



McMaster eBusiness Research Centre

**An Empirical Study of Canadian Consumer and
Physician Perceptions of Electronic Personal Health
Records**

by
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And
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ABSTRACT

Electronic personal health records have significant promise, in helping to empower consumers to take more responsibility for managing their own health. This paper reports on a preliminary study of Canadian physicians and consumers, based on statistical adoption models, to gather their perceptions of the potential for personal health record systems.

Keywords: electronic personal health records, survey, Canada, physicians, consumers, perceptions

INTRODUCTION

Computers have been used for record keeping and data storage in healthcare institutions for many years, beginning in the early days of computer adoption with administrative records, and growing to include clinical health records more recently in almost all such Canadian institutions. The adoption of computer-based clinical records in primary care (EMRs or Electronic Medical Record systems) as compared to hospital settings (EHRs or Electronic Health Record systems) has been slower with, for example, only 20% of Ontario physicians using EMRs (Chernos October 2007) in 2006. This is expected to have risen to 30% in 2009 (OntarioMD 2009) at the national level. At the same time, widespread Internet use and the availability of medical and healthcare information on the Web have made patients much more aware of diseases, symptoms, analyses, and treatments. A large percentage of the North American population is now relying on information from the Internet to educate themselves and to make and reinforce decisions about medications, treatments, and lifestyle choices for themselves and others (Bliemel and Hassanein 2007). One survey (CHF 2008) showed that online consumers are much more likely to tap the Internet to search for general or specific health-related information than they are to communicate with health professionals or use a health plan, hospital, or provider Web site. Internet sites can be outdated or inaccurate and almost never integrated with EHRs. Disturbing evidence comes from Wainstein et al (Wainstein, Sterling-Levis et al. 2006) who show that approximately 1 person in 5 will change a physician-directed decision based on information found on the Internet. To counter these problems, and to improve the likelihood that patients and their families have access to informed knowledge to assist in self management of conditions and diseases, patients and their caregivers could be linked online to relevant information on their own actual medical histories, including education and other support, and contact with health professionals through Electronic Personal Health Record (ePHR) systems.

A limited review of the topic “personal health record(s)” found few papers with any mention of a Canadian context, demonstrating the current paucity of research on personal health records in Canada. To fill this gap, we undertook convenience surveys of both Canadian patients and physicians, to develop a preliminary understanding of the perceptions of the Canadian population about the potential for ePHRs. The purpose of this paper is to summarize data gathered from these preliminary surveys, to draw some preliminary conclusions, and to suggest further directions for research. In this paper, we first describe ePHRs and their applications. Then two somewhat similar models of ePHR adoption are suggested for consumers and physicians. Data collection from consumers was through an online questionnaire based on the consumer model. For physicians, data were collected partly through interviews and partly through an online questionnaire based on the physician model. The data collection process is described and the results reported in a following section. Finally, we suggest some preliminary conclusions and propose further data collection and analysis to enhance the validity of the conclusions to date.

ELECTRONIC PERSONAL HEALTH RECORD SYSTEMS

Healthcare Information Technology (IT) may be able to empower patients and give them a role beyond an environment of being a passive recipient of healthcare services, to an active role in which the patient is informed, has choices, and is involved in the decision-making process (Demiris, Afrin et al. 2008). Such a role, called patient-centred healthcare, is becoming popular

in Western healthcare systems, since it can engage patients in managing their own healthcare, with the potential for better outcomes at lower costs. For patients to be effective in such a role requires access to information about their healthcare history and about healthcare topics that relate specifically to their diseases or conditions. This is why ePHRs – what they are, what they should include, how they can be provided, and how they can be accessed without compromising security and privacy – are becoming much debated topics.

Another motivation for increased use of ePHRs is an increased emphasis on delivery of ambulatory rather than institutional based care for chronically ill, recovering, and aging clients (e.g. Ontario's current "Aging at Home" initiative). This emphasis is driven largely by an aging population and increases in chronic illness and multiple co-morbidities. As technology and pharmaceutical advances occur, a greater proportion of acute (short term, serious illness or injury) patients are being released early from hospital and cared for at home to shorten expensive hospital recovery times and reduce costs. All of this has resulted in increased demand for outpatient and home healthcare services. These services can be formally delivered by a range of approaches (Eysenbach 2000), including but not limited to: visiting nurses, interventions such as Smart Homes (Martin, Nugent et al. 2007), or videophone communications combined with web sites to allow for long-distance care of relatives (Watari, Wetherell et al. 2006). This overall trend is associated with major health system restructuring initiatives, technological advances, and changing social values. The shift to homecare that is occurring is not just a shift in the site where healthcare is received, but it involves implications in funding, allocation, education, and delivery of home and community care services. Effective delivery of this type of care requires an increase in the flow of health information from healthcare institutions and practitioner offices to patients and community care providers, and in the reverse direction from patients to institutions and practitioners. The supporting system architectures depend to varying degrees upon agreed electronic health record standards for gathering and communicating patient record information.

ePHRs are considered to be patient centred health and/or medical records in electronic form that are accessible to patients themselves, but there is no consensus on what information they should include. The term ePHR as used in this paper will refer both to the records themselves and to the information systems used to support them so they can be created, updated, corrected, and accessed by patients/consumers and by their healthcare providers. In this paper, 'patient' will be used interchangeably with 'consumer', since most consumers are not patients, but all consumers will be patients at some time. As consumers of healthcare resources, individuals make decisions to manage their own health with the support of others (general practitioners, specialists, nurses, family, etc.) in their circle of care.

The use of information systems to help get patients involved in managing their own care and thus improve their health outcomes is well-motivated. A broad literature review (Dorr, Bonner et al. 2007) of 109 articles covering 112 healthcare information system descriptions, found that the majority of the articles reported positive results in improving the level of care; about two-thirds of the peer-reviewed articles reported positive findings, as did 94 percent of the uncontrolled experiments. The articles covered primarily chronic illnesses, such as diabetes, heart diseases, mental health issues, and multiple disease cases. In the instances where there was a randomized controlled trial, there was overall a positive correlation between exchanging data and positive health outcomes ($r=0.28$, $p=0.05$).

It is widely believed that homecare for the elderly, the chronically ill of all ages, and recovering patients is a cost effective way to attack some of the rising cost of healthcare in Canada. For example, there are limited benefits from early release from acute care (Shepperd and Iliffe 2005). Patients who do not receive home care are more likely to be unnecessarily re-hospitalized or moved to long term institutional care earlier, at much higher cost to individuals, their families, and society. Providing publicly supported homecare has not been found to decrease the amount of informal care provided, particularly for elderly patients (Li 2005). Consumer-centric information might help providers to deliver care more effectively and it could also help consumers to manage their own wellness better, follow prescribed treatment regimens, and make decisions regarding personal healthcare (Thompson and Brailer 2004; Cocosila and Archer 2005; Pagliari, Detmer et al. 2007). Delivering such services requires the integration of the current fragmented system (Archer 2005) of hospital and clinical care records (EHRs and EMRs), records from community services such as home care nurses and pharmacies, education and support, etc. As Martin et al (Martin, Nugent et al. 2007) state, we need to “integrate all of these into existing models of practice and the evolution, via service process re-engineering of innovative and dynamic models of care that are client-centered, affordable, sustainable and deliver ‘best value for money’ at local levels”.

It may be possible to integrate patient data that originates from a variety of sources on the patient’s situation, health issues, and preferences, into one source of information for patients and their caregivers through Electronic Personal Health Records. This may be a promising route to increased care efficiency and improved patient outcomes by self management of their own care, with the support of their circle of care. A recent Canadian survey (Ekos 2007) indicated that 68% of Canadians would be more comfortable about EHRs if they were able to access their own records in order to correct errors, but our study extends this further, to provide online records through ePHR systems that can be updated and accessed as needed by patients in support of their routine healthcare.

The objective of this paper is to report on an initial analysis of the research question “What are the perceptions of Canadian consumers and physicians concerning the value of electronic personal health records in supporting consumer health?” To address the research question, the study builds on other survey research that collected empirical data from consumers and healthcare providers. An example is the study by Klein (Klein 2007), who gathered data to examine patient-physician portal acceptance of a commercially provided portal supporting both physicians and patients.

PROPOSED MODELS OF STAKEHOLDER PERCEPTIONS OF EPHRS

As a preliminary approach to the study, two adoption models were developed that are intended for structured equation modeling (SEM) evaluation through Partial Least Squares (PLS) of the path structures that link the various constructs in the models. The two models that represent consumers and healthcare providers (Figures 1 and 2 respectively) are somewhat similar. Table 1 indicates the constructs used in the two models, the number of items in each construct, and the sources of validated studies used in construct/questionnaire design (not included here due to lack of space). The purpose of this small study was to gather information for an initial verification of

the models. The sample sizes were not sufficient to validate the models, but sufficient data were gathered to allow a regression study of some of the relationships. This may be followed up with an empirical study using considerably larger and random sample sizes, with models refined according to these preliminary results, in order to develop properly validated models. This section is a brief presentation of the two models upon which the questionnaires were based, for both the consumer/patient and physician surveys.

Table 1. Constructs Used in the Patient/Consumer and Physician Models

Construct	Items	Consumer/ Patient	Physician	Reference Source
Internet Dependence	4	X	X	(Wilson and Lankton 2004)
Computer Self Efficacy	4	X	X	(Venkatesh, Morris et al. 2003)
Personal Innovativeness With IT	4	X	X	(Agarwal and Prasad 1998)
Anxiety	4	X		(Venkatesh, Morris et al. 2003)
Data Sources	4	X	X	New
Satisfaction With Medical Care	3	X		(Wilson and Lankton 2004)
Health Knowledge	3	X		(Wilson and Lankton 2004)
Information Seeking	5	X	X	(Wilson and Lankton 2004)
Perceived Usefulness	4	X	X	(Davis 1989)
Attitude Towards Target	4		X	(Davis 1989)
Compatibility	3		X	(Moore and Benbasat 1991)
Perceived Privacy, Legal Risks	4		X	New
Behavioural Intention	3	X	X	(Venkatesh, Morris et al. 2003)

Figure 1. Model of Consumer/Patient ePHR Perceptions and Intentions

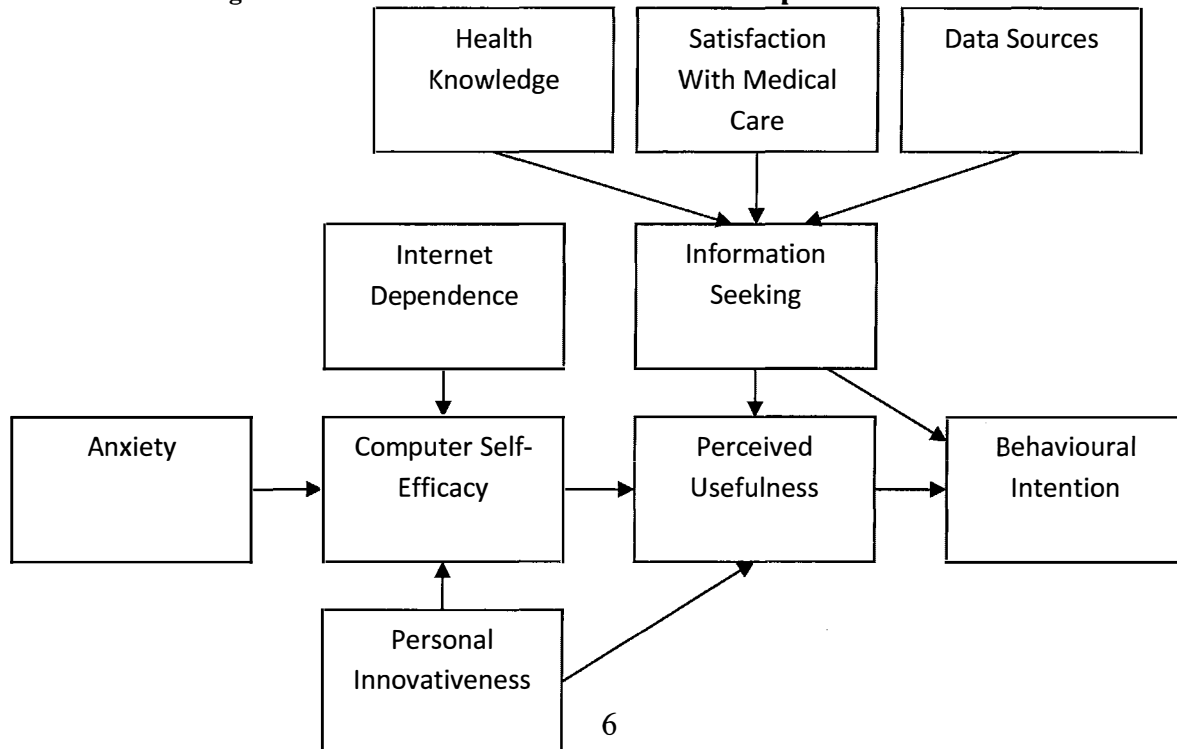
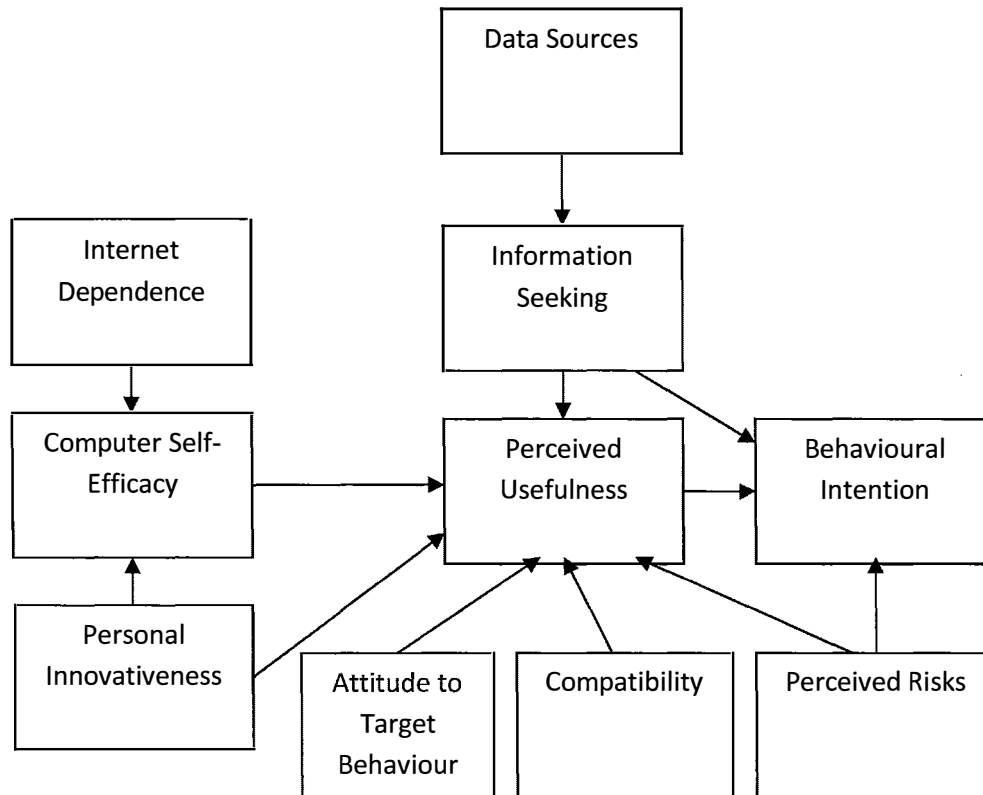


Figure 2. Model of Physician ePHR Perceptions and Intentions



SURVEY DATA COLLECTION

Two preliminary surveys were undertaken to gauge the perceptions of both Canadian consumers and physicians concerning the value of electronic personal health records (ePHRs). These were both convenience surveys, but an attempt was made to obtain participation from consumers and physicians in a fairly wide geographic distribution. The survey questionnaires and procedures were approved by the McMaster University Research Ethics Board.

Each of the surveys was prefaced by a description of what ePHRs are, what information might be stored in them, how consumers/patients might take advantage of them, and how they might affect their interactions with their family physicians.

Consumer Survey

There were a total of 45 participants in the online consumer survey – 20 from Alberta, 24 from Ontario, and 1 from Nova Scotia. The survey was conducted from September 2009 through January 2010. Most of the Alberta participants responded to information received through handouts at their family doctors' offices. The other participants were recruited via networking word of mouth. Approximately one-third were retired, with the remainder from a wide distribution of occupations. Participants were 67% female and 33% male. Of these, 38% claimed that they already maintained up-to-date personal health records (in either paper or digital form). 80% claimed that they were strongly interested in monitoring and maintaining records about their health. Because we believe that certain categories of consumers would be more

motivated to initialize and continue to use ePHRs, we collected information on this participant characteristic. However, only 4 were caring for children aged 12 and under, 10 had a chronic disease or were caring for someone with a chronic disease, 7 had a disability or were caring for someone with a disability, and 3 were responsible for the care of an elderly person. The numbers of these participants was not large enough to draw any specific conclusions about their motivations to use ePHRs in the small sample collected in this preliminary survey.

In addition to answering 13 demographic and other questions about their own particular situations, participants responded to a total of 42 statements related to the constructs shown in Figure 1 and derived from sources indicated in Table 1, involving their interests, behaviours, and perceptions of healthcare and personal health records. Participants were also invited to enter additional comments about ePHRs, and 60% did so. Figure 1 is a model showing the expected relationships among these constructs, with the sources for (mostly) validated and published constructs related to individual adoption and use of information systems appearing in Table 1. Their responses were entered on a seven point Likert scale that ranged from Strongly Disagree (1); Disagree (2); Slightly Disagree (3); Neutral (4); Slightly Agree (5); Agree (6); to Strongly Agree (7) for each statement. As a preliminary study, the initial sample was too small to apply structured equation modeling. However, a limited regression analysis was possible from this small sample, as outlined below.

Data Analysis - Supporting ePHR Costs. While most researchers agree that ePHRs would help to focus and support patients on self management of their health, there is always the question of who will pay the costs of providing this service. Given the currently rising costs of healthcare in Canada, it is unlikely that governments in Canada will be prepared to support the cost of ePHRs anytime soon. This may change if and when a body of evidence develops that ePHRs result in a major benefit to society as a whole, and that societal costs of healthcare will be reduced as a result. In the meantime, consumers are likely to have to pay the costs of such systems. For this reason, it is important to estimate the sensitivity of consumers to the cost of ePHRs. In the questionnaire, one set of statements gauged Willingness To Pay, with specific monthly fee ranges stated, and responses on the seven point Likert scale. The ranges were (in rates per month in Canadian dollars): \$0.00, \$0.01 to \$1.99, \$2.00 to \$4.99, \$5.00 to \$9.99, and \$10.00 to \$20.00. The response frequencies are shown in Figure 3. Note that not everyone responded to each of the statements, so the number of participants responding to each statement totals less than 45. As expected, there is a spike at 7 (Strongly Agree) for \$0.00. As the amounts grow, the distribution flattens across the seven responses, until it starts to spike at 1 (Strongly Disagree) for the larger monthly amounts. From the figure, it is clear that an amount that would meet about the same favour and disfavour across the study participants would be in the range of \$2.00 to \$5.00. For business calculations, values in this range would therefore be appropriate. Note that these results were determined from the perceptions of consumers in general, who have no particular motivation to maintain ePHRs. This compares with a result of approximately \$2.00 per month that was observed in a similar study (Adler 2006). A higher level of motivation and hence a willingness to pay more for ePHR services is likely to be the case for people with serious chronic illnesses. For example, published results from another source found diabetic patients were willing to pay \$5 to \$25 per month (Bryce, Zickmund et al. 2008).

Data Analysis – Consumer Questionnaire. To gauge the effect of the many possible aspects of consumer perceptions of their interests in adopting ePHRs, as reflected in the questions and statements in the online survey, a regression was used to determine their impact on a dependent variable that reflected Behavioural Intention to Use the (ePHR) system. Since there were many possible variables, step-wise regression was used. The results are shown in Tables 2 and 3. The order given in Table 2 is the order in which the variables were selected by the step-wise process. All the variables except variable 9 were scaled on the range of the integers 1 (Strongly Disagree) to 7 (Strongly Agree). Binary Variable 9 had No (0) and Yes (1) responses. One case was removed from the data because of many missing values, apparently due to the fact that the participant was a very infrequent Internet user. Variable averages were used to replace missing values where they occurred. The analysis of variance appears in Table 3. R^2 (adj) for the regression was 0.850. The maximum variance inflation factor for any of the coefficients was 2.96, indicating that there was not a serious impact from multi-collinearity in the final model.

Figure 3. Consumer Willingness To Pay for ePHR (monthly rates)

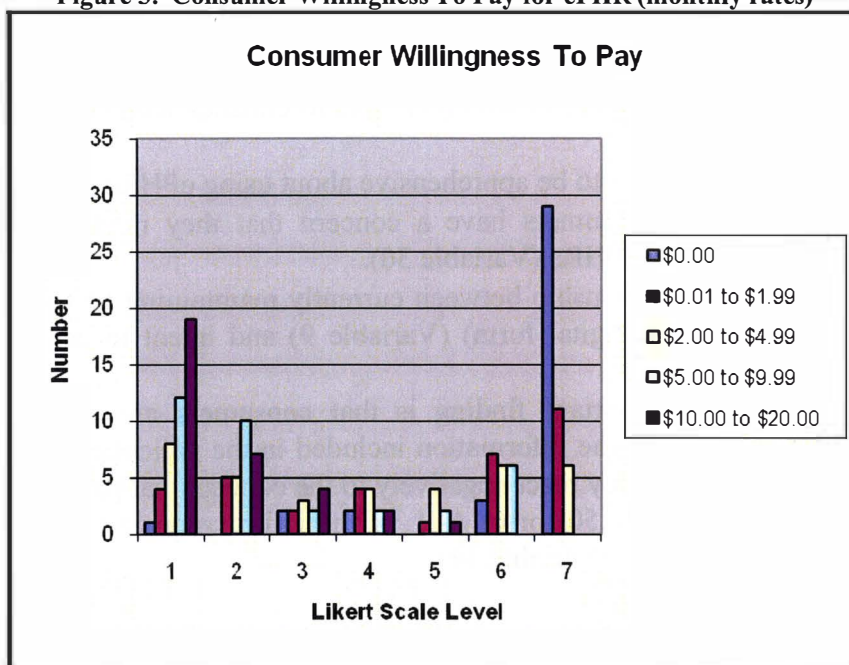


Table 2. Regression Variables Selected (Consumer Model)

Variable No.	Variable Name	Beta Coeff.	Sig.
	Dependent Variable		
56	If an Electronic Personal Health Record is made available to me, I intend to use it.		
	Independent Variables Selected in Step Wise Regression Process		
53	Using my own Electronic Personal Health Records would support critical aspects of my health care.	.354	.001
34	I believe that patients should have access to a copy of ALL the information about them from their physicians' records, as approved by their physicians.	-.437	.000
54	Using my own Electronic Personal Health Records would enhance my effectiveness in managing my health care.	.532	.000

31	I would hesitate to use an Electronic Personal Health Record system for fear of making mistakes I cannot correct.	-.216	.006
50	I believe that the results of laboratory and other tests should be made available to patients.	-.204	.007
37	I believe that physicians should have access to a copy of ALL information that patients enter into their own Personal Health Record, as approved by their patients.	.214	.006
9	Do you maintain up-to-date personal health records for yourself (in either paper or digital form)?	.136	.048

Note: Data shown in the table are for the final seven independent variable model.

Table 3. Analysis of Variance (Consumer Model)

	Sum of Squares	df	Mean Square	F	Sig.
Regression	62.255	7	8.894	35.868	.000
Residual	8.926	36	.248		
Total	71.182	43			

There are several significant findings from the analysis of the consumer perception data:

- Consumers believe that ePHRs would be able to enhance their healthcare (Variables 53 and 54)
- Consumers do not appear to be apprehensive about using ePHRs (Variable 31).
- On the other hand, consumers have a concern that they might make mistakes and lose information stored in their ePHRs (Variable 30).
- There is a positive relationship between currently maintaining an up-to-date personal health record (in either paper or digital form) (Variable 9) and intent to use an ePHR if it is made available to the consumer.
- Probably the most important finding is that consumers are positively inclined towards physician access to ALL of the information included in the patient ePHRs as approved by their patients (Variable 37), but they react negatively to the concept that patients should have access to lab and other tests (Variable 50) or to ALL of the information in their physicians' records, as approved by their physicians (Variable 34).

Data Analysis – Consumer Comments. In addition to the data gathered from responses to the structured statements in the online questionnaire, consumers were given an opportunity to enter unstructured comments. These tend to enrich the content of the study. For example, consumer concerns about security, confidentiality, and privacy issues were reflected by comments from several individuals. Individual comments appear below under specific topics:

Consumer Comments – Security, Confidentiality, and Privacy Issues. “My usual concerns exist about security of information and controlled access. It is important to convey to the public that their records would be safe, as well as the benefits to having access to one’s personal records.” “The potential for misuse of the records is sufficiently high as to make them untenable in any fashion.” “The major drawback to this plan is confidentiality. Otherwise, it would be practical and beneficial for patients.” “My concern is for total, complete privacy of the record.”

Consumer Comments – ePHR Content. “I feel very uncomfortable with this idea, since there are several ways to read a written statement.” “I am a subject in a double blind drug trial - ePHR

software would allow me to enter the lab results online.” “I used to enter information into an online Web site that accepted personal information, and provide information about various illnesses and conditions – unfortunately the site was shut down with no explanation.”

Consumer Comments – Patient Interactions With Physicians. “It would be an important bridge for emergency events and when changing physicians.” “It would be helpful for children/caregivers as we age.” “I should be able to present questions in advance of physician appointments so my physician is aware of my self observations and life style adjustments before the appointment.” “The system would have to be easy to access and manoeuvre through as well as having the capability to update information if incorrectly answered.” “My doctor keeps electronic records and updates them while I am in his office, so getting started could be easy.” “If we could incorporate setting up appointments and getting results from tests, it would be very useful.” “In my case, there was a lack of communication between a specialist and my primary care physician resulting in the improper use of a medication, with disastrous results to my healthcare” (paraphrased by us to avoid patient identification). “I am concerned that incorrect information could be entered by a patient and then accepted as accurate by the physician.” “An ePHR would be a boon for physicians, as patients sometimes forget to mention symptoms and concerns during their appointments.” “I love the concept for any physician I may encounter to also be able to get the full history of my health.”

Consumer Comments – Interest in ePHRs. “I feel that ePHRs would be useful to patients.” “I am looking forward to hearing more about them.” “I would feel much more involved in my personal healthcare and more aware of my situation.” “As we travel around the world, our medical records would be accessible.” “People who are not computer literate would not make use of them.” “I think that only a small percentage of those capable to use ePHRs would bother to take the time unless they are simple and easy to read. Time limitations are an issue for many people.” “The system should be set up so records would be accessible by caregivers in order to assist with their health.” “I think the idea is a good one and I would be more likely to keep it updated than what I am doing now. If people had a chance to track their medical and health information online, and there was a searchable database that explained common symptoms, it would encourage more people to take responsibility for their own health.” “I strongly believe that it would be a wonderful tool to help us take care of our health.” “If there is an easy system to use I would be able to take care of my health.” “It sounds useful.” “I do not use the Internet so often.”

Consumer Comments – Financing ePHRs. “I feel that the money and time spent on ePHRs would be better directed to other health services that lack funding.” “I do not believe that access to this should be denied to those who cannot afford to pay if it will also benefit them.” “Where I say \$5 a month would be reasonable for me because I am working, for those not in the workforce other solutions should be worked out.” “ePHRs should not be a cost to the user!”

Physician Survey

32 Canadian physicians completed the practitioner (physician) survey over the time period May 2009 through January 2010. Of these, 11 practice in the Province of Alberta, 14 in Nova Scotia, and 7 in Ontario. The majority (28) were general practitioners and 4 were specialists. 25 of the physicians were also interviewed after they completed the survey, to gather further insights and

perceptions that would help to enhance the survey information. In addition to answering 13 demographic and other questions in the survey, participants responded to a total of 42 statements developed from the model in Figure 2 and the sources in Table 1, related to different aspects of their interests, behaviours, and perceptions of healthcare and personal health records. Their responses were entered on a seven point Likert scale that ranged from Strongly Disagree (1); Disagree (2); Slightly Disagree (3); Neutral (4); Slightly Agree (5); Agree (6); to Strongly Agree (7) for each statement. These statements were in the ten constructs shown in Figure 2, as derived from the (mostly) published and validated sources in Table 1. There was considerable overlap with the constructs used in the consumer survey (Figure 1), so comparisons would be possible in a larger model validation sample in a future study. Participants were also invited to enter additional comments about ePHRs, and 60% did so. Participants were informed that, assuming that ePHRs were to be adopted by their patients at a future time, there would be a certain level of practitioner interaction with patients that involved either the use of information from their ePHR system records, or providing additional information to these records. That is, practitioners would not necessarily be using the patient ePHRs, but could be involved with them in some way, such as providing additional patient information to include, or in accessing them to gather additional information on patient progress, should patients adopt ePHRs.

Data Analysis – Physician Questionnaire. The sample size collected in the survey is not large enough for structured equation modeling, and only marginally suitable for a limited regression analysis. However, to gauge physician perceptions of consumer adoption of ePHRs, regression was used to determine their impact on one of the dependent variables that reflects Behavioural Intention to Use/Work with patients using the (ePHR) system. The results are shown in Tables 4 and 5. The order given in Table 4 is the order in which the variables were selected by the stepwise regression process. All the variables shown were scaled on the range of 1 (Strongly Disagree) to 7 (Strongly Agree). One case was removed from the data, because the participant did not select a valid value for the dependent variable. Averages were used to replace missing values where they occurred. R^2 (adj) for the final model was 0.630. Because of the small number of cases, the data were only minimally suited for regression analysis and only two variables were selected for the resulting model. Although the model appears to complement other findings from the study, it has little to offer in terms of explanatory power, and we rely more in this exploratory study on qualitative data collected from physician interviews and from comments included in their questionnaire responses, as outlined in the following section.

Table 4. Variables Selected in the Regression Process (Physician Model)

Variable No.	Variable Name	Beta Coeff.	Sig.
	Dependent Variable		
49	If my patients choose to use a Personal Health Record system, I predict that I would take advantage of it when possible in my practice.		
	Independent Variables Selected		
37	Allowing patients access to their own personal health records is compatible with all aspects of my work.	.760	.000
32	Overall, patient use of Personal Health Records would be useful in managing their health care.	.340	.019

Note: Data shown in the table are for the final two independent variable model selected by the step wise process.

Table 5. Analysis of Variance (Physician Model)

	Sum of Squares	df	Mean Square	F	Sig.
Regression	10.390	2	5.195	26.54	.000
Residual	5.481	28	.196		
Total	15.871	30			

The significant findings from the regression analysis of physician perceptions about ePHRs, as shown in Table 4, suggest that they believe that:

- allowing patients access to their own personal health records tends to be compatible with all aspects of the physicians' work, (Variable 37), and
- physicians believe that patient use of Personal Health Records would be useful in managing their health care (Variable 32)

Data Analysis – Physician Interviews. Comments gathered from interviews with 25 of the physicians who completed the survey are summarized into a series of topics below. Note that these are paraphrased comments, with a periodic attempt on our part to indicate whether one, a small number, or a larger number gave similar inputs. These summaries are not statistically valid results, but they can provide guidance for further development of ePHR physician and consumer surveys. Unstructured comments that physicians entered in the online survey are not included here, since they generally reflect the same information acquired during the interviews.

The general consensus among the physicians was that ePHRs are a good idea, but not for everybody, and they should not be used in a manner that provides open access to all consumers/patients to all the clinical information that is available. Physicians expressed a number of related concerns, suggestions, and comments that are summarized below, on: security and privacy issues, liability, ePHR content, patient entry of data, the impact of such systems on patient interactions with physicians, workflow management impacts, the actual interest of patients in ePHRs, compensation to physicians due to possible additional workload that might result, financing and implementing ePHRs, and their impact on quality of care. An attempt was made in summarizing the data to try to represent physician opinions and perceptions without editorializing the comments. Any insertion of our opinions below is indicated by “(our comment)”.

Physician Comments - Security, Confidentiality, and Privacy Issues. If patients are allowed to access or to download certain information currently maintained in their EMR records, physicians had concerns that it would then be necessary to do double charting or to change the way they entered EMR records, since these records might have information they did not want patients to see. Patients may also be concerned about information being shared with other physicians or government agencies, and may ask physicians not to put certain notes in their files or to disguise them so only the physician understands their meaning. This would also be the case with patient data entry into ePHRs. There was some concern that patients with access to EMR charts might abuse this access capability. Finally, for ePHR records maintained online in large databases, the potential for large-scale illegal access and theft would create a serious issue. This would not arise in the simpler situations where records are stored individually on paper (as in the British system, with newborns starting out with their own paper records that their parents maintain and carry with them).

Physician Comments – Liability. Legally, although patients are allowed to see their data, they do not own the records. But physicians have concerns about liability if something is missed or there is a mistake in the doctor's office. Is the physician more at risk when a patient records data in an ePHR for his/her physician to use? When more data are available from these records, and the doctor fails to find important details amongst data from the patients, is s/he then liable if something happens that he should have known about? EMRs are different, since the physician controls everything that goes into them. However, it appears that liability for missing data from ePHRs should not become an issue as long as proper legal agreements between patients and physicians are in place (our comment).

Physician Comments - ePHR Content. There was some agreement on what might be suitable for ePHR content, in terms of information shared from the physician's EMR records. Some physicians would allow access/downloading of lab data, X-ray data, consultation notes, medications, allergies, immunizations, etc. as well as problem histories. However, although diagnostic images and test lab results might be OK, actual histories and nursing notes are different, and most physicians would not allow patients to see this information unless it was filtered in some way. The problem with patient access to physician or nursing notes is that they may contain information that was not intended for the patient to view. In addition, information downloaded from the physician's EMR may not be in a form that patients can understand.

Physician Comments - Patient Entry of Data. Very few physicians suggested that patients should not do home monitoring and data entry (e.g. blood glucose, blood pressure, etc). However, it is common practice for diabetic patients to record their blood glucose levels in diaries, and other patients keep track of other medical information that could be of value to health self management and to their physicians. An ePHR would clearly assist patients interested in monitoring certain healthcare information (our comment). For geriatric patients, family members would be able to track all the information, such as medications, blood pressure, headaches etc., and this would assist them during physician consultations. Information supplied by ePHRs might be used (particularly in specialist offices) to supplant paper forms that patients currently fill out with their own history. Paper or digital information could be shared, queried, or modified as patients wish. For patients maintaining ePHRs, and who might have questions, content of their other health records is important (including EMR information from their family physicians).

There is also a question about the ultimate source of truth. For physicians, this has to be their clinical records, and anything entered in an ePHR by the patient or from other unlicensed sources would always be viewed with some degree of hesitancy. It is clear that data uploaded to the physician's EMR from ePHR sources would not normally be permitted in any circumstance (our comment). There was some concern about the accuracy of patient-entered data. Sometimes patients might have chronic symptoms that they don't disclose to their physicians, but might be more likely to enter into their own ePHRs. Self monitoring would be useful if the physician could review the records during an appointment (weight, bp, blood glucose, etc.). However, the physician would need to work with patients to build personal plans for them to follow in order to self-manage their health better.

Physician Comments - Patient Interactions With Physicians. The majority of physicians felt that there is no downside to letting patients have more access to information about their own healthcare. It empowers patients to take responsibility, and it's a way to keep them motivated and following their treatment plans. Patients would be able to do a better job of keeping track of events and measures, particularly useful for chronic care services. Patients would also be more likely to take responsibility for their own education, and they could take their information with them virtually when they travel or move. This would be particularly useful for people with serious chronic illnesses. Physicians would have to spend less time educating patients, and more time solving and managing their health problems. ePHRs could help to build a partnership between physician and patient for managing both preventive and reactive patient healthcare (our comment).

Patients with ePHRs would likely have more questions concerning data (lab test results, etc.), so it may be necessary to change the nature of the information and to support their access to patient self-education. A number of physicians pointed out that they generally share data with patients, and there is always a duty to explain the relevant information and to react to patient needs as they arise. Some make reports and notes available to patients as necessary. However, some physicians indicated that providing information such as lab tests directly to ePHRs might not be a good idea, since they require some interpretation (e.g. lipid levels) which physicians currently provide to patients. Interpretation of medical vocabulary would likely be an issue for patients, leading to patient anxiety. Many patients feel that it is their physician's mandate to store medical records, and they might not be interested in access to those records, other than through the physician's interpretation. Screening and prevention through diagnostic tests may require complex interpretation that the Internet or other sources may not necessarily provide. Some physicians suggested tagging downloaded information to limit patient access until it could be explained directly to the patients. Some patients are more likely to pick through data and find fault, or to become very focused on certain results, resulting in unnecessary consultations with their physicians. Patients might also tend to focus selectively on information related to specific aspects of complex illnesses.

Some physicians reported that a small number of their patients already track data related to their own illnesses. There was no consensus on whether improved care or enthusiasm keeps patients interested in maintaining their own records in such situations. Physician can help to set targets and track whether patients are getting closer to their targets. In this way, physicians would be in more of a coaching position with ePHRs, while providing strategic feedback of medical information. This could lead to corrections or explanations, with greater satisfaction levels of both physician and patient.

A small number of physicians already use e-mail to communicate with patients (send reminders, etc.). One physician indicated that patient adoption of ePHRs would require the physician's work style to change. A small number of physicians didn't believe there is value in patients accessing or entering information. In addition, some specialists felt that sharing data is good for patients, but not necessarily for some specialties (e.g. psychiatry).

Physician Comments - Workflow Management. Before ePHRs are implemented in a major way, the challenges associated with implementing them will have to be worked out. Successful

implementation of ePHRs will require physician champions. Change management is critical in implementing new systems (our comment). There is no one right way to go, because of the different backgrounds and personalities of people involved. It is important to analyze workflows in advance, and plan around people and their needs for information. To implement disease prevention requires a suitable level of patient self management. To ensure that data entered by patients into ePHRs are entered or updated reliably, the process needs to be broken down logically.

Physician Comments - Patient Interest in ePHRs. Patients for whom wellness is part of their focus would be more likely to be interested in using ePHRs (e.g. aged 40+ and getting annual checkups). ePHRs might also be of interest to patients with multiple healthcare providers and those who have no family doctor. The “worried well” have anxious and nit-picking personalities, usually leading to over-investigation, even when medical measures are just slightly outside the normal range. This particular group has the potential of causing unnecessary problems for their physicians if they were to maintain their own ePHRs. It is not yet proven that ePHR access will help many patients to manage their own health better (our comment). Opinions were expressed that the younger population is less likely than the +50 population to be interested in ePHRs. There is also limited potential for the elderly who are less likely to be computer savvy. Low income people are less likely to have Internet access, even if they are interested in using ePHRs.

Physician Comments - Physician Compensation. A number of physicians pointed out that, if ePHRs resulted in additional work for them, they would need to be compensated. Some patients may be motivated to monitor their health more regularly, but physicians don’t get extra pay for reviewing their results or if office visit frequency increases. There was considerable concern that e-mail communication would be an inevitable aspect of ePHRs, for which there is currently no compensation. Also, telephone discussions often do not get entered into charts, although e-mails likely would. There might be an increased possibility of nuisance visits or phone calls to physicians resulting from patient concerns arising from ePHR data.

Physician Comments - Financing ePHRs. ePHRs need a financial model, and this may need to be linked in some way to physician compensation. Canadian patients are very unwilling to pay for anything to do with healthcare, since they are accustomed to receiving health services “free”. Provincial medical authorities would be unlikely to provide financial support for ePHRs unless there was strong proof that they would reduce healthcare costs and improve quality of care (our comment). That proof does not yet exist (our comment). Some patients might be willing to pay for ePHRs, including the “worried well” and those with serious chronic illnesses that could see direct benefits from such support. With large immigrant populations there are likely to be language and economic barriers to ePHR access, and many people who could not afford ePHRs might view them as elitist.

Physician Comments - Implementing ePHRs. Some ePHR systems are already in use, and patients have tended to be empowered and enthusiastic about them. More EMR companies are currently developing shared health records that would provide controlled access to both physicians and patients. If EMR data were handled via an ASP (Application Support Provider) model, then patient portals would be relatively easy to implement, providing controlled access by

patients to their own data and allowing them to enter their own information (our comment). However, physicians tend to oppose centralized ASP support for EMRs (e.g. at the provincial level) because of concerns about patient privacy and confidentiality. Patients might also use portable devices like smartcards and USB flash drives to carry their health information with them. Although ePHRs could be useful, their adoption by patients would depend almost entirely on whether their physicians use EMRs (our comment).

To avoid increasing demand on physician time, a triage process might be helpful in re-directing patient communications to the right person. However, triage would work efficiently only for large numbers of patients (our comment). A bank of FAQs (Frequently Asked Questions) as well as access to online educational information could also be helpful. Entering questions and their responses could build a knowledge base over time that all patients could access (our comment). Online communities of patients with similar conditions could also help each other. One approach to initiating ePHRs would be to target some particular illness – e.g. diabetes or heart disease, as another way to get at information between doctor visits. Maintaining their own data and checking it regularly would help to motivate patient use of ePHRs.

Implementing ePHRs would require training and support for both primary care physicians and patients. ePHRs of any type would take financing, physician time, and possibly handpicking initial patients and/or implementing ePHRs locally with some physicians to get an understanding of how they work and what the benefits would be. Governments would have to work closely with physicians to ensure no loss of physician income while improving patient self management of their health. Potential users would need continuous access to online education and other relevant information to maintain their motivation (our comment).

Physician Comments - Quality of Care. Some physicians felt that ePHRs would help patients look after their own illnesses better. In some ways, ePHR support could be seen as an extension of the primary care networks that are being set up in some provinces (our comment). Measurement and attempted self- treatments by patients could cause problems that are similar to patients getting information from the Internet and not being able to determine correctly what their disease is. In addition, patients may take selective personal information to other providers. In order for an ePHR to accomplish its objectives of effectiveness and efficiency, it would have to reduce interactions with family physicians while helping patients to manage their own health better (our comment). If patients had more access to information, they would engage more – they might believe more in targets set by physicians and would tend to become more objectively focused.

DISCUSSION AND FUTURE RESEARCH

The objective of this paper was to report on a preliminary analysis of the research question “What are the perceptions of Canadian consumers and physicians concerning the value of electronic personal health records in supporting consumer health?” We believe we have a partial answer to that question, which is that the perceptions of both consumers and physicians appear to be positive towards ePHRs, but more research needs to be done and more data needs to be collected to make this answer more convincing. We also need to develop a better understanding of the best ways to actually implement ePHRs so they will successfully support patient self care

and maintain good patient-physician relationships. Because physicians, (particularly in primary care), play such an important role in the implementation and application of ePHRs, both consumers and physicians are equally important stakeholders in the future of ePHRs. We have tried to do as much as possible with the limited amount of data gathered from this preliminary survey. Findings are summarized separately below, for consumers and physicians.

Consumers

A statistical study of the limited data collected through the online survey indicated that consumers are generally interested and would welcome ePHRs. Whether consumers are sufficiently motivated to develop and continue to use ePHRs must be determined through a study of a larger sample. In particular, due to the small sample size, we were unable to establish whether there is significant additional motivation for certain categories of consumers such as those with serious chronic illnesses, disabilities, or those who are caregivers for the elderly to adopt and make extensive use of ePHRs in supporting self management of health. An unexpected finding was that, while consumers in general would be willing to share any information in their ePHRs with their physicians, they were less interested in accessing information that their physicians had about them.

It is clear that consumers, like physicians, are concerned about confidentiality and privacy issues that would arise from ePHRs, so these issues must be dealt with carefully if such systems are made available to the general public. Finally, we do not believe that the healthcare system would be willing to pay ePHR costs until and unless this service would prove to reduce overall costs with no reduction in quality of care. Our study of consumer willingness to pay in the survey revealed that, although there was opposition from some consumers to paying anything at all for ePHR service, a monthly payment of \$2 to \$5 CDN might be a suitable compromise for consumers from the general population.

Physicians

The online survey of physicians indicated that they were generally in favour of ePHRs, and that these would be useful in helping consumers to manage their own care. However, they do not believe that ePHRs would be useful for everyone. Including results from physician interviews, we found that physicians were not favourable towards open access to all consumers/patients of all the clinical information that is available in their records for a variety of reasons, including possible misinterpretation of results and an inability to understand medical information without some guidance. This could lead to a requirement for increased communications to physicians (possibly by e-mail). The result could be additional work by physicians, with compensation for their time becoming an additional issue. Potential support through a triage process was received positively. Triage would have another professional responding to patient requests while not burdening physicians unless there was a defined need for their interventions. Physicians also had concerns about confidentiality and privacy of ePHR information, and how physicians should take advantage of information entered by consumers into their ePHRs.

LIMITATIONS AND FUTURE RESEARCH

An obvious limitation to this survey is that the sample size was small and that it was basically a convenience survey, where participants were mostly contacted through third person networks.

The survey should therefore not be taken to be an accurate representation of the perceptions of Canadian physicians nor that of Canadian consumers in general. For example, the great majority of physician participants were EMR users, whereas less than 40% of Canadian physicians actually use EMRs.

More can and will be done with the data collected thus far, in order to extract additional useful information. For example, a qualitative analysis of the physician interview data and the unstructured online comments from consumers through *NVivo* coding by two or more independent workers would help to uncover relationships that exist in the unstructured data findings, possibly resulting in revisions to the proposed models. The preliminary survey data could also be utilized to partially verify the models through an analysis of reliability and a limited analysis of the suitability of the constructs in both models. This would help prepare the way for future studies that use larger samples (a minimum of 150 to 200 in each study, suitable for SEM (structured equation modeling) analysis of these models using the PLS (partial least squares) methodology to develop validated models. In addition, the consumer study would need to focus on specific population segments (e.g. consumers with serious chronic illnesses) that we believe would be the most highly motivated to use ePHRs on a regular basis.

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