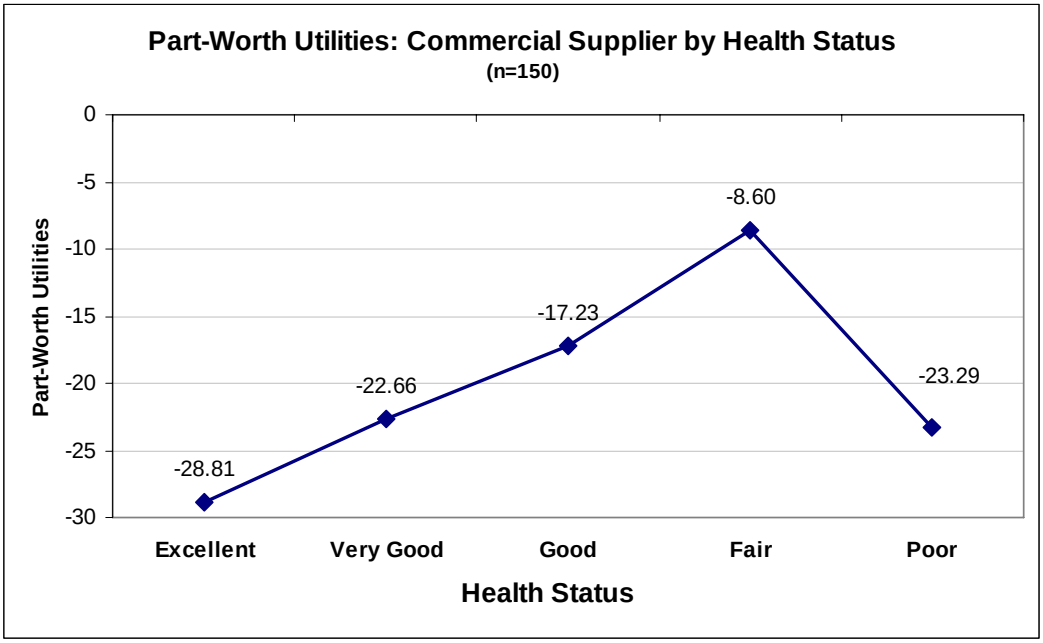

Figure 7 - Part-worth utilities for Commercial Supplier by Health Status

Market Simulations on Commercial ePHRs

A market simulation was run to determine which of three commercially available ePHR products was most preferred by our study sample. Next, sensitivity analyses were run on each of the commercial products. This approach shows how much a product's overall preference can be improved or made worse by changing its attribute levels one at a time, while holding all other attributes constant at base case levels. For these tests, three additional products were constructed based on products that currently exist in the marketplace: NoMoreClipBoard (NMC), mydoctor.ca, and the Bayer Contour® USB blood glucose monitoring system were chosen.

NMC is a commercial supplier of a top-rated integrated ePHR built on the Google platform. mydoctor.ca is a PHR module tethered to the Practice Solutions Electronic Medical Record (EMR) system. Practice Solutions is a subsidiary of the Canadian Medical Association and access to mydocotor.ca is granted to patients exclusively by a physician who uses this EMR. Bayer, a pharmaceutical company with a broad portfolio of products, sells its new Contour® USB blood glucose monitoring system directly to patients. The system includes a glucometer with a USB connector and a computer-based software application that helps patients record, organize and interpret their blood glucose readings. Each of these products was coded and entered into the market simulator. Table 8 presents the attribute levels used to construct each new ePHR product. Attributes levels chosen were based on information gleaned from each company's website.

ePHR Attributes	mydoctor.ca	NoMoreClipBoard	Bayer Contour
Self-Management Tasks	All Options	All Options	Monitor Blood Glucose
Exchange Partner	Physician or Nurse	Physician or Nurse	Physician or Nurse
Frequency of Exchange	Every 2-3 months	Every 2-3 months	Every 2-3 months
Exchange Medium	Internet-based application	Internet-based application	Print Copy
ePHR Service Provider	Healthcare Provider (Physician or Specialist)	Commercial Supplier	Commercial Supplier
Monthly Service Fee	$1.67	$0.83	$0

Table 8 - Base attribute levels of commercial ePHR products

Using the part-worth utilities estimated in the conjoint analysis, a market simulation was run in which the three commercial products competed against each other to see which product was most appealing to the sample. Our sample preferred the mydoctor.ca model (shares=86.09%) over the NMC model (shares=7.83%) and the Bayer Contour model (shares=6.08%). This was expected since the mydoctor.ca model was the most similar to the winning ePHR concept. Sensitivity analyses were run on each of the three products next. This involved changing the ePHR attribute levels one at a time and observing the change in preference for that product. The results of these tests are presented below as marketing strategies for each product.

Marketing considerations for mydoctor.ca

The mydoctor.ca simulation was run with all attribute levels set as in Table 9 below.

ePHR Attributes	mydoctor.ca	NoMoreClipBoard	Bayer Contour
Self-Management Tasks	All options	All options	Monitor Blood Glucose
Exchange Partners	Physician or Nurse	Physician or Nurse	Physician or Nurse
Exchange Frequency	Every 2 or 3 months	Every 2 or 3 months	Every 2 or 3 months
Exchange Medium	Internet-based application	Internet-based application	Printed copy
ePHR Service Provider	Healthcare Provider	Commercial Supplier	Commercial Supplier
Monthly Service Fee	**$0 to $25**	$0.83	$0

Table 9 - Market Simulation on mydoctor.ca: Attribute Levels Used

As shown in Figure 8 below, mydoctor.ca started in a greatly superior position over its two competitors. This was expected considering its similarity to our sample's winning ePHR concept. Only the Monthly Service Fee was varied (from $0 to $25) for mydoctor.ca. All other values remained the same. As mydoctor.ca service fees were increased from $0, its share dropped. NoMoreClipBoard shares benefited more than Bayer from the price increases of mydoctor.ca.

mydoctor.ca maintained its superior position to NoMoreClipBoard until its price hit between $10 and $15, the first of two points of competitive balance. mydoctor.ca's shares continued to be superior to Bayer until just under $25, beyond which it was dominated by each of the other products. mydoctor.ca has a great range of flexibility with its pricing and should consider where it can maximize its profit while maintaining a comfortable share position.

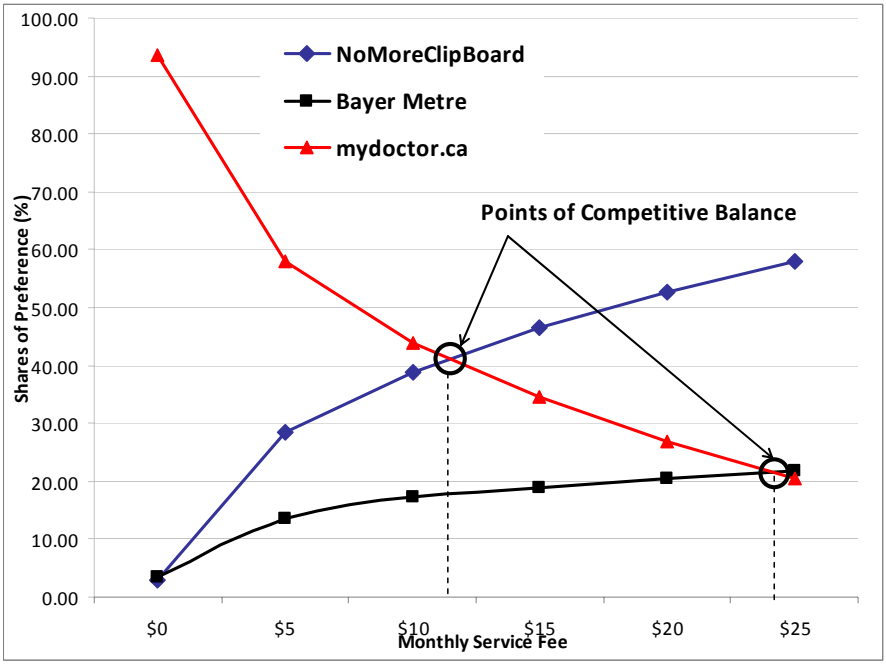

Figure 8 - Market simulation on mydoctor.ca: effect of service fees on shares

Marketing considerations for Bayer

The Bayer simulation was run with all attribute levels set as in Table 10 below.

ePHR Attributes	mydoctor.ca	NoMoreClipBoard	Bayer Contour
Self-Management Tasks	All options	All options	Monitor Blood Glucose
Exchange Partners	Physician or Nurse	Physician or Nurse	Physician or Nurse
Exchange Frequency	Every 2 or 3 months	Every 2 or 3 months	Every 2 or 3 months
Exchange Medium	Internet-based application	Internet-based application	Printed copy
ePHR Service Provider	Healthcare Provider	Commercial Supplier	Commercial Supplier
Monthly Service Fee	**$0 to $25**	$0.83	$0

Table 10 - Market simulation on Bayer: attribute levels used

As shown in Figure 9 below, Bayer began in an inferior position to the other two competitors. Only the Monthly Service Fee was varied for Bayer. All other values remained the same. As Bayer service fees were increased from $0, its share dropped almost to 0%. A similar market simulation was run with NMC, and as NMC service fees were increased from $0, its shares also dropped to almost 0%. If Bayer and NMC must increase their fees, they must find ways to make their products more attractive by manipulating the other attributes.

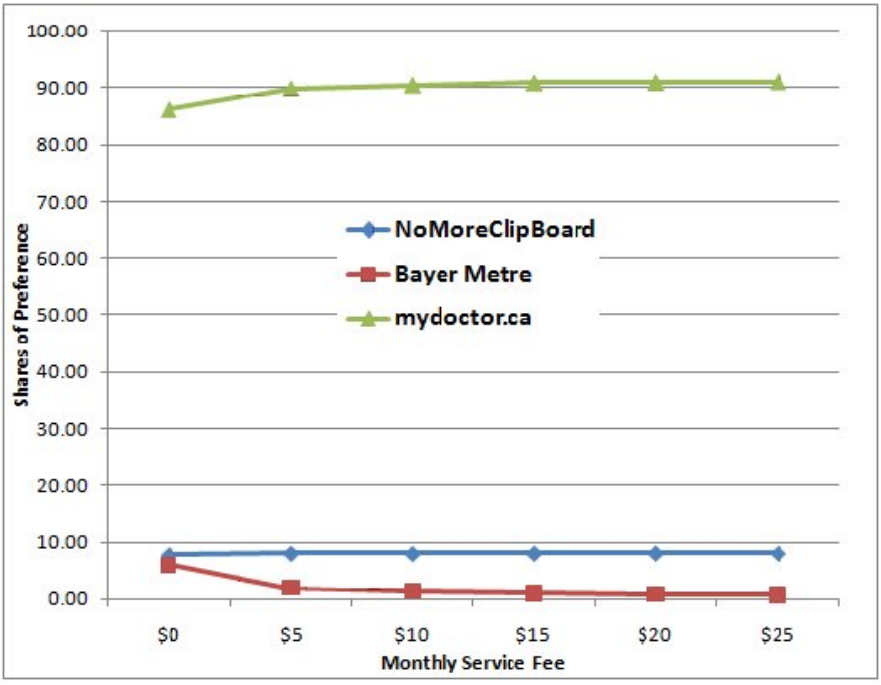

Figure 9 - Market simulation on Bayer: effect of service fees on shares

Summary of Results

In this study we showed how an ePHR service framework can be constructed using evidence from healthcare providers, research literature, and patient preferences. Figure 10 illustrates the generic ePHR service framework that resulted from this study. Three main sections of the framework were identified. Patient preferences and demographics are at the heart of a patient-centred service. This central element not only informs outcome measures necessary for healthcare service evaluations, but it informs and influences the attributes of a service-oriented product.

Generic ePHR Service Framework								Overall Shares
Service Attributes	Options	Patient Preferences (Importance or Shares)	Patient Demographics					Outcome Measures
			X1	X2	X3	X4	X5	
WHAT								
WHO								
WHEN								
HOW								
PLACE								
COST								

Figure 10 - Generic ePHR Service Framework

We also showed that by using adaptive choice-based conjoint methodologies patient preferences for an ePHR service that supports diabetes self-management can be quantified, the result of which was a winning ePHR concept. This winning concept was applied in market simulations and sensitivity analyses to study the dynamic effects attributes and patient preferences have on the overall utility of an ePHR service framework. Statistical analyses of variance were conducted to show relationships between patient characteristics and their preferences for ePHR attributes. The results of all of these analyses offer solid and strategic input to ePHR business case developers and to those developing system requirement specifications for ePHRs that support chronic disease self-management. Most importantly, this input reflects patient preferences, an essential component of patient-centred care.

CONCLUSIONS

By empowering patients as active participants in their own health care, PHRs offer the promise of reducing medical errors, improving disease management, and reducing the overall costs. Fulfilling this promise will require more than just information access; it will also entail using PHRs as transformational agents that can enable self-management by patients and improve patient-physician collaborations (Reti, Feldman, and Safran, 2009).

Keeping this in mind we designed a survey that elicited patient preferences for the features of a self-management intervention that is facilitated by an ePHR service. Patients from the study reported some hesitation about using an ePHR as defined in the survey, but many identified it as an interesting device and that would be an appropriate, helpful and excellent tool.

One objective of this study was to gain a better understanding of patients' preferences for the combinations of features and functions that make up ePHR services that support diabetes self-

management. The other was to gain an understanding of any factors that might influence patient preferences for an ePHR service and its features. Both objectives were accomplished. The conclusions reached are discussed below, followed by study limitations, future research directions, and some general comments in closing.

The Winning ePHR Service Framework and Sample Characteristics

Using ACBC methodologies, patient preferences were quantified into choice data which were used as a base for all further analyses. To our knowledge few, if any, projects have used ACBC methodologies to study ePHRs. Using this methodology we identified an ePHR service framework that supports diabetes self-management. Our sample was unwavering in their preference for this winning ePHR concept. They preferred an internet-based ePHR supplied by a healthcare provider that supports all diabetes self-management activities (monitoring blood glucose, managing medications and managing diet and physical activity). The sample also preferred to exchange their health information with their physician or nurse, once a month, at no cot.

The group of patients who might easily adopt this ePHR service to support their diabetes care consisted mainly of 30-69 year olds with diabetes (Prediabetes, T1D or T2D) who reported overall good to excellent health, were well educated, computer literate and were confident in their self-management skills and knowledge.

Marketing Strategies for ePHR Services

The winning ePHR concept was the basis for market simulations and sensitivity testing which were conducted to study the interactions and effects of attributes on the overall ePHR concept. These additional tests added to our understanding of the ePHR service itself. It was during the market simulations that variations in attribute levels and their effects on the ePHR as a whole, began to reveal themselves the most. A few main findings were observed, each of which could be incorporated into a strategic marketing plan for ePHR service developers.

- An ePHR service for self-management with an exchange frequency of every two to three months as opposed to once a month (with no change to the other winning attribute levels) may be a viable option considering this frequency interval is familiar to patients in Ontario, where three month visit intervals for diabetes care have already been established in accordance with diabetes care guidelines and the related physician incentives are already in place for these visits.
- Offering an ePHR service in the form of a monitoring device as opposed to an internet-based application (with no change to the other winning attribute levels) may also be a viable option, especially when targeting the diabetic population or populations with other chronic conditions (e.g. Hypertension) that require frequent physiological monitoring with devices.
- A third-party or commercial ePHR Service Provider, who sells directly to patients, showed negative impact on the shares of preference for the winning ePHR concept. A marketing strategy for these vendors might be to sell their ePHR service indirectly via the healthcare providers (either physician or specialist), the ePHR Service Provider preferred by our sample.

Effects of Patient Demographics on ePHR Services

A number of statistical analyses were conducted on the non-conjoint data, together with the sample's preference data for ePHR attributes and levels. Patient characteristics were better understood through these analyses and the significant findings are summarized below.

- The age and health status of patients appear to be related to a number of the attributes of an ePHR service. Our research indicates that it would be prudent to take these variables into consideration when developing an ePHR service and when creating marketing plans for the service.
- Surprisingly, patient level of activation for self-management did not appear to be significantly related to the ePHR service attributes identified in this study. Because our service framework is a more abstract level of an ePHR, this makes sense. We suspect patient activation level will come into play more significantly when the educational content of an ePHR and the frequency and type of provider feedback is analyzed.

Study Limitations

As with other research studies, this study had some limitations.

- The sample may not accurately reflect purchasers of ePHR services, many will not have the interest, authority or ability to purchase the service.
- Results from conjoint analyses reflect the potential market acceptance of products and services given proper promotion, distribution and time. Because ePHRs are evolving, so too is the market that will support them and the results may go out-of-date quickly.
- Due to the length of the survey and time to complete it we did not use the calibration section. This is where the respondent is re-shown their preferred ePHR concept and the winning ePHR concept from the choice tournament, along with previously accepted and rejected concepts. In this calibration section they are asked which concepts they would likely buy, if available. This would have enriched the findings.
- When developing ePHRs, a complete patient-provider feedback loop is required. This study addressed the exchange of observations and monitoring results as a one-way communication, from the patient to the provider or caregiver. An ePHR will have substantially more value if the patient receives timely communications with tailored recommendations or advice from an exchange partner.

Contributions to Theory and Practice

We developed an ePHR service that supports patients' chronic disease self-management and facilitates productive interactions between patients and physicians, two main components of the Chronic Care Model. Consumer theories related to marketing and decision sciences were applied by using adaptive choice-based conjoint methodologies. Complexity theories were subtly addressed in a discussion of chronic disease and multimorbidities and in the use of hierarchical Bayes estimations to quantify patient preferences, thus reducing the uncertainty of their future buying decisions by taking the frequency of their previous decisions into consideration.

In practice, market simulations were conducted by applying the study results to real-life product scenarios all with the intention of informing business models and information and computer technology systems requirement specifications.

Future Research

This study was investigational in nature and as a result a number of more specific research topics have emerged. These include conducting a willingness-to-pay analysis, investigating in more depth the relationships of age, health status, and patient activation to the service attributes (especially the monthly service fee and service provider attributes), incorporating other demographic factors (income, education etc.) and analyzing the service framework in the context of adoption as it relates to trust, privacy and health outcomes.

In Closing

Self-management of chronic disease is complex as most chronic health conditions like diabetes impose daily demands on patients. Patients with diabetes must make frequent medication, diet, physical activity, and emotional choices and ongoing behavioural changes. When insufficient self-management supports between office visits are provided, patients with diabetes are vulnerable to poorer health outcomes (Corser & Xu, 2009). The provision of standard diabetes education alone is simply not sufficient for many patients to effectively formulate diabetes self-management strategies and maintain the required associated behaviours. “Each patient’s diabetes self-management needs and strategies will continue to be a fundamentally personal phenomenon” (Corser & Xu, 2009). As one survey participant cautioned, “Not all diabetics should be painted with the same paint brush.” Incorporating patient preferences in their self-management strategies is essential.

The complexity of self-management transfers to the design ePHRs that support self-management. Dynamic approaches to the design may be helpful. Thinking about an ePHR as a participatory and adaptive process, rather than a set blueprint may lead to more effective designs (Leykum et al., 2007). Adaptive choice-based conjoint methodologies enabled us to do just that. Patients participated in the design of an ePHR concept that adapted to their preferences, perhaps not unlike what an ePHR might function like in practice.

Healthcare continues to move toward a more patient-centred model of care. Chronic illness care, a driver of this model, “seeks to promote a fuller understanding of the patient’s life and preferences, ‘activation’ or ‘empowerment’ of patients, and tailoring of management to patient preferences” (Wagner et al., 2005). Establishing an ePHR service that supports self-managed behaviour changes and helps achieve lifestyle and clinical targets, is considered an important element of solutions that attempt to address the diabetes challenge (Lavis & Boyko, 2009). The design of ePHR services that also take patients’ preferences into consideration, may help increase and sustain patients’ utility of these interventions, in alignment with a patient-centred model of care.

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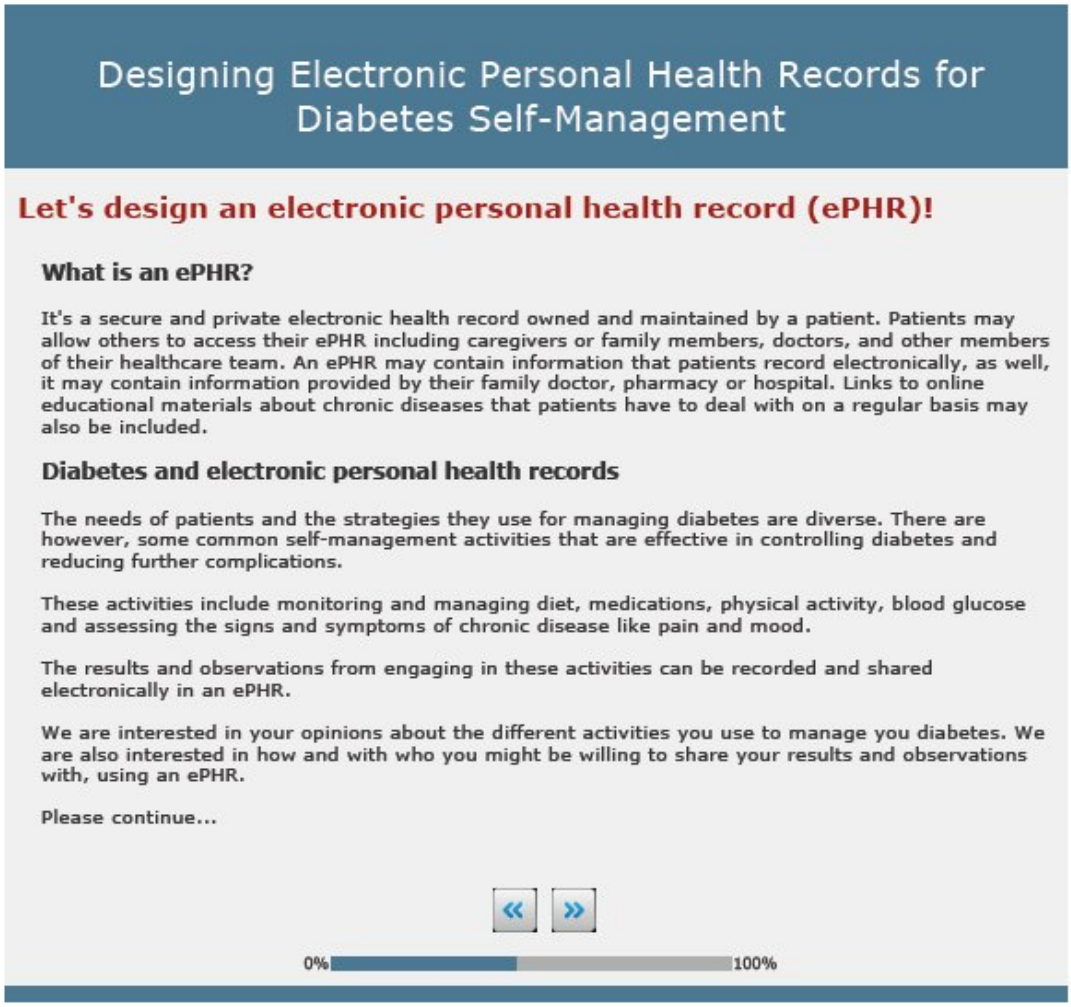
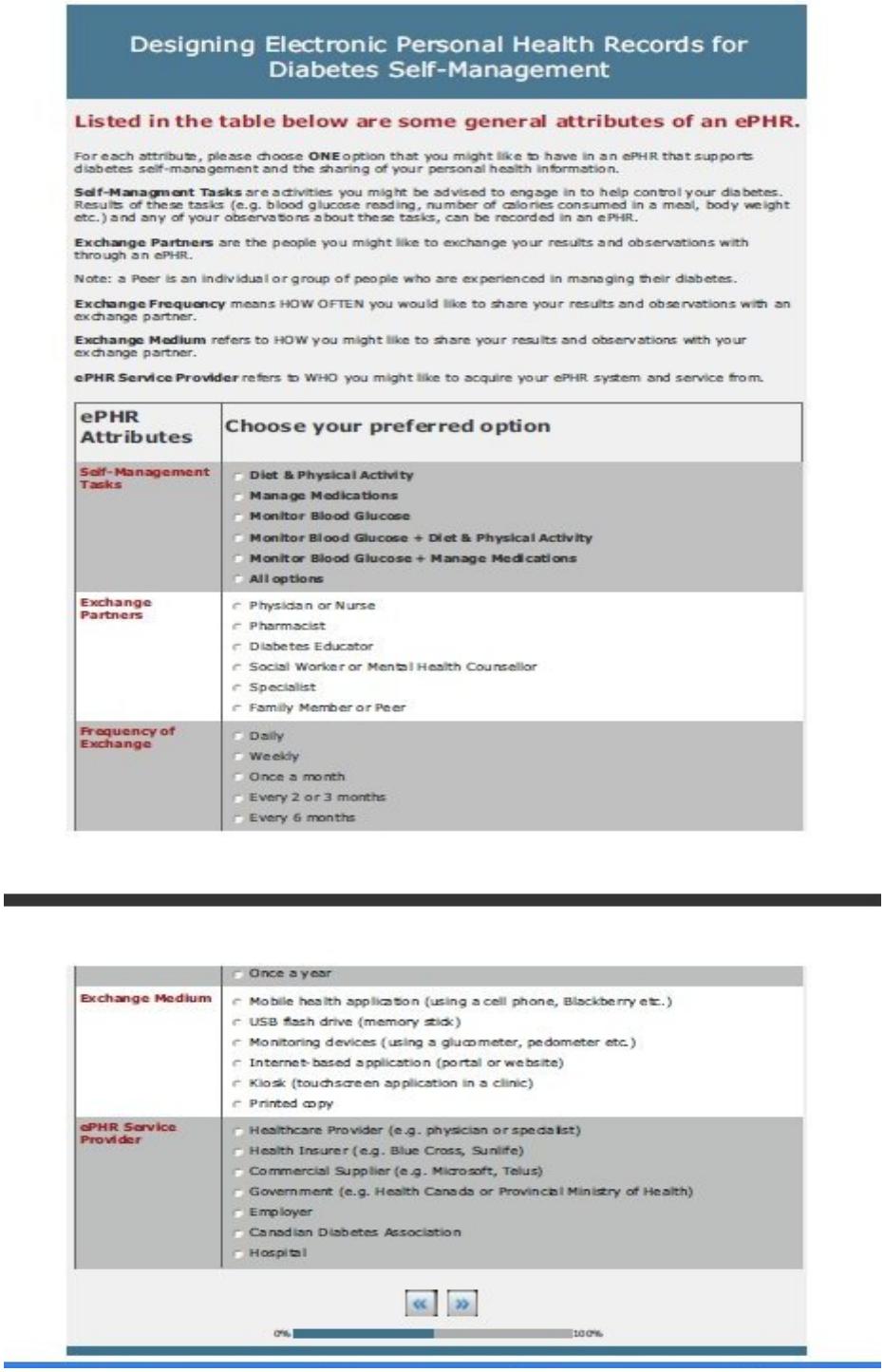
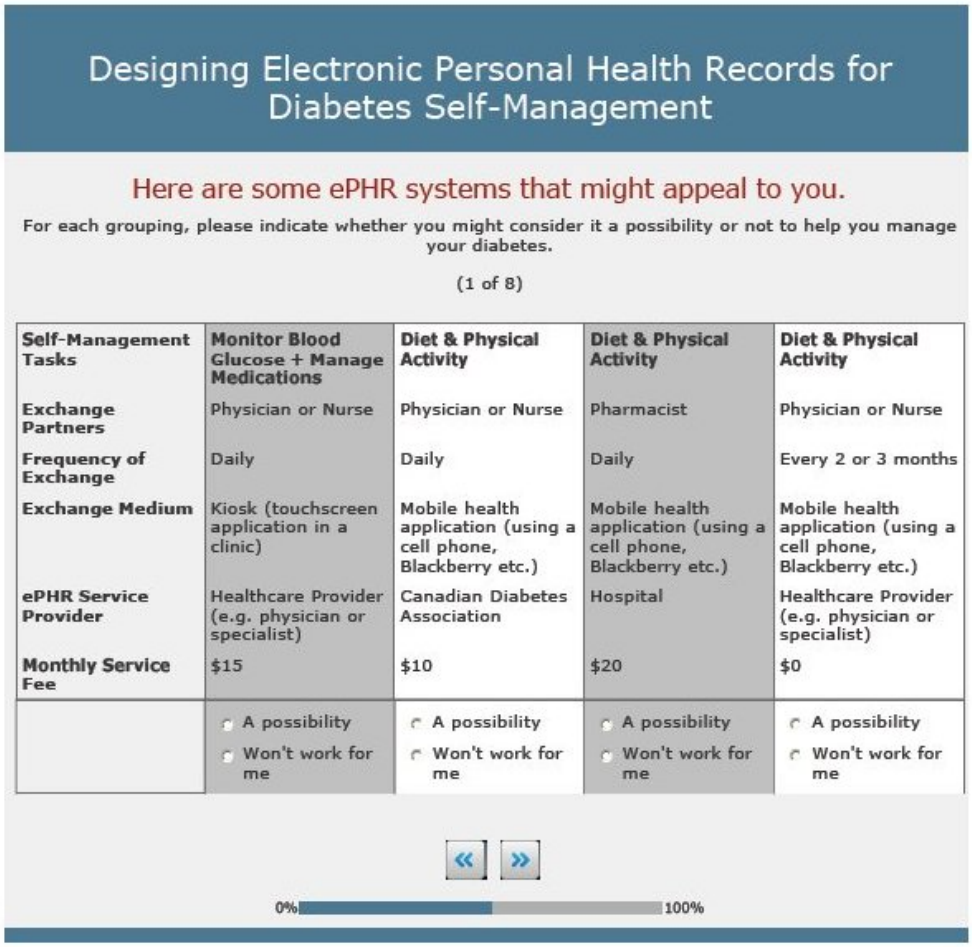
Appendix A
ACBC – ePHR Description



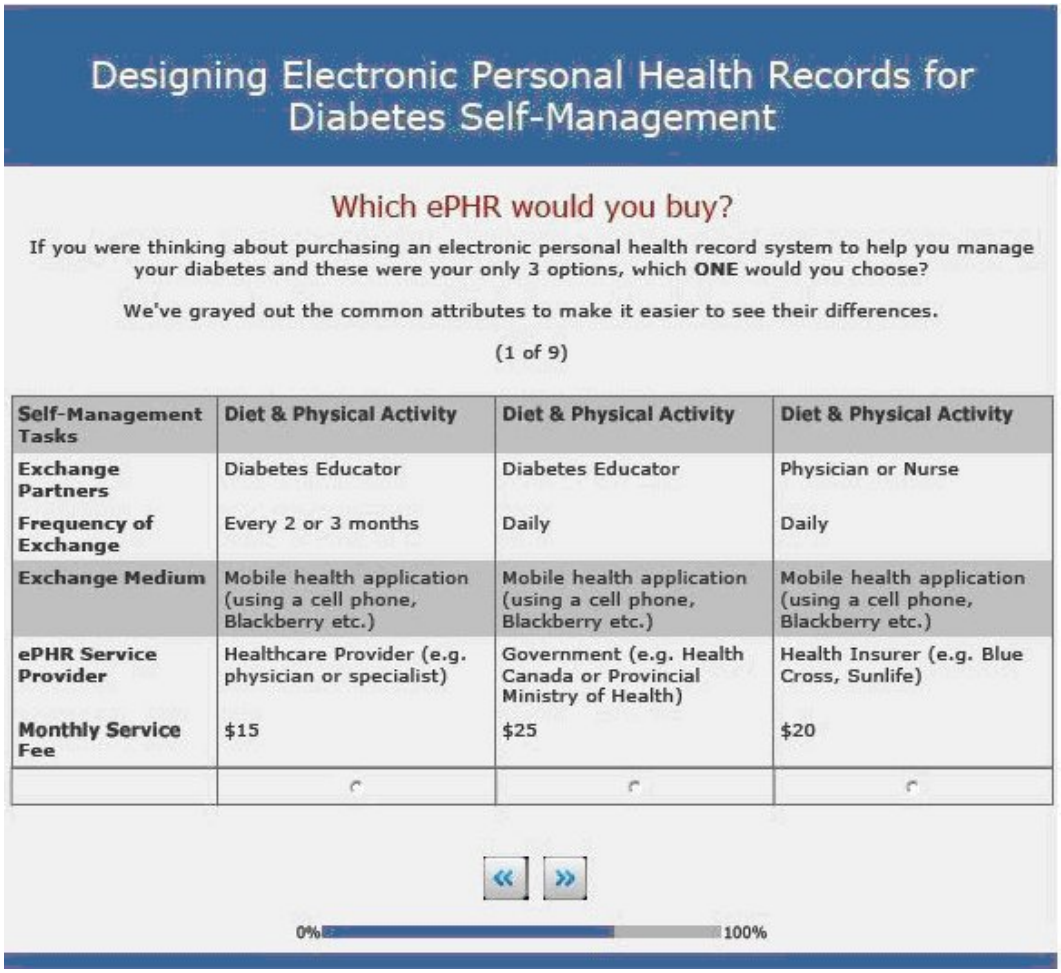
Appendix B
ACBC - Build-Your-Own Configurator



Appendix C
ACBC - Screening Section



Appendix D
ACBC - Choice Tournament Section



Designing Electronic Personal Health Records for Diabetes Self-Management

Which ePHR would you buy?

If you were thinking about purchasing an electronic personal health record system to help you manage your diabetes and these were your only 3 options, which **ONE** would you choose?

We've grayed out the common attributes to make it easier to see their differences.

(1 of 9)

Self-Management Tasks	Diet & Physical Activity	Diet & Physical Activity	Diet & Physical Activity
Exchange Partners	Diabetes Educator	Diabetes Educator	Physician or Nurse
Frequency of Exchange	Every 2 or 3 months	Daily	Daily
Exchange Medium	Mobile health application (using a cell phone, Blackberry etc.)	Mobile health application (using a cell phone, Blackberry etc.)	Mobile health application (using a cell phone, Blackberry etc.)
ePHR Service Provider	Healthcare Provider (e.g. physician or specialist)	Government (e.g. Health Canada or Provincial Ministry of Health)	Health Insurer (e.g. Blue Cross, Sunlife)
Monthly Service Fee	$15	$25	$20
	○	○	○

« »

0% 100%

Appendix E
Patient Activation Measure™

Patient Activation Measure, 13-Item

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. ***Your answers should be what is true for you and not just what you think the doctor wants you to say.***

If the statement does not apply to you, circle N/A.

1.	When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4.	I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6.	I am confident that I can tell a doctor concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7.	I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8.	I understand my health problems and what causes them.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9.	I know what treatments are available for my health problems	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
11.	I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
12.	I am confident I can figure out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
13.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

Appendix F

Characteristics of Sample

Non-Conjoint Variable	Total	%	Pre	%	T1	%	T2	%
Type of Diabetes	**150**		49	32.7%	48	32.0%	53	35.3%
Age	**150**							
18-29	9	6.0%	2	22.2%	6	66.7%	1	11.1%
30-49	45	30.0%	12	26.7%	18	40.0%	15	33.3%
50-69	85	56.7%	32	37.6%	20	23.5%	33	38.8%
70-89	11	7.3%	3	27.3%	4	36.4%	4	36.4%
Gender	**150**							
Female	79	52.7%	25	31.6%	23	29.1%	31	39.2%
Male	71	47.3%	28	39.4%	25	35.2%	18	25.4%
Province or Territory	**150**							
AB	16	10.7%	1	1.4%	10	14.1%	5	7.0%
BC	16	10.7%	6	8.5%	2	2.8%	8	11.3%
MB	8	5.3%	4	5.6%	2	2.8%	2	2.8%
NB	7	4.7%	1	1.4%	1	1.4%	5	7.0%
NL	3	2.0%	1	1.4%	1	1.4%	1	1.4%
NT	1	0.7%	1	1.4%	0	0.0%	0	0.0%
NS	7	4.7%	2	2.8%	2	2.8%	3	4.2%
NU	0	0.0%	0	0.0%	0	0.0%	0	0.0%
ON	69	46.0%	25	35.2%	20	28.2%	24	33.8%
PE	0	0.0%	0	0.0%	0	0.0%	0	0.0%
QC	14	9.3%	7	9.9%	3	4.2%	4	5.6%
SK	9	6.0%	1	1.4%	7	9.9%	1	1.4%
YT	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Chronic Diseases	**any**							
High cholesterol	68	45.3%	24	35.3%	18	26.5%	26	38.2%
High blood pressure	69	46.0%	26	37.7%	12	17.4%	31	44.9%
Stroke	5	3.3%	0	0.0%	2	40.0%	3	60.0%

Cancer	9	6.0%	0	0.0%	3	33.3%	6	66.7%
Heart disease	13	8.7%	2	15.4%	5	38.5%	6	46.2%
Lung disease	9	6.0%	5	55.6%	3	33.3%	1	11.1%
Other	30	20.0%	12	40.0%	8	26.7%	10	33.3%
Education	**150**							
Did not complete high school	5	3.3%	2	40.0%	2	40.0%	1	20.0%
High school	35	23.3%	14	40.0%	8	22.9%	13	37.1%
Some College or University	43	28.7%	18	41.9%	13	30.2%	12	27.9%
College or University Graduate	47	31.3%	8	17.0%	20	42.6%	19	40.4%
Graduate or Post grad degree	17	11.3%	6	35.3%	4	23.5%	7	41.2%
Other	3	2.0%	1	33.3%	1	33.3%	1	33.3%
Years with Diabetes	**150**		**Avg**		**Avg**		**Avg**	
0-10	101	67.3%	4.87		20.26		8.60	
11-20	24	16.0%						
21-30	15	10.0%						
31-40	4	2.7%						
41-50	5	3.3%						
50+	1	0.7%						
Perceived Health Status	**150**							
Excellent	9	6.0%	1	11.1%	5	55.6%	3	33.3%
Very Good	41	27.3%	18	43.9%	14	34.1%	9	22.0%
Good	61	40.7%	18	29.5%	20	32.8%	23	37.7%
Fair	32	21.3%	9	28.1%	8	25.0%	15	46.9%
Poor	7	4.7%	3	42.9%	1	14.3%	3	42.9%
Difficulty Paying for Supplies	**150**							
Strongly Agree	40	26.7%	12	30.0%	16	40.0%	12	30.0%
Agree	50	33.3%	14	28.0%	16	32.0%	20	40.0%
Disagree	38	25.3%	12	31.6%	11	28.9%	15	39.5%
Strongly Disagree	16	10.7%	6	37.5%	4	25.0%	6	37.5%
Don't Know	6	4.0%	5	83.3%	1	16.7%	0	0.0%

Non-Conjoint Variable (cont'd)	Total	%	Pre	%	T1	%	T2	%
Use PHRs	**150**							
Yes	83	55.3%	27	32.5%	29	34.9%	27	32.5%
Daily	39		10		16		13	
Weekly	18		2		10		6	
Monthly	15		6		4		5	
When an event occurs	20		11		3		6	
Other	2		2		0		0	
No	67	44.7%	22	32.8%	19	28.4%	26	38.8%
Test Blood Glucose	**150**							
Yes	123	82.0%	27	22.0%	46	37.4%	50	40.7%
No	27	18.0%	22	81.5%	2	7.4%	3	11.1%
Have a device to measure BG	**123**							
Yes	118	95.9%	27	22.9%	43	36.4%	48	40.7%
No	5	4.1%	0	0.0%	3	60.0%	2	40.0%
Keep records of BG	**123**							
Yes	82	66.7%	18		29		35	
No	17	13.8%	2		10		5	
Only unusual values	24	19.5%	7		7		10	
Patient Activation Measure	**150**							
Level 1	11	7.3%	3	27.3%	1	9.1%	7	63.6%
Level 2	18	12.0%	6	33.3%	5	27.8%	7	38.9%
Level 3	34	22.7%	10	29.4%	8	23.5%	16	47.1%
Level 4	87	58.0%	30	34.5%	34	39.1%	23	26.4%

Appendix G
Multimorbidities Reported by Patients

Aneurysms	Hypothyroidism
Arthritis	Kidney Disease
Asthma	Liver Disease
Back injury	Lung Disease
Bipolar Disorder	Neuroendocrine disorder
Cancer	Osteoarthritis
Crohn’s Disease	Osteopenia
Depression	Osteoporosis
Endometriosis	Pancreatitis
Fibromyalgia	Rheumatoid Arthritis
Gallbladder	Sarcoidosis
Glaucoma	Sleep Apnea
Heart Disease	Spinal degeneration
High Blood Pressure	Stroke
High Cholesterol	Ulcerative Colitis

Appendix H
Main Survey: Patient Comments

ePHR Concept
1. It looks like a very interesting device.
2. I think this is a great for diabetics like myself.
3. acceptable
4. It may be an excellent tool.....
5. much easier than logging results in to a book
6. sounds like it would be easy and efficient.
7. Good approach
8. I think that it is a great idea...I hope that there will be something in the near future...I think that it would be a great tool in helping people manage their diabetes!
9. i think it would be great
10. There's very little value in them unless they're part of a larger health Infostructure like CHI proposes to deliver someday. A patient might as well write the information down on a piece of paper. This line of research isn't of much value and isn't new. I ran an almost identical survey for a client nearly three years ago. The conclusion was that there wasn't enough public interest to make a sustainable business model for PHRs. Microsoft and Google have also studied PHRs before launching their HealthVault and Google Health technologies, so you might want to look at what they've done.
11. I like the overall concept of EPHR's.
12. i am not a believer in useing the internet for my records. i prefer to go and talk to my doctor
13. This is the first time that I have heard of this option. I know nothing about it and I am curious to know more.
14. Good idea
15. I think this a good idea for people who are on the run all or have be at work all day.
16. Very appropriate to observe and control changes in physiological parameters
17. Would be helpful to better keep control of my diabetes
18. I would want to see it manage all conditions, not just diabetes. Sometimes treatments for one ailment are not good for another ailment. All facts must be known to make good decisions.

Self-Management
1. I need better self discipline to be more consistent in my checking blood levels
2. might help but regular hbaic is pretty good to know how i\m doing
3. Need to have education to know how to keep track of everything to do with my diabetes. I asked the Doctor but she did not give me the information yet.
4. I am excersing every day for 2 hours and watching my diet
5. My doctor is the only individual who sees my current graphs which I plot with a trendline. If the trendline begins to rise in any 3-month period we can adjust with exercise first; then diet; then medication if needed.
6. Not all diabetics should be painted with the same paint brush ... some of us do look after ourselves. I do know that there are those that do not, but for everyone that does not there is one that does.
7. feel free to test your blood test and keep record and manage your activities and food
8. Since I know that I need to be accountable for myself, the'gimmic' of having to be responsible for keeping this type of record would help me stay committed to helping myself.
9. please keep working on this! It is the patient's responsibility, but such a system may make it more habitual for most.
10. This was a hard one. Just getting into the habit of using it. That is my problem now. Other than a record is kept in the glucose meter.
Cost
1. My only worry would be the cost as I am on fixed income like a lot of other diabetics. I just make ends meet now. With the new tax on July 1st.things will be worse. Where would I get the money for this kind of service?
2. As much as I am able to pay for those services, I'm still a little tight with money. So I can't pay that much, sadly! On the other hand, I know I need to be follow because I have a tendency, when on my own, to let go to often. :(Lately I looked for an operation to reduce the entry of my stomach (Lap-Band), but I'm a little afraid of the procedure and the problems that may arise!
3. I cannot afford to spend any more on health care as I am on a fixed budget.
4. $10/month = $120 per year - get real... that's a fair amount of testing equipment/drugs/whatever, for information which we should have already...
5. Also I am on disability and the product would have to be cost free
Exchange Partners (sharing of information)
1. The more input I can get regarding diet and exercise the better To be healthier and happier is my personal goal To achieve and then share success with others interests me.
2. I hope this electronic personal health records are NOT shared with employers, insurance companies.

3. It would be helpful to talk to someone on a regular basis, and to know someone actually cares and wants to help.
4. It would be great to be able to forward info and level-readings to my doctor from home, without having to make physical appointments with the doctor every 6-8-weeks. Other aspects of the concept (such as receiving info from nurses, doctors, diabetes-consultants, pharmacists, etc.) are also appealing.
5. I do not like insurers getting involved in test results - it is too tempting for them to consider raising fees if they are threatened with rising blood sugar results.
Exchange Frequency
1. Since I am a newly diagnosed type 2 diabetes patient, I would prefer that I be monitored for Glucose, diet, exercise, medication on a daily or weekly basis till some form of continuity happens and I am not up and down the glucose monitoring scale so that I may get a handle on this illness and not feel so frustrated.
2. Meeting with my physician every 3-months is important from the point of HbA1C blood work. I am always below 7. The highest 3-month reading I have ever had was 7.1.
3. Personally I would prefer the weekly exchange, however I do not feel the diabetes association is technically equipped to be a service option.
4. I like to write down on paper my bg results, carbs, boluses, correction boluses, basal, exercise and site changes. I find that downloading my results from my glucometer and pump doesn't occur frequently enough for me to see patterns that may need attention
Privacy and Security
1. My fear is how the information is being protected? Who has access?
2. My only caveat, is that this should be done through a SECURE website.
3. There are too many failures of security with electronic records. I don't want electronic personal health records.
Survey Design
1. You'd get better results by listing options, asking 1st, 2nd choice... Elimination Matrix Calcs are a nice "straight-jacket". Also, asking us to comment might provide useful info. The study seems unconcerned why "some" (Handicapped, seniors, working poor...) might need certain options. You should contact someone with experience in these matters, and query them. I think the study was designed, top down, to purposely arrive at a predetermined conclusion, desired by political masters.
2. found this survey very interesting.
Exchange Medium
1. I do not own a cell phone or blackberry etc.

Appendix I
Part-worth Utilities and Relative Importances for All Attributes

ePHR Attributes	Relative Importance (%)	Levels	Part-Worth Utilities
Self-Management Tasks	8.89	Diet & Physical Activity	-0.11
		Manage Medications	-7.76
		Monitor Blood Glucose	-11.29
		Monitor Blood Glucose + Diet & Physical Activity	4.20
		Monitor Blood Glucose + Manage Medications	-4.87
		All options	19.83
Exchange Partners	13.96	Physician or Nurse	36.04
		Pharmacist	0.56
		Diabetes Educator	19.19
		Social Worker or Mental Health Counsellor	-39.13
		Specialist	8.49
		Family Member or Peer	-25.16
Frequency of Exchange	16.72	Daily	-17.70
		Weekly	-5.38
		Once a month	27.23
		Every 2 or 3 months	20.77
		Every 6 months	-7.54
		Once a year	-17.38
Exchange Medium	16.73	Mobile health application (using a cell phone, Blackberry etc.)	-42.09
		USB flash drive (memory stick)	-19.23
		Monitoring devices (using a glucometer, pedometer etc.)	27.27
		Internet-based application (portal or website)	34.60
		Kiosk (touchscreen application in a clinic)	-20.81
		Printed copy	20.27
ePHR Service Provider	17.44	Healthcare Provider (e.g. physician or specialist)	44.37
		Health Insurer (e.g. Blue Cross, Sunlife)	-23.16
		Commercial Supplier (e.g. Microsoft, Telus)	-17.85
		Government (e.g. Health Canada or Provincial Ministry of Health)	5.49
		Employer	-35.59
		Canadian Diabetes Association	20.68
		Hospital	6.06
Monthly Service Fee	26.26	$0	82.43
		$5	33.64
		$10	9.25
		$15	-13.78
		$20	-44.85
		$25	-66.69

Appendix J
Segment 1 & 2 Characteristics

Variables		Segment 1 (n=80)		Segment 2 (n=70)	
Type of Diabetes	Pre	27	33.8%	22	31.4%
	Type 1	23	28.8%	25	35.7%
	Type 2	30	37.5%	23	32.9%
Average Years with Diabetes		9.37		13.11	
Age	18-29	4	5.0%	5	7.1%
	30-49	21	26.3%	24	34.3%
	50-69	46	57.5%	39	55.7%
	70-89	9	11.3%	2	2.9%
Gender	Female	42	52.5%	37	52.9%
	Male	38	47.5%	33	47.1%
Use PHRs	Yes	41	51.3%	42	60.0%
	No	39	48.8%	28	40.0%
PAM Level	Level 1	6	7.5%	5	7.1%
	Level 2	7	8.8%	11	15.7%
	Level 3	20	25.0%	14	20.0%
	Level 4	47	58.8%	40	57.1%
Health Status	Excellent	5	6.3%	4	5.7%
	Very Good	20	25.0%	21	30.0%
	Good	37	46.3%	24	34.3%
	Fair	17	21.3%	15	21.4%
	Poor	1	1.3%	6	8.6%
Education	Did not complete high school	3	3.8%	2	2.9%
	High school	20	25.0%	15	21.4%
	Some College or University	19	23.8%	24	34.3%
	College or University Graduate	24	30.0%	23	32.9%
	Graduate or Postgraduate degree	11	13.8%	6	8.6%
	Other	3	3.8%	0	0.0%
Difficulty Paying for Supplies	Strongly Agree	12	15.0%	28	40.0%
	Agree	23	28.8%	27	38.6%
	Disagree	27	33.8%	11	15.7%
	Strongly Disagree	14	17.5%	2	2.9%
	Don't Know	4	5.0%	2	2.9%

Appendix K
Total Sample and Segment Part-worth Utilities and Relative Importances

ePHR Attributes	Total Sample (n=150)	Segment 1 (n=80)	Segment 2 (n=70)
Self-Management Tasks			
Diet & Physical Activity	-0.11	-0.46	0.29
Manage Medications	-7.76	-6.90	-8.75
Monitor Blood Glucose	-11.29	-9.71	-13.09
Monitor Blood Glucose + Diet & Physical Activity	4.20	2.80	5.81
Monitor Blood Glucose + Manage Medications	-4.87	-6.80	-2.67
All options	19.83	21.07	18.41
Exchange Partner			
Physician or Nurse	36.04	35.82	36.30
Pharmacist	0.56	2.51	-1.66
Diabetes Educator	19.19	21.66	16.37
Social Worker or Mental Health Counsellor	-39.13	-49.08	-27.75
Specialist	8.49	11.64	4.89
Family Member or Peer	-25.16	-22.55	-28.15
Frequency of Exchange			
Daily	-17.70	-20.39	-14.62
Weekly	-5.38	-1.36	-9.98
Once a month	27.23	31.44	22.41
Every 2 or 3 months	20.77	19.30	22.45
Every 6 months	-7.54	-10.03	-4.69
Once a year	-17.38	-18.95	-15.58
Exchange Medium			
Mobile health application (using a cell phone, Blackberry etc.)	-42.09	-43.82	-40.11
USB flash drive (memory stick)	-19.23	-18.07	-20.55
Monitoring devices (using a glucometer,	27.27	30.52	23.55

pedometer etc.)			
Internet-based application (portal or website)	34.60	34.08	35.19
Kiosk (touchscreen application in a clinic)	-20.81	-20.27	-21.43
Printed copy	20.27	17.55	23.37
ePHR Service Provider			
Healthcare Provider (e.g. physician or specialist)	44.37	47.03	41.34
Health Insurer (e.g. Blue Cross, Sunlife)	-23.16	-17.90	-29.17
Commercial Supplier (e.g. Microsoft, Telus)	-17.85	-17.50	-18.24
Government (e.g. Health Canada or Provincial Ministry of Health)	5.49	4.98	6.07
Employer	-35.59	-42.79	-27.36
Canadian Diabetes Association	20.68	20.94	20.38
Hospital	6.06	5.25	6.98
Monthly Service Fee			
$0	82.43	47.84	121.97
$5	33.64	24.43	44.16
$10	9.25	9.15	9.36
$15	-13.78	-7.31	-21.17
$20	-44.85	-23.92	-68.76
$25	-66.69	-50.19	-85.55
Relative Importance of Attributes	**(%)**	**(%)**	**(%)**
Self-Management Tasks	8.89	9.80	7.84
Exchange Partners	16.73	18.62	14.58
Exchange Frequency	13.96	15.68	12.00
Exchange Medium	17.44	18.87	15.81
ePHR Service Provider	16.72	18.39	14.81
Monthly Service Fee	26.26	18.64	34.97

Appendix L
Crosstabulated Variables

Between-Subject Factors			
Variables	**Value & Label**	**N**	
Segments	1	Segment 1	80
	2	Segment 2	70
Type of Diabetes	1	Prediabetes	49
	2	Type 1	48
	3	Type 2	53
Years with Diabetes (4 categories)	1	0 - 3	39
	2	4 - 7	36
	3	8 - 13	34
	4	14 - 60	41
Gender	1	Female	79
	2	Male	71
Age (2 categories)	1	18 to 49	54
	2	50 to 89	96
Education (4 categories)	1	HS grad or less	40
	3	Some college or university	43
	4	College or University Grad	47
	5	Grad or Postgraduate degree, Other	20
Use PHRs	1	Yes	83
	2	No	67
Health Status (3 categories)	1	Excellent, Very Good	50
	3	Good	61
	4	Fair, Poor	39
Difficulty Paying for Supplies (4 categories)	1	Strongly Agree	40
	2	Agree	50
	3	Disagree	38
	4	Strongly Disagree, Don't Know	22
PAM Level (3 categories)	1	Levels 1 & 2	29
	3	Level 3	34
	4	Level 4	87

Appendix M
Significant Effects of Covariates on ePHR Levels

ePHR Attributes	Levels (* = winning level)	Part-Worth Utilities	Significant Effects					
			Type of Diabetes	PAM Level3	PHR Use	Age2	Health3	Segment
Self-Management Tasks	Diet & Physical Activity	-0.11	X					
	Manage Medications	-7.76						
	Monitor Blood Glucose	-11.29						
	Monitor Blood Glucose + Diet & Physical Activity	4.20	X		X	X		
	Monitor Blood Glucose + Manage Medications	-4.87		X				
	All options*	19.83					X	
Exchange Partner	Physician or Nurse*	36.04						
	Pharmacist	0.56						
	Diabetes Educator	19.19						
	Social Worker or MHC	-39.13						X
	Specialist	8.49						X
	Family Member or Peer	-25.16	X					
Exchange Frequency	Daily	-17.70	X					
	Weekly	-5.38						
	Once a month*	27.23						X
	Every 2 or 3 months	20.77						
	Every 6 months	-7.54						
	Once a Year	-17.38	X					
Exchange Medium	Mobile application	-42.09				X		
	USB (memory stick)	-19.23	X			X		
	Monitoring devices	27.27				X		
	Internet-based application*	34.60				X	X	
	Kiosk	-20.81	X				X	
	Printed copy	20.27				X		

ePHR Service Provider	Healthcare Provider*	44.37						
	Insurer	-23.16					**X**	**X**
	Commercial Supplier	-17.85					**X**	
	Government	5.49			**X**			
	Employer	-35.59			**X**	**X**		**X**
	Canadian Diabetes Assoc.	20.68				**X**		
	Hospital	6.06						
Monthly Service Fee	$0*	82.43						**X**
	$5	33.64				**X**	**X**	**X**
	$10	9.25						
	$15	-13.78						**X**
	$20	-44.85						**X**
	$25	-66.69						**X**

Appendix N
Market Simulations: Shares of Preference for ePHR Scenarios

ePHR Attribute	Winning ePHR Attribute Levels	Substitutions	Shares of Preference for Winning Concept	Shares of Preference for Modified Concept	Std. Err.
Self-Management Tasks	All options	Monitor Blood Glucose + Diet&Physical Activity	63.72	36.28	1.7
Frequency of Exchange	Once a month	Every 2-3 months	53.97	46.03	2.18
Exchange Medium	Internet-based	Monitoring device	56.10	43.90	2.44
Exchange Medium	Internet-based	Mobile	90.00	10.00	1.41
ePHR Service Provider	Healthcare Provider	Commercial Supplier	89.49	10.51	1.01
Exchange Partner + ePHR Service Provider	Physician or Nurse + Healthcare Provider	Diabetes Educator + Canadian Diabetes Assoc.	74.17	25.83	1.93
Frequency of Exchange + Exchange Medium	Once a month + Internet-based	2-3 times/mo + Device	57.05	42.95	2.78
Monthly Service Fee	$0	$5	79.32	20.68	2.43

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